

Chronic disease management along the continuum of care:
The role of the health system in supporting people with end
stage chronic illness

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Abstract

Australia faces increasing numbers of people with life limiting chronic disease as individuals live longer and advances in medical treatment help to prolong their lives. However, there is little acknowledgment that the continuum of chronic disease care must include attention to care needs at the end of life. Current policies and strategies assume that referral to palliative care services for people with advanced chronic diseases will be straightforward, despite uncertain disease trajectories and the need for complex and disease-specific interventions.

This thesis examines the health care system as it operates for people with chronic disease as they approach the end of their lives. I explored this topic from a range of perspectives, using a systems thinking framework to map the complexity of end of life care provision. I began with a national/state policy audit which identified how policies related to chronic disease and palliative care interact to facilitate end of life service provision. Using a 360⁰ review built through qualitative interviews with nine patients, six carers and ten key service providers, I examined health system functioning and access to care. I also interviewed twelve service managers and policy makers to explore their perceptions of system functioning and the changes required to make the system function more effectively. Once a picture of how the system functions was developed, I brought the results together using a complexity theory framework to understand why it functions in this way, and to determine the most appropriate places to intervene to bring about change.

The findings from these studies demonstrated that Australian policy makers have not developed effective policies to support appropriate end of life care models for people with chronic disease and there are few intersections between chronic disease and palliative care policies. Current funding mechanisms reflect this disjunction, leading to significant barriers to end of life care for people with advanced chronic disease. Advance care planning remains uncommon in chronic disease care and many health professionals remain uncomfortable about initiating conversations in this area. Despite over a decade of health system advocacy for integrated care, care silos remain entrenched and there is minimal integration between primary, secondary and community care.

This thesis demonstrates that people with advanced chronic disease require ongoing, systematic chronic disease care for symptom control and quality of life which should be combined with a palliative approach incorporating practical support with activities of daily living, ongoing advance care planning conversations; psychosocial and spiritual support and the ability to be cared for at home in the context of family and friends. To support such care, a whole of system approach and a multidisciplinary, integrated, primary care based model of care, with ongoing support from palliative care and hospice services is required. This is not currently available for most Australians.

In order to drive the changes required to provide such end of life care, culture and attitudes around end of life care need to change at both a community level and in health care organisations. Such changes can be facilitated by national programs, but also require system changes such as taking a public health approach to end of life care and making primary care the locus of end of life care for chronic disease. This will require reform of the structure and funding of primary care and the provision of incentives for quality end of life care. Above all, a shared vision of what end of life care in chronic disease should look like must be developed and the primary care sector, including general practice, specialist palliative care, community health providers and NGOs, should play a significant leadership role in driving the development and implementation of this vision and the system changes required.

Manuscripts contributing to this thesis

Burgess, T; Braunack Mayer, A; Crawford, G & Beilby J. 2013 Meeting end-of-life care needs for people with chronic disease: Palliative care is not enough. *Medical Journal of Australia*. 198(4): 186-187.

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Burgess T; Braunack-Mayer A; Crawford GB & Beilby J. 12th Australian Palliative Care Conference. 3-6 September 2013. Canberra, Australia.

Presentation: *Everybody's business? End of life care for chronic disease in Australia today.*

Burgess T; Braunack-Mayer A; Crawford GB & Beilby J. The 4th International Society of Advance Care Planning and End of Life Care Conference. May 9 – 11, 2013. Melbourne, Australia

Presentation: *How well does the Australian health care system support quality end-of-life care for people with chronic disease?*

Burgess T & Crawford GB. Hospice New Zealand 20th Palliative Care Conference September 14 – 16, 2012. Auckland, New Zealand.

Workshop/Presentation: *Meeting the end of life care needs of people with advanced chronic disease.*

Burgess T; Braunack-Mayer A; Crawford GB & Beilby J. 7th Health Services Research and Policy Conference. December 5 – 7, 2011. Adelaide, Australia.

Presentation: *Are current health policies failing people with chronic disease as they approach the end of their life?*

Burgess T; Braunack-Mayer A; Crawford GB & Beilby J. Public Health Association of Australia (SA Branch) 2011 State Population Health Conference. October 29, 2011. Adelaide, Australia.

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Thesis declaration

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

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Dated. 17th July 2016.

Thesis introduction

With increased longevity, more Australians are dying of advanced chronic disease as other causes of death, such as infectious diseases and injury, become less prevalent.¹ Current national and state policies in Australia assume that end of life care for people with life limiting chronic diseases can be addressed through up skilling health professionals in palliative care and/or referral to specialist palliative care services.²⁻⁴ However, there is little evidence that such strategies can address the needs of this growing population. End of life care provision for people with advanced chronic disease is now widely recognised as being in urgent need of improvement, as it is poorly coordinated and resourced and there are significant inequities in access to appropriate care.⁵⁻⁷

To date, there has been minimal examination of whether current health and social policies support provision of appropriate care at the end of life or whether the health system itself is able to support models of care which will meet the needs of these people as they approach the end of their lives. In 2010, Palliative Care Australia (PCA) suggested that part of the difficulty in developing such care lies in our lack of understanding of the indistinct boundaries between chronic and complex health care problems, ageing and dying.⁸ This is further complicated by the complexity of the Australian health system, with differing state and government responsibilities around the provision of acute, primary and rehabilitation care and public, private and non-government organisation (NGO) care providers.

There is increasing interest in the provision of more appropriate and comprehensive end of life care in Australia today. Recent suggestions and/or initiatives include increased referral to palliative care,² incorporating a palliative approach into chronic disease care,⁹ revised advance care planning legislation with accompanying programs to encourage completion of advance care directives,¹⁰ ambulatory palliative care clinics,¹¹ shared care initiatives between general practice and palliative care services,¹² end of life care coordinators for specific chronic diseases¹³ and screening on hospital admission to identify those who may be approaching the end of life.¹⁴ However, there has been little

consideration of how these initiatives can actually be incorporated into existing care models. It has been suggested that end of life care is everyone's business,¹⁵ but the reality is that making it everyone's business requires changes at all levels of the health system.

This thesis examines the broader health policies and systems which underlie the provision of end of life care for people with advanced chronic disease in Australia today. Successful policy and system change is only possible if all the parts of the various systems involved in end of life care are identified, their interactions and care provision mapped and their ability to meet the care needs of patients and carers assessed.

To develop this comprehensive picture of the health system, this thesis examines the following research questions:

1. *How can the health system provide care that meets the needs of people with advanced chronic disease and their carers/families?*
 - a. *How does the health care system currently support people with advanced chronic disease and their carers/families as they manage their chronic disease and address the issues required for end of life care?*
 - b. *How appropriate, available and accessible is end of life care for people with advanced chronic disease?*
 - c. *How do the complicated entities of chronic disease and palliative care interact in the Australian health care system at a national, state and local health service level?*
 - d. *Why does the health system function in the way it does to provide end of life care?*
2. *Where are the effective points of intervention to change the system and support and empower patients?*

To answer these research questions, I use complexity theory and Health Policy and Systems Research (HPSR)¹⁶ to explore the policies, systems and people at the heart of the health system.

The thesis is divided into three parts: Part 1 (Chapters 1, 2 and 3) provides the introduction and background to the research, including the methodology and

research design. Part 2 reports the results of the three phases of the research and Part 3 draws together the literature and the research results to answer the research questions and develop recommendations for a way forward for end of life care for people with advanced chronic disease in Australia.

In *Chapter 1*, I provide the background to the thesis, explaining in broad terms the issues I addressed in my research and the theoretical background underpinning the methodology and methods, which includes a brief overview of health systems, complexity theory and HPSR. This chapter includes a journal article which begins the discussion about the end of life care needs of people with advanced chronic disease and the role of palliative care for such patients.

Chapter 2 details the background and evidence around end of life care. I address a number of key questions including the differing definitions of palliative care, end of life care and chronic disease and the impact on service provision and planning of the different understanding of these terms. I examine current drivers for change including the scope of the problem, demographics, epidemiology and issues around ethics and quality of care. A number of barriers to the widespread provision of end of life care for chronic disease have been identified in the literature and I explore these in some detail. I then bring together the evidence around end of life care to explore these issues in the Australian context and I finish with an exploration of the strategies that can best support end of life care for people with advanced chronic disease.

Chapter 3 describes the methodology and methods I used to undertake this research, including the specific ethical issues involved when researching care at the end of life and the reflexivity required when using a qualitative approach in this sensitive area. The HPSR framework led to a three phase research design so I firstly describe the phase one health policy analysis I undertook, Phases two and three used a series of interviews and a systems analysis framework to explore system functioning with patients, carers, health care providers, service managers and policy makers. The data analysis process is then described and the chapter finishes with an examination of the rigour and quality assurance processes used throughout the research.

Chapter 4 describes my analysis of Australian policies at state and federal level related to chronic disease, end of life care and ageing and includes the journal article I wrote reporting on these findings. *Chapters 5 and 6* report the results of the systems analysis I undertook based on the three key domains of system structure, process of care and patient outcomes. This was developed from interviews with patients, carers and key service providers. *Chapter 7* completes the systems analysis, reporting on the results of interviews with chronic disease and end of life care service managers and policy makers.

Chapters four to seven allowed me to develop a comprehensive picture of how the health system currently functions for people with chronic disease approaching the end of their life, but this was only the first step in answering my research questions. *Chapters 8 and 9* bring together the results of my literature review and my policy and systems analysis. In *Chapter 8*, I use systems thinking and a complexity theory framework to examine why the system functions as it does, including examination of specific aspects such as culture, beliefs, education, assumptions and inappropriate models of care. I then explore the core elements for a best practice model of care that can effectively meet the needs of people with advanced chronic disease as they approach the end of their life. Understanding why the system functions as it does then enabled me to identify the most effective areas to intervene to bring about change.

Chapter 9 finishes the thesis by identifying a series of specific strategies and recommendations aimed at intervening in the system to move end of life care from a clinically focused chronic disease management model to a person centred, coordinated and integrated model of care which could facilitate a shift from a chronic disease management/palliative care clinical paradigm to a broader public health paradigm.

Part 1. Background

The genesis of this thesis was the growing recognition that the need for specific end of life care for people with advanced chronic disease is not being addressed in our current health system.^{8,17} Whilst there have been considerable efforts made to improve the management of chronic disease both nationally and internationally, there is minimal acknowledgement that end of life care forms part of the continuum of chronic disease management. Little attention has been paid to this aspect of care compared with prevention and systematic care processes.¹⁸ It is often assumed that referral to palliative care services will meet the needs of people with advanced chronic disease, but there has been little consideration of whether palliative care services are able to address the needs of this growing group of patients, either in terms of service capacity or the appropriateness of a model of care originally developed in the context of cancer.

To date, no systematic examination of the Australian health system in relation to the provision of end-of-life care for people with chronic illness has been undertaken. There may be significant organisational and systemic constraints and barriers preventing the provision of appropriate care. People with advanced chronic disease often have multiple co-morbidities and interact with the health system on a variety of levels. Their care is influenced by a range of factors including socio-economic status, geographic location, cultural background, personal support systems, and level of health literacy. An added complexity in end-of-life care is the context and understanding of death and dying at an individual and societal level.

This first part of my thesis examines in detail the current state of care for people with chronic disease approaching death including the drivers for change and the variety of systems, beliefs, models of care and funding processes which impact on the provision of such care in Australia today. In Chapter 1, I set the scene for the thesis, introducing my arguments and briefly outlining my research approach. In Chapter 2, I present the results of a literature review, exploring in detail the imperatives driving a new approach to end of life care in advanced chronic disease, examine what effective and efficient end of life care might look like and

review options for developing different models of end of life care. Chapter 3 details my research methodology and the research process, including recruitment, data collection and analysis frameworks.

Chapter 1. Setting the scene

1.1. Introduction

The provision of end of life care has gradually become recognised as a vital part of medical care, since Dame Cicely Saunders pioneered palliative care for people dying with cancer in the early 1960s.¹⁹ In most developed countries, palliative care is now a core element of the care provided for people as their cancer advances.²⁰ A growing recognition of the importance of similar care for people with advanced chronic disease is slowly being reflected in national and international palliative care policy.^{2,9,21} However, in practice, the specific end of life care needs of people with advanced chronic disease are still not recognised as a routine part of their care and there is increasing evidence that these care needs are not being met adequately or appropriately.^{7,22,23}

People with advanced chronic disease frequently move between the acute and primary care sectors as they approach the end of their life. Many have significant multi-morbidities, making their care even more complex. Care is provided across the health, ageing and disability sectors and there are multiple funding sources. In order to understand the complexity of how the health system functions for people with advanced chronic disease, identify where it should change and explore the most effective models of care, a comprehensive research methodology was required. Health Policy and Systems Research (HPSR)²⁴ allowed me to explore health service dimensions such as policy, planning, management and organisational functions and ensure that the context and care experiences of people with chronic disease were included.

HPSR uses systems thinking, based on complexity theory, as a framework to examine relationships and interactions both within the health system and between the health system and other systems involved in end of life care.¹⁶ In this chapter, I examine exactly what a health system comprises and how this is reflected in the Australian context. I then define some of the core concepts of complexity theory and chaos theory and how they relate to complex adaptive systems. I finish the chapter with an outline of the principles of systems thinking and HPSR as they

apply to the health system and describe how I specifically applied them to my research.

The following paper, published in March 2013, reflects my thinking as I began to examine the evidence around the care needs and experiences of people with advanced chronic disease approaching the end of their life, and my own experience of researching people with severe COPD.¹⁸ This research demonstrated that the needs of people with severe COPD are not being met; the care they receive is often uncoordinated, there is minimal involvement of palliative care services, communication is poor, and most people have difficulty accessing the services they need.¹⁸ What is not clear, either in the literature or in our research, is why this is so.²⁵ This first paper begins to explore the strategies and interventions that might assist the integration of chronic disease and palliative care at all levels of the health system.

Burgess, T; Braunack Mayer, A; Crawford, G & Beilby J. 2013 Meeting end-of-life care needs for people with chronic disease: Palliative care is not enough. *Medical Journal of Australia*. 198(4): 186-187.

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Following publication of this paper, I was contacted by someone frustrated at the lack of understanding in the health system of the needs of her ninety year old father with severe heart failure. He was subject to ongoing interventions and there was no discussion that he might be approaching death. Following his death, she encouraged me to continue this research:

*.....so other people do not have to die in the way my father has died.
Now I am not saying the hospital staff did anything wrong - their care
for him was very evident. However, there is a difference between
saving life and honouring the ending of a life.*

These concerns about the lack of care which both recognises disease management and combines it with supportive care for people with advanced chronic disease is reflected internationally, with similar issues to Australia raised in the US,²⁶ UK,²⁷ Canada,⁹ Germany²⁸ and Spain.²⁹ The pervasiveness of the problem points to issues with organisations, policies and systems, rather than failures in individual service provision. Thus, any examination of end of life care in Australia must begin with a review of the health system itself.

1.2. What is a health system?

In order to understand how the health system is working for people with end of life care needs, we need to first define the current health system in Australia and identify which parts are relevant for end of life care in advanced chronic disease. In 2007, the World Health Organisation (WHO)³⁰ defined a health system as consisting of:

“all organizations, people and actions whose primary intent is to promote, restore or maintain health. This includes efforts to influence determinants of health as well as more direct health-improving activities. A health system is therefore more than the pyramid of publicly owned facilities that deliver personal health services.”^{p.2}

The building blocks of a health system comprise:³⁰

1. service delivery
2. health workforce
3. information

4. medical products, vaccines and technologies
5. financing
6. leadership/governance.

The overall goals and outcomes of a health system are improved health (level and equity); responsiveness; social and financial risk protection and improved efficiency. However, the WHO³⁰ notes that it is the *relationships and interactions* between all the elements of the health system that actually make up the system – not the building blocks themselves. Any examination of the health system must look not only at the individual elements noted above, but how these all interact and the various levels at which they function – i.e. the complexity of the system.¹⁶

Applying this understanding of a health system to Australia, it is clear that Australia has a range of health system issues which have a direct impact on care provision in advanced chronic disease including:

- ongoing health system reform, including the changing role of primary care and an urgent need for more effective ageing policy and services.
- Split state/federal funding and responsibilities for the provision of end of life care services across sectors and levels of government.
- Chronic disease, palliative care and aged care being managed by different sections of the health system at a national level.
- Key support services being provided outside the health system (e.g. funding for home support services for people aged >65 years; housing).
- Most chronic diseases being managed and treated in disease “silos”.

These issues contribute to a very complex picture of chronic disease and end of life care provision in Australia today. People with a long standing chronic disease have interactions with the health system on a variety of levels, and they often have more than one chronic disease. Chronic diseases themselves are complex: trajectories differ, access to treatment and services varies, co-morbidities interact with each other and there are often few intersections between funding and health policies.³¹ Palliative care is also complex: the relationships between the physical, psychological, social and spiritual are different for every person, and so outcomes can also be very different.³²

To identify a framework to effectively explore how these multitudes of issues interact and impact on care, I first examined systems theory, as I thought this may allow me to look at the system as whole. Mingers and White³³ suggest that a systems approach allows: ^{p.1148}

- *viewing the situation holistically, as opposed to reductionistically, as a set of diverse interacting elements within an environment;*
- *recognizing that the relationships or interactions between elements are more important than the elements themselves in determining the behaviour of the system;*
- *recognizing a hierarchy of levels of systems and the consequent ideas of properties emerging at different levels, and mutual causality both within and between levels;*
- *accepting, especially in social systems that people will act in accordance with differing purposes or rationalities.*

Although a systems approach offered a comprehensive examination of health care, it did not provide a flexible enough framework to explore both the internal and external relationships in the health system. Because end of life care for advanced chronic disease involves so many different parts of the health system and is also strongly influenced by societal factors, a theoretical approach that provides a full analysis of the multiple interactions occurring at a variety of levels in the health care system was required. This led me to an exploration of complexity theory.

1.3. Complexity theory and complex adaptive systems

Complexity theory forms the basis of complexity thinking and complexity science.³⁴ Systems can be simple, complicated or complex. Complicated systems may have many different parts or elements, but these always work in a predictable manner – e.g. a jumbo jet engine.³⁵ Complexity arises when there are relationships between the system components and between the system and the environment and the relationships shift and change – i.e. the human body is a complex system.³⁶ If any component is removed from a complex system, it can adapt to the change, but complicated systems may not survive the removal of one major component.³⁷

Complexity theory takes a holistic view of systems, looking at the context, small details and changes and how they interact, rather than taking a reductionist view. Thus, both qualitative and quantitative research methods can be used to examine complex systems such as health care.³⁸

A core concept associated with complexity theory is chaos, and McMillan³⁸ suggests that complexity theory cannot be understood without a knowledge of chaos theory. Chaotic systems are not necessarily complex, and vice versa, but both are non-linear and sensitive to their initial conditions, so their evolution cannot be predicted.³⁷ In a chaotic system, a simple set of starting conditions may generate complicated and unpredictable outcomes.³⁹ Figure 1 outlines the key concepts of Chaos Theory.

Complex systems are poised between order and chaos because they have a high level of connectivity between all the parts of a system, so that each part is dependent on the other.³⁷ A Complex Adaptive System (CAS) is a self-organising system that can learn and adapt to changed circumstances in ways that are not always predictable. There is no central controlling mechanism in a CAS so the system is constantly learning and adapting to changing circumstances and revising and changing its structures.³⁵ It consists of a large number of elements interacting dynamically, so the system is not just the sum of its components, but also considers the relationships between these components.³⁵ If a system cannot learn and adapt it may be complex, but it is not adaptive – e.g. the weather is a complex system, but it does not learn over time.³⁸ When a system adapts and changes itself into a different system, the new system is often more complex and richer than the original, i.e. the whole is more than the sum of the parts.³⁸ All the elements of a CAS are interconnected, so change in one element changes the context for the others⁴⁰ and any element in the system can influence or be influenced by any other element. Unlike complicated systems, CAS interactions are non-linear, and respond only to locally available information, so small causes can have large results and vice versa.³⁵

The butterfly effect: All complex dynamical systems are highly responsive and have interconnected webs of feedback loops which are very sensitive to their initial conditions and small variations over time can lead to major changes. The idea that very small changes in one part of a dynamical system can have major effects in another part or on the system as a whole means that outcomes can be quite unpredictable, as how can we know the myriad of small changes that may be happening in a dynamical system at any one time? The butterfly effect shows that it is almost impossible to determine with any real degree of accuracy the long term outcomes of a series of events. However, this does not mean that the behaviour of the system cannot be explained – rather patterns, flows of behaviours and generic properties are identified.³⁸

Strange attractors: show great sensitivity to initial conditions and are bounded by a “basin of attraction” even though behaviours are unpredictable and unrepeated – i.e. they are not random or unrestrained behaviour – they have their own kind of patterning – e.g. the weather is unpredictable, but within bounds – for example monsoons never occur in the UK. This helps to explain why some innovations are adopted easily and others not (e.g. ideas that support particular mental models which may not be evident from the outside).³⁸

The edge of chaos: is the point of balance between ability and chaos, where the parts of a system never quite lock into place but never quite break up either. It can equally be called the “edge of stability” or the “edge of order” – e.g. water – solid ice is stable, steam is chaos – water is therefore the “edge of chaos” – it can go either way.³⁸ The quality improvement “plan/do/study/act cycle” can be seen as an example of working at the “edge of chaos” as it explores new possibilities through experimentation, autonomy and working at the edge of knowledge and experience.⁴⁰

Co-evolution: is when the elements of a system interact with each other in such a way that a symbiotic relationship is formed. Each agent in the exchange is changed and in complex systems, one or more system can be embedded in other systems (e.g. a hospital is embedded in a health care system which is embedded in a political system) and so if one system changes, so will all the others.^{38,40,41}

Universality and patterning: different systems behave in similar ways when they move from orderly to chaotic states. In healthcare, this is particularly important when considering implementing changes – structure, processes and patterns are intertwined and so patterns of relationships, beliefs, traditions and fear are key parts of any system. Different combinations of agents can lead to the same outcomes or the same combination of agents can lead to different outcomes.^{38,41}

Figure 1: Chaos theory concepts

An increasing number of studies are suggesting that a complexity framework provides unique and productive understandings of health care systems and can contribute to the development of effective interventions for a variety of chronic diseases and care settings.^{42,43} Plesk and Greenhalgh discuss the increasing complexity of health care systems, noting that mechanistic approaches that assume the same inputs will always give the same outputs regardless of context are no longer viable in health.⁴⁴ Sturmberg and Martin⁴¹ suggest that complexity theory allows us to understand health and disease in the context of individual people in their individual circumstances, helping to identify which care will best suits their needs. Complex systems display the following properties and the associated examples show how the health system demonstrates these properties:

The agent and the system are adaptive over time: changes occur in the system and the system will either change to incorporate them or actively resist them:⁴⁵ e.g. clinical care delivery may not change despite ongoing reforms, research and interventions.

Emergence: the behaviour of systems is not a property of any single part of the system, but comes from the interactions of many parts of the system, as all elements of the system are connected in some way: e.g. the prevention paradox.⁴¹

Feedback loops: when an output of a process within the system is fed back as an input: e.g. health services which reach the same groups of people and continually miss poorer populations.⁴⁶

Systems are embedded within other systems and co-evolve: each agent in the exchange is changed e.g. local systems are embedded in state systems which are embedded in national systems and agents can be members of a number of different systems.^{44,45}

Phase transitions: events that happen when a change reaches a “tipping point”: e.g. the development of herd immunity.⁴⁶

Agents’ actions are based on internalised rules: “*The lens that we use to investigate any phenomenon has a profound effect on what we see*”:⁴⁷ p.83 e.g. clinicians viewing patients as passive recipients of medical care rather than being perceived as key partners in care planning and decision making.

Attractor Behaviour: People will act in ways that conform to their priorities and inner beliefs: e.g. innovations are embraced by some health professions and actively opposed by others as they do not conform to their image of their role.⁴⁵

Tension and paradox are natural phenomena not necessarily to be resolved: Competition and disagreement can lead to new learnings and interventions:⁴⁴ e.g. attempting to apply general evidence based concepts to specific individuals and/or contexts.

Inherent non linearity: small causes can have large results and vice versa: e.g. large investments in health services can have minor impacts on reducing inequity.⁴¹

Inherent unpredictability: different combinations of agents can lead to the same outcomes: e.g. even though health systems can differ markedly between countries, comparisons often show very similar health outcomes.⁴⁴

Inherent Patterns: Although you cannot predict specifics, it is possible to make general statements:⁴⁶ e.g. you can know that smoking is bad for your health but how it will specifically impact on individuals cannot be predicted.

Open to environment: a system continually interacts with the environment: e.g. global epidemics can now arise because of the openness, fluidity and mobility of people within the system.⁴¹

Sensitivity to initial conditions: Processes may start at the same point but can follow very different trajectories over time: e.g. health reforms which may work well in one country but fail when transferred to another country's health system.⁴⁶

Viewing chronic disease management through a complexity lens offers a much more comprehensive understanding of the chronic disease process.⁴⁸ Each person with a life limiting chronic disease can have a completely different disease trajectory and require quite different supports and interventions, but the inevitable outcome of death remains the same.³² Complexity theory and the conceptualisation of health systems as complex adaptive systems allows exploration of the system as a whole and its impact on individuals. This is particularly important in the context of end of life care and chronic disease where so many different parts of the health and other systems are involved.

1.4. Systems thinking and Health Policy and Systems Research (HPSR)

Systems thinking is based on the application of complexity theory to systems generally and HPSR provides the methodological framework for the application of systems thinking specifically to the health system. I identified this as the most appropriate way to undertake the practical activity of researching the current Australian health system. De Savigny and Tahreed⁴⁹ define systems thinking as: *an approach to problem solving that views "problems" as part of a wider, dynamic system. Systems thinking involves much more than a reaction to present outcomes or events. It demands a deeper understanding of the linkages, relationships, interactions and behaviours among the elements that characterize the entire system.*^{p33} End of life care for chronic disease is an area where policy and systems issues impact directly on the care of vulnerable people and their families at a time when they are in need of the most support. As previously noted, it is the relationships and interactions between all the elements of the health system that actually make up the system³⁰ and any examination of the health system must look not only at the individual system building blocks, but how these all interact and the various levels at which they function.⁴⁹

Applying complexity theory and systems thinking to chronic disease and end of life care requires a methodology that enables the whole, dynamic health system to be reviewed, rather than individual building blocks in isolation.⁴⁹ Although individual chronic diseases can be life limiting, end of life care requires multidisciplinary input not only from specific disease experts, but from palliative care, ageing, disability, community and psychological services. The scope of the problem requires a systems response, rather than an individual service response, and so a methodology that allows the system as a whole to be explored is vital. HPSR is such a methodology. The Alliance for Health Policy and Systems Research²⁴ notes that *health policy and systems research focuses primarily upon the more downstream aspects of health: it focuses upon policies, organisations and programs but does not address clinical management of patients.*^{p.2} HPSR explores the broader dimensions of health services such as planning, management, and organisational function, but may also look at specific areas of functioning to understand systemic challenges.¹⁶

Applying an HPSR framework requires review at three different levels:¹⁶

- Macro level: examines issues from a very broad perspective considering international and national concerns and policy and service provision initiatives. This is particularly appropriate for end of life care where international initiatives are very relevant for Australia, where service provision can be funded federally but delivered through state based services.
- Meso level: examines organisational and local service provision – in end of life care, specifically how chronic disease management and end of life care services interact and integrate with each other.
- Micro level: deals with the impacts of health policy and service provision on an individual's access to, and quality of, care – in this instance as they approach the end of their life.

The key question asked in HPSR is *what actually happens and why?*¹⁶ In Australia's current health system, identifying both how the system is functioning and why it is functioning as it is for people approaching the end of life, is of key importance if changes are required and new models of care are to be developed.

1.5. Summary

In order to understand the complexity of care for people with chronic disease as they approach the end of life, I needed a holistic framework that considers both the health system and the personal contexts of care. Using complexity theory to map the various interactions between the chronic disease and palliative care elements of the health system allowed me to examine how these parts of the health system were interacting and locate the barriers and service gaps which were leading to sub-optimal care. A complexity lens allowed an exploration not only of how the health system was functioning, but also why it acted in specific ways that often resulted in different outcomes for different patients at different times. The associated methodology of HPSR allowed me to examine health policy and service provision at a systems level as well as the individual contexts and personal experiences of their health care. I used this to develop a coherent picture of the various parts of the health system and to document the complex relationships

between the national and state health departments and the acute, primary and community sectors.

In the next chapter, I will explore the background for my research, looking at population, system and individual imperatives around end of life care in advanced chronic disease; examine various definitions and understandings of palliative and end of life care and look particularly at how other countries are addressing similar issues and the models of care and system responses they have identified. In Chapter 3, I will describe in detail my methodology and how I have applied the HPSR framework.

Chapter 2. Literature review

2.1. Introduction

If Australia is to provide equitable and appropriate care for people with chronic disease as they approach the end of their life, a number of key concerns need to be addressed. A series of issues and questions arise when considering what impacts on the current provision of end of life care for people with chronic disease and answering the following questions provides the framework for this literature review.

- Are ‘*palliative care*’ and ‘*end of life care*’ the same thing for people with chronic disease?
- What are the drivers for the expansion of end of life care for people with chronic disease?
- What barriers exist to the delivery of end of life care for people with advanced chronic disease?
- How does current Australian policy and service delivery support provision of services for people with chronic disease approaching the end of their life?
- What strategies can facilitate the person centred, integrated care that is a key requirement for quality end of life care?

In this literature review, I examine the evidence around the imperatives compelling Australia to develop end of life care models for people with advanced chronic disease and how such imperatives are being considered in health policies and service planning and translated into models of care. In order to answer the questions posed above, I focus on the current provision of care, both nationally and internationally and the evidence around whether this care is meeting end of life care needs. My overarching argument is that Australia needs more effective end of life care models for people with advanced chronic disease.

I firstly provide some definitions of a number of terms that recur throughout the literature and policy and planning documents but actually have no agreed definition: e.g. end of life care, palliative care, a palliative approach and supportive care. I then examine some imperatives driving a greater awareness of

the end of life care needs of people with chronic disease, including demographics, epidemiology, ethics and quality of care issues. Next, I explore chronic disease care and how this articulates with end of life care needs, examine whether the chronic care model⁵⁰ is an appropriate model for end of life and explore the evidence around barriers to the implementation of specific end of life care models in chronic disease. Much of the literature to date has been international and it is important to consider these issues in the Australian context. I look briefly at the Australian health care system, the role of primary health care and review the evidence around access to care. Advance care planning (ACP) is a key component of end of life care and I examine the evidence around ACP in advanced chronic disease and recent Australian initiatives in this area. I finish with a review of alternative models of end of life care for chronic disease, both proposed and those already implemented and some key considerations for developing new models for the Australian context.

2.1.1. A note about the scope of this literature review

In this literature review, I examine the population at a general level, but do not look in any detail at specific populations such as culturally and linguistically diverse (CALD) communities and Indigenous Australians. Both these populations have significant barriers to accessing end of life care in chronic disease and there are major cultural issues that must be considered. A review of cancer care and knowledge in CALD communities identified major issues around communication, access, disempowerment, health literacy and inherited conditions and vulnerabilities from the originating country, noting the need for more research in these areas.⁵¹ CALD communities are very diverse, and adequately addressing culturally specific issues in the area of end of life care would require a major research initiative. Aboriginal and Torres Strait Australians have significantly higher levels of chronic disease than non-Indigenous Australians and the Australian Institute of Health and Welfare (AIHW) notes that 80% of the mortality gap between Indigenous and other Australians aged 35–74 years is due to chronic diseases.⁵² Aboriginal and Torres Strait Islander communities vary significantly between urban, rural and remote settings and there are specific cultural requirements in undertaking research more generally with Indigenous communities and specifically when dealing with end of life.⁵³

Therefore, I felt that the scope of the research I wished to undertake for this thesis was already very broad and complex and I would not be able to do proper justice to the very specific needs of CALD and Aboriginal and Torres Strait Islander peoples in the area of end of life care in the space available to me. Although I recognise that both these populations have significant levels of chronic disease, the very specific issues associated with end of life care with these communities were outside the scope of this research. However, I have included some discussion of CALD and Aboriginal and Torres Strait Islander populations in relevant sections in this chapter and also in Chapter 9 in my consideration of how we may more generally address the needs of these populations.

2.2. Are ‘palliative care’ and ‘end of life care’ the same thing for people with chronic disease?

The delivery of care at end of life for people with chronic disease is complicated by confusion about the meaning of the key terms: end of life care, palliative care, a palliative approach, supportive care and chronic disease. In this section, I summarise the range of definitions for each of these terms, and justify my choice of definition in each case.

2.2.1. End of life care

A shared understanding of the terms ‘*end of life*’ and ‘*end of life care*’ is vital if health services are to plan together for effective care for people as they approach the end of their life.^{54,55} In 2004, the National Institutes of Health (NIS) in the United States (US) noted that *There is no exact definition of end of life*⁵⁶ and this continues to be the case today. There is no agreement on what is meant by ‘*end of life*’ or ‘*end of life care*’ and how this may differ from ‘*palliative care*’ either in Australia or internationally. Definitions of end of life fall into two main categories – those that consider the last days or weeks of to be the end of life period life (sometimes also called the terminal stage) and those that take a much broader view that end of life encompasses a period of twelve months or more before death.⁵⁵

The Australian National Palliative Care Strategy (ANPCS) *Supporting Australians to Live Well at the End of Life* defines palliative care, but does not specify when people with life limiting illness should be considered to be near or at

the end of life.² CareSearch (the Australian palliative care knowledge network website: <http://www.caresearch.com.au/caresearch/tabid/738/Default.aspx>) notes: *There is no clear cut definition of the 'end of life'. In general it refers to the last few days of life when a person is irreversibly dying, also known as the terminal phase.* In contrast, Palliative Care Australia (PCA), the peak body for palliative care advocacy and policy in Australia, defines end of life as⁵⁷ *That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.*^{p.8}

There is considerable overlap in the literature between definitions of 'end of life' (being the period of time when people are considered to be approaching death imminently) and 'end of life care': i.e. the care provided in this period. The latter often carries an implicit definition of an end of life time period and the type of care that is suggested. There are also blurred understandings of the terms 'hospice palliative care'; 'palliative care'; 'end of life care' and 'palliative and end of life care'.⁵⁸ O'Connor⁵⁹ points out that there is significant literature suggesting that end of life care is a separate entity from palliative care with a focus on life limiting illness, rather than imminent death. A recent study of the palliative and oncology literature found no clarity regarding definitions of palliative care, end of life care, supportive care and hospice care, noting that this had clinical, administrative and academic implications.⁶⁰ The 2008 End of Life Strategy in the United Kingdom (UK)⁵⁵ suggests that 'end of life care' carries a broader focus than 'palliative care' particularly when combining social care with health care and this is supported by the *Quality of Death* report from the Economist Intelligence Unit⁶¹ which notes that *End-of-life care in this report includes palliative care but also refers to broader social, legal and spiritual elements of care relevant to quality of death.*^{p.5} In their 2015 National Consensus Statement, the Australian Commission on Safety and Quality in Health Care (ACQSHC) defines end of life as *The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.*^{62 p.33}

Lynn and Adamson discussed the changing concept of dying in their seminal report *Living well at the end of life*.²³ They noted that *at one time, a person was healthy, then sick and either recovered or died quickly*^{23, p.6} but now this has changed markedly: people with chronic illness can be very ill for long periods, with diminishing capacity and severe disease exacerbations and can be ‘*near death*’ for some months or years.²³ Lunney, Lynn and Hogan⁶³ have identified a number of different trajectories of declining function associated with both malignant and non-malignant disease, all of which are associated with the last year of life. In Canada, *The Way Forward Initiative* (TWF)⁶⁴ suggests the integration of a palliative approach into chronic disease management, with an increasing focus on palliative care in the last year of life.

If there is no shared understanding of when people are considered to be approaching their end of life period, the outcome is that key services are not accessed and appropriate care is not provided. Boyd and Murray call this ‘*prognostic paralysis*’,⁵⁴ noting that *...being alert to the possibility that a patient might benefit from supportive and palliative care is central to delivering better end of life care.*^{p 649} Thus, a broadening of the term *end of life*’ to encompass a much longer period than the just the terminal phase of an illness is vital in terms of care provision. Accordingly, in this thesis, the terms ‘*end of life*’ and ‘*end of life care*’ encompass more than the last days or weeks of life and refer to a period when people’s needs are changing as their condition deteriorates and the services they require are dictated more by symptoms and a focus on quality of life than by the proximity of death.

2.2.2. Palliative care and a palliative approach

There is a generally agreed WHO definition of palliative care which is reflected in the palliative care policies of many countries including the ANPCS:²

*an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*⁶⁵

However, confusion about the nature and scope of palliative care remains. In a 2012 Australian Senate Inquiry into palliative care in Australia, the role of palliative care services and the implementation of a palliative approach to care were discussed by participants.⁶⁶ It was recognised that the term palliative care was often misunderstood and some participants suggested that palliative care be disassociated with end of life care because of misconceptions about such care being only for terminal patients.⁶⁶ The confusion around the role of specialist palliative care services was identified and a recommendation made for the development of:⁶⁶

a uniform national palliative care pathway that clarifies when general palliative care moves into specialist palliative care, and maps the diagnosis and referral process to ensure that a palliative patient's journey involves coordinated access to all necessary services.^{p.xiii}

The WHO definition of palliative care talks about an approach to care rather than a specialist service⁶⁶ and the PCA defines a palliative approach as:⁵⁷

... a term that has been used to describe care that aims to improve the quality of life for individuals with an eventually fatal condition, and their families, by reducing their suffering through early identification, assessment and treatment of pain, physical, psychological, social, cultural and spiritual needs.^{p11}

A number of chronic disease and palliative care professionals have suggested the incorporation of a 'palliative approach' into existing care, rather than referring people with advanced chronic disease to specialist palliative care services.⁶⁷⁻⁶⁹ What then is the role of specialist palliative care in end of life care provision in chronic disease? To date, there has been minimal exploration of how specialist palliative care services can be effectively integrated into the management of chronic disease and more specifically, who has responsibility for care as a person's condition deteriorates as they approach the end of life. The ANPCS states that:²

Specialist palliative care services have a vital role in providing expert clinical advice – particularly for those with complex symptoms requiring palliation, as well as the provision of direct care for a small

number of patients and more broadly the provision of capacity building and support services to the broader health and human services sectors.^{p2}

Gillick⁷⁰ suggests that palliative care should not be thought of as care for dying people but rather the gold standard of all care. She argues that the basic tenets of palliative care: an interdisciplinary approach; advance care planning; attention to psychosocial issues and symptom control, should be the basis of care for all patients and palliative care should not be considered as separate from conventional medical care.⁷⁰ As such, palliative care specialists would be viewed as the same as other specialists, and called on for their expert skills and knowledge as required for complicated and complex patients.

One example of this is the *Advanced Illness Management (AIM) Program*⁷¹ in California, which uses an interdisciplinary team consisting of nurses, social workers, health coaches, and physicians, who provide specialized care for patients in the hospital, in the physician's office, and at the patient's residence, whether at home or in a residential care facility, through personal visits and by telephone. Crawford et al⁷² suggest that the palliative care specialist role includes consultation, particularly around the appropriate and timely use of pharmacological and non-pharmacological interventions; education, particularly around advance care planning conversations; skills training, particularly in the areas of psychological, spiritual and social support; support for developing inclusive care processes for the meaningful engagement of patients and families in care planning; facilitating access to hospitals and hospice where required and encouraging and supporting the development and use of bereavement support tools and programs.

2.2.3. Chronic disease

As with "end of life", there is no agreed definition of chronic disease.^{73,74} Goodman et al⁷⁴ have identified a number of definitions from both the academic literature and government and other publicly available sources, and found considerable differences between definitions in areas such as risk factors, duration, pathology and ability to be cured. They emphasise the importance of a

standardised definition, particularly for monitoring public health and measuring disease at a population level.

The Australian National Chronic Disease Strategy (ANCDS)⁷⁵ identified the core characteristics of chronic disease, which the AIHW expanded in 2010 to encompass:⁷³

- *complex causality, often associated with multiple risk factors*
- *gradual onset during which there may be no symptoms*
- *long lasting with persistent effects that progress over an individual's life*
- *sometimes associated with the development of other chronic diseases*
- *functional impairment or disability.*

The AIHW further notes that:⁷³.

Most chronic diseases are rarely cured and do not resolve spontaneously. They persist over time, and can become immediately life-threatening (for example, heart attacks associated with coronary heart diseases). Chronic diseases can be intensive in terms of management (for example, end-stage kidney disease) and most persist throughout an individual's life, but are not always the cause of death (for example, arthritis). People can live for many years with chronic conditions; however, quality of life can be significantly compromised through activity limitation and impairment and a need for prolonged assistance.^{p.2}

Based on the AIHW definition, the Australian government defines chronic disease as:⁷⁶

illness that is prolonged in duration, does not often resolve spontaneously, and is rarely cured completely. Chronic diseases are complex and varied in terms of their nature, how they are caused and the extent of their impact on the community. While some chronic diseases make large contributions to premature death, others contribute more to disability

A wide variety of diseases fall under the Australian definition of chronic disease. They encompass both mental and physical illness and can be life limiting (e.g.

chronic obstructive pulmonary disease – COPD and end stage renal disease – ESRD) and/or cause significant disability (e.g. arthritis and depression). Australia recognised the importance of addressing chronic disease through the development of a series of National Health Priority Areas (NHPA), beginning in 1996.⁷⁷ The nominated conditions were identified as imposing high social and financial costs on Australian society. Current NHPAs are⁷⁶

- asthma
- cancer control
- injury prevention and control
- cardiovascular health
- mental health
- diabetes mellitus
- dementia
- obesity
- arthritis and musculoskeletal conditions

Other conditions considered as chronic diseases include neurological diseases; osteoporosis; liver diseases such as hepatitis B and C, and cirrhosis and increasingly cancer and HIV/AIDS.⁷⁴

Although there are a variety of definitions of chronic disease, most definitions include a recognition that they are life limiting and have a significant impact on quality of life as they progress. Despite this recognition, the various approaches to the prevention and management of chronic disease models aimed at the provision of evidence based, best practice care rarely encompass specific end of life care interventions.⁷⁸ In section 2.5.1 below I will review the most common model of chronic disease management (CDM) and examine how this model and others can encompass end of life care.

2.2.4. Summary

Whilst Australia has a growing palliative care sector and a strong focus on chronic disease prevention and management as noted above, end of life care for people with non-malignant disease is still not well developed. Although there is a growing recognition that a chronic disease is life limiting, in Australia there is currently no clarity about when end of life care should begin and who has responsibility for the provision of such care. Gomez-Batiste et al⁶ have suggested a re-definition of palliative care to more explicitly address the needs of people with advanced chronic disease. If palliative care in Australia today did encompass the ‘*conceptual transitions*’ they suggest in Table 1,⁶ which broaden the scope of

palliative care and ensure consideration of the specific needs of end of life care for people with advanced chronic disease, palliative care and end of life care could be considered to be the same thing. However, these changes have not been adopted in Australia to date and palliative care continues to have a more narrow focus with limited ability to encompass both specific and supportive care. Therefore the terms ‘*end of life care*’ and ‘*palliative care*’ cannot yet be considered to be the same thing.

Table 1. Conceptual transitions in palliative care in the 21st century.⁶

Change from:	Change to:
Terminal disease	Advanced progressive chronic disease
Prognosis of weeks or months	Limited life prognosis
Cancer	All chronic progressive conditions
Disease	Condition (frailty, pluripathology, dependency)
Progressive course	Progressive course with frequent crises of needs and demands
Mortality	Prevalence
Dichotomy curative - palliative	Synchronic, shared, combined care
Specific OR palliative treatment	Specific AND palliative treatment as needed
Prognosis as criteria for intervention of specialist services	Complexity as criteria
Rigid one-directional intervention	Flexible intervention
Passive role of patients	Advance care planning
Reactive to crisis	Preventive case management
Palliative care services	Palliative care approach everywhere
Specialist services	Actions in all settings of healthcare
Institutional approach	Community approach
No planning	Public health approach
Fragmented care	Integrated care

2.3. What are the drivers for the expansion of end of life care for people with chronic disease?

2.3.1. Demographics

Australia is facing an ageing population with increasingly complex care needs as they approach end of life.² As the population ages, there is an increase in the

incidence and prevalence of life limiting chronic diseases, because the likelihood of developing these diseases and living with them increases with age. The WHO estimates that the number of people in the world aged 65 or older will grow from an estimated 524 million in 2010 to nearly 1.5 billion in 2050.⁷⁹ In developed countries in 2000, almost twenty percent of the population was aged 60 or older. This is expected to reach 33% by 2050, with the greatest rise in population expected in the over 80 age group.⁸⁰ Currently, Japan, Sweden, Italy and Germany have the oldest populations in the world, but countries such as China, Brazil and India and other developing countries with ageing populations will soon face issues of a similar magnitude.⁷⁹

The 2010 Intergenerational Report estimated that the number of Australians aged >65 years will increase from 13% to 25% by 2050, with a subsequent increase in the number of people with complex health needs, who will require specific care at the end of their life.²⁵ In 2010, 143,500 people died in Australia⁸¹ with a steady increase in the number of deaths over time, reflecting an increasing population, with an increasing number of older people.⁸¹ The Australian Productivity Commission reports that more than 160,000 Australians were accommodated in residential aged care facilities in 2010 with 55% of residents >85 years of age. It is estimated that 3.5 million Australians will be accessing aged care services by 2050.⁸² They further note that this will be accompanied by an increase in frailty and complexity of needs including end of life care needs. PCA suggests that annually, the proportion of people whose death might be expected is between 25% and 50%.⁸³ The Aboriginal and Torres Strait Islander population is also ageing and, by 2026, the proportion of Aboriginal and Torres Strait Islander peoples aged over 65 years is predicted to more than double.⁸⁴ Similarly, Australia's CALD population is ageing, with almost 20% of all Australians aged 50 years being people whose first language is not English.⁸⁵

Access to appropriate care at the end of life can be problematic for many older Australians.⁸² Given the expected increase in the number of older Australians with chronic disease, a significant increase in demand for end of life care services is anticipated.⁸² Rosenwax et al reported that at least 50% of people who died in 2008 had conditions where their death could be expected.⁸⁶ PCA has suggested that:⁸⁷

The issue though is not whether older people get less care, but whether they get less care on the basis of their needs compared with other patient groups.^{p.18}

Older people may not always access appropriate pathways to palliative care despite having common chronic conditions and some models of residential aged care act as barriers to appropriate end of life care.⁸⁷ The Australian government has recognised the importance of end of life care for ageing Australians and has developed guidelines for a palliative approach in both residential⁸⁸ and community based⁸⁹ aged care. The Productivity Commission Report *Caring for Older Australians* states that:⁹⁰ *Palliative and end-of-life care is ‘core’ business of any aged care system*^{p87} and they note that, for older people, a ‘good death’ incorporates elements such as advance care planning, respect for one’s wishes, symptom control and dying in a place of their choice.⁹⁰

2.3.2. The epidemiology of advanced chronic disease

Non-communicable diseases (NCDs) are causing a growing proportion of all deaths worldwide, as population growth and ageing drive large increases in the burden of mortality.⁹¹ The five main NCDs are cardiovascular diseases, diabetes, chronic kidney disease, cancers and chronic respiratory diseases. They are the largest global cause of death with cardiovascular diseases, diabetes, cancers and chronic respiratory diseases accounting for an estimated 86% of the burden of disease in developed countries and more than 65% of all deaths in 2008.⁹²

This international picture is reflected in Australia’s mortality data: in 2013, six of the top ten causes of death in Australia were chronic disease related (Table 1).⁹³ In addition to having an ageing population, the proportion of Australians with significant risk factors for the development of chronic disease is also growing, suggesting that there will be a major and growing need for end of life care for a large proportion of the Australian population in the future.

Table 2. Leading causes of death, Australia: 2013⁹³

1	Ischaemic heart diseases
2	Dementia and Alzheimer disease
3	Cerebrovascular diseases
4	Trachea, bronchus and lung cancer

5	Chronic lower respiratory diseases
6	Diabetes
7	Colon, sigmoid, rectum and anus cancer
8	Blood and lymph cancer (including leukaemia)
9	Heart failure
10	Prostate Cancer

An ageing population is not the only cause of the increasing prevalence of diseases such as diabetes, renal failure and heart disease: lifestyle factors also play a major role in their development. The Australian Institute of Health and Welfare (AIHW) reports that⁹⁴ *of all deaths in Australia in 2004, 20.5% occurred in people aged less than 65 years.*^{P.9.} They note that lifestyle factors such as smoking, poor diet, physical inactivity and excessive alcohol consumption are major contributors to the development of chronic disease and report that 97% of all Australian adults in the 2004/ 05 National Health Survey had at least one of these risk factors.⁹⁴ The major chronic diseases associated with these lifestyle risk factors are diabetes,⁹⁵ cardiovascular disease (CVD),⁹⁶ ESRD⁹⁷ and COPD.^{33, 34} Premature mortality is a particular issue in Aboriginal and Torres Strait Islander communities, with the AIHW reporting that *65% of deaths among Indigenous people occurred before the age of 65, compared with 19% of deaths among non-Indigenous people.*⁸⁴

Neurological diseases are also increasing in prevalence and incidence and these are perhaps the most likely of all diseases to contribute to the growing burden of disease, both nationally and internationally.⁹⁸ Four particular chronic diseases contribute to this burden – cerebrovascular disease; Parkinson’s disease (PD), multiple sclerosis (MS) and dementia (see Table 2).⁹⁸ Begg et al⁹⁹ suggest that neurological and sense organ disorders will be the third largest cause of health loss in Australia by 2023 and the AIHW report that the number of people with dementia is projected to triple between 2011 and 2050.¹⁰⁰ In CALD populations, the prevalence of mild cognitive impairment is currently 2 – 3 times higher than in non-CALD populations and the incidence of Alzheimer’s Disease is also projected to triple.⁸⁵

Table 3. Deaths attributable to neurological disorders as percentage of total deaths, 2005, 2015 and 2030.⁹⁸

	2005	2015	2030
Cerebrovascular disease	9.90	10.19	10.63
Alzheimer and other dementias	0.73	0.81	0.92
Parkinson's disease	0.18	0.20	0.23
Multiple sclerosis	0.03	0.03	0.02

Whilst individual chronic diseases are increasing in prevalence, there is also a growing number of people dying with more than one disease. In 2007, only one in five deaths in Australia had a single cause, with people dying with more than five chronic diseases increasing from 11% in 1997 to 21% in 2007.¹⁰¹ This is particularly marked in the 75–94 year age group. The AIHW specifically noted the increasing incidence of the comorbidity of CVD, diabetes and chronic kidney disease,¹⁰² noting that:¹⁰³

“These comorbidities mainly affect older people. With a rapidly ageing population, comorbidity will rise. Australian health systems need to be prepared to meet an increasing demand on health services from people with comorbidities.” p.:ix

Cancer is increasingly being considered a chronic disease, with early identification and better treatment contributing to greater longevity.¹⁰⁴ Traditionally, cancer as an entity has been considered separately from chronic disease, but the AIHW have identified that cancers are very commonly associated with other chronic diseases as an underlying cause of death.¹⁰¹ Philips and Currow¹⁰⁴ argue that the significant number of people now living with (rather than dying of) cancer means cancer should now be considered as a chronic disease, with appropriate longer term care processes developed.

2.3.3. Ethics and quality of care

By not providing access to appropriate care at the end of life, the health system may be seen to be contributing to unnecessary suffering.¹⁰⁵ This was recognised in Australia by the National Health and Medical Research Council (NHMRC) in 2011, with their publication of *An ethical framework for integrating palliative care principles into the management of advanced chronic or terminal*

conditions.¹⁰⁶ In this document, the NHMRC identifies the key ethical principles underlying the provision of palliative care for people with a life limiting illness and why health professionals are ethically obliged to work together to provide this care.¹⁰⁶

There is also a growing view that palliative care is a fundamental human right, which Brennan reports has been adopted by a number of different organisations and declarations – e.g. the Korea Declaration and the European Committee of Ministers.¹⁰⁷ Brennan, Gwyther and Harding broaden this argument to suggest that there is a:¹⁰⁸

...broad medical, moral and legal imperative – that the care of patients with life-threatening illness is a fundamental responsibility of governments, societies and health professionals.^{p.8}

They note an increasing interaction between palliative care, public health and human rights, as growing numbers of people with palliative care needs move the issue into the public health realm. The Australian Human Rights Commission¹⁰⁹ also suggests that it is the right of all older people to have an understanding of and access to advance care planning, noting that it is:

...essential to ensure older Australian's end-of-life wishes are respected. This is particularly important in view of the lack of confidence that many older Australians have that their end of life plans will be respected by their families and importantly, health professionals.^{p.15}

End of life care can also be seen as a quality issue: i.e. that appropriate end of life care is a core element of quality care for all people with advanced chronic disease. The ACQSHC has developed a series of standards for the safety and quality of care, including chronic disease care. Standard 9 relates to *Recognising and Responding to Clinical Deterioration in Acute Health Care*.¹¹⁰ It emphasises the need for advance care planning, despite there being currently no specific standards for end of life care more generally. In 2013, they noted that:¹¹¹

the quality and safety of end of life care in Australian acute health services is variable and frequently sub-optimal because of multiple complex and interlinked individual and systemic factors.^{p.244}

In response to this issue, in 2015, they released a national consensus statement on *Essential elements for safe and high quality end of life care*, which contains ten essential elements across the domains of processes of care and organisational prerequisites.⁶² PCA also sees end of life care as an important component of quality care and has developed a set of quality standards for palliative care,¹¹² noting that:¹¹³

Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, primary generalist, primary specialist and support care providers and the community – working together to meet the needs of all people.^{p.1}

2.3.4. The role of carers

Whilst health professionals provide a number of aspects of care for people with advanced chronic disease, the vital role of informal carers is often overlooked. Informal carers are defined by the Productivity Commission as:⁸²

individuals providing [aged] care on a regular basis (often on an unpaid basis and without contract), for example, spouses/partners, family members, as well as neighbours or friends.^{p.xiii}

Informal carers contribute significantly to the care of both older people and those with a chronic disease, particularly as they approach the end of their life¹¹⁴ and TWF states that *carers are essential at end of life*.¹¹⁵ Whilst the majority of informal carers undertake this role willingly, carers of all ages have been shown to suffer adverse events, including physical, social, emotional, psychological and financial impacts.¹¹⁴ Carers are estimated to contribute 1.32 billion hours of unpaid care each year in Australia.¹¹⁶ With an expected decrease in the availability of informal carers as the population ages and fewer young people take on this role, there is a looming crisis in caring.⁸² The Australian government recognised the importance of carers with the development of the *National Carer Strategy* in 2011¹¹⁷ and PCA suggests that carers are *co-workers* in end of life care, and that a key domain of care at the end of life should be *involved and supported carers*.⁸

The imperatives to extend end of life care provision are becoming more urgent as our population ages and they begin to demand access to better quality of care as

they approach the end of their life.¹⁷ It is in the area of chronic disease care that the most change is required, as ageing and lifestyle factors mean more people will be diagnosed with life limiting chronic diseases.¹¹⁸ In the next section I will examine how end of life care is currently being considered and provided for people with advanced chronic disease, both internationally and in the Australian context.

2.4. What barriers exist to the delivery of end of life for people with advanced chronic disease?

Although there is a clear need for specific end of life care for people with advanced chronic disease and growing evidence that this need will increase significantly in the coming years, the current health system is not addressing these needs. The literature identifies a number of barriers for people with chronic disease accessing end of life care including:

- ***A lack of knowledge on the part of many health care professionals about end of life and dying.***⁸ The NHMRC states that palliative care should be introduced early in a life limiting illness, in conjunction with active treatment and that every health professional should have some ability to provide palliative care,¹⁰⁶ as does the ANPCS.² However, a recent systematic review identified that many health care professionals are very uncertain about when it might be appropriate to begin palliative care¹¹⁹ and, at least in COPD, there is no clear cut transition to when a person can be considered be entering the ‘*end of life*’.^{18,120} Boyd and Murray⁵⁴ suggest two transition points to palliative care – one around whether a patient would benefit from beginning supportive and palliative care and the next around whether a patient may be reaching the last days of their life. Both Boyd and Murray and the UK Gold Standards *Prognostic Indicator Guidance*¹²¹ suggest that the surprise question: *Would you be surprised if this patient were to die in the next 6 – 12 months?* is a useful indicator for initiating palliative care. However, Small et al¹²² caution that this may not be useful in COPD and heart failure (HF) as this question may inhibit the broader use of palliative and supportive care for these conditions.
- ***A lack of specific pathways to care.***^{123,124} Proactive end of life care pathways have been identified as core elements of quality end of life care¹²³ and the UK

*Gold Standards Framework in Primary Care*¹²⁴ and the *Catalonia WHO Demonstration Project for Palliative Care Implementation*²⁹ are useful examples of how these can function. In Australia, PCA⁸ notes that there are significant issues in the provision of end of life care that relate to the interface between the primary, acute and community settings as well as between health care professionals and health services themselves and Mitchell et al²² identify that there are currently no systematic processes for identifying and managing end of life care.

- ***Aboriginal and Torres Strait Islander communities:*** There are many different Aboriginal and Torres Strait Islander communities in Australia and so there is no one “Indigenous Australian” experience of death and dying.¹²⁵ There is currently minimal recognition of the central role of family, community and Elders in decision making processes, nor is there widespread knowledge of the concept of palliative or end of life care in many Indigenous communities.¹²⁵ Anderson and Devitt¹²⁵ note that cultural safety is not sufficiently considered in developing end of life care services for Aboriginal and Torres Strait Islander communities and there has only been slight progress in the development of culturally responsive services.
- ***CALD communities:*** Recognition of the diversity of CALD communities and their differing cultures is a key issue in addressing end of life care for people from diverse backgrounds.⁸⁵ Cultural traditions and practices as people approach the end of their life differ significantly and this can be compounded by language barriers and culturally inappropriate health care practices.⁸⁵ Another issue complicating the provision of care is that many people from non-English speaking backgrounds lose their ability to speak English as they age, particularly if they also have dementia.¹²⁶
- ***Philosophical issues:*** a) societal attitudes to death and reluctance to acknowledge/discuss them and b) the place of death in medicine and health care which means that, in hospitals, intervention is always the first choice.¹²⁷⁻¹²⁹ These issues were recognised as major concerns in the UK End of Life Care Strategy,²¹ which funded the *Dying Matters* program¹³⁰ to help communities raise the profile of end of life care. In Australia, PCA⁸ notes a *societal reluctance to talk about death, which limits discussion about*

important issues such as dying at home and stopping futile treatments.^{p.1} The consequences of this societal reluctance to recognise the importance of death and dying include a lack of recognition of the needs and experiences of people at the end of life and of their families.¹³⁰ Price and Cheek¹²⁸ argue that the current discourse around chronic disease indicates that death is something that could be avoided with death being seen as a ‘*failure*’ of care. Callaghan suggests that:¹²⁷

every physician must understand that every one of his patients will eventually die, sooner or later, and either on his own watch or that of some other physician. Medicine has known that ancient truth since the beginning, but has of late tried to ignore it^{p.118}

He suggests that “*The culture and ethos of hospitals is biased towards aggressive care*” and that the denial of death as inevitable has led to major costs in the health system as it invents ever more costly ways of trying to keep death at bay.¹²⁷ The area of chronic disease in particular has focused attention on attitudes to death and dying as, although medical interventions can assist people to live longer with their chronic diseases, they cannot cure them. Health professionals and people who have lived with their chronic diseases for many years are just beginning to realise the inevitability of death.¹²⁷

2.5. How does current Australian policy and service delivery support provision of services for people with chronic disease approaching the end of their life?

To understand how end of life care for people with chronic disease is provided in Australia, we need first to understand how chronic disease more generally is managed. Once we understand how CDM functions and the care it encompasses we can assess how end of life care articulates with CDM processes.

2.5.1. The management of chronic disease

The *Chronic Care Model* (CCM) developed by Bodenheimer, Wagner and Grumbach^{131,132} has become the most widely used model of CDM⁵⁵ and is the basis of most CDM programs in Australia.¹³³ The key components of this model are to:⁵⁰

- create a culture, organization and mechanisms that promote safe, high quality care
- assure the delivery of effective, efficient clinical care and self-management support
- promote clinical care that is consistent with scientific evidence and patient preferences
- mobilize community resources to meet needs of patients

The last decade has seen CCM used in the development of a number of disease specific models of care.¹³⁴⁻¹³⁷ Fromer¹³⁸ argues that the CCM, implemented in the broader context of a patient centred medical home,ⁱ can improve patient outcomes in COPD through a proactive rather than reactive approach. In Australia, the Victorian Human Services Hospital Admissions Risk Program (HARP) demonstrated that a shared care model, based on CCM principles, resulted in improved patient outcomes for people with COPD and HF.¹³⁹

The 2006 Australian National Chronic Disease Strategy (ANCDS)⁷⁵ identifies a continuum of care in chronic disease which is based on CCM and the continuity of care model,⁷⁸ moving from health promotion and prevention, through early intervention to management and self-management, rehabilitation and finally end of life care. However, in practice, early intervention and disease management have been the focus of care, with end of life care largely ignored.

As the focus on chronic disease has intensified over the last fifteen years, the issue of managing multi-morbidities has increasingly been recognised. Care management is usually focused around the treatment of one chronic disease¹⁴⁰ but in fact, multi-morbidities are now the norm,¹⁰¹ which has major implications for a chronic care model focused on a single disease. People with multi-morbidities have a poorer quality of life, spend more time in hospital, are more likely to be depressed and die earlier than people with only one disease.¹⁴⁰ They have

ⁱ The Patient centred Primary Care Collaborative defines a patient centred medical home as: *a model or philosophy of primary care that is patient-centered, comprehensive, team-based, coordinated, accessible, and focused on quality and safety. It has become a widely accepted model for how primary care should be organized and delivered throughout the health care system, and is a philosophy of health care delivery that encourages providers and care teams to meet patients where they are, from the most simple to the most complex conditions.*
<http://www.pcpcc.org/about/medical-home>

increasingly complex care needs and current health policies in Australia are failing to address the challenges associated with multi-morbidity, particularly in an ageing population.¹⁴¹ This has particular implications for end of life care, with multi-morbidities being a key indicator in identifying the need for end of life care on a number of prognostic indicator tools, e.g. the Gold Standards Framework¹²¹ and Scottish Prognostic Indicator Tool (SPICT).¹⁴²

2.5.2. End of life care in the current Australian context.

There is clear evidence that end of life care should be considered in any CDM model. In 2003, Lunney et al.⁶³ identified three clear trajectories of functional decline at the end of life: chronic disease, cancer, and frailty and dementia, each with varying needs across time:

- The chronic disease trajectory described long term functional limitations with intermittent serious episodes, eventually resulting in death.
- The cancer trajectory identified a relatively lengthy period of higher function, followed by a rapid decline in health and functionality until death.
- The final trajectory of prolonged dwindling in frailty and dementia was of decreased and decreasing functionality over a longer period of time.

Lynn and Adamson¹⁴³ further described a “trajectory model of care” where both curative and palliative care occurred simultaneously, as opposed to a “transition” model of care, where aggressive medical care continues until close to death, when all care then becomes palliative. The concept of trajectories of care has been widely accepted^{22,144,145} and is reflected in the ANPCS.²

Any health intervention or health system change requires a policy driver, support from service planners and managers and the resources and structures to implement it.¹⁴⁶ I will now examine the current Australian health care system, how it facilitates or hinders access to advance care planning and end of life care and the role of primary care in the provision of CDM and end of life care.

The Australian health care system

The Australian health care system operates at state and federal levels and is funded through a universal health insurance system, but also has a significant private sector.¹⁴⁶ The federal government has responsibility for collecting taxation, which it then distributes to state and territory governments to fund public

hospitals.¹⁴⁷ Through the Australian Department of Health (previously the Australian Department of Health and Ageing (DoHA), the federal government directly funds primary care services such as general practitioners (GPs) and allied health professionals.¹⁴⁷ Aboriginal and Torres Strait Islander Health is funded approximately equally between the federal (44.8%) and state and territory governments (46.6%)¹⁴⁸ with Aboriginal Community Controlled Health Organisations providing the majority of chronic disease management and community based care.¹⁴⁸ Funding for specific health related programs aimed at “Closing the Gap” between Indigenous and non-Indigenous health outcomes began in 2009.¹⁴⁸ However, there is considerable overlap in responsibility for health system functioning, and so formal ministerial councils such as the Australian Health Minister’s Conference (AHMAC) and the Council of Australian Governments (COAG) provide a forum for negotiation between state and commonwealth health administrations.¹⁴⁶

This separation of responsibility for health service provision impacts on chronic disease and palliative care services directly. In DoHA,ⁱⁱ the Population Health Division has responsibility for CDM (through the Chronic Disease Branch) and Palliative Care (through the Cancer and Palliative Care Branch).¹⁴⁹ DoHA only funds services for people older than 65 years with chronic and complex diseases; those younger than 65 years are funded through Disability Services at a state level.¹⁵⁰ There are a number of other policy areas within DoHA which impact on chronic disease services, including the Primary and Ambulatory Care Division which administers general practice¹⁵¹ and the Ageing and Aged Care Division, responsible for administering community aged care packages, which fund individually planned and coordinated packages of care to support older people to stay in the community.¹⁵²

Each state and territory has a Department of Health and states and territories are primarily responsible for hospital and community health services and funding (excluding general practice). Thus hospital and out patients department (OPD) services in public hospitals for chronic disease and palliative care are a state

ⁱⁱ This information was correct as at 2013, however the Department of Health was restructured following the 2013 election. However, the essential structure has not changed significantly.

responsibility, whilst chronic disease initiatives in general practice and primary care services are a federal responsibility. However, in palliative care for example, a 2009 COAG initiative provided \$500 million to states and territories for the enhancement of sub-acute care services (including palliative care).¹⁵³

One of the most important issues arising from the current structure and financing of the health system in Australia is the separation of different areas of care into ‘silos’.¹⁵⁴ The National Health and Hospitals Reform Commission identified this as a major issue for people with chronic and complex diseases, particularly for accessing appropriate care and knowing how to navigate such a divided system.¹⁵⁴ This is a particular issue for people with multi-morbidities who are often seen by a variety of specialists as well as their GP between whom there is frequently minimal or inadequate communication.¹⁵⁵

In 2011, 46% of Australians had purchased insurance to cover the costs of using the private health system.¹⁵⁶ The majority of private health funding is directed to hospital services, but private health insurance may allow easier access to specialist services and some equipment.¹⁵⁶ However, the majority of palliative care services in Australia are provided through public hospital budgets that may include community coordination of care with private health funds providing minimal to no support for home based palliative care services.¹⁵⁷

The role of primary care

Both the ANCD⁷⁵ and the ANPCS² emphasise the important role that primary care and general practice play in the management of advanced chronic disease. In Australia, CDM is delivered primarily through general practice, and it is generally assumed that, because four out of five Australians visit a GP at least once a year, general practice is the most appropriate place to deliver a wide variety of population health focused activities.¹⁴⁶

General practice is funded at a national level through the Medicare Benefits Schedule which includes a number of rebate mechanisms, the major element of which is “fee-for-service”. This is based on a paradigm where¹⁴⁶ *an individual professional has an individual relationship with an individual patient for which there is an individual payment.*^{p166} Medicare allows for four levels of complexity of consultations and includes a time based element. Levels A and B are under 20

minutes whilst C and D allow for longer consultations, and supplements are paid for home visits, residential aged care visits and out of hours consultations. This system rewards service volume rather than quality of care. GPs may also charge a 'co-payment' as well as the nominated Medicare item cost, as long as the service is not 'bulk billed', i.e. it is not directly billed to Medicare.¹⁴⁶ This payment structure has significant implications for the provision of end of life care which often requires longer consultations, out of hours care and home visiting.

Since 1998, a series of reforms have been undertaken within the Medicare schedule, aiming to better support primary care, management of chronic diseases, immunisation and regular health checks.¹⁵⁸ These are funded through a 'blended payments' system, where funding is provided by a mix of fee-for-service and extra payments to support practice activities, including systematic care infrastructure for chronic diseases such as diabetes. To be eligible for blended payments practices must be accredited.¹⁴⁶ Fee for service provides approximately 70% of general practice funding with the other 30% coming from a variety of other payments.¹⁵⁹

The CCM forms the basis of CDM in general practice and funding mechanisms such as *Enhanced Primary Care* items and *Practice Incentive Programs* were introduced to support this model.¹⁴⁶ A number of states have provided supplementary funding to support general practice CDM initiatives, focused around the concept of hospital avoidance. Thus South Australia developed their GP Plus Health Strategy¹⁶⁰ and NSW¹⁶¹ and Victoria¹³⁹ developed specific chronic disease initiatives, working with general practice. In 2010, the federal government funded a specific Indigenous Chronic Disease Package (ICDP), under the Closing the Gap initiative but in 2014, this became part of the Indigenous Australians' Health Programme.¹⁶² Both of these programs were focused on primary care.

However, funding end of life care in general practice is more problematic. Whilst GPs may be willing to undertake palliative care, they may feel they have neither the skills nor experience to do this effectively, or that they do not have the community based services to support them.¹⁶³ Mitchell et al²² note that key elements of care such as home visiting and after hours care are not part of the practice of many GPs. They suggest that a coordinated, national approach is

required and the adoption of a systematic program such as the UK's Gold Standards Framework would assist general practice to better care for people at the end of life.²²

Access to care

Although the ANPCS states that palliative care should be available to all people regardless of their condition,² by far the majority of people receiving palliative care services in Australia have a cancer diagnosis.¹⁶⁴ What type of care then, can people with non-malignant disease access as they approach the end of life? The AIHW tracks palliative care hospital admissions and specialist care provision,¹¹⁸ however they noted in 2012 that it was difficult to identify the level of palliative care services provided in general practice, as there are no specific item numbers in the Medicare Schedule to identify a palliative care consultation.¹⁶⁵ The available data (from surveys such as the Bettering the Evaluation of Care and Health – BEACH) suggest that 1 in 1000 encounters in general practice were palliative care encounters, but this does not differentiate between malignant and non-malignant diseases.¹⁶⁵ In 2008, PCA noted that:⁸

The health system in the main is designed to treat and cure disease and to provide short-term, episodic care of acute illness. Acute care systems are focused on providing treatment and cure - increasing survival and reducing mortality. For patients who are dying this can result in the delivery of care that is either inappropriate or inadequate.^{p.14}

They note the importance of values when developing end of life care services and suggest that the goals of end of life care should be:⁸

...to preserve and protect the person's dignity and autonomy, to respect their choices and preferences, and to provide care that is both compassionate and competent.^{p.20}

McNamara and Rosenwax¹⁶⁶ assert that the Australian health care system has failed people with chronic conditions, and that dying is currently *dreadfully mismanaged*. Their 2007 population based study of dying in Western Australia found that there was little support for people during the dying process, and indeed many people with non-malignant disease were not aware that they were dying.¹⁶⁶

Although a high level of health service usage was reported, participants reported that pain and symptom management was a major issue and that many of their concerns were ignored.¹⁶⁶ Our 2012 study of advanced COPD in Australia found that the care needs of people with advanced COPD were not being met.¹⁸ This reflects the international experience that people with end stage chronic disease,⁶⁷ advanced COPD,¹²⁰ HF,¹⁶⁷ multiple sclerosis,¹⁶⁸ ESRD¹⁶⁹ and multi-morbidities¹⁷⁰ have significant unmet needs. In 2013, the Health Performance Council of South Australia highlighted the difficulties both Aboriginal and Torres Strait Islander Communities and CALD communities have in accessing end of life care, noting issues with cultural safety, a lack of cultural awareness and culturally appropriate services, language issues, health literacy and a lack of programs specifically focussed on vulnerable communities.¹⁷¹

2.6. What strategies can facilitate the person centred, integrated care that is a key requirement for quality end of life care?

