People with cancer from rural areas undergoing treatment in metropolitan hospitals: Rural-urban differentials and the impact of cancer treatment

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Abstract

Discrepancies in health outcomes between rural and urban populations are well documented in broad health categories but less clear in relation to cancer care and outcomes. Those living in a rural or remote area are faced not only with the trauma of the diagnosis but may also need to have treatment at a specialist metropolitan centre, entailing relocation for at least some of the treatment time. This study was conducted in three phases to examine and clarify the issues of concern to patients from rural and remote areas undergoing cancer treatment in a metropolitan setting.

Secondary data analysis of cancer registry and government reports showed that the incidence of cancer was 4% lower for rural residents compared with metropolitan residents. A significant survival advantage was demonstrated for urban residents in 10 types of cancer. There were differences in the prevalence of some risk factors that appeared to favour the rural population, with rural residents indicating a higher participation in Pap smear screening and greater use of precautions against sun damage.

A focused literature review was conducted to investigate research on rural and remote patients receiving cancer treatment in the metropolitan setting. This identified potential issues related to rural residents with cancer including: the need for travel; psychosocial concerns; information and communication; financial costs; and accommodation while away from home. Overall the research in the Australian setting was limited in number and mostly conducted with disease specific groups.

In the third phase, a survey of 96 patients from rural and remote areas undergoing cancer treatment in the metropolitan setting showed that participants were satisfied with their treatment but there appeared to be a tendency to understate problems related to treatment. This study identified that for many participants, attending for treatment without their partner or spouse was inconceivable and the lack of routine financial support for this was problematic. In relation to health care, participants being treated in the private sector were less likely to see a dietician or a social worker. Barriers were also seen in the lack of coordination of treatment, lack of reimbursement for psychosocial support, inadequate information provision and lack of appropriate practical support in accommodation and transport. Interviews with health care professionals complemented these findings and showed support for strategies to improve psychosocial support.
This study showed that the lack of financial support for a companion during treatment was an important contributory factor affecting satisfaction with care. To ensure an equitable and acceptable degree of quality of care, financial support should be routinely provided to enable rural residents to be accompanied by a support person when travelling to access cancer treatment. Investigation of the process of treatment itself is also needed to ensure that all the supports designed to ensure access for rural residents are appropriate and suited to their needs.
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Declaration

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 is made in the text.

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### Abbreviations used

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<tr>
<td>RAH</td>
<td>Royal Adelaide Hospital</td>
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<tr>
<td>TQEH</td>
<td>The Queen Elizabeth Hospital</td>
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<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
</tr>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
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<td>AACR</td>
<td>Australasian Association of Cancer Registries</td>
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Chapter 1 - Introduction

Introduction

This thesis examines rural-urban cancer differentials and the impact of cancer treatment in the metropolitan setting on rural residents. These areas are important as a diagnosis of cancer is typically a distressing event in the life of the person concerned and also typically precipitates a need for support. For the person living in a rural or remote area a diagnosis of cancer means that they are not only faced with the trauma of a potentially life limiting disease, but are also likely to require treatment at a specialist centre in a metropolitan setting. Unlike their metropolitan counterparts, attending for treatment usually entails leaving home, either for several short periods or for fewer longer periods. This then involves navigating through an unfamiliar specialist health service environment as well as an unfamiliar living environment while being away from family and friends who would normally be considered to have an important supportive role in the adjustment to a diagnosis of cancer. Examining and clarifying the issues of concern to rural and remote patients undergoing cancer treatment in a metropolitan setting is the major focus of this study.

Purpose of the study

This study seeks to determine whether there are differences in the incidence and mortality of cancer in rural and urban populations in South Australia, and to document the experiences of rural and remote South Australians who receive cancer treatment in Adelaide and hence to develop an understanding of their needs.

The objectives of this study are to:

1) identify any differences in prevalence of cancer risk factors, incidence of cancers and cancer mortality according to geographic area of residence in South Australia;

2) identify key issues impacting on the care and treatment of rural and remote patients receiving cancer treatment in Adelaide;

3) determine the extent and relative importance of these issues; and

4) suggest strategies that might improve services.
The significance of cancer

Cancer can be defined as a group of diseases in which cells are growing in an uncontrolled and purposeless way (The Cancer Council South Australia, 2006) which can invade nearby tissues and can spread through the blood and lymphatic systems to other parts of the body. Cancer occurs in all societies and is therefore an issue of global significance. International cancer information is published by the World Health Organisation (WHO) using statistics from the Globocan database. Globocan contains information provided by the International Agency for Research on Cancer. The age-standardised incidence of cancer world-wide (excluding non-melanocytic skin cancer) in 2002 was estimated at 161.5 per 100,000 (female) and 209.6 per 100,000 (male), with mortality at 92.1 (female) and 137.7 (male) (Ferlay, Bray, Pisani and Parkin, 2001).

