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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Contents

CONTENTS ...................................................................................................................................................... I
LIST OF TABLES ............................................................................................................................................... VI
LIST OF FIGURES .......................................................................................................................................... VII
ABSTRACT ........................................................................................................................................................ VIII
MANUSCRIPTS CONTRIBUTING TO THIS THESIS ....................................................................................... X
CONFERENCES PRESENTATIONS ARISING FROM THIS THESIS ............................................................... XI
ACKNOWLEDGEMENTS .............................................................................................................................. XII
THESIS DECLARATION ................................................................................................................................. XIV
THESIS INTRODUCTION ............................................................................................................................. 1

PART 1. BACKGROUND .................................................................................................................................... 5

CHAPTER 1. SETTING THE SCENE .................................................................................................................... 7
  1.1. INTRODUCTION ........................................................................................................................................ 7
  1.2. WHAT IS A HEALTH SYSTEM? ................................................................................................................ 12
  1.3. COMPLEXITY THEORY AND COMPLEX ADAPTIVE SYSTEMS .......................................................... 14
  1.4. SYSTEMS THINKING AND HEALTH POLICY AND SYSTEMS ......................................................... 19
  1.5. SUMMARY .............................................................................................................................................. 20

CHAPTER 2. LITERATURE REVIEW .................................................................................................................. 22
  2.1. INTRODUCTION ........................................................................................................................................ 22
  2.1.1. A note about the scope of this literature review .................................................................................. 23
  2.2. ARE ‘PALLIATIVE CARE’ AND ‘END OF LIFE CARE’ THE SAME THING FOR PEOPLE WITH
        CHRONIC DISEASE? .............................................................................................................................. 24
  2.2.1. End of life care ..................................................................................................................................... 24
  2.2.2. Palliative care and a palliative approach .......................................................................................... 26
  2.2.3. Chronic disease ................................................................................................................................. 28
  2.2.4. Summary ............................................................................................................................................ 30
  2.3. WHAT ARE THE DRIVERS FOR THE EXPANSION OF END OF LIFE CARE FOR PEOPLE WITH
        CHRONIC DISEASE? .............................................................................................................................. 31
  2.3.1. Demographics .................................................................................................................................... 31
  2.3.2. The epidemiology of advanced chronic disease .............................................................................. 33
  2.3.3. Ethics and quality of care .................................................................................................................. 35
  2.3.4. The role of carers ................................................................................................................................ 37
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.4. What barriers exist to the delivery of end of life for people with advanced chronic disease?</td>
<td>38</td>
</tr>
<tr>
<td>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?</td>
<td>40</td>
</tr>
<tr>
<td>2.5.1. The management of chronic disease</td>
<td>40</td>
</tr>
<tr>
<td>2.5.2. End of life care in the current Australian context</td>
<td>42</td>
</tr>
<tr>
<td>2.6. What strategies can facilitate the person centred, integrated care that is a key requirement for quality end of life care?</td>
<td>47</td>
</tr>
<tr>
<td>2.6.1. Person centred care</td>
<td>47</td>
</tr>
<tr>
<td>2.6.2. Integrated and coordinated care</td>
<td>49</td>
</tr>
<tr>
<td>2.6.3. Advance care planning</td>
<td>50</td>
</tr>
<tr>
<td>2.6.4. Public health approaches to palliative care</td>
<td>52</td>
</tr>
<tr>
<td>2.7. Summary</td>
<td>54</td>
</tr>
<tr>
<td>CHAPTER 3. METHODOLOGY</td>
<td>56</td>
</tr>
<tr>
<td>3.1. Introduction and background</td>
<td>56</td>
</tr>
<tr>
<td>3.2. Ethical issues and approvals</td>
<td>57</td>
</tr>
<tr>
<td>3.3. Reflexivity</td>
<td>60</td>
</tr>
<tr>
<td>3.4. Research design</td>
<td>63</td>
</tr>
<tr>
<td>3.4.1. Phase 1: Policy review</td>
<td>65</td>
</tr>
<tr>
<td>3.4.2. Phase 2: Case reviews</td>
<td>67</td>
</tr>
<tr>
<td>3.4.3. Phase 3: Service manager and policy maker and perspectives</td>
<td>77</td>
</tr>
<tr>
<td>3.4.4. Data analysis</td>
<td>79</td>
</tr>
<tr>
<td>3.5. Research quality and rigour</td>
<td>86</td>
</tr>
<tr>
<td>3.6. Summary</td>
<td>89</td>
</tr>
<tr>
<td>PART 2. ANALYSIS AND RESULTS</td>
<td>91</td>
</tr>
<tr>
<td>CHAPTER 4. FALLING THROUGH THE CRACKS? END OF LIFE CARE AND CHRONIC DISEASE HEALTH POLICIES</td>
<td>93</td>
</tr>
<tr>
<td>4.1. Introduction</td>
<td>93</td>
</tr>
<tr>
<td>4.2. Health policy analysis results</td>
<td>94</td>
</tr>
<tr>
<td>4.3. Summary</td>
<td>104</td>
</tr>
<tr>
<td>CHAPTER 5. CASE REVIEW RESULTS: SYSTEM STRUCTURE AND THE PROCESS OF CARE</td>
<td>105</td>
</tr>
<tr>
<td>5.1. Introduction</td>
<td>105</td>
</tr>
<tr>
<td>5.2. System structure</td>
<td>106</td>
</tr>
<tr>
<td>5.2.1. Environment factors</td>
<td>107</td>
</tr>
<tr>
<td>5.2.2. Chronic disease management/end of life characteristics</td>
<td>110</td>
</tr>
<tr>
<td>5.2.3. Economic factors</td>
<td>117</td>
</tr>
</tbody>
</table>
CHAPTER 6. CASE REVIEW RESULTS: PATIENT OUTCOMES ........................................ 139