So far in this chapter, I have argued that end of life care for people with chronic disease presents a major challenge to health systems throughout the world.¹⁰⁸ I have identified the imperatives for a better model of end of life care, which include addressing the systemic and societal barriers to the provision of appropriate end of life care for people with advanced chronic disease. Whilst palliative care has now become a core part of cancer care in most western countries, this is not so for people with chronic disease.¹⁷² In this final section I explore a range of possible policy responses and appropriate models of service provision that can help to address the challenges associated with end of life care. These include person-centred care, a renewed focus on integrated and coordinated care, advance care planning and a public health approach to end of life care.

Although all health care systems are different, particular approaches, e.g. the CCM, can have relevance across systems. Some of these approaches are particularly relevant for end of life care.

2.6.1. Person centred care

Patient centred care should be at the core of care at the end of life. PCA states that:⁸

Putting individuals at the centre of care is similarly fundamental in the development of an integrated, person focused system that delivers quality care at the end of life for all.^{p.36}

In 2001, the US Institute of Medicine published their seminal report on the quality of healthcare *Crossing the Quality Chasm. A new health system for the 21st Century*.¹⁷³ They identified that quality care has six key elements: it must be safe; effective; patient centred; timely; efficient and equitable. Patient centred care was defined as¹⁷³ *providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions*.^{p.6} The ACQSHC have suggested that patient centred care should become a dimension of quality in its own right and it is their first essential element of safe and high quality care.⁶² This also has implications for the provision of end of life care for chronic disease, as it emphasises a patient's right to coordinated and continuing care, access to high quality care and the development of new and appropriate models of care.¹⁷⁴ Mead and Bower¹⁷⁵ note that patient centred care is a clear response to limitations found in the biomedical model of health care, and a biopsychosocial framework is closely associated with patient centred care.

Duncan¹⁷⁶ describes a variety of related terms: '*patient centred care*', '*person centred care*', '*client centred care*', '*relationship centred care*' and '*family centred care*'. Each of these terms has relevance depending on the context, but both Duncan¹⁷⁶ and McCormack et al¹⁷⁷ suggest that the term '*person centred*' is the most generally applicable. Entwistle and Watts¹⁷⁸ note that there are many different interpretations of person centred care and suggest that person centred care is about treating '*patients*' as '*persons*', rather than more generic and impersonal '*patient*'. In Australia, the ACQSHC¹⁷⁴ uses the term '*patient centred care*' whilst PCA⁸ uses both '*patient centred care*' and '*person centred care*'. In this thesis, I will use the term '*person centred care*'.

Although there is no agreed definition of person centred care, Duncan identified three core components:¹⁷⁶

a) the recognition of each individual as a unique human being; b) the recognition that each person is an autonomous being with a capacity

to make choices and c) that in order to achieve person centred care in practice, a sensitive and informed flexibility in each health care encounter is essential.^{p35}

He goes on to note that person centred care is *always experienced at an individual level* but is impacted on by health professionals and systems.¹⁷⁶ Thus, if end of life care is centred on the needs of individuals, it is likely that those needs will encompass services from a variety of sectors and health care providers: generally this includes at least a specialist and a GP. For someone to experience *the right care, at the right time in the right place*, care must be integrated and coordinated.¹⁷⁹

2.6.2. Integrated and coordinated care

Integrating a palliative approach into the ongoing management of disease is a key element of the UK End of Life Care Strategy,²¹ TWF in Canada⁹ and the Catalonian Palliative Care initiative.⁶ TWF has identified a number of innovative care models and a commitment to person centred care, care coordination and the integration of primary, secondary and tertiary care are some of the key common factors amongst these models.¹⁸⁰ The ANPCS emphasises the importance of the integration of palliative care into routine care:²

Palliative care is also an intrinsic part of all health and human services in their overall responsibilities in providing comprehensive care to their clients. Integration and collaboration with specialist palliative care services can then ensure capacity building and enhanced quality of care.^{p-2}

The basis of best practice care for chronic disease is systematic management,^{75,181} incorporating coordinated, multidisciplinary care¹⁸² and the integration of care between the acute and primary care sectors where multiple providers may be involved.⁵⁰ The key components of care coordination have been identified in a number of reviews^{181,183,184} and include assessment, care planning, allocation of responsibility for care, communication, undertaking CDM interventions and monitoring and evaluating care. The *Medical Home* movement in the US encompasses patient-centred interactions, enhanced access and care coordination as key concepts in the development of this model of care.¹⁸⁵

The UK is undertaking significant work to improve the integration of care – both within the health system and between the health and social care systems.^{186,187}

Integrated care:¹⁸⁶

can be defined as an approach that seeks to improve the quality of care for individual patients, service users and carers by ensuring that services are well coordinated around their needs.^{p3}

As with the coordination of care, keeping the individual's needs and perspectives at the centre of the integration of care is vital.¹⁸⁶ Cameron et al¹⁸⁸ identified a number of barriers to integration, particularly a lack of understanding and appreciation of the differing roles of team members and concerns about sharing information.

Although person centred, integrated coordinated models of care offer strategies to improve the structure of the health system in providing end of life care, the expert knowledge and skills in this area lies with specialist palliative care services. In the growing discussions around the integration of a palliative approach with CDM, the role of specialist palliative care is not clearly delineated.

2.6.3. Advance care planning

A key strategy supporting person centred care is advance care planning (ACP). Conversations about likely prognosis, the type of care that people want as they approach the end of their life and what they would consider a 'good death' help to develop specific care pathways for people as they approach the end of their life.¹⁸⁹ Information about ACP and Advance Care Directives can stimulate discussion at a societal level¹⁹⁰ and training in how to have these conversations helps health professionals to overcome their reluctance to have 'difficult conversations'.¹⁹¹ Both national¹⁹² and international¹⁹³ studies have demonstrated that ACP improves the quality of end of life care. It is an integral part of a palliative care approach and a core component of international end of life care strategies.^{21,58} In 2012, the Royal Australian College of General Practitioners (RACGP) stated that ACP should be incorporated into routine general practice.¹⁹⁴ The ANPCS highlights the need to promote the greater uptake of ACP, and the only end of life care related key direction nominated in the ANCDS was the development of ACP methods. In 2011, A *National Framework for Advance Care Directives*¹⁹⁵ was

released, with the aim of supporting the development of policy and practice, as legislation regarding end of life care is a state and territory responsibility.

In Australia, there are a number of issues associated with ACP. A 2011 study identified¹⁸⁹ *significant differences in how ACP is conceptualised in Australia* p.197. Whilst most practitioners agree on the aims of ACP, there are significantly different ideas around the process of ACP implementation, particularly documentation. Some participants in the 2011 study viewed ACP as a process allowing consumers to define their treatment preferences, whilst others saw it as ongoing discussion, incorporating both wishes and values.¹⁸⁹ A 2012 Australian study identified a number of barriers to ACP, grouped in three main areas: patient centred; practitioner centred and system centred.¹⁹⁶ The researchers identified a lack of knowledge about ACP and advance directives and uncertainty about responsibility and differing legislation across Australia as major issues.¹⁹⁶ Another Australian study of GPs identified that some GPs fear that ACP discussions can disrupt patient-family relationships, and GPs concern around this and potential litigation can act as a key barrier to ACP.¹⁹⁷ Brown et al¹⁹⁸ identified that professional support was required to assist with advance care planning discussions and the completion of legal documentation.

Sylvester and Detering¹⁹⁹ note that the *Respecting Patient Choices* program can assist health professionals to learn to facilitate difficult discussions around end of life and advance care planning, and the *Respecting Patient Choices* website provides information regarding appropriate Australian documentation.¹⁹¹ Corke²⁰⁰ suggests that personal values profiling can assist patients to understand their personal preferences when considering the end of their life and this can assist them and their families in discussions with clinicians around advance care planning. However, Sudore and Friend²⁰¹ argue that the focus of advance care planning should be to help patients and substitute decision makers to prepare for *in the moment* decision making, rather than attempting to complete advance care directives for future treatment.

Overall, there is considerable agreement that discussions around end of life care preferences are important and constitute a key element of quality in end of life care.¹⁰⁶ However, there is little agreement about timing, responsibility, methods

and the content of the discussion and a lack of knowledge of ACP processes and legislative requirements.

Given the increasing numbers of people with advanced chronic disease requiring end of life care and the system changes required to support a move to a more integrated and coordinated system built around person centred care and with a clear focus on advance care planning, a public health approach to the provision of palliative care is increasingly being suggested as a way to improve care provision.²⁰²⁻²⁰⁵

2.6.4. Public health approaches to palliative care

Public health approaches take a population view of health issues, with a focus on maintaining health rather than treating disease;²⁰⁴ for end of life care, this encompasses a focus on quality of life rather than maintaining health. Paul and Sallnow²⁰⁶ note the relevance of a public health approach for a range of palliative care professionals and the particular success of those services that are engaged with their communities. Kellehear¹²⁹ suggests that a '*health promoting palliative care*' model provides a useful public health approach, based on critical and participatory principles.¹²⁹ He has adapted the Ottawa Charter principles to provide a focus on death, dying and loss (Table 4) and suggests that²⁰⁴ *health promoting palliative care means adopting and adapting death education into an agenda of health education.*^{p.418}

Table 4. Ottawa Charter principles and health promoting palliative care¹²⁹

Ottawa Charter Health Promotion PrinciplesApplied to Death, Dying and Loss
Building public policies that support health	Building public policies that support people living with life threatening illness, loss and those caring for both
Creating supportive environments	Creating supportive environments for those living with life threatening illness, loss and those caring for both
Strengthening community action	Strengthening community action for death, dying, loss and care
Developing personal skills	Developing personal skills to cope with death, dying, loss and care
Reorienting health services	Reorienting health services to enhance this support in matters to do with death, dying, loss and care and reorienting end of life care services (palliative, aged, bereavement, emergency care) etc towards health promotion

In 2007, Stjernsward, Foley and Ferris²⁰⁷ suggested that a strategy based on public health principles could provide a way to educate the population regarding palliative care and the integration of a palliative approach into government policy and health care practice. They outlined a five step public health model: 1) engage opinion leaders; 2) undertake a situational analysis; 3) develop an action plan; 4) establish a national steering committee and 5) develop components of the model.

One approach to bringing palliative and end of life and care together with chronic disease has been developed in Catalonia. through a WHO demonstration program.²⁹ The project was specifically focused on all life limiting diseases, including chronic diseases and dementia as well as cancer.²⁹ Gomez-Batiste et al⁶ describe a ‘community-oriented, population-based, public-health’ approach to advanced chronic disease which incorporates a public health approach, expanding care to cover life limiting illnesses across time and health care settings.⁶ They developed a specific tool to identify eligible patients: the Necesidades Paliativas (NECPAL)¹⁴⁴, which was based on the GSF²⁰⁸ and the SPICT.¹⁴² The program is based on nine elements for planning a population based palliative care approach:^{6, p374}

1. Public health, population-based and community-oriented perspective.
2. Needs assessment and context analysis (quantitative & qualitative).

3. Defining target population ([prevalence survey(s)]).
4. Clear leadership and consensus with stakeholders.
5. Defined model of care and intervention.
6. Measures: identification and registry, implementation of specialist services, and improvement of conventional services.
7. Education, training, and research.
8. Quality evaluation and improvement.
9. Systematic evaluation of results/indicators.

The significant burden of advanced chronic disease and the associated need for end of life care is a major public health issue. Public health approaches have the potential to impact at a population level to improve equity of access, quality of care and education for both health professionals and the broader community.²⁰² One option is to develop targets for palliative care related public health initiatives, as is being trialled in Germany.²⁰⁹ In Australia, the Palliative Care Outcomes Collaboration (PCOC) measures a variety of palliative care quality indicators across all states of Australia and the datasets developed through this process have the potential to provide a major pillar in the development and implementation of a national public health approach.²¹⁰

2.7. Summary

There is increasing evidence that the end of life care needs of many Australians with chronic disease are not being met. This will be an increasing problem both in Australia and internationally as people age and the incidence of life limiting chronic diseases rise. The need for a greater focus on end of life care is being emphasised as both an ethical imperative and a quality of care issue. However, health systems are currently structured to manage chronic disease with little provision for moving between the systematic, interventional CDM model of care and more supportive care models.

I identified a number of barriers to the more extensive provision of end of life care including a lack of a common understanding of when the end of life period begins and of the concept of palliative care, impacting significantly on communication

about the need for such care. The uncertain trajectory of many chronic diseases makes identification of an end of life period problematic for many health care professionals who may also feel they do not have the knowledge or skills to provide appropriate end of life care. However, perhaps the biggest barrier to overcome is the societal taboo around talking about death and dying, which impacts significantly on the ability of both health professionals and families to have end of life care planning conversations and contributes to palliative care continuing to be seen as a specialty relevant only for the last days of life.²⁰⁴

Whilst there are a number of building blocks in place to improve end of life care in Australia, the framework to connect them has not yet been developed. National and state frameworks for ACP¹⁹⁵ and a growing recognition of the importance of carers¹¹⁷ are contributing to better programs in these areas. New ageing policies and programs have the potential to contribute significantly to end of life care.⁸² Health reform processes at a state and federal level are improving chronic disease management, particularly in primary care,²¹¹ but they do not currently incorporate end of life care. Care which is person centred, integrated and primary care based has been identified as the appropriate model for end of life care in chronic disease, and public health approaches which support systematic identification of people with end of life care needs and public education programs are proving to be successful in the international context. However, the changes required to enable such models of care in Australian health and social systems have not yet been undertaken.

In the next chapter, I will describe the methodology and methods I used to explore end of life care provision in South Australia and how the health care system actually functions to support patients and their carers as they approach the end of life and to support health care professionals in the provision of such care.

Chapter 3. Methodology

3.1. Introduction and background

There is a growing recognition that the care needs of people with advanced chronic disease as they approach the end of their life are not being met adequately or appropriately^{7,22,23} However, there has been little research into why this is happening. As outlined in the previous chapter, provision of end of life care in advanced chronic disease involves two distinct models of care: chronic disease management and palliative care. Care is provided across different parts of the health system and also through the ageing and disability sectors. Therefore, understanding how and why gaps in care occur requires an appreciation of how these two models articulate at a policy and service provision level and the ability to understand how care is provided across these various sectors.

The HPSR framework described in Chapter 1 allowed me to review and describe health policy, health care provision and the experience of patients and carers using a qualitative methodology incorporating a mixture of interviews, case reviews and document analysis. I explored the macro, meso and micro levels of the health system which specifically impact on end of life care. The research I undertook was exploratory and descriptive – i.e. I sought to understand the experience and needs of people approaching the end of their life in accessing services and how the health system responded to those needs.¹⁶

This chapter begins with a review of the ethical issues associated with research at the end of life and how I addressed these in this research. I then discuss how the research impacted on myself and my research participants and how I addressed this in the section on reflexivity. I then detail the research design and data analysis processes, finishing with a discussion of how I assured research quality and rigour throughout my research process.

3.2. Ethical issues and approvals

As the “micro” level of my research encompassed direct contact with people approaching the end of their lives, consideration of ethical issues was a key part of my research process. The National Health and Medical Research Council (NHMRC) recognises that people who are approaching the end of their life are a particularly vulnerable population.²¹² Death and dying are sensitive and emotive topics; there is a high likelihood that research participants may become upset during the course of the research²¹³ and talking about death and dying may raise personal as well as societal fears and concerns.²¹⁴ It is the potential for distress to participants about which ethics committees are particularly concerned, as well as concerns that participating in research activities such as interviews may constitute an unacceptable burden for such gravely ill people.²¹⁴

I identified a range of ethical issues in the development of the methodology and methods proposed for this research. My first considerations were around general ethical principles:¹⁰⁶

Clinical integrity: I explored the types of care that would best meet patients’ needs as they transition from interventional to end of life care and aimed to provide guidance on how services could be changed to ensure this. Participation in the research did not compromise patient care in any way. However, I was sensitive to this possibility.

Personal autonomy: Respect for the wishes of the individual was paramount, so matters such as the timing and location of interviews were always negotiated around the needs and wishes of the participant. The research itself identified how options for ensuring the wishes of patients and carers regarding their care are considered by health professionals.

Beneficence: I was aware at all times of the burden of disease for both the patient and carer, and only undertook project activities such as interviews if the patient and their carer were well enough and willing to participate. The research itself examined patients’ and carers’ perceptions of their best interests in the care available to them.

Justice: The purpose of the research was to examine the current use of resources and service allocation and to assess whether this met the needs of people

approaching the end of their life, through exploring these issues in individual case reviews.

In researching people with chronic disease approaching the end of their life, a number of specific concerns have been identified including: perceptions that research in the palliative care setting is too difficult; perceived conflicts between the goals of research and the goals of care; research being a burden on patients and families/caregivers and a belief that new interventions are not better than existing treatments.²¹⁴ However, our previous research exploring the care needs of people with end stage COPD identified that participants welcomed the opportunity to discuss many of the issues around the care of their advanced disease as they had no other opportunity to do this¹⁸ and there is evidence that a substantial number of palliative care patients are willing to participate in research.²¹⁴ It has also been suggested that *not* undertaking research with palliative populations actually compromises the ability of health professionals to provide high quality, effective care.²¹⁴ Furthermore, Crowther and Lloyd-Williams²¹³ report that people approaching the end of their life are very often competent, able to assess risk and provide informed consent.²¹³ The National Palliative Care Strategy notes the importance of undertaking research in end of life and palliative care to ensure appropriate and effective care systems² and Le Blanc, Wheeler and Abernethy²¹⁴ suggest that it is in fact, unethical *not to conduct high-quality research that explores and informs therapeutic decisions, even at the end of life.*^{p.249}

The vulnerability of the proposed research population and the issues noted above were a key consideration for me in the development of the methodology and methods proposed for this research. Because I wished to interview people in the last year of their life and their carers, specific safeguards were developed to ensure the safety of participants. The ethical requirements outlined in Chapter 4.4 of the *National Statement on Ethical Conduct in Human Research*²¹² were incorporated into the methodology. All participants were made aware of the long term nature of the project outcomes: i.e. informing policy and service provision and that it was unlikely to provide any direct benefits to them or their families, but that it could assist people with similar conditions in the future. I designed the research methods to try to ensure that the research imposed a minimal burden on

the participant and their carer, but I recognised that it was possible that some of the questions asked during interviews would be upsetting for them. Therefore, I worked with one of my supervisors (a palliative care physician with significant counselling experience) to ensure that access to support and counselling was available, if required.

All interview participants were given a study information sheet and consent form and informed consent was obtained from all participants before participation in any interview. All interviews were recorded and transcribed verbatim and participants were informed of this on the consent form and verbally prior to commencement of each interview. Participants could withdraw from the project at any time and could refuse to answer any questions in the interview. If they did withdraw, they could also withdraw their data from the study, provided data analysis had not commenced. All personal information was treated in confidence and all participants were offered summary reports of the results and access to the full report if they wished. In any publications arising from the research, no participants can be individually identifiable. Because of the vulnerable nature of the population, and the fact that participants were in the advanced stages of their disease, I interviewed participants in their home rather than the hospital (although this was offered to all participants). For home interviews, I developed a safety protocol consisting of notifying my supervisor/s that I was undertaking a home interview, including the date, time and address, and phoning them before entering the house and on completion of the interview.

I sought ethics approval from three separate human research ethics committees (HRECs). Initial approval was sought from the University of Adelaide HREC. Early recruitment was undertaken at the Royal Adelaide Hospital (RAH) so ethics approval was sought from the RAH Ethics Committee. I also sought approval from Calvary Health Care Adelaide (CHCA) HREC, to recruit through the Calvary North Adelaide and Calvary Wakefield hospitals.

Following submission of the ethics applications, the University of Adelaide HREC required clarification of two points only, which were immediately addressed. Both the RAH and University of Adelaide HRECs felt that an attempt should be made to ensure patients had not died before seeking follow up interviews and it was agreed that I would contact the referring health professional

before each interview regarding the health status of the participant. The RAH and CHCA HRECs were very concerned about patients becoming distressed through their participation in the research. The RAH HREC requested that the name of the project was changed as the original title “*When chronic disease management becomes end of life care: the role of the health system in facilitating transition.*” was felt to be too confronting for participants who may not have considered that they were approaching the end of life. I therefore agreed to change the title of the research to: *Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness* and I revised all project documentation accordingly. The RAH HREC was concerned about the potential distress caused by interviews and requested that all participants were contacted the day following the interview to ensure they had no ongoing distress. The CHCA HREC requested further clarification on the supports to be made available to participants should they become distressed by the interview.

All of the concerns of the three HRECs were addressed as requested and approval was obtained from all institutions following submission of revised documentation. Copies of all HREC approvals can be found in Appendix 1.

3.3. Reflexivity

Having undertaken a variety of research projects using a qualitative research methodology, I am aware of the importance of reflexivity and identifying my possible biases and the knowledge, experience and assumptions I bring to a particular research project. I regard acknowledging this and recording my ideas and ongoing thoughts throughout the project as a key element of ensuring the rigour of my research. Liamputtong²¹⁵ suggests that reflexivity makes research findings more credible and that, by making your influence as a researcher on the research explicit, people can assess the relevance and value of the research. She goes on to note that²¹⁵ *It is a crucial strategy that is essential for the whole research process.*^{p.26} Gilson²¹⁶ notes that reflexivity is a key process for rigour in HPSR, particularly because HPSR recognises health policy and systems as socially constructed and so it is crucial that all the factors influencing interpretation of data are transparent.

In coming to this research, I brought with me a variety of experiences: personal, professional and research related, which would inform and impact on the way I conducted this research. My initial professional training was in nursing, and I have experience in both acute hospital and community nursing. I have nursed family members at the end of their life and some years ago worked on a booklet entitled *Talking to patients about death and dying*.²¹⁷ However, I was aware that I am not a palliative care nurse and I wanted to be very careful that I was not perceived by any research participants to be an expert in this area. My area of expertise is more in primary health care and chronic disease management. I recently completed research in end of life care for people with advanced COPD and so brought to this research my knowledge and experience of the issues associated with advanced chronic lung disease and my impressions and assumptions around the experiences and needs of people as they approach the end of their life. I had to be aware though, that the context for people with diseases other than COPD may well be different and I could not assume that the current system was not necessarily working for them. I was also aware that many health professionals find having conversations about end of life issues quite difficult, but I was not sure that this aspect of end of life care was still the same as it was when I developed the *Talking to patients about death and dying* booklet, so I had to be sure that I did not assume that no-one was having these conversations.

Undertaking interviews with people as they approach the end of their life requires a flexibility of approach in allowing people to talk about what *they* think is important rather than just focussing on any particular research questions that I might have. I found that many patients had not had the opportunity to speak with anyone else about their condition, their treatment and how they were coping, until I spoke with them. This meant that the very first interview I undertook lasted for nearly four hours. I had to balance my knowledge that the patient was very ill and a long interview would tire her out, with her very obvious need to talk about all that had happened to her and what it had meant for her and her partner's life. Some participants were happy just to answer the questions, but many actually wanted a much longer interaction. It was often quite draining to spend such long periods with people listening to some of the very difficult things they had experienced, but in some ways I saw that as the agreement: i.e. people would

participate in the research at a difficult time for them and one part of my role in the research partnership was to listen to them.

I developed a summary of each interview for each of the case studies, in order to help me take an overview of the history and context of each participant, to help me to pull together the key points from the interviews and to identify any particular issues that would need following up later in the research. This consisted of a demographic summary, a disease progression history, a summary of services required and accessed and specific problems and issues facing the participant and their carer (if they had one). At the end of the summary, I recorded a reflection which was added to following each interview. Copies of these summaries can be found in Appendix 7. Talking to people as they approach the end of their life and hearing their sometimes very difficult stories meant that I needed to ensure that I had some way of processing their stories and not allowing the emotional aspects to become too overwhelming. This was sometimes challenging because of the privacy and confidentiality requirements surrounding research, so discussing particular aspects of interviews with my partner or friends was often not possible. I was able to discuss particularly difficult interviews in regular fortnightly meetings with supervisors, which helped.

Towards the end of the research, I was faced with two particularly difficult situations when arriving to interview participants. Although I have not practised as a nurse for some years, in both instances I had to call on my nursing knowledge to help address the situation. In the first incident, it was evident when I arrived that the participant was very ill and required medical assistance. The GP did not do home visits and the family was reluctant to call an ambulance as they did not feel it was an emergency. I was able to reinforce previously suggested advice and convince them to call an ambulance. It was quite distressing as the family seemed unable to deal with the problem and the condition of the participant seemed to be worsening fairly quickly. After I left the family, I contacted both the hospital and my supervisors as I was concerned about what might happen, and also re-contacted the family that evening. The participant was admitted to hospital for three weeks for a variety of different problems. In the second incident, I similarly found the participant very distressed when I arrived. She lived alone and had multiple problems and was having trouble breathing and walking. I was unsure

whether this was the result of the very hot day and the patient being very upset, or whether it was a medical problem and so stayed to try and calm her down. Over a period of hours, her condition improved markedly and I was able to help her shower and drink some fluids, but again had to contact the hospital to ensure that the health team was aware of the issues.

I also brought to this research a long standing interest in qualitative research methodology and my experience teaching this subject at a postgraduate level. I find teaching qualitative research methods an ongoing learning process for myself as well as my students and so I was able to draw on this teaching experience to explore questions around appropriate theoretical and analytic frameworks for this research. Recognising my role in this research and my specific assumptions and responses to the individual case reviews and the interviews with policy makers and service managers was actually only the first step. I then needed to include these insights into the actual research and so I have incorporated them into the overall analysis framework and they have been specifically identified as informing the discussion and conclusion.

3.4. Research design

In order to answer my research questions, I developed a three phase research design incorporating a variety of methods. Each of the chosen methods contributes to answering my research questions in the following ways:

1. How can the health system provide care that meets the needs of people with advanced chronic disease and their carers/families?

Literature review/case reviews (patient, carer and KSP interviews)/policy analysis

a) How does the health care system currently support people with advanced chronic disease and their carers/families as they manage their chronic disease and address the issues required for end of life care?

Case reviews; policy maker and service manager interviews; policy analysis

b) How appropriate, available and accessible is end of life care for people with advanced chronic disease?

Case reviews; policy analysis

c) How do the complicated entities of chronic disease and palliative care interact in the Australian health care system at a national, state and local health service level?

Case reviews; policy maker and service manager interviews; policy analysis

d) Why does the health system function in the way it does to provide end of life care?

Complex adaptive system analysis: Literature review; policy analysis; Case reviews; policy maker and service manager interviews

2. Where are the effective points of intervention to change the system and support and empower patients?

Complex adaptive system analysis: Literature review; policy analysis; KSP; policy maker and service manager interviews

Figure 2 details the research design, with the expected outcomes from each phase.

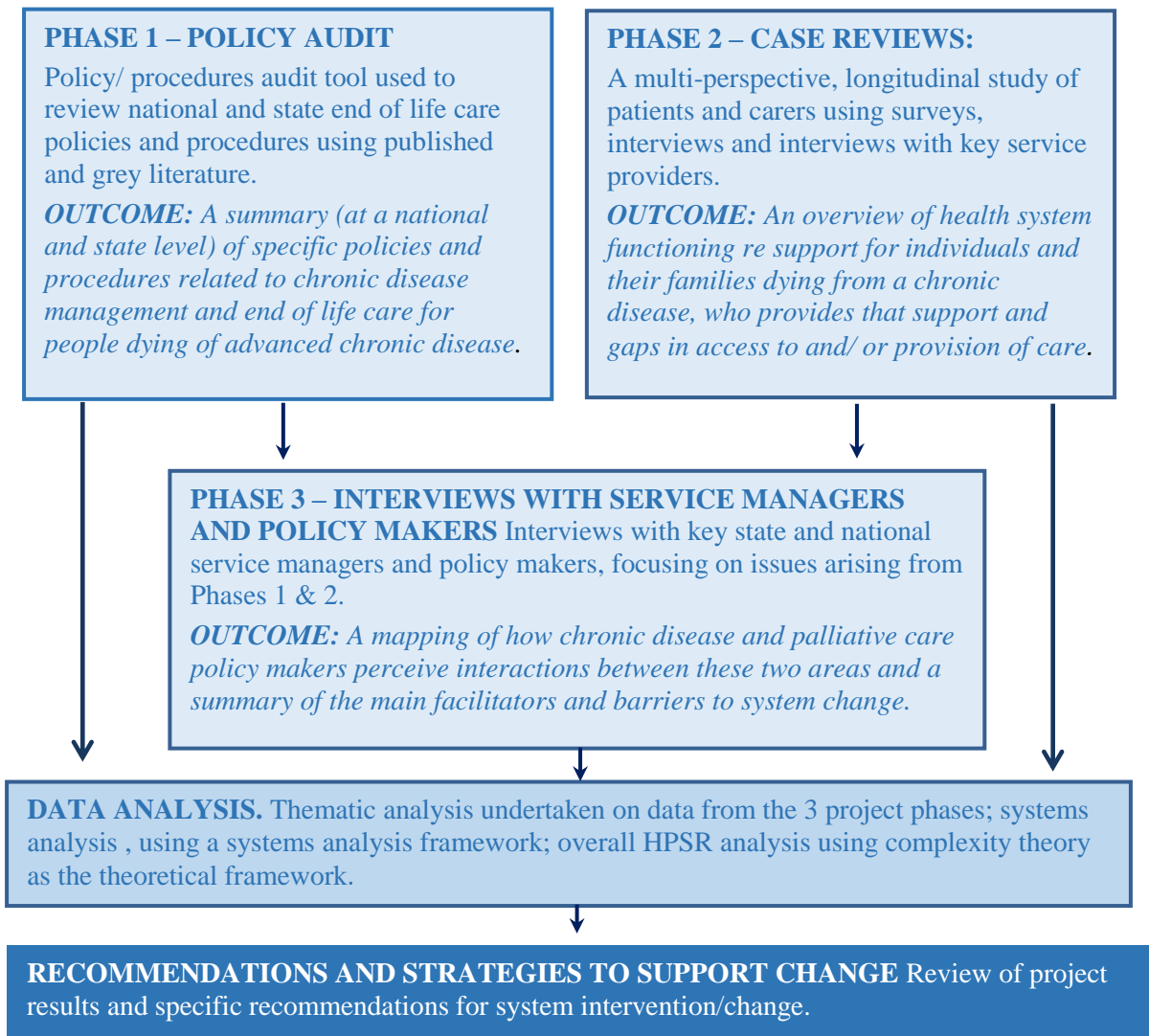


Figure 2. Research design

3.4.1. Phase 1: Policy review

Aim: A review of national and state chronic disease and end of life care related policies and service provision using published and grey literature, providing a summary (at a national and state level) of specific policies and procedures related to chronic disease management and end of life care for people dying of advanced chronic disease.

Design: The policy review design is described in Figure 3.

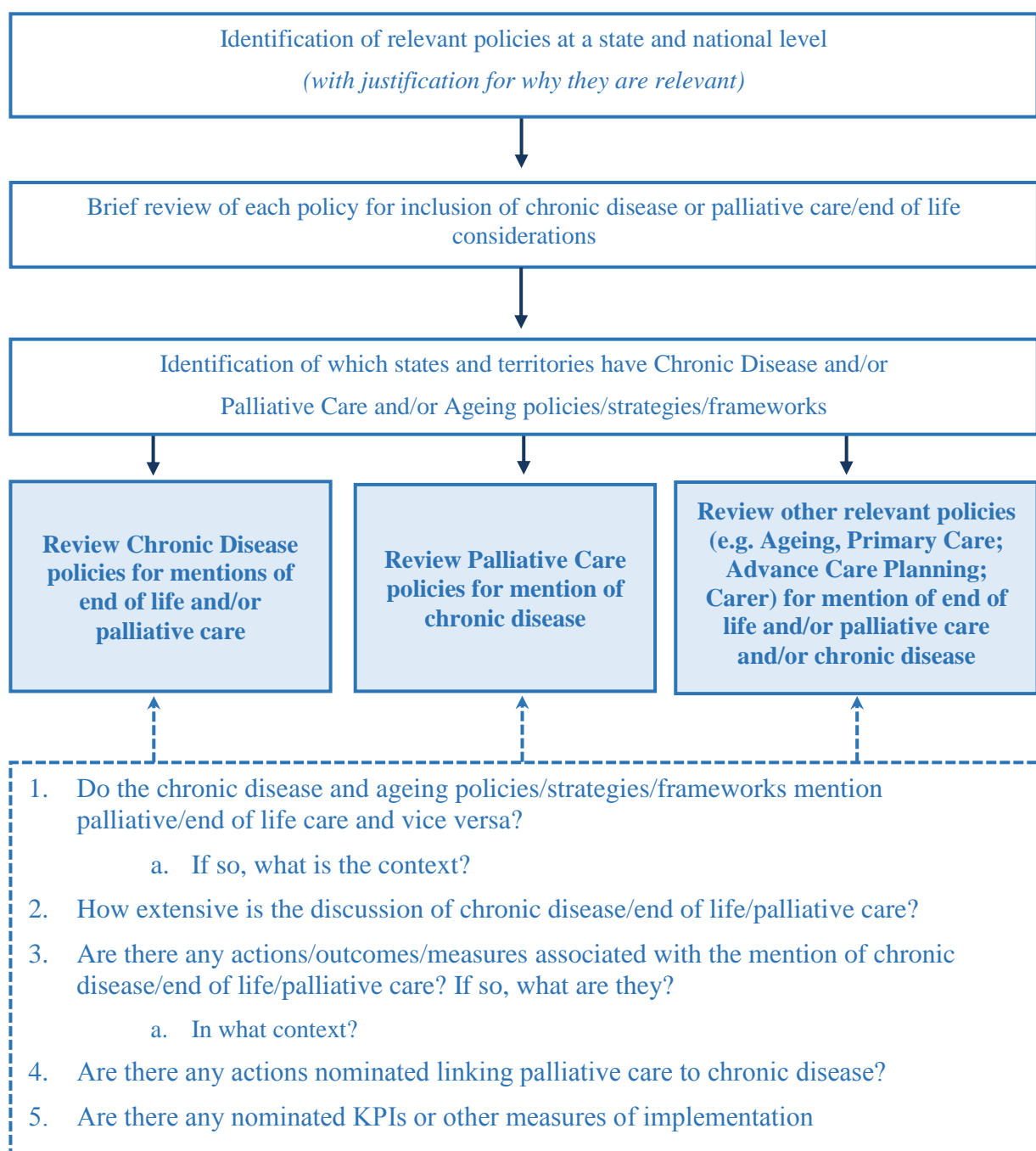


Figure 3. Policy review methods

3.4.2. Phase 2: Case reviews

Aim: To undertake a multi-perspective, longitudinal study²¹⁸ of fourteen patients and their carers/families to provide an overview of health system functioning, including support for individuals and their families dying from a chronic disease, who provides that support and gaps in access to and/or provision of care.

Sample: As I noted previously, HPSR has three levels of research: macro, meso and micro.¹⁶ Phase 2 of this research focused on the meso (organisational and service) level to some degree, with the inclusion of the key service provider (KSP) interviews, but the main focus of the case reviews was the micro level – the experience of individuals.

Although there are many life limiting chronic diseases, diseases such as COPD, HF, ESRD and neurological diseases such as PD and MS are consistently cited as requiring specific end of life care and support. There is increasing evidence that the services required by people with advanced chronic disease have disease-specific features – that there is no ‘*one size fits all*’ model of care.²¹⁹ It is therefore important to examine the care needs of specific chronic diseases in the Australian context to identify best practice models of care. Having recently undertaken research exploring end of life care needs for people with COPD,¹⁸ in this research I decided to focus on three specific areas of chronic disease to act as exemplars for end of life care needs more broadly:

Heart failure: In 2002, Murray et al²²⁰ identified that people with HF had at least an equal need for palliative care as people dying with lung cancer, with subsequent research further emphasising this need.²²¹ The UK,²²² the European Society of Cardiology,²²³ the American Heart Association²²⁴ and the National Heart Foundation of Australia²²⁵ have all recognised the importance of palliative care in advanced HF and in 2010, Davidson et al²²⁶ released guidelines for palliative care in general practice in Australia for people with advanced HF, noting the importance of both the primary and secondary care settings.

End stage renal disease: Current end of life care for people with ESRD is not meeting their needs.²²⁷ In 2013, the Australian Renal Supportive Care Working Group released a position statement on renal supportive and palliative care, outlining three potential pathways for people with ESRD – dialysis, transplantation

and conservative treatment, noting that more people will be opting for the conservative pathway as the population ages.²²⁸ The statement emphasises the importance of a palliative approach in providing appropriate care for people choosing the conservative pathway.²²⁸ This follows on from a review of symptom management for ESRD from the UK²²⁹ and the development of UK guidelines for end of life care in advanced renal disease in 2012.^{230,231} Murtagh et al²³² suggest that there is a specific trajectory for renal disease, which is different from other chronic diseases, and this has specific clinical and policy implications.

Neurological Disease: Although it is recognised that there are a number of neurological diseases where a palliative approach is required for advanced disease, this research focused on two diseases where there is a growing incidence and minimal recognition to date of the importance of a palliative approach: PD and MS. The UK end of life program identified the growing need for a palliative approach and the specific issues associated with neurological diseases²³³ and outlined a number of specific challenges and in 2014, Palliative Care Australia (PCA) and the Neurological Alliance Australia released a position statement calling for much broader recognition of the need for palliative care for people living with neurological conditions in Australia.²³⁴ In 2013, Miyasaki²³⁵ noted that: *Palliative care for Parkinson's disease (PD) is a new concept in neurodegenerative care.*^{p.366} and clinicians have been noting for some time the need for a stronger focus on palliative care for people with advanced PD and particularly the chronic/ palliative interface.^{137,236,237} Campbell, Jones and Merrills²³⁸ identified common themes for the provision of palliative care for people with MS and PD, including the importance of communication, the need to provide significant psycho-social support and the control of distressing symptoms.

To ensure that I could include patients with the three identified chronic diseases and identify information rich cases to inform the research and analysis, I used a purposive, stratified, criterion sampling strategy.²¹⁵ This was consistent with qualitative methodology where the emphasis is on depth rather than volume of data.²¹⁵ I aimed to recruit fourteen patients and their families from three hospitals: the RAH and the Calvary North Adelaide and Calvary Wakefield private hospitals, providing a cross section of demographics and chronic diseases. Sampling criteria were:

- Seven males and seven females.
- Four participants with ESRD; four HF and six with neurological disease (e.g. PD and MS).
- Four participants from rural South Australia.
- Six participants from the private health care system.
- Four participants between 40 and 65 years of age.
- Ten participants over 65 years of age.

Specific exclusion criteria were:

The participant living in high or low level residential care: Patients in residential care are already receiving a different level of care from people living in the community and there have been a number of recent projects identifying best practice in the provision of palliative care in the nursing home setting, so these people were excluded from this research

The participant being under 40 years of age: The majority of people with a chronic disease approaching end of life are over 65 years, with a significant minority between the ages of 40 and 65, so people under 40 years of age were excluded.

The participant having significant cognitive impairment: Because of the requirement for interviews and feedback from the participants themselves, an adequate level of cognitive functioning was required.

The participant having received active treatment for cancer in the last 2 years, and/or having metastatic disease: Patients with a current cancer diagnosis, or who had recently experienced cancer may have had knowledge of/were able to access care different from the majority of people with chronic diseases and so may not have been representative of the wider population.

The participant being listed for a heart or renal transplant: If the patient was listed for a transplant, or had already had one, they had access to a range of care not available to the majority of people with a chronic disease and so may not have been representative of this wider population.

The participant being of Aboriginal or Torres Strait Islander descent: It was recognised that Aboriginal and Torres Strait Islander peoples have a significantly

higher incidence of chronic disease and die at an earlier age than non-Aboriginal Australians; however, the issues impacting on both cause and treatment of chronic disease, access to care and cultural issues for Indigenous Australians were beyond the scope of this project.

The participant being unable to speak enough English to participate in an interview: It is recognised that people from culturally and linguistically diverse (CALD) backgrounds have a prevalence of chronic disease equal to those from non-CALD backgrounds, however as this was an unfunded project, no funding was available to employ interpreters for participants without adequate English.

Recruitment and Retention: I chose a hospital focus for recruitment as PCA reports that, whilst chronic disease management is mainly community based, people are much more likely to be admitted to hospital and die there rather than at home.²³² I hoped that using three hospitals (the RAH, Calvary North Adelaide and Calvary Wakefield Hospitals) would provide the maximum opportunity for recruitment, which was important because the stratified criterion sampling strategy required recruitment of specific age groups, locations and specific chronic disease groups.

The Royal Adelaide Hospital (RAH): The RAH is the largest hospital in South Australia is located in the centre of Adelaide. It provides care for rural, urban and some interstate patients. I contacted the medical directors of the renal, neurological and cardiology units by mail, and outlined the proposed research and recruitment requirements. I followed up the letter one week later with a phone call and made an appointment for a face to visit to describe the research in more detail. One of my supervisors accompanied me to each of these appointments. The three medical directors were all highly supportive of the research and each suggested a particular specialist as the contact for recruitment. As the research progressed, a physician working in a general medical ward and the chronic heart failure team were also briefed about the research and agreed to support recruitment.

The Calvary North Adelaide and Calvary Wakefield Hospitals: These two major private hospitals are operated by a Catholic health provider and are situated centrally in Adelaide. They see a wide variety of patients and provide both surgical and medical care. One of my research supervisors worked at one of these

hospitals and so, following an initial letter to introduce the research, he met with cardiologists and the Discharge Planner to explain the project and ask for their support.

The Multiple Sclerosis (MS) Society: The MS Society is the major community based non-government support organisation for people with MS in Australia. They offer a variety of services as well as undertaking advocacy around MS and supporting MS research. As recruitment of participants with multiple sclerosis proved to be very slow, I wrote to the Multiple Sclerosis Society regarding the project and met with them with two of my supervisors and they also agreed to support recruitment.

I provided all health professionals who agreed to support recruitment with the Participant Information Sheet and asked them to make initial contact with the proposed participant. This initial contact consisted of asking if the proposed participant and their carer were interested in participating in the research. If they responded positively, their contact details were passed on to myself, with their permission. I then contacted them to explain the project and forwarded the patient information sheet and consent form and arranged an interview time. Patient Information Sheets and recruitment letters for all participants can be found in Appendix 2.

To assist the clinicians in their recruitment, I developed a “Recruitment Checklist” to help identify possible participants (see Appendix 1). Previous end of life research identified specific criteria for patients approaching the end of life with ESRD,²³⁹⁻²⁴¹ PD and other neurological diseases,^{236,237} HF^{226,242} and COPD.^{18,243} I identified relevant clinical indicators for each individual disease being targeted and also included the ‘*surprise question*’: i.e. *would I be surprised if this patient died in the next six – twelve months.*^{54,241} Small et al¹²² raised the concern that the “surprise question” could inhibit the commencement of a palliative approach, particularly for people with COPD and heart failure. However, all the physicians I approached to help with recruitment could not agree with a standardised set of clinical indicators, and preferred to use the surprise question as their sole criteria for recruitment.

Issues with Recruitment: Although all the clinicians I spoke with were very supportive of the project and agreed to assist with recruitment, this proved very difficult in practice. Following an initial recruitment of three people with neurological disease and two with ESRD, recruitment slowed markedly and so I contacted other clinicians as noted above: i.e. a physician working in a general medical ward; the chronic heart failure team at the RAH and the MS Society. This resulted in the recruitment of two further participants with MS and two with HF (one of whom also had PD). I recontacted the heart failure and renal clinicians every few weeks reminding them about the project and asking for any further participants, but they could identify no further participants.

I was able to recruit only one male participant and only one rural participant. I was able to recruit five participants aged >65 years and four aged <65 years. However, one participant who was 83 years old withdrew from the project following the first interview, leaving equal numbers of participants over and under 65 years of age. No participants were able to be recruited from the Calvary North Adelaide or Calvary Wakefield Hospitals, despite regularly contacting them and reminding them of the project. I had hoped to finish recruitment within six months of obtaining ethics approval, but the delays and difficulties described meant that I had to extend the recruitment period to twelve months, and then stop, having recruited only nine participants.

Case review summary

The patients in this research had a primary diagnosis of ESRD, HF or a neurological disease. Seven patients had multi-morbidities. Table 5 provides a summary of patient details and further details of each individual case review can be found in Appendix 7. These case review summaries also include a summary of the individual results of the World Health Organization Quality of Life (WHOQOL-Bref) measure, the Patient Health Questionnaire (PHQ-9) and the Adult Carer Quality of Life Questionnaire (ACQoL).

Table 5: Case review patients

	Patient	Primary Diagnosis	Other Diagnoses	Carer
1	62 year old woman from a rural town	Multiple System Atrophy	Bronchiectasis Gastric reflux Anxiety Hyperthyroidism	71 year old husband
2	77 year old woman	Parkinson's Disease	Osteoarthritis Hypotension	79 year old husband
3	79 year old woman	Progressive Supra-nuclear Palsy	Osteoarthritis Cataracts Epilepsy	81 year old husband
4	76 year old woman	End Stage Renal Disease	Fibrosis (lung) Angina/CVD ⁱⁱⁱ Osteoarthritis CVA ^{iv}	None
5	83 year old woman	End Stage Renal Failure ^v	Polymyalgia Osteoarthritis	None
6	64 year old man	Heart Failure	Diabetes Renal failure Gout Angina Sleep apnoea Anxiety	64 year old wife
7	39 year old woman	Multiple Sclerosis	None	63 year old mother
8	60 year old woman	Heart Failure	Parkinson's disease Chronic back pain Lymphoedema Cellulitis Asthma Depression	None
9	56 year old woman	Multiple Sclerosis	None	81 year old mother

Data collection

Interviews: Data were collected using three semi-structured interviews with participants and their carers. Interview 1 was at the commencement of the project and explored participants' understanding of their illness and the stage it had reached; their current service needs; access to services and where and how that

ⁱⁱⁱ Cardiovascular disease

^{iv} Cardio-vascular accident – a stroke.

^v Patient withdrew following initial interview

service was provided; gaps or overlap in service provision and any end of life care discussions. Interview 2 followed three months later and included a review of needs and services accessed since the first interview with a focus on primary care/community based services. Interview 3 was six months after Interview 2 and explored any changes in participants' disease status; care requirements; understandings of their condition etc. I also obtained ethics approval to undertake a follow up interview with carers (if they felt able) should any participants die during the project. However, no participants died during the research period, although two participants died not long after their final interview.

If a participant nominated a carer, I interviewed that carer three times, at the same time points as the participants. They were given a choice of being interviewed together with the person they were caring for or separately from them. Six participants had carers and, in all instances, the carer chose to be interviewed with the participant. One carer missed the second interview, but all other carers were interviewed three times. Carer questions focused on the experience of caring and the needs and service access issues for the participant from their perspective. I also explored their own needs as a carer.

I asked each participant for permission to contact their key service providers (KSPs), in order to obtain their perspectives on caring for people as they approached the end of life. KSPs included GPs, specialists, personal care services, community services, allied health services and any other carer nominated by the participant. I contacted each nominated KSP by letter, explaining the project and asking them to participate in a semi structured phone interview and followed this up a week later with a phone call. Copies of the letter template for KSPs can be found in Appendix 4. Interview questions for KSPs were around barriers in accessing care and support, issues around talking about end of life and advance care planning, integration and coordination of care and identifying when a palliative approach should begin.

Copies of all interview schedules can be found in Appendix 5.

It proved quite difficult to gain the participation of many KSPs in the interview process. Most GPs said they felt it was a very important topic, but did not have time to participate in the project and suggested I speak to their professional bodies

(i.e. the Royal Australian College of General Practitioners and the Australian Medical Association). Two of eight GPs agreed to be interviewed. Many of the specialists agreed to be interviewed, also nominating end of life care as an important issue for them, and one rural community health service participated. Requests to interview representatives from Disability SA and a private personal care provider were unsuccessful. One rural participant required the support of a disability advocate to help in accessing in-home services and the advocate agreed to participate in an interview. Table 6 provides a summary of KSP participants.

Table 6. Key service provider interviews

	Rural	Urban
GPs		2
Cardiologist (HF)		1
Nephrologist (ESRF)		1
Neurologist (PD, MS)		1
Respiratory Specialist (Bronchiectasis)	1	
Generalist Physician ^{vi}		1
Disability Advocate ^{vii}	1	
Community Health Services	1	1

Demographic data were collected on enrolment from both the participant and their carer. This included information on co-morbidities; social security and health insurance status; hospital admissions; emergency department presentations; referrals to specialist and/or community services; family/carer support and details of the family GP (see Appendix 6).

Quality of Life (QoL): Identifying how people perceive their quality of life is an important aspect of care and there is a growing recognition of the importance of the measurement of this concept, especially in end of life care.²⁴⁴ QoL has been identified as an independent risk factor for mortality in ESRD²⁴⁵ HF,²⁴⁶ PD,²⁴⁷ multi-morbidities²⁴⁸ and more generally in end of life care²⁴⁹ is increasingly being recognised. There is much debate about the methodological challenges of

^{vi} The general physician did not care for any particular patients but was responsible for the care of patients in the general medical ward, including people with heart failure, chronic obstructive pulmonary disease (COPD), neurological diseases, dementia, frailty etc.

^{vii} An advocate working for a government funded, rural disability advocacy service.

measuring quality of care at the end of life²⁵⁰ and there is blurring between instruments which measure quality of life, quality of death and quality of care. Carr and Higginson²⁵⁰ note that the use of QoL measures “*reflects a growing appreciation of the importance of how patients feel and how satisfied they are with treatment in addition to the traditional focus on disease outcomes*” p.1357

Because I was researching a variety of diseases, I believed a generic QoL tool would allow me to compare results across participants. It would also allow for the likely existence of co-morbidities. I examined a number of generic tools including the SF36/12; the Palliative Outcome Scale; Gold Standards Framework measures²⁵¹ and the WHOQoL BREF.²⁵² Skevington and McCrate²⁵³ compared the WHOQoL BREF with the SF36 and found that the WHOQoL BREF had good to excellent psychometric properties and could be used at both an individual and population level. In comparison with the SF36, the WHOQoL BREF was shown to encompass factors such as environment, employment, family relationships and spirituality – all very relevant domains for this study.²⁵⁴ It has previously been used in stroke,²⁵⁵ neurodegenerative diseases²⁵⁶ and HF²⁵³ and so I chose this tool as the QoL measure to track differences across the three interviews, as the patient’s condition worsened.

Copies of the quality of life and depression scales used in this research can be found in Appendix 6.

Depression scales: There is strong evidence of the links between chronic disease and depression, with increased mortality and morbidity in the presence of depression.²⁵⁷ The PHQ-9 is a simple screening tool which has been validated for screening for major depression in the primary care population.²⁵⁸ I therefore chose this measure to assess levels of depression in participants at the three interviews.

Issues with the QoL and Depression Scales: It became evident in the first data collection period that the QoL and Depression scales were not appropriate for many of the participants. For participants with severe neurological disease, many of the questions posed difficulties; e.g. *how well are you able to get around?*; *How often in the last two weeks have you been moving or speaking so slowly that other people have noticed?* All participants with neurological disease were confined to wheelchairs with minimal ability to move and had significant speech

problems so these two questions scored very highly, but they were actually a part of how these participants lived and they did not really perceive them to be their major issues. Two participants were on antidepressants and all felt they had little energy. Having developed an interviewer/participant relationship with the participants in a number of instances I also felt it was an inappropriate intrusion for some participants to ask about their sex lives. Following discussions with my supervisors, we agreed that we would continue to use the measures across the three interviews, and see if any changes occurred across time, and also if there were any patterns across the participants, but that the measures would not form part of any formal analysis.

Carer Quality of Life: There is growing recognition of the adverse mental and physical health effects in carers supporting people as they approach the end of life.¹¹⁴ In 2012, Joseph et al²⁵⁹ reported on the development and validation of a quality of life measure for adult carers. This is a 40-item instrument which measures a carer's quality of life in eight domains: support for caring; caring choice; caring stress; money matters; personal growth; sense of value; ability to care; and carer satisfaction.^[58] Using this tool allowed comparison of carer QoL across participants and diseases and so it was used for all participating carers.

A copy of the Adult Carer Quality of Life Questionnaire can be found in Appendix 6.

3.4.3. Phase 3: Service manager and policy maker and perspectives

Aim: To explore policy makers' and service managers' responses to:

- perceptions of what end of life care for people with advanced chronic disease encompasses and how such care can be provided in the current system.
- specific issues raised by participants and their carers and in the initial review of national and state end of life care policies and procedures.
- options for expanding the provision of this care as the number of people requiring such care expands dramatically over the coming years.
- workforce, resource and financing implications.

Sample: Policy makers in chronic disease management and end of life care (including palliative care) in South Australia and at a national level were

identified, as well as NGO organisations and service managers at a state and local level in both primary and acute care. We also included palliative care experts who have been involved in both service planning and policy making for end of life care for chronic disease. My research supervisors and I have an extensive network of contacts at both a state and national level in palliative care and chronic disease management and we used these to identify the most relevant participants.

Data Collection: I sent a formal letter and project summary to the proposed participants explaining the research and asking them to participate in either a phone or face to face interview (see Appendix 4). The covering letter noted that the rapidly growing need for end of life care was being recognised at a policy and service planning and management level and suggested that there were a number of barriers and issues associated in ensuring these services were available to all who need them. They were asked if we could discuss these issues and the sorts of strategies and policies that they thought would be required to address them. The letter was followed up a week later by a phone call and a time made for the interview. A variety of interview schedules were developed which had the same basic questions but were adjusted to ensure their relevance for the person being interviewed – i.e. policy maker, service manager or NGO participant (see Appendix 5). Table 7 provides a summary of policy maker and service manager participants. A number of participants also worked (or had previously worked) as GPs or in palliative care services.

Table 7. Policy maker and service manager interviews

	State	Commonwealth
Government (Policy)	2	1
Local primary care planning and administrative agency (Medicare Local)		1
Palliative Care (Policy and service management)	4	
General practice (Education, training and service management)	2	
NGO (Policy)	1	1

3.4.4. Data analysis

The three distinct phases of the research meant that specific data analysis processes were required for each separate phase, as outlined in Figure 4. The analysis of policies related to chronic disease and end of life care involved a comparison of all policies against each other for evidence of articulation and an application of the filter questions and recording of the results. Chapter 4 contains a more detailed explanation of the policy review. Patient, carer, key service provider (KSP) and policy maker/service manager interviews were thematically analysed. Because I wanted to provide a detailed description of the health system as it operates for people with chronic disease, my initial broad coding framework was deductive and based on the system parameters outlined by Bainbridge et al,²⁶⁰ I brought the results of the three phases together in the discussion, using complexity theory as the analytical framework.

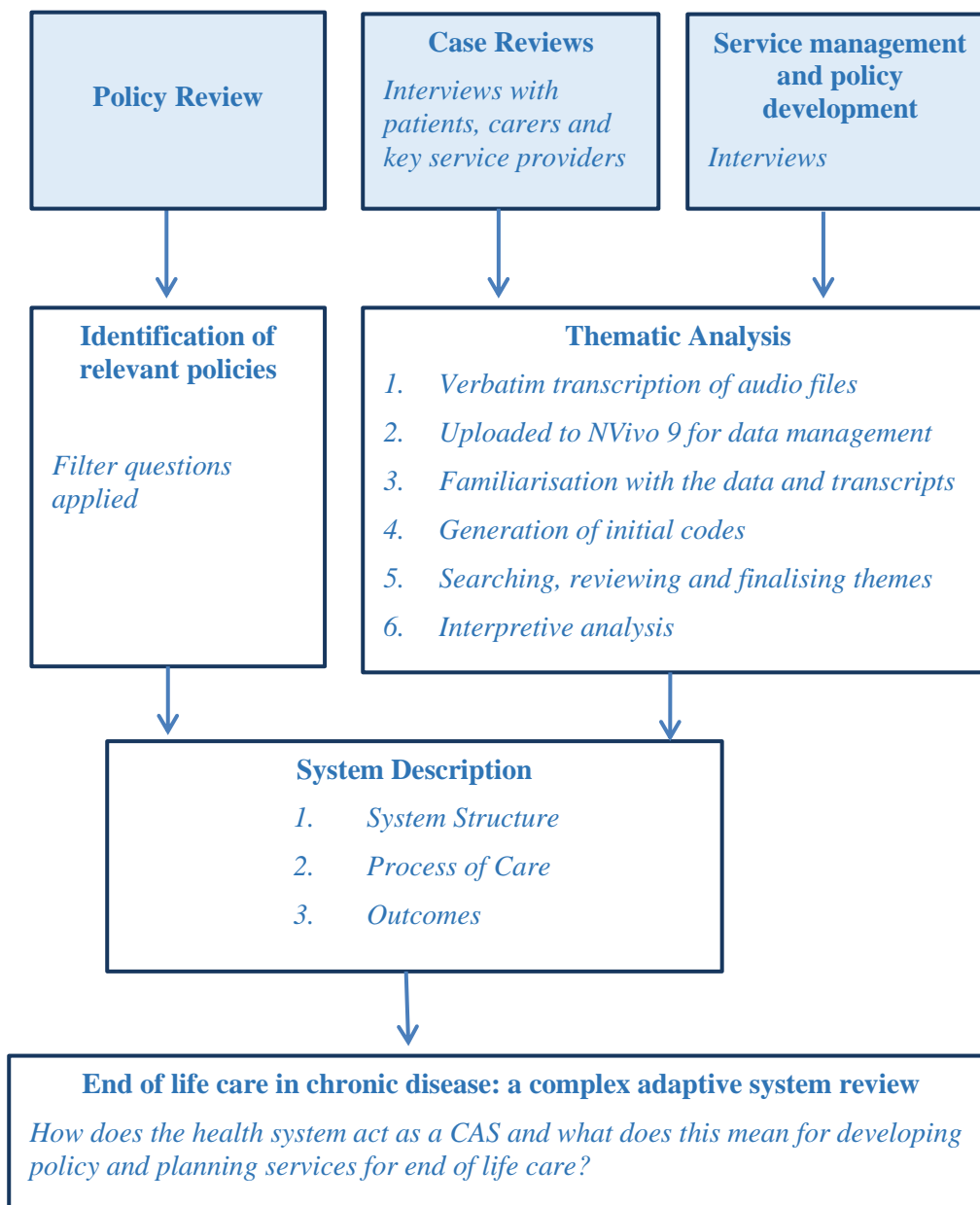


Figure 4. Analysis design

Thematic analysis: Case reviews and service manager/policy maker interviews

The case reviews and service manager/policy maker interviews resulted in three separate data sets: patient and carers; key service providers (KSPs) and service manager/policy maker with each data set being analysed separately using the thematic analysis framework described by Braun and Clarke.²⁶¹ Braun and Clarke provide clear guidelines and a six step process which begins with transcription of interviews and familiarisation with the data.²⁶¹ The next step of the analysis was

an inductive coding process followed by a more detailed analysis, examining the data to identify specific themes which helped to explain how the health system was functioning for them in their particular circumstances. An initial 36 themes were identified, with a large number of sub themes and codes. These themes, sub themes and codes were then reviewed to see which themes were closely related or were variations or elements of the same broader concepts. Following a final review, four major themes were identified:

1. End of life care
2. Advance care planning
3. Models of care
4. The carer experience

Details of the themes, sub themes and codes can be found in Table 8. Data were organised and managed using NVivo qualitative data analysis software (QSR International Pty Ltd. Version 9, 2010).

Table 8: Codes and themes

THEME 1: END OF LIFE CARE	THEME 2: ADVANCE CARE PLANNING
<i>SUB THEME: ACCESSING THE RIGHT CARE</i>	Advance care planning
Age >65 yrs / <65 yrs	A different life
Accessing the right information	Abandonment
Access to ADL support	Nothing more can be done
Accessing the right medical care	Unrealistic expectations
Access to equipment	
Costs of care	THEME 3: MODELS OF CARE
Disability Services	Care coordination
Doing things differently	Future options
Family and friends support /responsibility for care	Staying at home
Nursing Homes	Workforce
Transport	

<i>SUB THEME: CLINICAL CARE</i>	THEME 4: THE CARER EXPERIENCE
Culture	Access to information
Disease process	Appreciation
Medical care	Coping
Communication	Frustration
MND	Lack of support
Psychosocial care	Supports
Medical Education	Self care
	Tasks

I then applied an overarching systems analysis framework to these themes to provide a final detailed picture of the health and other related systems as perceived by patients, carers and KSPs. This framework was developed by Bainbridge et al²⁶⁰ for the evaluation of palliative care networks. It was based on Donabedian’s seminal work, looking at system structure, processes of care and patient outcomes (SPO).²⁶² They developed their framework on evidence from a variety of models of health systems evaluation, with specific consideration of the complexities of the provision of end of life care needs.²⁶⁰ It incorporates specific constructs for collaborative care, community readiness and client centred care which are directly relevant for end of life care for chronic disease. However, because I was examining those parts of the health system that function for chronic disease and end of life care, rather than a palliative care network, some of Bainbridge et al’s domains required adjustment to make them relevant to the chronic disease end of life care context rather than the palliative network context: e.g. “*network characteristics*” needed to be made relevant for systems encompassing chronic disease and end of life care as a network has different processes for collaboration and integration from primary care or hospitals.²⁶⁰ Table 9 details Bainbridge et al’s²⁶⁰ domains as applied to end of life care for chronic disease.

Table 9. Conceptual framework domains in examining end of life care for chronic disease ²⁶⁰

Patient Outcomes	System Structure	Process of Care
Satisfaction with domains of care and access	Environment factors	Provider characteristics
Availability of care	Population size	Beliefs/attitudes
Free flow and accessibility of information	Population demographics	Interpersonal style
Physical care	Community awareness/ perceived importance of health issue	Specialty training and experience
Pain and symptom management	Profession/specialty base	Extent of collaboration amongst providers
Psychosocial care	CDM/EoL system characteristics	Common goals/shared values
Management of expected death	History/evolution	Reciprocity
Perceptions of client centeredness of care	CDM care structure	Respect
Appropriate involvement of family and friends	Extent of participation in EoL care	Shared decision making and problem solving
Collaboration/ team management	Policies and procedures	Trust
Education and shared knowledge	Power equality	Information transfer
Rapport	Promotion of end of life (EoL) in CDM care	Communication
Respect for patient needs and preferences	Ideals	Information systems and materials
Sensitivity to nonmedical and spiritual dimensions of care	Vision/culture	Standardized assessment and monitoring of patient need

Perceptions of continuity of care	Economic factors	Organization factors
Relational	CDM EoL resources	Care team composition and Role recognition
Informational	Extent of volunteerism	Educational opportunities
Managerial	Financial incentives	Incentives to encourage collaboration/client centred care
	Capacity for 24/7 care	Leadership
		Standards of practice

The service manager/policy maker interviews were analysed initially using a deductive process, again using the thematic analysis framework described by Braun and Clarke.²⁶¹ The initial deductive analysis was based on the interview schedule, to give a broad overview for addressing the issues identified above – phase 2 of Braun and Clarke’s model – generating initial codes and themes. I then undertook a more inductive analysis, looking for more specific themes and sub themes which I then reviewed and refined into three final major themes (see Figure 5).

Major themes and codes

Deductive analysis themes

- Integrating care
 - Facilitators
 - Barriers
 - Integrating care across silos
- Patient centred care
 - Understanding
 - Provision
 - System changes
- The role of primary care
 - Structure
 - Funding
- Care co-ordination
 - Barriers
 - Facilitators
 - Role
- Disease Trajectories
 - Transitions to end of life care
 - Flexibility – active and supportive care
- >65/<65
- Policy articulation
- Advance care planning
 - Culture change
 - Having the conversations
 - Strategies
- Carers
 - Role
 - System change
- Future options
 - Workforce
 - Resources

End of life care

- Philosophies of Care
 - Palliative care
 - The role of palliative care/Benefits
 - Chronic disease
 - A palliative approach //Transitions
- Barriers
 - Definitions
 - >65/<65
 - Accessing palliative care
 - Culture
 - Fear / Expectations
 - Being overwhelmed
 - Confidence
- Psychosocial issues
- Carers
 - Recognition
 - Needs
 - Supports
- RACFs
- Changing the system
 - Flexibility/Options for change

Models of care

- General practice
 - General practice palliative care
 - Role definition
 - Corporatisation
 - Practice nurses
- Community based palliative care services
- Access
- Communication

Care Co-ordination

- Importance
- Role
- Who should do it?
 - General practice
 - Palliative care
 - Royal District Nursing Service (RDNS)
- Barriers
- Concerns

Patient Centred Care (PCC)

- Definition
 - Consumer directed care
- Empowerment
- Importance
 - PCC and Palliative Care
- How do you action PCC?

Advance Care Planning

- Advance Care Planning and End of Life
 - Barriers
 - Legal issues/lawyers
 - Policy
 - Time
- Conversations
 - How to have the conversation
 - Who should do it?
 - When?
- Culture
- Community attitudes
- Medical / Health Professional Culture
- Enablers
- RACFs
- Training and education

Education

- Undergraduate training
- Specialist training
- GP training
- Ongoing education
- How?

Integrating Care

- Who
 - Responsibility
 - Aged care/Palliative care interface
 - Palliative care
- How
 - Enablers
 - Communication
 - Governance / Co-ordination
 - Policy
 - Technology
 - Barriers/Silos
- Systems
 - Culture

Funding

- Funding
 - Chronic disease
 - Palliative care
- Two tiered system
 - Commonwealth/State
 - Primary care / Acute care
- Funding models
- Accessing funding
- Drivers

Final themes

End of Life Care

Philosophies of end of life care
Advance care planning
Enablers

Key principles underpinning end of life models of care

Patient centred
Integrated
Co-ordinated
Embedded in primary care

Figure 5. Thematic analysis: Management/policy stakeholders

Final analysis

Following my thematic analyses, I used systems thinking to draw together the results of the literature review, policy analysis, case reviews and policy maker and service manager interviews using an overarching HPSR framework to answer the main research question. In the final phase of the analysis, I sought to understand how the various aspects of the health system either facilitate or hinder care at the end of life. In particular, how the various relationships between the different parts of the health system interact with each other are key to understanding how to support system change for people with advanced chronic disease.⁴⁸ Sturmberg and Martin⁴¹ suggest that complexity theory allows us to understand health and disease in the context of individual people in their individual circumstances, helping to identify which care will best suits their needs. This is vital in end of life care in chronic disease, where each person can have a completely different disease trajectory and require quite different supports and interventions.³² Therefore, once I had developed a clear description of the end of life care system and how it functions, I used a complexity theory framework to try to establish why the system was functioning as it was and the most effective ways to bring about change.

HPSR suggests that health systems are complex adaptive systems,⁴⁹ so part of this application of complexity theory was to determine how the health system functions as a CAS for people with chronic disease at the end of life and what implications this might carry. Using a complexity lens to look at how health policy and the health system function for end of life care allowed a much broader view of both the functions and the relationships within the system,⁴⁷ particularly when examining the different models of care for chronic disease and palliative care.

3.5. Research quality and rigour

Ensuring the quality, validity and rigour in any research process is vital if the research results are to be perceived as trustworthy and credible.²¹⁵ Gilson et al²¹⁶ suggest that this is extremely important in undertaking HPSR and it is premised on *transparent information on study design and the processes of data collection, analysis and interpretation.*^{p.e1001079} They go on to suggest that rigorous research

involves 1) an active process of questioning and checking; 2) a constant process of conceptualising and re-conceptualising; 3) crafted, interpretive judgements based on enough evidence, particularly about context and 4) researcher reflexivity – being explicit about how your own assumptions influence interpretation.²¹⁶

Liamputtong²¹⁵ suggests that key strategies to ensure rigour fall into two categories:

1. Research design and processes: methodological choices; prolonged engagement and fieldwork; rich description; interpretation and evidence; reflexivity and triangulation.
2. Research participants, peer researchers and outsiders: member checking; peer review; an audit trail.

Gilson²¹⁶ provides ten principles for ensuring rigour and Table 10 outlines how I incorporated these principles into my research.

Table 10. Processes for ensuring rigour in qualitative data collection and analysis

Principles ²¹⁶	Application in this research study
Prolonged engagement HPSR tends to draw on lengthy and perhaps repeated interviews with respondents, and/or days and weeks of engagement within a case study site	Participants and their carers were interviewed 3 times over a period of nine months.
Use of theory To guide sample selection, data collection and analysis, and to draw into interpretive analysis	The research was undertaken using an HPSR framework and so a “systems thinking” approach informed the research design – i.e. 3 phases incorporating policy review; eight in depth case reviews and interviews with key policy makers and service managers. The analysis was informed by complexity theory, exploring how the health system functions for people with advanced chronic disease using a complex adaptive systems framework
Case selection Purposive selection to allow prior theory and initial assumptions to be tested or to examine ‘average’ or unusual experience	A census of all relevant Australian policies related to chronic disease, palliative care and ageing was undertaken. A purposive criterion sampling strategy was used for the case review sample to ensure a range of gender, age and chronic diseases.
Sampling Of people, places, times etc, initially, to include as many as possible of the factors that might influence the	Specific criteria for each chronic disease were also developed to assist in identifying people in the last year of their life.