Cancer is a health care concern both in developing and developed countries. However, there is considerable variation of incidence and mortality, according to risk factors in regional areas such as smoking and according to the region’s degree of development (Parkin, Pisani and Ferlay, 1999). For example, incidence of and mortality from preventable cancers such as cervical cancer differ between developed and developing countries with 78% of all cases occurring in developing countries (p54).

The significance of cancer in Australia

The burden of disease due to cancer in Australia is an increasing problem as it is in other developed countries. The overall age-standardised incidence of cancer has actually been falling in both men and women since the early 1990s but the total burden of cancer in the Australian population has been increasing largely due to the ageing population (Coates, 1998, p8). Cancer is currently the underlying cause of death for 30% of all registered deaths (ABS, 2008b), and is the leading cause of disease burden (19%) followed by cardiovascular disease (18%) then mental disorders (13%) (AIHW, 2008a). Furthermore, cancer is also the leading cause of the total burden of disease and injury in Australia with 82% of the burden due to premature death (AIHW, 2008a). In terms of the actual numbers involved, one in three men will develop cancer within the first 75 years of life (average life expectancy 79.0 years) and one in three women in Australia will develop cancer within the first 85 years of life (average life expectancy 83.8 years) (AIHW & AACR, 2007). It is estimated that in 2006 there were 106,000 new cases and 39,200 deaths attributed to cancer, excluding non-melanocytic skin cancers (AIHW & AACR, 2007).
Such statistics provide important information on the epidemiology of cancer and how common it is in the population but it is also important to have an understanding of the impact on the individuals and families concerned. The health care problem of cancer is managed through ‘actions which reduce the burden of cancer in the community: research, prevention, early detection, treatment, palliation, patient and family support and education’ (Burton, 2002, p3). Knowledge of the epidemiology of cancer is an essential part of understanding its impact and developing strategies to improve outcomes, but an understanding of patients’ experiences, expectations and needs is also essential if services are to provide the highest quality care possible and to reduce the burden in the community.

The rural-urban health divide

In 2006 32% of Australians were living in rural or remote areas (ABS, 2008a). Health outcomes differ in Australia between rural and urban populations. Indicators of population health which can be measured and compared include life expectancy, death rates, injury and hospital separation rates. The degree of rurality in which people are living is known to have an impact on life expectancy: for males it ranges from 79.0 years in major cities to 72.1 years in very remote areas, and for females from 83.8 years in major cities to 77.6 years in very remote areas (AIHW, 2008e). Issues of rural health care include lack of transport, difficulty in communication and shortages of health care professionals (Strasser, 2003). These issues may be further exacerbated by trends in population demographics that can increase barriers to health care access. Andrews argues that policy development is required to ensure the needs of ageing populations in rural areas are met, including improved coordination, support for community and non-government organisations, and greater use of technology in communication (Andrews, 2001). This is in the context of problematic access to health care in rural Australia due to the large numbers of population centres with small numbers of residents spread across the continent. For example, a rural health stock-take undertaken in 1999 identified 541 centres with a population of 1,001-4,999 and 918 with a population of 200-1,000 (Best, 2000, p34).

Other factors affecting health care provision are that there is a lower ratio of general practitioners in rural areas than in major cities (AIHW, 2005a) and a lack of supply of health care professionals overall (Larson, 2002b). Recent data shows that the ratio of general practitioners to population was highest in Major Cities and was 0.78, 0.72, 0.65 and 0.69 times
the Major Cities rate in Inner and Outer Regional and Remote and Very Remote areas respectively (AIHW, 2005a). The supply of specialists is even lower however this is as expected as a minimum population of people is required to support the costs and infrastructure required for specialist care. Specialist medical practitioners are 0.45 and 0.3 times as prevalent in Inner and Outer Regional areas respectively as in Major Cities and less prevalent again in remote areas (AIHW, 2005a).