6.1. INTRODUCTION ............................................................................................. 139

6.2. SATISFACTION WITH DOMAINS OF CARE ......................................................... 141
   6.2.1. Availability of care .................................................................................. 141
   6.2.2. Free flow and accessibility of information ............................................. 145
   6.2.3. Physical care ......................................................................................... 146
   6.2.4. Psychosocial care ................................................................................. 148
   6.2.5. Availability of care ................................................................................. 151
   6.2.6. Free flow and accessibility of information ............................................. 156
   6.2.7. Physical care ......................................................................................... 157
   6.2.8. Psychosocial care ................................................................................. 159
   6.2.9. Summary of satisfaction with domains of care .................................... 160

6.3. CLIENT CENTEREDNESS OF CARE ................................................................. 161
   6.3.1. Appropriate involvement of family and friends ..................................... 161
   (Specifically in decision making and information giving .................................. 161
   6.3.2. Collaboration/ team management and education and shared knowledge .. 162
   6.3.3. Rapport ................................................................................................... 164
   6.3.4. Respect for patient needs and preferences ............................................ 164
   6.3.5. Sensitivity to nonmedical and spiritual dimensions of care ................. 165
   6.3.6. Appropriate involvement of family and friends ..................................... 165
   6.3.7. Collaboration/team management and education and shared knowledge .. 166
   6.3.8. Rapport ................................................................................................... 167
   6.3.9. Respect for patient needs and preferences ............................................ 167
   6.3.10 Sensitivity to nonmedical and spiritual dimensions of care .................. 168
   6.3.11 Summary of client centeredness of care ............................................... 168

6.4. CONTINUITY OF CARE ................................................................................ 168

6.5. SUMMARY .................................................................................................... 169

CHAPTER 7. RESULTS: SERVICE MANAGERS AND POLICY MAKERS ............... 172

7.1. INTRODUCTION ............................................................................................. 172

7.2. END OF LIFE CARE ..................................................................................... 173
   7.2.1. Philosophies of end of life care ............................................................. 174
List of tables

Table 1. Conceptual transitions in palliative care in the 21st century .............................................. 31
Table 2. Leading causes of death, Australia: 2013. ............................................................................... 33
Table 3. Deaths attributable to neurological disorders as percentage of total deaths, 2005, 2015 and 2030. ......................................................................................................................... 35
Table 4. Ottawa Charter principles and health promoting palliative care ............................................. 53
Table 5: Case review patients .................................................................................................................. 73
Table 6. Key service provider interviews .............................................................................................. 75
Table 7. Policy maker and service manager interviews .......................................................................... 78
Table 8: Codes and themes .................................................................................................................... 81
Table 9. Conceptual framework domains in examining end of life care for chronic disease .............. 83
Table 10. Processes for ensuring rigour in qualitative data collection and analysis ............................... 87
Table 11: System structure analysis summary ....................................................................................... 106
Table 12: Process of care analysis summary .......................................................................................... 122
Table 13. Patient outcomes analysis summary ....................................................................................... 140
Table 14. Summary of the results of the systems analysis .................................................................... 200
Table 15. Complex adaptive system characteristics of the health system applied to end of life care ........................................................................................................................................... 205
## List of figures

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Chaos theory concepts</td>
<td>16</td>
</tr>
<tr>
<td>2</td>
<td>Research design</td>
<td>65</td>
</tr>
<tr>
<td>3</td>
<td>Policy review methods</td>
<td>66</td>
</tr>
<tr>
<td>4</td>
<td>Analysis design</td>
<td>80</td>
</tr>
<tr>
<td>5</td>
<td>Thematic analysis: Management/policy stakeholders</td>
<td>85</td>
</tr>
<tr>
<td>6</td>
<td>The changing roles of clinicians and patients in a person centre care system</td>
<td>217</td>
</tr>
<tr>
<td>7</td>
<td>Common issues for patients, carers and families as they approach the end of life</td>
<td>223</td>
</tr>
<tr>
<td>8</td>
<td>An example of a primary care based model of end of life care</td>
<td>228</td>
</tr>
</tbody>
</table>
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 360° 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


Conference presentations arising from this thesis


Presentation: *Understanding the Complexity of End-of-Life Care in Advanced Chronic Disease.*

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


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?*


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


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


Presentation: *Complexity theory and end of life care: how can the Australian health system better support care at the end of life care for people with advanced chronic disease?*
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This thesis is dedicated to my parents, Mary and Alexander Buclaw, who are no longer with us. They always believed that I had the ability to complete a PhD and would have been delighted and proud to see that they were correct.
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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