Principles²¹⁶	Application in this research study
<p>behaviour of those people central to the topic of focus (subsequently extend in the light of early findings)</p> <p>Gather views from wide range of perspectives and respondents rather than letting one viewpoint dominate</p>	<p>A range of policy makers and service managers were identified at a state and national level, as well as in the acute and primary care sectors and across chronic disease and palliative care.</p>
<p>Multiple methods (case studies)</p> <p>Use multiple methods for case studies</p>	<p>Three methods were used for this research:</p> <p>A policy review of all state and national policies related to chronic disease, palliative care and aged care.</p> <p>A multi-perspective longitudinal qualitative approach for the case reviews.</p> <p>Semi structured interviews for policy maker/service manager perspectives.</p>
<p>Triangulation</p> <p>Looking for patterns of convergence by comparing results across multiple sources of evidence (e.g. across interviewees, and between interview and other data), between researchers, across methodological approaches, with theory</p>	<p>Comparisons were undertaken between the experiences of the participants and the interviews with their health service providers</p> <p>Policy provisions outlined in the chronic disease/palliative care related policies will be compared to actual provision of, and access to, services.</p>
<p>Respondent validation (Member checking)</p> <p>Review of findings and reports by respondents</p>	<p>A summary of each case review was developed, including demographic data, history of the disease, access to services and a summary of each interview was developed and offered to participants.</p>
<p>Negative case analysis</p> <p>Looking for evidence that contradicts your explanations and theory, and refining them in response to this evidence. Preliminary case study reports initially reviewed by other members of the research team</p>	<p>The nine case reviews offered a wide range of experiences of the health system ranging from excellent access to services and high satisfaction levels with care to some quite distressing incidents of sub optimal care and occasionally a complete lack of access to appropriate care. A comparison of access to care and possible barriers was undertaken across the case review participants.</p>
<p>Peer debriefing and support</p> <p>Review of findings and reports by other researchers. Preliminary cross-case analysis fed back for review and comment to study respondents; feedback incorporated into final reports</p>	<p>Regular fortnightly meetings with supervisors provided the opportunity to debrief about participant interviews, and the sometimes very difficult situations of participants, particularly in regard to access to services. It also allowed discussion of health system functioning and the meaning of some of the experiences of participants, as regards health system functioning.</p>

Principles ²¹⁶	Application in this research study
<p>Clear report of methods of data collection and analysis (Audit trail)</p> <p>Keeping a full record of activities that can be opened to others and presenting a full account of how methods evolved to the research audience</p>	<p>Detailed records of project activities were kept including:</p> <p>A record of all contacts with case review participants.</p> <p>A record of all contacts and responses from service providers contacted for the case reviews.</p> <p>A record of all interviews undertaken, their transcription and their review.</p> <p>A number of short discussion papers examining particular issues arising in the research – e.g. identifying clinical indicators for recruitment for each chronic disease; choosing the QoL and depression measures and exploring a framework approach and complexity theory in relation to end of life care.</p>

3.6. Summary

In seeking to address the overall aim of the research *to inform policy development and service planning and provision through identifying how the Australian health system (at a local, state and national level) hinders and/or facilitates end of life care for people with advanced chronic disease*, I identified the need to use a wide range of research approaches. Because many of the research participants were either approaching the end of their life, or caring for people at the end of their life, it was important to address the specific ethical issues arising in this type of research and to also be aware of the importance of reflexivity in identifying my assumptions and biases and in recognising the possible emotional impacts of such research. An HPSR framework provided a comprehensive method of organising data collection and because this process required data from the macro, meso and micro levels, the research framework included a review of international models of care, a policy analysis, the voices of people with advanced chronic disease and their carers and the viewpoints of health policy developers and service managers.

A qualitative approach (with a strong emphasis on ensuring the rigour of the research process) allowed the most flexible approach to collecting and analysing the data and then bringing the various data analyses together to formulate the overall results. The use of complexity theory as the overall theoretical framework

for the data analysis allowed an in depth examination of health system functioning and how this might be adapted and changed to adequately and appropriately support people with end stage chronic disease.

In Part 2 of this thesis, I will present the results of my analyses of the three phases of my research methodology.

Part 2. Analysis and results

Health policy and system research (HPSR) recognises that the health system operates at macro, meso and micro levels and that any systems analysis requires an examination of these three levels. In order to provide a detailed picture of how the system is actually functioning, this analysis requires each level to be reviewed individually and then combined to explore their interactions.¹⁶ In practical terms, a macro level review appraises national and state policies related to end of life and chronic disease care; the meso level explores how local health systems and organisations function to provide end of life care for people with chronic disease; and the micro level involves examination of the impact that these systems and organisations have on day-to-day care for individuals with advanced chronic disease and their carers.¹⁶

The next four chapters present the results of my analysis of the current Australian health care system as it operates for people with advanced chronic disease who may be in the last year of their life. Chapter 4 appraises the variety of health and other policies that impact on how end of life care is funded and provided in Australia today: the macro level. Chapter 5 examines the system structure and care processes: the meso level of care provision. Chapter 6 presents the micro level of care: patient outcomes: i.e. how the Australian health system impacts on the health and everyday lives of people with advanced chronic disease from the perspective of patients, carers and their key health service providers (KSPs). Chapter 7 provides an overview of how health service managers and policy makers perceive the health system for end of life care to be currently functioning and how it should function. This chapter will contribute to both the macro and meso level reviews.

Together, these chapters provide the evidence to allow me to answer the first of my research questions:

How can the health system provide care that meets the needs of people with advanced chronic disease and of their carers/families?

- a. How does the health care system currently support people with advanced chronic disease and their carers/families as they manage their chronic disease and address the issues required for end of life care?*
- b. How appropriate, available and accessible is end of life care for people with advanced chronic disease?*
- c. How do the complicated entities of chronic disease and palliative care interact in the Australian health care system at a national, state and local health service level?*
- d. Why does the health system function in the way it does to provide end of life care?*

Chapter 4. Falling through the cracks? End of life care and chronic disease health policies

4.1. Introduction

Health policy provides the overarching framework under which all health strategies and services are funded and developed. It has been defined as²⁶³ “*courses of action that affect that set of institutions, organisations, services and funding arrangements that we have called the health care system*”.^{p22} The term ‘*public policies*’ is used to describe policies for which governments are primarily responsible and when health care policy provisions overlap - for example, with respect to preventive health and primary health care – they must articulate if effective services are to be developed and delivered. Gilson¹⁶ notes that whilst health policies can be seen as formal written documents *these formal documents are translated through the decision making of policy actors (such as middle managers, health workers, patients and citizens) into their daily practice....ultimately these daily practices become health policy as it is experienced, which may differ from the formal document.*^{p28}

As noted earlier, a core component of my research was identifying how the health system impacts on individuals and so this concept of *health policy as it is experienced* fits closely with my research philosophy. Health policy analysis is a core element of my chosen research framework, Health Policy and Systems Research (HSPR) which:²⁴ *focuses primarily upon the more downstream aspects of health: it focuses upon policies, organisations and programs but does not address clinical management of patients.*^{p2} Analysing health policy helps us to understand past experience, and it can also support advocacy for policy change.¹⁶ An examination of relevant health policies, and their impact on the specific end of life care needs of people with advanced chronic disease, allowed me to identify the extent to which the need for end of life care and services is recognised by government. Because chronic disease and end of life care do not stand alone, but interact with various parts of the health system, a variety of policies such as those related to ageing and disability were likely to impact on care. Therefore, any examination of policy needed to identify all

relevant policies, not just chronic disease and palliative care. All of these policies have direct implications for the planning, funding and integration of services.²⁶³

In Australia, health related policies are developed at both a state and national level.¹⁴⁶ This means that not only do different policy areas such as palliative care and chronic disease have to interact with each other, the same policies have to interact at different levels. In ageing and disability care, local government also plays a significant role in service provision. Another factor requiring consideration in policy and service provision in the Australian health system is the role of private health insurance and private health services.²⁶⁴

To date, there has been little examination of how the differing policies related to chronic disease and end of life care interact and facilitate service provision. The following paper describes an audit of Australian health policy which I undertook to identify how the complex entities of chronic disease and end of life care articulate at a policy level and what this means for the quality of, and access to, appropriate services for people with chronic disease approaching the end of their life.

4.2. Health policy analysis results

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Australian health policy and end of life care for people with chronic disease: An analysis



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ABSTRACT

End of life care for people with advanced chronic disease is a growing international imperative, with the majority of deaths in the world now related to chronic disease. The provision of care that meets the needs of people with advanced chronic disease must be guided by appropriate policy. The key policy areas impacting directly on end of life care are related to chronic disease, palliative care and, increasingly, aged care.

This paper describes the outcomes of an audit of Australian chronic disease and end of life/palliative care policies. We identified that chronic disease health policies/strategies demonstrate a focus on prevention, early intervention and management, with scant recognition of end of life care needs. The majority assume that a referral to palliative care will address end of life care needs for people with chronic disease. By contrast, palliative care policies recognise the need for the incorporation of a palliative approach into advanced chronic disease care, but there are few connections between these two policy areas. Whilst palliative care policies intersect with carer and advance care planning policies, chronic disease policy does not. Key concerns requiring consideration when developing policy in this area are discussed and possible policy options identified.

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1. Introduction

Governments around the world have become increasingly aware of the threat to public health posed by the emergence of an epidemic of chronic disease [1]. The United Nations has reported that non-communicable diseases – i.e. chronic diseases and cancers – are causing a growing proportion of all deaths worldwide, as population growth and ageing drive large increases in the burden

of mortality [2]. Non-communicable diseases are now the largest global cause of death with cardiovascular diseases, diabetes, cancers and chronic respiratory diseases accounting for more than 65% of all deaths in 2008 [1].

In Australia, the rise in chronic diseases has been particularly striking. The most common causes of death in Australia in 2007 were chronic disease related, and this increased with age [3]. Diabetes is expected to become the leading cause of disease burden by 2023 [3], with an associated projected increase in the incidence of end stage kidney disease (ESKD) of nearly 80% by 2020 [4]. The 2010 Australian Intergenerational Report estimated that people aged 65 years and over will increase from 13% to 22.6% by 2050, with a subsequent increase in the number of people with complex health needs, who will require specific care at the end of their life [5]. This change is anticipated in other developed nations [2] (Tables 1–3).

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Table 1
Mortality rates for Australia and the average among OECD countries, for selected causes of death (a) and by sex, 2009 (b) (deaths per 100,000 population) [54].

	Males		Females	
	Australia	OECD average	Australia	OECD average
Coronary heart disease	98.9	117.5	52.3	60.4
Stroke	36.0	54.8	33.9	42.3
Lung cancer	39.9	51.9	19.5	19.0
Chronic lower respiratory disease	4.6	4.8	3.4	2.5
Diabetes	15.1	18.4	10.4	14.1

Table 2
Leading underlying broad causes of death in Australia (a), by age group, 2007 [3].

	All ages (% of deaths)		15–24 years (% of deaths)		25–44 years (% of deaths)		45–64 years (% of deaths)		65–84 years (% of deaths)		85 years & over (% of deaths)	
	M	F	M	F	M	F	M	F	M	F	M	F
	Cancer and other tumours	32.3	26.0	8.2	14.2	14.5	35.0	42.6	55.8	37.5	33.3	20.0
Cardiovascular disease	31.3	36.5			12.8	11.5	24.5	13.9	31.6	32.4	42.3	48.6
Respiratory system diseases	8.6	8.2						5.9	9.5	8.8	11.6	8.7
Injury and Poisoning	7.3		72.1	53.8	50.3	27.7	10.0	7.1				
Endocrine related disorders									4.1	4.8		
Nervous system disorders			4.4	5.6								
Digestive disorders							5.4					
Mental disorders		5.4									5.9	8.3
Ill defined conditions			5.6	7.8	5.9	4.5						

The increase in chronic diseases, both in Australia and other developed nations, has been accompanied by the development of a range of health policies focused around chronic disease management. These policies attend to prevention, early intervention and management as they relate to chronic disease. Relatively little attention, however, has been paid to end-of-life care [6], despite the fact that the majority of chronic diseases are life limiting, and that those approaching the end of their lives will require specific care.

Currently, there is an assumption that a referral to palliative care services will address the end of life needs of people with chronic diseases. However, palliative care services have been designed largely to meet the needs of cancer sufferers, for whom there is often a clear transition to an “end of life” period, which triggers referral and

a shift to a different style of care. However, there is growing evidence that, for a number of chronic diseases, there is no clear transition to end-of-life, but rather, a slow period of decline, where both interventional care and a palliative approach are required [7–9].

One way to assess the extent to which there is an appropriate transition from interventional to palliative care is to examine those policies and service frameworks which influence the funding and provision of health services in this domain [10]. The Palliative Care Council of New Zealand undertook a review of government health policy in relation to the provision of Palliative Care Services in New Zealand, and noted that end of life care for people with chronic disease was not adequate; however, the Council did not look specifically at interactions with chronic

Table 3
Estimated leading causes of death in 2030, by income group, with chronic disease related deaths highlighted [55].

	World		High income countries		Middle income countries		Low income countries	
	% of total deaths	(rank)	% of total deaths	(rank)	% of total deaths	(rank)	% of total deaths	(rank)
Ischaemic heart disease	13.4	(1)	15.8	(1)	12.7	(2)	13.4	(1)
Cerebrovascular disease	10.6	(2)	9.0	(2)	14.4	(1)	8.2	(3)
HIV/AIDS	8.9	(3)			6.2	(4)	13.2	(2)
COPD	7.8	(4)	4.1	(5)	12.0	(3)	5.5	(4)
Lower respiratory infections	3.5	(5)	3.6	(6)			5.1	(5)
Trachea, bronchus lung cancers	3.1	(6)	5.1	(3)	4.3	(5)		
Diabetes mellitus	3.0	(7)	4.8	(4)	3.7	(6)	2.1	(9)
Road traffic accident	3.9	(8)			2.5	(9)	3.7	(7)
Perinatal conditions	2.2	(9)					3.9	(6)
Stomach cancer	1.9	(10)	1.9	(9)	3.4	(7)		
Alzheimer's and other dementias			3.6	(7)				
Colon and rectal cancers			3.3	(8)				
Prostate cancer			1.8	(10)				
Hypertensive heart disease					2.7	(8)		
Liver cancer					2.2	(10)		
Diarrhoeal diseases							2.3	(8)
Malaria							1.8	(10)

disease policies or strategies [11]. In the UK, the National End of Life Care Programme (developed as part of the End of Life Care strategy) is working with the National Health Service to develop care frameworks for specific chronic diseases such as heart failure [12], chronic obstructive pulmonary disease [13], neurological diseases [14] and kidney failure [15].

In Australia, there has been little examination of how the various policies related to chronic disease and end of life care (and increasingly healthy ageing) interact and facilitate service provision for people with chronic disease approaching the end of their life. We examined Australian health policies to identify the level of priority placed on end of life care for people with chronic disease and whether policy directions and guidance were provided for service planners to develop high quality end-of-life care for people with chronic disease. This paper therefore describes and analyses Australian health policy to address the following questions:

- (1) How well do chronic disease, palliative care and ageing policies and strategies intersect to ensure that people with advanced chronic disease, and their carers, receive the care specified in these policies?
- (2) What links are there between the policies, strategies, funding and service provision required to meet the needs of people with advanced chronic disease at the end of their life?

The paper concludes with a series of new options with the aim of stimulating consideration of a new policy framework.

2. Materials and methods

We performed a systematic search of all Australian federal, state and territory government websites for national and state policies relating to end of life care and chronic disease. Websites were initially identified using Google, and then searched to identify relevant, current or recent policies and strategies relating to end of life care/palliative care and chronic disease management, as well as primary health care and disability care. Search terms used included “chronic disease”; “integrated care”; “palliative care”; “end of life care”; “disability”; “primary health care” AND “policy/strategy/framework”; “state health plan”; “health action plan”; “health priorities”. A specific search was undertaken to identify policies and strategies related to advance care planning and carers. Palliative Care Australia and state Palliative Care Council websites were reviewed to identify current activities and advocacy related to palliative care policies and strategies, including proposed revisions/renewals. A further search was undertaken to identify policies and strategies related to ageing/aged care. Again, federal, state and territory government websites and relevant community organisations such as the Council on the Ageing (COTA) were searched. Search terms included “ageing”; “healthy ageing”; “aged care”; “seniors”; “older Australians” AND “policy/strategy/framework”; “action plan”; “plan”.

Policies were categorised into those relating to chronic disease, palliative care and aged care and each was reviewed using the following questions:

- (a) Do the chronic disease and ageing policies/strategies/frameworks mention palliative/end of life care and vice versa?
- (b) If so, what is the context?
- (c) How extensive is the discussion of chronic disease/end of life/palliative care?
- (d) Are there any actions/outcomes/measures associated with the mention of chronic disease/end of life/palliative care? If so, what are they?

3. Results

In Australia, a complex web of policy, strategic plans, action plans, service delivery models and health reform processes guide the provision of chronic disease and palliative care services. These policies range across the health, aged care, community services and human services domains in federal, state/territories and local government jurisdictions. Policies and strategies in Australia are generated at a national level by the Australian government and by each of the eight states and territories that make up the Commonwealth. In terms of funding responsibility, a variety of different government agencies fund chronic disease and palliative care services. In the Australian Department of Health and Ageing (DoHA), the Population Health Division has responsibility for Chronic Disease Management (through the Chronic Disease Branch) and Palliative Care (through the Cancer and Palliative Care Branch). DoHA funds personal care services for people over 65 years with chronic and complex diseases through packages of care such as Community Aged Care Packages (CACP) and Extended Aged Care at Home (EACH) packages [16] and programmes such as Home and Community Care [17]. However, people under 65 years are funded through Disability Services at a state level, where access to funding and services is much more problematic [18]. Other areas of DoHA influencing chronic disease services are the Primary and Ambulatory Care Division (responsible for general practice, Medicare Locals and a variety of primary care initiatives) and the Ageing and Aged Care Division, responsible for community care and aged care packages. Each state has a Department of Health and states and territories are primarily responsible for hospital and community health services and funding (excluding general practice). Thus, any policy audit needs to consider the various levels at which policies and strategies are developed and service provision occurs.

3.1. Chronic disease and palliative care

Most chronic disease policies and strategies note the importance of a continuum of care, focussing particularly on prevention, early intervention and management, but with little consideration of end of life care. All palliative care policies recognise the growing need for end of life care for people with chronic disease. Throughout all chronic disease policies/strategies there is an assumption that all

clinicians and health workers will participate in chronic disease care, from prevention, through early intervention to active disease management. The National Palliative Care Strategy states that the scope of palliative care includes primary care providers in a variety of settings and should be available in both generalist and specialist care [19], whilst the NSW Palliative Care Strategic Framework states that: “palliative care has to be recognised as core business for health services” [20]. Whilst the provision of chronic disease care by a wide variety of health professionals is supported by a range of action plans, educational opportunities, funding and infrastructure, there is no evidence that such processes have been developed for the provision of end of life care.

Table 4 summarises national, state and territory policies with respect to chronic disease and palliative care and outlines the results of the policy audit.

- Although there is a National Chronic Disease Strategy (NCDS) [21] and a National Palliative Care Strategy (NPCS) [19], only South Australia (SA) has current policies in both areas.
 - The SA Chronic Disease Action Plan for South Australia 2009–2018 [22] reflects the NCDS, noting the importance of advance care planning in end of life care.
- Whilst Victoria [23] and New South Wales (NSW) [20] have current palliative care strategies, their chronic disease management frameworks have moved to specific programmes of integrated care, implemented at more local levels. There appear to be few formal links between these programmes and palliative care services.
 - The Victorian Health Priorities Framework 2012–2022, and the associated Metropolitan and Rural and Regional Health Plans focus on chronic disease management, and note the importance of end of life care [24].
 - Future Directions for Health in NSW. Towards 2025 notes the importance of addressing chronic disease, but makes no mention of end of life care [25].
- Western Australia (WA) and the Northern Territory (NT) do not have Palliative Care strategies; their chronic disease strategies specifically identify end of life and palliative care as action areas with targets to be measured.
 - The WA Chronic Health Conditions Framework nominates specific service components for end of life care [26].
 - The Health Networks Branch of WA Health released a *Pathway for Renal Palliative Care Services in Western Australia* in July 2012 [27].
 - The NT *Chronic Conditions Prevention & Management Strategy 2010–2020* and associated Implementation Plan clearly identify access to palliative care as a key action area [28].
- The Australian Capital Territory (ACT) currently has neither a palliative care nor chronic disease strategy; the *Primary Health Care Strategy 2011–2014* has a major focus on chronic disease, but end of life care is not mentioned [29]. A draft *ACT Palliative Care Services Plan 2012–2017* was released in September 2012 and is currently out for consultation [30]. It recognises the growing importance of end-of-life care for people with advanced chronic

disease and has identified six key goals with 15 associated strategies for implementation over the next five years.

- Tasmania has a current *Chronic Disease Action Framework*, with a focus on prevention and management; palliative care is mentioned only briefly [31].
- The Queensland Strategy for Chronic Disease 2005–2015 refers to the development of a State-wide Integrated Strategy for Palliative Care, and states it will support this development; this policy has not been developed to date [32].

3.2. Ageing

There is currently no national Ageing or Healthy Ageing policy in Australia. However, the Productivity Commission conducted an inquiry in 2010 to comprehensively review aged care and provide recommendations for future policy options. The final report of the Productivity Commission was submitted in June 2011 [33] and the Australian government released their response in April 2012 [34]. The report [33] recognises that “While further advances in the management of some diseases are expected, more people will require complex care for dementia, diabetes and other morbidities associated with longevity, as well as palliative and end of life care” (p. xxii) and goes on to state that the aged care system should aim to “ensure that all older Australians needing care and support have access to person-centred services that can change as their needs change” (p. xiv).

In response to the report, the Australian government is developing a 10-year action plan to address the report recommendations and identify how older Australians can stay engaged socially and economically [34]. From 1 July 2012, the Commonwealth took over the funding of basic community care services in all states and territories except WA and Victoria, and has allocated an extra \$3.7 billion over five years through the *Living Longer, Live Better* package [34]. If the reforms proposed by the Productivity Commission are enacted, this will have a significant impact on the delivery of chronic disease and end-of-life service delivery.

All states and territories have healthy ageing or ageing strategies, frameworks or action plans (see Table 5) but there is generally minimal consideration of end-of-life or palliative care needs, other than a focus on advance care planning. A National Framework for Advance Care Directives was released in Australia in 2011 [35], and a number of states and territories are also developing advance care planning strategies. The only “Key Direction” related to end of life care in the *National Chronic Disease Strategy* [21] concerned advance care planning and this helped provide the impetus for the national framework [35]. There are also other policies at both state and national levels which mention service provision and end of life care, including primary health care policies; carers policies and disability policies (impacting on services available to people less than 65 years).

4. Discussion

There are currently few intersections between chronic disease and palliative care policies, at either a national or state level and current funding mechanisms reflect this

Table 4
Australian chronic disease and palliative care (and related) policies at December 2012.

	Chronic disease	Palliative care	Other ^a
National	National Chronic Disease Strategy 2006	Supporting Australians to Live Well at the End of Life. The National Palliative Care Strategy 2010	<ul style="list-style-type: none"> ● Building a 21st Century Primary Health Care System – The National Primary Health Care (PHC) Strategy. ● National Carers Strategy. ● National Framework for Advance Care Directives ● National Disability Strategy 2010–2020 ● Directions for Aged Care 2004–2011 ● Carers (Recognition) Act 2008 ● Queensland Carer Action Plan, 2011–2014 ● Future Directions for Health in NSW. Towards 2025 ● Towards 2030: Planning for our changing population. The Integrated Primary and Community Health Policy 2007–2012 ● Carers Action Plan 2007–2012 ● ACT Primary Health Care Strategy 2011–2014 ● Caring For Carers Policy (2003) ● Access health. Healthcare for all in the ACT (2007)
QLD	Queensland Strategy for Chronic Disease 2005–2015	No current policy. Previous Strategic Directions for Palliative Care Services 2000–2005	
NSW	No current policy. The Connecting Care (Severe Chronic Disease Management) Programme supports CDM focussed through local health districts	Palliative Care Strategic Framework 2010–2013	
ACT	No current policy. Previous: Chronic Disease Strategy 2008–2011	Consultation currently being undertaken on the Draft ACT Palliative Care Services Plan 2012–2017. Previous: Palliative Care Strategy 2007–2011	
VIC	No current policy. The Integrated Chronic Disease management programme in Victoria co-ordinates CDM and care is focussed through PCPs	Strengthening palliative care: Policy and strategic directions 2011–2015	<ul style="list-style-type: none"> ● Victorian Health Priorities Framework 2012–2022 Metropolitan Health Plan ● Victorian Health Priorities Framework 2012–2022: Rural and Regional Health Plan ● Tasmania’s Health Plan. Primary Health Services Plan (2007) ● Tasmania’s Health Action Plan (2010) ● South Australia’s Health Care Plan 2007–2016 ● GP Plus Health Care Strategy (2007) ● Health Policy For Older People 2010–2016 ● Health Service Framework for Older People 2009–2016 ● WA Health Operational Plan 2011–2012 ● WA Primary Health Care Strategy; Acts Amendment (Advance Health Care Planning) Bill 2006 ● Building the Territory for all Generations – A Framework for Active Ageing in the Northern Territory (2007)
TAS	Connecting Care: A Chronic Disease Action Framework for Tasmania 2009–2013	No current policy. Previous Tasmanian Palliative Care Plan 2002–2005	
SA	Chronic Disease Action Plan for South Australia. 2009–2018	Palliative Care Services Plan 2009–2016	
WA	WA Chronic Health Conditions Framework 2011–2016	No current policy Pathway for Renal Palliative Care Services in Western Australia. July 2012	
NT	Chronic Conditions Prevention & Management Strategy 2010–2020	No current policy. Previous: Palliative Care Strategy 2005–2009	

^a “Other” policies have some reference to chronic disease management and/or end-of-life/palliative care.

disjunction. Most jurisdictions do not have policies in both areas – only three Australian states have current palliative care policies and only two states have chronic disease policies which directly discuss end of life care. Recent reforms in ageing policy are yet to address end of life care. The policy focus to date has been on managing disease, in the context of a relatively static understanding of patient needs. There has been minimal policy guidance or agreement on how or when care at the end of life should be provided or who should provide it. This is reflected in the differing funding and administrative mechanisms for aged care, palliative care and chronic disease management.

There is little evidence that policy makers have been able to develop effective policies to drive appropriate models of care for people with advanced chronic disease as they approach the end of their lives. There appears to be little recognition of the need for care models to change as patient need changes. Palliative care policies do recognise the growing needs of people with advanced chronic disease, but these services, which developed to meet the needs of people with cancer, may not be able to meet the needs of the rapidly increasing population of

people with advanced chronic disease. In addition, it is not clear that the current Australian palliative model of care is one that will actually best meet the needs of this large and diverse group of people. The existing policies which shape end-of-life care appear to be underpinned by assumptions about the trajectory of end-of-life care which may not hold for chronic diseases. There needs to be a refocusing in the development of new policy options to include some of the following perspectives:

- (1) Many chronic disease policies and strategies assume that chronic disease follows a steady and identifiable progression through ill health to end-of-life and that there is a clear transition to an “end of life” period. There are also varying understandings of the length of this “end of life” period, ranging from the last weeks of life [36] to the last year of life [37]. Contrary to the assumptions in these policies, the trajectory of many chronic diseases includes major exacerbations during which a person may die at any time, followed by periods of relative recovery and stability. This pattern can continue for a number of years, making a predictable

Table 5
Australian ageing policies at December 2012.

Victoria	Improving care for older people: a policy for Health Services 2003	Notes the need to: (1) adopt a strong person-centred approach to the provision of care and services (2) better understand the complexity of older people's health care needs (3) improve integration within Health Service's community-based programmes and between Health Services and ongoing support services available in the broader community And that care planning includes discussion with the older person and their carers regarding their future care and palliation wishes
NSW	NSW Ageing Strategy 2012	Notes the need to: Support people in the "Middle Years" to undertake advance care planning; complement existing processes around designing palliative care services
Queensland	Positively Ageless. Queensland Seniors Strategy 2010–2020	Provision of support for Advance Care planning and associated legal documentation
South Australia	Improving with Age – Our Ageing Plan for South Australia. 2006	Notes the importance of "high quality palliative care services are available to meet the individual needs of older people within hospitals, the community and at home"
Western Australia	Age-friendly WA Strategy 2012	The Department for Communities is encouraging local government authorities to embrace the World Health Organisation's Age-friendly Communities concept which is part of an international effort to prepare for the ageing of our community. Local government council areas are being funded to develop ageing strategies
Tasmania	Inclusive Ageing: Tasmania 2012–2014 Strategy	No mention of care needs at the end-of-life
Northern Territory	Building the Territory for all Generations – A Framework for Active Ageing in the Northern Territory. 2007	Notes that the NT government will: Provide appropriate support for and access to culturally secure and technically sound palliative and respite services
Australian Capital Territory	ACT Strategic Plan for Positive Ageing. 2010–2014. Towards an Age – Friendly City	No mention of care needs at the end-of-life

transition to "end of life" problematic [38]. Whilst there is general agreement about the timing for referral to palliative care for people with cancer, no such consensus exists in chronic disease. Despite a number of studies attempting to identify clinical symptoms in a variety of chronic diseases which could trigger referral to palliative care [39–41], clinicians have reached no consensus. Recent studies, including an Australian study examining end of life care for COPD, identified that there is no clear transition to end of life, making it difficult to judge the appropriate timing of referrals [7,42]. All of these factors lead to further confusion when attempting to fund and implement services.

- (2) There appears to be an assumption that care for people with advanced chronic disease should move from a chronic disease management (CDM) model of clinical care to a palliative care model. There is growing evidence, however, that appropriate care should combine elements of both active disease management and a palliative approach, as neither model alone can meet the needs of people with advanced chronic disease [7,43,44]. Each model has distinct characteristics which are important for the care of people with advanced chronic disease. CDM is a systems focused care model, incorporating regular review, coordinated healthcare interventions and patient self management [45]. By contrast, palliative care is patient/family centred and holistic and focuses on symptom management and support for the patient and their family [46]. Despite these differences, both models of care are structured around a multidisciplinary team approach and

recognise the importance of care co-ordination and clear communication. Thus, a model of end of life care which combines elements of CDM and palliative care is feasible; however, for these two models of care to interact successfully, each may need to expand to incorporate their differing perspectives of care and blend systematic management interventions with the flexibility of person-centred care.

- (3) Such a blending of care models also requires that health professionals change their philosophical understanding of the basis of care provision. Callaghan suggests that a major reason that the need for end of life care has not been recognised more widely is because many health professionals still view death as a "defeat", noting that, whilst medicine has devised ways of keeping people alive longer with chronic diseases, health professionals have often not accepted that death is an inevitable part of living [47]. Thus, the focus in chronic disease management is often on medical interventions rather than discussions about treatment options, prognosis and patient preference, which are the focus in palliative care. By referring people with end stage chronic disease to a palliative care service rather than providing end of life care themselves, health professionals could therefore avoid discussions about death and dying and avoid caring for dying people. Health professionals' attitudes to dying may also reflect the attitudes of the community more generally: there is a "societal taboo" about discussing death, dying and bereavement [48] which is being recognised and addressed internationally through programmes such as

“Dying Matters” in the UK [48] and *The Conversation Project* in the US [49].

- (4) There is growing advocacy amongst palliative care support organisations in countries such as Australia [50], Canada [51], and New Zealand [11] for care to be based on patient need rather than prognosis. The UK End of Life Care Strategy actively promotes and supports end of life care for people with chronic disease and advocates a person-centred approach to care [48], as does the Australian Commission on Quality and Safety in Health Care [52]. A person centred approach to end of life care for people with advanced chronic disease would mean that care would be provided based on patient need rather than being determined by prognosis or age. Kellehear [53] has outlined a model of palliative care based on health promotion principles which has the potential to contribute to effective policy development. He suggests five key goals for developing services including: providing education for health, dying and death; providing social supports, encouraging interpersonal reorientation; encouraging reorientation of palliative care services and combating death-denying health policies and attitudes [53].

5. Conclusions

Australian chronic disease management strategies/policies document the importance of a continuum of care and access to specialist palliative care but do not generally identify specific strategies or provide funding mechanisms to support these. Existing palliative care strategies recognise the growing importance of end-of-life care and the need for integration of services for people with chronic disease, but identify few strategies to facilitate such integration. For people under 65 years with chronic diseases, there are major inequities in service provision [7]. In the wake of the report of the Productivity Commission, ageing policies currently under development may be able to clearly articulate the need for funding and support for older people as they approach the end of their life. In the meantime, the intersections and links between policies and strategies for chronic disease, palliative care and ageing and with funding and service provision are few. Current policies reflect a lack of understanding of the needs of people with advanced chronic disease and there is little consensus around how such services should be provided.

Outside of palliative care policy, policies impacting on care for people with advanced chronic disease do not treat end of life care as a priority. However, the growing numbers of people requiring end of life care dictate the need for health policies to prioritise this aspect of care. Whilst palliative care principles and expertise can inform a model of care for people with advanced chronic disease, it is not clear that an actual referral to a palliative care service will provide the most appropriate care. The need to foster recognition that active disease management and palliation are complementary, not mutually exclusive, is key as is a move to truly person-centred care. The philosophical differences underlying chronic disease management and palliative models of care mean that articulation between these care

models will require negotiation before people with chronic disease, and their carers and families, can access appropriate and timely end of life care.

Conflict of interest

All authors state that they have had no actual or potential conflict of interest including any financial, personal or other relationships with other people or organisations, within three years of beginning the manuscript entitled: *Australian health policy and end of life care for people with chronic disease: an analysis* that could inappropriately influence, or be perceived to influence, their work.

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4.3. Summary

The drivers of policy in any government are diverse²⁴ and *are likely to be political and value driven*.^{p.4} In 2005, Australia spent more than half of all health expenditure on chronic disease,²⁶⁵ and so a focus on disease prevention and management to reduce the cost of treatment is a government imperative. Thus, many of the policies related to chronic disease had this aim. This is not a policy driver for palliative care policy, which focuses more on quality of life as an outcome. The focus on management and prevention also largely ignores the life limiting nature of many chronic diseases and so one of the aims of this audit was to help raise the awareness of policy makers and health professionals that end of life care was not being addressed appropriately in chronic disease policies. Currently, chronic disease policies assume that a referral to palliative care services will address the needs of people with a wide range of chronic diseases and that current policies and service frameworks will allow this transition of care. Palliative care policies assume that all health professionals are willing to make palliative care '*everyone's business*' but there has been little interaction between palliative care and chronic disease health professionals that indicates that these assumptions are valid or viable.

Chapter 5. Case review results: System structure and the process of care

5.1. Introduction

In the next two chapters, I report the results of the case reviews I undertook, interviewing people with advanced chronic disease^{viii} their carers^{ix} and, where possible, the key service providers (KSPs) with whom they interacted. In analysing the interview transcripts, I used the systems analysis framework developed by Bainbridge et al²⁶⁰ (described in detail in Chapter 3) which allowed me to develop a comprehensive picture of the current Australian health system as it functions for people with chronic disease approaching the end of their life. An inductive thematic analysis was initially undertaken to provide a detailed picture of how the system was perceived by all participants and then the Bainbridge et al conceptual framework domains were applied to the results to provide a detailed picture of how the system was perceived by all participants.

This chapter describes the results of the analysis for the system structure and process of care domains of the Bainbridge et al framework.²⁶⁰ The way the system is structured dictates how care can be provided as it is related to human and material resources, organisational processes and the environment in which they function. The process of care looks at the activities that are undertaken to provide care.²⁶⁰ Therefore, if the system is structured around chronic disease management and silos of care, the flexibility and collaboration required for end of life care may be difficult to achieve.

Patients, carers and KSPs provided a detailed picture of how the health system and process of care functions for them on an everyday basis. There was a general agreement that although the provision of adequate and appropriate end of life care

^{viii} To distinguish the information provided by different participants in this research, people with advanced chronic disease are referred to as patients throughout Part 2.

^{ix} In the analysis of my interviews, two types of carers are referred to: 1) informal carers – in this research they were close family members and 2) paid carers - funded through packages of care and provided through carer agencies. Unless specifically nominated as paid carer, the term carer refers to informal carers.

for chronic disease was an important and growing issue, there was a significant lack of awareness of its importance in the community generally and amongst health professionals. Whilst all patients had access to specialist and general practice care, levels of access varied markedly and participants reported care for their chronic disease, but very little consideration of end of life aspects of care such as advance care planning. There was confusion amongst KSPs about who actually had responsibility for end of life care and they expressed uncertainty about the role of general practitioners (GPs), palliative care services and other community services. No leadership or a vision for end of life care in chronic disease was identified by participants and all identified inadequate funding of key services such as support for activities of daily living (ADLs) as a major problem.

5.2. System structure

Bainbridge et al²⁶⁰ identified three broad domains of system structure, each of which incorporate a number of sub domains, and these domains and sub domains provided the analytical structure. Relevant themes from the thematic analysis were applied to these domains and sub domains and Table 11 summarises the results of this analysis.

Table 11: System structure analysis summary

System structure components ^x	Summary of results: Patients and carers	Summary of results: KSPs
Environment factors <i>Population size</i> <i>Population demographics</i> <i>Community awareness/perceived importance of health issue</i> <i>Profession/specialty base</i>	Chapter 2, Section 2.3.1 describes the population and demographics in Australia of people with chronic disease nearing the end of life. Patients and carers reported: <ul style="list-style-type: none"> • little recognition in the broader community of end of life issues • little community awareness of the need for advance care planning 	KSPs: <ul style="list-style-type: none"> • recognised that there are growing numbers of people with advanced chronic disease but thought it was not generally recognised by both the community and health professionals that many chronic diseases are life limiting, • said that most health professionals thought that end of life care was still seen as the

^x Sub domains marked with * were not discussed by patients or carers and those marked ** were not discussed by KSPs.

System structure components ^x	Summary of results: Patients and carers	Summary of results: KSPs
		role of specialist palliative care services, but some health professionals did feel it was part of their ongoing role.
<p>CDM/EoL system characteristics</p> <p><i>History/evolution</i></p> <p><i>CDM care structure</i></p> <p><i>Extent of participation in EoL care</i></p> <p><i>Policies and procedures*</i></p> <p><i>Power equality*</i></p> <p><i>Promotion of EoL in CDM care</i></p> <p><i>Ideals*</i></p> <p><i>Vision/culture*</i></p>	<ul style="list-style-type: none"> • a disjointed, siloed care structure with minimal coordination of care • access to specialist and general practice (GP) care • particular access issues for people aged <65 years • generally not having end of life or advance care planning discussions with their health service providers 	<ul style="list-style-type: none"> • reported a continuing tension between the provision of curative and supportive services • recognised that end of life care is a major and growing issue for people with advanced chronic disease • noted that people had difficulty accepting that chronic disease can be terminal, resulting in unrealistic expectations of treatment and care • reported care silos
<p>Economic factors</p> <p><i>CDM EoL resources</i></p> <p><i>Financial incentives**</i></p> <p><i>Capacity for 24/7 care</i></p>	<ul style="list-style-type: none"> • an inability to access care including ADL support, transport, 24 hour care; difficulty paying for medication, GP care and incontinence aids in many instances. 	<ul style="list-style-type: none"> • reported that available resources, including funding, workforce, health services, equipment and transport, were inadequate for people with advanced chronic disease

5.2.1. Environment factors

The environment in which a health system exists has a major impact on how it functions. The extent of the need for a service, community demand and availability of health service professionals all help to shape the type of care provided. This analysis demonstrated that, whilst there is a major and growing need for end of life care for people with advanced chronic disease, there was minimal recognition by patients and carers that chronic diseases can be life limiting. The majority of health service providers recognised that this was a

growing issue, but they were uncertain about who had responsibility for providing end of life care, and what training should be provided to whom and at what level.

Patient and carer perceptions

Population size and demographics: In Chapter 2, I discussed the scope of the problems arising from the convergence of an ageing population, substantial improvements in medicine and technology leading to significantly decreased early mortality and a substantial increase in lifestyle related chronic disease. Thus we know that the marked increase in older Australians with at least one chronic disease demands the development of a system which adequately and appropriately supports people as they approach the end of their life.

Community awareness/perceived importance of EoL care: *encompasses the concept that the level of awareness that the community more broadly has of the issues surrounding end of life care predicts the success of various interventions and the level of services demanded and provided by the system.*²⁶⁰

No patients or carers discussed a broader community awareness or media discussions of end of life care issues. Knowledge of advance care planning (ACP) was minimal and only two patients had completed advance care directives, one because she had previously worked in a solicitor's office and the other through his solicitor. One carer said he knew nothing about these documents until his wife told him. Another issue noted by patients was the decline in visits from friends as their diseases progressed. One noted that *"They don't seem to face up too well to illness"*

....she knew these things through her work experience but um – otherwise you'd never know would you?That there's such a thing as that document you know. I didn't know there was such a thing as that document until we talked about it.^{xi}

CI_Int1^{xii}

I mean people have got a different way of handling things haven't they? Some people are I don't think it's that they don't care any less, I think it's just some people have a different way of handling things. **CI_Int2**

Profession/specialty base: *suggests that a prerequisite for being able to access appropriate end of life care with advanced chronic disease(s) is being able to*

^{xi} I use the payout '....' to denote either that this is not the beginning of the sentence, or that I am linking two sentences where the data between is not relevant.

^{xii} Quotes are attributed using the following abbreviations: **P**=Patient; **C**=Carer; **PC**=a joint interview between patients and carers, where the patient had difficulty speaking (Patients 1,2,3 and 9) and **Int** indicates whether it was interview 1,2 or 3

*access appropriate health service providers with some knowledge of end of life care.*²⁶⁰

Almost all patients had multi-morbidities and saw a variety of specialists and other health service providers. However, patients reported minimal discussions around end of life care. Only one patient had seen a palliative care service, and that was a brief visit whilst she was hospitalised. A counsellor spoke to her, but there was no further follow up, despite having told her they would see her again in her last week of life.

Well I seen him last month and he doesn't want to see me anymore, he reckons everything's okay so there's no sense in me going. I mean if anything goes wrong with the kidneys the heart specialist will tell me in any case so - everything's stable so there's no problems.

P6_Int2

KSP perceptions

Community awareness/perceived importance of EoL care

KSPs noted that many people, including medical professionals, still did not recognise that many chronic diseases were terminal, leading to unrealistic expectations for care. They suggested that the community was aware that “*people with cancer can accept being told you're going to die*”, but found chronic diseases “*really difficult to accept as a cause of death*”. They thought that the community was unwilling to accept that treatment could not continue and this was exacerbated by family and friends in general encouraging them to continue to ask for interventions rather than confronting the issue of dying.

They suggested that “*a lot of the younger doctors are more aware of the limitations of treatment*” and one KSP used dialysis as an example of an intervention that should not be used just because it is available. KSPs perceived education to be a key strategy to address this problem,

People with the more chronic diseases find that really difficult to accept as a cause of death, I think: But surely you can treat this; it worked before; you can do that; you can do that. There's less an acceptance that it can cause or can lead to death.

S4^{xiii}

...when dialysis came in in the 70s, it was limited who could take it Then it became more widely available, so everybody got put on it. Now people are pulling back and saying, well, let's assess whether this is the right thing to do or not. So I can see why it happened, but people are pulling back and assessing it.

S4

^{xiii} KSP quotes are attributed as follows: **GP**=general practitioner; **S**=specialist (includes the generalist physician for the purpose of anonymity); **Com**=community health service which includes the Disability Advocate for the purpose of anonymity).

for both health practitioners and the general public. Another KSP noted that it was not sufficient just to have a website and assume people know about it – education needs be much more proactive.

Profession/specialty base

All KSPs were aware of the importance of patients being able to access appropriate health professionals as they approached the end of life, but there was no real agreement on exactly who the appropriate professionals were. A number discussed the concept of end of life care being ‘*everybody’s business*’ but no-one believed that the current system actually facilitated that. There was a continuing tension between the provision of curative and supportive services and confusion over responsibility for care e.g. between specialists and GPs, GPs and palliative care services and between community health services and hospital services. Many KSPs said they were happy to provide this care but would like the support of palliative care services when required. KSPs said that long term, established community services work best to support people with advanced chronic disease. Overall, there were not enough personnel with end of life care experience and skills to provide coordinated and appropriate care.

Well, I think it’s outside the traditional way that hospital doctors see their role, number one, and also I don’t think that it’s promoted as strongly by the healthcare system. S2

While I remain active as a [specialist], in many instances I would involve teams that are more au fait with what services can be provided. They can be geriatricians, discharge planning units and palliative care, for that instance. But what it is, is it’s an awareness of the fact that - for me - is that no longer are we initiating therapy to prolong life, but initiating therapy with the prime focus of ensuring that they’re as free of discomfort and pain as possible for them now. S3

5.2.2. Chronic disease management/end of life characteristics

How the different parts of the health system function has a direct impact on the type and quality of care provided. The Australian health system is very diverse and services are funded and provided at three different levels – federal, state and local. The system also operates in five sectors – acute care, primary care, rehabilitation, aged care and disability. In this research, patients, carers and KSPs were very clear about the disjointed and fragmented nature of the health system as it was functioning for people as their disease deteriorated and their care needs

changed. Whilst chronic disease management needs were generally being met, there was little consideration of end of life care needs. Although patients could all access specialist medical care, they found it difficult to understand how the broader system worked to provide support services, respite and residential care.

There were diverging reports between patients who said they felt their health care providers had told them nothing more could be done for them but did not have broader end of life care planning discussions, and KSPs, who felt such discussions were vital and that it was their role to have such discussions. KSPs reported a lack of vision around end of life care in the health system, which has a continuing focus on intervention with little consideration of supportive care. All participants agreed that health professionals caring for people with advanced chronic disease were reluctant to have advance care planning discussions and a number of KSPs said they had direct experience of caring for dying people who had no previous discussion of their prognosis.

Patient and carer perceptions

History/evolution/chronic disease care structure

Patients and carers described a disjointed, siloed care structure where there was little coordination of care and patients and carers had to negotiate to find appropriate services. All patients had a GP they saw regularly, as well as a variety of specialists and allied health professionals, but they perceived them as individual service providers, rather than a coordinated care structure. Patients under 65 years highlighted a major problem with the historical division of care funding, as support services for people under 65 are funded through the disability sector and those over 65 through the health care sector. This led to delays and restricted services for these patients and perceived inequities of access to care between people with similar conditions but of different ages. Identifying information about nursing home or residential aged care was also a problem – nursing homes

*Yes, because I was only 61, but at the time, I couldn't have an aged care assessment, which seems to me bloody stupid to me ... because you know, if you've got a problem it doesn't matter your age does it? If you're sick, you're sick and you have to be assisted with what you need. And so the ACAT Team came and spoke to me, two women from there, and they said well....they couldn't just do an assessment, and I said why not, because we can't and I said well that seems stupid to me. **PI_Int1** No, well, once you have the assessment, I can ringthe nursing home direct, which you can't unless you've had an assessment. So you'd have to go into hospital and the assessment team goes to the hospital and get you into the - eventually into a*

are administered by aged care services and so patients found it difficult to identify how to access nursing home care and find out about associated costs. A number of carers had worked out that they needed to have an Aged Care Assessment Team (ACAT) assessment to be eligible for nursing home funding, but noted that the system was still very opaque after approval, in terms of availability, access and cost.

nursing home. You find this out as you go along. That's why I had the assessment done.

PC3_Int1

Promotion of end of life care in chronic disease: examines how the various services and providers recognise and support end of life care for people with chronic disease and how committed they are to the provision of such care.

Only one patient reported discussing end of life care with any of their chronic disease service provider. Another patient said she asked about prognosis but her specialist said it was uncertain; she did recognise that at some point she would die, but wanted some sort of time line. Patients did report discussions about what they perceived to be 'nothing more can be done' and most had moved to some sort of acceptance that they would have no further interventional treatment.

No. No-one has and we don't – well, I've asked the time limit You know, because it really – you know, I used to before, sort of think that I might have been dead in three months, six months – or I didn't know. You just don't knowNow, nearly 12 months has gone and I was thinking about it....they just tell me there's no cure and nothing to help you.

P1_Int1

KSP perceptions

History/evolution/chronic disease care structure

KSPs also spoke about a fragmented system with inconsistent levels of communication and a lack of knowledge of available services. They felt that, at a time when they most needed continuity of care, services for patients approaching the end of their life were disjointed, and patients often saw a variety of different clinicians, particularly if they were admitted to hospital or attended hospital outpatients' departments. Specialist nurses with expertise in areas such as respiratory or cardiac disease

....my biggest disappointment is that the services end up being disjointed. On the whole I think we can access some of what someone needs but that discontinuity means the services are not as effective as they could be.

S5

So I think one thing that we could do a whole lot better is actually have regular meetings with the other organisations, just so that everybody knows which bit that you're actually putting in.

Com1

were seen as very important to support and coordinate care, but were often not available. One KSP reported patients were “*confused about the whole system*” and care coordination was seen as vital in addressing such confusion. However, whilst the GP was often suggested as the appropriate care coordinator, few GPs actually took on this role.

KSPs also highlighted the issue of accessing care for people under 65 years of age and the problem this causes for both patients and health practitioners. They expressed concern that the difficulties people under 65 years had in accessing care impacted on both their physical and mental health. For some KSPs, identifying who provides what services and how to access them was a major problem and they noted that there is currently no central point of contact for advice. This was exacerbated by delays in actually getting patients assessed, in funding approval and in care provision following approval.

Working in the rural context raised particular issues, but also had specific advantages, in terms of local knowledge. KSPs were upset that rural patients had to travel to Adelaide for almost all their specialist care and services for rural areas were being designed in urban contexts which did not take account of local conditions. They also spoke of variations in care in rural areas: “*It's not uniform; it's dependent on their local council, what they've got.*”

Extent of participation in end of life care/ideals/vision and culture: refers to the number of chronic disease health professionals participating in EoL care, how involved they are in that care and how important they perceive both EoL care and a culture that supports it.

All KSPs felt that provision of specific care for people with chronic disease as they approached the end of life

....you get to this scenario of over 65 or under 65 you know. That's the scenario basically. So if you're over 65, you're laughing in a sense as long as you plan ahead and get it in place. Under 65, it's just one of those things.

GPI

Basically knowing as much as we can about the different services out there and how they're accessed.

Com2

So sometimes it takes a little while for the person's needs to be met. So we can only provide what we can provide.

Com1

So you can roll out programs from Adelaide or Melbourne and the health departments can tell the country health people that they need to do stuff. But unless you have someone locally who really is passionately driving for it, then stuff doesn't tend to happen quite so well.SI

I guess I'm the type of doctor who enjoys all aspects of medicine and I enjoy looking

was important, and that it was not the specific role of palliative care services to provide this, although in many instances palliative care services should be involved in some way. However, they noted that many of their colleagues, particularly specialists, did not feel this way. One KSP suggested it was the role of the specialist to “*set the cultural tone*” for the care team, and another specialist emphasised the importance of recognising that “*Death is the end result of certain illnesses that specialists know most about.*”

A number of KSPs discussed their role in initiating the conversation about end of life care. The majority said they were happy to do this, with many saying they thought it was specifically their role and valued their ability to undertake the conversation. They all recognised it was an ongoing conversation that took time: “*this is sitting on the bed chatting time*”. One GP said that they did not have end of life care discussions enough with their patients and suggested that no GPs did it enough, mainly because they were so busy “*doing everything else*” and another noted that they would not often instigate a discussion but were happy to have one if the patient instigated it.

A recurring theme was the need to educate health professionals about having end of life conversations. KSPs recognised the difficulties health professionals have in moving from a curative to a supportive culture and the importance of helping patients to understand that, if care changed, it was not because “*nothing more can be done*” but rather that different care was needed. Many KSPs reported a reluctance to refer their patients to palliative care services for a variety of reasons. Although they recognised the value of palliative care expertise for

after people as long as I can.

GPI

So I think it is about providing that culture and I'm aware that I'm not the same as other doctors. There are many doctors that wouldn't even stop and talk about that but I know that the woman in the bed will get better care if I open that discussion with my nursing staff and that we're all on the same page and I say, yes I think she really has deteriorated a lot.

S5

I just think it's part of my job. That discussion is part of my job, and acceptance and acknowledgement and so that they get my opinion. **S3**

....because this is not a walk in, walk out. This is a walk in, sit on the bed, open ended questions and letting the consultation finish when they're ready to finish, not when you're ready to finish. Although also acknowledging that this is not something that can be dealt with all at one sitting, to come back as new questions will be raised and whatever. **S3**

I also feel there's two ways in thinking about there's nothing else that can be done. I think even when there's no curative treatment or a treatment that is fundamentally going to improve the ultimate prognosis, there are ways you can palliate these conditions that if you're not reviewing the patient you don't get an opportunity to do.

S2

particular patients, many felt that they themselves could adequately provide the required care. One specialist thought a multidisciplinary team which included palliative care was really important for health professionals to learn from each other and another noted the need for providing a framework for health professionals to support end of life care conversations. They also noted the importance of having a culture that supported such conversations, not only in health care but in the community more generally.

The neurologist that knows what the patient can expect in the 12 months from their illness should be able to help the patient understand that and should be able to articulate that without making them feel abandoned.S5

Policies and procedures should reflect clearly delineated obtainable objectives and goals around provision of end of life care for people with advanced chronic disease.

KSPs identified two areas of policies and procedures that impacted on their provision of care for people with advanced disease: access to care for people under 65 years and advance care planning, particularly completion of required documentation. They noted that identifying appropriate funding and accessing services through disability services was difficult and time consuming. Some specifically identified delays in accessing services and equipment as an issue and could not understand why people with the same needs were processed in different systems based on age. A number suggested that the procedures for approval of funding and services within the disability sector was cumbersome and was often the cause of major delays.

....there needs to be more services but they need to be streamlined so that they happen quicker. Things happen quicker and it's not bogged down in a whole lot of policy and procedure. Also too if people on the ground could have a bit of a play in the vision making process as well. Com2

Advance care planning was discussed by all KSPs. Most were aware of the *Advance Care Directives Act, 2013 (SA)*, but were unsure about how this would interact with existing programs such as *Respecting Patient Choices*.¹⁹¹

I think getting it nitted out in a legal sense should still be done by some sort of a legal person, not necessarily a lawyer, but someone who knows the legalities, the legal ins and outs. GPI

Not all KSPs agreed about the value of documentation of

I think it should all be documented. We - on a busy ward - out of a busy ward

end of life care wishes. Some felt the discussion was the most important aspect of the process whilst others felt the documentation was vital. Many continue to be concerned about a lack of standardised procedures for access to advance directives in emergency or hospital situations, noting people can attend different hospitals which may not be aware of the existence of any documentation. Another concern was around how often such documents were updated and how this could be tracked.

Promotion of end of life care in chronic disease

All KSPs were concerned about the provision of appropriate end of life care for people with advanced chronic disease, particularly those with multi morbidities. KSPs worked in a variety of organisations including major public hospitals, GP practices and community health services (both rural and urban) and they reported variability in levels of support for end of life care in chronic disease in these organisations. KSPs working in the major public hospitals reported that whilst they tried to support end of life care appropriately, many of their colleagues did not see it as their role. One KSP thought an agreed framework for end of life care would be helpful and a number felt that a multidisciplinary clinic would be very useful. Perceptions of the role of palliative care services varied between KSPs but, overall, there was agreement that only people with difficult or complex symptoms and issues needed their input. However, access to palliative care services varied markedly between organisations.

A number of KSPs commented on the differing trajectories of chronic disease, both between diseases and in individuals. Not knowing how long patients would survive was an issue for planning care, particularly if

around here, I do that poorly. But it all should be documented, absolutely, just for acknowledgement, particularly if for whatever reason the patient changes their mind....absolutely it's got to all be documented. So - in part because it's good medicine, and in part for the lesser issues of these other things - but because it's good medicine. Documenting everything's good medicine. S3

So one has the feeling that each service should be aware of how their patients feel at this stage and that service has probably got some work to do in terms of, is it going to outsource its end of life care for its patients to someone who will look after them and if so could they have a systematic way of doing that.

S5

I think it's a number of different levels of the way we deliver care. We need to change both at a hospital level and a community level. S2

I think we probably need to give your run-of-the-mill clinician who's just a little bit anxious and not understanding how much they have to contribute to end of life care, a little bit more of a framework. S5

Some will follow a really direct trajectory down. Others keep going for a long time.

S4

....I think most of us do quite poorly working out treatment paths for our elderly,

they wanted to involve palliative care services, and they recognised that care needs change as disease progresses. Closely related to uncertain disease trajectories, was the issue of discussions about prognosis. A number of KSPs thought that most non-palliative care practitioners did not know “*how to really broach it*” and one specialist said that they thought that “*it’s a discussion that probably a lot of doctors avoid, myself included*”. Three KSPs reported that they frequently care for people with very advanced disease who had had no discussion of prognosis and also the relief many patients felt when someone finally had the discussion with them.

Advance care planning and end of life care conversations were a major point of discussion for KSPs. All thought the conversation very important, and were very clear that such discussions should take place well before a person reached the terminal stage of their illness; a number suggested they be had as early as possible and one KSP suggested a database prompt to ensure advance care plans were completed. One GP noted that exacerbations of illness were a useful flag. There was consensus that families should be included in end of life care conversations whenever possible and KSPs commented on how easy it made care once the initial conversation had occurred and wishes recorded. It was suggested that an appropriate conversation required an unrushed and prolonged consultation: “*it is not something that you can do in the last 30 seconds of your consultation before you send people out.*”

debilitative patients with multi-organ disease. S3

....I used to go right, talk to the medical team, this person hasn't had their diagnosis, you need to do that for before I get involved, you know? Com4

When I looked at her I could see a woman who was terminal and hadn't actually had any discussion in that regard and her husband and her were extremely grateful for that discussion to occur. S5

I try and bring it up with people in their sort of 60s, 70s, have you thought about this, though it's such a long way ahead. If they've recently had a flare up of their obstructive airways disease. GP2

it's a really good model for clinical care, is if you have a reasonably lengthy conversation where the patient and time is not always measured in minutes here, it's about engagement and the patient's presence in the conversation, your presence in the conversation. If you have that hard yards, detailed, nitty-gritty stuff up front your subsequent conversations are easier and quicker. S5

5.2.3. Economic factors

The level of resources provided to a health system and how those resources are allocated dictates the extent of care that can be provided to people accessing the

system. The fragmented funding mechanisms in the Australian health care system mean that there is no clear funding stream for end of life care for chronic disease. KSPs identified at least thirteen different funding sources they needed to work with. Patients and carers also reported difficulties accessing adequate hours of home care and equipment and KSPs talked about the constant juggling required to access funding and care for their patients. Both groups said that there was a high need for 24 hour care and real difficulty in accessing funding to provide such care.

Patient and carer perceptions

*Chronic disease end of life resources refers to the provision of adequate resources and infrastructure including cash, financial investments, skilled professionals, equipment, office space, and technology.*²⁶⁰

Patients and carers did not specifically identify resources available for end of life care as an issue; rather they talked about the difficulties accessing extra care as their condition deteriorated. This was particularly so for people under 65 years who used disability services and who needed extra hours of ADL support and access to transport when they could no longer drive. Increasing costs of medication, visits to GPs and accessing and paying for particular incontinence aids were nominated as causing problems. One patient noted that she was relatively well off and still found it very difficult, noting that “*if you were really struggling, it would be a very difficult life.*” One patient living in supported accommodation had no financial problems and was able to access services as she needed, including private specialist services if public health waiting lists were too long.

I'd like to....not have to go through what we've gone through and have to beg for help. I know it's all about money, but there's people who need help who've paid taxes all their life like us and have to... I'd like politicians to get out there in the thick of it and see how difficult it is for people.

P1_Int3

The only problem with him is I have to pay for everything and therefore most of the time I can't afford to go there. [the gap] is \$13.20 or something like that.

P6_Int3

There's an awful lot of expenses – you know like the physio costs me \$52 and the chemist bills and everything you do. **P1_Int3**

*Capacity for 24 hour care: is an essential component for end of life care in each of the relevant professional disciplines.*²⁶⁰

Access to medical care after hours was an issue for patients, as was access to home visits by GPs. For one

....it would cost them a hell of a lot more money if I was in a home I mean I don't know how

patient in particular, accessing 24 hour care was a major issue. As her condition deteriorated and she became virtually immobile, she was very concerned that her husband was becoming exhausted turning and taking her to the toilet a number of times per night. They had great difficulty accessing care overnight through disability services and, after months of negotiation and the involvement of a disability advocate, were allocated four nights per month. However, this was only for the financial year, and the whole process had to be renegotiated in the new financial year, which was one month after the initial allocation.

much it costs the government to have someone in a home but it is a lot of money and they just don't.
PI_Int1

KSP perceptions

Chronic disease end of life resources

KSPs outlined the significant number of separate funding sources and organisations for care for people with advanced chronic disease.^{xiv} These included:

- Medicare for both medical and allied health services (through the Enhanced Primary Care packages)^{xv}
- private health insurance
- home and community care (HACC) funding and other services provided through local councils
- community care packages
- extended aged care at home (EACH) packages^{xvi}
- respite care funding
- Commonwealth respite care services

*If it was possible, in a perfect world, I guess if there was some money, like disability moneys or whatever, put aside for people with these conditions. I don't know how - if there could be a blueprint and you could go, okay, there's x amount of dollars and there's a little bit aside in the kitty in case this goes on for a little bit longer than what we thought. So that you could play with and reduce and increase services as you wanted. **Com 1** The funding for us to get out and do it just isn't there. Patients with chronic disease cannot afford you know significant cost. For us to do it in those hours when we've then got to do the other stuff in the in hours, Medicare just doesn't fund it appropriately at all.*

^{xiv} A number of these packages were revised in July 2014, but equivalent funding mechanisms remain.

^{xv} Now called Chronic Disease Management:
http://www.health.gov.au/internet/main/publishing.nsf/content/health-medicare-health_pro-gp-pdf-allied-cnt.htm

^{xvi} From July 1, 2015, all Home Care Packages changed to be provided on a Consumer Directed Care (CDC) basis. <http://www.myagedcare.gov.au/aged-care-services/home-care-packages>

- community health services
- hospital based outreach teams
- disability services
- residential aged care funding
- Red Cross transport services
- palliative care services

For in-home services, once funding is approved, the actual services are provided on a brokerage basis, so care then has to be negotiated with service provision organisations. KSPs identified issues associated with all of these funding sources including lengthy delays; complex eligibility criteria; knowing which funding sources were appropriate for which patients; not enough remuneration; minimal capacity to provide extra care as disease progresses and uncertainty about which services may be the most appropriate.

Funding was discussed by all KSPs in a variety of contexts. They noted the complexity of identifying who was eligible for what funding, as was the fact that the available funding was inadequate. The financial resources of individuals impacted on their care, with those people with greater financial capacity accessing more comprehensive services. Funding community health services such as the community heart failure team was identified as being really important, and one specialist suggested that they should be better resourced and this would have positive outcomes for patients.

The importance of funding and support for carers was emphasised by many KSPs. They recognised that there were significant financial and emotional costs involved in caring for someone with advanced chronic disease and that there was a lot of variation in the capabilities of carers. They all thought it important to ensure carers

GP2

I think if you look at everything, we're certainly not resourced for pall care to provide this for everyone so where are you going to resource this? You're going to have to resource it somehow.

S5

It depends on where they're getting them through, it depends on the capacity of their extended families who try and source some of it. But also sometimes their financial capacity as well.

GP2

The heart program nurses tend to keep a pretty close eye on patients with chronic disease in the community and raise the flag when things aren't going well. They do that quite well.

S1

I don't feel there's much support for the carers. I really think they need some more support. Getting them in - just simple things like, a lot of them haven't even got the Centrelink payments as a carer. They weren't aware that they could do that.

S4

We've got to really empower and give as many resources as

could access available funding – both for respite and carers’ allowances. The National Respite Carer’s program was identified as being very useful as was the Commonwealth Carer’s Respite Service which can provide carer support in emergencies. A number of carers identified respite access to nursing homes as a particular issue, especially for younger people.

possible to be able to support and care for the carer. S3

Capacity for 24 hour care

KSPs recognised the importance of accessing out of hours care including both medical and ADL support and talked about how difficult it was to access such care. Accessing 24 hour medical care was an ongoing issue and for people with complex medical needs; locum care by practitioners unfamiliar with the patient’s history was a particular difficulty.

I guess the other thing that people are needing, as time progresses a little bit, is the overnight care. That one can be a little bit tricky because it has to be funded by somewhere.

Com1

5.2.4. System structure summary

Patients, carers and KSPs described a system in which end of life care is an ‘*add-on*’ to chronic disease care as health professionals begin to recognise the increasing needs of people with advanced chronic disease. Patients and carers accessed specialist care for their often multiple chronic diseases, but there were few linkages between these services or with their GPs, leading to fragmented service provision. There was no particular consideration of increasing care needs in being able to access equipment and assistance with showering, toileting, eating and mobility. Historical rules around funding responsibility led to marked inequity in access to care. All patients and KSPs agreed more resources were needed, particularly for ADL support and for transport.

Patients did not access palliative care services and almost all had not had end of life care discussions with their health service providers. There was confusion in the system regarding who had responsibility for end of life care and advance care planning and although there was rhetoric around end of life care being ‘*everyone’s business*’, in reality this was not so. KSPs were aware of the importance of end of life care discussions but said that many of their colleagues were reluctant to have

these conversations, often because they did not know how to begin them. Because of the confusion around end of life care responsibility, patients often had unrealistic expectations about the prognosis of their chronic disease and did not recognise that it could be terminal, as no-one had discussed their disease, prognosis or care wishes with them.

The next section will report on how care is provided in the current system, and impact that such a disjointed system has on the process of care.

5.3. Process of care

The process of care domain as defined by Bainbridge et al²⁶⁰ comprises four broad domains and a variety of sub domains. Table 12 summarises the results of this analysis.

Table 12: Process of care analysis summary

Process of care components	Summary of results: Patients and carers	Summary of results: KSPs
Provider characteristics <i>Beliefs/attitudes</i> <i>Interpersonal style</i> <i>Specialty training and experience</i>	Patients and carers: <ul style="list-style-type: none"> thought their health care providers were caring and helpful and were generally satisfied with their care. 	KSPs: <ul style="list-style-type: none"> strongly believed in the importance of end of life care and ensuring patients did not feel ‘abandoned’. thought that it was important to work with palliative care teams but not necessarily to transfer care.
Extent of collaboration amongst providers <i>Common goals/shared values</i> <i>Reciprocity</i> <i>Respect</i> <i>Shared decision making and problem solving</i> <i>Trust</i>	<ul style="list-style-type: none"> did not speak about collaboration. 	<ul style="list-style-type: none"> reported minimal collaboration between health service providers expressed respect for the expertise of palliative care professionals, but palliative care services were not involved with any of the patients reported there was often confusion over who had overall responsibility for a patient’s care, particularly between GPs and specialists.

Process of care components	Summary of results: Patients and carers	Summary of results: KSPs
<p>Information transfer <i>Communication</i> <i>Information systems and materials</i> <i>Standardized assessment and monitoring patient need</i> <i>CDM EoL</i></p>	<ul style="list-style-type: none"> regularly saw a variety of health service providers but reported minimal communication between health services and professionals and virtually no coordination of their care mostly reported that they had a good relationship with their GPs, many were concerned about communication with their specialists and disability services. 	<ul style="list-style-type: none"> thought communication between services and health professionals could be improved and identified e-health records and other IT innovations as potentially very useful.
<p>Organization factors <i>Care team composition</i> <i>Educational opportunities</i> <i>Incentives to encourage collaboration/client centred care</i> <i>Leadership</i> <i>Role recognition</i> <i>Standards of practice</i></p>	<ul style="list-style-type: none"> did not discuss this domain. 	<ul style="list-style-type: none"> did not identify any standards of practice, specific guidelines or benchmarks and ongoing educational opportunities for end of life care in chronic disease leadership around end of life care at a local, state or commonwealth level was not discussed

5.3.1. Provider characteristics

The way health service providers interact with patients and carers is always important, but is particularly important for end of life care where patients and carers are coming to terms with approaching death. Health professionals' perceptions of their role and responsibilities and the training they have had directs the care they will provide, who they will collaborate with and how they will help patients and carers approach end of life. In this research, patients and carers perceived that their individual health care practitioners were caring and supportive. However, a number reported dissatisfaction with the quality of the care and the attitudes of hospital staff and paid carers. Patients were concerned that they had been told that “*nothing more could be done for them*” but KSPs said

they were careful to never say that, although patients may perceive that is what they said.

KSPs discussed in detail the importance of supporting people as they approach the end of life through care planning, documentation of wishes and ensuring that patients feel that someone cares. KSPs talked about a number of issues arising when working with other health professionals, including confusion about overall responsibility for care, an unwillingness of other services to work together and/or address end of life care issues and communication concerns. They thought education of health professional at all levels was a key strategy to address these issues.

Patient and carer perceptions

*Beliefs and attitudes: described as what motivates providers towards providing collaborative, person-centred care.*²⁶⁰

Patients described a wide range of attitudes towards their care across all of their service providers. Most were satisfied with their GP and felt they were supported; two patients, however, felt their GP could have provided more appropriate care. Patients with neurological disease commented on a lack of knowledge amongst GPs of their disease, its progression and treatment options. Specialists were generally perceived to be very helpful, and one carer noted that their specialist wanted to refer them to a panel of neurologists to explore any further options for his wife's rare neurological disease. The community heart nurses were also perceived to be very caring and supportive as were some of the allied health professionals. Hospital care, however, was not perceived to be supportive and many patients reported that their needs were not respected in terms of medication management, provision of information, access to specialists and respect for the patient. However, two

We've known him a long time, you know, we've been going to him for about 25 years. He has been quite helpful and - but one of the things I did notice, he had - I don't think he knew about PSP^{xvii} until the specialist told us what it was.

PC3_Int3

I found the GP - he was very good in all these different things - he sent OTs around, but I don't know if that's because I was over 75, and you're entitled to a medical every year and these things fall in with that. He was very helpful at providing us with different sorts of information.

PC3_Int1

*....he [physio] comes here to the house to me he's a really lovely man. Very considerate and he offered to come and I took it up and it's been an effort to keep it going really. **PI_Int1***

^{xvii} Progressive Supranuclear Palsy

patients who had been admitted to hospital were very satisfied with their care.

Interpersonal style: described as the professionalism displayed by health care providers associated with the degree to which professionals are able to work together.

Patients discussed two particular aspects of interpersonal style – how their health professionals interacted with each other regarding their care and the perception that their health professionals had told them that “*nothing more can be done*”. No one said that they felt that their care was provided by a team or that any of their health service providers communicated with each other, other than letters from the specialist to the GP.

We went to see Dr [Neurologist], but our GP doesn't um yeah. He leaves it to the specialist. C2_Int3

'Cause there's nothing much he can do he's very good he keeps a check on me.