Rural residents are less likely to see a general practitioner than urban residents, which may be due to the distances patients are required to travel and higher costs, partly due to lower rates of bulk billing in rural areas (Larson, 2002b). Cultural aspects also have an important influence on rural residents’ access to health care services, for example a greater focus on disease and cure rather than prevention and maintenance of health can explain some differences in health care access patterns (Dixon and Welch, 2000). Dixon further argues that the perception and level of socio-economic status are also important aspects for rural residents, with economic deprivation and the associated drop in self esteem equally important in influencing health care behaviours (Dixon and Welch, 2000).

Some strategies to optimise health care access for rural populations have been to increase the local availability of health care professionals and to supplement this with the use of information technologies such as tele-health (Best, 2000). The principle focus has been on general practitioners as the key providers of primary health care. However, strategies such as the use of video and teleconferencing and maintaining health care services in centres with small populations are expensive and the establishment of such services, particularly in remote areas, cannot necessarily be considered a feasible or acceptable measure for all rural and remote areas (AIHW, 1998).

In the context of challenges related to the delivery of rural health care it is important that a thorough knowledge of the needs, capacities and preferences of rural communities be developed, particularly in areas where rural patients are likely to have special needs. Assessment of current rural health care delivery and outcomes has highlighted the importance of community involvement in rural health care services, including having input into how such services are planned and delivered (Best, 2000).
Rural residents diagnosed with cancer

Rural residents diagnosed with cancer are not only faced with the challenge of dealing with the emotional impact and the need to absorb information about the cancer and its treatment, but also the need to travel and to make decisions about the practical issues involved in the management of their diagnosis of cancer. These decisions may include how to get to the treatment centre, whether to travel alone or with a companion, how to continue managing the household, and how to manage the associated costs of travelling to and being in the metropolitan centre. These issues and the financial impact of being away from home are a significant source of anxiety and stress (Burman and Weinert, 1997b; Davis, Girgis, Williams and Beeney, 1998; McGrath and Seguerra, 2000; Lehman, Hedges and Hunt, 2002) at a time when the stress commonly associated with a diagnosis of cancer is already being experienced.

Rural cancer treatment

Provision of specialist cancer treatment in rural areas is often limited due to lack of facilities and staffing, particularly in relation to the infrastructure required for radiotherapy treatment facilities (Clinical Oncological Society of Australia, The Cancer Council Australia and National Cancer Control Initiative, 2003). This is typically due to the size and geographic location of towns. Treatment may be initiated in a specialist centre and follow up care provided in the rural area by the general practitioner which reduces the number of visits and length of time needed at the treatment centre. However, in most cases, the management of cancer requires ongoing input from a specialist team of health care professionals.

The main cancer treatments used, radiotherapy, chemotherapy and surgery, are not readily available to all rural residents and there is currently a lack of centralised information on the availability of local cancer services for rural residents. This makes it difficult to comprehensively summarise and assess the adequacy of services. A number of strategies are used to assist cancer treatment provision in rural and remote areas, similar to those which may be used for health care delivery generally. These include video conferencing with medical specialists in metropolitan areas (Olver and Selva, 2000), visiting medical specialists flying into rural areas on a regular basis, and the expansion of the role of nurses in rural areas to provide a higher level of care to patients with cancer (Hegney, McCarthy and Pearson, 1999). Although these strategies are intended to improve access to treatment there is little information
about which interventions are preferred by patients and whether the outcomes are equivalent to treatment provided exclusively in the metropolitan specialist setting.

There are several areas where those living in rural or remote areas have expanded or increased needs in relation to cancer treatment. All those diagnosed with cancer are likely to have a significant need for information about the disease and its treatment (Galloway, Graydon, Harrison, Evans Boyden, Palmer Wickham, Burlein Hall, Rich van der Bij, West and Blair, 1997; Sanson-Fisher, Girgis, Boyes, Bonevski, Burton and Cook, 2000; Jenkins, Fallowfield and Saul, 2001; Long, 2001). Those who live in a non-metropolitan area are likely to have expanded information needs, particularly information about practical services (Wilkes, White and O'Riordan, 2000).

Provision of psychosocial support is also important in the management of patients diagnosed with cancer. This is recognised in the publication of national guidelines for the psychosocial support of patients with cancer (National Breast Cancer Centre and National Cancer Control Initiative, 2003). In the context of rural residence there is limited research available examining the impact of a cancer diagnosis and the psychosocial implications specific to residents from these settings.

These issues of access to specialist treatment and support for patients from non-metropolitan areas need attention to ensure rural patients with a diagnosis of cancer are managed appropriately and equitably according to their needs and the setting in which they are receiving treatment. More information is needed on the experience of the rural resident treated for cancer in the metropolitan setting to inform strategies developed to improve care. Both the experience of treatment itself and the broader management of the whole treatment experience for rural residents are important.

**The importance of health care policy**

Health care delivery for rural populations is dependent on cooperation between the local community, the health care sector and government (Lipscombe and Gregory, 2000). Federal and State government policies determine the level of funding and the nature of health care services provided and thus are a critical influence on health care delivery. Policy may be defined as ‘a statement of government intent, and its implementation through the use of policy instruments’ (Bridgman and Davis, 2000, p174). Government directed health care policy
influences all areas of health care for minority and marginal groups such as populations in rural areas and an understanding of current policy and policy development is important when examining specific areas of health care.

Issues of policy are equally important in the delivery of cancer treatment. Debate over policy on cancer care provision in Australia has been informed by reports from bodies concerned with cancer control (Clinical Oncological Society of Australia, The Cancer Council Australia et al., 2003) and consultative meetings with health care professionals and consumers (Cancer in the Bush: Optimising clinical services, 2001). These reports identify that support for patients in rural areas is lacking and make a number of recommendations to improve care delivery, particularly issues of access to cancer treatment. For example, the ‘Optimising Cancer Care in Australia’ report made the recommendation:

‘That there be a national review of matters that affect access to cancer care, including an investigation into problems with travel, as an urgent matter. Particular attention should be paid to populations that may be experiencing disproportionate difficulties with access and the magnitude of that impact on cancer outcomes. This would include Australian Aboriginals and people living in isolated areas or just inside travel subsidy distance limits.’ (Clinical Oncological Society of Australia, The Cancer Council Australia et al., 2003) p47.

Given that there are national and local responsibilities for cancer care delivery and a lack of central, reliable data about cancer support and treatment outcomes for rural residents, an examination of the situation for patients reliant on these health care services is important to determine where specific improvements are needed.

The role of cancer control agencies

Support for rural patients with cancer also includes the work of cancer control agencies such as Cancer Council Australia and the Leukaemia Foundation. Non-government bodies such as these provide important support for rural residents diagnosed with cancer through practical measures such as accommodation in capital cities, transport, and psychosocial support measures, for example hosting and facilitation of support groups (Cancer Council Australia, 2008; Leukaemia Foundation of Australia, 2008). How this support fits with that offered by health care providers poses an issue as to where health care provider and government responsibilities begin and end. Burton describes quite clear differences in the areas in which government and non-government organisations are active, with the government focus mainly
on cancer diagnosis, treatment and palliation and non-government funding cancer research, prevention, support and education (Burton, 2002). He describes a complementary approach being used with consistent and comprehensive measures used to control cancer in Australia. Examination of areas where support services interface with health care provision and patient use could be used to determine whether there are gaps between national health care policy aims and end point of use.

It is clear that cancer and rural health are significant issues both globally and in Australia. Key issues for rural patients are the level of access to care and the support provided to ensure high quality health management of their disease. Rural health care is facilitated through the implementation of Federal and State health care policy. It is important to ensure that there are not significant gaps between policy recommendations and outcomes as perceived by consumers and health care providers. Information is also required to quantify differences in health care outcomes between rural and urban residents with cancer, the experiences and needs of patients requiring treatment in the metropolitan setting and how these can be improved within the current health care framework.

**Thesis development and context**

This thesis addresses the issues of cancer incidence and outcomes, delivery of cancer treatment, and support to rural residents in the context of the need for rural residents to access cancer treatment in the metropolitan setting. The study was conducted over considerable time through the development of specific study phases addressing the areas of relevance for this thesis, with the early phases informing subsequent study development. This has meant that parts of the thesis are set in a past time frame, specifically the focused literature review, which was conducted for the period 1973 to April 2002. Literature published since that time is addressed in the discussion and integration of findings and conclusions chapters.
**Structure of the thesis**

This thesis is presented in six chapters, each dealing with a separate component of the study. This first chapter introduces the rationale for the thesis topic with an overview of the background of the thesis topic and sets the scene, identifying the purpose of the study to be addressed in the body of the thesis.

**Chapter two: Background**

The treatment of cancer for rural residents involves consideration of rural health, cancer in Australia and cancer treatment. This chapter provides a background in these three areas through: an overview of rural health in Australia; a summary of the epidemiology of cancer in Australia; and description of the commonly used modes of cancer treatment.

Information on rural health describes the context of specialist cancer care for rural and remote residents. Terms and issues related to rural patients and cancer services are outlined.