P1_Int1

KSP perceptions

Beliefs and attitudes

Three key themes were identified in describing the beliefs and attitudes of KSPs. These were around “*Nothing more can be done*”; advance care planning and the provision of care. There were mixed responses amongst specialists to the concept of telling patients that interventional treatment options may have been exhausted and they would benefit from a more palliative approach. Some specialists thought it was important to not allow patients to continue to have unrealistic expectations about their care and the course of their disease, whilst others thought that it was important to emphasise the change in focus of care: i.e. care will continue but it will be different care. One KSP suggested that doctors rarely say “*nothing more can be done*” – rather that it is what people hear: “*a sense or feeling that the patient gets*”. KSPs linked these discussions to

I never like to definitively discharge a patient from ongoing follow up even if there's, in quotes, nothing more that can be done, because I think there's definitely - it's helpful to patient. S2

....it's unhelpful if patients feel abandoned and they're written off and it's just a slippery slope to death. S2

....you try and say it as diplomatically as possible because they've been drummed into their head that we're going put this machine into you and it's going to make you feel better and we're going to do this, this and that and this and that - just unrealistic expectations. Com4

We sort of expect it to dawn on the patient and the carer, like if they've come X number of times to the clinic and the doctor doesn't have much else to offer that it will dawn on them that this is a palliative situation.S2

discussions around prognosis and acceptance and helping people “*when they're not really accepting that they're in terminal care*”. Two KSPs were particularly concerned that patients should not feel ‘*abandoned*’ as their care needs and providers changed. Some KSPs acknowledged the reluctance of many specialists to discuss prognosis and changing care needs, suggesting that there is often no specific conversation about transitions in care. Another specialist said they tried to use very specific language when talking about prognosis and dying: “*I try my best to use black and white words, in an empathetic way, not grey words*”.

When discussing the provision of medical care, KSPs recognised the importance of respecting patients’ needs, trying to help them understand what was happening. They thought it was important to work with other specialties and services to ensure appropriate care. The generalist physician emphasised the importance of people feeling someone cared about them: “*making that human connection and about feeling that someone is there for them*” and there was a growing recognition that “*You can't see dying as this abnormal event that has to go off to a special team to look after it.*”

The service provision viewpoint is not my area of expertise, so I often find myself very much adopting a consultative approach in regards to this. S3

Interpersonal style

Whilst all KSPs expressed a willingness to work with the variety of other KSPs and services, the success of these multiple interactions was very varied. There was confusion about the timing of referral to palliative care services; uncertainty about whether palliative care services would accept referrals; who was responsible for actual service provision; concerns that some KSPs were not interested/willing to undertake end of life care and confusion over who had the responsibility for initiating

Sometimes we get a little bit confused as to what's the precise role of palliative care / a palliative care nurse in the earlier stages of palliative care, versus GP role, in terms of what they should do, what they're expected to do, how much input they should have....Some GPs are happy to do a lot of it, some GPs don't want to do any of it.

GPI

They go, that person has withdrawn; refer them to palliative care. I'm, like, hang on. They haven't got any problems that we need to refer

an end of life care focus when multiple KSPs were involved. Communication with palliative care services was raised as an issue by some KSPs, who were concerned about the level of feedback they received following referral and two KSPs suggested that it would be useful to be able to work more closely with palliative care teams.

Speciality training: describes the professional education, skills and experience of health service providers.

Most KSPs spoke about the value of having some degree of training in end of life care. Some spoke specifically about communication training for end of life care conversations, some non-medical KSPs spoke about having training in the *Respecting Patient Choices*¹⁹¹ program. The majority of KSPs had had no end of life care training, but one GP had undertaken a palliative care placement in their training and another GP thought that some training could be useful.

Some KSPs suggested that the concept of chronic diseases as terminal was still not widely recognised, and older doctors in particular had not had any training in palliative care and only associated it with cancer. All of the medical KSPs recognised the importance of training and education in end of life care, both at a medical school level and ongoing education for specialists and generalists, although they also recognised there could be considerable resistance to such training. One specialist noted that each speciality teaches how to treat a specific disease and that 20% of patients may die, but no-one teaches that “100 per cent of people are going to die at some point. That's never brought in. I think you need to change it from that level upwards, that death is part of life.”

to palliative care. We can deal with all these things.

S4

I think a little bit of training would be useful. I think it's something that wasn't - I never came across it in med school or in hospital practice or anything like that. It's something I don't profess to be an expert in, so if some specific training or information so that doctors are more up to speed with it. GPI

So that's probably one thing I'd mention. If I had to mention one thing and education. Education even amongst doctors and I'm including specialists there. GPI I think you always get some people who will not accept it; some doctors who will not accept it. I actually don't think it's worth wasting your time keeping - going at them. It's not going to - you're not going to get through to them. Change the others and go from there. S4

One KSP discussed the importance of reflective practice for specialist trainees and medical students. They saw having experience in talking to people about end of life care and understanding what illness and approaching death means for patients and their families as very important. This KSP also noted the difficulty of teaching students empathy as this is “*a cultural and an upbringing thing more than it's something you can get with one lecture throughout the first four years of medical school*”. Another KSP noted that palliative care training was being introduced into the renal registrar training program and so would become mandatory, but that this was not yet mandatory for cardiac or neurology training.

....with encouragement, all of them have come to me with reflective pieces that talk about patient focused end of life care discussions and it is astounding how much these guys know, see and understand. S5

This was the beginning of developing their own comfort and self-awareness about how patients are people and how illness changes their lives, might stop them earning their money and just this whole concept of thinking about it more deeply and from the patient perspective. S5

5.3.2. Extent of collaboration

Collaboration between health professionals is a core element of best practice care, and Bainbridge et al outline the key components of collaboration, which are examined below.²⁶⁰ There was no recognition by patients and carers of the extent of collaboration between providers. KSPs talked about collaboration but there were few facilitators in the system to promote collaboration. They also talked about their respect for the role of GPs, palliative care services and community nurses but there were very few examples of shared decision making and there was confusion over responsibility for disease management, particularly between GPs and specialists.

KSP perceptions

Common goals/shared values: incorporates evidence of clear objectives and working relationships between community providers.

Whilst common goals and shared values could be identified within some teams and services providing care for people with advanced disease, there were no formal linkages between any services and care providers. The individual diseases of people with multi-morbidities

I don't know what level of general practice liaison occurs in the development of these programs. Maybe it does, maybe it doesn't, but I haven't heard about it. GPI

I'm very happy with the specialists, generally, but occasionally a specialist, especially an in-hospital

continued to be treated quite separately and it was often only the GP who had an overview of all conditions. One specialist highlighted the importance of working with GPs, especially with complex patients and ensuring clear communication channels, but another felt that GPs could be confused about who has responsibility for care once specialists became involved in care. There was also some confusion about the role of palliative care and other services in end of life care, with no clear communication channels.

specialist or a registrar, will initiate or attempt to initiate a particular drug without full knowledge of all the circumstances and I would disagree with that particular action. The patient will come back expecting a particular approach and I would have to disagree and then you end up having a confused patient.

GPI

Reciprocity: *describes the recognition by health professionals of the benefits of working with other health professionals.*

Some reciprocity was identified by KSPs, but it was generally not discussed. The rural community health service had a number of links with other health and disability service providers and valued their role as part of the community multidisciplinary team. Some KSPs greatly valued their links with multidisciplinary teams associated with general medicine ward and heart failure support. A number of KSPs felt that greater reciprocity would improve their relationship with palliative care teams.

I know our heart failure team here is excellent ... That - for my limited knowledge in this area - is some of the greatest benefit for heart failure teams, is trying to keep people out of hospital.

S3

I don't have a very good relationship with them [palliative care] and I think that's probably because we've got a lot of work to do and methods of communication are difficult. They don't know how we're set up and we don't know how they're set up.

Com4

Mutual respect: *valuing the contributions of different health professionals and appreciating differing professional perspectives.*

KSPs expressed mixed opinions about the level of respect accorded to them and the respect they had for other KSP perspectives. This was particularly evident in KSP interactions with palliative care services. There was general recognition and respect for the skills and expertise of palliative care health professionals, but a number of KSPs felt that, rather than having a collegial relationship with palliative care services, there were few interactions following referral. However, one GP noted

So I think there's a real tension so when I see someone's become more frail or my nurses see someone's become more frail I guess we make a decision at that point as to whether we think they really will fit someone else's idea of a palliative patient so we can get more services.

S5

I think in the country rather than the city, GPs do that probably more because, well, by the nature of being a country GP I think you have to be more

he had a very good relationship with his local palliative care service. Rural GPs were seen as knowing their local communities well and so able to access appropriate local services.

holistic. Secondly, they'll know the local system a lot better than I will. S2

Shared decision making and problem solving: incorporates integrating the expertise of a variety of health professionals to derive solutions.

Very few instances of shared decision making and problem solving were identified in the KSP interviews. Discussions focused on a lack of shared decision making, with concerns expressed about palliative care services making care decisions without consulting the referring physician; a lack of communication leading to uncertainty about who should initiate care; GPs referring people to hospital for treatment when supportive care was more appropriate and community nurses unable to communicate with specialists for advice so patients ending up in an emergency department. One patient with severe disability who could not access services required the intervention of a public advocate to facilitate care meetings and shared decision making.

You won't really know how quickly someone's going to deteriorate. It's very difficult to suddenly convince another clinician who's never seen the patient before and it's a rigmarole. S5

At the moment it's just all a mixture of private, with public and sometimes they're not interested so we're left on our own to do that. In the end, we just have to take them to ED. Com3

Trust: incorporates trusting your own abilities as well as confidence in others.

Although KSPs mentioned the importance of trust between health service providers and patients and carers, there was very little discussion of trust between health service providers.

5.3.3. Information transfer

Communication is the core of information transfer, both between health service providers and between health service providers and patients and carers. The ability to share information in a timely manner across boundaries is vital for care coordination. It is particularly important for people approaching the end of their life to be able to have honest, timely and appropriate conversations about their prognosis and how to ensure quality of life in their remaining days. Patients had particular concerns about communication around prognosis and almost all had not

had advance care planning discussions. KSPs in this research recognised the importance of adequate communication but noted specific concerns around communication between hospitals and GPs and with palliative care services. Technology was seen by both patients and KSPs as a useful facilitator for access to care.

Patient and carer perceptions

Communication: *pervades all aspects of provider collaboration and patient-centred interactions.*²⁶⁰

Patients and carers talked about communication with their service providers in a number of areas. The majority felt they could talk to their GP, but there were some concerns about communication with specialists. One patient reported that they felt rushed by one specialist and another changed one of her specialists, citing a lack of communication as one reason for this. Communication around prognosis and treatment was also discussed. One patient and carer were frustrated because, despite questioning, *“We haven’t really been able to plan anything because we don’t know what’s happening.”* This patient had significant difficulties communicating with disability services who said they would attend meetings or phone and did not do either, resulting in services not being organised. The patients with access to community cardiac nurses felt they had very good communication with them: *“Because they tell you what’s going on, they do they support you in every way”*.

Main thing really is to sort of ask questions of the doctors cause they don’t – a lot of them don’t tell you anything and they sort of give you these tablets and say take them and they don’t tell you what they’re for or anything I find the doctors don’t tend to appear forthright in telling you what’s going on. That’s what I feel should happen more to help people out, because I mean if you know more what’s going on, you can understand the situation, you know.

P6_Int1

I liked the way he worked. He was up front.

P8_Int1

“OK that’s all - right see ya” As if he was in a hurry to get rid of me.

P6_Int1

Information systems and materials: mechanisms to facilitate the exchange of information.

Patients and carers discussed two aspects of information systems and materials: access to information about supports and treatments and using technology and the internet to identify supports and equipment. One carer had found it very difficult to identify what resources and supports were available and felt that he was only able to find about services and supports little by little over time and that there should be access to a central information source.

I think there definitely needs to be one source where you can go and get information on the help that's available. You seem to go from one department to another, sort of thing. It's - there should be one source....it's a job to know who you go around to....You'll be stabbing at different places, to get the right answer. C3_Int1

A number of patients and carers reported using the internet to source cheaper equipment and one patient with deteriorating speech identified an iPad app that assisted with communication. One older carer noted that his iPad and laptop “keeps me alive” whilst another checked the internet daily for the availability of nursing home respite care.

So, I went on the internet and found the main place to go for information would be Parkinson's in Victoria, because that's the headquarters virtually of the national association of PSP sufferers.They put me right with - they've got leaflets and they're going to send some out. It's the knowledge of it. C3_Int1

Standardised assessment and monitoring of patient need: refers to useful clinical tools and assessment instruments and the adoption of these into broader organized approaches.

Patients and carers over 65 years of age were very familiar with ACAT assessment processes for accessing care and funding. They also talked about assessments in relation to accessing nursing home care.

KSP perceptions

Communication

KSPs identified communication as a key facilitator for care. They raised a number of issues regarding communication between health service providers themselves and between health service providers and patients. They identified communication between hospitals and GPs, particularly in discharge planning as

*But communication's at the top of the list. Com4
....making the main care providers central and communicating better would be key. S5
Communication is improving. It's certainly improving and I guess I noticed that because my in box is full a lot from communication from different*

a major issue, although one GP commented that this was improving. One specialist emphasised the importance of ensuring clear discharge letters. This same specialist also noted the importance of feedback: “*but I do think there needs to be better communication with a feedback loop; that's how things would really improve.*” Another specialist suggested that a personal communication from a referring GP to the consultant or registrar would greatly improve care when people are sent to the Emergency Department.

One KSP noted that it was important to recognise that patients may not always take in what you say to them, so this needs to be considered in communication.

Information systems and materials

KSPs discussed three major areas in terms of information systems and materials:

1. The most commonly discussed theme was accessing information for both service providers and patients and carers via the internet. KSPs noted that many of their clients were already using the internet to access resources and so greater use should be made of the internet to provide information about services, standardised information regarding diseases, treatments and other patient resources. KSPs also mentioned the potential of the internet to make appointments and referrals and noted that electronic communication was already being used for some discharge letters. The use of social media in supporting patients was also mentioned. Three cautions were offered: the need to keep databases of services and service providers up to date; the need to ensure appropriate design of websites so people can

sources. So I think it's improving, but there are always holes. **GPI**

I think there's a lot of evidence to say that in a medical consultation the patient may remember only a fraction of what's said or comprehend only a fraction of what's said. **S2**

A lot of our patients do use computers. There's no reason that it can't be online. Then you can bring in the specific bits for your area. **S4**

But a national information - what symptoms are, how we can manage them, what to worry about, what not to worry about, what trajectory of life is likely to be - just stuff that patients can have and look at again. **S4**

I've just started to use telemedicine for some of my rural patients with particularly more severe Parkinson's disease that have difficulty travelling or would have to travel enormous distances to come to an appointment. Particularly where the appointment is held in the GP's practice so the patient is at the GP, you're on Skype or whatever it is, and you and the GP and the patient and the carer are all in on the same consultation. I think that's a....very direct way of communicating. **S2**

The electronic patient record will help I think with that sort of thing. Well, we're going to get electronic patient record in SA

easily access detailed information; and the need to ensure privacy and confidentiality.

2. One KSP spoke at length on the importance of the greater use of telemedicine, particularly for patients in rural areas and noted the value of including the GP in the consultation.
3. KSPs suggested that the electronic patient record will be an important facilitator of continuity of care, but recognised that GPs were not currently included in the South Australian (SA) system and there was still some time to go before the national system was more broadly implemented.

Health but if that then links in or it can be accessed by general practice or....in a secure way then, yeah, that sort of will address some of those issues of not knowing what's gone on at recent other appointments, or whether drugs have been changed and that sort of thing.

S2

Standardised assessment and monitoring of patient need

KSPs described few standardised assessments or monitoring processes, other than the ACAT process, which all recognised as being the gateway to accessing services for people over 65 years. One KSP described a new standardised referral method from SA Health called *Access2HomeCare*²⁶⁶ where all patients wanting services must be referred for assessment and referral to a central hub where their needs would be reviewed and services allocated according to the assessment. This was “*meant to be more streamlined and efficient*” but it can only be accessed by people over 65 years of age (or 50 years if the person is an Aboriginal or Torres Strait Islander).

What happens with an access point is that people will actually go straight to the access point of referral, instead of coming to an organisation. **Com1**

5.3.4. Organisation factors

A key contributing factor to quality of care is how that care is organised, particularly in terms of who is providing care, how they are trained, who is leading them and how quality is measured. Whilst all patients in this research had access to GPs and specialists, access to allied health services varied and, although KSPs emphasised the importance of a multidisciplinary approach to end of life care, few examples of this were identified. There was little discussion about

leadership in this area, although it was recognised that there was no leadership or guidance around complex end of life care.

KSP perceptions

Care team composition

A number of KSPs discussed the value of having a multidisciplinary team to provide care and noted that they were particularly valuable for heart failure, renal failure and neurodegenerative diseases. A wide range of health professionals were identified as being useful in such teams, including nurses, allied health, psychologists and palliative care teams. The community heart failure team had access to a range of health professionals and the outpatient clinic one specialist organised was multidisciplinary. The rural community nursing team identified as being multidisciplinary and the renal specialist was attempting to organise a multidisciplinary end of life care clinic. GPs did not identify as being part of any care team.

So I think these conditions need multidisciplinary care and I think that does enhance that sort of referral to the services that you're talking about. S2

Educational opportunities: consist of training and workshops, the provision of technical assistance, and venues providing professionals the opportunity to learn from one another.

KSPs talked about the need for education in a variety of areas, but particularly in recognising the need for end of life care and how to have conversations about end of life issues. The renal specialist noted that there were specific symptoms in end stage renal disease where special knowledge was required and two specialists noted that although they had not had training in end of life conversations, it could be useful training for young doctors in medical school. Another noted that it was very important to identify strategies to target older clinicians

You need to educate and inform for caring health professionals. If you have a health professional that engages in the patient and engages in the patient's journey, then this is part of the journey. S3

and other KSPs noted that the *Respecting Patient Choices*¹⁹¹ program was useful.

Leadership: is often cited as the single most important factor contributing to collaborative client-centred care.

Leadership was rarely discussed by KSPs although one KSP was concerned that there was no person or group to provide guidance for complex end of life care.

Role recognition

KSPs discussed the various roles of health service providers as people approach end of life at length and no-one was really clear about which health service providers had responsibility for which services. Particular areas identified by KSPs included:

1. The role of palliative care services compared to the role their service could provide for people approaching the end of life.
2. The role of disability services and palliative care for people in their terminal stages of disease.
3. Overall responsibility for care and care coordination between specialists and GPs.

....the real difficulty is whether people have access to - is what's the difference between a terminal - advancing chronic disease and a disability, in terms of the services that people can access. S1

I think I'd prefer the suggestion that the sort of services that palliative care could offer but could potentially be offered by other services should be in place in those other services or those other places. S2

I think that's probably my role but, again, it's something that a lot of other people could equally do; GP for example or a care coordinator if such a person existed. But yeah, I would say it is my role. S2

Standards of practice: are benchmarks by which team members can compare current and target values for indices of inter-professional working, client-centred care or other performance qualities.

No KSPs talked about standards of practice for end of life care for advanced chronic disease. They identified some processes that they or their service had put in place to try to ensure quality of care e.g., a database prompt to ensure end of life care conversations are undertaken at an appropriate time. Other KSPs noted that nursing homes and some community health services required these conversations when applying for services. However, such discussions did not always include goals of care –

We give the information and say, look, this would be a really good idea, if you haven't power-of-attorney. Because often, particularly in the aged sector and with ACAT, we do have chronic disease aside a little bit, just with our general clients. Com1

they could just be around establishing power of attorney and/or medical power of attorney.

5.3.5. Summary of the process of care

There were mixed perceptions of the process of care by patients and carers. Whilst most patients believed their GPs and specialists provided appropriate care, there was little collaboration or communication reported between health care providers. There was no shared decision making and KSPs were confused about who had overall responsibility for care. There was dissonance between patient perceptions of the process of care and the processes KSPs reported. KSPs believed that it was important not to give the impression that “*nothing more can be done*” and that advance care planning conversations were important and could help avoid such perceptions. However patients, particularly those with neurological disease, had the impression that “*nothing more could be done for them*” which they found difficult to accept, particularly given that none had actually had an end of life care conversation with their GP or specialist. KSPs emphasised the importance of ensuring patients did not feel abandoned, and were concerned that this could happen if all care was transferred to a palliative care service which did not know them. They believed that some training in end of life care and conversations was important from medical school through to interns and in continuing medical education.

5.4. Summary

Patients, carers and KSPs provided a detailed picture of how the health system and process of care functions for them on an everyday basis. Overall, they reported that, whilst the current structure of the health care system supports chronic disease management, it does not have appropriate policies and procedures, nor does it facilitate important aspects of end of life care such as the integration of care, care coordination and adequate provision of resources. KSPs reported that care continues to be delivered in disease specific silos of care and I found little evidence of a collaborative or team based approach to care. All participants identified a lack of community awareness of the issues associated with advanced chronic disease and end of life care, and KSPs reported this deficit in many health practitioners as well.

Advance care planning and end of life care conversations are not currently supported by the system structure and do not form a part of the routine process of care. All participants identified issues around the way that end of life is delivered – i.e. the process of care. They identified communication as an issue and all recognised the need for better communication between health service providers and patients and between health service providers themselves. A number raised the issue of the reluctance of many health care professionals to initiate a conversation about end of life care. All KSPs recognised the importance of such discussions, but patients were more focused on discussions about prognosis and possible treatments. There was confusion amongst KSPs about who actually had responsibility for end of life care, and they were uncertain of the role of GPs, palliative care services and other community services. Although multidisciplinary teams were identified as the most appropriate model for end of life care in chronic disease, few examples were identified and patients did not report a team approach to any of their care.

Perhaps one explanation for why the system is not meeting the end of life care needs of people with chronic disease is that KSPs did not identify any recognition of, or support for, end of life care at a leadership level in any of the organisations providing care for patients and there was little reciprocity or trust identified between different health services. Thus, whilst all patients had access to specialist and GP care, the actual care provided was not able to meet many of their needs. In Chapter 6, I will examine how the system structure and processes of care described in this chapter impact on the actual care outcomes for patients and carers.

Chapter 6. Case review results: Patient outcomes

6.1. Introduction

Chapter 6 reports the results of the analysis of the *Patient Outcomes* domain of Bainbridge et al's conceptual framework.²⁶⁰ In describing how the system functions for end of life care in chronic disease, it is the voices of people with chronic disease and their carers that are the most important. Therefore, this chapter focuses on how patients, carers and KSPs perceive access to care; examines how appropriate that care provision was for the particular situations of patients and carers, explores the level of integration and care coordination and how end of life care issues were considered and addressed. It demonstrates how the structure of the system and the processes of care described in Chapter 5 come together to shape the outcomes described by the participants in this research.

Seven of the nine patients in this research had significant multi-morbidities and saw a number of specialists. Six of the nine patients expressed concerns about a variety of aspects of their care whilst two patients were satisfied with the care they were receiving – both medical and ADL support. Four patients had experienced significant problems in accessing ADL support, two because of their age, and these patients and their KSPs felt that having an age-based criterion for access to funding and care led to significant inequities. The role of carers and providing adequate support for them was a key concern for all participants and both patients and KSPs returned again to the topic of the importance of end of life care conversations.

The outcomes reported here provide a detailed picture of how people with advanced chronic disease in South Australia perceive that the current system addresses their needs and aspirations. Table 13 summarises the three domains and the results of the analysis. Detailed results for each domain are then discussed.

Table 13. Patient outcomes analysis summary

Patient outcomes components	Summary of results: Patients and carers	Summary of results: KSPs
<p>Satisfaction with domains of care and access</p> <p><i>Availability of care</i></p> <p><i>Free flow and accessibility of information</i></p> <p><i>Physical care</i></p> <p><i>Pain and symptom management</i></p> <p><i>Psychosocial care</i></p>	<p>Patients and carers:</p> <ul style="list-style-type: none"> • reported varying access to care, particularly access to ADL support and equipment and marked differences in quality of care • had more access to care and equipment if they were more financially secure and had higher levels of health literacy • had difficulty accessing information about what services were available and how to access them • recognised the importance of psychosocial supports, both formal and informal and identified a variety of coping mechanisms • emphasised the need for better support for carers 	<p>KSPs:</p> <ul style="list-style-type: none"> • recognised the key importance of access to ADL supports for people with advanced chronic disease and the difficulties in access for people under 65 years and in accessing services and equipment through disability services • recognised the importance of psychosocial care particular around adjusting to a terminal diagnosis • thought access to information for patients and carers was very important
<p>Perceptions of client centeredness of care</p> <p><i>Appropriate involvement of family and friends</i></p> <p><i>Collaboration/ team management</i></p> <p><i>Education/shared knowledge</i></p> <p><i>Rapport</i></p> <p><i>Respect for patient needs and preferences</i></p> <p><i>Sensitivity to nonmedical and spiritual dimensions of care</i></p>	<ul style="list-style-type: none"> • reported few discussions around of end of life care needs or wishes but many reported wanting discussions around prognosis • identified few instances of collaborative or team care • preferred to stay at home, but were concerned about access to enough care to enable this to happen • Felt that most health practitioners were more interested in physical care than non-medical or spiritual care 	<ul style="list-style-type: none"> • identified few instances of collaborative care, but recognised the importance of collaboration • did not believe that all patients should be referred to palliative care services – rather they would prefer support and advice in continuing to care for their patients • recognised the vital role of carers who also felt there was not enough recognition of the importance of the caring role nor enough support for carers

<p>Perceptions of continuity of care <i>Relational</i> <i>Informational</i> <i>Managerial</i></p>	<ul style="list-style-type: none"> identified few instances of continuity of care except for specialists sending letters to GPs following regular appointments 	<ul style="list-style-type: none"> identified issues and barriers in all three areas of continuity of care
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6.2. Satisfaction with domains of care

Bainbridge et al identified “domains of care” as the areas in which the health system (including palliative care) responds to the needs of patients, as perceived by patients themselves.²⁶⁰ This incorporates patient perceptions of the quality of, and satisfaction with, their care. Although patients were generally satisfied with the level of the specialist and general practice medical care they received, they reported minimal access to psychosocial supports which they thought was very important. KSPs also supported this, noting that this should also be a specific consideration for carers. Patients reported little contact with palliative care services whilst KSPs were somewhat confused about the role of palliative care services in non-malignant disease. The area of most dissatisfaction for patients and carers was around the quality of, and access to, supports for ADLs. KSPs also identified this as a major problem and were particularly concerned about access for people aged less than 65 years. Both patients and KSPs noted the importance of the role of carers and felt that they were not provided with adequate support.

6.2.1. Availability of care

*(Defined as services accessible to people who need them, when they need them, is a key factor impacting on satisfaction).*²⁶⁰

The availability of care for patients and carers was mixed. Whilst all saw specialists and GPs, access varied and the cost of care, equipment and medications was also an issue. Patients and carers said they had particular difficulties with identification of appropriate services, assessment processes, delays with funding and quality of services for ADLs and they were also concerned about the levels of support provided for carers.

Patient and carer perceptions

Access to ADL supports

Patients and their carers had a wide range of ADL support needs and accessing the care they needed was a subject to which patients and carers kept returning. Six patients had severe neurological diseases and were unable to care for themselves. Four had full time family carers whilst the fifth was in supported accommodation with access to 24 hour care, although her mother also provided regular care for her. Her mother also provided care for her husband who had severe PD. One patient had severe heart failure as well as PD and another had severe heart failure, compounded by renal disease which worsened over the course of the research. Three carers undertook all ADL care for their spouses with neurological disease (both were men). Even with paid carer support, family carers still had to provide a significant amount of ADL support.

Whilst most patients had experienced some delays in assessment and funding approvals for accessing ADL support, as noted previously, patients under 65 years faced the most significant barriers. For two patients under 65 years this was particularly problematic – one could not get support despite severe heart failure until she was also diagnosed with PD whilst the other required the intervention of a public advocate to access services. This patient was in hospital for six weeks awaiting an assessment of her eligibility for home care through the disability service.

Patients spoke of issues around knowing what care was available, the quality of care provided, a lack of

....the other day, as I said, she was wet in the wheelchair and so I had to get her into bed and um you know, change and wash her and everything and you've gotta turn her on her side.I still have to do a lot of things. I have to do bowel care 'cause nobody can do it. They got to be assessed if they gotta do it. No - I gotta do all that. **C7_Int1**

*Well, the heart was part of it but the winner was the Parkinson's. That's what - that was the pull - the hardest part. But because of the Parkinson's and being so bad - my Parkinson's very aggressive. So that is what won with Disability SA. **P8_Int1** Yes, because I was only 61, but at the time, I couldn't have an aged care assessment, which seems to me bloody stupid because you know, if you've got a problem ... it doesn't matter your age does it? If you're sick, you're sick and you have to be assisted with what you need. **P1_Int1***

....[the carers] take a long time just to get Sandra^{xviii} ready, washed. They just wash Sandra, they brush her teeth. You know they gotta turn her

^{xviii} All names used in the quotes provided are pseudonyms.

continuity of carers and difficulties accessing care through the night.

Access to equipment was also problematic. Most patients had been seen by occupational therapists (OTs) who provided advice regarding equipment and home modifications. One younger patient was wheelchair bound with very limited movement and she had ongoing problems with her wheelchair (in one instance the battery exploded) and she faced significant barriers in obtaining a new wheelchair or even maintenance for her old one.

Many patients said that the cost of equipment, medication and transport was an issue for them. Four patients used their own funds to purchase equipment that they required, rather than waiting to try and access it through public funding. However, for very expensive equipment, such as the special beds required by two patients, there were major delays and difficulties in access.

Patients and carers were also concerned about transport. Getting people in and out of cars was an issue and access to disabled parking spaces was consistently raised as a difficulty when patients went to see health professionals, or visited other public venues. Cost was also an issue as, even though wheelchair modified taxis were subsidised, many patients could still not afford them.

Access to medical care

All patients saw at least one specialist regularly; seven patients saw more than two medical practitioners because of significant multi-morbidities; two patients saw five medical practitioners (including their GP) regularly and one patient was taking at least 14 tablets per day. Patients with neurological disease commented that, although they

on her back.oh I see the way they're doing it and oh I just don't like it. C7_Int1

Yeah, what I've found is that the OT comes and they're very good. But they come really, they don't supply you with anything, they put you in touch with people who supply things. C3_Int2

You get another bottle but I only paid \$5.80. So I got it - you get it - I ended up getting it for free about May because I'm on so much medication. ... You've got to have 52 scripts to get it for free. It doesn't take me long to get there because I'm on a lot of medication.we shouldn't have to pay but heck, \$5.80 is a blessing, you know

P8_Int1

....but I think we keep up with Dr [neurologist] because he'd be in touch with any progress being made, medications and all that sort of thing, more so than the GP. So I think there's a need there for me to keep - twice a year or something to see the specialist, in case there are things to be done, or things that can be done. CP3_Int1

knew there was little that could be done, they saw their neurologist in case new treatments or medications had been identified. They all had a regular GP but there were varying levels of satisfaction with access to them. Two patients had to wait up to four weeks to see their GP, but could access other GPs in the medical centre for urgent care. One patient found the cost of co-payments a barrier to seeing their GP, and only two GPs offered home visits. Two patients with multiple sclerosis (MS) were immobile and required electronic wheelchairs. Neither of their GPs had facilities in their surgery to enable specific examinations out of the wheelchair but one of these GPs did do home visits.

All patients accessed a variety of community nursing services, including the Royal District Nursing Service (RDNS). Heart failure patients greatly valued their access to the heart failure nurses and cardiac rehabilitation services, but other services were not felt to be so supportive. Only one patient had contact with a palliative care team, who said they would provide support in the last week of life. Patients also accessed a wide range of allied health services including speech therapists, physiotherapy services, dieticians and occupational therapists.

A number of patients had considered the possibility of being admitted to a nursing home. The carers all considered the care they provided was currently better than the care a nursing home could provide, but recognised that nursing home care could be required in the future. One patient was very upset that he could not find out how much nursing home care would cost, as he

To try and see him there's like a two week wait at least. But to see other doctors there who are not familiar with Anne, you know, if it was an emergency I suppose you could get in almost at any time. But we prefer to see the doctor we were with originally.

PC3_Int3

I had nurses out here when she had her hip replacement – that was a bit difficult and, but only for a week or so and I thought, and Johanna thought too, well she is rather that I do it and no strangers in the house.

C3_Int1

Of course the heart failure team are very important - they've played a very important role in my life - wonderful - just wonderful. You couldn't wish for nicer people.

P8_Int3

So you'd have to go into hospital and the assessment team goes to the hospital and get you into the - eventually into a nursing home. You find this out as you go along.

PC3_Int1

....if Sue was to go into a home like that, she couldn't possibly get the same care as what I can give her here really, because it's a one on one - it's just not physically possible. 'Cause it's one on 12 or one on 15 or one on 10 or whatever.

PC1_Int3

would first have to complete extensive paperwork so Centrelink could determine a final cost.

Carer impacts

Five patients had full time family carers who provided the majority of care for their partners/relatives. They were all aware of the availability of respite support and the Carer's Allowance and had used varying levels of support, depending on their need. Three patients were aware of the outings and supports provided by Carers SA, but did not want to go on outings without their spouses, and one had used counselling services provided by Carers SA. One rural patient had difficulties organising care for his wife when he had to come to Adelaide for a series of tests, and another kept putting off care for carpal tunnel syndrome and crushed vertebrae because of caring for her daughter. One patient was very critical of the level of support available for carers, noting the high level of commitment required and the significant financial implications when carers had to give up work. A number of carers were frustrated about trying to get extra care and services to enable them to keep their spouse at home.

Particularly when you want - if I want to keep Anne at home then you need - they should, I would have thought, supply me with all the things that you've applied for to help you stay at home. **PC3_Int3**

I think it's disgusting that they're - I think they're exploited and I've always said that even before I got sick. The carer needs a lot of help, probably more than the patient in a different way - the patient gets their help, gets their drugs and whatever, and in my case they can't do any more than that about it, and I think there's not much care, much consideration given to the carer. **P1_Int1**

6.2.2. Free flow and accessibility of information

(Denotes the level of availability, accessibility and user friendliness of information about all aspects of care and services).²⁵⁴

Patients wanted easier access to information about available services and supports and were all anxious to have more extensive and detailed information on their disease and prognosis.

Accessing the right care

Patients and carers detailed a range of areas in which they had problems identifying appropriate care and supports.

....but you know there's a lot of services out there that you don't hear about - they won't tell you where you can get -

One carer noted that he was continually finding out about new services or supports from either other carers or other services. He found it very frustrating that there was no one service that could be contacted which could direct him to the care he might need, although he did note that the Commonwealth Respite Service had been particularly helpful. Another patient expressed her frustration with her disability service as she found it very difficult to find out what care she was able to access. Patients and carers were also confused about what services were available through funding packages such as the EACH packages and the variety of agencies providing care, including Domiciliary Care SA, community health services, private or NGO care providers such as ECH Inc. Adelaide, local councils and disability services.

unless somebody else has – they talk about it and they let you know. C7_Int3

Once you do an assessment you'd think they would send you things like that to let you know what you're entitled to. You get the impression that the government make all these things available but don't tell you in case you use them. C3_Int3

6.2.3. Physical care

(Incorporates medical and practical aspects of care, as well as pain and symptom management).²⁶⁰

All patients discussed their physical care and reported varying levels of satisfaction with the way their conditions were treated by specialists and GPs. All had levels of distress because of disease-related symptoms and many also experienced significant pain.

Medical care

All patients were heavily dependent on medical interventions, and the degree of medical intervention required was dictated by their levels of multi-morbidity, with the most mobile patient dependent on renal dialysis three times per week. Patients had varying levels of satisfaction with their medical care – the majority were happy with their specialists, however three were very

dissatisfied because of a perceived lack of communication and inadequate provision of care.

Most patients did not see their GP as the person with overall responsibility for their care – they said they saw their GP for scripts, annual check-ups, immunisations and any other smaller issues that might arise. Four of the six people with neurological disease felt their GP knew little about their condition but were satisfied with their overall care. One patient called her care “*dispersed*” as she felt her four specialists as well as her GP all had responsibility for her care.

Five patients had at least one hospitalisation during the course of the research and they described a variety of experiences. Two carers were very satisfied with the care provided whilst another was so upset with the hospital care she wrote a letter of complaint to the hospital. A recurring issue for patients with PD was the timing of medication, as these must be given at specific times to avoid symptoms such as freezing and loss of mobility. One carer was greatly distressed by the nursing care in a private hospital and felt he had to spend “*from early in the morning until late at night*” at the hospital to ensure his wife’s care was adequate. Another patient felt that the staff at the hospital did not really care about him, providing him with the wrong medication, not fully addressing his pain and he was unable to regularly see the same doctors.

All of the patients experienced a wide range of pain and other symptoms which were being addressed using a variety of strategies, but almost all felt that their symptoms were not being adequately addressed. One patient had recently been referred to a pain clinic and said that this was already helping her long term back pain. A

....the GP never really got into the act, only if I need a prescription for new tablets or whatever it is, but Dr [Neurologist] is in contact with the GP of course and so....The GP is alright.

PC2_Int1

Oh I see him [GP] every now and then. I have to go and see him again because I’ve run out of tablets and I need a flu injection at the moment too as well.

P6_Int2

....when she went to get her hip done, she had it done [hospital 2]. They were absolutely excellent, and they were really very helpful.

PC3_Int1

Every time I’ve been in hospital, I start ringing the bell early and one time I was an hour and a half late getting my tablets and then that puts you out for the rest of the day and I was really crook – crooker than I should’ve been because I didn’t have my tablets on time and then they all come and say “I’m sorry, I’m sorry” but you know, it’s damn terrible – you feel bad enough without that happening to you.

P1_Int3

Today is a different day from what tomorrow is really. You just get up and take every day as it comes because, you know like now I’m beginning to get the, I get muscle spasms in my legs in bed and that’s really terrible too because you can’t – it hurts yeah and you can’t sleep and what it does then is it shakes you up inside and

number of patients had multiple causes of their pain. Some had constant spasms from their neurological disease as well as back pain and neck pain. Others had pain from peripheral vascular disease linked to their heart failure, arthritis and injuries associated with falling, hernias and cramps. They reported that their symptom management was often best supported by allied health intervention. A number of patients attended rehabilitation services where they could access physiotherapists, OTs and speech therapists. One patient had physiotherapy at home, to help alleviate her bronchiectasis as well as help her mobility. She also accessed acupuncture and chiropractic support.

then you get all uptight.

P1_Int1

....we have really struggled and had really bad times and every day it came back. There was never an end of it.

PC2_Int1

Carer perspectives on their own wellbeing

Carers were very aware of the importance of maintaining their own health, and how important this was for the person they were caring for. Four of the six carers were over 70 years of age and all carers had previously experienced ill health. All carers put the health of the person they were caring for before their own health, and delayed having tests and/or accessing treatment if they felt it would interfere with their caring. They felt that the care they provided was superior to care that patients could get from paid carers, in nursing homes or in hospital. One patient said that she felt the only reason she was still alive was because of the quality the care provided by her partner.

I think I make her life as pleasant as possible. I keep her nails painted, so I've learned to do all that. I learned to, I put her makeup on. The kids have bought me a little set – basic things, you know. But that – I think that helps with her quality of life. So she's presentable all the time.

C3_Int1

6.2.4. Psychosocial care

(Described as care which meets the emotional, psychological and existential needs of patients and their families in helping to alleviate grief, fear and other psychological and social problems).²⁶⁰

Addressing psychosocial issues was recognised by all patients as being as important as physical care. Carers were concerned for both the psychological health of the person they were caring for and for themselves and all employed a wide variety of coping mechanisms.

Formal psychological support

The majority of patients had accessed some sort of formal psychological support to help them cope with their illness. It was initiated by their GP, their specialist or through the community heart failure nurses. Some patients recognised that their disease caused them distress at certain times but they were able to identify this and find support. Only one patient had accessed counselling, although initially she did not want this support. She reported that, as her sessions progressed, she felt this support had been of huge benefit in helping her to accept and cope with her disease. One patient was on high levels of anti-anxiety medication, but was still quite depressed because of both his illness and family circumstances. He also was very distressed that he could no longer have sexual intercourse, and had not discussed this with any of his health professionals.

Carers said they were amazed that patients were not more distressed and depressed, given the nature of their disease. Three patients and carers had attended Parkinson's Australia support groups and found them very helpful for information and also to interact with people in relatively similar situations. The two patients with MS had very different opinions of the value of the support from the MS Society, with one finding them very helpful and the other very critical of the cost and support provided. One patient was offered a counsellor through a rural palliative care service; however, they could not attend at the nominated time and follow up did not occur.

*....I don't know that you'd call it depression, because of my ahh feeling like no energy, if I had to go to a thingy, I feel like it's a real effort to go to appointment. **P6_Int1***

*I said don't be frightened to do that if it's not right. I said always talk about it, don't hold it in. If you need to vent out, go and see a psychologist. **P8_Int3***

*....that is where it came up about depression and things like that....she obviously, she was depressed at certain stages and I said – of course wouldn't you be depressed if you have to live like that? **C2_Int1***

*....Because they [heart nurses] tell you what's going on, they do they support you in every way you know. Ask questions – how are you going? how's your blood pressure? Has your weight gone up? And all this type of thing – and she passes that on to the cardiac doctor if need be so....I only have to pick up the phone and ring. **P6_Int1***

The two patients with heart failure thought the service provided by the community heart failure nurses who undertook home visits as well as providing phone support and organising and supporting cardiac rehabilitation programs was very helpful.

Coping

All the patients and carers remained positive most of the time. Deterioration in their condition upset people in the short term until they found ways of coping with the new situation. One patient became greatly upset when her deteriorating speech meant she could no longer communicate by phone with her son who lived in Melbourne and she said: *“In my case, everything I do is a frustration”* because her mobility was so restricted and her speech and swallowing were deteriorating steadily. Other patients talked about a number of different causes of frustration: one patient said he felt he never had time to himself as he seemed to always have tablets to take or exercises to do, and he was also frustrated at not being able to drive or be as mobile as he used to be. Another patient with no carer nominated loneliness as a problem and all were frustrated with their restricted mobility, with two patients saying that their home now felt like a prison.

Willpower, determination and the support of the family were the key coping mechanisms patients identified in helping them to live with their disease(s). Being there for the family rather than *“throwing in the towel”* was important and having a positive attitude was also identified as being very important: *“you change your attitude, you change everything”* – trying to focus on what they did have rather than what they did not and accepting what they could do rather than worrying about what they could not do. Both carers and patients

It's pretty tough, very tough you know you don't expect to end up in your life like this - you expect but I don't know what you expect but it's very debilitating and demoralising and it's pretty hard to take.

P1_Int1

....I mean that's how hard I used to work. And now – I mean I can't even get up – if I get up I can't even climb that chair – I'm shaking when I climb that chair now – because my knees are I mean – it's changed completely and that's what I find really hard.

P6_Int1

Fear of the unknown - that's probably – we've talked about that. A lack of independence. I feel like a prisoner in my own home.

P1_Int1

Um It will never be the same as before when you can do whatever you like, eat whatever you like and travel wherever you like, but they've got to – it's a different life . I think the thing is that you accept it and you plan your life around it and I think once you accept it everything is fine. OK your life changes. Righ.t

P4_Int1

....well it's something that totally changes your life of course, it's a big commitment. A commitment which I certainly won't shirk away from. So, so yes it does change your life.

C1_Int1

recognised that they now had a different life from the one they had previously enjoyed. Carers also nominated the importance of keeping busy and thought it was very important for patients to go out and try to enjoy activities they had always done, so one carer took his wife out every day if possible – for a drive, to bingo, and shopping. However, as her disease progressed this became increasingly difficult. Another carer regularly attended concerts and the theatre with her daughter and her paid carers also organised outings.

Carers recognised the need for psychosocial support for themselves too, but all were very committed to their caring role and found this to be very fulfilling. Each carer identified coping mechanisms for their own specific needs – one needed time out for exercise and sleep, another found his ‘happy hour’ every night very beneficial. Few wanted formal counselling or to access carer support groups and all enjoyed undertaking activities such as going out with the person they were caring for. All carers were very empathic, recognising how difficult the illness must be for the patient.

Sometimes I get frustrated I can't help him more when he's been ill. I'm trying to do a good job and it hurts to see him like that. C6_Int1

Key service provider perceptions

6.2.5. Availability of care

KSPs identified many of the same issues as patients and carers regarding access to ADL supports and equipment and expressed frustration at having to try and balance everyone's needs within a limited resource pool. They talked about the role of palliative care services, saying that one reason they referred patients to them was a perceived easier access to ADL supports and there were mixed impressions regarding the role of the GP. They recognised the important role carers play in the overall care of people with advanced chronic disease and commented that the provision of respite care was vital.

Access to ADL supports

KSPs were very aware of the importance of appropriate access to ADL support. Specialists said that the provision of home supports had major impacts on the physical and mental wellbeing of both patients and carers. They noted that there were marked differences in the capabilities of carers and these needed to be considered when identifying the extent of ADL support required. Some specialists did not see that organising this support was their responsibility, whilst others were happy to provide information and facilitate access to such supports. Community health services identified trying to balance their various clients' needs as an issue, noting that providing care for one client could mean that funding may not be available for other clients. The myriad of funding schemes was also an issue, with service providers juggling funding for services between Home and Community Care (HACC) funding, EACH and other community care packages, respite care funding and disability services.

A number of KSPs discussed difficulties getting access to care for people under 65 years through disability services, despite often quite significant disability, but they did note that these services were often overwhelmed with clients. Other issues included long delays in being approved for care and the provision of extremely time limited services: "They will give her like 20 minutes to 15 minutes or 25 minutes on a particular day and they will specify if you need extra assistance, we might send a second person out for 15 or 20 minutes." One KSP suggested that the organisation of disability services contributed to inefficiencies, particularly around the requirement for central approval for funding services for

....so home supports, providing some of the more complicated activities of daily living, assistance with some of the most complicated activities of daily living, so that the kind of spouse or partner or children don't need to have - need to do that all the time. That's I think paramount. SI I find that an issue - a real issue is this dichotomy between over 65 and under 65. The over 65s go through a system where you do an ACAT assessment and they get assessed for all sorts of different aspects of their care and they get access to funded home supports and then as time goes by, low level residential care and high level residential care and all that sort of carry on. But if you're under 65 ... I've got a particular person who is 60-odd, 61 with high needs, but his needs are not adequately catered for. But when he falls 65, they will be. GPI

I really felt when we dealt with Sue, that Disability SA weren't monitoring her close enough given that the illness she had is in decline, and they should really be finding some way to tag those clients and say hey look, you know, we at least need to pick up the phone and call these people every three or six months and just say hey, how's it going? Because logically their needs are gonna change, you know.

Com2

patients and a need for closer monitoring of patient needs.

Another issue for KSPs was the delay in getting assessments and, following approval, in accessing care funding. Specialists noted that they referred people over 65 years for ACAT assessment but were not aware of how long assessment and funding processes took. Community services noted that they could sometimes step in when there were delays with funding, but this was a strain on their budgets. They also suggested that the current system is already overstretched and unlikely to cope with the increased demand from an ageing population.

All KSPs recognised that transport was an issue for patients. They noted that transport was required to attend medical appointments and to undertake ADLs such as shopping and, more generally, just to get out of the house. Being in a rural area was as a particular problem as specialist care is generally based in Adelaide.

All KSPs emphasised the importance of carers in providing ADL support and felt that they should be better resourced. Better access to respite services was consistently nominated as a key need although access to emergency respite was felt to be adequate. One specialist noted that carers were sometimes reluctant to accept respite care, and were surprised when patients actually enjoyed it. They recognised that having a carer did not mean that other ADL supports were not required; as the disease progressed, care became more complex and carers became more exhausted.

Access to equipment

Although accessing equipment was often an issue, KSPs identified disability services as a particular problem.

Also, a lot of the patients can't easily get to places, so the access physically is sometimes an issue, transport to it. Which I'm sure is far bigger for country people than what we face in the city. GP2

I don't feel there's much support for the carers. I really think they need some more support. Getting them in - just simple things like, a lot of them haven't even got the Centrelink payments as a carer. They weren't aware that they could do that.

S4

....that's not just therapy that you put in your mouth as a tablet, but all things. If they need things such as shower

Funding for equipment was also difficult; KSPs recognised that people with ongoing chronic illness often had significant financial issues and so buying their own equipment was not possible. Another issue was that the condition of people with chronic disease deteriorates over time, and so waiting for long periods of time for equipment often meant the equipment was inappropriate or too late to be of benefit when it was finally provided.

Accessing the right care

In terms of helping people to access the right care for their needs at the right time, there was some confusion about whose responsibility this was – particularly about who should escalate care and who should refer to palliative care. Similarly to patients and carers, KSPs noted that it could be very difficult to identify all the agencies providing services and then make choices about the most appropriate one. They also recognised that patients and carers were often reluctant to emphasise their need for services for fear of being perceived as “difficult”. The combination of inflexible systems that had difficulty accommodating changes and people with deteriorating and changeable conditions highlighted the absence of a proactive system that could meet these needs. The importance of the capability and financial resources of carers was raised by a number of KSPs, as people with very strong family support were able to both provide more care and negotiate the care system more effectively.

KSPs discussed the role of palliative care services for their patients at some length. Some were unsure about who could be referred to palliative care services and how to refer people, whilst others did not see a need to refer to palliative care if their needs were being met adequately

*chairs or rails at home, or what particular component of the house do they live?Lots of these different things are very important. S3
Then I find that people then are in the Disability SA system and it can be very difficult to access some of the things they need. For example - equipment. I've known many patients waiting a long time for wheelchairs or home modifications S2*

*Then they have specialist fatigue from dancing around between people without anyone actually being the full person that pulls it in. GP2
Probably the biggest areas that we would advocate for is people with things like MS or maybe some of the neuro-muscular type diseases, because the illness is very long and ongoing and the level of disability changes. Those people do find that they really need to be very, very proactive, that they make sure the services are keeping up with their needs. Com2
It also depends of course on family support and environment supports and community standing. They all have a little bit of a play in what sort of extra supports a client can get as well. Com1*

I have to refer to pall care and then decide if the patient really fits their brief. If they don't think someone is - well I think they're chronically over stretched and so if they feel someone's not really going to benefit from their services they might say no. So I have had situations where it's not

by other services. Most perceived that patients could access more services through palliative care and that being a palliative care patient facilitated continuity of care on admission to hospital. Palliative care services appeared reluctant to take on patients with an uncertain prognosis and GPs reported that they were sometimes confused over their role and the role of the palliative care service.

All KSPs identified multidisciplinary teams as providing the most appropriate model of care for people with advanced chronic disease and it was suggested that the palliative care service should be part of such a team, rather than a handover of care. A multidisciplinary approach for diseases such as PD and MS was important and it was suggested that teams were also particularly helpful in providing psychosocial support for both patients and carers. The community heart failure nurses and multidisciplinary teams for neurological disease were highlighted as useful examples. However, some multidisciplinary teams did not function as well as they could, because of a lack of participation by the relevant health professionals, e.g. GPs.

KSPs had varying opinions about the role of the GP in end of life care. GPs themselves thought it was part of their role, but reported restrictions such as time and funding. GPs were seen as very important, particularly in rural areas where there were fewer speciality services and GPs were much more familiar with local systems than urban GPs. Some specialists thought it very important to keep the GP central to care whilst others felt that GPs were disinterested and that care and decision making were the specialist's responsibility. Some community services were concerned that GPs did not

usually an outright refusal but there's clearly a reluctance to take much on and that's not good for the patient because they get mixed messages about, yeah, look, you can call us if you need us but then if someone's calling too much they might get ticked off a bit.

S5

So I think these conditions need multidisciplinary care and I think that does enhance that sort of referral to the services that you're talking about.

S2

Because we're a multi-d organisation, the speech therapist might need to be involved as well, as often they are with MS as well. So that all comes together through the palliative care team

Com1

Unfortunately the doctors are missing from the team a lot of the time, that's the problem.

S5

The funding for us to get out and do it just isn't there. Patients with chronic disease cannot afford you know significant cost. For us to do it in those hours when we've then got to do the other stuff in the in hours, Medicare just doesn't fund it appropriately at all.

GP2

So I kept the GP central to this process because I think that, although I can help, because the complexities are something the GP is struggling with and the GP articulated that they were struggling with the complexities.

S5

refer to them and did not see them as a resource but others thought that GPs were expected to know too much.

6.2.6. Free flow and accessibility of information

KSPs saw access to information as a key strategy for empowering patients and carers and supporting appropriate care. They recognised the importance of improving the health literacy of their patients and the increasing role of the internet, but there were differences in how they saw their own role and the role of other service providers in how information is actually provided.

KSPs consistently said that ensuring access to information for patients and carers was one of their key roles. Specialists saw their role as guiding people to where they could access information whilst community service providers and GPs tended to see themselves as actual providers of information. A number raised the issue of how they themselves could keep up to date with what services were available and how to access them. Community based services change quite frequently and KSPs were frustrated and spoke of wanting to access a 'one stop shop' for information. They recognised that provision of information was not a static process, and that patients' and carers' information needs changed throughout the course of their disease. One suggested that there needed to be a systematic process of identifying these patients so their needs could be met. There was also confusion amongst service providers about which palliative care services their patients should access.

KSPs identified the internet as a key resource for patients and carers, with some reservations. They recognised that the internet could provide many resources, but patients needed to be encouraged to use it more. The accuracy of

I think my main role is providing information as to, well, what I can do medically, what I can't do medically and what other facilities there are beyond medical care that patients can access and how they can go about accessing that. I like, where possible, to be able to point people in the right direction. S2

I find it a bit difficult because it seems that there are a lot of different agencies in the community that provide that sort of care but knowing what the central point of contact is to advise people to approach is difficult. S1

....it becomes a complicated exercise of working out what service is available for whom and when. Also I get a little bit frustrated when systems change because there's a relearning process with a change of system. GPI

The internet is a very good source for that though. We do utilise the internet, and we go out and talk to a lot of services as well. Com2

I look at a lot of other services web sites and some of them are

the information, e.g. around service availability, was an issue, as was the quality of some websites. However, the potential of the internet to provide accurate information, allow real time contact, social media based support groups and facilitating referrals was discussed by a number of KSPs.

Health literacy was seen as an important prerequisite for being able to access accurate information and care. Educating the community was seen as very important to empower patients and carers and enable them to be proactive in seeking out information and support. Being able to use the internet to access information was perceived to make patients and carers more willing to question specialists and GPs. Support groups were also identified as important sources of information.

quite customer focused, right, and it's there to inform the person that goes to that site, but others are just very basic and they don't really speak to the client. Com2

*So Sue and her husband, they've figured out how to use their resources to negotiate their way through the system reasonably well, I think. But it takes a certain amount of wherewithal to do that. S1
....the main one I think is education really, education of the public to understand what's there and services going out and promoting themselves as well. Com2*

6.2.7. Physical care

KSPs particularly focused on the type of care people with advanced chronic disease and multi-morbidities require as they approach the end of life. They acknowledged the expertise of palliative care professionals and valued their input, but felt that, given enough resources, they could continue to care for their patients until the end of life.

All KSPs discussed the particular issues associated with caring for people with advanced chronic disease as they approached the end of their life. They recognised that: “*death is part of the continuum of specialist care, it is*” and suggested that younger doctors were more aware of the limitations of treatment and a greater need for end of life care. One KSP noted that: “*people aren't still used to thinking of chronic disease, as I say, as terminal illness.*” As a result, interventional care often continued when a focus on supportive care may have been more appropriate.

My sense is, with some of the specialities that have - for want of a better term - well-advertised chronic debilitating - is that the word - diseases, then it's easier. So I speak of respiratory with chronic obstructive pulmonary disease. I speak of neurology with strokes - significant strokes - and to a slightly lesser extent, but really on the same thing, cardiac disease....I would like to think well skilled in knowing when people are approaching end of life issues. S3

No-one believed there should be a blanket referral of all patients to palliative care services and they recognised that it was not possible for palliative care services to care for everyone who was dying. Most believed they were able to appropriately support the majority of patients, given the right resources. KSPs distinguished between referrals to palliative care services and initiating palliative therapies themselves but noted that sometimes this could be difficult – e.g. trying to get morphine prescribed for dyspnoea. Again, a specific role was identified for palliative care services when symptoms were difficult to manage or psychosocial interventions were required, but the generalist physician in particular saw it as their role to provide terminal care. Some KSPs believed that the input of specialist nurses in diseases such as cardiac failure, respiratory disease and neurological disease was more appropriate in many instances than a palliative care service.

There was a recurring theme of valuing advice and short term interventions from palliative care services as required and there was clear recognition of the skill and expertise of palliative care providers. Some KSPs found that support from some palliative care services was easier to access than care from others: one GP reported that he could always get support from his local team, whilst a specialist said they always had to consider carefully who to refer for a palliative care consultation, as sometimes palliative care services would not accept referrals.

A particular issue raised by KSPs was the complexity of caring for people with multi-morbidities. They commented on the time consultations took to manage the care of these patients; the implications of taking multiple medications; how to manage care in a holistic way; to

But I think you can't expect palliative care to deal with everybody who's dying. You can't see dying as this abnormal event that has to go off to a special team to look after it. It's going to happen to every single one of our patients. None of us get away from that. S4

So I think we have a duty to have that holistic approach. But the possibility of bringing the palliative care team for complex patients - ones where we're having a problem - we need a specialist team to come in and assist us with that. S4

The physician model of care is one where you do continue care of your patients into end of life. For the majority of them I wouldn't have trouble managing their symptoms but for some I will seek other help from specialists in pain, psychological management, all of those things that pall care is so good at. S5

I think most of us do quite poorly working out treatment paths for our elderly, debilitating patients with multi-organ disease. The 88 year old lady with severe aortic valvular stenosis and chronic obstructive pulmonary disease and kidney failure that

prevent unnecessary hospital admissions; and unnecessary referrals to palliative care.

I just have been seeing every six months in my clinic and patting on the head every six months. S3

6.2.8. Psychosocial care

All KSPs recognised the importance of ensuring access to psychosocial care for people with advanced chronic disease.

KSPs recognised that *“the psychological thought of having to move to end-stage is pretty traumatic for the patients and their families”* and patients and carers needed support to understand this move from curative to supportive care. The importance of the conversation about this change in care being empathic was emphasised with one KSP noting the very negative impact if people are simply told *“I can't help you any more, you're going to die and that's it, get your affairs in order”* as they had seen happen. They recognised the importance of hope, but realistic hope – not for a cure but rather quality of care. They also discussed ensuring people did not feel abandoned when their care changed – that they are not *“written off and it's just a slippery slope to death”*. They felt this was particularly important if the patient was referred to palliative care services – there should be a smooth transition and a more *“handover model of care”*. KSPs tended to talk more about psychological than social supports, but did mention the importance of support organisations such as the MS Society and Parkinson's SA in providing social support for people with neurological disease

But sometimes that's provided by these agencies who come in and they may simply take the patient out for an outing or even just sit with the patient while the carer goes out and does something that they need to do. I think that can be very beneficial because people get someone to chat to and unburden themselves to. If that person occasionally has contact with someone with a trained psychological background - trained in counselling and that sort of thing that would be quite good, I think. S2

KSPs noted that access to trained counsellors was also important, and that this service could be accessed through Medicare as well as palliative care services following referral. They talked about the importance of being able to unburden themselves to someone,

Yeah, I think it would be good for people to get some sort of trained psychological support over and above the direct care that they receive for activities of daily living

S2

particularly if people are isolated and/or do not have a carer. The importance of bereavement care was mentioned by only one KSP.

Psychological support for carers was also seen as very important. It was suggested that often carers do not recognise how tired they are and it is one of the roles of service providers to monitor this and identify when they are need of respite. Indeed, it was suggested that many hospitalisations of patients are because carers are no longer able to manage.

...time out from caring is very important. S3

There needs to be access to respite facilities regularly, respite facilities that are appropriate, comfortable and people can slot into easily, that's not necessarily in a nursing home. S1

6.2.9. Summary of satisfaction with domains of care

Overall, patients were satisfied with most aspects of their medical care, but were dissatisfied with access to ADL support and the level of information provided by health professionals. Cost of care, medications and equipment was an issue for many and one patient saw their GP only rarely because of the out-of-pocket consultation cost. Support systems were not flexible enough to support their escalating needs with increasing debility and this was particularly so with disability services except for patients with cardiac failure who had some level of team care through the community heart failure nurses All patients and carers were aware of the importance of addressing psychosocial needs and utilised a variety of coping mechanisms including formal psychological support. KSPs emphasised the importance of recognising the changing care needs of people with advanced chronic disease, both physical and psychosocial, and were also particularly concerned about difficulties accessing ADL support. They were confused about the role of palliative care services, recognising their expertise in end of life care, but KSPs felt that if they had better input from palliative care services and adequate resources, they could provide the appropriate mix of interventional and supportive care themselves The importance of psychosocial care was emphasised by patients, carers and KSPs who also highlighted the vital role of informal carers.

6.3. Client centeredness of care

Client-centred care is care that respects values, needs, and preferences of patients and their carers and families (where applicable). It is holistic and is based around relationships built between health care providers and patients and includes information giving, direct care and a clear focus on quality of life.²⁶⁰ Patients and carers in this research had mixed experiences of the client centeredness of their care. Whilst all carers reported high levels of involvement in care and KSPs all said that care and family involvement was vital, carers often expressed a need for more information, particularly around prognosis and more support for the person they were caring for. There were few examples of collaborative care, particularly for patients with multi morbidities who continued to see separate specialists and there was minimal coordination or continuity of care. Although KSPs said that non-medical and spiritual care was very important, a number of patients and carers felt that they had been left to deal with their illness alone.

Patient and carer perspectives

6.3.1. Appropriate involvement of family and friends

(Specifically in decision making and information giving).²⁶⁰

The involvement of family, friends and carers varied markedly across patients. Not all patients had carers, and some people had very strong involvement of family with their care whilst others had minimal support. Where patients had carers, they were closely involved in patient care and support. Access to information, particularly about services and prognosis was highlighted by carers as being very important.

Patients reported that their carers were closely involved in all their care and so attended all doctors' appointments and other care visits. Carers themselves expressed frustration when they felt specialists were saying "nothing further could be done" and so they looked for information themselves, particularly on the internet. Two patients and their carers felt that they did not get sufficient information from either specialists or GPs and

I was at all meetings with Sue from the very start, so you sort of follow the progress as you go along there was nothing that I wasn't informed about.

CI_Int1

He said to me there's not a lot of point me going up to Adelaide [unclear] he said make an appointment any time you want to, but he said there's nothing - I just can't do any more for you.

P1_Int2

So it seems an awful lot of things are available which it's

that they had to fight to identify what was happening, especially when there was a rapid change in their condition. Carers were also concerned about difficulties identifying available services. One carer rang Carers Support looking for information but found that “*they don’t actually supply anything*”. Patients were very concerned about how much caring impacted on their carers, physically, mentally and emotionally and so were anxious that their carers were also able to access information and supports.

only by word of mouth from other people you find out what they are. It’s like the district nurse told me about CASA where you can get assistance with pads and things like that.

PC3_Int3

6.3.2. Collaboration/ team management and education and shared knowledge

*(In terms of timely and complete information about patient prognosis, progress, and disease process).*²⁶⁰

A major theme that kept recurring for patients and carers was the difficulty of coping with an unsure prognosis. Whilst most patients knew there was no cure for their disease(s), they felt that there had been no discussions about whether they were actually going to die soon. Many patients and carers were distressed about this lack of discussion. Only one carer said he did not want to know his wife’s prognosis, but he did use the internet to find out about the possible progression of her disease.

Although all patients had very advanced disease, eight of the nine did not feel that they had participated in clear discussions with their health service providers specifically about their prognosis. All except for one patient knew they had a life limiting disease which had major impacts on their life and ability to function as they had previously, but felt that without a clear prognosis they could not effectively plan for their future. A number of patients wanted more information on their prognosis. However, patients said that the neurologist and GPs did not want to give definitive answers because of the uncertain trajectory

You know – to be told you’ve got a disease that there’s no cure for and there’s no treatment.

P1_Int1

I always wanted to know what was, what was the end result - know what the end result is – but how it’s going to pan out. And I haven’t ever been told that and it would be helpful....But I think, if you know, you can plan. We haven’t really been able to plan anything because we don’t know what’s happening.

P1_Int1

....that was the disappointing part of it – he can’t do anything. It’s up to us to, to

of their disease. Patients and carers were upset because they knew no further treatments could assist their condition, but found that difficult to accept.

The patient with renal disease had spoken with her nephrologist and understood that if she stopped dialysis she would die, and that was her wish if she had a stroke or other illness “*but for me, not to be able to do anything is no life*”. The patient with heart failure and PD also talked about a ‘*do not resuscitate*’ order but had not yet discussed this with her GP. She was fairly overwhelmed with her illness and said she had “*enough to deal with just with everyday living and getting through it*”.

The hardest thing for people to accept was that their specialist could do nothing further for them, but they wanted to continue regularly visiting their specialist: “*because we live in hope that he’s going to ring us, but you know, there really is no hope*”. Another carer was asked to approve a tracheostomy for her daughter admitted to hospital with pneumonia, but received no information about why and refused. No further conversations were undertaken with the patient or carer about their future wishes should such an issue recur.

Patients and carers were not particularly aware of collaboration and team management around their care. They recognised that their specialist communicated with their GPs, but did not mention any collaborative care or communication between the various specialists they saw for their multi-morbidities. One patient was very concerned because on admission to hospital he was given inappropriate medications and blamed this on a lack of communication about his co-morbidities. Another concern expressed by carers was patients being discharged from hospital without appropriate follow up.

make whatever you can of your life and that was it. PC2_Int1
I talked with my doctor – that was not really successful as I mean we have talked with Dr [Neurologist] about what is the use of living you know at stages.

PC2_Int1
No-one has and we don’t – well, I’ve asked the time limit You know, because it really – you know, I used to before, sort of think that I might have been dead in three months, six months – or I didn’t know. You just don’t know....Now, nearly 12 months has gone and I was thinking about it- they just tell me there’s no cure and nothing to help you.

P1_Int1
....all we hope is that maybe some more medication, some information might come which is helpful you know.PC3_Int2

I went to the hospital because I couldn’t handle it. Of course when I was there they gave me all the - even though they knew what tablets I was on they should have realised I wasn’t allowed to have the stuff they gave me. Of course my doctor reckons they’re stupid idiots, they would have killed you - they nearly killed you because of all the tablets they gave me to try and stop the pain.

P6_Int2
....[they]sent us home and just, see you later. And I thought: I need support now. Quite scary.
C6_Int3

6.3.3. Rapport

(Described as feeling that care professionals had attempted to build a connection with them, which in turn fostered qualities of interdependence, including trust).²⁶⁰

Seven patients said that they had a good rapport with their health service providers, particularly their GP and specialist. This was clearly very important to them – one patient said: “*I can talk to him about anything. I talk to him about anything and everything. I trust him*”. Patients and carers also though it important to have a rapport with their paid carers, particularly as care is provided in their own home.

*She worked with dementia in Perth But she's just as experienced and just has really good rapport. C9_Int2
....well, I think they are the best carers. But I've been through different ones and it's hard inviting anyone to your home that you don't know.
P8_Int3*

6.3.4. Respect for patient needs and preferences

(By health care professionals).

All patients' preferences were to stay at home, so the key issue for them was having access to support for ADLs to allow this to happen. For most patients, it was a struggle to access enough care, especially if care was required at night. Access to appropriate equipment was also an issue as was finding residential respite care – one patient took his very disabled wife to Melbourne for respite care while he visited his daughter there, as he could not get appropriate care in Adelaide. Another patient came home from respite with significant pressure sores. Few people had the option of home visits by their GP, resulting in a need to travel to the surgery or the emergency department.

*No. I think the answer we get from most people is, if it's an emergency, call an ambulance. The hospital's not far away. That seems to be the answer, rather than a home visit.
PC3_Int2*

6.3.5. Sensitivity to nonmedical and spiritual dimensions of care

(By health care professionals).

Overall, patients had mixed experiences with their health service providers' recognition of needs other than clinical care. The two patients with access to the community heart failure nurses were clear that these nurses supported their social as well as their medical needs. Four patients said their GP was very supportive. One patient without a carer was advised by their GP to move to hostel accommodation as he felt she needed support and access to care and organised the paperwork etc for her. A number of patients and carers had become quite fatalistic about their future and no longer expected any real support from their health practitioners.

*But in general terms, we have the problem, okay and we are used to it and um but we sort of still - well we sort of still happy with the two of us....and try the best we can. C2_Int1
Nothing really - we've sort of given up looking for improvements. People just now leave us as we are and hope for the best and try to make the most of it. That's it.
C2_Int3*

KSP perspectives

KSPs were very positive about the involvement of family and friends in patient care. They talked about the importance of involving families in advance care planning discussions and recognised the important role carers play in caring for patients. Although KSPs discussed the importance of a multidisciplinary approach to care, there were very few examples identified, particularly between GPs and other services.

6.2.6. Appropriate involvement of family and friends.

KSPs mainly discussed involving family and friends in discussions around advance care planning. They emphasised the importance of including families in end of life care discussions and specific care options and that all such conversations should be ongoing. They noted that sometimes families blocked such discussions, particularly if they were also carers, as they “*don't want to seem like they're failing*”. KSPs were also aware of the financial burden of caring on carers and also that

....It's quite a confrontational statement to have when you've got said patient and maybe relative in the room because the response would be what it would be for me, which is - do you think Mum's about to die? Why are you having this discussion?I think things are well but I think we've got to plan - and my classic line is, if you plan for the worst, you're never surprised.

S3

identifying supports and following up available care “often does end up falling on the family”.

One KSP noted that there needed to be an awareness of the limitations of carers and they should not be expected to undertake activities for which they are not trained. They also noted the need for standardised, accurate and up to date information on a variety of chronic diseases for family and friends to refer to as their disease progresses.

....carers can just do as much as they can do and sometimes they need to step back and let a professional get involved for the sake of the carer and also the sake of the person with the disability as well. Com2

6.3.7. Collaboration/team management and education and shared knowledge

Whilst all KSPs talked about the importance of collaboration and team management, few examples of either were given. The GP was consistently identified as the most important person to co-ordinate care, but the community heart failure nurses noted that they had little contact with general practice or palliative care teams, and specialists had no contact with GPs other than discharge letters. This was a particular issue if care or medications were changed. Some expressed surprise that GPs were not more interested in collaborative end of life care. Whilst one GP reported good relationships with local palliative care teams, the other reported little contact with them.

I think the ideal care coordinator is the doctor and a GP and if there ever was an area of medical practice which should be a general practice specialty, it should be this and that's chronic diseases. GP1

I'm very happy with the specialists, generally, but occasionally a specialist, especially an in-hospital specialist or a registrar, will initiate or attempt to initiate a particular drug without full knowledge of all the circumstances....and the patient will come back expecting a particular approach and I would have to disagree and then you end up having a confused patient. GP1

One specialist noted that they ran a multidisciplinary clinic for following up after discharge from hospital. They saw many patients with advanced chronic disease and organised supports and information through their clinic. However, they reported difficulties in collaborating with other specialists and palliative care services and were upset about disjointed care because of a lack of communication.

She's already got a disjointed care by multiple specialists, none of whom were talking about the big issue that she's dying and we need to look at her symptom management more and plan. S5

6.3.8. Rapport

One KSP felt strongly that the most appropriate care provider for people with end stage disease was the provider they felt most comfortable with and whom they trusted, rather than someone with extensive expertise and experience. Rapport was often talked about in the context of end of life care discussions, with KSPs noting that these conversations took time so that trust could be established and people could feel they were being listened to. Making time for extended conversations earlier in a person's illness trajectory meant greater clarity in later, shorter discussions when a person's condition had deteriorated. One GP noted that they were in a particularly good position to establish rapport and undertake end of life care discussions as they often knew the person and family well, understood their situation and had a history of caring for the family.

So a patient who says, I trust my GP, I can rely on my GP at this stage in my illness, they very usually made a reasonable choice and it may not be on the basis of specialist knowledge, it may be on other tangibles for them and that's equally valid.

S5

That way they've got that bond, that trust, people have hopefully discussed direction of care or are in the process of discussing direction of care and there's a trust and an understanding there about someone's wishes.

S5

6.3.9. Respect for patient needs and preferences

All KSPs talked about the importance of talking to their patients and families and identifying their care preferences, but recognised that sometimes the system did not support this. A number of KSPs noted the need for advocates as sometimes patients and their families do not know the system well enough, and this was particularly so if their needs were changing fairly quickly.

Most people don't have that wherewithal. Then, how well they go depends on who they encounter in the system to be an advocate for them

S1

But unless you have someone locally who really is passionately driving for it, then stuff doesn't tend to happen quite so well.

S1

One KSP talked about the introduction of consumer directed care suggesting it was a very positive way of ensuring patients' care preferences can be met, but noted that whilst some people would be very able to organise their own care, others would need considerable support.

You're there to provide care for the patient and engage in all health care professionals that it's that patient. I just think it's part of my job. That discussion is part of my job, and acceptance and acknowledgement and so that they get my opinion

S3

6.3.10. Sensitivity to nonmedical and spiritual dimensions of care

All KSPs highlighted the importance of considering nonmedical and spiritual care. They emphasised the importance of maintaining a human connection and the need to provide “*that ongoing source of support and information to patients, so they – because otherwise I think they can feel very abandoned and very alone*”. One KSP said she was always available by phone for “*simple questions*” so they could feel that problems could be solved together rather than that nothing could be done.

KSPs recognised that people may not always hear what is said to them in consultations and it was important to ensure that they did not have unrealistic expectations and so helping people to accept their prognosis was also an important task: “*I can't make you better, but I'm going to try and make you feel better*”.

a lot of the kind of qualities that a patient's looking for in their care is really just that kind of human connection and that sense of being not abandoned but cared for and respected and a good nurse of any genre can provide a lot of that.

S5

That's why I think it can be everyone's business. It's really just about making that human connection and about feeling that someone is there for them

S5

Then the biggest job for me is acceptance that that's a path that they believe is appropriate. Just because I believe it's appropriate doesn't mean it's not appropriate - doesn't mean it's appropriate. Once there's acceptance, that's the biggest role for me.

S3

6.3.11. Summary of client centeredness of care

Overall, there was recognition by KSPs of the importance of a patient centred approach to care, but the care reported by patients and carers did not often reflect this. Although carers were perceived as vital for the support and wellbeing of patients and KSPs emphasised the need to support them, carers themselves felt that they needed more information from health professionals and more support to care for their family member, rather than support for themselves as carers. A lack of collaboration amongst health professionals and services was identified by both patients and KSPs as a problem in supporting patient centred care and KSPs cited system constraints as another barrier. KSPs were concerned about patients having unrealistic expectations about treatment and prognosis, but patients said they had few opportunities for discussions to clarify their condition.

6.4. Continuity of care

Three types of continuity were identified by Bainbridge et al²⁶⁰ relational continuity, defined as patients seeing their usual practitioner; informational continuity, defined as communication and knowledge where patient information

flows easily between involved care providers and managerial continuity, defined as coordination of care so that transition between care providers is clear and seamless for the patient. All these aspects have been previously discussed in Chapters 5 and 6, and the care described demonstrated very low levels of continuity of care in all three domains.

6.5. Summary

In this chapter I have reported on perhaps the most important of the three domains of system functioning identified by Bainbridge et al: patient outcomes. I have demonstrated that there are major gaps in the three domains of patient outcomes identified by Bainbridge et al - access to care, client centeredness and continuity of care resulting in sub optimal outcomes for patients and carers. Whilst all patients had access to specialist and GP care, the level of access varied markedly and there were significant barriers to accessing ADL, psychosocial and specific end of life care supports. There was a mismatch between patient/carer and KSP accounts at many points related to care provision and, particularly, around end of life conversations. Whilst all KSPs noted the importance of having end of life care conversations, only one patient reported that she had actually such a conversation, although four others had advance care plans which they had accessed through a variety of sources. Patients and carers said that they found it particularly difficult not to have had clear discussions about prognosis. KSPs thought it important that patients did not feel abandoned or that nothing more could be done, but patients and carers said that was exactly how they felt.

Patients and KSPs identified a particular problem with collaboration between health professionals and health services, including palliative care services. Whilst GPs were seen by KSPs as key care coordinators, patients did not see them as their primary care provider and KSPs recognised that poor communication between specialists, hospitals and GPs was a major issue. This was closely linked to a lack of coordination of care between providers and across sectors.

The vital role of carers was recognised by patients and KSPs and all felt there was not enough recognition of the importance of the caring role, nor enough support for carers. Carers themselves wanted more information about supports and

services available for patients and more support to enable them to keep patients at home for as long as possible.

In Chapter 7, I will examine how service managers and policy makers perceive the health system structure and process of care is functioning for people with advanced chronic disease and how this impacts on patient outcomes and what might need to change to address the issues raised in Chapters 5, 6 and 7.

Chapter 7. Results: Service managers and policy makers

7.1. Introduction

This chapter describes the findings from the final phase of my research in which I interviewed service managers and policy makers. The main purposes of the interviews were:

1. To explore service managers'/policy makers' responses to the issues raised by:
 - patients and their carers;
 - the initial review of national and state end of life care policies and procedures;
 - existing gaps in policy.
2. To explore service managers'/policy makers' perceptions of:
 - best practice end of life care for people with advanced chronic disease;
 - how such care can be provided in the current system;
 - what options there are for expanding the provision of this care;
 - workforce, resource and financing implications.

I identified two major themes through my analysis of the service manager/policy maker interviews:^{xix} 1) Issues specifically around the provision of end of life care, which included major sub-themes of philosophies of end of life care, advance care planning and strategies to enable appropriate end of life care and 2) identifying appropriate models of care, with major sub themes of patient centred care; integrated care and coordinated care and the chapter is laid out under these themes. The chapter finishes with a summary of the suggestions of service planner/policy makers around changing the system.

^{xix} The thematic analysis model is detailed in Chapter 3, Section 3.4.4

Overall, health service planners and policy makers recognised the growing importance of end of life care for people with chronic disease and thought such care was the responsibility of all sectors, not just palliative care. They emphasised the importance of a palliative approach to care and recognised that there was no clear transition point for initiating this approach; rather, it should be integrated into normal care in response to patient need. They identified a number of significant issues including: a death denying culture; a health system focused on interventional rather than supportive care; a lack of shared understandings around end of life between different health professionals; difficulties with access to care and funding and lack of education for most health professionals in end of life care issues. Advance care planning was recognised as a key strategy for improving end of life care, particularly the facilitation of end of life care conversations.

Participants then canvassed a variety of possible models of end of life care, which could provide a way to address the key issues around philosophies of care, culture, advance care planning, funding and education. The concept of person centred care as the basis for an end of life care model was explored, as were issues around developing multidisciplinary, coordinated care models, integrated across the acute and primary care sectors. Many participants also highlighted the importance of consumer education and engagement to help drive change.

7.2. End of life care

All of the policy makers and service planners agreed that the provision of appropriate and accessible end of life care for people with advanced chronic disease was very important and was not currently generally available. Variation in philosophies of end of life care was suggested as one possible reason for why such care was not part of routine care. Participants canvassed a wide range of issues impacting on current and future provision of end of life care including the role of specialist palliative care services; they focused particularly on advance care planning (ACP) and other enabling strategies for supporting better end of life care.

7.2.1. Philosophies of end of life care

All participants talked to some degree about the varying philosophies and cultural attitudes to end of life care, both within the health system and in society more generally, which underlie the provision of care for people with chronic disease. Two specific aspects were discussed: 1) community awareness and willingness to discuss end of life care issues and 2) the medical/health professional culture which values intervention over support. They thought there was a general culture of death denial in society and a fear of talking about death and dying and this was reflected in the health system, where end of life conversations were often avoided. Participants suggested that health care professionals themselves have a focus on interventional and curative care and a number thought that the fact that “*we are all going to die at some point*” is still not really accepted by many health care professionals; the idea that hospitals and specialists are there to cure people is still very pervasive.

Participants felt that specialists often saw themselves as interventional and once interventions were no longer required, they did not see the delivery of end of life care as their role. Participants discussed the need for a “*cultural shift*” for health professionals: doctors need to move away from the notion that they are there just to “*make people better*” to “*talking about a time when I might not make you better or you might choose to have a different path*” and to stop trying every available treatment. One participant noted that many doctors no longer experience “*seeing how a family comes together,*

But while you've got a culture that is still death-denying, you've got physicians being trained to cure even though they are looking after people that have all got end-of-life illnesses, without that culture change, we're going nowhere.

SM/PM_10^{xx}

So there is still a culture in this country of death doesn't happen, it's a failure of medical care. Therefore don't talk about it because then that shows our fallibility, if you like, because we haven't found the cure for mortality

SM/PM_10

....there's a lot of fear about how you manage somebody at the end of life, how you manage somebody's dying and I think that there's a discomfort about difficult conversations

SM_12

But often when we talk to the general public they tell us that it's their doctors that won't talk to them about it. You know it's the clinicians who are reticent to start the conversations especially about advance care planning and potentially for a number of the barriers that you've already identified. That they just recognise well I don't want to start this conversation because it's going to be too expensive and we don't have an hour and potentially they don't feel they have the confidence and the skillset to

^{xx} Quotes are attributed using the following abbreviations: **SM**=service manager; **PM**=policy maker; **SM/PM**=participants who undertook both roles.

how they will celebrate the dying patient by knowing that she's all right, that they can help, they can be there". It was noted that community awareness, promoting cultural shifts and changing the conversation were not just the role of the health department but other organisations and NGOs can also play a role.

A number of participants talked about the importance of a policy framework to support end of life care noting that such policy must be informed by public debate. They thought that raising awareness must involve the whole community, including clinicians and cited examples such as the *Dying Matters* project from the UK.¹³⁰ Another key point raised by a number of participants was that community education around life limiting illnesses (including dementia) was required before any process of developing advance care directives could begin: *"You need to have systems that encourage the conversations. You need to have a society of people that aren't terrified at the mention of death"*.

Participants pointed to a lack of agreed understandings of core concepts in end of life care as a key issue underlying the reluctance of many health care professionals to provide end of life care. There was no agreement on the meaning of terms such as end of life, terminal care, dying, supportive care and palliative care. Confusion arose around time frames for these understandings – is terminal care provided in the last week of life or the last months of life? Is end of life the last 12 months or the last 12 hours of life? If end of life is the last 12 months of life, the clinical care required for this period is very different from the clinical care of someone in the last few days of life. Many participants also discussed the concept of 'transition' to an end of life

have the conversation anyway.

PM_6

I think it's a significant problem that we've got. Now, the policy. I actually think policy needs to be informed by public debate and I don't think we've got enough public debate or any debate or discussion around end-of-life in our community, because I think what would be really useful is let's have more discussions in this space, then policy can be reflective of the community's views, opinions.

SM_1

Before you actually get people to take on planning and actually writing up documents, I think that there needs to be a greater education to the general community around what are life-limiting illnesses.

SM/PC_10

....but I think also people with chronic disease sort of slip into their chronic disease without realising that it's a chronic disease and then I think they can sort of slip into their end of life phase without realising.

SM_7

The chronic diseases I believe, most of them don't have a very clear point where you can say here we're at the approaching end of life phase of this illness.

SM_12

I think transition is really difficult. Unless it's absolutely as plain as the nose on your face, people often don't see it.

SM/PM_10

But what it probably means more is that the respiratory physician and the cardiac physician need to be better at doing it themselves.

PM_9

phase and most agreed that such a transition was very unclear and that “*just looking for a transition is perhaps flawed in this group of patients.*” They said there was “*no clear cut time when you would refer*” and there were no real ‘*tipping points*’ for people with chronic disease. Participants suggested that this was one of the factors making it difficult for palliative care services to become involved in care, as people are still requiring ongoing active management as well as supportive care. This also made it appropriate that specialties themselves provide end of life care rather than referring to palliative care. It was noted however, that advice and support from palliative care services earlier in the disease trajectory could avert many issues that arise as the disease advances, particularly in the areas of psychosocial care and symptom control.

Palliative care services in a death denying society

One response to the death-denying culture discussed above has been to make end of life care the remit of specialist palliative care services, allowing other service providers to avoid taking responsibility for providing end of life care. One participant noted that specialist palliative care is seen: “*within the hospital context as the holders of the end of life, the terminal care mantra, so that their job is to look after dying patients*” and so other health professionals do not really see end of life care as their role. The skills and expertise of palliative care services were highly regarded: “*it is what medicine ought to be*”. Participants said that the underlying philosophy of palliative care was patient centred and they were able to cross boundaries in a way other services could not; their ability to support psychosocial and spiritual needs was particularly valued. Participants

I think palliative care services need to get better about recognising that you can discharge patients or people because I think they have not been trained to do that.

SM/PM_10

....there isn't often a clear endpoint with many of the chronic illnesses and that's that ambiguity of living with ongoing active management and palliative care needs. That's the difference.

PM_8

I get worried about this notion that palliative care has to be for everybody with a chronic disease because I just think it's unsustainable, it's not feasible.

It's probably not acceptable.

SM_7

....It's like you hand over to palliative care because you don't feel that you can achieve anymore. It's not seen as: I'm also going to help my patient have great quality of life until the end. It's not seen that way. It's seen as a giving up kind of thing.

PM_6

I mean really it's a sharing of care and it may be that you received a palliative approach for some part of your care but then you might go back to active treatment....There's no reason there has to be some hard and fast line that you jump over.

PM_6

....that's what palliative care philosophically has always done is focus on the needs of that person and their

generally perceived palliative care to be more holistic, patient centred and focused on responding to patient need than most other medical specialities. However, one participant was afraid that palliative care services were becoming too specialised and were almost becoming a “silo” in the way other specialities had developed.

Although palliative care services were greatly valued by participants, there was general agreement that: “*Not everybody who is dying needs specialist care — they just need good support, pain management and care*” and this was linked to a discussion about using a palliative approach rather than referral to a palliative care service. Participants thought this was important, so people did not feel abandoned or were told that “*nothing more could be done*” A number of participants suggested that being able to confer with palliative care services for advice and support but not actually transfer care and/or developing models of shared care would be very useful. GPs and generalist services were recognised as being able to provide appropriate care and one participant emphasised that building a palliative approach into usual care should be the norm, rather than an acceptance that people with advanced disease should be referred to palliative care.

immediate surrounding family, carers, whatever. It really included always the concept of a multi-disciplinary approach.

PM_8

*Some of that is a system view and some of it's an expectation that once you're involved you will stay for the longer term. I think some of that's been driven by our cancer model because it's usually a relatively short contract within a finite ending of death, it can be predicted. SM_12
....an understanding that palliative care is as it is needed. That it doesn't have a time span. It's not about terminal care. It's really as it's needed in the disease trajectory and it's certainly not restricted just to the end.*

PM_6

7.2.2. Advance care planning

Advance care planning (ACP) is a vital part of end of life care,² encompassing both ongoing conversations about the care people want as their condition advances and the documentation of those wishes. There was consensus from all participants that ACP was very important for people with advanced chronic disease but should not be only considered as an end of life care activity. Participants were concerned about who had responsibility for initiating end of life care conversations and emphasised the need for training for all health professionals. They also talked about the role of technology, guidelines and record keeping and the education of the community as enablers for advance care planning.

Advance care planning processes

A major theme identified across all participants was a lack of a standardised approach to ACP and the development of advance care directives. Participants were concerned that there were no systems for storing and accessing documentation: “*we don't know if it's been done and where is the documentation or evidence to support a conversation about end of life planning*” and agreed that the *Advance Care Directives Act 2013 (SA)* making advance care directives legally binding would be very useful. They also noted that ACP was becoming a priority issue at state and national level and one participant suggested that it should be part of a generalised approach for healthy ageing.

Well I think it's raising the profile of advance care planning and I think that it's useful that it's encouraging people by the fact that it will actually become more of a legally binding document. You know you hear people at public forums and stuff saying well advance care planning it's not really, it doesn't mean much because doctors will overturn itBut I think if people are actually more confident about the rigour of it then that's going to encourage people more.

SM_7

Advance care planning is certainly a policy issue that is increasingly becoming a high priority within the Department and for our medicine as well.

PM_3

Conversations

Conversations are at the heart of ACP and participants said that: *“It's a failure of good medical care actually not to have a conversation”*. They commented that the implications for patients and for health care costs of not having the conversation were significant. Some participants suggested that many patients are very happy and grateful to have such discussions about their goals of care and future care options, but other participants said there were many people who did not want to do so and were very upset when such conversations were initiated. Some discussed the issue of *‘destroying hope’* and related this to a fear that health professionals cannot cope with the feelings such interactions may raise and feel a need to keep intervening rather than accepting the time has come for a purely supportive focus of care.

One major issue that participants raised was around who has responsibility for initiating such conversations and most participants thought it was either the role of the treating specialist or the GP. Palliative care services were seen as being the *“experts”* but most participants thought: *“...that's something that all clinicians should either be skilled in doing themselves or should know who they can call on to do it”*. The role of GPs was also discussed and one participant reported that they had *“surveyed GPs last year and hardly any of them initiate conversations about advance care planning or about end of life care at all”*. Participants also expressed concern that that many patients are treated by junior doctors in hospital who do not see such conversations as their role. Only one participant felt strongly that it was not the role of the treating physician to have such conversations, as there could be unconscious bias or a vested interest in

I think that it's the conversations that really come down to. I think big conversations with people are more important in many ways than just having a piece of paper. SM_7

I think as a profession, we as doctors have this sense that we have to do things. We've got to keep trying, keep trying, keep trying and we probably do put off that conversation about there is no point to keep trying any more. SM_2

....and a fear of evoking negative emotions that you won't know how to deal with or won't be able to contain if they all start flooding out. SM_12

There's an over-arching issue around the who because we've become too specialised. If you had more generalists it would be easier because it's not just a palliative care physician. You can't just refer it to palliative care - you need to have that conversation. PM_4 I mean when they're in hospital they're often managed by quite junior people who are just trying to keep their head above water and not sort of - who've never - yeah. Your average medical resident's not going to approach that subject. SM_7

encouraging the patient to further treatment but another participant who was a clinician felt “*you'd be missing something if you didn't include the treating physician's current understanding of where the patient was at.*”

A number of participants identified strategies that health professionals can use to initiate and support end of life care conversations, and emphasised the need for more than one discussion and the time required to properly undertake them. They recognised that education of health professionals was a key strategy in helping them to have a discussion about the goals of care and also that “*You need to have systems that encourage the conversations*”. They also suggested that older physicians may not have training in having such conversations and they were not standard procedure in most acute care services.

You know it's the clinicians who are reticent to start the conversations ... they just recognise well I don't want to start this conversation because it's going to be too expensive and we don't have an hour and potentially they don't feel they have the confidence and the skillset to have the conversation anyway. **PM_6**

7.2.3. Strategies to enable appropriate end of life care

Whilst participants identified a number of issues associated with the provision of appropriate end of life care for people with chronic disease, they also talked about specific strategies which would help to facilitate change, including new technologies; review of funding mechanisms and training and education; and greater use of evidence to develop appropriate models of care.

New technologies

Participants discussed the potential of technologies to act as key enablers of better end of life care including: new hardware and software; systems processes such as guidelines, position statements and decision support software facilitating the greater use of evidence. They thought that the inclusion of advance care plans on the person controlled electronic health record and state e-health records and the development of decision support software to guide discussions and planning were important. They also highlighted the importance of

....we need the conversations but then also the technologies or decision support in its broader sense of enabling those conversations to be had. **SM_1**

....health records would be an amazing enabler because then if a person presents anywhere, you know exactly what it is before it's too late and you've implemented something or put them on life support or whatever. **SM_5**

integrating end of life care into “*guidelines, from position statements into guidelines, disease-specific guidelines and that sort of thing*” as well as the need to: “*get research done that has findings that are too clear to avoid taking notice of.*” The role of NGOs in advocating for end of life care and for developing guidelines was noted as was the “challenging fiscal environment”. One participant summed it up as “*somebody needs to create that shared community-based approach that delivers care to that community.*”

It was noted that there was still much work to do in these areas before they were functioning to full potential and that “*I don't think anything can substitute for actual discussion between the clinicians and including the patient and their carers.*”

Funding

Participants highlighted the need to change both the structure and amount of funding available for end of life care. They said that access to care was impacted by fragmentation of funding sources, most notably the difficulty of accessing care for people aged < 65 years: “*it shouldn't be based on age. It should be based on need and anything else is ageist.*”. Policy makers noted that this was under review at a state and federal level but the differing funding responsibilities of state (disability) and commonwealth (health and ageing) made changing this process complex.

Some participants highlighted a need for better access to palliative care. They suggested increased funding to address the large numbers of patients with chronic disease who may require care and to facilitate the longer term input such care may require. It was suggested that

....I know you did mention the e-health stuff and I think that will have a positive benefit, I suppose and then to the extent to which the sign up....Obviously if either people aren't signing up or if health care providers aren't signing up to look at the information then the utility of that won't be there. PM_3

Other things within the system help people with chronic disease – there is [sic] other supports that are available.

SM_2

There are programs that have restricted access that are built around financial constraints

SM_12

I think the division between disability and health services is probably an impediment to good integrated care.

SM_1

See once again, you're going to have the State responsible for the under-65s and you're going to have the Commonwealth responsible for the over-65s. So you're going to have the divides again.

SM_5

“palliative care services are concerned about being swamped” and that there are differing funding sources for chronic disease and palliative care, so balancing these to provide care is a challenge.

Training and education

Participants emphasised the need for training and education of health professionals, noting that communication skills, advance care planning discussions and information about supportive care were important educational requirements. They said that education at all levels was required, from medical students, through junior doctors, registrars, generalists and specialist providers. A number of participants said that, whilst medical students have skills training in medical school, they require ongoing support and education once they become junior doctors. Some participants felt senior consultants were good at having end of life care conversations and there should be systems in place to allow them to better support junior doctors.

Education has got to be the key issue but its education to the point of a change in culture

PM_8

So I think that there's a lot of work to be done about improving the communication skills of all health practitioners and particularly medical practitioners.

SM_12

We've done a lot of that in undergraduate work but people see bad habits when they get into clinical practice. You can learn these skills and you need to practice them and you can improve them but how do you engage senior clinicians to want to be able to do this to see that they need this skill for their work

SM_12

7.2.4. Summary of end of life care

There was a general consensus amongst service managers and policy makers about the importance of appropriate and accessible end of life care for people with advanced chronic disease and that such care is not currently generally available.

The reasons posited for the lack of such care focused around underlying philosophies of care including: a death denying society; a medical culture valuing intervention and cure over supportive care; no shared understandings of when people could be considered to be approaching end of life and inadequate education of health care professionals. All participants agreed on the vital role of ACP in end of life care, seeing it as including both ongoing conversations about the care people want as their condition advances and the documentation of those wishes. They expressed concerns about who had responsibility for initiating such

conversations and identified training and education, and increased funding and technology as key enablers for better end of life care. No-one thought the provision of end of life care was the sole remit of palliative care services.

7.3. Models of care

All participants were concerned about the inability of current models of care to meet the needs of people with advanced chronic disease. They canvassed a variety of possible approaches and models that could provide more appropriate care. One patient-focused approach recurred in discussions throughout the research: person (or patient or client) centred care. I asked all participants about the concept of person centred care in the context of end of life, and there was a wide variety of understandings of what this concept encompassed.

Participants also discussed two system-focused approaches to care: integration and care coordination. They particularly highlighted the importance of the integration of care between the primary and acute sectors and the importance of communication, but most felt that significant barriers currently exist, preventing such care integration. Care coordination was also considered a vital component of any model of end of life care, but there was no consensus about who should act as the primary care coordinator and how it could be funded. In this context, they discussed the role of general practice as care coordinator. Finally, they also evaluated existing models including general practice as the main provider of end of life care and the Western Australian Silver Chain model.

7.3.1. Patient centred care

There was general agreement that patient centred care is a holistic approach that focuses on the patient, their family, and their specific needs (physical, emotional, spiritual and psychological). The differences between this and consumer directed care and patient driven care were discussed as was the importance of patient centred care as a tool for empowerment. It was suggested that the patient could be *“the person in the middle of it all who in a way controls the traffic between the GP and the specialist rather than being kind of tossed between the*

*Well if the question of patient-centred care is really - it's just good medicine. PM_9
I mean person centred care should be about meeting the needs of the person and meeting their values and their goals of care as opposed to care being dictated by clinical need or by the needs of the clinician even. I think that's really the difference. Whether it's a strictly medical model or whether it's a more holistic model that always keeps the person at the centre. I think also what's nice about person centred care is that it enables*

two". Another aspect of patient centred care was identified as ensuring the patient has access to information to enable them to make informed decisions about their treatment, but another participant warned that this was quite challenging "*because I think it assumes that a high degree of health literacy ... it assumes a high degree of kind of motivation and control and we all know that there's a diversity in that.*"

One caution was that patient centred care "*doesn't necessarily mean that the patient gets everything they want, but if there are impediments to them getting through the system it should be made as easy as possible for them.*" One participant warned that we should talk about 'person-centred' rather than 'patient centred' because "*as soon as you say patient you're saying it in relation to a clinician so already it stops being a person*". Another participant said that actually implementing patient centred care was very difficult in the current system and that perhaps it was more about a "*sense of teamwork*". They emphasised that there was no patient centred care without clear and detailed conversation and ongoing communication.

7.3.2. Integrating care

It was generally agreed that end of life care services need to be much better integrated. The first step in achieving this was identified as "*the knowledge of what systems are there*" including services in both the acute and primary care sectors. Participants noted that there are multiple providers of care at the end of life, but there was no consensus on which specific services should be integrated, who had responsibility for integration, how this could be achieved and what levels of integration were required. It was suggested that one health care

you to look beyond the person with the terminal illness to also include their loved ones.

PM_6

I think maybe when I was talking about the patient centeredness around that, before, I mean maybe what else I mean is actually the sense of teamwork....Yeah, the patient is part of the team but the patient's outcome being the goal for the team. SM_7

So I think patient-centred care is - that's where it starts, is with critical conversations in environments where they are conducive to being held and facilitating a patient to actually say what it is that they want based on their values and their beliefs, then having the facilitation skills probably to check the understanding within the family. SM/PM_10

....before you can facilitate those components of care, actually a service mapping is required. SM_1

....there needs to be at least one person that is generating a plan and that plan being shared so that the various components of care are either working towards or can influence the modification of that plan if it's not meeting its needs. SM_1

....there are still - this problem of the specialisation of medicine and the huge number of specialists in all sorts of areas and handing

professional should have responsibility for overall integration of an individual's care, as generally, nobody took on this role.

Taking responsibility for care was closely linked to communication and many participants noted that: “*very rarely is there actual discussion about ‘what do you think about this?’*” and one said that communicating across sectors (particularly between the acute sector and general practice) was really challenging. A number of participants discussed the difficulty of integrating care between general practice, specialists and palliative care for end of life care and the value of the case conferencing process in general practice.

Participants highlighted the importance of informal contacts between health service providers, and felt the current system has made these increasingly difficult: “*but so much palliative care with specialists happened in corridors and car parks.*” They linked this issues such as the increasing specialisation of medicine and a lack of recognition of the skills of GPs.

Integration initiatives around the aged care/palliative care interface were noted, specifically around advance care planning and mutual protocols. The fear that palliative care services would be overwhelmed by having to take on every dying patient was mentioned, as was the scope of the need for care which cannot be met: “*So the more you start offering the more you'll need to offer. It's not like you actually get to a point of having met the need*”. Participants expressed concern that the current system does not allow for integration – specifically that palliative care services are still focused on a cancer model and that bringing in palliative care services in for

things over to each other, and nobody taking complete control of the whole patient.
PM_9

I think it's certainly conversations that need to occur probably at a three-way level, which is those representing general practice, those in terms of chronic disease management specialties as well as palliative care specialists around how do we get some shared understanding. In some cases it might need to be disease-specific.
SM_1

There used to be a college of physicians where everyone got together. Now you only go to specialist meetings. You go and meet other specialists in your own area and it's not good.
PM_9

*....when you work in the acute, your work stops as that person leaves the door and then the same with Community, the same with aged care. SM_5
But if they are talking about coming in, doing an episode of care and then discharging people, where's the integration and where's the continuity? I believe there's a lot of scope to work out.*
PM_8

specific episodes could lead to a lack of continuity of care.

A number of barriers to integrating care were identified, particularly around systems issues, such as the funding and responsibility split between state and commonwealth and the silos between specialist disease services and between sectors: *'It's systematic isn't it? People just don't maintain those linkages between the different links in the chain'*. This was closely linked to discussions about 'silos of care' which were highlighted as a particular issue for people with multi-morbidities. It was also suggested that it would be useful if there were electronic 'tripwires' i.e. *"in a hospital setting that someone that's known to quite a few teams would flag if they've been admitted and that you might have a review"*.

The importance of having appropriate governance and policy frameworks was raised, with participants saying that the different governance frameworks of primary care, acute care and other sectors involved in end of life such as disability and ageing made integrating care and the development of cross-jurisdictional policy very complex. Providing forums to bring together the various sectors was suggested as a way to break down barriers as was educational initiatives such as the Program of Experience in the Palliative Approach (PEPA)^{xxi} which facilitates GP placements in palliative care services.

7.3.3. Care coordination

Participants considered care coordination a very important aspect of end of life care, particularly access to

*I think it is an issue, the fact that the funding responsibility does split between the commonwealth and the state and territory governments does pose a barrier to a full, formal integration. PM_3
....the other barriers to this is that some of it is federal government, some of it is state government and that some of it's hospital and some of it's community, and then is it primary care, general practice or specialist care. SM_12
But I don't know how you break down the silos within the big organisations. SM/PM_10*

*I think through policy and through education and consistent change management. You've got to set it at the top and you've got to make sure that it's supported and goes down.
The best way to foster that is shared education, shared facilitation of pathways, all those things that you do as joint activities rather than individual systems. SM_5*

So I think that somebody who has an oversight, coordinating care role is very important and

^{xxi} *"The Program of Experience in the Palliative Approach (PEPA) forms part of the Palliative Care Education and Training Collaborative. Specifically, PEPA aims to enhance the capacity of health professionals to deliver a palliative care approach through their participation in either clinical placements in specialist palliative care services or interactive workshops."*
<http://www.pepaeducation.com/about/what-is-pepa.aspx>

someone who knows a person over time and can identify subtle signs of deterioration or when extra equipment or services are needed. They felt that this role should not be to take over care, but rather make sure that “*that people had the resources around them*” and be able to spend the time required to access those resources. One participant thought the role should encompass advocacy and assist people to navigate the system, and suggested this was the point of consumer directed funding.

There was considerable discussion about whether the GP was the most appropriate person to co-ordinate care. A number of participants thought that general practice was the most appropriate setting for care coordination, but the GP was recognised as generally not having enough time to do this. They noted that care coordination is very time consuming and there is not currently a viable remuneration option for either GPs or practice nurses.

A variety of other health professionals/positions were identified as possibly taking on responsibility for care coordination including GP liaison nurses in hospitals, hospital based respiratory and community heart failure nurses, the RDNS and palliative care nurses. A number of concerns were raised about palliative care nurses taking on this role, noting that “*it's unrealistic to expect one person to be able to do everything and I see that with palliative care nurses*”. Some participants suggested that care coordination was traditionally seen as the role of palliative care nurses, but taking on such a role greatly increases the potential for burnout and for “*stepping on people's toes, alienating people*” and such a role could actually disempower patients and be paternalistic.

somebody who can see them at home.

SM_12

I think the one critical thing is having somebody who could help coordinate the care of people with chronic diseases at the end of life or to look at end of life issues. **SM_12**

But we don't have the time to do the care coordination. That was assumed to be our role, but it's really time consuming.

SM_11

But a general practice would say it's a business. How do we make any money out of it?I think you would struggle to get general practice on board for employing them as a care coordinator for a practice nurse. They'd say there are other roles for a nurse to be doing. **SM_11**

But I think other disciplines look to care coordination. I'm thinking about palliative care nurses again, it's just the panacea for everything.

SM_7

....I think if we focus just on dedicated care coordinators it potentially can abdicate responsibility from the rest of the care system, and say oh well, just leave it up to the care coordinator, whereas I think it's a shared responsibility.

SM_1

7.3.4. Existing models

There was considerable discussion around existing and appropriate models of end of life care for people with advanced chronic disease. Much of the discussion focused on the role of general practice and the diversity of general practices that is now the norm. Participants suggested that “*the ideal is that general practitioners should be involved in end of life care as much as possible*”, but many identified barriers to such care, including: a lack of time; the changing nature of general practice; a move away from home visiting; increasing numbers of part time GPs; the fee for service model and a lack of appropriate remuneration. They said that a number of people do not have a GP: “*they're people that have never had a GP*”. However, a number of participants noted that GPs who did undertake palliative care really valued this as a key part of their practice and they often did home visits and extended care without remuneration because “*it's incredibly rewarding and it's an incredibly rewarding part of our practice*”.

Participants commented on the increasing corporatisation of general practice. These practices are focused around more acute, walk in, walk out medicine with little capacity for the long term, time consuming care advanced chronic disease requires. They also suggested that using bulk billing as an indicator of good general practice rewards the wrong things – i.e. episodic rather than continuing care. The current workforce configuration in general practice was questioned, with funding models not allowing sufficient flexibility, particularly for practice nurses. Models such as capitation and enrolment in GP practices were discussed but most participants felt that such changes would not be

*I just don't think general practice is set up anymore to encourage the things that are absolutely necessary to support end of life care SM_7 I actually do believe that primary care is a really good place to centre the care around, mainly because of the general - a generalist will look at the whole health requirements. SM_1
....it's part of the contract we have with our patients and you do it and it's incredible. Then you look after a person, they die, you then see their children or their wife or whatever and the cycle continues and I think that is what makes old school practices fantastic. SM_7*

*....we've encouraged a sort of version of general practice where we're kind of rewarding almost the wrong things, or promoting the wrong things but then we're criticising GPs when they won't do end of life care for someone they may never have seen. SM_7
But I mean capitation in its basic sense is sort of an idea of continuity, that you've got a disease and you can only see me about it. I mean maybe rather than having to legislate for capitation maybe we should look at systems that build continuity. SM_7*

generally accepted. One participant noted that it was possible to use Medicare and Enhanced Primary Care (EPC) item numbers (now called Chronic Disease Management item numbers)^{xxii} to provide end of life care, but questioned the ability of such funding models to provide optimum care and suggested that *“Rather than going: this is the optimum model and this is now how we have to fund it. So it's back to front, so we try and fit what we think is the optimum model into the current structures and it's challenging, it's really hard”*.

Participants discussed role definition and how much care palliative care services and specialists were actually willing to share with general practice. They noted that whilst some GPs are willing to undertake end of life care, the majority are not and there was some concerns over GP knowledge and skills in palliative care. It was also noted that *“One of the fundamental tenets of the plan [SA Palliative Care Services Plan 2009 – 2016] is that primary care will be the main provider of palliative care and yet there hasn't been any organised strategy across South Australia to make that happen as yet.”* GP access to hospitals was cited as a barrier to care, as was communication between specialists and GPs.

A number of participants highlighted a model in Western Australia developed through the Silver Chain organisation as providing high quality, integrated and cost effective end of life care. Participants felt that this model was very supportive of helping people to die at home and the team based nature of the model and the inclusion of salaried GPs was very useful. However, one participant sounded a caution that this particular model was somewhat restricted in terms of people accepted into

I think education has got to be the key issue but it's education to the point of a change in culture.

PM_8

I think it should be general practice, I think. I'm aware of - I'm tied up in all sorts of different organisations and discussions about nurse practitioners and the role of the GP as gatekeeper and your practice of that and all that sort of stuff. So I know there is a whole bunch of stuff around that. But by and large general practice is the right location.

SM_11

I am really taken with the Silver Chain palliative care model; it's very impressive. Having met a number of the team, the nurse practitioners, the social workers, the GPs, the whole team that does it - they've got the skill set of everybody that they need.So that kind of more regional model, where there's a whole team, everybody is on a roster and we're covering that whole community, makes a lot of sense to me. But it's not cheap.

SM_2

^{xxii} See Chapter 2, Section 2.5.2 for an explanation of Medicare

the program and may not be suitable for the much larger group of people with advanced chronic disease.

7.3.5. Summary of models of care

Participants agreed that an appropriate model for end of life care should be person centred, integrated across primary and secondary care and operate across disease silos to ensure the coordination of care. However, there were different understandings of what was meant by patient centred care and how such a care model could be implemented. All participants agreed that there were significant systems barriers to the integration of care including uncertainty about where the final responsibility for care would lie, little clarity around the role of palliative care services, split funding responsibilities between the state and federal governments and appropriate governance frameworks. There was also no clarity around how care could be coordinated and who would do it.

7.4. Changing the system

All participants discussed options for changing the system. Four key areas were identified in which change could be effected: care settings; governance and funding; health care practitioners and consumers. There was general agreement that although end of life care was currently focused in hospitals, acute care was not the appropriate setting. Whilst participants identified that a ‘one size fits all’ approach was not applicable, they suggested that: “it’s important that we continue to work together to try and get that seamless approach”. They emphasised the importance of collaboration between the acute and primary sectors and between speciality and general practice, although they also noted that hospital engagement strategies to make specialties aware of the importance of palliative and supportive approaches alongside interventions were important. They saw education as a key driver of such change. Another key

....but I think it's a major re-design. It's a re-design in care issue. SM/SP_10

....the acute hospital system would have to completely and utterly change. The acute hospital system is not set up to deliver palliative care and nor is it set up really to deliver person centred care as it currently stands. I mean if you think about it everything about the acute system is designed to get you well again. PM_6

Hospital engagement strategy is something that we are yet to really see come alive. That's where you have the palliative medicine perspective at any of those ward rounds or team meetings where people with end-stage kidney disease are actually having robust conversations about where to from here, to dialyse or not to dialyse. SM/PM_10

For specialists, hospital-based specialists, to actually acknowledge and/or recognise the skill set of primary care physicians and health

driver was identified as quality and safety, including national standards: *“everything we should do should be about quality of care and the safety of our patient. The objective should be: do you know how?”* Participants thought that the concept of patient centred care was vital in the development of an appropriate model of care and emphasised that patient centred care must be flexible and include the carer.

All participants thought that culture change in health professionals was very important, and suggested: *“that we need to be creating formal hybrids of all the chronic disease specialist people with palliative care”*. They identified that getting the different disease group professionals to advocate for change was important but recognised that this could be a long term process. They suggested that it was the role of palliative care professionals to educate generalists and that developing processes to allow communication and collaborative processes between the acute and community sectors would be beneficial and encourage health professionals: *“Instead of looking at it as a turf war, look at it as enhancing each other.”*

Policy support and governance were identified by participants as important drivers of change, including the development of national standards and guidelines. They recognised that different jurisdictions impact on the ability to provide integrated services, but *“getting that to actually happen will be quite challenging.”* Bringing people together at a higher level in forums to discuss greater integration was also identified. Participants further suggested that changing funding mechanisms was a possible driver to support end of life care in general practice, particularly using Medicare to support new

professionals. With adequate resourcing actually we can look after a lot of these patients and they don't need to go to hospital. They don't need to spend their last days dying in hospital.

SM_2

So your heart failure nurses, your respiratory nurses, your renal dialysis nurses - giving them a portfolio in end-of-life care, bringing them into a service like this, providing them with some skilling up and some training so that they can go back into their own cohorts and be the beacon in the dark almost.

SM/PM_10

Again these are quite high level policy issues that there's been an awareness of but there hasn't been a formal response to those things at this stage.

PM_3

....if you could pool that funding with Medicare funding, with maybe a little bit of additional funding, you could then create exactly that kind of model.

SM_2

Obviously rewarding for type of complexity under a Medicare funded system is valuable.

SM_11

models of care such as regionally based end of life care teams based in primary care organisations (such as Primary Health Networks – PHNs).

The other vital strategy for effecting change in this area was consumer engagement. Participants agreed there needed to be more consumer education about the issues associated with end of life care for chronic disease and noted that consumer demand for such care would be a key driver: “Often that's quite an effective way of driving change by turning up at your doctor and saying why am I not having x, y or z”. Supporting advocacy by consumer organisations for better access to care and better understanding of the role of palliative care was also suggested. Participants also advocated for better recognition of carers as part of the care team as well as a greater use of volunteers to help support end of life care.

Clearly we're not doing this the best possible way, so let's work out then as a community of clinicians or of consumers about what we think needs to happen to change that. Clearly empowered consumers will also help. SM_2

People need to be able to access palliative care trained volunteers. That's what we believe....Part of a discussion the other day was that people could access those volunteers without having to be part of a palliative care service. So there have got to be mechanisms in place to support those volunteers. PM_8

7.5. Summary

Policy makers and service planners recognised that the health system, as it is currently configured, is not meeting the end of life care needs of a growing number of Australians. Whilst there was consensus about the reasons why the system may not be meeting these needs, there was little clarity around strategies to bring about change and the systemic changes that need to occur.

Participants thought that the underlying death denying culture of the community was a problem as was the interventional focus of medical care; they agreed that culture change through ongoing education, better communication and more focused policy development was required. They also thought a vital driver of policy change was raising community awareness around the importance of advance care planning and end of life care conversations.

Although integration was seen as important, there was no real agreement about what an integrated service might look like and there were differing understandings of the concept of patient centred care. The role of specialist palliative care services was very unclear, with some participants feeling more funding and a

larger workforce was required to help palliative care services to deal with the large numbers of people with advanced chronic disease whilst also saying that palliative care was part of the role of all health practitioners. Although all practitioners acknowledged the skills and expertise of palliative care practitioners, their role in the provision of integrated and flexible care models for advanced chronic disease was not so apparent. It was generally agreed that general practice and primary care should play a key role in end of life care but there are considerable resourcing issues (including funding and workforce) to be resolved before this can occur effectively.

In these last four chapters, I have answered my first research question: *“How can the health system provide care that meets the needs of people with advanced chronic disease and their carers/families?”* I have shown that the current system does not adequately support people with chronic disease approaching the end of life and their carers/families. Nor does it appropriately address their end of life care issues. Whilst all the patients in this research had access to GP and specialist care for their chronic diseases, they were not able to access appropriate end of life care. The multiple sections of the health system, the split funding and the variety of policies at a federal, state and local level rarely interface and interactions between the various silos in the health system are minimal. This caused significant difficulties and inequities in access to care for people with chronic disease. Despite these problems, all participants however, were able to articulate strategies that would provide care that met the needs of people with advanced chronic disease.

Whilst all participants knew there were problems with end of life care and had ideas for how to improve it, the system itself shows little sign of changing. We need an in depth understanding of why the system is currently functioning as it is and why it has not been able to change if we are to intervene to change it. Thus, the next two chapters will take the results of the systems analysis I undertook in this research and use complexity theory to help to understand why the system functions as it does and to answer the second of my research questions about where to intervene to change the system.

PART 3. Interpretation, discussion and conclusions

In much the same way that chronic diseases are managed in silos of specialist care, so the development of end of life care for people with advanced chronic disease has been considered separately by individual components of the health care system in Australia: hospitals, palliative care services, primary care,^{xxiii} community care, disability services and ageing. There is ample evidence demonstrating that end of life care must be integrated, multidisciplinary, person centred and primary care based and many of the health service providers, planners and policy makers who participated in this research nominated such a model as the most appropriate way to support end of life care. Despite this, the results of the systems analysis reported in Part 2 demonstrate that there few linkages across sectors and no clear pathways for end of life care.

In the previous chapters, I used systems thinking as the theoretical framework to develop a detailed picture of how the health system currently functions for people with chronic disease approaching the end of their life.²⁶⁷ Using a systems thinking approach allowed me to take a very broad view of the services provided, the variety of systems and sectors involved in providing that care and the culture of those organisations and health professionals. However, identifying exactly *how* the system is functioning was only the first step in answering my two main research questions. The next step was to understand *why* the health system functions as it does and this is the focus of the final section of my thesis.

In Chapter 8, I draw together the results of my research to answer research question 1 and questions 1a-d:

1. *How can the health system provide care that meets the needs of people with advanced chronic disease and of their carers/families?*
 - a. *How does the health care system currently support people with advanced chronic disease and their carers/families as they manage*

^{xxiii} I nominate primary care, rather than the more specific focus of general practice, as the role of Primary Health Networks, community based palliative care services, private health practitioners and private health insurance are currently not clear and it may be that differing groups in primary care can play key roles in the provision of end of life care.

their chronic disease and address the issues required for end of life care?

- b. How appropriate, available and accessible is end of life care for people with advanced chronic disease?*
- c. How do the complicated entities of chronic disease and palliative care interact in the Australian health care system at a national, state and local health service level?*
- d. Why does the health system function in the way it does to provide end of life care?*

In the first section of the chapter, I answer questions 1a -1c and demonstrate how the health care system is functioning for people with advanced chronic disease and examine the type of health system and models of care that can provide an equitable and effective system which meets the end of life care needs of people with advanced chronic disease. I then use complexity theory as the interpretive framework to answer question 1d and explain ‘why’ the system functions in the way that it does. I draw all these together at the end of the chapter, to answer question 1 itself.

In Chapter 9, I look to the future and answer research question 2:

- 2. Where are the effective points of intervention to change the system and support and empower patients?*

Knowing why the system functions as it does enabled me to identify the most appropriate points of intervention for short term change and those areas which will require more sustained effort. I identify specific strategies for changing the health system to better support end of life care and I finish with a series of recommendations to support such system change.

Chapter 8. Meeting the end of life care needs of people with advanced chronic disease in Australia today.

8.1. Introduction

The patients and carers who participated in my research clearly identified that many of their care needs were not being met by the current health system. There was also consensus amongst service providers, planners and policy makers that current models of care were not generally meeting end of life care needs for people with advanced chronic disease. In this chapter, I will use systems thinking and complexity theory to draw together the results of my literature review, policy analysis and systems analysis to provide a detailed picture of how the health system is currently operating for people with chronic disease as they approach the end of their life.

I begin with an overview of my thesis, summarising how the system is functioning. I then explore why it is functioning in the way it is. This will enable me to answer my research questions about the model of care which best supports end of life care in chronic disease and where we should intervene to change the system. I will suggest that many of the contradictions I identified in my analysis can be explained if one recognises that the health system operates as a complex adaptive system (CAS). I detail the key characteristics of a CAS and demonstrate how they are manifested in end of life care. I explore how multiple funding sources, workforces, organisational structures and cultures need to work together to meet the individual needs of patients and their carers and how a death denying society and an intervention focused health care system impact on the care that is funded and provided.

I next consider the key elements that should underpin any model of end of life care: person centeredness, care coordination and integrated care. I explore what a model of care underpinned by these three elements might look like, again using complexity theory to identify why the rhetoric about developing systems underpinned by these three elements is so different from the reality of how the

system actually operates. I suggest that any such system should be based in primary care/general practice and that this should be complemented by a public health approach. Lastly, I bring these diverse findings together to identify how we can move forward to a best practice model of end of life care in Australia.

8.2. Overview of research findings

This research began with the premise that the end of life care needs for people with advanced chronic disease in Australia are not being met. In Chapter 1, I set the scene for the research, providing the rationale for the methodology and theoretical base I chose to examine my research questions: HPSR and complexity theory. In Chapter 2, I examined both international and Australian literature on end of life care for chronic disease and identified a growing body of evidence for the need for end of life care in advanced chronic disease, the type of care that might be appropriate and a growing policy interest in this area. I noted that there is no agreed definition of the term '*end of life*' and that palliative care is becoming increasingly specialised and is often misunderstood to be care only for the dying. Whilst there is growing recognition of the importance of managing chronic diseases as they increase in prevalence and incidence, few management models actively incorporate end of life care interventions. I identified a number of barriers to implementing end of life care in the literature including: a lack of knowledge about end of life care; a lack of clear pathways and models of care; a reluctance to provide both interventional and supportive care concurrently and a death denying culture in society more generally.

In Chapter 3, I outlined in detail my research design, identifying the various methods through which I would answer my research questions. I also discussed the ethical issues associated with end of life care research and how I ensured the rigour of my research.

Chapter 4 reported on the analysis of Australian policies related to end of life care, chronic disease and ageing. The key findings included a recognition that chronic disease policies have a very different focus from end of life care policies (prevention and management vs quality of life). I argued that chronic disease policies assume that a referral to palliative care services will address the needs of people with chronic disease and palliative care policies assume that all health

professionals are willing to undertake some degree of end of life care. Of particular concern was a lack of any ageing policy which acknowledged the growing need for end of life care in an increasingly ageing Australia population and a similar lack of consideration of the likely impact of this ageing population on end of life care needs in chronic disease or palliative care policies.

In Chapters 5 and 6, I reported on the health system analysis of end of life care I undertook using the Bainbridge et al²⁶⁰ analytical framework. In Chapter 5, I focused on how patients, carers and their service providers perceived the system structure and process of care they experienced. They described an under resourced and inequitable system, with little clarity around responsibility for end of life care provision, resulting in uncoordinated and fragmented care. In Chapter 6, I identified patient outcomes from both the patient and service provider perspectives, with inequities in access to care and difficulties accessing ADL supports highlighted by all participants. A lack of end of life care conversations was reported by patients, whilst service providers reported confusion about who had responsibility for advance care planning although they recognised its importance.

Chapter 7 described the results of interviews with policy makers and service managers who recognised that the current health system is not meeting the end of life care needs of Australians with advanced chronic disease. They highlighted issues such as the education of health professionals, a need to change the culture of health professionals who are often reluctant to alter the focus of care to supportive rather than interventional care, and a death denying culture in society more generally. There was no agreed vision for end of life care or any shared understandings of key concepts such as '*end of life care*'. In addition, participants did not identify any clear delineation of roles and responsibilities. They supported primary care as the most appropriate place to manage end of life care but there was no real agreement about what an integrated end of life care model based in primary care might look like.

8.2.1. Summary of answers to research questions 1a – 1c.

The findings of the systems analysis enabled me to answer research questions 1a – 1c concerning how the current health care system functions for people with advanced chronic disease. Table 14 provides a detailed summary of these results.

How does the health care system currently support people with advanced chronic disease and their carers/families as they manage their chronic disease and address the issues required for end of life care?

Care provision for people with advanced chronic disease and their carers is sub-optimal. The need for more appropriate end of life care is widely recognised by health care professionals and policy makers, but the provision of such care is hindered by contradictory health policies, inadequate funding and the way services are currently structured. Specialist silos of care have few links with general practice or palliative care services and there is minimal recognition of the need to integrate a palliative approach with active disease management. Although advance care planning is identified as vital in supporting people as they approach the end of their life, there is currently minimal discussion of the care people may want as their condition deteriorates. Clinicians may feel that they do not have the skills to undertake such conversations and patients are often confused about their prognosis, may not know how to ask about it or may not want to know about it. Unpaid carers provide the majority of care for people with advanced chronic disease, but their role is consistently under recognised and the systems, information and resources to appropriately support them are inadequate.

How appropriate, available and accessible is end of life care for people with advanced chronic disease?

The end of life care currently provided for people with advanced chronic disease is generally neither appropriate nor accessible and specific care is often not available. The siloing of specialist services (including specialist palliative care) means there is often little coordination of care between service providers and most people cannot access psychosocial and/or spiritual support or specialised symptom control services. There are also few links between these services and general practice, which provides ongoing chronic disease management. Although there are shared care arrangements between community palliative care services

and general practice in a number of areas in Australia, people with advanced chronic disease are often not considered for this service. This means that the care provided as people approach the end of life is often fragmented and contradictory (especially if a person has multiple morbidities). People with advanced chronic disease have significant issues accessing basic care such as ADL support, especially if they are under 65 years of age.

How do the complicated entities of chronic disease and palliative care interact in the Australian health care system at a national, state and local health service level?

End of life care continues to be provided in isolated care silos so there is little interaction between chronic disease services and the services required as people approach the end of their life, including palliative care. This siloing of services means there is no shared vision for end of life care in advanced chronic disease in Australia. There continues to be confusion about who has the overall responsibility for end of life care and although general practice is the logical place for these services to come together, there is no agreement or service structures that support this. At a policy level, there is no articulation between chronic disease and palliative care policies with many chronic disease policies assuming that people with advanced chronic disease can be referred to palliative care services whilst palliative care policies promote the concept of palliative care being “everybody’s business”.

Table 14. Summary of the results of the systems analysis

System Structure	Source
The current system structure is not able to meet the end of life care needs of people with life limiting disease. It does not recognise the need to integrate a palliative approach, including the expert care required for symptom control and quality of life and the active disease management required as people with chronic disease move towards death over months and sometimes years.	Ch 2: 2.2.1; 2.2.2; 2.4 Ch 5: 5.2.2; 5.2.3 Ch 6: 6.2.1; 6.2.2 Ch 7: 7.2.1
Chronic disease policies reflect this lack of understanding with an underlying assumption that people should be referred to palliative care services when they reach the end of life, although there is no agreed definition of what constitutes the end of life period. Many policies emphasise advance care plans and documentation rather than end of life care more generally.	Ch 4: 4.2 Ch 7: 7.2.1
Current resources including funding, workforce, health services, community services, equipment and transport are inadequate and this is exacerbated by the split funding responsibilities across federal, state and local government.	Ch 2: 2.5.2 Ch 5.2.3 Ch 7: 7.2.3

System Structure	Source
Whilst the need for specific end of life care as is increasingly recognised by health practitioners, individual disease responses are being developed, perpetuating silos of care rather than the integrated approach required. This is a particular problem for people with multi-morbidities, which should be a key trigger for initiating a palliative approach.	Ch 2: 2.5 Ch 5: 5.2.2 Ch 6: 6.2.2; 6.2.3 Ch 7: 7.3
Primary care is suggested as the appropriate setting for both chronic disease management and end of life care but current general practice structures, funding, access to support services, silos of care, communication processes and workforce configurations make this very difficult.	Ch 2: 2.5.2 Ch 5: 5.3.2 Ch 7: 7.3
Process of Care	Source
There is no leadership or a shared vision for what end of life care in advanced chronic disease in Australia should look like, nor are there any generic standards or guidelines, although some specific chronic diseases such as renal disease are developing their own guidelines.	Ch 3: 3.4.2 Ch 5: 5.3.4 Ch 7: 7.4
There is minimal evidence of coordinated care for chronic disease and end of life care and few examples of a true multidisciplinary team approach to care, especially between specialist services and general practice.	Ch 5: 5.3.3 Ch 6:6.2.2; 6.2.3; 6.3.2; 6.3.7 Ch 7: 7.3.3
The potential of technology to facilitate coordinated and continuing care, provide accurate information, support patients and foster communication is recognised but its use is still minimal.	Ch 5: 5.3.3 Ch 7: 7.2.3
Whilst some specialists and GPs believe undertaking end of life care planning and assisting patients and families to access supports is their job, others do not believe end of life care is part of their role.	Ch 2: 2.5.2 Ch 5: 5.2.1; 5.2.2; 5.3.1; 5.3.2; 5.3.4 Ch 6:6.2.1; 6.2.2 Ch 7: 7.2.1; 7.2.2; 7.3.2; 7.3.4
Although some education on end of life care is occurring in undergraduate medical programs and physician training, the practice students are exposed to when they work in hospitals has a major impact on what they perceive to be their role, and often appropriate end of life care for people with chronic disease is not modelled. There is very little continuing education in end of life care and having end of life conversations for any health professionals.	Ch5: 5.3.1; 5.3.4 Ch 7: 7.2.3
Most people are able to access care, but the quality of care and levels of access vary markedly. Patients reported high levels of trust and satisfaction with their care providers. Service providers recognised the shortcomings in the system and attempted to identify strategies to allow appropriate patient care.	Ch 4: 4.2 Ch 6: 6.2.1;6.2.5
Patient Outcomes	Source

<p>The need for access to expert psychosocial support and symptom control for advanced chronic disease is not generally recognised or addressed</p>	<p>Ch 2: 2.2.1 Ch 6: 6.2.1; 6.2.3; 6.2.4; 6.2.7; 6.2.8 Ch 7: 7.2.1; 7.3</p>
<p>The biggest issue for people as their disease progresses is access to support for ADLs. These are difficult to access, restricted in terms of time available for care and numbers of caregivers, inconsistent in quality and sometimes unreliable. Access to transport is also a key issue.</p>	<p>Ch 4: 4.2 Ch 5:5.2.2;5.2.3 Ch 6:6.2.1; 6.2.5</p>
<p>Although many health professionals recognise the importance of end of life care conversations, such discussions are still uncommon and so patients and their carers are left with uncertain prognoses and unresolved fears. A lack of advance care planning also means that interventional care goes on long after any benefit is achieved and unrealistic expectations of cure and longevity are not addressed.</p>	<p>Ch 2: 2.4; 2.6.3 Ch 4: 4.2 Ch 5:5.2.2;5.3.3 Ch 6:6.2.2; 6.2.6; 6.3.8; 6.3.10 Ch 7:7.2.2</p>
<p>The role of carers continues to be largely undervalued. Many health professionals recognise the importance of the carer and the role they play in supporting and coordinating the care of people with advanced chronic disease, but the systems, information and resources to appropriately support them are not currently adequate.</p>	<p>Ch 2: 2.3.4 Ch 5: 5.2.2; 5.2.3 Ch 6:6.2.1; 6.2.2; 6.3.6 Ch 7: 7.4</p>

By bringing together the evidence from the literature review, the policy analysis, the experience of patients, carers and service providers and the data and perceptions of the policy makers and service managers, I demonstrated that the current health care system is not adequately supporting people with advanced chronic disease; that the care provided is often not appropriate, available or accessible; and that there are few intersections between end of life care and chronic disease management processes at either a policy or practice level.

8.3. Why does the health system function as it does?

A description of how the health system is currently functioning for people with advanced chronic disease is not enough to identify how the health system can actually provide appropriate care and where we can best intervene to achieve those changes. In this final part of my thesis I use a systems thinking framework to bring together and make sense of the many complex factors and contradictions impacting on how care is designed, implemented and experienced for people with advanced chronic disease. First I show how end of life care can be seen through the lens of a CAS. Then I examine the implications that looking at end of life care in this way has, in terms of the mistaken assumptions it makes plain, the

confusion about when end of life begins, and the dissonance between chronic care management (CCM) and a palliative approach. Finally, I consider how using complexity theory can illuminate our understanding of the use of advance care directives.

8.3.1. Complexity theory and end of life care

The systems thinking framework I chose which brings my various analyses of the end of life care system together, is based on complexity theory. Complexity theory provides a valuable framework for considering the many factors impacting on how care is designed, implemented and experienced.⁴¹ In this section, I will demonstrate how the current Australian health system for people with advanced chronic disease functions as a CAS. This will enable an understanding of why the system functions as it does and therefore how effective strategies for change can be developed.

End of life care in Australia is provided at the interface of three very different models of care in the acute, primary and community sectors:

- **Chronic disease management** which focuses on systematic care, self management and interventions, but has developed few appropriate systems for people with multi-morbidities;
- **Palliative care** which has traditionally been cancer focused, mainly concentrating on the last days and weeks of life; and
- **Ageing** which encompasses much more than health, but where health is a key issue, impacting significantly on quality of life.

Very few links exist between these three different models of care, and, although there is rhetoric around the importance of integration and coordination of care across the health system, the reality is very different. Sturmberg et al²⁶⁸ suggest *“that the health portfolio is one of many disconnected segments at the policy level. In addition the health portfolio itself is segmented into many discrete disease/condition-specific silos. Each has its own budget line, promotes its own agendas and priorities and competes against others in the continuous competition to gain/maintain funding”*.^{p205} The result of such fragmentation is a system where the core drivers of service provision are budget outcomes and/or disease specific clinical outcomes. A person centred approach which requires integration of care,

flexibility of care provision across silo boundaries and an emphasis on quality of life conflicts with these drivers. My research reflects this fragmented and competing system in the provision of end of life care for people with advanced chronic disease in Australia in both current policies and in the care experienced by patients.

8.3.2. End of life care as a complex adaptive system

The relationships between the different parts of the health system and how they interact with each other are key to understanding how to support system change for people with advanced chronic disease.⁴⁸ In end of life care, multiple funding sources, workforces, organisational structures and cultures must work together flexibly to meet the individual needs of patients and their carers. The varied results that such a complex web of service provision provides for different patients can be understood if the systems providing care are considered complex adaptive systems, embedded in larger systems, but responsive to local contexts and each constantly changing and evolving.⁴¹ In addition, end of life care involves complexity at a societal level as well as at a systems level, because death and dying are part of the fabric of society, even though society finds death a difficult subject.

In Chapter 1, I explained complexity theory and described the basic characteristics of a complex adaptive system.^{35,40,41,269} Drawing on the results of my research, Table 15 provides examples of how these basic characteristics can be applied to the health system when considering end of life care for chronic disease.

Table 15. Complex adaptive system characteristics of the health system applied to end of life care

Complex Adaptive System Characteristics	End of life care examples
The agent and the system are adaptive over time.	Adaptation can be perceived as positive or negative, and systems will adapt to support their in own best interests. Thus, from more generalist beginnings, the health system has developed silos of care for individual diseases which strongly resist change, even with the need for integrated care for the increasing incidence of multi-morbidities
Emergence: the behaviour of systems is not a property of any single part of the system, but comes from the interactions of many parts of the system, as all elements of the system are connected in some way.	Although palliative care is promoted as ‘everyone’s business’, system functions such as funding, education, structures and incentives all interact to ensure that end of life care is still seen as only the business of palliative care.
Feedback loops: when an output of a process within the system is fed back as an input.	Although health professionals are encouraged to complete advance care directives with their patients, there are rarely systems in place for other health care professionals to access written documents. Thus, patients often receive care they do not want because their directive was not available. Once health professionals experience this a number of times, they may begin to refuse to complete advance care directives as they believe they will not be accessed.
Systems are embedded within other systems and co-evolve: a system is influenced by other systems to change and also influences other systems to change. ^{44,45}	Specialist care, primary care and palliative care are embedded in hospitals, health services and the broader health care system: e.g. political changes can result in health system reform which impact all services, including palliative care services.
Phase transition events that happen when a change reaches a “tipping point”.	The growing cost of treating increasing numbers of specific chronic disease such as diabetes and CVD pushed governments to develop chronic disease management and prevention programs, but no tipping point for prioritising end of life care has yet been reached.
Agents’ actions are based on internalised rules: “The lens that we use to investigate any phenomenon has a profound effect on what we see.” ^{47 p.83}	When health professionals look at someone with end stage COPD, do they see a chronic disease that has to be managed or a person with advanced disease who needs a particular series of supports to ensure quality of life?
Attractor Behaviour: people will act in ways that conform to their priorities and inner beliefs.	Health professionals see that providing a cure is the purpose of health care and so continue with aggressive interventions for advanced chronic disease rather than move to supportive care and an acceptance that people are approaching the end of their life.

Complex Adaptive System Characteristics	End of life care examples
Tension and paradox are natural phenomena not necessarily to be resolved: Competition and disagreement can lead to new learnings and interventions: ⁴⁴	Multidisciplinary teams have been shown to provide the most appropriate end of life care and within those teams, each profession approaches care a little differently. The coming together of these differing views and professional experience can lead to better care.
Inherent non linearity: small changes can have large results and vice versa.	Access to services and quality of care can be quite different in the same health service, depending on age, diagnosis, socio demographic and health literacy status: e.g. major changes to the structure of palliative care services in urban area may have little impact in a rural area.
Inherent unpredictability: different combinations of agents can lead to the same outcomes.	A major barrier often cited by health professionals in identifying if someone is approaching the end of their life is the unpredictability of the trajectory of different chronic diseases, with an associated unwillingness to develop systems that encompass such trajectories.
Inherent Patterns: although you cannot predict specifics, it is possible to make general statements. ⁴⁶	Although the pattern of decline for each person with advanced chronic disease might be different, they will all decline and they will all need some level of supportive care.
Open to environment: a system continually interacts with the environment	Death denying societies and a medical culture which focuses on intervention and cure mean that funding and health culture care services favour interventional rather than palliative care.
Sensitivity to initial conditions.	End of life care began as palliative care, being a speciality built around the needs of people dying with cancer and it is still essentially structured to meet those specific needs.

My analysis in Chapters 5, 6 and 7 identified a number of contradictions between the care experienced by people with chronic disease and the care that health professionals, service planners and policy makers thought they were receiving. This raises questions about the differences between the rhetoric and the reality of end of life care provision including:

- Why was so little being done to effectively address the existence of silos of care and the problems resulting from this, despite a widespread recognition of this problem?

- Why did so few patients have conversations about end of life care when all service providers, planners and policy makers identified this as being so important?
- Why was it so difficult for people with severe disability to access care in the community regardless of age, to allow them to be cared for at home?
- Why was there little recognition of the constraints in general practice which impact considerably on their ability to provide end of life care?
- Why was the rhetoric around the importance of person centred care not reflected in the actual care provided, particularly in relation to the importance of carers and families?

To help to answer these questions, I have applied the characteristics of a CAS described in Table 16 to the system description developed from my analysis to help me to better understand how and why health system elements interact, or do not interact, with each other to provide end of life care. I first needed to understand the internalised rules (i.e. the norms, values, expectations and beliefs) of the various health professionals working in chronic disease and end of life care: i.e. the lens they were using to view service provision.⁴⁷ This lens is informed by personal and professional cultures, organisational knowledge and by the assumptions people bring to a situation.⁴⁷ The systems analysis I undertook allowed me to identify a number of assumption operating for health professionals and these assumptions impact strongly on how they see their role and the role of other service providers and they underlie the provision of care for people with advanced chronic disease in Australia:⁴⁷

- *Palliative care services are the most suitable care service for people with advanced chronic disease and these services have the capacity to enrol these patients as required.* Non-palliative care health professionals perceived that palliative care services had better access to services such as ADL supports, equipment and extra care and this was an often cited reason for referral. However, when patients discussed their care needs, very few required the specialist knowledge and expertise of palliative care professionals, except sometimes in areas such as symptom control and pain relief. Chronic disease policies at state and national levels included this

assumption. Palliative care services reported concerns they would be “overrun” with people requiring care and also suggested that palliative care services may not have the specialised knowledge required to care for specific chronic diseases.

- *People with advanced chronic disease can easily access the care they require at home.* Specialists and health service providers recognised their patients’ need for ADL support, transport and 24 hour care, but some service providers seemed to feel that once a referral was made, services would automatically be provided. However, significant delays in assessment and accessing services were reported and many health care providers commented on the inequity of access for people aged under 65 years. Once people did access care, the available services were limited unless patients had extra financial resources.
- *There is adequate support available in the community to allow people to be cared for effectively at home.* This is closely linked to the above assumption: it was assumed that access was easier than it actually was and that adequate community services are actually available. Much ADL care was brokered by service providers who engaged private or NGO organisations to provide care. There were mixed reports of the adequacy of care provided by such organisations including not attending to provide care, not undertaking the agreed care, poor quality of care and not responding to patients’ needs and wishes.
- *General practice can and will provide end of life care for the majority of Australians.*

Whilst the National Palliative Care Strategy and the literature review undertaken in this research emphasised the important role that general practice should play in end of life care, the GPs and some specialists in this research identified that general practice is not structured or resourced, and does not currently have the workforce, to undertake end of life care for the majority of patients with advanced chronic disease. Many GPs do not want to undertake this work and there is also a significant concern amongst GPs that they do not have the time required to undertake best practice end of life care. GPs in this research identified that current Medicare and Chronic Disease Management arrangements are not adequate to finance comprehensive end of

life care, although some GPs are attempting to do this. Another issue impacting on the provision of end of life care is the growing corporatisation of general practice, where the longer consults, care coordination, home visits and after hours care required by many people with advanced chronic disease are not generally accommodated.

- *Patients only have one serious chronic disease so they only ever need the disease they are admitted to hospital for treated and reviewed.* Throughout the research period, a number of participants in this research were admitted to hospital for an exacerbation of one of their diseases, and almost all patients had multi-morbidities which had implications for treatment, but which were not managed on admission. One participant with multiple sclerosis (MS) was admitted with pneumonia and had no review of her MS whilst another participant with hypertension, heart and renal failure as well as severe anxiety and gastrointestinal problems was admitted with a deep vein thrombosis (DVT) and not reviewed by any specialist other than a gastroenterologist. This was also an issue for patients attending emergency departments, where the presenting problem was addressed, but there was no consideration of other co-morbidities. One patient experienced adverse events because the interactions of drugs were not considered. The cumulative effects of having multiple chronic diseases were also not considered – except in the instance of one patient aged <65 years who noted that getting PD as well as her heart failure was a real “winner” for her in terms of accessing services.
- *Pathways of care developed at a state or federal level will work at a local level.*

Chapter 2 highlighted the complicated structure of funding and service provision for healthcare in Australia, which is split across federal, state and local levels. Participants in this research explained how this impacts at a local level, with the need to juggle a variety of funding sources to provide care and the difficulties for rural health services in trying to comply with specific care pathways developed in urban areas. Complexity theory notes the importance of context and in Australia, programs and services are often devised at a state level for urban settings, but do not really consider rural, remote and peri-urban contexts. Services will evolve differently in different areas, but funding

rules, reporting requirements and service design do not really support these differences. Rosstad et al²⁷⁰ highlight the challenges in developing care pathways involving specialists and primary care, noting that disease specific pathways, which are the focus of many pathways in Australia, are not feasible or sustainable. Rural GPs are much more involved in hospitals than are their urban counterparts, and there are often much closer relationships between rural palliative care services and GPs. This is not always the case and funding mechanisms in larger rural areas may not support such collaborative work. The impact of split funding and responsibility for primary and acute care is reflected in the lack of joint planning and attempts at cost shifting.

As indicated in the commentary above, my research has demonstrated that the assumptions above are inaccurate. Arndt and Bigelow²⁷¹ note that, because a CAS is non-linear, an initial incorrect assumption can have major impacts on the system. Complexity theory tells us that people will act in ways that reflect their inner beliefs and priorities (attractor behaviour) and so the care they provide will also reflect such beliefs.²⁷² If health professionals, service managers and policy makers are planning, developing and implementing end of life care influenced by inaccurate assumptions such as those noted above, then the resulting health services will not be able to appropriately address patient and carer needs.