Description of the status of cancer in Australia includes prevention and screening, incidence, prevalence, mortality rates and trends as well as specific information on cancer in rural and remote areas of Australia.

Finally, the characteristics of the cancer population and aspects of common cancer treatments are described. This includes description of the impact of cancer treatments and associated clinical care and discussion of issues specific to patients from rural and remote areas. Specific cancer types are discussed to further examine issues of care provision. The advantages and disadvantages of providing cancer treatment in rural areas are addressed as well as broader issues of cancer care, such as the psychosocial needs of patients and their families.

**Chapter three: Methods**

There were three major components or phases in this study and the methods for each phase are outlined. The first was an analysis of cancer registry and population survey data to determine differences in prevalence of cancer risk behaviour, incidence and outcomes for metropolitan and non-metropolitan residents in South Australia.

A focused literature review was conducted to identify research in the area of care outcomes of rural and remote residents with cancer who access cancer treatment in a metropolitan setting.

A questionnaire was then developed using information from the literature review and 96 rural and remote patients receiving cancer treatment in Adelaide were surveyed. Focused interviews
were conducted with selected survey participants to further explore themes arising from the survey. Selected health care professionals were also interviewed to gain insight into their perspectives on issues for rural residents with cancer.

**Chapter four: Results**
The results of the three phases of the study are presented in this chapter. The analysis of cancer registry and population survey data is presented to provide information on outcomes focusing on those that differ between rural and urban populations, providing a rationale for the focus of this study on cancer care and outcomes in rural populations.

The focused literature review summarises publications addressing metropolitan based cancer care provision for rural and remote populations for the period of the review.

The survey responses and analysis are presented in sections in order of priority according to the survey participants. Illustrative biographies are used to describe individual situations and highlight issues arising from the survey. The views of health professionals are presented in the last section of the chapter.

**Chapter five: Discussion and integration of findings**
This chapter integrates the findings of the survey data analysis, the focused literature review, the survey and the case studies with participants and health care professionals. Current literature is used to discuss the findings in relation to research and health care policy. Areas of need and their significance to patients are discussed. Areas common to the survey findings, the views of health care professionals, and the capacity of infrastructure of the health care system providing the care are identified. A model of health care analysis is presented to suggest a way in which the views of patients and health care professionals can be integrated in the context of health care organisations.

**Chapter six: Conclusions**
The conclusions arising from this thesis and recommendations for practice and future research are presented. Recommendations based on the issues arising from the study are made and discussed in relation to current policy in health care.
Chapter summary

Rural residents are potentially more vulnerable to adverse outcomes related to cancer due to their geographic location of residence. This thesis investigates the situation for rural residents using three sequential approaches. Differences in cancer risk factors, prevalence, incidence and outcomes for rural residents compared with urban populations are investigated through analysis of cancer registry and population survey data to determine areas of need. The literature is then examined to identify previous research on care outcomes for rural residents with cancer. The literature findings are used to inform development of an investigation into issues impacting on rural residents receiving cancer treatment in South Australia and ways in which these can be mitigated.

The following chapter provides a background and context for the thesis in the areas of rural health in Australia, epidemiology of cancer in Australia and a description of the commonly used modes of cancer treatment.
Chapter 2 - Background

This study examines broad areas of outcomes and support of rural and remote residents with cancer and their needs. Understanding of the study topic involves three areas: 1) rurality and health care, 2) the extent and significance of cancer in Australia, and 3) cancer diagnosis and treatments and their impact. This provides a context to the thesis and identifies issues of relevance to the study including information on the study setting, South Australia.

Rurality and health care

Introduction

Large areas of Australia are sparsely populated with 68.4% of Australians living in metropolitan areas, 29.2% in regional areas and 2.3% in remote areas in 2001 (ABS, 2008a). This unequal population distribution combined with the large geographical area of Australia, cultural and cost issues and shortages of health care providers can result in barriers to health care access. Aspects of rural health in Australia covered in this section include definitions of rurality, characteristics of the rural population, access to health care in rural areas and attitudes towards health care. Key characteristics of South Australia are also described to provide a context for the population of interest in this study, those who need to travel to Adelaide for cancer treatment.