As well as the incorrect assumptions underlying the provision of end of life care, another important way that the values and beliefs of health professionals impact significantly on care provision comes from how they understand when someone can be considered to be approaching the end of their life. This is important because a lack of a shared understanding of when care should shift from an interventional to a supportive focus means that referrals may not be made to appropriate services, communication is impaired and end of life care conversations are not initiated or continued. No participants in my research (patients, carers, health service providers, managers and policy makers) had a shared understanding of when people could be considered to be approaching the end of their life and there was little recognition that this lack of understanding was resulting in minimal communication between chronic disease, palliative care and general practice services.

This absence of a shared understanding of the meaning of end of life was reflected in my research in a number of ways:

- *Patients had trouble accessing services because their death was not considered imminent – i.e. they did not yet require terminal care.* If end of life is considered to be the same as terminal care i.e. the days and perhaps week before death, then palliative care has significant experience, knowledge and skills in this area. However, we know people with chronic disease move slowly towards death and so when then is end of life for this group? We know the trajectory of decline in chronic disease can go for a number of years, so when does the ‘end of life’ period begin in the trajectory? This uncertainty can lead to continuing interventions, long after any health benefits have been achieved, either in the disease itself or the patient’s quality of life. If health professionals perceive end of life care to be terminal care, and palliative care services are perceived to be for terminal care, then a prolonged decline is not perceived to be the end of life. Whilst there is increasing recognition that there are significant needs for symptom control (e.g. dyspnoea in COPD and heart failure), ADL support and particularly for psychosocial and spiritual support, many of the patients in my research had difficulties accessing these services. One reason could be that they were still perceived to have a chronic disease, which although life-limiting was not yet ‘terminal’ in the understanding of service providers. Indeed, one patient was told by a palliative care service after an initial consultation that they would not see her again until the last week of her life, despite the overwhelming disability and major symptom burden associated with her degenerative neurological disease.
- *Clinicians avoid discussing end of life care because of the lack of evidence around when to change the focus of care from interventional to supportive.* The strong emphasis given to the importance of evidence based medicine directs health professionals to look for concrete and measurable evidence for when a chronic disease could be considered advanced enough to initiate supportive care. As noted in Chapter 3, there are a plethora of evidence based clinical indicators in diseases such as COPD, heart failure and renal failure to identify when people may be in the last six or twelve months of life, but there was no agreement amongst the specialists who assisted in recruitment for this

research that these were particularly reliable. However, interestingly all agreed on the clinical judgement question *would I be surprised if this patient died in the next 12 months?*⁵⁴ This belief in the importance of evidence could also be a factor in the reluctance to discuss prognosis that was noted by patients. Because of the uncertainty of chronic disease trajectories, discussing time limited prognoses was avoided, even by service providers who said they were very comfortable to have end of life care discussions, which left patients feeling lost and confused. But there is an inherent pattern in life limiting chronic diseases: although trajectories may be different, the outcome is always the same. Therefore, it is possible to confirm that patients are moving towards death, and so patient needs and fears can be discussed, even if no specific time line can be provided.

Another area of dissonance for health professionals working with people with advanced chronic disease occurred between their support for the chronic care model (CCM)¹³¹ which is based in general practice and incentivised through the Medicare system,¹⁴⁶ and the differing emphasis and requirements of a palliative approach. As discussed in Chapter 2, the CCM is disease focused, advocating systematic care for specific diseases, regular review and monitoring, education and self-management with a strong focus on clinical information systems and decision making support.¹³¹ For health practitioners focused on such an approach to care, the palliative approach of crossing boundaries to access care, responding to patient need, being flexible according to the context of the patient and focusing strongly on psycho-social and spiritual needs⁷⁰ does not conform with their internalised rules.

Munday et al³² point to the complex interplay between physical, psychosocial and spiritual issues for patients at the end of life; therefore complexity can be found at all levels of the system – personal, organisational and system-wide. Sturmberg et al²⁷² suggest that in a system that puts people at the centre of care, achieving the best possible experience of health should be the main focus of care instead of the current financial and administrative focus. They note that, in a CAS, the system constantly re-aligns itself around the main drivers which are currently disease management and/or cost containment rather than patient experience. Thus, systems are adaptive over time and this adaptation is not always positive.

One example identified in my research where drivers of care do not support flexible, person centred end of life care was that specialist palliative care services are increasingly becoming siloed and less accessible. Sturmberg et al have noted that, in the face of split funding responsibilities and reducing budgets, one response has been to develop silos of care, to protect funding and services as well as the stature of the care of specific diseases.²⁶⁸ Some policy makers and service planners in this research suggested that specialist palliative care could be seen to be moving from a previous role which provided flexible care across boundaries to becoming an expert silo, providing advice and highly specialised care in an attempt to secure funding and status. My research identified that some palliative care services are responding to changing care needs by focusing more on advice and ambulant care in health settings rather than the more traditional home visiting model of palliative care. Some rural health services have adapted through allowing flexible care responsibilities, but others remain inflexible – e.g. the rural health service interviewed in this research allows GPs to care for their patients in hospital if they have private health care, but not if they are public patients.

8.3.3. Advance care planning and complexity theory

A particular focus of state and federal policy and of the service providers, managers and policy makers in this research, was the need for appropriate advance care planning. The importance of conversations about the care people with chronic disease wish for as their disease progresses was emphasised. However, my research demonstrated that very few patients had these discussions, despite this strong focus. In this section, I have used complexity theory and viewing the health system as a CAS to attempt to explain this contradiction.

The role of culture in shaping end of life care in Australia cannot be ignored. This research reflected a widespread reluctance amongst both health professionals and patients to admit that further interventions would be of no benefit in their particular illness. Because a CAS interacts closely with its environment, a death denying culture in the community and a culture of heroic intervention in hospitals impacts on health service providers who express it in various ways: e.g. not wanting to take away hope and uncertainty about when ‘*the best time*’ was to have ‘*the conversation*’. Whilst the health professionals in this research said they were comfortable discussing end of life care issues, and some had had training in

programs such as *Respecting Patient Choices*,¹⁹¹ they said that their colleagues often were not comfortable with, and frequently avoided, such conversations and/or did not think it was their role. Furthermore, minimal educational opportunities were identified for health care professionals, particularly specialists and GPs, to enable them to develop their skills in end of life care planning. This reflects a health system with drivers that reward interventional services with funding and limit funding for supportive services such as ADLs.

Another aspect of the impact of a death denying society is unrealistic expectations of treatment in advanced chronic disease. As noted above a barrier raised by health professionals in my research was the issue that uncertain trajectories in chronic disease made timing for end of life conversations problematic. However, a CAS recognises inherent patterns – thus, whilst trajectories may differ, the outcome of death is always consistent in life limiting chronic disease and therefore uncertain trajectories are not an excuse for avoiding advance care planning conversations.

Whilst service providers in the research unanimously agreed about the importance of end of life care conversations, there was little consistency around actually initiating these conversations and only one of the health professionals interviewed had spoken with their patient about end of life care needs. This could be the result of another problem they acknowledged – a lack of clarity around who had responsibility for care. GPs reported uncertainty about whether conversations had been had and did not want to cut across specialists' responsibilities. Although patients had been nominated by specialists because they could be in the last year of life, there seemed to be little recognition by their KSPs that they had actually entered the end of life phase. Because systems in a CAS are embedded in other systems, unless there are clear lines of communication and clarity about roles and responsibilities, many people will '*fall through the cracks*' in terms of access to care and having end of life care conversations.

The idea that advanced chronic disease requires a type of care focused on support for quality of life, rather than on interventional care, was not being adequately communicated to patients who perceived they were being told that "*nothing more could be done*". Many service planners and policy makers focused on the importance of completion of documentation, with the assumption that this would

include appropriate end of life care conversations. However, the need for ongoing end life care conversations, linked to changing needs and disease states, and a lack of any system that ensures broad use of advance care planning documentation means such documentation, when it does exist, may have limited value. A feedback loop operates where an advance directive is ignored because the health service does not have access to it, so GPs and specialists then question the value of completing them.

I identified minimal community awareness of the process of advance care planning. New legislation in South Australia was introduced in July 2014, and was accompanied by a community awareness program.¹⁰ However, if the lenses that health professionals and patients use do not perceive that chronic disease is life limiting in the same way that they perceive cancer is life limiting, such campaigns will not resonate widely.

8.3.4. Summary of answers to research question 1d.

Research question 1d asks why the health system functions in the way it does to provide end of life care. Viewing the health system as a CAS allowed me to answer this question. I was able to identify a number of reasons why the provision of end of life care for people with chronic disease was not meeting their needs. A series of inaccurate assumptions have informed policy making and service planning, particularly around the roles of general practice and specialist palliative care services in the provision of end of life care. Current funding mechanisms drive care which perpetuates both silos of care and a focus on clinical rather than person-centred outcomes, exacerbated by few intersections between palliative care and chronic disease policies. A lack of shared understanding of the term '*end of life*' has led to confusion over who has responsibility for end of life care and advance care planning conversations and the split responsibility between federal and state governments for health services has led to inflexibility and unrealistic expectations around the role of general practice in end of life care. There is still little recognition that many chronic diseases are life limiting and a belief that uncertain disease trajectories are a barrier to initiating end of life care.

As I noted at the beginning of this section, one important reason for understanding why the system works as it does was to be able to propose effective changes. In

the next section, I will examine some of the core elements that should underpin end of life care models and explore the value of complexity theory in moving to change our current models of care to begin to meet the needs of people with advanced chronic disease.

8.4. Core elements of end of life models of care for advanced chronic disease

In order to answer my overarching research question 1: *How can the health system provide care that meets the needs of people with advanced chronic disease and of their carers/families?* I needed to identify the key elements comprising a best practice end of life care system that supports and empowers patients and carers. In the next section of this chapter, I will explore three concepts: person centred care, coordinated care and integrated care and how they are reflected in current models of care. I introduced these concepts in chapter 2, and they recurred throughout my research, in interviews with patients and their carers, in the policy analysis and in interviews with health professionals, policy makers and service managers. I will then suggest a public health approach to end of life care provision, which provides the opportunity to address end of life care at a population level, to help systematically ensure that all people requiring end of life care have access to appropriate services.

8.4.1. Person centred care

Patient and carer needs must drive health system services if we are to develop a model of care that meets the needs of people with chronic disease as they approach the end of life and which addresses the issues and barriers that I have detailed in this thesis.⁶² Thus it is essential that person centred care should be the first core element of any model developed. However, as I noted in Chapter 2, there has been little agreement on a definition of person centred care and the health professionals in my research reflected this lack of a shared understanding of the meaning of person centred care. Although there is no agreed definition of person centred care, Duncan identified three core components:^{176, p35}

- a) the recognition of each individual as a unique human being
- b) the recognition that each person is an autonomous being with a capacity to make choices

- c) that in order to achieve person centred care in practice, a sensitive and informed flexibility in each health care encounter is essential.

In Figure 6, The Health Foundation²⁷³ summarise how the roles of patients and clinicians would change in a person centred care system.

	Current practice	Person centred care
Roles and beliefs	Patients passive, believe clinician has the answers and will improve their health	People active partners and managers of their health
	Clinical expert gives advice, fixes, cares for and promotes dependency	Clinician cares about, listens and uses expertise to support and enable patient as a partner in decision making and management of their health and care
	Policy and practice assume knowledge creates behaviour change	Policy and practice recognise that knowledge, skills, confidence, self-efficacy and motivation create behaviour change
Model	Primarily medical	Biopsychosocial
	Values clinical outcomes	Values outcomes that matter to people
Who	Workforce = clinicians	Workforce = clinicians + peer support workers + navigators + health coaches + ...
How	Clinician shares results and information during consultation	Person receives results and information at appropriate time to enable them to set their agenda and make their decisions
	Clinical training in ‘communication’ skills used to enable them to get patients’ agreement to clinician determined goals	Clinical training in skills to support people to determine and enact their own goals
	Compliance with clinically determined goals and treatment plans	Collaborative care and support planning with adherence to co-produced goals

Figure 6. The changing roles of clinicians and patients in a person centre care system.²⁷³

My research reflected the very clinical focus of current care described in Figure 6 and demonstrated that despite policy rhetoric around person centred care, the system is not currently structured to support this. If care is person centred, advance care planning will become an automatic part of meeting patient and carer needs, whereas my research demonstrated that this is not currently occurring. As disease trajectories differ for each individual, supportive care will be provided according to need rather than prognosis.

8.4.2. Coordinated care

Coordinated care is a core component of person centred care.²⁷⁴ Daveson et al²⁷⁵ note that *In the midst of advanced progressive illness, coordination is a shared complex intervention that comprises an essential mix of relational, structural and information element*^{e95523} and this complexity of care coordination at the end of life is often overlooked and/or underestimated. There is increasing evidence that care coordination is a key strategy for improving care outcomes and lowering costs.²⁷⁶ In my research, the absence of coordinated care was a major issue for a number of patients and carers. Service providers and policy makers felt that care coordination was the role of general practice in Australia; however, whilst some GPs reported being happy to undertake end of life care, they said that many of their colleagues were not. One service provider noted that palliative care nurses had often acted as de facto care coordinators once they became involved in care but, as the role of palliative care services changed and people with chronic disease/s required more ongoing complex care, this was not a practical role for them.

If general practice is viewed as part of a CAS, many of the structural and philosophical constraints on care coordination in general practice become evident. There are no real drivers for general practice to undertake end of life care, as GPs are currently rewarded on throughput rather than quality and incentives for CDM do not extend to end of life care. Addicott²⁷⁷ reported that although the literature highlights a key role for general practice in end of life care, GPs themselves have a different view, with concerns around their ability to address psychosocial needs and symptom management as well as confusion over roles and responsibilities. Rodwell and Gulyas²⁷⁸ describe how general practices have changed and adapted to the different environments in which they work and identified seven different configurations of general practice in Australia, a number of which are not conducive to end of life care. They emphasise that general practice could not be seen as a homogenous care setting, and so assuming that all general practices can undertake care coordination and end of life care is erroneous.²⁷⁸

8.4.3. Integrated care

Tsasis et al²⁷⁹ define integrated care as *coordinating services across multiple healthcare professionals, organizations, and sectors, and prioritizing patient needs and preferences*.^{p2} In their review of why integration did not work in Local Health Networks in Ontario, they suggest that treating the health system as a CAS allows a broad understanding of the drivers and barriers to integrated care.²⁷⁹

They specifically identified the following issues:

- a lack of understanding of the role of other health professionals and how they and their services function;
- a lack of relationships between services and a limited time and resources to develop such relationships;
- a lack of a shared vision and understanding of the meaning of integration;
- no broad guiding principles instead of the existing top-down control and rigid structures;
- inflexible funding mechanisms which do not allow integrating boundaries across health and community sectors;

Their analysis resonates strongly with the results of my research when looking at integration between sectors to provide end of life care; their summary of the network issues in Ontario are also relevant to the issues faced in South Australia today: ²⁷⁹

...integration is challenged by system complexity, weak ties and poor alignment among professionals and organizations, a lack of funding incentives to support collaborative work, and a bureaucratic environment based on a command and control approach to management. Participant descriptions of the healthcare system and their integration experiences reflected many of the characteristics of CAS, including the presence of a wide variety of interacting elements, an inherent unpredictability that makes planning and alignment difficult, and the need to understand interdependencies, including points of apparent contradiction.^{p.7}

Curry and Ham²⁸⁰ identified three levels of integration in the UK context — macro: across organisations; meso: across population groups and micro:

approaches such as case management and Medical Homes. They suggest that all three levels need to be considered, but that the meso level of clinical and service integration is particularly important. They specifically examined integrated care for people with chronic and complex conditions and suggested that:²⁸¹

organisational integration will not deliver benefits if clinicians do not change the way they work.^{p.2} noting that it may be better to develop linkages and processes that foster collaboration and allow coordination and continuity of care rather than trying to develop one integrated organisation.²⁸¹ Given the split responsibilities for care across the state and federal level in Australia, this latter type of integration is likely to work most effectively for end of life care.

Integration at any level cannot occur unless there is a shared understanding of what integration aims to achieve and there is clear and ongoing communication between the integrated organisations and professionals and the patients and carers whom they are supporting. In my research, no-one identified or articulated a clear vision for end of life care across the health system and a lack of communication at all levels was a constant theme, contributing to many barriers to care, such as: a lack of clarity in roles and responsibilities; confused and fearful patients and carers; conflicting treatments for multi-morbidities; a lack of advance care planning and limited access to ADL supports. Tsasis et al²⁷⁹ suggest that information sharing, understanding roles and responsibilities and developing shared visions and approaches can bring multidisciplinary groups together so that new ideas and opportunities can emerge – a key characteristic of a CAS.

8.4.4. A public health approach

So far, I have examined elements underpinning models of care which are focused on the individual: person centred and coordinated care in an integrated system. However the scope of this growing problem points to the need for such individual measures to be supported by a broader public health approach. The WHO defines public health as: *all organized measures (whether public or private) to prevent disease, promote health, and prolong life among the population as a whole.*²⁸² They have also emphasised the importance of a public health approach to end of life care, stating it should be integrated into policies, structure and financing of health systems.²⁸³ Thus, the focus is on the population as a whole and the growing burden of disease, the costs to the community, inequities of access to care and a

lack of end of life care education in health professionals all provide a strong argument for why palliative care should be a public health priority.²⁰²

In 1999, Kellehear published a seminal book on *Health Promoting Palliative Care*,¹²⁹ advocating the use of public health principles and in particular, health promotion in palliative care. He suggested health promotion principles:¹²⁹ *might greatly renew support for a focus on living with dying that addresses the early stages of dying — the part of palliative care that now seems too difficult for current policy-makers and funding sources.*^{p.xii} It is precisely this area of living with dying that was so difficult for the patients in my research, as they were unable to access the care and support they needed. Health promotion principles offer a useful framework for addressing another core issue identified in the literature and echoed throughout my research: the lack of community awareness of death and dying generally and specifically around the life limiting nature of many common chronic diseases.

Gomez-Batiste and colleagues¹⁴⁴ have used a public health approach to develop a comprehensive end of life care program for people with advanced chronic disease in Catalonia, in Spain. The majority of care in this program is provided in primary care, rather than referral to palliative care services. In the Australian context, a public health approach could assist in overcoming one of the issues identified in this research: the limited ability of GPs to recognise that a patient's condition has significantly deteriorated. The routine use of a population level screening tool could assist GPs in identifying patients who may require a palliative approach. A variety of end of life identification tools have been developed: the Supportive and Palliative Care Indicators Tool (SPICT)¹⁴²; The Gold Standards Framework (GSF)²⁰⁸ and the NECPAL CCOMS-ICO©) from Catalonia¹⁴⁴ (see Appendix 9 for examples of these tools). However, as with all screening programs,²⁸⁴ Gomez-Batiste et al caution that, once someone is identified as requiring a palliative approach, there must be a system in place to allow the implementation of such an approach. This system should have at least the ability to:¹⁴⁴

1. identify multidimensional needs;
2. develop a systematic, multidimensional, therapeutic care plan;
3. identify patients' values and preferences: clinical ethics and ACP;
4. include the family and the main caregiver in care planning;

5. employ case management, follow up, continuing care and coordination of care between different services.

Thus, if Australia is to implement a public health approach for end of life care and initiate systematic screening processes, necessary system supports must be put in place first, as they do not currently exist.

8.4.5. Summary

The combination of clinical and public health systems approaches in developing best practice models of end of life care is vital. The literature consistently highlights the importance of person centred, coordinated and integrated care and participants in my research echoed the need for such care. However, the ageing population in Australia with its associated increasing incidence of people with chronic disease who will approach the end of life requires a focus on the population as well as the individual. The need to raise community awareness of the issues around death and dying and the systematic identification of people needing specific end of life care requires a primary care based model and in Australia we currently do not have any models that encompass these two approaches. In the next section I will explore how such models of care can be developed.

8.5. Moving to a best practice model of end of life care

In this last section, I complete my answer to research question 1: *How can the health system provide care that meets the needs of people with advanced chronic disease and of their carers/families?* Ferris and Librach²⁸⁵ demonstrate the complexities of the end of life care process (figure 7), showing the variety of systems, services and providers that need to be involved and coordinated as people approach the end of their life. Whilst our current system for CDM considers some of these areas, my research demonstrates that there is no consistency or coordination of these various aspects and, for people with chronic disease approaching the end of life, psychological, spiritual, loss and grief support and end of life care management are generally completely missing. We therefore need to move from our current model of care to a truly person centred model which reflects Gillick's contention, noted in Chapter 2, that holistic, integrated palliative care should actually be the gold standard for all health care?²⁸⁵ As I

describe below, this will require changes in the policies, culture and systems that shape the provision of end of life care in Australia today.



Figure 7. Common issues for patients, carers and families as they approach the end of life²⁸⁵

8.5.1. Policies

- Current chronic disease policies/strategies reflect an assumption that palliative care will address the needs of people with advanced chronic disease. There is a need to move to an explicit recognition of end of life as a distinct period in the continuum of chronic disease care, where the focus of goals of care change from intervention to support. Such support must include psychosocial and spiritual care.
- There are currently no links between ageing, chronic disease and end of life care policies and strategies, yet the ageing of the population has significant implications for the health system. Policies should recognise that:
 - the disability associated with chronic disease increases as disease advances and this is often associated with ageing.
 - carers are also ageing. If paid carer support is not provided to assist informal carers, people will be forced into residential aged care as the health of the informal carer deteriorates.
 - there are not enough ADL services available to meet the existing needs of people with advanced chronic disease and as the number of people with chronic disease rises as the population ages this will become an even more significant problem.
- Policies should explicitly recognise that the locus of end of life care should be in the primary care sector rather than in acute care. However, it should also be recognised that not every general practice can, or wishes to, undertake end of life care.
- Meeting changed goals of care and moving the locus of care will have significant implications for service funding and provision.

8.5.2. Culture

- We live in a death denying society in Australia and this is reflected in the culture of our health care organisations.¹²⁷ There is often a reluctance by both health care professionals and patients, their carers and families to acknowledge that the end point of advanced chronic disease is death, and so interventional rather than supportive care is the norm in advanced chronic disease.

- Changing the culture of a health care organisation is extremely challenging and is intertwined with systems changes, particularly leadership, health workforce training, and service structure and delivery.
- The psychological and emotional issues in end of life care can be profound and confronting for the health professionals involved. This is because health professionals are also members of a broader society which is uncomfortable with death and, as everyone must, they have to face their own death and the death of loved ones.

8.5.3. Systems

- Systems are currently structured for interventional care, provided through individual disease-focused silos. Changes will be required at all levels of the health system to meet the end of life care needs of people with chronic disease and to support health professionals in providing appropriate end of life care.
- End of life care for people with advanced chronic disease must be recognised as a core component of the care people receive, and should not be considered the remit of specialist services – either disease specific or palliative care: indeed, appropriate end of life care requires collaboration across a wide variety of health professionals. This could be enhanced by systems which treat palliative care clinicians and services as partners rather than expecting them to provide all of the care required by people as they approach the end of their life. Palliative care clinicians are experts in communication, advance care planning, integrated holistic care and treating the varied and often very distressing symptoms of advanced chronic diseases such as COPD, heart failure and most commonly, cancer. Their experience and expertise can help services at a local level to develop the flexible, patient centred care that is at the heart of end of life care. However, palliative care services have neither the workforce nor resources to support the more prolonged scope of end of life care in chronic disease, but palliative care clinicians can play a vital role in providing education, support and advice to other health care providers, particularly primary care practitioners.
- Integrated and coordinated care can be best provided through general practice rather than the fragmented specialist care system, but mechanisms must be

developed to support communication and care coordination across the acute and primary care systems. Such mechanisms could include:

- Primary Health Networks (PHNs)^{xxiv} prioritising end of life care as one of their key support roles for general practice and primary care services.
- New workforce options such as end of life care coordinators who cross boundaries between the acute, primary and community care sectors to provide significant support to both health care practitioners and patients and families. The importance of a primary care based care coordinator was identified in my previous research on end of life care for people with COPD. Their role should include: acting as a care navigator for patients and carers, supporting and enhancing communication between the patient, carer and all levels of the health system and supporting general practice to implement a patient-centred model of care and a palliative approach:¹³
- The specific end of life care needs of the ageing population must also be considered. Many of the people in this population will have multiple chronic diseases, which they are likely to have lived with for years. End of life care conversations are vital in determining the type of care they wish for as their condition deteriorates and they approach the end of their life and options must be available for them to choose to either remain at home or enter residential care and receive appropriate end of life care.
- As well as reorienting clinical care systems and moving to a primary care focus for end of life care, the implementation of a public health approach would facilitate more equitable access to care through a systematic identification of care needs, as well as helping to address cultural issues around death denial and the interventional culture of medicine. A paradigm shift is required to move end of life care from a palliative care clinical paradigm to a broader public health paradigm:²⁸⁶ *Given that death is both inevitable and universal, the care of people with life-limiting illness stands equal to all other public health issues.*^{p.767}

^{xxiv} Primary Health Networks are being established in Australia in July 2015 to replace Medicare Locals, Their objectives are increasing the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes and improving coordination of care to ensure patients receive the right care in the right place at the right time

A primary care based end of life care model

As an example of how such a system change could be actioned, Figure 8 outlines a primary care based model of end of life care. I have developed this using evidence from the literature, suggestions arising from my data analysis and from my own knowledge of the Australian primary health care system.

- Primary Health Networks (PHNs) offer a major opportunity to progress end of life care for chronic disease.²⁸⁷ Local PHNs could drive change and provide the support required for general practice to become the hub for end of life care.
- PHNs could establish an overall planning process for end of life care to drive a person centred, coordinated model of care. Close links with the Local Health Networks (LHNs)^{xxv} could be used to enhance collaboration across the acute and primary care sector boundaries and guidance could be provided through an alliance of patients with chronic disease, carers, general practices, palliative care services, disability services, community and allied health services, specialists and hospitals.
- A community based end of life care coordinator role could be established. Many smaller general practices who may be interested in providing end of life care may not have the structure, workforce or funding to provide the comprehensive level of care required. Thus, end of life care coordinators could be facilitated through PHNs and provide both direct services to patients through working with individual general practices and/or provide advice and support to larger practices who choose to undertake care coordination for people with chronic and complex disease. These care coordinators would work across the acute and primary care sector boundaries with strong links to disability and other community and allied health services. They would work particularly closely with local palliative care services. Larger general practices interested in end of life care could directly employ an end of life care coordinator.
- At a general practice level, GPs and practice nurses could work closely with the end of life care coordinator to identify patient and carer needs and facilitate access to care. The PHN and the care coordinator could also support the general practice to develop business cases and meet eligibility requirements for any new Medicare item numbers established. Drawing on the Catalonian model,¹⁴⁴ a systematic process of identifying

^{xxv} Local Health Networks (LHNs) in South Australia manage the delivery of public hospital services and other community based health services as determined by the State Government. In SA this includes palliative care services and *Hospital the Home*.

- patients who would benefit from a palliative approach could be undertaken by the practice nurse, working in the first instance with the end of life care coordinator.
- Both formal and informal links between primary care and acute care are vital. PHNs and LHNs could broker such communication processes, through strategies such as the development of protocols and facilitating networking between health practitioners in both sectors e.g. consultation and support between specialist, hospital based services such as respiratory or cardiac failure nurses and the community based care coordinators.
 - The personally controlled electronic health record (myHealth Record) offers the opportunity to facilitate care coordination.²⁸⁸ The end of life care coordinator could support people in their understanding and use of myHealth record to facilitate care across all health care providers nominated by the patient
 - PHNs could support general practices to use the Medicare funded *Health Assessment for people aged 75 years and older*²⁸⁹ as an appropriate opportunity to discuss advance care planning and complete advance care directives.
 - The PHN could lead the public health approach to end of life care, which would incorporate a community development approach, in conjunction with the state government. This would include initiatives to support culture change and the reorientation of health services towards a greater consideration of supportive as well as interventional care and encouraging end of life care conversations, building on Kellehear's framework.¹²⁹ They could facilitate the systematic approach to proactively identifying patients who may require a palliative approach, similarly to the systematic approach to identifying patients with diabetes. They could work with other PHNs and palliative care experts to agree a tool to identify such patients, based on existing evidence based tools, modified where appropriate for the Australian context.
 - PHNs could take on a broader advocacy role, working with professional organisations such as the RACGP, the RACP and the AMA to identify how to resource the required: changes e.g. through revising Medicare item numbers and/or making end of life care eligible for Practice Incentive Payments.²⁹⁰ Such reforms should also facilitate access to allied health services such as psychologists, physiotherapists and occupational therapists.

Figure 8: An example of a primary care based model of end of life care

8.6. Limitations of this study

There are a number of limitations of this study. It was undertaken in South Australia and so reflects the health system as it operates in that state. As each state is responsible for its own health system, particularly acute care and disability services, there will be differences between states as to how services are provided. However, federal funding and the responsibility for services such as general practice are constant across Australia.

Another limitation of this study was my inability to include an in-depth exploration of the end of life care needs of Australians from Aboriginal and Torres Strait Islander and CALD backgrounds. Because of the complexity of the social and cultural issues surrounding end of life care for these communities, I felt I could not do justice to these groups within the scope of this PhD and I recognise that this is an issue for a multicultural society such as Australia. However, I have considered these populations in my literature review and made recommendations that include these two population groups. In doing so, I acknowledge that these recommendations are extensions of my research, rather than recommendations based on empirical work conducted with Aboriginal and Torres Strait Islander peoples or peoples from CALD backgrounds.

I was able to recruit only 9 participants, one of whom dropped out following the first interview, despite ongoing contact and reminders with the participating specialists. However, eight patients and six carers were interviewed three times, 10 of their key service providers were interviewed as well as 12 policy makers/service planners - a total of 64 interviews. Whilst this was fewer than my proposed sample, the stories of the participants resonated with the health professionals, service managers and policy makers I spoke to, who identified many of the same issues from the system point of view that participants had identified from their experience of the health service. This was reinforced by the letter I received following the publication of my first journal article in March, 2013 from the daughter of an elderly man with heart failure man describing the problems they had experienced in accessing appropriate end of life care.

8.7. Summary

The complexity of the provision of end of life care in chronic disease is frequently underestimated. My research has identified that end of life care models must balance supportive and interventional care; coordinate the multiple health and disability services required to provide care and equipment; address psychosocial and spiritual needs; manage discussions about end of life and advance care planning and support carers. A societal reluctance to discuss death and dying and to recognise the life limiting nature of many chronic diseases and issues around funding, workforce and service provision add to the complexity.

Chronic diseases generally follow very different trajectories from cancer so it is often difficult to determine an '*end of life*' phase and care needs vary markedly, taking into account both the various chronic diseases and individual patient needs. Because the health system is a CAS, small changes in some parts of the system can lead to major changes throughout the whole system. By using complexity theory to examine the health system, I have highlighted a variety of specific issues which have had major impacts on the provision of end of life care including: no clear vision of how end of life care should actually be provided for people with chronic disease in Australia today; health professional attitudes and actions including incorrect assumptions and confusion over roles and responsibilities and system drivers focused on budgets and specific disease outcomes. A key issue I identified was a lack of shared understandings of terms such as end of life and palliative care. This resulted in the assumption that people with advanced chronic disease should be referred to palliative care services, but no clarity about when this should occur, nor what type of care best suited their needs.

I identified three concepts in the literature and in this research as the core of any end of life model of care: person centeredness; care coordination and integration of care. A model of care based on these elements offers the capacity to address many of the issues identified above. I have identified that end of life care must be person centred, multidisciplinary, coordinated and integrated and reflect the core principles of palliative care including an holistic approach to care which includes physical, psychological, emotional and spiritual concerns.

This individually focused, person centred model of care should be complemented by a public health approach to end of life care incorporating health promotion strategies such as community based education programs and community discussions around appropriate end for life care. Associated population health approaches such as systematic approaches to identifying and supporting people who might benefit from end of life care should be located in general practice and this also offers the opportunity to address the considerable inequities which currently exist in access to care.

The complexity of the structure of the health system for end of life care and the relationships within the health system and between the health system and other sectors mean that it can be difficult to determine the best places to intervene to achieve change. In my final chapter, I will examine how we can move to an equitable system which meets the end of life care needs of people with advanced chronic disease.

Chapter 9. Providing appropriate and equitable end of life care for people with advanced chronic disease

9.1. Introduction

The research presented in this thesis demonstrates that, although Australia has a consensus around the growing need for specific end of life care for chronic disease and the knowledge, evidence and ability to change the health system, we still do not have a system of care that meets the needs of people with advanced chronic disease as they approach the end of their life. End of life care for advanced chronic disease, by its very nature, must be considered across the system. It requires ongoing, systematic chronic disease care for symptom control and quality of life; a palliative approach to help determine required levels of supportive care; ongoing end of life care planning conversations and the provision of psychosocial and spiritual support; practical ADL support; and the ability to be cared for at home in the context of family and friends.

In this final chapter of the thesis, I bring together my various analyses, my interpretation of the results and my contention that the health system operates as a CAS for end of life care in chronic disease to suggest how we can provide care that meets the needs of people with advanced chronic disease. I thus answer my research questions about the most appropriate, and effective models of care and how we can intervene to change the system. Firstly, I suggest three overarching strategies to facilitate system change and suggest ways that care can initially be redesigned within the parameters and resource limitations that currently exist. I focus particularly on promoting primary care in Australia as the appropriate setting for person centred, coordinated and integrated end of life care. I then summarise the overarching message of my thesis, which calls for changes in the policies and systems that provide end of life care for people with chronic disease and for strategies which will facilitate changes in the culture and attitudes of society and health care organisations around death, dying and end of life care and make specific recommendations for how such changes could be achieved.

9.2. What do we need to do?

In the same way that end of life care itself is very complex, there are no simple solutions for changing the way end of life care for chronic disease is provided in Australia today. A broad systems approach is required to develop appropriate models of care and solutions to the complex end of life care issues identified in this thesis. I have identified that major systems change is required, and such significant change processes cannot be achieved quickly. No single intervention will change the overall system, and it is not possible to change the whole system at once.

Initially, we need to redesign the care we can provide within the parameters and resource limitations that exist. Three overarching strategies will facilitate this system change. It should be noted that although there are three distinct strategies described here, they are intertwined and should be implemented together.

Develop an overarching public health approach to end of life care in chronic disease which incorporates:

- an agreed definition of end of life care in advanced chronic disease.
- a public awareness campaign about the uncertain trajectories, and ultimately life limiting nature, of many chronic diseases.
- supporting community based organisations such as Palliative Care Australia to build on processes to systematically include the broader community in conversations about the type of care that people want as they approach the end of life and how such care should be provided.
- a systematic approach to incorporating end of life care explicitly into the chronic care model.
- recognition that the current provision of end of life care is particularly inequitable in vulnerable communities such as Aboriginal and Torres Strait Islander peoples and people from CALD backgrounds.
- placing the responsibility for coordination and implementation of end of life clearly in primary care and general practice.
- implementing public health approaches to systematically identify and support people approaching the end of life.

Recognise that end of life care must be better resourced through:

- developing appropriate funding mechanisms through Medicare to support primary care and general practice to take the leading role in supporting end of life care.
- acknowledging that the current resources available for people as they approach the end of life, particularly in relation to ADLs, are clearly inadequate.
- allocating specific funding to develop partnerships with vulnerable populations such as Aboriginal and Torres Strait Islander communities and people from CALD backgrounds to better understand and include their specific cultural needs in end of life care provision.
- acknowledging the need for the provision of twenty four hour/seven days a week care and providing adequate funding and services to support this.

Actively promote primary care as the appropriate setting for integrated, person centred coordinated end of life care through:

- the development of a shared vision for what end of life care looks like between the hospital and acute sector which is informed by the broader community's needs and priorities.
- general practice taking on a significant leadership role to drive the changes required.
- policies and strategies that place the responsibility for the coordination and implementation of end of life care with primary care and providing funding and support to primary care and general practices specifically to provide this care.
- recognising that the ageing population will mean increased numbers of people with multiple chronic diseases who will require end of life care.
- developing strong partnerships between primary care and palliative care services.
- developing ongoing partnerships between primary care and representatives from vulnerable communities to inform and support the development of culturally appropriate policies and strategies around end of life care.
- exploring new workforce options such as end of life care coordinators who can cross boundaries between the acute, primary and community care sectors.

9.3. Recommendations

1. The Royal Australian College of General Practitioners (RACGP) should initiate and lead a process to develop an end of life care partnership between themselves and the Royal Australian College of Physicians (RACP), the Australian Medical Association (AMA), the Royal College of Nursing Australia (RCNA), the Australian College of Rural and Remote Medicine (ACRRM), the Australian and New Zealand Society for Palliative Medicine (ANZSPM),), the National Aboriginal Community Controlled Health Organisation (NACCHO), the Australian Primary Health Care Nurses Association (APNA), COTA Australia, the Federation of Ethnic Communities Council of Australia (FECCA) and Palliative Care Australia (PCA) to provide leadership in the area of end of life care, develop an agreed definition of ‘*end of life*’ and drive a shared vision for best practice end of life care in Australia.
2. National and state policies and strategies around chronic disease and palliative care should explicitly recognise end of life as a distinct and significant period in the continuum of chronic disease care. This should also include a clear distinction between the specialist palliative care model and the end of life care required by people with advanced chronic disease. Such policy should also consider how chronic disease and palliative care policies can address the specific needs of an ageing population with multiple chronic diseases.
3. Specialist palliative care services should be considered as partners in care, providing expert advice, education and consultation as appropriate, not as the sole providers of end of life care.
4. The federal Department of Health should work with the RACGP, ACCRM, ANZSPM, NACCHO, APNA, PCA, FECCA, the Public Health Association of Australia (PHAA) and PHNs to adapt the Catalonian public health model of end of life care²⁹ as described in Chapter 2, for use in Australian general practice.
5. The funding of chronic and complex care in Australia should include specific recognition of end of life care needs. This includes:

- a. incorporation of people with chronic disease and their carers as an integral part of the planning of end of life health care services, not just their own health care plan. This should be done at the local PHN level.
 - b. adequate remuneration for GPs to undertake specific end of life clinical care (including longer visits, end of life care conversations, after hours care and home visits).
 - c. supporting general practice and primary care to develop capacity to provide end of life care which specifically considers the issues for an ageing population with multiple chronic diseases in both the community and residential care setting.
 - d. the development of a specific designation for general practices to become accredited “end of life care” practices. Such a designation would allow for extra funding to the practice to support end of life care activities such as consultations with palliative care services, access to psychosocial and spiritual care and carer support. The accreditation criteria should be based on the *ACQSHC National Consensus Statement on essential elements for safe and high quality end of life care*.⁶²
 - e. funding for, and access to, adequate and appropriate psychological, spiritual and bereavement care for patients approaching the end of life. This could be done through broadening the scope of the current Access to Allied Psychological Services (ATAPS) program through Medicare.
 - f. funding for, and access to, adequate and appropriate ADL support for patients approaching the end of life.
 - g. the RACGP, RCNA, APNA, ACRRM, NACCHO and Palliative Care Nurses Australia (PCNA) should jointly develop the role of an end of life care coordinator. This should be funded as part of the chronic and complex care funding provided to primary care through Medicare.
6. Develop and support the role of PHNs as core support organisations for integrated, end of life care. This should include:
- a. supporting general practice and primary care to prioritise end of life care as a key element of care for all chronic and complex diseases, particularly when co-morbidities are present.
 - b. partnerships with aged care representative organisations (including Aboriginal and Torres Strait Islander and CALD organisations) at a local

- level (e.g. COTA and organisations providing residential aged care) to ensure that the end of life care needs of the ageing population are addressed.
- c. supporting general practices to develop and implement quality improvement initiatives to support coordinated and integrated end of life care. Examples of such initiatives include the Australian Primary Health Care Collaborative initiative²⁹¹ and the IHI-QI from the Institute for Healthcare Improvement in the US.²⁹²
 - d. the development of partnerships with LHNs to foster and support communication and processes bridging the acute and primary care sectors.
 - e. the development of partnerships with local Aboriginal and Torres Strait Islander and CALD representative organisations to support PHNs in developing appropriate linkages between primary and acute care specifically for these vulnerable populations
7. The immediate transfer of the responsibility for funding and access to ADL support for people aged <65 years to the health sector. The current system is inequitable and causes significant problems for people who have very severe disease and who are the least able to advocate for themselves.
 8. The Australian Government Department of Health should develop guidelines and protocols setting out the quality and realistic levels of care to be provided by paid carers and develop a process for monitoring and quality assurance of such care.
 9. All specialist medical and nursing colleges should mandate the regular updating of communication skills (particularly around end of life care conversations) as part of their continuing medical education programs.

9.4. Summary

In this thesis, I have examined the broader health policies and systems which underlie the provision of end of life care for people with advanced chronic disease in Australia today. I proposed a set of strategies for how the health system can provide equitable and high quality care that better meets the needs of people with advanced chronic disease and their carers/families and suggested how these changes could be best implemented. A systems thinking perspective allowed me

to examine how the various parts of the health and other systems providing end of life care function as a whole, rather than looking at each section in isolation.

I showed that care is not currently meeting the needs of people with advanced chronic disease. I have described major gaps and barriers, as well as what was working well for patients and carers. I also identified why much of the system functions as it does, through: drivers focused on systems functioning and financing rather than patient care; incentives such as funding and prestige which reward an individual disease focus and encourage competition and the development of silos of care; a variety of incorrect assumptions around end of life care and the capabilities of general practice; a health system culture which favours interventional over supportive care; and a broader death-denying community culture.

Systemic changes are required to provide appropriate and equitable models of care and such models cannot be developed unless these system changes occur. This will require the establishment of an overall vision for the provision of care that Australians would like for people with chronic disease as they approach the end of their life. Appropriate models of care must be person centred, multidisciplinary, coordinated and integrated and consider the most vulnerable Australians as well as reflecting the core principles of palliative care including a holistic approach which includes physical, psychological, emotional and spiritual concerns. Strong, committed leadership across sectors is required to drive the development of new end of life care policies and to advocate for culture change in the education of health professionals and the management of health care organisations. There is already wide recognition that end of life care for advanced chronic disease requires improvement and it is possible to build on this good will. This thesis has provided one set of strategies for how this can be achieved.

Appendices

Appendix 1: Ethics approvals

- University of Adelaide
- Royal Adelaide Hospital
- Calvary North Adelaide and Calvary Wakefield Hospitals

Appendix 2: Participant information sheets and consent forms

- Patients
- Carers
- Key service providers
- Service managers and policy makers

Appendix 3: Recruitment checklist

Appendix 4: Invitation letter templates:

- Patients / Carers
- Key service providers
- Service managers and policy makers

Appendix 5: Interview schedules:

- Patients
- Carers
- Key service providers (KSPs) – specialists; community; advocate
- Key Stakeholders (policy makers; service managers; community organisations)^{xxvi}

^{xxvi} Each of these interview schedules differed slightly to consider the specific role of the stakeholder. I have included here the core interview schedule and each schedule differed only slightly from this.

Appendix 6: Data collection tools

- Demographic data collection form
- PHQ-9 (*Patient Health Questionnaire-9*)
- WHOQOL (*World Health Organization Quality of Life instrument*)
- AC-QoL (*Adult Carer Quality of Life Questionnaire*)

Appendix 7: Case review summaries^{xxvii}

1. Sue and Trevor Smith
2. Johanna and Alexander van Dyke
3. Anne and Ray Jones
4. Lil MacIntyre
5. Ellie Shaw
6. Frank and Diane Sharp
7. Sandra and Nettie Kewell
8. Kate Daly
9. Helen and Mary (and Fred) Dalgleish

Appendix 8: End of life care screening tools

- The Supportive and Palliative Care Indicators Tool (SPICT)TM
- The Gold Standards Framework (GSF)
- The NECPAL CCOMS-ICO© from Catalonia (*Necesidades Paliativas [Palliative Needs]*)

^{xxvii} All names in these case reviews are pseudonyms

Appendix 1. Ethics approvals



RESEARCH BRANCH
RESEARCH ETHICS AND COMPLIANCE UNIT

SABINE SCHREIBER
SECRETARY
HUMAN RESEARCH ETHICS COMMITTEE
THE UNIVERSITY OF ADELAIDE
SA 5005
AUSTRALIA

TELEPHONE +61 8 8303 6028
FACSIMILE +61 8 8303 7325
email: sabine.schreiber@adelaide.edu.au
CRICOS Provider Number 00123M

20 January 2011

Professor A Braunack-Mayer
School of Population Health and Clinical Practice

Dear Professor A Braunack-Mayer

PROJECT NO: H-223-2010

When chronic disease management becomes end of life care: the role of the health system in facilitating the transition

I write to advise you that the Human Research Ethics Committee has approved the above project. Please refer to the enclosed endorsement sheet for further details and conditions that may be applicable to this approval.

Approval is current for one year. The expiry date for this project is: 31 January 2012

Where possible, participants taking part in the study should be given a copy of the Information Sheet and the signed Consent Form to retain.

Please note that any changes to the project which might affect its continued ethical acceptability will invalidate the project's approval. In such cases an amended protocol must be submitted to the Committee for further approval. It is a condition of approval that you immediately report anything which might warrant review of ethical approval including (a) serious or unexpected adverse effects on participants (b) proposed changes in the protocol; and (c) unforeseen events that might affect continued ethical acceptability of the project. It is also a condition of approval that you inform the Committee, giving reasons, if the project is discontinued before the expected date of completion.

A reporting form is available from the Committee's website. This may be used to renew ethical approval or report on project status including completion.

 **PROFESSOR GARRETT CULLITY**
Convenor
Human Research Ethics Committee



RESEARCH BRANCH
RESEARCH ETHICS AND COMPLIANCE UNIT

SABINE SCHREIBER
SECRETARY
HUMAN RESEARCH ETHICS COMMITTEE
THE UNIVERSITY OF ADELAIDE
SA 5005
AUSTRALIA

TELEPHONE +61 8 8303 8028
FACSIMILE +61 8 8303 7325
email: sabine.schreiber@adelaide.edu.au
CRICOS Provider Number 00123M

7 April 2011

Professor A Braunack-Mayer
School of Population Health and Clinical Practice

Dear Professor Braunack-Mayer

PROJECT NO: H-223-2010

When chronic disease management becomes end of life care: the role of the health system in facilitating the transition

Thank you for the letter dated 21.3.11 requesting amendment to the above project. I write to advise you that on behalf of the Human Research Ethics Committee I have approved the request to:

- (i) recruit patients from the Wakefield and Calvary Hospitals following ethics approval from the hospitals,
- (ii) amend the number of participants as detailed in the letter, and
- (iii) exclude participants with COPD.

The ethical endorsement for the project applies for the period until: 31 January 2012

Please note that any changes to the project which might affect its continued ethical acceptability will invalidate the project's approval. In such cases an amended protocol must be submitted to the Committee for further approval. It is a condition of approval that you immediately report anything which might warrant review of ethical approval including (a) serious or unexpected adverse effects on participants (b) proposed changes in the protocol; and (c) unforeseen events that might affect continued ethical acceptability of the project. It is also a condition of approval that you inform the Committee, giving reasons, if the project is discontinued before the expected date of completion.

A reporting form is available from the Committee's website. This may be used to renew ethical approval or report on project status including completion.

Yours sincerely

PROFESSOR GARRETT CULLITY
Convenor
Human Research Ethics Committee



Government of South Australia
SA Health

25 May 2011

Ms Teresa Burgess
Senior Lecturer
Discipline of Public Health
School of Population Health and Clinical Practice
UNIVERSITY OF ADELAIDE

ROYAL ADELAIDE
HOSPITAL

North Terrace
Adelaide SA 5000
Tel: +61 8 8222 4000
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ABN 80 230 154 545
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Research Ethics Committee
Level 3, Hanson Institute
Tel: (08) 8222 4139
Fax: (08) 8222 3035
Email: Heather.O'Dea@health.sa.gov.au

Dear Ms Burgess,

Re: "When chronic disease management becomes end of life care: the role of the health system in facilitating the transition."

RAH PROTOCOL NO: 110432.

I am pleased to advise that Research Ethics Committee APPROVAL is granted to the above project on the above date. The following have been reviewed and approved:

- Protocol/Application – University of Adelaide
- Participant Information Sheet, Consent & Complaints Form – Patients
- Participant Information Sheet, Consent & Complaints Form - Carers
- Participant Information Sheet, Consent & Complaints Form – Key Service Providers (Hospital)
- Participant Information Sheet, Consent & Complaints Form – Key Service Providers (Community)
- Participant Information Sheet, Consent & Complaints Form – Key Policy and Service Provision Stakeholders
- Participant Demographics and Data Sheet
- Patient Interview Schedules – Interviews 1, 2 & 3
- Carer Interview Schedules – Interviews 1, 2 & 3
- Focus Group Schedule (Hospital)
- Interview Schedule (Community)
- Recruitment Criteria Checklist

Please quote the RAH Protocol Number allocated to your study on all future correspondence. Research Ethics Committee deliberations are guided by the NHMRC National Statement on Ethical Conduct in Human Research 2007.

GENERAL TERMS AND CONDITIONS OF ETHICAL APPROVAL:

- Adequate record-keeping is important. If the project involves signed consent, you should retain the completed consent forms which relate to this project and a list of all those participating in the project, to enable contact with them in the future if necessary. The duration of record retention for all clinical research data is 15 years.
- You must notify the Research Ethics Committee of any events which might warrant review of the approval or which warrant new information being presented to research participants, including:
 - (a) serious or unexpected adverse events which warrant protocol change or notification to research participants,
 - (b) changes to the protocol,
 - (c) premature termination of the study,
 - (d) a study completion report within 3 months of the project completion.
- The Committee must be notified within 72 hours of any serious adverse event occurring at this site.
- Approval is ongoing, subject to satisfactory annual review. Investigators are responsible for providing an annual review to the RAH REC Executive Officer each anniversary of the final approval date using the Annual Review Form available at: <http://www.rah.sa.gov.au/rec/index.php> The REC must be advised with a report or in writing when this study is complete so that the file can be closed.

Yours sincerely,

Dr A Thornton
CHAIRMAN
RESEARCH ETHICS COMMITTEE



CHCA-HREC Ref No: 11-CHREC-F003 (please quote in all correspondence)

24th November 2011

A/Professor Gregory Crawford
 Mary Potter A/Professor of Palliative Medicine
 C/- Mary Potter Hospice
 Calvary North Adelaide Hospital
 89 Strangways Terrace
 North Adelaide SA 5006

Dear A/Professor Crawford

Re: **Study Title:** Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness

Principal Investigator: A/Professor Gregory Crawford

APPROVAL DATE: 24th November 2011

Calvary Health Care Adelaide (CHCA) Human Research Ethics Committee (HREC) has received the above study proposal which was considered at the HREC meeting held on 18th August 2011, and re-submitted to the meeting on 17th November 2011 with requested amendments.

Final approval has been granted.

The following documents are noted and approved:

Documents received 24 th November 2011	Date
Cover letter to HREC - resubmission	22/11/11
Carer demographics/data collection sheet	
Standard consent Form corrected	
AC-QoL Questionnaire revised	

Documents received 12 th September 2011	Date
Cover letter to HREC - resubmission	09/09/11
Amendments to research protocol	12/09/11
CHCA HREC Submission with tracked changes	
Standard consent Form/Information sheet/complaints Patients with tracked changes	06/09/11
Standard consent Form/Information sheet/complaints Carer with tracked changes	06/09/11
Standard consent Form/Information sheet/complaints Hospital with tracked changes	06/09/11
Standard consent Form/Information sheet/complaints Community with tracked changes	06/09/11
Standard consent Form/Information sheet/complaints Service provision Stakeholders with tracked changes	06/09/11
Patient interview schedule – interview 1 with tracked changes	
Draft Carer interview schedule – interview 1 with tracked changes	
Recruitment Criteria Checklist – Parkinson's Disease	
Recruitment Criteria Checklist – Multiple Sclerosis	
Recruitment Criteria Checklist – Cardiac Failure	
Recruitment Criteria Checklist – Renal Failure	
AC-QoL Questionnaire and manual	

“Being for others”

Calvary Health Care
 Adelaide Ltd
 ABN 85 106 314 229

Calvary North Adelaide
 Hospital

89 Strangways Terrace
 Adelaide SA 5006
 Ph: 08 8239 9100
 Fax: 08 239 9104

Calvary North Adelaide
 Hospital

Calvary Central Districts
 Hospital

Calvary College Grove
 Rehabilitation Hospital

www.calvarysa.com.au

The documents considered at the meeting held on 18th August 2011 were:

Document Title	Date
Cover letter to Mr H Kok	02/05/11
Cover letter to Ms S Imgraben	02/05/11
Letter of support from Ms S Imgraben	05/05/11
Initial CHCA HREC Submission and Declaration by Investigator	05/05/11
HREC approval letter University of Adelaide	20/01/11
HREC approval letter SA Health	25/05/11
HREC approval letter University of Adelaide for amendment	20/07/11
HREC submission cover letter	26/07/11
Amended CHCA HREC Submission	26/07/11
Recruitment Criteria Checklist	
Standard consent Form/Information sheet/complaints Patients	
Standard consent Form/Information sheet/complaints Carer	
Standard consent Form/Information sheet/complaints Hospital	
Standard consent Form/Information sheet/complaints Community	
Standard consent Form/Information sheet/complaints Service provision Stakeholders	
Patient demographics/data collection sheet	
Patient questionnaire PHQ9	
Patient questionnaire WHO QOL – BREF	
Patient interview schedule – interview 1, 2, 3	
Draft Carer interview schedule – Interview 1, 2, 3	
Draft Key Service Providers (Hospital) Focus Group Schedule	
Draft Key Service Providers (Community) Focus Group Schedule	
Certificate of Placement clinical trials 31/12/2010 to 31/12/2011	31/12/10

As you would be aware, researchers are responsible to conduct research that is designed and conducted in accordance with the **Australian Code for the Responsible Conduct of Research (2007)** and the **National Statement on Ethical Conduct in Human Research (2007)**, in addition to other (State and local) jurisdictional obligations.

Please note, the Chief/Principal Investigator is required to notify the CHCA HREC, via amendment or progress report of any of the following:

- Any significant change to the project and the reason for that change, including an indication of the ethical implications (if any);
- Any other unforeseen events or unexpected developments;
- Anything that may change the ethical or scientific integrity of the project;
- The inability of the Principal Researcher to continue in that role, or any other change in study personnel;
- A delay of more than twelve months in the commencement of the project; and/or
- Termination or closure of the project.

Ethical approval is granted subject to the researcher agreeing to meet the following terms and conditions:

1. Compliance with the National Statement on Ethical Conduct in Human Research (2007) & the Australian Code for the Responsible Conduct of Research (2007);
2. To regularly review the CHCA HREC website and comply with all submission requirements as they change from time to time;
3. Submit an annual report on each anniversary of the date of final approval using the correct reporting template from the Calvary website and a final report at the completion of the project;

4. Confidentiality of research participants **MUST** be maintained at all times;
5. Any reports or publications derived from the research should be submitted to the HREC at the completion of the project; and
6. All requests for access to medical records at any Calvary site must be accompanied by this approval letter.

If you do not agree with any of the above you should notify us immediately.

Yours Sincerely

Dr Andrea Averis
Chair, CHCA Human Research and Ethics Committee

cc. Sr Anne Sheridan - CHCA Director of Mission
cc. Ms Sue Imgraben - Calvary North Adelaide Hospital CEO

Appendix 2. Participant Information Sheets and Consent Forms

Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness



Participant Information Sheet - Patients

Purpose of the study

The number of Australians with advanced chronic disease is increasing and the Australian health care system has not yet developed appropriate policies and services to help meet the changing needs of these people and their families. As disease progresses, it can have a big effect on the way people live and the services that they might need. This project will look at the types of care and support that will be most useful for people with your illness and your carers and families and how the health system might need to change to make these services available.

What's involved

We will follow a group of people with a variety of chronic diseases and their families for a period of approx nine months to learn more about the care they receive and whether this is meeting their needs as the disease progresses. We will also be talking to the main health professionals who are providing your health care and with policy makers at local, state and Commonwealth level. Your participation in this project would involve:

- If you are interested in being part of the project, one of the nurses will provide your contact details to the researchers, **with your verbal consent**, and a member of the research team will then talk to you in more detail about the project.
- We would like to talk to you three times over the next nine months. **Interview 1** will be at the commencement of the project, and we would like to talk to you about your understanding of your illness and the stage it has reached, what services you currently need, how and where you access services and any gaps or overlap in service provision. We will undertake this interview whilst you are still in hospital. **Interview 2** will be three months later, and will include a review of needs and services you have accessed since the first interview with a focus on primary care/community based services. **Interview 3** will be six months after Interview 2 and explore any changes in your disease status, care requirements, understandings of your condition etc.
- Interviews 2 and 3 will either be in your home, if you are happy for Ms Burgess to visit you there. The interview will take between 40 minutes and one hour
- These interviews will be audio taped, if we have your permission to do so. Once we have written the interviews up using the audio recordings, you are

welcome to read them if you want to. We will ask you at the end of each interview, and if you want to see them, we will send them to you once they are transcribed.

- We also have some questionnaires that we would like to complete which look at the sorts of services that you might be needing and your quality of life.
- With your agreement, we would also like to talk to the person who you think is your main carer (if you have one). We will ask them similar questions to what we ask you, but from their point of view.

Possible benefits of the study

This research will suggest areas in which health services may need to change and recommend strategies to assist and manage the changes required. It will provide important background information needed if we are to intervene to change the health system in the areas of chronic disease management and palliative care. We hope this information will lead to improvements in healthcare, but there will be no direct benefits for you personally

Your rights and protections

- Your participation in this research is completely voluntary and you have the right to withdraw your agreement to participate at any stage you wish to, and your medical treatment will not be affected in any way.
- You may refuse to answer any questions asked during the interview.
- We understand that some of the questions we ask may be upsetting as we will be talking to you about your disease and the impact it has had on your life. If you would like to talk to someone following the interview, we can organise this through the hospital.
- When the Project Team reports on this project, your name or any personal details will never be mentioned, and you will not be identified in any publications that may be written.
- Whilst we will take all steps to keep your information confidential, we have to tell you that it may be subject to disclosure by law, should this be required.

Study Contacts

If you have any issues you would like to discuss please don't hesitate to contact either:

Ms Teresa Burgess, Project Manager
Mayer, Chief Investigator

☎ 08 8303 3468 or 0424 586 826

✉ teresa.burgess@adelaide.edu.au

annette.braunackmayer@adelaide.edu.au

Professor Annette Braunack-

Mayer

☎ 08 8303 3569

✉

If you wish to speak to someone independent of the project, or make a complaint, please see the attached “CONTACTS FOR INFORMATION ON PROJECT AND INDEPENDENT COMPLAINTS PROCEDURE” form.

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE



THE UNIVERSITY
of ADELAIDE

STANDARD CONSENT FORM FOR PEOPLE WHO ARE
PARTICIPANTS IN A RESEARCH PROJECT

1. I,
(please print name)
consent to take part in the research project entitled:
Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness.

2. I acknowledge that I have read the attached Information Sheet entitled:
Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness

3. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.

4. Although I understand that a purpose of this research project is to improve the quality of health care, it has also been explained that my involvement may not be of any benefit to me.

5. I have been asked for my permission to digitally record any proposed interviews, and I have given this permission.

6. I have been informed that, while information gained during the study may be published, I will not be identified and my personal responses will not be divulged.

7. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, now or in the future.

8. I am aware that I should retain a copy of this Consent Form, when completed, and the attached Information Sheet.

.....
(signature) (date)

WITNESS

I have described to (name of subject)
the nature of the research to be carried out. In my opinion she/he understood the explanation.

Status in Project:

Name:

(signature) (date)

We will be recruiting participants from the Royal Adelaide Hospital, the Calvary North Adelaide Hospital and the Calvary Wakefield Hospital.

Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness



Participant Information Sheet – Carers

Purpose of the study

The number of Australians with advanced chronic disease is increasing and the Australian health care system has not yet developed appropriate policies and services to help meet the changing needs of these people and their families. As disease progresses, it can have a big effect on the way people live and the services that they might need. This project will look at the types of care and support that will be most useful for you and the people with the illness you are caring for and how the health system might need to change to make these services available.

What's involved

We will follow a group of people with a variety of chronic diseases and their families for a period of approx nine months to learn more about the care they receive and whether this is meeting their needs as the disease progresses. We will also be talking to the main health professionals who are providing that health care and with policy makers at local, state and Commonwealth level. If the person you care for agrees to participate in this research, your participation in this project would involve three interviews:

- **Interview 1** will be at the commencement of the project, and we can either talk to you and the person you are caring for separately or together (whichever you prefer). We will be asking about what the illness has meant to you, what services the person you are caring for currently needs, how and where you access services and any gaps or overlap in service provision. We will undertake this interview whilst the person you are caring for is still in hospital.
- **Interview 2** will be three months later, and will include a review of needs and services you and the person you are caring for have accessed since the first interview with a focus on any care you are accessing outside of the hospital (eg your GP)
- **Interview 3** will be six months after Interview 2 and explore any changes in the progress of disease, care requirements, understandings of the specific condition of the person you are caring for and the sorts of things as a carer that you require etc.
- Interviews 2 and 3 will be in your home, if you are happy for Ms Burgess to visit you there. The interview will take between 40 minutes and one hour
- These interviews will be audio taped, if we have your permission to do so. Once we have written the interviews up using the audio recordings, you are welcome to read them if you want to. We will ask you at the end of each interview, and if you want to see them, we will send them to you once they are transcribed

Possible benefits of the study

This research will suggest areas in which health services may need to change and recommend strategies to assist and manage the changes required. It will provide important background information needed if we are to intervene to change the health system in the areas of chronic disease management and palliative care. We hope this information will lead to improvements in healthcare, but there will be no direct benefits for you personally.

Your rights and protections

- Your participation in this research is completely voluntary and you have the right to withdraw your agreement to participate at any stage you wish to, and the medical treatment of the person you are caring for will not be affected in any way.
- You may refuse to answer any questions asked during the interview.
- We understand that some of the questions we ask may be upsetting as we will be talking to you about the impact that the disease has had on you on the person that you are caring for. If you would like to talk to someone following the interview, we can organise this through the hospital.
- When the Project Team reports on this project, your name or any personal details will never be mentioned, and you will not be identified in any publications that may be written.
- Whilst we will take all steps to keep your information confidential, we have to tell you that it may be subject to disclosure by law, should this be required

Study Contacts

If you have any issues you would like to discuss please don't hesitate to contact either:

Ms Teresa Burgess, Project Manager
Investigator

☎ 08 8303 3468 or 0424 586 826

✉ teresa.burgess@adelaide.edu.au

annette.braunackmayer@adelaide.edu.au

Professor Annette Braunack-Mayer, Chief

☎ 08 8303 3569

✉

If you wish to speak to someone independent of the project, or make a complaint, please see the attached "CONTACTS FOR INFORMATION ON PROJECT AND INDEPENDENT COMPLAINTS PROCEDURE" form.

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE



THE UNIVERSITY
of ADELAIDE

STANDARD CONSENT FORM FOR PEOPLE WHO ARE
PARTICIPANTS IN A RESEARCH PROJECT

1. I,
(please print name)
consent to take part in the research project entitled:
Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness.

2. I acknowledge that I have read the attached Information Sheet entitled:
Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness

3. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.

4. Although I understand that a purpose of this research project is to improve the quality of health care, it has also been explained that my involvement may not be of any benefit to me.

5. I have been asked for my permission to digitally record the proposed focus group, and I have given this permission.

6. I have been informed that, while information gained during the study may be published, I will not be identified and my personal responses will not be divulged.

7. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, now or in the future.

8. I am aware that I should retain a copy of this Consent Form, when completed, and the attached Information Sheet.

.....
(signature) (date)

WITNESS

I have described to
(name of subject)
the nature of the research to be carried out. In my opinion she/he understood the explanation.

Status in Project:

Name:

(signature) (date)

We will be recruiting participants from the Royal Adelaide Hospital, the Calvary North Adelaide Hospital and the Calvary Wakefield Hospital.

Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness



Participant Information Sheet – Key Service Providers

Purpose of the study

The number of Australians with advanced chronic disease who are approaching the end of their lives is increasing and the Australian health care system has not yet developed appropriate policies and services to help meet the changing needs of these people and their families. As disease progresses, it can have a big effect on the way people live and the services that they might need. This project looks at the types of care and support that will be most useful for people with advanced disease and their carers and families and how the health system might need to change to make these services available.

What's involved?

We are following a group of people with a variety of chronic diseases and their families for a period of approx nine months to learn more about the care they receive and whether this is meeting their needs as the disease progresses. We are also talking to the main health professionals who are providing that health care and with policy makers at a local, state and national level.

Your participation in this project would involve participating in a short interview to discuss the care provided for patients within the context of your particular service, to identify gaps and unmet needs and to discuss available services for end of life care for patients in the advanced stages of their disease. The interview will be audio taped, if we have your permission to do so. Once we have written up the interview using the audio recordings, you are welcome to read the transcript if you want to. We will ask you at the end of the interview, and if you want to see it, we will send it to you once it is transcribed.

Possible benefits of the study

This research will suggest areas in which health services may need to change and recommend strategies to facilitate and manage the changes required. It will provide the essential background information needed if we are to intervene to change the health system in the areas of chronic disease management and palliative care. We hope this information will lead to improvements in healthcare, but there will be no direct benefits for you personally.

Your rights and protections

- Your participation in this research is completely voluntary and you have the right to withdraw your agreement to participate at any stage you wish to
- You may refuse to answer any questions asked during the interview
- When the Project Team reports on this project, your name or any personal details will never be mentioned, and you will not be identified in any publications that may be written.
- Whilst we will take all steps to keep your information confidential, we have to tell you that it may be subject to disclosure by law, should this be required

This research has been approved by the University of Adelaide Human Research Ethics Committee and the Royal Adelaide Hospital Research Ethics Committee

Study Contacts

If you have any issues you would like to discuss please don't hesitate to contact either:

Ms Teresa Burgess, Project Manager

☎ 08 8303 3468 or 0424 586 826

✉ teresa.burgess@adelaide.edu.au

Professor Annette Braunack-Mayer, Chief Investigator

☎ 08 8303 3569

✉ annette.braunackmayer@adelaide.edu.au

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE
STANDARD CONSENT FORM FOR PEOPLE WHO ARE PARTICIPANTS
IN A RESEARCH PROJECT



1. I,
(please print name)
consent to take part in the research project entitled:
Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness.

2. I acknowledge that I have read the attached Information Sheet entitled:
Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness

3. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.

4. Although I understand that a purpose of this research project is to improve the quality of health care, it has also been explained that my involvement may not be of any benefit to me.

5. I have been asked for my permission to digitally record the proposed interviews, and I have given this permission.

6. I have been informed that, while information gained during the study may be published, I will not be identified and my personal responses will not be divulged.

7. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, now or in the future.

8. I am aware that I should retain a copy of this Consent Form, when completed, and the attached Information Sheet.

.....
(signature) (date)

WITNESS

I have described to
(name of subject)
the nature of the research to be carried out. In my opinion she/he understood the explanation.

Status in Project:

Name:

(signature) (date)

We will be recruiting participants from the Royal Adelaide Hospital, the Calvary North Adelaide Hospital and the Calvary Wakefield Hospital.

Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness



Participant Information Sheet – Key Policy and Service Provision Stakeholders

Purpose of the study

The number of Australians with advanced chronic disease who are approaching the end of their lives is increasing and the Australian health care system has not yet developed appropriate policies and services to help meet the changing needs of these people and their families. As disease progresses, it can have a big effect on the way people live and the services that they might need. This project will look at the types of care and support that will be most useful for people with advanced disease and their carers and families and how the health system might need to change to make these services available.

What's involved

We will follow a group of people with a variety of chronic diseases and their families for a period of approx nine months to learn more about the care they receive and whether this is meeting their needs as the disease progresses. We will also be talking to the main health professionals who are providing that health care and with policy makers at local, state and Commonwealth level.

Your participation in this project would involve participating in a short interview to discuss the issues raised by participants and their carers, existing gaps in policy as well as your perception of what end of life care for people with advanced chronic disease encompasses, how such care can be provided in the current system, what options there are for expanding the provision of this care as the number of people requiring such care expands dramatically over the coming years and the workforce, resource and financing implications. The interview will be audio taped, if we have your permission to do so. Once we have written up the interview using the audio recordings, you are welcome to read the transcript if you want to. We will ask you at the end of the interview, and if you want to see it, we will send it to you once it is transcribed.

Possible benefits of the study

This research will suggest areas in which health services may need to change and recommend strategies to facilitate and manage the changes required. It will provide the essential background information needed if we are to intervene to change the health system in the areas of chronic disease management and palliative care. We hope this information will lead to improvements in healthcare, but there will be no direct benefits for you personally.

Your rights and protections

- Your participation in this research is completely voluntary and you have the right to withdraw your agreement to participate at any stage you wish to
- You may refuse to answer any questions asked during the interview
- When the Project Team reports on this project, your name or any personal details will never be mentioned, and you will not be identified in any publications that may be written.
- Whilst we will take all steps to keep your information confidential, we have to tell you that it may be subject to disclosure by law, should this be required.

Study Contacts

If you have any issues you would like to discuss please don't hesitate to contact either:

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Investigator

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Professor Annette Braunack-Mayer, Chief

☎ 08 8303 3569

✉ annette.braunackmayer@adelaide.edu.au

If you wish to speak to someone independent of the project, or make a complaint, please see the attached "CONTACTS FOR INFORMATION ON PROJECT AND INDEPENDENT COMPLAINTS PROCEDURE" form.

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE



THE UNIVERSITY
of ADELAIDE

STANDARD CONSENT FORM FOR PEOPLE WHO ARE PARTICIPANTS IN
A RESEARCH PROJECT

1. I,
(please print name)
consent to take part in the research project entitled:
Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness.

2. I acknowledge that I have read the attached Information Sheet entitled:
Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness

3. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.

4. Although I understand that a purpose of this research project is to improve the quality of health care, it has also been explained that my involvement may not be of any benefit to me.

5. I have been asked for my permission to digitally record the proposed interviews, and I have given this permission.

6. I have been informed that, while information gained during the study may be published, I will not be identified and my personal responses will not be divulged.

7. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, now or in the future.

8. I am aware that I should retain a copy of this Consent Form, when completed, and the attached Information Sheet.

.....
(signature) (date)

WITNESS

I have described to
(name of subject)
the nature of the research to be carried out. In my opinion she/he understood the explanation.

Status in Project:

Name:

(signature) (date)

We will be recruiting participants from the Royal Adelaide Hospital, the Calvary North Adelaide Hospital and the Calvary Wakefield Hospital.

Appendix 3. Recruitment checklists

RECRUITMENT CRITERIA CHECKLIST

1. Name of Patient: _____ Pt ID: _____
2. Hospital: _____
3. Would you be surprised if this patient died in the next 12 months?
4. The patient is not living in high or low level residential care
5. The patient is able to speak adequate English
6. The patient is over 18
7. The patient has no significant cognitive impairment
8. The patient has received no active treatment for cancer in the last 2 years and / or does not have metastatic disease
9. The patient has not had / is not listed for a transplant
10. The patient been hospitalised >2 times in the past_12 months
- _____

CARDIAC FAILURE

- a) One of these hospitalisations was for acute heart failure
- b) Other criteria will be decided in consultation with staff in the acute care unit assisting with recruitment and are likely to include consideration of
- i. Respiratory Rate (breaths/min)
 - ii. Systolic blood pressure
 - iii. Blood Urea Nitrogen
 - iv. Sodium Concentration

RENAL FAILURE

- a) One of these hospitalisations was for acute renal failure
- b) Other criteria will be decided in consultation with staff in the acute care unit assisting with recruitment and are likely to include consideration of
 - i. GFR rate <15%
 - ii. Systolic blood pressure
 - iii. Creatinine
 - iv. Haemoglobin
 - v. Urinary protein

NEUROLOGICAL/CVA

- a) One of these hospitalisations was for acute exacerbation of symptoms
 - b) Other criteria will be decided in consultation with staff in the acute care unit assisting with recruitment and are likely to include consideration of
 - i. Rigid predominant motor symptoms
 - ii. Age
 - iii. Level of dysphagia
 - iv. Level of cognitive impairment
-

- 11. The patient is eligible for the study
- 12. A *Consent Form* has been signed
- 13. A *Demographic Details Form* has been completed for this patient

Appendix 4. Recruitment letter template

[Date]

BY EMAIL



[Name]
[Address]

Dear [Name],

We are writing to you regarding a proposed qualitative study we wish to undertake entitled: “*When chronic disease management becomes end of life care: the role of the health system in facilitating the transition*”. The research forms part of a PhD study in Public Health through the University of Adelaide. It will use a qualitative methodology with a case study method to examine Australian health policy and practice in end of life care for people with advanced chronic disease at both the state and national levels; evaluate how policy and practice impact on individuals and their families and identify systemic barriers and enhancers to the provision of appropriate and accessible care. This will allow the identification of specific areas in which to intervene to develop health policy and services to support quality end of life care for this growing group of Australians.

The Principal Investigator in this project is Professor Annette Braunack-Mayer, with co-supervisors Associate Professor Gregory Crawford and Professor Justin Beilby from the University of Adelaide, who are supervising Ms Teresa Burgess who is the student undertaking the PhD.

We are hoping to be able to recruit participants with heart failure, chronic renal disease, Parkinson’s Disease (and other neurological diseases) and stroke through the Royal Adelaide Hospital as well as the Queen Elizabeth, Calvary and Wakefield Hospitals. We aim to recruit ten patients and their families across these 4 hospitals, and to follow them for a period of 9 – 12 months. Specific recruitment criteria would be developed in consultation with each hospital unit. The case study includes interviews with patients and their families, and we also want to include the views of health professionals working with them, both in acute care and the community. Therefore, the involvement we would be asking from your Unit is:

- Assistance recruiting up to a maximum of 3 patients and their families
- Assistance developing recruitment criteria for people with advanced chronic renal disease
- Participation in a focus group of Unit staff at a time and venue convenient to you to discuss issues arising around caring for people with this disease as they approach the end of their life.

This project has been approved by the University of Adelaide Human Research Ethics Committee: Ethics Approval number H-223-2010, and we are currently applying to the RAH Ethics Approval for reciprocal approval. The RAH Ethics Committee has requested a letter of support from the Departments from which we intend to recruit and so I am writing to you to request a letter providing your in-principle support for this project. If you are happy to provide this, and we receive approval from the RAH Ethics Committee, we would be very happy to come to the Renal Medicine Unit and discuss the research in more detail with you and your staff and identify how we can work best together.

Patient follow-up to recruitment by specialist/MS Society

[Date]



DISCIPLINE OF PUBLIC HEALTH

Ms Teresa Burgess
School of Population Health and Clinical
Practice
The University of Adelaide
SA 5005 Australia

Telephone: +61 (08) 8303 3468
Email: teresa.burgess@adelaide.edu.au

[Name]

[Address 1]

[Address 2]

Dear [Name],

Thank you very much for agreeing to be part of the research project we are undertaking through the Royal Adelaide Hospital, looking at the supports available to people with advanced chronic disease and whether these are meeting their needs.

I have attached an Information Sheet about the project, to give you a little more information about what we are doing and why.

I have also attached a Consent Form and reply paid envelope and if you are both happy to participate in the project once you have read the information, could you sign a consent form each and send it back to me?

As you have explained, it may be difficult to answer the questions verbally, so I have also included the Interview Questions, so you can think about them beforehand, and write down some of the answers, if that is easier. Please ring me if you have any questions about this.

If all is OK, I will visit on [date] at [time] and each interview should take between 40 mins and one hour and I will ring you next Thursday or Friday to make sure it is still OK to visit.

If you have any queries at all, please do not hesitate to contact me and if change your mind, that's no problem.

Thank you again or agreeing to speak to me,

Yours sincerely

Teresa Burgess
Discipline of Public Health
School of Population Health and Clinical Practice
University of Adelaide

Service Managers and Policy Makers letter

[Date]



DISCIPLINE OF PUBLIC HEALTH
Ms Teresa Burgess
School of Population Health
The University of Adelaide
SA 5005 Australia

[name]

Telephone: +61 (08) 8313 3468
Email: teresa.burgess@adelaide.edu.au

[address]

Dear [name],

I am a PhD student at the University of Adelaide, and I am writing to you as my research has included discussions with two of your patients/clients: [names], who have given their permission for me to contact you.

They have been participating in a research project which we are undertaking entitled: "*Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness*". This research is examining Australian health policy and practice in end of life care for people with advanced chronic disease and evaluating how policy and practice impact on individuals and their families. We are also looking at systemic barriers and enhancers to the provision of appropriate and accessible care.

Our research includes a series of interviews with people who are approaching the end of their life and who have a variety of chronic diseases. As part of understanding the issues that have arisen for them as [name's] disease has progressed, I was wondering if it would be possible to interview you, and if so, to organise a phone interview at a time convenient to you? We are particularly keen to speak with you regarding specific issues for rural areas.

Dr [specialist] from the RAH referred [names] and I have met with them three times over the last 9 months, and they have been very generous in sharing their story with me. I have attached the proposed interview schedule, so you can see the sorts of questions we will be asking. We would be expecting the interview to take approx 30 minutes. I have also attached an Information Sheet providing more details about the project.

This is not a funded research project, as it is my PhD and so I am unable to offer you any reimbursement for your time.

Would you be able to suggest a time in the next few weeks when I might be able to contact you to discuss the research further? I can be contacted on 0424 586 826 or teresa.burgess@adelaide.edu.au

Thank you very much for considering this request.

Yours sincerely

Key Service Provider Recruitment letter

[Date]



BY EMAIL

DISCIPLINE OF PUBLIC HEALTH

Ms Teresa Burgess
School of Population Health
The University of Adelaide
SA 5005 Australia

[Name]

Telephone: +61 (08) 8313 3468
Email: teresa.burgess@adelaide.edu.au

[email address]

Dear [Name],

We are currently examining the impact of Australian health policy and practice on people with advanced chronic disease through a project entitled: *Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness*.

We have completed a policy audit of state and federal policies related to end of life care, and a case study examining the experiences of a group of people with advanced chronic disease, their carers and health service professionals.

We have identified that there is little articulation between chronic disease and palliative care policies and a number of other policies which impact on end of life care (eg ageing, advance care directives, primary health care and carer policies). This is reflected in the experiences of the people and health professionals with whom we spoke.

We know that the rapidly growing need for end of life care is recognised at a policy and service planning level, however there are a number of barriers and issues associated in ensuring these services are available all who need them, and we would like to speak with you regarding these issues and the sorts of strategies and policies that you think will be required to address them.

This research forms part of my PhD research, and my supervisors are Professor Annette Braunack-Mayer, Professor Justin Beilby and Associate Professor Gregory Crawford.

I was wondering if it would be possible to organise an interview with you, which would last approximately 45 minutes, and can be either face to face or by phone. I have attached a summary of the project results to date, an Information Sheet providing more details about the project and the interview schedule. I am very flexible and am happy to fit in with whatever time suits you best.

I will contact you in the next week or so to see if it might be possible to talk with you about this project. If you need any further information, I can be contacted on 0424 586 826 or teresa.burgess@adelaide.edu.au.

Thank you very much for considering this request.

Yours sincerely,

Teresa Burgess, 2016

Appendix 5. Interview schedules

Chronic disease management along the continuum of care: the role of the health system in supporting people with advanced chronic illness



Patient interview schedule – Interview 1

Introduction: As you know, the number of Australians with advanced chronic disease is increasing and the Australian health care system has not yet developed appropriate policies and services to help meet the changing needs of these people and their families. As disease progresses, it can have a big effect on the way people live and the services that they might need. We want to look at the types of care and support that will be most useful for people with heart failure and your carers and families and how the health system might need to change to make these services available.

Today, I want to discuss with you some of the issues that have arisen for you as your disease has gotten worse, and the sorts of services/supports that you think might help. Everything you say will be treated in confidence and your name or any personal details will never be mentioned in any reports or discussions, and you will not be identified in any publications that may be written. Are you still happy to participate in this project and complete the interview with me?

If anything we discuss today upsets you, let me know straight away and we can stop, and if you would like to discuss any issues that might arise through this interview in more detail with someone, just let me know, and I can make sure I talk to *[your specialist]* and he will arrange for someone from the hospital who will be able to help. If you think of anything after I go that upsets you, or that you would like to talk over with someone, please don't hesitate to ring either myself or Lynn.

Before we begin our conversation, I have a couple of questions to ask you just to provide us with some background, and I have two questionnaires that I would like you to complete, to give us an idea of how you are coping with your illness (*Interviewer completes the Demographic Data Sheet, the PHQ-9 and the WHOQoL BREF*)

If it's OK with you, I am going to record our conversation – just let me know if you want me to turn the recorder off at any time, and I am happy to do so.

Interview guide:

1. How are you feeling today?
2. Can you tell me a little about what it has been like for you managing with this disease?
3. You've had this disease for a long time now, and I can see that it is quite severe now. Can you tell me what it's like for you at the moment, in terms of coping day to day with your illness and the things you need to do?
4. Your primary carer is *[name of carer]*? Do you have other family members or friends who assist you and your carer?
5. Who provides the majority of your medical care?

- a. If a GP, how often do you see them? Does the GP come to your home or do you go the surgery?
 - b. If not a GP – what are the issues associated with this?
6. Have you found that having *this* illness has interfered with you being able to access services for any other problems you may have – eg seeing other specialists?
7. What do you think is the biggest problem for you at the moment?
8. Can you tell me about the types of services/ supports you are using now?
 - a. Are these services helpful for you - are they meeting your needs?
 - b. At different times, as your illness progresses, have you found that the services you might need have changed much?
 - c. Are there other supports/services which you can think of that may assist you, but that you haven't been able to access?
9. Looking back, what's the **one** thing that you think would make the most difference to you, if it were possible to have it, in dealing with this illness?
10. In a perfect world, can you describe for us how treatment for your illness would work so that you felt that you were getting the best care possible?
11. Is there anything else you would like to tell us that might be helpful for you, or other people with a similar illness?
12. We've talked about services that are available or might be useful – do you think there are any services that should be provided specifically for carers?

Advance Care Planning

[explain the term] Advance care planning aims to keep you involved in your medical decisions, both now and in the future, whether you are healthy or have an illness. Advance care planning is especially important when you become so unwell that you can no longer speak for yourself, because, having created a plan in advance, your doctors and family can understand how you would like to be cared for.

13. Have you thought about your future care and what the focus might be if your condition worsens?
14. Has the specialist or anyone at the hospital had a conversation with you (and you carer?) about your future wishes and what types of treatment you may or may not want?
 - a. If yes - has this been documented in any way?
 - b. If yes - how useful do you think it was/would be to be able to discuss this with someone?
 - c. If no - whose responsibility do you think it is to talk to you about these sorts of things?
15. How do you see things going from here?
16. Would you like to talk more with someone about your future wishes?
17. Is there anything else you would like to say at all about living with your illness, or any other aspects of your care?

Thank You

Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness



Patient interview schedule – Interview 2

Introduction: It's been three months since we last met, and I hope all has been going well for you. Just a quick summary of the research we are doing – we are looking at the types of care and support that will be most useful for people with *[your illness - name]* and your carers and families and how the health system might need to change to make these services available. Last time, we spoke about the sorts of services and supports you were using, and what you might like in a perfect world!

Today, I want to discuss with you any issues that might have arisen for you over the last three months and any new services you might have started to receive or think you might need. As before, everything you say will be treated in confidence and your name or any personal details will never be mentioned in any reports or discussions, and you will not be identified in any publications that may be written. Are you still happy to participate in this project and complete the interview with me?

Also, as we said before, if anything we discuss today upsets you, let me know straight away and we can stop, and if you would like to discuss any issues that might arise through this in more detail with someone, just let me know, and I can make sure you are referred to someone from the hospital who will be able to help. I will also leave the contact details for a person at the hospital who can help, if you think of anything after I go that upsets you, or that you would like to talk over with someone.

If you wouldn't mind, first I would like you to fill out the same two questionnaires as last time, to give us an idea of how you are coping with your illness (*Interviewer completes the Demographic Data Sheet, the Patient Outcome Scale and the QoL Measure*)

If it's OK with you, I am going to record our conversation – just let me know if you want me to turn the recorder off at any time, and I am happy to do so.

Interview guide:

1. How are you feeling today?
2. How have the last few months been for you, in terms of your illness?
3. How is *[name of carer]* going?
 - a. Have other family members or friends been able to assist you and your carer?
4. Is *[previously nominated major health service provider]* still providing most of your health care services?
 - a. How is that working for you?
5. How is accessing other services for any other problems you may have going – eg seeing other specialists?
6. Can you tell me about the types of services/ supports you are using now?
 - a. Are these services helpful for you - are they meeting your needs?

- b. Have they changed much from last time we spoke?
 - c. Has anyone spoken to you about the services offered through Palliative Care?
 - d. Are there other supports/services which you can think of that may assist you, but that you haven't been able to access?
7. Last time you nominated *[problem]* as your biggest problem - what do you think is the biggest problem for you at the moment?
 8. Last time you nominated *[difference]* as the **one** thing that you think would make the most difference to you, if it were possible to have it, in dealing with this illness. Is that still the same?
 9. In a perfect world, can you describe for us how treatment for your illness would work so that you felt that you were getting the best care possible?
 10. Is there anything else you would like to tell us that might be helpful for you, or other people with a similar illness?
 11. We've talked about services that are available or might be useful – do you think there are any services that should be provided specifically for carers?

Advance Care Planning

12. Last time we talked a little about Advance Care Planning – have you had a chance to talk to anyone about this (if you wanted to)?
 - a. *If an Advance Care Plan has been developed:* – was this a useful process for you and *[patient's name]*? In what ways?
 - b. *If an Advance Care Plan has not been developed:* – have you had a chance to talk to anyone about this (if you wanted to)?
13. Would you like to talk more with someone about your future wishes?
14. Is there anything else you would like to say at all about living with your illness, or any other aspects of your care?

Thank You

Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness



Patient interview schedule – Interview 3

Introduction: It's been six months since we last met, and I hope all has been going well for you. Just to remind you about the research we are doing – we are looking at the types of care and support that will be most useful for people with *[your illness - name]* and your carers and families and how the health system might need to change to make these services available. We have previously spoken about the sorts of services and supports you were using, and what you might like in a perfect world.

Today is our last meeting and I want to discuss with you any issues that might have arisen for you over the last three months and any new services you might have started to receive or think you might need. As before, everything you say will be treated in confidence and your name or any personal details will never be mentioned in any reports or discussions, and you will not be identified in any publications that may be written. Are you still happy to participate in this project and complete the interview with me?

Also, as we said before, if anything we discuss today upsets you, let me know straight away and we can stop, and if you would like to discuss any issues that might arise through this in more detail with someone, just let me know, and I can make sure you are referred to someone from the hospital who will be able to help. I will also leave the contact details for a person at the hospital who can help, if you think of anything after I go that upsets you, or that you would like to talk over with someone.

If you wouldn't mind, first I would like you to fill out the same two questionnaires as last time, to give us an idea of how you are coping with your illness (*Interviewer completes the Demographic Data Sheet, the Patient Outcome Scale and the QoL Measure*)

If it's OK with you, I am going to record our conversation – just let me know if you want me to turn the recorder off at any time, and I am happy to do so.

Interview guide:

1. How have the last few months been for you, in terms of your illness?
2. How is *[name of carer]* going?
 - a. Have other family members or friends been able to assist you and your carer?
3. Have you been admitted to hospital since I last saw you?
 - a. How many times?
 - b. What was the main reason?
4. Can you tell me about the types of services/ supports you and *[patient's name]* are using now?
 - a. Are these services helpful - are they meeting your needs?
 - b. Have they changed much from last time we spoke?

- c. Are there other supports/services which you can think of that may assist you, but that you haven't been able to access?
 - d. Has anyone suggested you access services provided through a Palliative Care Team?
5. Is *[previously nominated major health service provider]* still providing most of your health care services??
 - a. How is that working for you?
6. Last time you nominated *[problem]* as your biggest problem - what do you think is the biggest problem for you at the moment?
7. Last time you nominated *[difference]* as the **one** thing that you think would make the most difference to you, if it were possible to have it, in dealing with this illness? Is that still the same?
8. In a perfect world, can you describe for us how treatment for your illness would work so that you felt that you were getting the best care possible?
9. Is there anything else you would like to tell us that might be helpful for other people with a similar illness?
10. We've talked about services that are available or might be useful – do you think there are any services that should be provided specifically for carers?

Advance Care Planning

11. Last time we talked a little about Advance Care Planning
 - a. *If an Advance Care Plan has been developed:* – was this a useful process for you? In what ways?
 - b. *If an Advance Care Plan has not been developed:* – have you had a chance to talk to anyone about this (if you wanted to)?
12. Would you like to talk more with someone about your future wishes?
13. Is there anything else you would like to say at all about your illness and/ or the experience of living with a serious illness over a long period of time?

Thank You

Chronic disease management along the continuum of care: the role of the health system in supporting people with advanced chronic illness



Carer interview schedule – Interview 1

Introduction: As you know, the number of Australians with advanced chronic disease is increasing and the Australian health care system has not yet developed appropriate policies and services to help meet the changing needs of these people and their families. As disease progresses, it can have a big effect on the way people live and the services that they might need. We want to look at the types of care and support that will be most useful for people with *[name illness]* and their carers and families and how the health system might need to change to make these services available.

Today, I want to discuss with you some of the issues that have arisen for you as the disease that the person you are caring for has gotten worse and the sorts of things that you think might help. Everything you say will be treated in confidence and your name or any personal details will never be mentioned in any reports or discussions, and you will not be identified in any publications that may be written. Are you still happy to participate in this project and complete the interview with me?

If anything we discuss today upsets you, let me know straight away and we can stop, and if you would like to discuss any issues that might arise through this in more detail with someone, just let me know, and I can make sure I talk to *[your specialist]* and he will arrange for someone from the hospital who will be able to help.

I will also give you the contact details for Carers SA who will be able to help if you think of anything you would like to discuss after I leave.

If it's OK with you, I am going to record our conversation – just let me know if you want me to turn the recorder off at any time, and I am happy to do so.

Interview guide:

1. Can you tell me a little about what it has been like for you caring for *[patient's name]* as his/her disease has progressed?
2. Do you have other family members or friends who assist you with caring for *[patient's name]*?
3. What do you think is the biggest problem for *[patient's name]* at the moment?
 - a. What is *your* biggest problem at the moment
4. Can you tell me about the types of services/ supports you are accessing for *[patient's name]* now?
 - a. Are these services helpful - are they meeting his/her needs?
 - b. Are you accessing any services for yourself?
5. At different times, as *[patient's name]* illness has progressed, have you found that the services he/she needs have changed much?

6. Are there other supports/services which you can think of that may assist *[patient's name]*, but that you haven't been able to access?
7. Do you have any medical problems that you are being treated for at the moment?
 - a. Who provides the majority of *your* medical care?
8. Looking back, what's the **one** thing that you think would make the most difference to you, if it were possible to have it, in caring for *[patient's name]*?
9. In a perfect world, can you describe for me how someone with *[name illness]* would be cared for so that you felt that they were getting the best care possible?
10. Is there anything else you would like to tell me that might be helpful for other people caring for someone with a similar illness?
11. We've talked about services that are available or might be useful – do you think there are any services that should be provided specifically for carers?

Advance Care Planning

[explain the term]

Advance care planning aims to keep people involved in their medical decisions, both now and in the future, whether they are healthy or have an illness. Advance care planning is especially important when people become so unwell that they can no longer speak for themselves because, having created a plan in advance, doctors and family can understand how people would like to be cared for.

12. Have you been able to talk with *[patient]* about their future care and what the focus might be if their condition worsens?
13. Has the specialist or anyone at the hospital had a conversation with you and *[patient's name]* about *[patient's name]* future wishes and what types of treatment he/she may or may not want?
 - a. If yes - has this been documented in any way?
 - b. If yes - how useful do you think it was/would be to be able to discuss this with someone?
 - c. If no, how useful do you think it would be to be able to discuss this with someone?
 - d. If no - whose responsibility do you think it is to talk to you about these sorts of things?
14. Would you like to talk more with someone about this?
15. Is there anything else you would like to say at all about *[patient's name]* illness, or the experience of caring for someone with a serious illness?

Thank You

Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness



Carer interview schedule – Interview 2

Introduction: It's been three months since we last met, and I hope all has been going well for you. Just a quick summary of the research we are doing – we are looking at the types of care and support that will be most useful for people with *[name of illness]* and their carers and families and how the health system might need to change to make these services available. Last time, we spoke about the sorts of services and supports available and that the person you are caring for was using, and what services might look like in a perfect world!

Today, I want to discuss with you any issues that might have arisen for you and *[patient's name]* over the last three months and any new services you might have accessed or think you might need. As before, everything you say will be treated in confidence and your name or any personal details will never be mentioned in any reports or discussions, and you will not be identified in any publications that may be written. Are you still happy to participate in this project and complete the interview with me?

Also, as we said before, if anything we discuss today upsets you, let me know straight away and we can stop, and if you would like to discuss any issues that might arise through this in more detail with someone, just let me know, and I can make sure you are referred to someone from the hospital who will be able to help. I will also give you the contact details for Carers SA again, who will be able to help if you think of anything you would like to discuss after I leave.

If it's OK with you, I am going to record our conversation – just let me know if you want me to turn the recorder off at any time, and I am happy to do so.

Interview guide:

1. How have the last few months been for you and *[patient's name]*?
2. Have other family members or friends been able to assist you and *[patient's name]*?
3. How are you feeling at the moment?
4. Last time you nominated *[problem]* as *[patient's name]* biggest problem - what do you think is his/her biggest problem at the moment?
 - a. And *your* current biggest problem?
5. Can you tell me about the types of services/ supports you are accessing for *[patient's name]* at the moment?
 - a. Are these services helpful - are they meeting his/her needs?
 - b. Has anyone suggested you access services provided through a Palliative Care Team?
6. Are there other supports/services which you can think of that may assist you, but that you haven't been able to access?
 - a. Are you accessing any services for yourself?

7. Have you been able to access any services specifically for carers?
 - a. If not, would you like to?
8. Last time you nominated [*difference*] as the **one** thing that you think would make the most difference to you, if it were possible to have it, in dealing with this illness? Is that still the same?
9. In a perfect world, can you describe for us how someone with [*name illness*] would be cared for so that you felt that they were getting the best care possible?
10. Is there anything else you would like to tell us that might be helpful for you, or other people with a similar illness?

Advance Care Planning

11. Last time we talked a little about Advance Care Planning
 - a. *If an Advance Care Plan has been developed:* – was this a useful process for you and [*patient's name*]? In what ways?
 - b. *If an Advance Care Plan has not been developed:* – have you had a chance to talk to anyone about this (if you wanted to)?
12. Would you like to talk more with someone about your future wishes?
13. Is there anything else you would like to say at all about [*patient's name*] illness, or the experience of caring for someone with a serious illness?

Thank You

Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness



Carer interview schedule – Interview 3

Introduction: It's been six months since we last met, and I hope all has been going well for you. Just to remind you about the research we are doing – we are looking at the types of care and support that will be most useful for people with *[name of illness]* and their carers and families and how the health system might need to change to make these services available. We have previously spoken about the sorts of services and supports you were using, and what you might like in a perfect world!

Today is our last meeting and I want to discuss with you any issues that might have arisen for you over the last six months and any new services you might have started to receive or think you might need. As before, everything you say will be treated in confidence and your name or any personal details will never be mentioned in any reports or discussions, and you will not be identified in any publications that may be written. Are you still happy to participate in this project and complete the interview with me?

Also, as we said before, if anything we discuss today upsets you, let me know straight away and we can stop, and if you would like to discuss any issues that might arise through this in more detail with someone, just let me know, and I can make sure you are referred to someone from the hospital who will be able to help. I will also give you the contact details for Carers SA who will be able to help if you think of anything you would like to discuss after I leave.

If it's OK with you, I am going to record our conversation – just let me know if you want me to turn the recorder off at any time, and I am happy to do so.

Interview guide:

1. How have the last few months been for you, in terms of *[patient's name]* illness?
2. Have other family members or friends been able to assist you in caring for *[patient's name]*?
3. Has *[patient's name]* been admitted to hospital since I last saw you?
 - a. How many times?
 - b. What was the main reason?
 - c. Did this make any difference to the services required when he/she was discharged?
 - d. What impact did the hospitalisation (s) have on you?
4. Can you tell me about the types of services/ supports you and *[patient's name]* are using now?
 - e. Are these services helpful for *[patient's name]* - are they meeting his/her and your needs?
 - f. Have they changed much from last time we spoke?

- g. Are there other supports/services which you can think of that may assist you, but that you haven't been able to access?
 - h. Has anyone suggested you access services provided through a Palliative Care Team?
5. Looking back over the last nine months, what have been the biggest problems for you in caring for *[patient's name]*?
6. How could the system have worked differently to make it easier for you?
- a. Have you been able to access any services specifically for carers?
7. Last time you nominated *[difference]* as the **one** thing that you think would make the most difference to you, if it were possible to have it, in dealing with this illness? Is that still the same?
8. Is there anything else you would like to tell us that might be helpful for other people with a similar illness to know?

Advance Care Planning

9. Last time we talked a little about Advance Care Planning
- c. *If an Advance Care Plan has been developed:* – was this a useful process for you and *[patient's name]*? In what ways?
 - d. *If an Advance Care Plan has not been developed:* – have you had a chance to talk to anyone about this (if you wanted to)?
10. Would you like to talk more with someone about your future wishes?
11. Is there anything else you would like to say at all about *[patient's name]* illness, or the experience of caring for someone with a serious illness over a long period of time?

Thank You

Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness



Key Service Providers Interview Schedule (Specialist)

Introduction: Many thanks for agreeing to talk to me today. As you know, the number of Australians with advanced chronic disease who are approaching the end of their lives is increasing and the Australian health care system has not yet developed appropriate policies and services to help meet the changing needs of these people and their families. As disease progresses, it can have a big effect on the way people live and the services that they might need. We want to look at the types of care and support that will be most useful for people with chronic disease and their families and how the health system might need to change to make these services available.

Overall, this research will identify where the current gaps in services exist, where the barriers are for patients and their families in accessing the care they require, suggest areas in which to intervene and recommend strategies to facilitate and manage the changes required. We hope to provide the essential background information needed if we are to intervene to change the health system in the areas of chronic disease management and palliative care. By identifying the systemic and organisational constraints and barriers to the provision of quality end of life care, we can identify the most effective levels and points of intervention to assist with changing the system and overcoming these constraints and barriers.

Today, I want to discuss with you the issues that arise for you in caring for people with chronic disease who are approaching the end of their life, the sorts of services that would be useful and any issues accessing them, and how you think the system might need to change to support these people.

Everything you say will be treated in confidence and your name or any personal details will never be mentioned in any reports or discussions, and you will not be identified in any publications that may be written.

If it's OK with you, I am going to record our conversation – just let me know if you want me to turn the recorder off at any time, and I am happy to do so.

Interview guide:

1. Can you tell us a little about the main services that you have found that your patients with advanced chronic disease require and whether these services are easily accessible?
2. Do you think the services that people with advanced chronic disease *are* able to access at the moment are meeting their needs? / If not – why not?
 - a. In terms of being able to access services for people, what are the major issues that you come across when trying to refer them?
 - b. Do you think there any differences between specific chronic diseases in being able to access services?
 - c. What do you think would make a difference?

3. In what ways do you think the services that patients with advanced chronic disease require change as their condition deteriorates?
 - a. What are the barriers or facilitators for patients in access to /changing / extending services as their conditions deteriorates.
 - b. How do you think the system should work to enable patients to seamlessly access services to support them as their disease advances and they approach the end of their life?
4. We know that people with advanced chronic disease can have a long trajectory of decline, with acute, severe episodes and then improvement. Do you have any ideas or suggestions for how care can best be provided given this varying process?
5. What strategies do you think would help to improve continuity and coordination of care across the acute, primary and community sectors?
6. Do you refer patients to palliative care services?
 - a. What factors influence your decision whether to make a referral
7. What do you think are the key issues for specialists in initiating and continuing conversations around advance care planning and completing documentation such as a Medical Power of Attorney and Anticipatory Directions?
 - a. Do you routinely raise the issue of Advance Care Directives with patients with advanced disease?
 - b. Whose responsibility do you think it is to begin this discussion?
8. The issue of “caring for carers” is a growing one – do you feel there is enough support currently for carers?
 - a. What role do you think you play in supporting carers?
9. In a perfect world, what services (and access requirements) would you like to see for patients with advanced chronic disease?
10. In terms of supporting infrastructure for sustaining services and care for patients with advanced chronic disease, what do you think are the most important elements the health services need to address (eg: Workforce? Training? IT?)

Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness



Key Service Providers Interview Schedule. (Community)

Introduction: Many thanks for agreeing to talk to me today. As you know, the number of Australians with advanced chronic disease who are approaching the end of their lives is increasing and the Australian health care system has not yet developed appropriate policies and services to help meet the changing needs of these people and their families. As disease progresses, it can have a big effect on the way people live and the services that they might need. We want to look at the types of care and support that will be most useful for people like *[name the patient and illness]* and their carers and families and how the health system might need to change to make these services available

Overall, this research will identify where the current gaps in services exist, where the barriers are for patients and their families in accessing the care they require, suggest areas in which to intervene and recommend strategies to facilitate and manage the changes required. We hope to provide the essential background information needed if we are to intervene to change the health system in the areas of chronic disease management and palliative care. By identifying the systemic and organisational constraints and barriers to the provision of quality end of life care, we can identify the most effective levels and points of intervention to assist with changing the system and overcoming these constraints and barriers.

Today, I want to discuss with you the issues that arise for you in caring for people with chronic disease who are approaching the end of their life, the sorts of services that would be useful and any issues accessing them, and how you think the system might need to change to support these people.

Everything you say will be treated in confidence and your name or any personal details will never be mentioned in any reports or discussions, and you will not be identified in any publications that may be written

If it's OK with you, I am going to record our conversation – just let me know if you want me to turn the recorder off at any time, and I am happy to do so.

Interview guide:

1. Can you tell us a little about the main services that you found that your patients with advanced chronic disease *[like patient's name]* require and whether these services are easily accessible?
2. Do you think the services that people with advanced chronic disease are able to access at the moment are meeting their needs? / If not – why not?
3. In terms of being able to access services for people like *[patient's name]*, what are the major issues that you come across when trying to refer them?
 - a. Are there any differences between specific chronic diseases in being able to access services?

4. In what ways do you think the services that patients like [*patient's name*] require change as their condition deteriorates?
5. What are the barriers or facilitators for patients in access to /changing / extending services as their conditions deteriorates.
6. How do you think the system should work to enable patients like [*patient's name*] to seamlessly access services to support them as their disease advances and they approach the end of their life?
7. We know that people like [*patient's name*] can have a long trajectory of decline, with acute, severe episodes and then improvement. Do you have any ideas or suggestions for how care can best be provided given this varying process?
8. We have said that [*patient's name*], has advanced disease and is approaching the end of his/her life. Have you been able to discuss this issue of end of life care with [*patient's name*]?
 - a. Have you raised the issue of Advance Care Directives with [*patient's name*]?
 - b. Whose responsibility do you think it is to begin this discussion?
9. What about support for carers?
 - a. What role do you see your service playing in also supporting carers?
10. In a perfect world, what services (and access requirements) would you like to see for patients with advanced chronic disease?
11. In terms of supporting infrastructure for sustaining services and care for patients with advanced chronic disease, what do you think are the most important elements the health services need to address
12. Workforce?
 - a. Training?
 - b. IT?

Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness



Key Service Providers Interview Schedule (Advocate)

Introduction: Many thanks for agreeing to talk to me today. As you know, the number of Australians with advanced chronic disease who are approaching the end of their lives is increasing and the Australian health care system has not yet developed appropriate policies and services to help meet the changing needs of these people and their families. As disease progresses, it can have a big effect on the way people live and the services that they might need. We want to look at the types of care and support that will be most useful for people like Di and Doug Vause and their families and how the health system might need to change to make these services available.

Overall, this research will identify where the current gaps in services exist, where the barriers are for patients and their families in accessing the care they require, suggest areas in which to intervene and recommend strategies to facilitate and manage the changes required. We hope to provide the essential background information needed if we are to intervene to change the health system in the areas of chronic disease management and palliative care. By identifying the systemic and organisational constraints and barriers to the provision of quality end of life care, we can identify the most effective levels and points of intervention to assist with changing the system and overcoming these constraints and barriers.

Today, I want to discuss with you the issues that arise for you in caring for people with chronic disease who are approaching the end of their life, the sorts of services that would be useful and any issues accessing them, and how you think the system might need to change to support these people.

Everything you say will be treated in confidence and your name or any personal details will never be mentioned in any reports or discussions, and you will not be identified in any publications that may be written.

If it's OK with you, I am going to record our conversation – just let me know if you want me to turn the recorder off at any time, and I am happy to do so.

Interview guide:

1. Can you tell us a little about the main services that you found that your clients with advanced chronic disease like [name] require and whether these services are easily accessible?
2. Do you think the services that people with advanced chronic disease are able to access at the moment are meeting their needs? / If not – why not?
 - a. In terms of being able to access services for people like [name], what are the major issues that you come across when trying to refer them?
 - b. Are there any differences between specific chronic diseases in being able to access services?

3. In what ways do you think the services that patients like [name] require change as their condition deteriorates?
 - a. What are the barriers or facilitators for patients in access to /changing / extending services as their conditions deteriorates.
 - b. How do you think the system should work to enable patients like Di to seamlessly access services to support them as their disease advances and they approach the end of their life?
4. We know that people like [name] can have a long trajectory of decline, with acute, severe episodes and then improvement. Do you have any ideas or suggestions for how care can best be provided given this varying process?
5. What about support for carers?
 - a. How accessible so you think support for carers is?
6. In a perfect world, what services (and access requirements) would you like to see for patients with advanced chronic disease?
7. In terms of supporting infrastructure for sustaining services and care for patients with advanced chronic disease, what do you think are the most important elements the health services need to address (e.g. Workforce? Training? IT?)

Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness



Service Manager and Policy Maker Key Stakeholder Interview Schedule

Introduction: Many thanks for agreeing to talk to me today. As you know, the number of Australians with advanced chronic disease who are approaching the end of their lives is increasing and the Australian health care system has not yet developed policies and services to meet the changing needs of these people and their families. As disease progresses, it can have a big effect on the way people live and the services that they might need.

The aim of this research was to identify where the current gaps in services exist, where the barriers are for patients and their families in accessing the care they require, suggest areas in which to intervene and recommend strategies to ensure equitable access for all to best practice end of life care. By identifying the systemic and organisational constraints and barriers to the provision of quality end of life care in the areas of chronic disease management and palliative care, we hoped to identify the most effective levels and points of intervention to facilitate and manage the system changes required.

Today, I want to discuss with you the results of our research to date, including the issues raised by the policy audit of national and state end of life care policies and procedures, including existing gaps in policy and the results of the interviews with participants and their carers and their experience of care as they approach the end of life.

Everything you say will be treated in confidence and your name or any personal details will never be mentioned in any reports or discussions, and you will not be identified in any publications that may be written.

If it's OK with you, I am going to record our conversation – just let me know if you want me to turn the recorder off at any time, and I am happy to do so.

Interview guide:

11. Whilst there is increasing recognition that palliative care provides active and holistic care for patients who live with an advanced, progressive illness and it should be available to anyone with a life limiting illness, in practice, palliative care services still focus mainly on people with cancer in the terminal stages of their illness.
 - a. How do you think the system can change to encompass a broader understanding of end of life care?
 - b. What processes would facilitate an increasing focus on supportive and palliative care for people with advanced chronic disease?
 - c. How do you think we can we address the fear of palliative care services that they will be swamped by the large number of people with advanced chronic disease, when they feel their current resources restrict the care they can provide to terminally ill patients?
 - * *The impact of current funding climates*
12. Palliative care takes a patient/person centred holistic approach to care and “person centred care” is increasingly being recognised as a core element of

quality and a way to improve health service provision. There is little agreement however on what constitutes patient centred care.

- a. What is your understanding of patient centred care?
 - b. How do you think understandings of what patient centred care means can be better aligned across the health system?
 - c. How do you think our current models of chronic disease care could be changed to provide a more patient centred approach?
13. A major issue often cited in our research was knowing how to integrate palliative and chronic disease care when the trajectory of chronic disease is so unpredictable and there is growing evidence that there is no “transition” to end of life in chronic disease. This meant people were unsure of when to initiate palliative care (either referral or moving to a supportive care model)
- a. How do you think the flexibility that is required to allow both active disease management and supportive care can be built into the current system?
14. Primary care is often cited as the most appropriate service to effectively provide end of life care, with general practice as the care co-ordinator. However, our research identified that the current financial and organisational structure of general practice does not allow the time required for effective end of life care, nor does it reimburse adequately for end of life care requirements such as advance care planning, home visits, family and psycho-social support etc.
- a. How do you think these issues can be addressed for primary care?
15. Integrating and co-ordinating care across the acute, primary and community sectors remains a very difficult issue in Australia and was again highlighted as a key issue in our research, particularly those with co-morbidities and between chronic disease and palliative care services
- a. What do you think are the key facilitators that could be used to improve integration and co-ordination across the acute/primary/community sectors?
 - b. What about integration across disease specific care silos?
 - c. Do you think dedicated care coordinators are a useful strategy for facilitating both integration and person centred care?
16. Our research identified that, although most health professionals felt that advance care planning was very important, the majority found it, for various reasons, difficult to do. Whilst new advance care planning frameworks are being introduced at state and federal levels, actually having the conversations comes down to individual health professionals.
- a. In the short term, how can this be facilitated?
 - * *Culture change?*
 - b. What strategies do we need to put in place to ensure that advance care planning discussions are a routine part of the accepted spectrum of health care?

17. Carers are increasingly identified as vital in care provision for people with advanced chronic disease. Whilst there are now some supports in place, a key issue raised in our research was access to respite and psycho-social support
 - a. How do you think the system can change to support carers more effectively?
18. What options do you see for expanding the provision of end of life care as the number of people requiring such care expands dramatically including
 - a. Changing workforce needs
 - b. Increased resources, including financial implications
 - c. Facilitating culture change

Appendix 6. Data collection tools

Demographic data collection forms

Participant Demographics and Data Sheet

1. Participant ID: _____

2. Today's Date _____

3. Participant's name: _____

4. Participant's Address: _____

5. Postcode: _____

6. Phone Number: _____

7. DOB: _____

8. Gender: M F

9. What is the participant's country of birth? _____

10. What is the main language spoken at home? _____

11. Is the participant of Aboriginal descent? Yes No

11a. Is the participant of Torres Strait Islander descent? Yes No

12. Does the participant have a social security benefit card? Yes No

12a. If yes, what type of card?

Gold Repat Health Card DVA	<input type="checkbox"/>	Pensioners Concession Card	<input type="checkbox"/>
White Repat Health Card (DVA)	<input type="checkbox"/>	Disability Support pension	<input type="checkbox"/>

Seniors Health Card Other

12b. Please Specify Other:

13. Does the participant have private health insurance? Yes No

14. Does the participant currently drive a motor vehicle? Yes No

15. What is the participant's BMI? _____

16. Does the participant have any other illnesses/diseases? Yes No

17a. Co-morbidity Type:

Diabetes COPD

IHD CHF

Arthritis Other

17b. Please Specify Other:

18. No of hospital admissions in the last two years : _____

19. Has the participant nominated a GP/s? Yes No

20. Was the participant referred to any other service? Yes No

20a. If yes, who were they referred to:

Palliative Care Team Specialist

RDNS / FOCUS ACAT Referral

Hospital OPD DomCare SA

Hospital specialist nurse Self Management programs

Patient Support groups QUIT support

Meals service Transport services

Rehab (outpatient) Local Council services

Other

20b. Please Specify OPD / Other:

Carer Demographics

1. Carer ID: _____

2. Today's Date _____

3. Carer's name: _____

4. Carer's Address: _____

5. Postcode: _____

6. Phone Number: _____

7. DOB: _____

8. Gender: M F

9. What is the carer's country of birth? _____

10. What is the main language spoken at home? _____

11. Is the carer of Aboriginal descent? Yes No

11a. Is the carer of Torres Strait Islander descent? Yes No

12. How many hours does the carer spend caring per week?

0-10 hours 11-20 hours 21-30 hours 31-40
hours

41-50 hours 51-60 hours 61-70 hours > 71-
hours

13. How long has the person been a carer? _____ years

The Patient Health Questionnaire²⁵⁸

PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

NAME: _____ DATE: _____

Over the last 2 weeks, how often have you been bothered by any of the following problems?
(use "✓" to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself in some way	0	1	2	3

add columns: + +

(healthcare professional: For interpretation of TOTAL, please refer to accompanying scoring card.) TOTAL:

10. If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	Not difficult at all	_____
	Somewhat difficult	_____
	Very difficult	_____
	Extremely difficult	_____

PHQ-9 is adapted from PRIME MD TODAY, developed by Drs Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke, and colleagues, with an educational grant from Pfizer Inc. For research information, contact Dr Spitzer at ris0@columbia.edu. Use of the PHQ-9 may only be made in accordance with the Terms of Use available at <http://www.pfizer.com>. Copyright ©1999 Pfizer Inc. All rights reserved. PRIME MD TODAY is a trademark of Pfizer Inc.

ZT242043

Fold back this page before administering this questionnaire

INSTRUCTIONS FOR USE

for doctor or healthcare professional use only

PHQ-9 QUICK DEPRESSION ASSESSMENT

For initial diagnosis:

1. Patient completes PHQ-9 Quick Depression Assessment on accompanying tear-off pad.
2. If there are at least 4 ✓s in the blue highlighted section (including Questions #1 and #2), consider a depressive disorder. Add score to determine severity.
3. **Consider Major Depressive Disorder**
—if there are at least 5 ✓s in the blue highlighted section (one of which corresponds to Question #1 or #2)
Consider Other Depressive Disorder
—if there are 2 to 4 ✓s in the blue highlighted section (one of which corresponds to Question #1 or #2)

Note: Since the questionnaire relies on patient self-report, all responses should be verified by the clinician and a definitive diagnosis made on clinical grounds, taking into account how well the patient understood the questionnaire, as well as other relevant information from the patient. Diagnoses of Major Depressive Disorder or Other Depressive Disorder also require impairment of social, occupational, or other important areas of functioning (Question #10) and ruling out normal bereavement, a history of a Manic Episode (Bipolar Disorder), and a physical disorder, medication, or other drug as the biological cause of the depressive symptoms.

To monitor severity over time for newly diagnosed patients or patients in current treatment for depression:

1. Patients may complete questionnaires at baseline and at regular intervals (eg, every 2 weeks) at home and bring them in at their next appointment for scoring or they may complete the questionnaire during each scheduled appointment.
2. Add up ✓s by column. For every ✓: Several days = 1 More than half the days = 2 Nearly every day = 3
3. Add together column scores to get a TOTAL score.
4. Refer to the accompanying PHQ-9 Scoring Card to interpret the TOTAL score.
5. Results may be included in patients' files to assist you in setting up a treatment goal, determining degree of response, as well as guiding treatment intervention.

PHQ-9 SCORING CARD FOR SEVERITY DETERMINATION

for healthcare professional use only

Scoring—add up all checked boxes on PHQ-9

For every ✓: Not at all = 0; Several days = 1;
More than half the days = 2; Nearly every day = 3

Interpretation of Total Score

Total Score	Depression Severity
1-4	Minimal depression
5-9	Mild depression
10-14	Moderate depression
15-19	Moderately severe depression
20-27	Severe depression

The WHOQoL Bref²⁹³

WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks.

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5

Scoring the WHOQoL Bref²⁹³

The WHOQOL-BREF (Field Trial Version) produces a quality of life profile. It is possible to derive four domain scores. There are also two items that are examined separately: question 1 asks about an individual's overall perception of quality of life and question 2 asks about an individual's overall perception of their health. The four domain scores denote an individual's perception of quality of life in each particular domain. Domain scores are scaled in a positive direction (i.e. higher scores denote higher quality of life). The mean score of items within each domain is used to calculate the domain score. Mean scores are then multiplied by 4 in order to make domain scores comparable with the scores used in the WHOQOL-100. Explicit instructions for checking and cleaning data, and for computing domain scores, are given in Table 3. A method for the manual calculation of individual scores is given on page 1 of the WHOQOL-BREF assessment form. The method for converting raw scores to transformed scores when using this method is given in Table 4, on page 11 of these instructions. The first transformation method converts scores to range between 4-20, comparable with the WHOQOL-100. The second transformation method converts domain scores to a 0-100 scale.

Where more than 20% of data is missing from a assessment, the assessment should be discarded (see Step 4 in Table 3). Where an item is missing, the mean of other items in the domain is substituted. Where more than two items are missing from the domain, the domain score should not be calculated (with the exception of domain 3, where the domain should only be calculated if < 1 item is missing)..

From: Graeme Hawthorne <graemeeh@unimelb.edu.au>
Sent: Thursday, 25 August 2011 11:26 AM
To: Teresa Burgess
Subject: RE: Request for permission to use the WHOQoL Bref

Dear Teresa –

Thank you for the registration for your project for the WHOQOL-BREF. This project has now been registered with the Australian WHOQOL Field Centre; your registration number is 2011/15

You can find more details about the WHOQOL family of instruments at the Australian WHOQOL Field Centre website (<http://www.psychiatry.unimelb.edu.au/qol/>).

Registration also entitles you to additional WHOQOL technical support; including access to the WHOQOL manual; advice on data entry and maintenance; imputing missing data; the WHOQOL scoring algorithms; and assistance with interpretation of WHOQOL data including population norms.

Regarding your comment on the Skevington & McCrate paper re use of the WHOQOL-BREF at the individual patient level. The conclusion they reach regarding individual use is subject to the variation in scores. There are two points.

- They rely upon a high Cronbach alpha ($= 0.92$) for justification. By itself, however, this is not sufficient evidence for an instrument to be used at the patient level. A high alpha is a function of the number of items \times the covariance between items – the greater the number of items and the higher the covariance the higher the alpha. It does not address variation in scores per se.
- The other point is that the variation has to be taken into account. For a patient/person to demonstrate clinically significant change (CID) in response to therapy, their post-therapy score must be such that it is outside the normal range of scores obtained by patients with the condition of interest. Suppose patients with COPD had a mean score on instrument X of 10 and the standard deviation (SD) was |3|; i.e. the range of scores defined by 1 SD was 7 – 13. For patient Y, whose baseline score was 8 and their post-treatment score was 12, we could not be certain that the intervention had made a clinically important difference to their health state since their post-treatment score was still within the normal range of scores (7-13) for patients with COPD.

If we apply this concept of clinically important difference to the WHOQOL-BREF and use the data in the Skevington & McCrate paper, we get the following for chronic pain (condition selected here at random):

Physical mean = 39.04 (SD = 20.86)

Psychological mean = 53.07 (SD = 18.68)

Social mean = 59.34 (SD = 23/64)

Environment mean = 58.82 (SD = 17.90)

If we apply the principle above for CID to any one of these we would get something like this:

Chronic pain Physical health normal mean score = 39, bandwidth (+- 1=SD) = 18 to 60. So, we offer our treatment to a patient whose pre-treatment score is, say, 35. Post-treatment she would have to obtain a score of at least 61 for us to say that we have made a clinically important difference – a change score of at least 26.

Now, this example is a bit simplistic because I have done it just to illustrate the problem. It's all really a bit more complicated than this and the paper that you should read on this topic is Jacobson & Traux (1991). There are several other papers on this topic since then that offer refinements, but theirs is the classic paper. Have a look at their formula for the Reliable Change Index (RCI). If I use the RCI with the Skevington & McCrate data for chronic pain on physical health I get the following statistics:

Mean (time 1) = 39.04

SD (time 1) = 20.86

Test-retest reliability = 0.66

Results:

Test-retest standard error of measurement = 12.16

Alpha standard error of measurement = 5.90

RCI needed to indicate clinically important difference = 34- points.

So, our patient would need to go from 35 at baseline to 69 at followup for us to say that we had made a clinically important difference to her.

Yes, you can use the WHOQOL-BREF at the individual patient level, but to show a clinically important difference you need to have very large effects! This is why I say that the WHOQOL instruments were designed for group assessments and changes in mean scores.

JACOBSON N & TRAUX P. (1991). Clinical significance: a statistical approach to defining meaningful change in psychotherapy research. *Journal of Consulting and Clinical Psychology*. 59 (1): 12-19.

Should you require any further assistance please feel free to email at your convenience.

Cheers –

Graeme

A/Professor Graeme Hawthorne

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THE ADULT CARER QUALITY OF LIFE QUESTIONNAIRE (AC-QOL)²⁹⁴

Developed by Hannah Elwick, Stephen Joseph, Saul Becker & Fiona Becker: The University of Nottingham and the Princess Royal Trust for Carers (Reformatted with permission for use in older people).

How to Fill in the Questionnaire

This questionnaire asks you about different aspects of your life as a carer. Please think about your experience as a carer within the last two weeks and please tick the box that applies next to each statement. There are no right or wrong answers; we are just interested in what life is like for you as a carer. The questionnaire shouldn't take more than 10 minutes.

Please answer all questions as honestly as you can.

Support for Caring

	Never	Some of the time	A lot of the time	Always
01. I have a good level of emotional support				
02. My needs as a carer are considered by professionals				
03. I am happy with the professional support that is provided to me				
04. I feel able to get the help and information I need				
05. I have all the practical support I need				

Caring Choice

	Never	Some of the time	A lot of the time	Always
06. I feel that my life is on hold because of caring				
07. My social life has suffered because of caring				
08. I feel I have less choice about my future due to caring				
09. I feel I have no control over my own life				
10. Caring stops me doing what I want to do				

Caring Stress

	Never	Some of the time	A lot of the time	Always
11. I feel depressed due to caring				
12. I feel worn out as a result of caring				
13. I am mentally exhausted by caring				
14. I am physically exhausted by caring				
15. I feel stressed as a result of caring				

Money Matters

	Never	Some of the time	A lot of the time	Always
16. I worry about going into debt				
17. I feel satisfied with my financial situation				
18. I am able to save for a rainy day				
19. I worry about money				
20. There is enough money in our house to pay for the things we need				

Personal Growth

	Never	Some of the time	A lot of the time	Always
21. I have become a more tolerant person through my caring role				
22. Because of caring, I have learnt a lot about myself				
23. Because of caring, I feel that I have grown as a person				
24. I have experienced many positive things through caring				
25. I feel that I have become a better person by caring				

Sense of Value

	Never	Some of the time	A lot of the time	Always
26. I feel valued by the person I am looking after				
27. The person I look after respects me for what I do				
28. The person I look after makes me feel good about myself				
29. I get a lot from the person I am looking after				
30. I have a good relationship with the person I am caring for				

Ability to Care

	Never	Some of the time	A lot of the time	Always
31. I am satisfied with my performance as a carer				
32. I can take care of the needs of the person I am caring for				
33. I feel I am able to make the life of the person I am looking after better				
34. I can manage most situations with the person I care for				
35. I am able to deal with a difficult situation				

Carer Satisfaction

	Never	Some of the time	A lot of the time	Always
36. Caring is important to me				
37. I resent having to be a carer				
38. I feel frustrated with the person I am caring for				
39. I enjoy being a carer				
40. I am satisfied with my life as a carer				

1.5 Interpretation of the Scores

Scores can be worked out for the total quality of life using the whole questionnaire, or for each subscale.

Scores on the overall questionnaire have a possible range of **0 to 120** with **higher scores indicating greater quality of life**.

0-40 Indicates a low reported quality of life, and may suggest problems or difficulties

41-80 Indicates a mid-range reported quality of life
81+ Indicates a high reported quality of life

Scores on each of the eight subscales have a possible range of **0 to 15**, with **higher scores indicating greater quality of life** on that subscale.

0-5 Indicates a low reported quality of life, and may suggest problems or difficulties

6-10 Indicates a mid-range reported quality of life on that subscale

11+ Indicates a high reported quality of life on that subscale

From: Stephen Joseph <Stephen.Joseph@nottingham.ac.uk>
Sent: Monday, 30 January 2012 9:17 PM
To: Teresa Burgess
Subject: RE: Using the AC-QoL

Dear Teresa,

Yes these amendments seem fine, very useful to older people. We would appreciate if you could keep us informed about your research and what you find out.

Best wishes with your PhD studies,
Stephen

Stephen Joseph
School of Sociology and Social Policy
University of Nottingham NG7 2RD
Tel: 0115 9515410

What doesn't kill us: The new psychology of posttraumatic growth.
<http://www.whatdoesntkillus.com/>

From: Teresa Burgess [<mailto:teresa.burgess@adelaide.edu.au>]
Sent: 30 January 2012 03:44
To: saul.becker@nottingham.ac.uk
Subject: Using the AC-QoL

Dear Professor Becker,

My name is Teresa Burgess and I am currently undertaking a PhD study in Adelaide, Australia entitled: *Chronic disease management along the continuum of care: the role of the health system in supporting people with end stage chronic illness*. As part of this study, I am using the AC-QoL developed by yourself and colleagues for the Princess Royal Trust for Carers. I have attempted to contact Hannah Elwick with my query, but unfortunately her email address at Nottingham University did not work and I have been unable to identify an alternative. I was therefore wondering if you could either assist me with my query, or direct me to the appropriate person who may be able to assist? We commenced using the AC-QoL last year, but as many of my research participants are older, they are having some difficulty with the format, specifically the small font. I also recently requested Ethics Approval for the project from a private hospital here in Adelaide, and their Ethics Committee also suggested that we revise the format to make it easier to read.

I am therefore writing to you to ask if it was possible to revise the format for our project participants – we would change none of the content of the questions at all – just the font size and page orientation. I have attached a draft of what this might look like. Many thanks for considering this request, and I look forward to your response,

Regards

Teresa Burgess

Appendix 7. Case review summaries

These case review summaries are a record of the notes I wrote after each of my interviews with the nine project participants. I developed the summaries to have a record of my impressions of the interview and of the participants themselves as well as reminding me about the individual circumstances of each participant. Some of the interviews were very difficult to listen to, as people told me the story of their illness and writing up my summaries helped me to work through the feelings that these interviews sometimes aroused. I also used these notes to summarise and collate the demographic and other information I collected about each participant and their carer.

CASE REVIEW ONE: SUE AND TREVOR SMITH

Demographics

- * Sue: 63 year old woman who had always lived in a small rural city.
- * Trevor: 67 year old man who had always lived in a small rural city.

Social Circumstances

- * Both had private health insurance and are financially very secure.
- * They owned their own home.
- * They both ran a hardware store for 25 years and had 15 employees, so they were always very busy and active.
- * Sue ran the business side and Trevor worked in the store.
- * They had two sons, one living close by and one in Melbourne, who visits regularly.

Disease History

- * Sue had Multiple System Atrophy (MSA)^{xxviii} which has progressed fairly rapidly. She had felt ill for nine years, and was diagnosed with PD in 2007. The PD drugs were not really helping and were being increased regularly until she was on massive doses. Her neurologist would not consider deep brain stimulation and so they investigated this for themselves. They went to Queensland to have this done, but the doctor up there said she was not a suitable candidate, and suggested Sue did not have PD, but rather MSA. On her return to South Australia, she was referred to a new neurologist. A series of tests and consultations were undertaken and MSA was diagnosed (but the neurologist felt that there were signs of MSA on the initial brain scan some years before). This diagnosis was made in November 2010.
- * Sue also had:
 - bronchiectasis, which was diagnosed before the neurological disease.
 - a thyroid problem and she had had radioactive iodine and was on thyroxine.
 - gastric reflux.
 - anxiety (the neurologist put her on anti-anxiety tablets a few years ago).

Major Problems Identified

- * Access to more ADL services to support her to stay at home and take some of the burden off Trevor.
- * Access – being in a wheelchair (and such a big one) meant that there were very few places that could actually be accessed, so Sue always had to think before she went out whether there was wheelchair access.

^{xxviii} The National Institute of Neurological Disorders and Stroke states that: *Multiple system atrophy (MSA) is a progressive neurodegenerative disorder characterized by a combination of symptoms that affect both the autonomic nervous system (the part of the nervous system that controls involuntary action such as blood pressure or digestion) and movement. The symptoms reflect the progressive loss of function and death of different types of nerve cells in the brain and spinal cord.* http://www.ninds.nih.gov/disorders/msa/detail_msa.htm

- * Sue felt her lack of independence strongly – *“like a prisoner in my own home”*.
- * The time to diagnosis could have been quicker – in hindsight it would have been better to be referred to Dr [neurologist], although there would have been *“no real advantage in terms of treatment”*.
- * Regular admissions to hospital for exacerbations of her bronchiectasis.

Advance Care Planning

- * Sue used to work in a Solicitor’s office and so has organised all of her advance care planning documents.
- * Her GP had copies, but the local hospital didn’t, as when she went to leave it there, the appropriate person was not available.
- * Sue and Trevor said that they had had open and frank discussions with the family as they think it is important everyone is aware of what’s happening. However, Sue says no-one had told her what to expect. They knew MSA was a fairly new thing and there wasn’t a lot of information around about it and the internet is fairly vague. Sue wanted to know her life expectancy but the neurologist and the GP couldn’t answer her.
- * Sue said she knew everyone was different but she really wanted to know more about the disease and how much longer she may have had to live. She said she was honest and open with the neurologist and said she wanted *“no bullshit”* after the diagnosis and he just gave her a website to look at with no real discussion. She said she understood it was difficult for him too, but *“if you know, you can plan”*; some people may not want to know but she’s always wanted to know how it would pan out. There was a fear of the unknown.
- * Sue thought that a counsellor would be the most appropriate person to raise such discussions, if she hadn’t known about the process.

Access to Services

Clinical Services:

- * Sue saw a respiratory physician from Victoria for her bronchiectasis – he also consulted in her home town monthly. She had regular bronchoscopies for this and got infections and pneumonia often. She worried about going into hospital because she believed she was much more at risk of getting worse infections and she had already contracted pseudomonas in a hospital.
- * She saw a neurologist in Adelaide, and this became more difficult (i.e. travelling to Adelaide) as the disease progressed
- * She had reflux and took tablets for that and also took Zoloft for anxiety, which she had been on for a few years.
- * She went out to see her GP regularly (although he had offered home visits). They said he was very busy and they didn't want to impose that on him unless they had to and Trevor thought it was good to get Sue out and the GP had everything at his clinic.
- * Sue was seen by the Palliative Care Team in the local hospital who said they would come in the last week of life and explained the sort of care they would provide.

Home Based Services

- * The local Community Health Service provided equipment – a self-help bed pole and handle for the bed, a shower chair, a walking frame for the shower – an Occupational Therapist came out and assessed the house and helped make changes. They personally purchased a hospital-type bed (which made things MUCH easier) and a nebuliser and walker. The head of the Community Health Team visited regularly and reviewed Sue's needs.
- * The community package of care provided to Sue was one hour of personal care in the morning to get up and shower and one hour in the evening to put to her to bed. This provided a respite period for Trevor. He received 3 hours/week of respite care and they had a cleaner for one and half hours a

fortnight. Care was contracted out to ParaQuad SA. They also provided a wheelchair.

Other:

- * Across the nine months of the project, Sue saw a variety of health professionals including physiotherapists, masseurs, acupuncturists, aroma therapists, all of whom helped for short periods of time



Particular Problems/Issues

By April 2011, Sue was needing significant support to stay at home. She was admitted to the local hospital, but they would not discharge her without this support and this became a major problem. The hospital arranged an ACAT assessment, however the ACAT team were not able to help, as Sue was only 61 years old at the time. This meant that funding for home support was really only available through Disability SA (DSA). A meeting was held with DSA, the Home Support Co-ordinator at the local hospital and various other groups (about 12 people). DSA agreed to provide support and put together a package of care, but the next day it became clear they would not do this. Commonwealth support

workers provided care at home for two weeks for Sue however they said they could not continue doing this and a series of meetings at DSA in Adelaide were cancelled over a 2 week period. Sue and Trevor heard about a disability advocate who could assist in liaising with DSA. Within a week he had facilitated access to a package of care with DSA. Sue and Trevor felt that the government departments were all out of money and so they put people off until they absolutely had to provide care. Sue and Trevor noted that the people working at DSA were very nice and caring and had no criticism of them, but felt that basically the system was very dysfunctional and does not work. As the disease progressed over the period of my research, Sue's needs increased significantly, but they were again obliged to turn to the disability advocate to get further services from Disability SA.

PHQ-9/WHOQOL/Carers

PHQ_9^{xxix}

Interview 1*	7 (mild)	Missing answers for questions 8 & 10
Interview 2*	19 (moderately severe)	Missing answer for question 10
Interview 3*	11 (moderate)	Missing answers for questions 8, 9 & 10

* *On antidepressants*

^{xxix} See page 50 for information on scoring the PHQ-9

WHOQOL^{xxx}

	Raw Score	Transformed Scores	
Domain 1: Physical Health			
Interview 1	15/35	28.6	
Interview 2	17/35	35.7	
Interview 3	12/35	17.9	Missing 3 answers
Domain 2: Psychological Health			
Interview 1	16/30	41.7	Missing 1 answer
Interview 2	15/30	37.5	Missing 1 answer
Interview 3	12/30	25.0	Missing 5 answers
Domain 3: Social Relationships			
Interview 1	4/15	8.3	Missing 1 answer
Interview 2	4/15	8.3	Missing 1 answer
Interview 3	5/15	16.7	Missing 1 answer
Domain 4: Environment			
Interview 1	25/40	53.1	
Interview 2	25/40	53.1	
Interview 3	25/40	53.1	Missing 1 answer

Few changes between interviews were noted in any of the four domains.

^{xxx} As noted in Section 3.4.2 of the thesis, the WHOQoL Bref proved to not be appropriate for measuring QoL in my participants. It is included in the appendices to provide a full record of the data collected. I have noted any changes in domains over time.

Carer QoL Summary^{xxxi}

	Interview 1	Interview 2	Interview 3
Support for Caring	5	7	8
Caring Choice	9	9	8
Caring Stress	11	6	7
Money Matters	15	15	13
Personal Growth	11	10	13
Sense of Value	14	13	14
Ability to Care	11	10	11
Carer Satisfaction	14	13	13
TOTAL	90	83	87

Trevor's scores indicated an overall high perceived quality of life in all 3 interviews, however his lower scores in the first three domains indicated some issues in those particular areas.

Reflections

Sue and Trevor were a very caring couple in an incredibly difficult situation. They had obviously had a full life working together, and then Sue was increasingly disabled, in very distressing ways. Her bronchiectasis was particularly difficult in combination with the MSA as it made coughing very difficult, so she was constantly trying to clear phlegm ineffectually from her throat and lungs. She could not move without assistance and her speech deteriorated across the period of the research. This was particularly distressing for her, as it meant her son in Melbourne could not understand her when she rang him. By the third interview, Sue had been catheterised, and this gave Trevor some relief as he no longer needed to take her to the toilet, especially at night.

The first interview extended over 4 hours, as no-one had ever spoken to Trevor or Sue about the issues that were raised in the interview around how it had been

^{xxxi} Interpretation of the scores for the ACQoL can be found on page 57. I have noted any changes over time.

for them to live with this illness. Because Sue's story was quite distressing this was a very exhausting interview, but it also made me wonder about who they could have spoken to? The GP was very busy, all the KSPs came to do their specific tasks and no-one seemed to see it as a responsibility or a need to explore how they were coping with her illness. Sue had earlier seen a counsellor who felt she was coping well and so did not return.

Whilst they were both very pragmatic and talked about their ACPs and the seriousness of the illness, at the 1st and 2nd visits, they had not really accepted that the condition was terminal. They knew it would lead to Sue's death at some point, but didn't recognise that this was likely to be in the next 12 months. By the third visit, they had recognised this, and the tone of our discussions changed somewhat.

Trevor was very organised and loving in his caring role. He observed that caring totally changed your life – that it was a big commitment. He recognised the strain of Sue's diagnosis and made use of a counsellor paid for by Carer's SA when Sue was first diagnosed. He also organised daily respite and really valued the time he could spend with his son and grandchildren. Sue's condition greatly distressed Trevor (he was very down at the second visit) but he recognised the need for support and was very sensible in exercising, keeping up with the family etc, Sue was very upset because she recognised the huge burden and strain that Trevor had taken on in looking after her and felt it was very unfair, but there was nothing to be done, as that was their commitment to each other.

CASE REVIEW TWO: JOHANNA AND ALEXANDER VAN DYKE

Demographics

- * Johanna: 77 year old woman born in Holland.
- * Alexander: 80 year old male born in Holland.
- * Both had lived in Australia for many years.

Social Circumstances

- * Johanna lived in her own home with her husband as carer.
- * They owned their own home and had no obvious financial worries.
- * They had private health insurance and pensioner benefits and Alexander received the Carer's Benefit.
- * They had one daughter who lives nearby and one grandson. Their son lives in Canada. They were close to their grandson, but didn't see a lot of family and friends – *"don't ask for it and don't need it."*

Disease History

Johanna

- * Johanna and Alexander had been managing her PD since 1996. They always knew there was no cure, but the first 10 years were OK – the disease started with a tremor in the thumb and slowly went to the fingers, arm and whole left side. She had been in a wheelchair for the last 5 years – she could walk only very short distances. Gradually the medication was increased and increased, and then because of the high doses, her dyskinesia is got worse and worse (e.g. involuntary kicks, facial ticks etc).
- * At one stage, a new medication regime was suggested and Johanna was admitted to hospital and this was a terrible experience as medications were never given on time, and timing is vital for Parkinson's medication. She was there for a fortnight, but nothing was achieved. Johanna had to have a hip operation for arthritis (referred by her neurologist) and on that admission

there was a notation put into the Patient Notes about timing of medication and this was much better and the hip operation went well.

- * Her neurologist had tried everything – pumps, injections, tablets, pallidotomy (which helped her mouth tremor) etc. He noted that her disease was the most difficult to treat he had ever had. At the last visit before our second interview, the neurologist said he had no suggestions for improvement and essentially said “*make what you can of your life*” which the Van Dykes found very disappointing.
- * She had deep brain stimulation (DBS) and although mornings and evenings were still very difficult there was some improvement during the day. Although Johanna was older than is usual for DBS, because she had had previous successful surgery and nothing else was working, when it became available in Adelaide it was done. That was a very difficult period for them both.

Alexander

- * Alexander had been caring for Johanna for 8 years, and spent >71 hours/week caring for her.
- * His health was OK at the time of the research although he had diabetes and had had 2 heart attacks and an aortic aneurysm repaired nine years ago at the age of 70. Most medical care was provided by the GP.

Major Problems Identified

- * The biggest problem identified across the interviews was not being able to walk and talk.

Advance Care Planning

- * Alexander and Johanna had discussed euthanasia, which they believed should be available legally, under strict controls. They felt that if Johanna knew that it was available it would give her some peace. They tried to talk to the GP about it but this but found it difficult to engage him.

- * They had signed Anticipatory Directions and had a special file with all of their wishes written in it.

Access to Services

Clinical Services:

- * Neurologist
- * GP: Alexander said that the GP didn't really do anything – he was more for prescriptions and if Johanna needed to be seen for female related issues, she saw a female GP (who put her on anti-depressants).

Home Based Services

- * RDNS: came a couple of times following the DBS hospitalisation to review treatment for bed sores developed in hospital, but Alexander was able to take over this treatment.
- * Although Johanna needed help to do everything, Alexander did not want home help, as he felt he could cope with attending to all of Johanna's needs. He had thought about getting some assistance for cleaning but hadn't done that.

Other:

- * Hampstead Hospital Rehabilitation / gym
- * Parkinson's Australia support groups.
- * Johanna couldn't walk at all and Alexander had bought all the equipment he needed to care for her. This included a wheelchair, indoor and outdoor walking frames, fold up toilets etc.
- * At the first interview, the GP had recently referred Johanna to Hampstead Rehabilitation Hospital for rehabilitation therapy including physiotherapy and speech therapy and they were both very pleased with the progress resulting from this treatment. They went three times/week at 12 midday (as mornings were difficult) for twelve weeks however, at the second interview, Alexander noted that it had been good, but it stopped working and her walking and talking deteriorated. It was alright starting off with the physio, but gym was too much.

- * They attended the Adelaide Voice Clinic and Johanna had a laryngoscopy hoping that they would be able to help her speech, however they could not help at all. Alexander noted that there was no improvement in her speech and they would “*just let it happen now*”.
- * Although Alexander had had contact with Carers SA, he was not interested in the services they provided, particularly the respite and daytime trips, as he did not wish to go out without Johanna, and would have felt bad going out and having a good time and leaving her behind.



Particular Problems/Issues

- * Johanna had significant difficulty speaking and when she could speak, it was in a low whisper, so Alexander answered most of the questions for her, whilst she was sitting beside him. She also could not stand or walk at all, and her ability to concentrate seemed to lessen at each interview.
- * Alexander had investigated a local nursing home, in case he could longer go on caring for Johanna, however when he enquired about the cost of a number of nursing homes, he could not get a straight answer so was not sure how much it would cost. He says the system is not good when you can't even find out how much it would cost – the nursing homes say “CentreLink will tell you when you register for admission”. He would resent paying an

exorbitant amount for it. He felt he would not have a problem getting a bed when required at the nursing home, but even though they had offered a bed a number of times, he was insistent that she have a single room. Also, he wanted to keep her at home for as long as he could as he believed that nursing homes were not wonderful places to go into – he said that if Johanna was alone she would have had to go into a home and that would be terrible.

- * Alexander noted that a simple device for calling your partner or carer is needed by people with disabilities. Something that could hang around their neck. He used a doorbell for Johanna to press when she needed him. The disability supply shop didn't have anything and he couldn't find anything on the internet.

PHQ-9/WHOQOL/Carers

PHQ_9*

Interview 1	-	-
Interview 2	7 (mild)	Missing answers for questions 8 & 10
Interview 3	1 (mild)	Missing answers for questions 8, 9 & 10

* *On antidepressants*

WHOQOL

	Raw Score	Transformed Scores	
Domain 1: Physical Health			
Interview 1			
Interview 2	14/35	25.0	
Interview 3	13/35	21.4	Missing answers for 2 questions

Domain 2: Psychological Health			
Interview 1			
Interview 2	15/30	37.5	
Interview 3	10/30	16.7	Missing answer for 1 question
Domain 3: Social Relationships			
Interview 1			
Interview 2	8/15	41.7	Missing answer for 1 question
Interview 3	8/15	41.7	Missing answer for 1 question
Domain 4: Environment			
Interview 1			
Interview 2	33/40	78.1	
Interview 3	31/40	71.9	

There were few changes between interviews in the WHOQoL.

Carer QoL Summary

	Interview 1	Interview 2	Interview 3
Support for Caring	8	5	10
Caring Choice	9	10	11
Caring Stress	11	13	11
Money Matters	9*	8	15
Personal Growth	5*	5	5
Sense of Value	12*	8	9
Ability to Care	7*	9	10
Carer Satisfaction	7*	8	5
TOTAL	68	66	76

* Missing answers to questions 18, 23, 24, 31, 36 and 39

Alexander had a perceived mid-range quality of life score.

Reflections

Alexander appeared to be very self-sufficient and cared for Johanna very well. He was very organised and really wanted no help. His routine and the activities he undertook were very important to him and people coming in interfered with these. He was very devoted to Johanna and ensured she always looked nice, took her out to the shops etc and went to Parkinson's support group meetings. He was quite outraged that Carers SA offered trips and other activities for carers and did not include the person with the illness and could not understand why people would want to go out and enjoy themselves, leaving the person being cared for without that possibility.

Despite appearing very pragmatic and matter-of-fact, he noted at the first interview that one of their (his?) biggest frustrations was hearing stories about cures for PD on programs such as *A Current Affair* and then finding them out to be untrue. He still maintained a strong hope that a cure could be found, in the face of Johanna's deteriorating condition.

At the first interview, he noted they would have found the possibility of being able to access euthanasia a comfort, even though he doubted they would use it. He recognised that Johanna would probably need to go to a nursing home at some point, especially if anything ever happened to him, so had links with the local Resthaven residential care home. He felt he could definitely care for her more effectively than a nursing home, and was really reluctant to have any assistance with care.

Alexander used the internet very effectively to look up information, find equipment etc. He was given an iPad for his 80th birthday, and was very excited about using it. I think the fact that they were relatively well off and he could buy whatever equipment he thought he needed meant he was even more self-sufficient and he was quite health literate.

Johanna died in April 2013, and I was very surprised to hear that she had died, as she has seemed quite well (relatively) at our last interview. She was not talking

or walking and was very distracted, but looked healthy, especially compared to Sue and Anne, who deteriorated significantly over the nine months of their participation. I was saddened for Alexander as she had been his whole life and I'm not sure how he will adjust to not having to do all the tasks he did for her every day. His family did not seem to provide strong support, other than his grandson of whom he was very fond.

CASE REVIEW THREE: ANNE AND RAY JONES

Demographics

- * Anne: an 80 year old woman, born in the UK,
- * Ray: an 82 year old man, also born in the UK.
- * Both migrated to Australia many years ago and raised their family here.

Social Circumstances

- * They had five children, twelve grandchildren and nine great grandchildren and they were very close to all their children. Two live in South Australia, one in Queensland, one in the Northern Territory and one in Victoria.
- * They lived in their own home, which had been the family home for some time.
- * They had private health insurance and pensioner benefits.
- * They were part of their local community and had an active social life before Anne's illness.
- * Anne used to read a lot and found it very difficult not being able to read or assist around the house as she used to.
- * Ray loved to work in the garden and missed having the time to do that.

Disease History

Anne: was diagnosed with Progressive Supranuclear Palsy (PSP)^{xxxii} in 2010 (although Ray felt there were signs before this of some disease). The PSP significantly affected Anne's ability to move and speak, which she found very

^{xxxii} *PSP is a rare neurological condition affecting the parts of the brain that control walking, eye movements, balance, speech and swallowing. Symptoms can be managed with a range of therapies and treatments, but symptoms become progressively worse over time. There are currently around 1300 Australians diagnosed with PSP, although many others may have the condition but be wrongly diagnosed. People with PSP are at risk of developing serious complications such as pneumonia, choking, head injury and fractures. As the condition progresses, these complications can cause death.* PSP Australia. <http://www.psp-australia.org.au/>

frustrating. Ray and Anne were obviously very close and Ray answered many questions for Anne, speaking for her when she could not get the words out. Her cognitive ability in the first interview did not appear impaired and she was able to agree or disagree with Ray's responses on her behalf. By interviews two and three, Anne was much sleepier and less able to participate in the conversation, although she did understand what was being asked. Her speech was slower and more difficult to understand, and she napped more frequently. At the third interview, Ray noted that she had also begun to have difficulty swallowing.

* Anne also had:

- epilepsy
- arthritis (requiring hip replacement in 2009)
- cataracts
- urinary incontinence.

* Just before enrolling in the project, Anne broke her collarbone, and that caused major problems for Ray, as it was so difficult to lift her.

Ray: had no health problems, and recognised that his good health was a key reason that Anne could stay at home. He was on medication for hypertension, but had no problems with this. When we first met he had been caring for Joan for approximately 12 months and devoted more than 71 hrs/week to this care. He was devoted to Anne and tried to keep life as normal as possible, taking Anne out whenever he could shopping and getting her hair done at the hairdresser and he learned how to apply her makeup himself. Over the research period, Anne was less and less able to go out to places such as the casino and dinner, but was able to fly to Melbourne where she went into the nursing home where her daughter worked, for respite care. Ray really enjoyed this break, staying with their daughter and visiting Anne in the nursing home every day.

Major Problems Identified

- * At the first two visits, the major problem identified was difficulty moving around – Anne had been able to use a walker, but by time I met her, she was no longer able to do this.
- * By the second visit she could no longer stand alone at all and by the third visit both her speech and swallowing had deteriorated significantly, but she still had some use of her arms.

Advance Care Planning

- * At the first and second interviews, Ray did not want to consider or discuss Anne's prognosis, although he had organised an ACAT so she would have access to residential care if required. By the third visit, he had asked the neurologist about Anne's prognosis, but he was still unclear about what the prognosis was. He told me she would not die from PSP but rather associated complications, but he was not aware of the likelihood of these complications.
- * He had completed a Power of Attorney (POA) document but was unsure whether this was a medical POA and whether he had signed an Advance Care Directive. He was going to check with his GP at the next visit.

Access to Services

- * Ray took his caring duties very seriously and devoted himself to caring tasks. At the first interview, he was receiving no home based support, other than some home modifications organised through an occupational therapist, who had come to the house following Anne's hip replacement. However, he recognised that support for cleaning could be helpful and by the third visit, had organised a cleaner to come fortnightly.
- * He was very practical and recognised that options needed to be put in place in case anything happened to him, so Anne had an ACAT and had been assessed as eligible for high level care. There were few nursing homes with

high care beds in their local area, so Ray had been exploring the options both for respite and if anything longer term was required.

- * He was very loath to get support for showering Anne and getting her in and out of bed, as he didn't want to be tied to a strict timetable.
- * He knew he was eligible for an EACH package, but didn't actually know what this would provide.

Clinical Services:

- * Neurologist based at the RAH
- * Urologist
- * Ophthalmologist (cataracts)
- * Orthopaedic Surgeon (Arthritis of the hip and hip replacement)
- * GP
- * Physio/OT/nurses from the Repatriation General Hospital following the hip replacement
- * OT (through a Commonwealth program delivered in general practice)

Home Based Services

- * Commonwealth Carers Respite Services (restricted access)
- * ACAT completed – eligible for high level care, but very few nursing homes in the area have high care beds.
- * Cleaner fortnightly
- * Awaiting an EACH package
- * RDNS

Other:

- * Parkinson's support group
- * Support for financing special urinary incontinence pants



Particular Problems/Issues

- * Ray felt that the biggest problem he had was finding out where to get help. He felt there was help 'out there' if you knew how to find it, but there was nowhere where it was aggregated and easy to find.
- * He felt he had accessed the care he required, but it had been really hard and he found out bits of information from a wide variety of people, so there was lots of anxiety involved until he could access it.
- * He also had a daughter who was a nurse, and she helped him with accessing some equipment, and he also used the internet to source equipment.
- * He thought it would be very helpful to have one central repository of information, especially when people need help in emergency situations (eg when his wife broke her collarbone).

PHQ-9/WHOQOL/Carers

PHQ_9

Interview 1	19 (moderately severe)	Missing answer for question 10
Interview 2	19 (moderately severe)	Missing answer for question 10
Interview 3	10 (moderate)	Missing answers for questions 8, 9 & 10

WHOQOL

	Raw Score	Transformed Scores	
Domain 1: Physical Health			
Interview 1	12/35	17.9	
Interview 2	12/35	17.9	Missing answer for 1 question
Interview 3	11/35	14.3	Missing answers for 2 questions
Domain 2: Psychological Health			
Interview 1	13/30	29.2	
Interview 2	15/30	37.5	Missing answer for 1 question
Interview 3	10/30	16.7	
Domain 3: Social Relationships			
Interview 1	4/15	8.3	Missing answer for 1 question
Interview 2	8/15	41.7	Missing answer for 1 question
Interview 3	6/15	25.0	Missing answer for 1 question
Domain 4: Environment			
Interview 1	29/40	65.6	
Interview 2	27/40	59.4	
Interview 3	25/40	53.1	

Anne's perceived quality of life scores dropped in most of the domains at the time of the last interview.

Carer QoL Summary

	Interview 1	Interview 2	Interview 3
Support for Caring	9	10	12
Caring Choice	10	10	8
Caring Stress	12	14	12
Money Matters	13	15	15
Personal Growth	9	8	11
Sense of Value	15	15	15
Ability to Care	15	15	11
Carer Satisfaction	11	12	15
TOTAL	94	99	99

Ray had a high quality of life across all the interviews

Reflections

Ray was a devoted carer who was very health literate, using the internet to search out information and equipment for Anne, but he found it very frustrating not knowing what support was available and having no central point to access to try to find out. Given he was very astute and internet savvy, this must be an even bigger problem for people who cannot use the internet to access information and resources.

He cared deeply for Anne, and was determined that things should be as normal as possible for her, taking her to have her hair done every week and learning how to put makeup on and taking her out whenever possible. By the third interview, caring for Anne had become very difficult, but he still tried to make things as normal as possible.

He and Anne were very close and he answered most questions for her, however, occasionally it seemed that she would change her responses so as not to upset

Ray (e.g. when asked if she was happy with the way she looked, or if her life was meaningful).

He said he needed minimal help, especially for Anne's personal care and had very well established routines that he didn't like to break. He did not want to know about Anne's prognosis or consider that she might be dying, but I think he gradually came around to accepting this, by my last visit. However, he did explain that she would not die of PSP, she would die of something else like pneumonia, but did not seem to realise that PSP would make getting infections like pneumonia much more likely.

Their strong family support was very important to both of them, and I think helped Ray cope. He had taken Anne to Victoria not long before my last visit and she had been in respite care there, at the nursing home in which her daughter worked. This was quite an undertaking, however they both seemed to take it in their stride.

It was very evident though, that should Ray's health deteriorate in any way, it would be very difficult, if not impossible, for Anne to remain at home. By the last visit, she had deteriorated significantly and could not stand at all. Her speech was very difficult to understand and she was beginning to have difficulties swallowing. Ray was 82 when the interviews finished and I really wonder how much longer he will be able to care for her. Ray had explored all the nursing homes in the area, but was not really happy with any of them.

I think the closeness and strength of the family support was probably the major lesson from this family. All the children were close and supportive of both their parents, visiting often and offering help with getting equipment, ensuring Anne's' comfort and supporting Ray.

CASE REVIEW FOUR: LIL MACINTYRE

Demographics

- * 78 year old woman, born in Hong Kong with a Chinese mother and Scottish father.
- * Married to an Englishman and had lived in Australia for many years.

Social Circumstances

- * Lil had 4 daughters, one in Sydney, one in Qld, one in Melbourne and one in Adelaide and 4 grandchildren.
- * She lived with her husband in her own home but he is not her carer.
- * She was quite independent and drove herself until recently.
- * She had private health insurance and pensioner benefits and enough money to meet her needs and to live comfortably.

Disease History

- * Lil had had end stage renal failure for 15 years and had dialysis 3 times/week.
- * She had also had a coronary by-pass operation and a pacemaker inserted, but she still had episodes of angina
- * A couple of months before being enrolled in the study, she had a TIA (mini-stroke) whilst driving and ended up in McLaren Vale with no idea how she got there. Following hospitalisation and tests, she could no longer drive.
- * She also had severe arthritis and fibrosis of her lungs.

Major Problems Identified

- * Lil felt that her only problem really was just “slowing down” which she put down to ageing: *“from the neck up I think I can do all sorts”*.

Advance Care Planning

- * Lil had written down all her instructions about her death in a book – she had planned her funeral and also spoken to her nephrologist about not continuing with dialysis if her health deteriorated.
- * She had also spoken with her GP and heart specialist and they were aware of her wishes.
- * She was adamant she didn’t want to go into a nursing home and that no-one else should have to be responsible for such decisions. She didn’t want her daughters to care for her and didn’t think her husband would be able to cope with caring for her.

Access to Services

Clinical Services:

- * Nephrologist based at the RAH
- * Cardiologists (private) – pacemaker and CVD
- * Neurologist
- * Rheumatologist
- * GP

Home Based Services

- * Cleaner fortnightly

Other:

- * Red Cross provides a driver service to dialysis
- * Access Cabs



Particular Problems/Issues

- * Lil did not consider she really had any particular problems really. She really missed being able to drive, following her stroke, and also missed having the fruit which was forbidden because of her renal failure. She was finding it more difficult to do her gardening but had organised the garden so she would not have to bend too far.

PHQ-9/WHOQOL/Carers

PHQ_9

Interview 1	6 (mild)	Missing answer for question 10
Interview 2	9 (mild)	Missing answer for question 10
Interview 3	0 (none)	Missing answer for question 10

WHOQOL

	Raw Score	Transformed Scores	
Domain 1: Physical Health			
Interview 1	27/35	71.4	
Interview 2	24/35	60.7	
Interview 3	24/35	60.7	
Domain 2: Psychological Health			
Interview 1	13/30	29.2	
Interview 2	15/30	37.5	
Interview 3	10/30	16.7	
Domain 3: Social Relationships			
Interview 1	4/15	8.3	Missing answer for 1 question
Interview 2	8/15	41.7	Missing answer for 1 question
Interview 3	6/15	25.0	Missing answer for 1 question
Domain 4: Environment			
Interview 1	29/40	65.6	
Interview 2	27/40	59.4	
Interview 3	25/40	53.1	

There were minimal changes across the 3 interviews.

Reflections

- * Lil was an amazingly positive woman. She had a very hard childhood, living through the Japanese occupation of Hong Kong as a young girl, and coping with all the associated hardships of hunger, poverty etc. Her philosophy was that there's always someone worse off.
- * She had a number of severe illnesses which would make many people consider themselves invalids (particularly the pain from her arthritis and fibrosis – her fingers were very deformed and she has to straighten her fingers daily to allow her sew and sometimes needed Endone for the pain in her back and shoulders) but she says there's no point moaning and groaning or you have no life!
- * Whilst she seemed quite vital, given her many disease, she was actually very frail and her cardiovascular problems (both heart and strokes) seemed very volatile. She was losing weight and was very slight, but was quite indomitable
- * She said she looks around her at dialysis and sees people who think they were sick, so they act sick and lead a miserable life. She didn't believe her ESRD meant she was sick and so she continued to paint (and teach painting!), sing in a choir, do tapestry and was very social.
- * She did not think her husband could act as a carer and refused to consider allowing any of her daughters to care for her either. She was very forthright in saying she wanted dialysis to cease immediately if she became incapacitated and appeared to have thought through this in some detail and understood what this meant.
- * It was fascinating to talk to her and she had a wealth of stories from her life.
- * Lil's financial status and high levels of health literacy seemed to have contributed to her ability to cope with her illness and work with the system to access all the services she needed (which were very few).

CASE REVIEW FIVE: ELLIE SHEARER

Demographics

- * 83 year old female
- * Born in Australia
- * Widowed –lived alone

Social Circumstances

- * She had no children, but had a nephew and niece who she was close to.
- * Owned her own home, which was built by her husband. She was very close to her husband and obviously missed him greatly. Because she built her home with her husband, she was extremely reluctant to leave it, as she still felt his presence there.
- * She had a Gold DVA card and no financial concerns.
- * She was still driving her car and had an active social life – going to the theatre/ concerts/ lunch/ a flutter

Disease History

- * Renal failure for approximately 15 years but did not have dialysis
- * Polymyalgia
- * Osteoarthritis
- * Dysphagia

Major Problems Identified

- * Nocturnal polyuria
- * *“Running out of puff”* because of the polymyalgia

Advance Care Planning

- * Had not spoken to her nephrologist or GP re future plans/advance care planning.
- * Although asked twice, she avoided answering my questions on this topic.

Access to Services

Clinical Services:

- * Nephrologist
- * GP
- * Cardiologist
- * Neurologist

Home Based Services

- * DVA provided commode
- * Someone (?) came out to identify what could be provided – given a dark green lambswool mattress overlay

Other:

- * Dysphagia Unit at the Repatriation General Hospital
- * Handyman
- * Ellie reported a lot of support from Legacy, her neighbours and her local community and friends, as well as her niece and nephew
- * MedicAlert bracelet

Particular Problems/Issues

- * She was getting increasingly frail – very sensitive to cold, and looked very thin (she had lost a significant amount of weight - ?unsure over what time period).

PHQ 9 / WHOQOL

PHQ_9

Interview 1	4	Missing answer for question 10
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WHOQOL

	Raw Score	Transformed Scores	
Domain 1: Physical Health			
Interview 1	12/35	17.9	Missing answers for 2 questions
Domain 2: Psychological Health			
Interview 1	24/30	75.0	
Domain 3: Social Relationships			
Interview 1	5/15	16.7	Missing answers for 2 questions
Domain 4: Environment			
Interview 1	39/40	96.9	

Reflections

In many ways this was a difficult interview. Ellie appeared quite frail, but was very talkative. She told me all about her neighbours and her family, and a lot of her history, but overall very little about her illness and treatment. When I looked back at the interview and transcripts, Ellie had spoken to me for over 2½ hours and whilst she had told me a lot about her personal history, we had not explored her experiences of her illness in any great depth. I also felt she thought I had stayed too long, however it had actually been very difficult to get away, and she had extended much of the conversation herself. She missed her husband terribly and their lives were obviously very intertwined and so was very reluctant to leave the house where all her memories were.

When I rang back to organise a second interview, Ellie was not keen to speak to me, as she said she had to go to hospital for an operation and was not at all well. I followed up with the nephrologist, and Ellie had a skin cancer removed. I felt she was really very reluctant to speak to me again and so I decided I would not ask her to continue her participation in the project.

CASE REVIEW SIX: FRANK AND DIANE SHARP

Demographics

- * Frank was a 64 year old male, born in the UK of an Austrian mother and English father.
- * Diane was a 64 year old woman, born in New Zealand.

Social Circumstances

- * Frank was married with one son (their youngest son is dead) and they lived in a Housing Trust home, which they really liked, however it was very crowded as their son and grandson were living with them.
- * They had no private health insurance and sometimes struggled to make ends meet.
- * Frank used to work very hard – up to 18 hours/day driving a taxi, and he used to be a painter. He found it very hard to accept he could now do so little, because he felt so weak and had no energy.

Disease History

Visits One and Two

- * Had a quadruple bypass and was very short of breath – had a lung collapse 2yrs ago and “*no one took any notice*”. He had 3 mild heart attacks and a recent bout of pneumonia. He had 11 tablets in the morning, 4 at lunch and 4 at dinner.
- * He felt that there wasn’t enough support post-bypass – he was very depressed but there was no support for this.
- * He also had diabetes and renal failure (since the heart bypass). His diabetes was quite unstable (between 4 and 9) and he self tested daily with a glucometer. He took Insulin bd.
- * At the first visit he reported major problems with fluid retention.

- * He used a sleep apnoea machine as he had trouble breathing – first through his nose then through his mouth - ? this contributed to him getting pneumonia. He needed a new apnoea machine, as the one he had was not functioning properly.
- * He had a severe cough following his pneumonia (which often ended in dry retching), and the community cardiac nurses recognised this as a reaction to his hypertension medication. He was upset that the GP had not identified this when he complained to him about his cough.

Visit 3

- * Frank was discharged from hospital not long before visit 3 and he had a full “body scan” before discharge, but had to go back to ED two days later for severe bleeding.
- * He was then put on Heparin and aspirin. He had large blood clots in his legs and was receiving Heparin bd, administered by the RDNS. Diane said he was not having regular blood tests to check his blood clotting ability. He had a number of bleeding episodes once he went home, particularly bleeding from injection sites.
- * His kidneys had shut down before his hospital admission, but they improved slightly after discharge.
- * His medication was changed – he was then taking 14 tablets every morning.
- * A mild thyroid problem was discovered whilst he was in hospital (?hypothyroidism)
- * Whilst in hospital, he was given tablets for the “heebie jeebies” (?anxiety) however these gave him hallucinations. He also got quite confused in the first week he was in hospital, being unsure of the day and what was happening.
- * He also got pain from his pacemaker from lying in the wrong position and had constant lower back pain.
- * He was very unsteady on his feet and required a walker.
- * The cardiac nurses reported that he had also been diagnosed with gastroparesis.

Major Problems Identified

- * Lack of energy and feeling weak
- * Communication was a real issue *“you ask questions but a lot of doctors don’t tell you anything – they give you tablets, but don’t tell you what they’re for and they don’t tell you what’s going on. They give you one thing for one problem and someone else gives you something for something else and no-one says how long you have to take them”*.

Visit 3

- * Diane reported that the nurses in the RAH were not helpful, for example, when Frank asked for water for his sleep apnoea machine at night, they did not provide this.
- * He used the “mask” frequently at home as it helped his pain (?).
- * He was supposed to see his GP but could get there as Diane didn’t drive and his son had recently started a new job. The GP didn’t do home visits.
- * Diane reported that the bed had been *“flooded”* with blood a number of times, and she was finding it difficult to keep it clean. She had no plastic or rubber sheets and was unsure how to access them.
- * Diane noted that she gave the hospital all Frank’s tablets when he was admitted, but they did not give any back, and it was very expensive to get new ones.

Advance Care Planning

Frank and Diane reported that no-one had spoken to them about how Frank’s disease might progress and what care they might want. When asked about having a Power of Attorney document, they said that someone (?) had mentioned that and they were going to send them a document, but they had not yet received it.

Access to Services

Clinical Services:

- * GP
- * He saw specialists in:
 - Renal (every 6 /12)
 - Diabetes (through the RAH and the GP)
 - Gastroenterologist (previous bleeding from his gut, but no problems at the 1st and 2nd visit, however this was a major problem again by the 3rd)
 - Respiratory / sleep apnoea / chest clinic (every 6 – 7 months)
 - Cardiologist (every month)
 - Community cardiac nurses (weekly home visits), who they reports as being an excellent support: *“The cardiac nurses are really helpful – they tell you what’s going on and support you in every way. They ask questions about your health and pass it on if required”*

Home Based Services

- * None at the first and second visits
- * Because Frank had deteriorated so much by the third visit, he was being assessed for a variety of home assistance services. RDNS had been visiting to give heparin injections.

Other:

- * He would have liked an electric scooter (gopher). He had a walker with wheels from a friend and a wheelchair from his son (who died), which was a bit heavy. He had trouble on long walks
- * When they went shopping at the local shopping centre, he could use a free gopher there for a couple of hours.
- * He had the Medicare Safety Net and got the Glucometer through the “Diabetes Scheme”.
- * He went to Hampstead Hospital to the heart failure gym once a week.
- * He had a borrowed shower chair

- * The Handicap sticker for his car made a big difference as he couldn't walk long distances, but there was not enough disabled parking – there are lots of women / baby parks, but not enough for disabled people.

Visit 3

- * The Housing Trust were helping with modifications to the house, installing rails in the bathroom etc.
- * Frank had an assessment of some sort, but it was unclear who was doing the assessment or why.
- * Someone was showering Frank 3 times a week, but Diane said that was going to cease and she could not afford further assistance.
- * A physiotherapist came to assess Frank for mobility



Particular Problems/Issues

- * Franks' father had recently died and he had not really ever gotten on with him. His mother died many years ago and he was close to her. After his father died, he found out that his father had changed his will and left all his money and land to Frank's sister. This caused him significant stress and led to an estrangement from his sister.

- * Frank had a son with Reye's Syndrome^{xxxiii} who died a couple of years ago. He was burned to death after he dropped lighter fluid in his lap whilst refilling a lighter. The whole family felt guilty about this.
- * Frank's other son and grandson were living with them and he found that very difficult. His son has had depression and was suicidal, and he didn't help around the house or pay enough rent. Frank felt he had nowhere to go in the house and that his son and grandson were a big burden on them both.

Diane

- * She ran a home massage business
- * She sometimes got frustrated she couldn't help more when Frank had been so ill: *"It hurts to see him so ill"*
- * He often had a lot of pain and was grumpy and that was hard for her.
- * At visit 3, Diane said she had problems getting to the shops and chemist, and her neighbour drove her the other day, now that Frank can't drive her any more.
- * She said the whole time she was really worried about Frank and worried about something happening to him. She knew she had to "calm down", but was very stressed.

PHQ-9/WHOQOL/Carers

PHQ_9

Interview 1	3 (none)	Missing answer for question 10
Interview 2	4 (none)	Missing answer for question 10
Interview 3	13 (moderate)	Missing answer for question 10

^{xxxiii} The National Institute of Neurological Disorders and Stroke states that Reye's Syndrome is: *primarily a children's disease, although it can occur at any age. It affects all organs of the body but is most harmful to the brain and the liver--causing an acute increase of pressure within the brain and, often, massive accumulations of fat in the liver and other organs*
http://www.ninds.nih.gov/disorders/reyes_syndrome/reyes_syndrome.htm

WHOQOL

	Raw Score	Transformed Scores	
Domain 1: Physical Health			
Interview 1	20/35	46.4	
Interview 2	24/35	60.7	
Interview 3	18/35	39.3	
Domain 2: Psychological Health			
Interview 1	21/30	62.5	
Interview 2	20/30	58.3	
Interview 3	18/30	50.0	
Domain 3: Social Relationships			
Interview 1	11/15	66.7	
Interview 2	11/15	66.7	
Interview 3	7/15	33.3	Missing answer for 1 question
Domain 4: Environment			
Interview 1	31/40	71.9	
Interview 2	35/40	84.4	
Interview 3	34/40	81.3	

Frank's physical health and social relationship scores dropped markedly between visits 2 & 3.

Carer QoL Summary

	Interview 1	Interview 2	Interview 3
Support for Caring	3		7
Caring Choice	13		14
Caring Stress	12		11
Money Matters	7		2
Personal Growth	6		14
Sense of Value	9		14
Ability to Care	14		9
Carer Satisfaction	12		15
TOTAL	76		86

Diane had a mid range – high quality of life, although she felt there was little support for her caring.

Reflections

- * Frank was a very ill man, but at the first two visits was quite functional and did not really seem to recognise the seriousness of his various illnesses. He was keen to get out and about again, as he found driving a really big release from stress. He was still driving but could only walk very short distances. His diabetes seemed to be quite uncontrolled, with daily high blood glucose, and he couldn't really tell me who was monitoring this. He had had very high doses of insulin, but again, I couldn't quite work out who was responsible for monitoring this.
- * He was still very upset about a fight over his father's will, where his father left all of his property to his sister. He always felt his father did not like him. Both he and his wife were still deeply affected by the death of his younger son who was severely disabled following a fever as a baby and who dropped a lighter in his lap in his wheelchair and burned to death. I can't imagine how

you get over something like that, and both parents felt very guilty that they weren't with him when he had the accident as they thought they could have prevented it. They were out to dinner with friends and think they were enjoying themselves while their son died.

- * His elder son and grandson were living with them in a small house and he resented that as he felt they didn't pull their weight and were living off them. (Interesting, considering his relationship with his father).
- * I was very concerned when I went to see him before the 3rd interview, and really felt he needed to be in hospital. It was hard to get a straight story from either Frank or Diane, but it seemed that had very recently seen the GP. The community cardiac nurse had told them to get an ambulance but they seemed reluctant – it was only for emergencies! – but they eventually did. The fact he then spent 3 weeks in hospital would indicate that his treatment generally was pretty poor – possible because it was really difficult to identify who was actually taking responsibility for his care.
- * Once home again it was really difficult to get a clear idea of what had actually happened – DVTs, renal failure, gastroparesis, anxiety, not sure what's happening with the diabetes? He had deteriorated significantly so I was really not sure what would happen with him.
- * Both were not very health literate (I think hence their poor treatment in hospital) and were very financially stressed, and this added to their concerns.
- * Diane was also deeply affected by the death of her son, and she had a very difficult personal history. She was a very short woman and Frank was a large man, so her ability to physically care for him was limited. She also did not have a lot of problem solving ability.

CASE REVIEW SEVEN: SANDRA AND NETTA KEWELL

Demographics

- * Sandra was 39 years old
- * Netta, Sandra's mother, was 63 and was born in Italy but has lived in Australia for many years and married an Australian. She was widowed some years ago.

Social Circumstances

- * Both had private health insurance and Sandra had some superannuation funding from a previous position.
- * Netta owned the house they live in.
- * Sandra was a large woman and quite heavy and so only had a shower once a week. She had regular carers, funded through Disability Services who washed her and got her in and out of bed every day and took her shopping. A volunteer came once a week to visit her and her urinary catheter was changed every 5 weeks by the RDNS.
- * Netta was Sandra's main carer and undertook all the care not done by the external carers, including bowel care.
- * They got equipment through DSA but had a lot of problems with Sandra's wheelchair –the battery blew up and they were never been happy with how the chair functioned, but it was very difficult to get another one.
- * They both felt they have had little support from the MS Society, who they thought could have done more for them. Sandra used to be able to access rehabilitation services through the MS Society (equipment, swimming etc) however a charge was levied for this and so she stopped going, as there were also expenses associated with taxis to get there etc. Both Sandra and

Netta said that the MS Society was split up all over Adelaide and it was too hard to keep track of who provides what services where.

Disease History

- * Sandra was diagnosed with MS in 1999.
- * Her sister was diagnosed with MS in 2000 – she is 4 years younger than Sandra, but was not yet severely affected.
- * Sandra broke her leg in 2004 and prior to this she was able to use a walker. Since then however she had been in a wheelchair. Her tremor was quite severe and she was no longer able to feed herself, answer the phone etc.
- * In 2011 she spent time in respite care, but she returned with a major pressure sore on her buttocks and had to be admitted to hospital (where she also contracted a number of different infections). The pressure sore took a significant amount of time to heal and required regular dressing by the RDNS. Netta said that Sandra was prone to pressure sores (particularly on her heels) and needed regular preventive care, which was hard to get in respite care.
- * Sandra's spasms were getting worse and her medication was not helping much.
- * In winter 2012, she was admitted to hospital with both a urinary tract infection and pneumonia, but said that she was very badly treated there and Sandra has written a letter of complaint to the hospital.

Netta: had a crushed vertebra and pain down her leg as well. Her hip was “bad” and she also had carpal tunnel syndrome and a sore left arm and shoulder. She had been told not to do anything and rest, but that was just not practical – it was too hard not to and there was always cleaning etc. It was also hard to drive as her car did not have power steering and she felt she could not go into hospital to get treatment for her back, as no-one would then care for Sandra properly.

Major Problems Identified

- * Ongoing spasms were a major issue, and these were not being helped by medication.
- * Not being able to use her hands, so she couldn't feed herself, answer the phone etc, Both Sandra and Netta find this a major issue.

Advance Care Planning

- * No-one had spoken to either Sandra or Netta about this, although Netta noted that they had considered whether Sandra might need to go into a home at some time, but they were thinking more about independent living than a nursing home.

Access to Services

Clinical Services:

- * Neurologist^{xxxiv}
- * GP
- * Urologist

Home Based Services

- * RDNS
- * Personal carers

^{xxxiv} Both Sandra and Netta feel there is little point going to the GP or neurologist, as neither can examine her properly as they don't have any lifting equipment

Other:

- * Respite care



Particular Problems/Issues

Sandra required significant support for her activities of daily living and this was a big drain on Netta, both physically and emotionally. Sandra could not feed herself or use her hands at all, so she depended on Netta for eating, changing TV stations etc and she was quite demanding. In terms of getting in and out of bed and washing, both Sandra and Netta were very unhappy with both the amount and quality of the care provided and with the service provider. If carers did not come, as was not uncommon, it was up to Netta to organise Sandra and this was very difficult for her, given that Netta was very slight. They also had problems accessing appropriate equipment and the ongoing difficulties with Sandra's wheelchair caused real problems as this was her only mobility. Also of concern was that neither her GP nor the neurologist were able to examine Sandra out of her wheelchair, as they had no method of lifting her or an appropriate bed.

PHQ-9/WHOQOL/Carers

PHQ_9

Interview 1	3 (none)	Missing answers for questions 8 &10
Interview 2	4 (none)	Missing answers for question 10
Interview 3	3 (none)	Missing answers for questions 8 & 10

WHOQOL

	Raw Score	Transformed Scores	
Domain 1: Physical Health			
Interview 1	14/35	25.0	Missing answers for 3 questions
Interview 2	10/35	10.7	Missing answers for 3 questions
Interview 3	14/35	25.0	Missing answers for 3 questions
Domain 2: Psychological Health			
Interview 1	18/30	50.0	
Interview 2	21/30	62.5	Missing answer for 1 question
Interview 3	17/30	45.8	Missing answer for 1 question
Domain 3: Social Relationships			
Interview 1	8/15	41.7	Missing answer for 1 question
Interview 2	3/15	0	Missing answers for 2 questions
Interview 3	7/15	33.3	Missing answer for 1 question
Domain 4: Environment			
Interview 1	27/40	59.4	Missing answer for 1 question
Interview 2	30/40	68.8	
Interview 3	28/40	62.5	

Sandra's scores varied across visits in most areas

Carer QoL Summary

	Interview 1	Interview 2	Interview 3
Support for Caring	8	7	7
Caring Choice	7	12	12
Caring Stress	10	*	11
Money Matters	7	11	9
Personal Growth	6	10	10
Sense of Value	6	7	7
Ability to Care	14	9	13
Carer Satisfaction	14	13	12
TOTAL	72	69	81

* Missing answers to 18, 23, 24, 31, 36 and 39

At visits one and two, Netta had mid-range quality of life, but at visit three she reported a high quality of life.

Reflections

- * Both Sandra and Netta seemed to have adjusted to their life and were generally coping well. I think a big issue for the future would be if Netta's health broke down, and it didn't seem likely that she would be able to continue to lift Sandra for too much longer, as she was quite slight. Netta really valued her caring role though.
- * Sandra seemed well enough in herself, and I'm not sure that she was approaching the end of her life (although her MS was very severe and she was hospitalised with pneumonia, so life was still precarious).
- * It was hard to determine Sandra's cognitive ability as she had speech difficulties, but some of her responses were a little strange and I'm not sure if this was MS related or whether she had always been like that.

- * They were both very anxious for a cure (like so many other participants) and had tried herbs and other cures from the US and NZ, which had been pretty useless.
- * They were both not very health literate and so tended to accept things like Sandra not being properly examined by doctors because they didn't have lifting equipment or ask further questions about the need for a tracheotomy when Sandra was hospitalised.
- * They had had no advance care planning discussions and with MS, this is an issue. They didn't seem to have any really trusted health care professionals though, who could introduce and follow up this discussion.

CASE REVIEW EIGHT: KATHRYN (KATE) DALY

Demographics

- * 62 year old woman.
- * Lived alone - separated from her husband.
- * Born and grew up in rural SA of Ukrainian heritage, but moved to Adelaide following her marriage.

Social Circumstances

- * 2 daughters – one lived in Queensland and one in Adelaide.
- * 3 grandchildren – 2 girls in Queensland and a grandson with autism in Adelaide.
- * Both daughters were supportive; however her daughter in Adelaide had little free time because of working and caring for her son with autism. Her daughter in Queensland often rang, and rang every day when Kate was in hospital.
- * Kate's sister lived in the country and so they didn't see each other frequently.
- * Kate felt she didn't have enough money for her daily living expenses. She drew a Disability Support pension and had no private health insurance. She owned her own home, but was still paying off the mortgage.
- * At the first visit, Kate was still driving her car, but by the third visit she was no longer able to do so. She had vouchers for Access Cabs. The expense involved in using these and also using Red Cross Transport was a concern for Kate, particularly as she wanted to regularly go to Hampstead Hospital for cardiac rehabilitation sessions.

- * When I first visited, Kate could go out and see people, however by the third visit she was feeling very socially isolated and alone and felt her friends had deserted her. She had previously volunteered at a local hospital and a nursing home and had sold Avon cosmetics, and really missed these social interactions. She was very upset and lonely, but looking at ways she could begin to socialise again and make new friends.
- * Just before my third visit, Kate's GP suggested she should move into hostel accommodation as he felt she was no longer coping living alone. Kate had agreed to begin the process for finding such accommodation, and felt it might help her social isolation as well.

Disease History

- * Kate had a number of major health problems:
 - Heart Failure (associated with two leaking heart valves and a pacemaker)
 - Parkinsonism (?Parkinson's Disease, ? PSP - diagnosed in 2009, following 2 years of falls)
 - Lymphoedema (and associated cellulitis)
 - Chronic back pain
 - Incisional hernia (abdomen and chest)
 - Asthma and pneumonia
- * Diagnosis of Kate's Parkinsonism was delayed even though she was hospitalised following falls. Initially, it was suggested she was addicted to the morphine she required for her back pain and this was reduced, and her hand tremor was ignored. It was finally diagnosed by her heart specialist who referred her immediately to a neurologist. An exact diagnosis could not be finalised as she could not have an MRI because of her pacemaker.

- * Kate changed her neurologist not long before enrolling in the project. She was very pleased with the new neurologist and felt the tablets he changed her to completely changed her ability to walk and undertake tasks. At the first visit she was getting ready to use an electric wheelchair, but by the third visit she was walking again with her walker, and getting out into the garden.
- * She also changed her cardiologist, as she was not particularly happy with her previous one.
- * She had two severe episodes of lymphoedema in the research period, with associated severe cellulitis.
- * She had an extremely large incisional hernia which was being managed by the high risk surgical clinic at the RAH. They needed to stabilise her iron levels and ensure she could withstand surgery. At the time of the last visit, she was due to be seen by the RAH clinic a month later with the possibility of surgery to repair the hernia.
- * She saw a psychologist, who was referred through the chronic heart failure program at the RAH. She felt he had helped her significantly although she was very resistant initially. She saw him again before my third visit.
- * Kate's back pain was being treated by the Pain Clinic at the RAH. She had commenced with them just before my first visit and was very satisfied with their support.

Major Problems Identified

- * At the first visit, Kate identified her biggest problem as every day coping: trying to walk - and get from A to B to C. She could function slowly with the walker, although her large hernia and lymphoedema also caused mobility issues. Over the period of my research she had a number of falls associated with her limbs freezing, and then she could not get up and was therefore on the floor for long periods of time.

- * By the third visit, Kate identified transport, loneliness and socialising as her major issues. She felt her friends had deserted her and her carers were now her only friends.
- * In terms of transport, she found the cost very difficult to cope with, despite vouchers and support from the Red Cross.

Advance Care Planning

- * At the first visit, Kate said she felt she couldn't deal with the issue of advance care planning – not because she was depressed, but rather because she was trying to cope with so many things, she just couldn't face it. She had not had a discussion about this with any of her key service providers.
- * By the third visit, Kate said she wanted to have “*Do Not Resuscitate*” (DNR) put in her notes, but she had not discussed this with anyone or completed a Medical Power of Attorney or an advance care directive. She felt they would be a good idea, and said she would follow up with her GP. She said it wasn't her heart problems that made her want a DNR order, but rather the Parkinson's “*because it's a cruel death*”.

Access to Services

Clinical Services:

- * Neurologist
- * Cardiologist x 2 (one for the pacemaker and another for the heart failure)
- * Pain Clinic
- * GP
- * High Risk Surgery Clinic (RAH)

- * Chronic Heart Failure program (RAH) – including access to cardiac rehabilitation programs at Hampstead Hospital and sessions with a clinical psychologist.

Home Based Services

- * Disability SA OT organised rails and ramps, changed taps and the shower. The home environment was friendly Kate felt safe, and able to manage things and be self-sufficient
- * Personal care
- * Cleaning
- * Shopping

Other:

- * Taxi Vouchers
- * Red Cross transport services
- * Home Access program through the local council for cleaning gutters and washing windows



Particular Problems/Issues

- * I was due to visit Kate for the third interview, and I had to postpone it as she there had been an attempted break in to her house and she was very distressed by this. Her GP had put in motion plans to move Kate to a hostel, as he felt she was not able to cope alone at home any longer and Kate had agreed to this, despite her reluctance to leave her own home. Kate felt being in a hostel might ease her loneliness and be safer.
- * A couple of days later, I visited Kate, and she was just returning from the GP when I arrived. She was in a highly distressed state and could not stop crying. She said she had pains throughout her body, mouth ulcers, itchy skin and scalp and was very depressed. She attributed her problems to stopping iron tablets, and had gone to the GP to get some iron tablets.
- * The GP (not her regular one) needed to take blood iron levels before prescribing iron, and so Kate had to go for a blood test the next morning and then return to the GP later in the afternoon (two return trips that required her to find transport).
- * Kate had not eaten or drunk all day and it was extremely hot weather and her air conditioner was not working properly. I remained with her for 5 hours until she had calmed down, showered, eaten and drunk and taken her medication. Following her up the next day, she continued to improve and after a couple of days reported that the iron tablets had improved all her symptoms and she was feeling much better. I returned a week later to complete Interview 3.

PHQ-9/WHOQOL

PHQ_9

Interview 1	11 (moderate)	Missing answer for question 10
Interview 2	12 (moderate)	Missing answers for questions 5, 8 10
Interview 3	16 (moderately severe)	Missing answers for questions 8 & 10

WHOQOL

	Raw Score	Transformed Scores	
Domain 1: Physical Health			
Interview 1	17/35	35.7	
Interview 2	23/35	57.1	
Interview 3	19/35	42.9	
Domain 2: Psychological Health			
Interview 1	22/30	66.7	
Interview 2	19/30	54.2	
Interview 3	21/30	62.5	
Domain 3: Social Relationships			
Interview 1	12/15	75.0	Missing answer for 1 question
Interview 2	4/15	8.3	Missing answer for 1 question
Interview 3	7/15	33.3	Missing answer for 1 question
Domain 4: Environment			
Interview 1	31/40	71.9	
Interview 2	29/40	65.6	
Interview 3	22/40	50.0	

Kate's perceived quality of life scores deteriorated across the three visits in all areas except physical health.

Reflections

Kate had multiple health and social problems and it was difficult to see how she could continue to live alone in her house. Her husband had left her when she became ill, and although she was close to her daughters, neither were in a position to actively provide help. She spoke at length about how important a positive attitude was, and said that she had experienced a lot of difficulty initially with her various illnesses. She credited her psychologist with helping her to turn around her attitude and noted that once her attitude changed, the health professionals she dealt with were much nicer to her. She had accepted her disability and did what she could – she did things differently from what she may have liked to because of the disability, but she had help and *“if you don’t give it a go, you don’t know whether you can do it or not”*.

Each one of Kate’s health issues would have been major by itself, but the combination particularly of PD and her heart failure was really devastating. On the first visit, the lymphoedema in her legs was huge and they were seeping fluid (and they had improved since her hospitalisation!) and on the second they were worse, as she had had a fall in the night and ended up on her knees and couldn’t get up. She was there for a number of hours before the ambulance came and helped her up. She had great difficulty walking, compounded by her back pain. On the second visit she showed me her incisional hernia which was huge, and its central position meant she had difficulty moving.

She had regular appointments with her various health service providers and the community cardiac nurses were in regular touch. She went to Hampstead Hospital for regular rehabilitation and enjoyed the gym, despite her various physical difficulties. She had a good relationship with her GP who she also saw regularly. Kate had access to a variety of assistants for cleaning and shopping, but no personal care. She was not afraid to ask for help from various sources and was using services from DSA, the Red Cross and the local council.

Kate could cope with everything when her condition was stable, but this was quite fragile as if anything changed, her coping ability greatly diminished. She

was highly distressed on my third visit and it was hard to identify the cause – she blamed the fact that her iron tablets had ceased because she was supposed to have an iron infusion through the High Risk Surgical Clinic at the RAH, but she felt they kept fobbing her off. She said she had a lot of pain, but she was also very emotionally distressed and petrified at being left alone. Of most concern was that she was in that state when she saw her GP and the GP sent her home. She needed to return the next day following blood tests, but this entailed Kate finding someone to take her to the pathology service and bring her home the next morning and then take her to the GP in the afternoon and bring her home. Whilst access to transport is not the GP's issue, there was actually no-one whose issue it was, except Kate, who was in a highly distressed state. Also, given her difficulty walking and getting around, it seemed that there must be a better way than to make her go out twice in one day. I was concerned that the GP had not dealt with her distress (or appeared to consider something like Valium). If I had not been there, I think Kate could have worked herself into such a state she would have called an ambulance for assistance.

CASE REVIEW NINE: HELEN AND MARY (AND FRED) DALGLIESH

Demographics

- * Helen: 56 years old from Adelaide
- * Mary (Helen's mother): 81 years from Adelaide
- * Both had private health insurance and Helen had superannuation.

Social Circumstances

- * Helen lived with a partner until 5-6 years ago. He also had MS but died. Following this, someone from Julia Farr Options asked if Helen would like to live in a supported care house at Woodville with full time care, and she accepted. She then moved into supported care in Klemzig (through Julia Farr Options). This is a couple of kilometres from Margaret's house.
- * Helen had access to on-site care as required and they also took her out to concerts etc and on trips and to visit her family.
- * Helen was severely incapacitated and did not speak or move. She appeared to be cognitively intact however, and enjoyed movies, concerts, watching TV etc.
- * Mary was 81 years old but very vital and had obviously fought hard and long to ensure that Helen had as full and comfortable life as possible.
- * She saw Helen a number of times throughout the week and Helen spent most Sundays at Mary's house, where her siblings also visited. Her siblings also visited her at Klemzig.
- * Mary also cared for her husband Fred, who had had PD for 12 years (the last 4 years very severe) and dementia. He lived at home with her, and she had help and support at home for him through an EACH package (through Helping Hand and ACH), which her GP helped to organise.
- * Altogether, Mary spent >71 hrs/week in caring.

Disease History

- * Helen had MS for 30 years, and had been in a wheelchair for the last 10 years. She was still able to work as a teacher up to her early 40's and used a walker and scooter to get around.
- * Helen had a suprapubic urinary catheter and had been being fed through a tube into her stomach for 6/12. She spoke very quietly and with difficulty, so her mother Mary answered most questions. She had very restricted movement and developed quite a strong facial tick.

Major Problems Identified

- * Facial tic
- * Social isolation

Advance Care Planning

- * At the first interview, although Mary said that she had a Medical Power of Attorney for Helen, she said that no-one had really had a conversation with either herself or Helen about what Helen's wishes might be as her disease progressed. She thought the most appropriate person to do that was probably Helen's GP who knew her very well.
- * At the third visit, Mary reported that she had completed a long document about what Helen's wishes about her care might be. This was initiated through Julia Farr Options and they helped Mary to complete the form.

Access to Services

Clinical Services:

- * Neurologist
- * Urologist
- * Dermatologist

- * Podiatrist
- * OT
- * Dietician
- * Speech pathologist
- * Mary and Helen reported that they had exceptional GPs. Fred's GP gave Mary all the papers and contacts required for her to get a range of home supports for Fred, and Helen's GP did home visits and was very caring.

Home Based Services

- * Options (through Julia Farr)

Other:

- * DSA provided help with some equipment, although a special bed and mattress were self-provided.
- * The MS Society had been very helpful and Helen went to exercise classes and did go to their swimming pool (although she then moved to a pool at Woodville).
- * The MS Society organised visits from an OT/ dietician and speech pathologist.
- * Mary got respite support for 12 hrs/week and had an EACH package to help her care for her husband.



Particular Problems/Issues

- * Mary's main concern for Helen was social isolation. Helen lived alone in her unit, and staff came in and out regularly to get her in and out of bed and undertake various tasks, but she generally spent quite long periods alone.
- * Her GP saw her regularly for scripts and general review and prescribed anti-depressants, although both Helen and Mary did not identify depression as an issue at the time of the interviews.

PHQ-9/WHOQOL/Carers

PHQ_9*

Interview 1	5 (mild)	Missing answers for questions 5, 8, 9 & 10
Interview 2	3 (none)	Missing answers for questions 5, 8 10
Interview 3	1 (none)	Missing answers for questions 5, 8, 9 & 10

* On antidepressants

WHOQOL

	Raw Score	Transformed Scores	
Domain 1: Physical Health			
Interview 1	11/35	14.3	Missing answers for 4 questions
Interview 2	11/35	14.3	Missing answers for 3 questions
Interview 3	10/35	10.7	Missing answers for 3 questions
Domain 2: Psychological Health			
Interview 1	20/30	58.3	Missing answers for 2 questions
Interview 2	16/30	41.7	Missing answer for 1 question
Interview 3	16/30	41.7	Missing answer for 1 question
Domain 3: Social Relationships			
Interview 1	8/15	41.7	Missing answer for 1 question
Interview 2	8/15	41.7	Missing answer for 1 question
Interview 3	2/15	-8.3	Missing answers for 1 question
Domain 4: Environment			
Interview 1	30/40	68.8	
Interview 2	28/40	62.5	Missing answer for 1 question
Interview 3	33/40	78.1	

Helen's perceived quality of life remained fairly steady over the three visits, except in the area of social relationships which dropped markedly at visit 3.

Carer QoL Summary

	Interview 1	Interview 2	Interview 3
Support for Caring	14	15	14
Caring Choice	15	13	9
Caring Stress	10	14	12
Money Matters	15	15	9
Personal Growth	10	7	7
Sense of Value	10	11	8
Ability to Care	10	9	8
Carer Satisfaction	13	15	13
TOTAL	97	99	80

Mary reported a high quality of life during the first two visits, but this had dropped slightly to the mid range at visit 3.

Reflections

- * Because they were well off financially, and very health literate, Mary was able to ensure Helen was in her own home and was well cared for and was able to go out regularly and also go away on holidays (e.g. last year to see a musical in Melbourne and this year to Wallaroo).
- * The level of the clinical care required by Helen was very high and Mary was able to use her private health insurance and financial status to purchase necessary equipment and organise care more quickly than through the public system. e.g. when Helen required a changed supra-pubic catheter, this was done privately as the waiting list in the public system was too long.
- * Helen required hospitalisation in the RAH in winter 2012 for a urinary tract infection and pneumonia. In stark contrast to Sandra (who also had MS and was hospitalised in winter 2012 for pneumonia), her experience of care was “wonderful” and Mary said she had “very good attention”. The reasons for such a different experience of care were hard to identify, but could be

related to the marked difference in levels of health literacy and socio-economic status between Mary and Helen and Sandra and Netta.

- * It appears all of Helen's needs were able to be met, despite the extreme disability caused by her condition. The only area of concern was social isolation, however strong family ties and the regular attendance of caregivers meant that she did have regular contact, even if not as much as her mother would prefer.
- * In late 2013, Helen's condition deteriorated suddenly and she entered status epilepticus. She was transferred to intensive care but died soon after. At the same time, her father's condition deteriorated significantly and he also died in hospital at around the same time as his daughter.

Appendix 8. End of life screening tools

The Supportive and Palliative Care Indicators Tool

Last updated 22nd April 2015¹⁴²



Supportive and Palliative Care Indicators Tool (SPICT™)



The SPICT™ is a guide to identifying people at risk of deteriorating health and dying. Assess these people for unmet supportive and palliative care needs.

Look for two or more general indicators of deteriorating health.

- Performance status is poor or deteriorating (the person is in bed or a chair for 50% or more of the day); reversibility is limited.
- Dependent on others for most care needs due to physical and/or mental health problems.
- Two or more unplanned hospital admissions in the past 6 months.
- Significant weight loss (5-10%) over the past 3-6 months, and/ or a low body mass index.
- Persistent, troublesome symptoms despite optimal treatment of underlying condition(s).
- Patient asks for supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of one or more advanced conditions

Cancer

Functional ability deteriorating due to progressive metastatic cancer.

Too frail for oncology treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; swallowing difficulties.

Urinary and faecal incontinence.

No longer able to communicate using verbal language; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/ or progressive swallowing difficulties.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:

- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe chronic lung disease with:

- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

Liver disease

Advanced cirrhosis with one or more complications in past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

Review supportive and palliative care and care planning

- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals, and a care plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Record, communicate and coordinate the care plan.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™, April 2015

The Gold Standards Framework Prognostic Indicator Tool

4th Edition. 2011¹²¹

More details of Indicators – the intuitive surprise question , general and specific clinical

Step 1 The Surprise Question

For patients with advanced disease of progressive life limiting conditions - Would you be surprised if the patient were to die in the next few months, weeks, days?

- The answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

Step 2 General Indicators

Are there general indicators of decline and increasing needs?

- Decreasing activity – functional performance status declining (e.g. Barthel score) limited self-care, in bed or chair 50% of day) and increasing dependence in most activities of daily living
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity
- General physical decline and increasing need for support
- Advanced disease - unstable, deteriorating complex symptom burden
- Decreasing response to treatments, decreasing reversibility
- Choice of no further active treatment
- Progressive weight loss (>10%) in past six months
- Repeated unplanned/crisis admissions
- Sentinel Event e.g. serious fall, bereavement, transfer to nursing home
- Serum albumen <25g/l
- Considered eligible for DS1500 payment

Functional Assessments

Barthel Index describes basic Activities of Daily Living (ADL) as 'core' to the functional assessment. E.g. feeding, bathing, grooming, dressing, continence, toileting, transfers, mobility, coping with stairs etc .

PULSE 'screening' assessment - P (physical condition); U (upper limb function);

L (lower limb function); S (sensory); E (environment).

Karnofsky Performance Status Score 0-100 ADL scale .

WHO/ECOG Performance Status 0-5 scale of activity.

Step 3 Specific Clinical Indicators - flexible criteria with some overlaps, especially with Those with frailty and other co-morbidities.

a) Cancer – rapid or predictable decline

Cancer

- Metastatic cancer
- More exact predictors for cancer patients are available e.g. PIPS (UK validated Prognosis in Palliative care Study). PPI, PPS etc. 'Prognosis tools can help but should not be applied blindly'
- 'The single most important predictive factor in cancer is performance status and functional ability' - if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less.

b) Organ Failure – erratic decline

Chronic Obstructive Pulmonary Disease (COPD)

At least two of the indicators below:

- Disease assessed to be severe (e.g. FEV1 <30% predicted)
- Recurrent hospital admissions (at least 3 in last 12 months due to COPD)
- Fulfils long term oxygen therapy criteria
- MRC grade 4/5 – shortness of breath after 100 metres on the level of confined to house
- Signs and symptoms of right heart failure
- Combination of other factors – i.e. anorexia, previous ITU/NIV resistant organisms
- More than 6 weeks of systemic steroids for COPD in preceding 6 months.

Heart Disease

At least two of the indicators below:

- CHF NYHA Stage 3 or 4 - shortness of breath at rest on minimal exertion
- Patient thought to be in the last year of life by the care team - The 'surprise question'
- Repeated hospital admissions with heart failure symptoms
- Difficult physical or psychological symptoms despite optimal tolerated therapy.

Renal Disease

Stage 4 or 5 Chronic Kidney Disease (CKD) whose condition is deteriorating with at least 2 of the indicators below:

- Patient for whom the surprise question is applicable
- Patients choosing the 'no dialysis' option, discontinuing dialysis or not opting for dialysis if their transplant has failed
- Patients with difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy
- Symptomatic Renal Failure – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload.

General Neurological Diseases

- Progressive deterioration in physical and/ or cognitive function despite optimal therapy
- Symptoms which are complex and too difficult to control
- Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure
- Speech problems: increasing difficulty in communications and progressive dysphasia. Plus the following:

Motor Neurone Disease

- Marked rapid decline in physical status
- First episode of aspirational pneumonia
- Increased cognitive difficulties
- Weight Loss
- Significant complex symptoms and medical complications
- Low vital capacity (below 70% of predicted using standard spirometry)
- Dyskinesia, mobility problems and falls
- Communication difficulties.

Parkinson's Disease

- Drug treatment less effective or increasingly complex regime of drug treatments
- Reduced independence, needs ADL help
- The condition is less well controlled with increasing "off" periods
- Dyskinesias, mobility problems and falls
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)
- Similar pattern to frailty- see below.

Multiple Sclerosis

- Significant complex symptoms and medical complications
- Dysphagia + poor nutritional status
- Communication difficulties e.g. Dysarthria + fatigue
- Cognitive impairment notably the onset of dementia.

c) Frailty / Dementia – gradual decline

Frailty

Individuals who present with Multiple co morbidities with significant impairment in day to day living and:

- Deteriorating functional score e.g. performance status – Barthel/ECOG/Karnofsky
- Combination of at least three of the following symptoms:
 - weakness
 - slow walking speed
 - significant weight loss
 - exhaustion
 - low physical activity
 - depression.

Stroke

- Persistent vegetative or minimal conscious state or dense paralysis
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment / Post-stroke dementia.

Dementia

There are many underlying conditions which may lead to degrees of dementia and these should be taken into account. Triggers to consider that indicate that someone is entering a later stage are:

- Unable to walk without assistance and
- Urinary and faecal incontinence, and
- No consistently meaningful conversation and
- Unable to do Activities of Daily Living (ADL)
- Barthel score <3.

Plus any of the following:

- Weight loss
- Urinary tract Infection
- Severe pressures sores – stage three or four
- Recurrent fever
- Reduced oral intake
- Aspiration pneumonia.

It is vital that discussions with individuals living with dementia are started at an early to ensure that whilst they have mental capacity they can discuss how they would like the later stages managed.

The NECPAL CCOMS-ICO® tool (*NECesidades PALiatives Centro Colaborador de la Organización Mundial de la Salud – Institut Català d’Oncologia*).

English Version, 2011²⁹⁵



Tool to identify
Advanced-Terminal patients in need of
palliative care within health and social services

**NECPAL CCOMS-ICO® Tool
Version 1.0**

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NECPAL CCOMS-ICO® TOOL (Necesidades Paliativas [Palliative Needs])

TOOL TO IDENTIFY ADVANCED-TERMINAL PATIENTS IN NEED OF PALLIATIVE CARE WITHIN HEALTH AND SOCIAL SERVICES

What does the NECPAL CCOMS-ICO® TOOL use for?

- It is a strategy to identify patients who require palliative care, especially in general health services (primary care, conventional hospital services, etc.)
- The aim of the tool is to identify patients in need of any type of palliative care
- Once the patient is identified, a palliative approach needs to be initiated. That consisting in implementing the recommendations made explicit in the *6 Steps for Palliative Care provision*. (see details further on)
- Identifying such situation **does not contraindicate nor limit measures of specific treatment of disease** if prescribed or can improve the patients' wellbeing or life quality
- Palliative care can be implemented by any health team in any health service

What does the NECPAL CCOMS-ICO® TOOL NOT use for?

- To determine prognosis or survival
- To contraindicate, necessarily, symptom control measures for a specific disease or the treatment of diverse processes
- To define the criteria for the intervention of specific palliative care teams. Such intervention would, in all cases, be determined by the complexity of each case and the proposed intervention
- To reject therapeutic curative measures that could improve the patients' quality of life

To whom should the NECPAL CCOMS-ICO® TOOL be administered?

To patients with **advanced chronic diseases**, with the following diagnoses and conditions:

- **Cancer** patient especially affected by the disease
- Patient with **chronic obstructive pulmonary disease (COPD)** especially affected by the disease
- Patient with **chronic heart disease** especially affected by the disease
- Patient with **chronic neurological disease** (including CVA, ALS, MS, Parkinson, motor neurone disease) especially affected by the disease
- Patient with **serious chronic liver disease** especially affected by the disease
- Patient with **serious chronic renal disease** especially affected by the disease
- Patient with **dementia** especially affected by the disease
- **Geriatric** patient who, although not suffering from any of the previous referred diseases, is in situation of **particularly advanced frailty**
- Patient who, although not being geriatric nor suffering from any of the previous referred diseases, suffers from any other **particularly serious and advanced chronic disease**
- Patient who, without being included in any of the previous groups, has recently **being admitted or taken care at home with a higher degree of intensity than expected**

What is considered as being a positive identification?

Any patient with :

- **Surprise Question** (question 1) with answer '**NO**', and
- At least **other question** (2, 3 or 4) with **POSITIVE** answer, according to the established criteria

What are the 6 Steps for Palliative Care provision?

They are the basic recommendations for palliative care provision towards the identified patients. They consist of:

1. Identifying Multidimensional Needs
2. Performing an impeccable Model of care
3. Elaborating a Therapeutic Multidimensional and Systematic Plan (Square of Care)
4. Identifying the patients' values and preferences: Clinical Ethics and Advance Care Planning
5. Making the family and the main caregiver participant
6. Carrying out case management, follow-up, continuous and urgent care, coordination and comprehensive actions among different services

NECPAL CCOMS-ICO® TOOL
(Necesidades **P**aliativas [Palliative Needs])

TOOL TO IDENTIFY ADVANCED-TERMINAL PATIENTS IN NEED OF PALLIATIVE CARE WITHIN HEALTH AND SOCIAL SERVICES

1. THE SURPRISE QUESTION – an intuitive question integrating co-morbidity, social aspects and other factors	
Would you be surprised if this patient dies within the next 12 months?	<input type="checkbox"/> No <input type="checkbox"/> Yes

2. CHOICE / REQUEST OR NEED¹ – explore if any of the following questions is affirmative	
Choice / Request: Have either the patient with advanced disease or the main caregiver requested , in explicit or implicit manner, palliative/comfort treatments exclusively? Do they suggest limitation of therapeutic effort or reject specific treatments or those with curative purposes?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Need: Do you consider this patient requires palliative care or palliative treatment at this moment ?	<input type="checkbox"/> Yes <input type="checkbox"/> No

3. GENERAL CLINICAL INDICATORS OF SEVERITY & PROGRESSION – explore the presence of any of the following criteria of severity and extreme frailty	
Nutritional Markers , any of the following, in the last 6 months : <input type="checkbox"/> Severity: serum albumin < 2.5 g/dl, not related to acute episodes of decompensation <input type="checkbox"/> Progression: weight loss > 10% <input type="checkbox"/> Clinical Perception of nutritional decline (sustained, intense/severe, progressive, irreversible) not related to concurrent conditions	<input type="checkbox"/> Yes <input type="checkbox"/> No
Functional Markers , any of the following, in the last 6 months : <input type="checkbox"/> Severity: serious established functional dependence (Barthel score < 25, ECOG > 2 or Karnofsky score < 50%) <input type="checkbox"/> Progression: loss of 2 or more activities of daily living (ADL's) even though there is adequate therapeutic intervention <input type="checkbox"/> Clinical Perception of functional decline (sustained, intense/severe, progressive, irreversible) not related to concurrent conditions	<input type="checkbox"/> Yes <input type="checkbox"/> No
Other markers of severity and extreme frailty , at least 2 of the following, in the last 6 months : <input type="checkbox"/> Persistent pressure ulcers (stage III – IV) <input type="checkbox"/> Recurrent infections (> 1) <input type="checkbox"/> Delirium <input type="checkbox"/> Persistent Dysphagia <input type="checkbox"/> Falls (> 2)	<input type="checkbox"/> Yes <input type="checkbox"/> No
Presence of emotional distress with psychological symptoms (sustained, intense/severe, progressive) not related to acute concurrent conditions	<input type="checkbox"/> Yes <input type="checkbox"/> No
Additional Factors on use of resources. Any of the following: <input type="checkbox"/> 2 or more urgent (unplanned) hospital (or skilled nursing facilities) admissions due to chronic disease in the last year <input type="checkbox"/> Need of complex/intense continuing care, either at an institution or at home	<input type="checkbox"/> Yes <input type="checkbox"/> No
Co-morbidity: ≥ 2 concurrent diseases	<input type="checkbox"/> Yes <input type="checkbox"/> No

¹ In Mediterranean/Latin countries, where the patient's autonomy is less evident than in Anglo-Saxon/north European countries, the family or team members are usually the ones who request either palliative care, limitation of therapeutic effort, or both measures

4. SPECIFIC CLINICAL INDICATORS OF SEVERITY & PROGRESSION PER DISEASES – explore the presence of specific bad prognosis criteria for the following selected diseases

CANCER (it requires the presence of one single criterion)	<input type="checkbox"/> Yes <input type="checkbox"/> No
<input type="checkbox"/> Patients with confirmed diagnosis of metastatic cancer (stage IV; and also stage III in some cases –e.g. lung, pancreas, stomach and oesophagus cancers) who present low response or contraindication of specific treatment, progressive outbreak during treatment or metastatic affection of vital organs (CNS, liver, severe pulmonary disease, etc.) <input type="checkbox"/> Significant functional deteriorating (Palliative Performance Status (PPS) < 50%) <input type="checkbox"/> Persistent, troublesome symptoms, despite optimal treatment of underlying condition(s)	
CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD) (presence of two or more of the following criteria)	<input type="checkbox"/> Yes <input type="checkbox"/> No
<input type="checkbox"/> Breathlessness at rest or on minimal exertion between exacerbations <input type="checkbox"/> Difficult physical or psychological symptoms despite optimal tolerated therapy <input type="checkbox"/> In case of having functional respiratory tests (with caveats about quality of testing), disease assessed to be severe: FEV1 <30% or criteria of restricted severe deficit: CVF < 40% / DLCO < 40% <input type="checkbox"/> In case of having arterial blood gases (ABG), accomplishment of oxygen therapy at home criteria or such treatment underway <input type="checkbox"/> Symptomatic heart failure <input type="checkbox"/> Recurrent hospital admissions (> 3 admissions in 12 months due to exacerbations of EPOC)	
CHRONIC HEART DISEASE (presence of two or more of the following criteria)	<input type="checkbox"/> Yes <input type="checkbox"/> No
<input type="checkbox"/> Heart failure NYHA stage III or IV, severe valve disease or inoperable coronary artery disease <input type="checkbox"/> Shortness of breath at rest or minimal exertion <input type="checkbox"/> Difficult physical or psychological symptoms despite optimal tolerated <input type="checkbox"/> In case of having echocardiography: ejection fraction severely affected (< 30%) or severe pulmonary hypertension (Pulmonary pressure > 60 mmHg) <input type="checkbox"/> Renal failure (FG < 30 l/min) <input type="checkbox"/> Repeated hospital admissions with symptoms of heart failure/ischemic heart disease (> 3 last year)	
CHRONIC NEUROLOGICAL DISEASES (1): CVA (it requires the presence of one single criterion)	<input type="checkbox"/> Yes <input type="checkbox"/> No
<input type="checkbox"/> During acute and sub acute phases (< 3 months post-stroke): persistent vegetative or minimal conscious state > 3 days <input type="checkbox"/> During the chronic phase (> 3 months post-stroke): repeated medical complications (aspiration pneumonia despite antispasmodic measures), pyelonephritis (>1), recurrent febrile episodes a despite antibiotics (persistent temperature post > 1 week of antibiotics), pressure ulcers stage 3-4 or dementia with severe criteria post-stroke	
CHRONIC NEUROLOGICAL DISEASES (2): ALS & MOTOR NEURONE DISEASES, MÚLTIPLE SCLEROSIS & PARKINSON (presence of two or more of the following criteria)	<input type="checkbox"/> Yes <input type="checkbox"/> No
<input type="checkbox"/> Progressive deterioration in physical and/or cognitive function despite optimal therapy <input type="checkbox"/> Complex and difficult symptoms <input type="checkbox"/> Speech problems with increasing difficulty communicating <input type="checkbox"/> Progressive Disphagia <input type="checkbox"/> Recurrent aspiration pneumonia, breathless or respiratory failure	
SERIOUS CHRONIC LIVER DISEASE (it requires the presence of one single criterion)	<input type="checkbox"/> Yes <input type="checkbox"/> No
<input type="checkbox"/> Advanced Cirrhosis: stage Child C (determined in lack of complications or having treated them and optimized the treatment), MELD-Na score > 30 or with one or more of the following medical complications: diuretic resistant ascites, hepatorenal syndrome or upper gastrointestinal bleeding due to portal hypertension with failed response to pharmacologic and endoscopic treatment and with contraindicated transplant and TIPS. <input type="checkbox"/> Hepatocellular carcinoma: present, in stage C or D (BCLC)	
SERIOUS CHRONIC RENAL DISEASE (it requires the presence of one single criterion)	<input type="checkbox"/> Yes <input type="checkbox"/> No
<input type="checkbox"/> Serious renal failures (FG < 15) in patients to whom substitutive treatment or transplant is contraindicated	
DEMENTIA (presence of two or more of the following criteria)	<input type="checkbox"/> Yes <input type="checkbox"/> No
<input type="checkbox"/> Severity criteria: unable to dress, wash or eat without assistance (GDS/FAST 6c), urinary and faecal incontinence (GDS/FAST 6d-e) or unable to communicate meaningfully -6 or less intelligible words- (GDS/FAST 7) <input type="checkbox"/> Progression criteria: loss of 2 or more activities of daily living (ADL's) in the last 6 months, despite adequate therapeutic intervention (non valorable in hyperacute situation due to concurrent processes) or difficulty swallowing, or denial to eat, in patients who will not receive enteral or parenteral nutrition <input type="checkbox"/> Use of resources criteria: multiple admissions (> 3 in 12 months, due to concurrent processes –aspiration pneumonia, pyelonephritis, sepsis, etc.- that cause functional and/or cognitive decline)	

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