Definitions of rurality

There are many understandings of ‘rural’ and ‘remote’ as used to describe areas in Australia. A variety of terms including rural, remote, regional, bush and country are widely used to refer to populations living in non-urban areas of Australia with these terms incorporating wide variations of meaning and interpretation. Perceptions of rurality are frequently comparative and are shaped by one's perception of what is rural (Davis and Droes, 1993). For example a person living more than a half hour drive from a city may describe themselves as ‘living in the country’, yet be considered an urban dweller by someone living in a small town a greater distance away from that city.
Additionally, the terms rural and remote are commonly used together when health care access issues are discussed yet the two terms refer to areas and issues that can be quite different. Use of the term remote in relation to health care services typically refers to areas that are distinctly geographically isolated, often with a small, dispersed, socio-economically disadvantaged population, limited availability of health care staff and facilities, with limited transport options that may be further reduced by the impact of seasonal weather patterns (Wakerman and Lenthall, 2002). Broader indicators of rurality may include cultural groups, perceptions of rurality, the population density, the proportion of Aboriginal and Torres Strait Islander population, socio-economic status and health status (Wakerman and Lenthall, 2002). For the purpose of identifying issues related to specialist cancer care for rural and remote residents in this thesis, the more generic terms rural or non-urban are used unless referring to issues specifically relating to rural or remote areas.

Three main systems of rural classification have been used most commonly in Australia. The seven-level Rural, Remote and Metropolitan Areas (RRMA) classification system was developed in 1994 and is based on the size of population centres and measure of remoteness (Wakerman and Lenthall, 2002). Criticisms of this type of geographical classification are that it fails to take into account variations within rural settings (Harris and Leininger, 1993) and the degree of urbanisation seen in Australia (ABS, 2000).

The Accessibility and Remoteness Index of Australia (ARIA) was developed in 1997 to measure rurality in terms of accessibility to services (Glover, Harris and Tennant, 1999). Four categories of service centre (relating to the population of the centre) are used within the ARIA index with the distance from the service centre used to calculate the degree of remoteness of an area. This produces a range of values from 0 (high accessibility) to 12 (high remoteness).

The ARIA system has been further revised in what is referred to as ARIA+ and is now used in the third main system of classification, the revised Australian Standard Geographical Classification (ASGC) Remoteness Structure. The ASGC was developed by the Australian Bureau of Statistics based on the ARIA system and uses six categories to delineate geographic areas, these being Major Cities, Inner Regional, Outer Regional, Remote, Very Remote and Migratory (ABS, 2001a). The purpose of the revision was to incorporate the concept of geographical remoteness into the statistics collected and disseminated by the Australian Bureau of Statistics (ABS, 2001b).
The map below (see figure 2.1) provides a useful demonstration of the ASGC application and shows how much of Australia is categorised Remote and Very Remote. This highlights why rural and remote health service delivery is such an important issue in Australia, as although the numbers of rural and remote residents are smaller than their urban counterparts, the practicalities of accessing basic or specialist health care can be significant.

![Map of Australia showing Remoteness Areas](image)

Figure 2.1: Remoteness areas of Australia. Source: Australian Bureau of Statistics preliminary estimated resident population, based on the 2006 Census of Population and Housing (ABS, 2008a).

The number of classification systems which have been developed, the lack of equivalence between them and the fact that all are in current use means that care needs to be taken when using data reported based on the different terms used. Direct comparison between categories in the different systems cannot be made (AIHW, 2003d). However, table 2.1 below shows broad similarities that allow interpretation of reports and studies based on the generic terms used.
The ARIA system is used for reporting the research findings in this thesis, however the terms used in the literature cited throughout the thesis has not been altered. System-specific terms used are identified by the use of capital letters, for example Inner Regional.

**Characteristics of the study setting: South Australia**

South Australia covers a total area of 984,377 square kilometres representing one eighth of the Australian continent and has large arid areas of low population (Crettenden, 1999). South Australia's population is approximately 1.5 million (ABS, 2003a) comprising one eighth of the total population of Australia. The spread of residence is very uneven, with more than 99% of the State's population living in the southern half of the State and only 17.6% in urban centres outside Adelaide (Crettenden, 1999, pp3,68).

South Australia has the highest median population age in Australia, at 38.2 years, compared with the lowest in the Northern Territory at 30.3 years, and 36.1 in the whole Australian population (ABS, 2003d). South Australia also has the highest proportion of people aged 65 years and over (14.5%). Of particular note is the low average income of the older population, with the majority (73.0%) earning an annual individual income of less than $15,600, and a further 11.4% receiving an income in the range of $15,600 to $20,799 (ABS, 2002). In overall
gloss income per week, the median South Australian household income is $665, compared with the national median of $773 (ABS, 2003c).

Rural areas of South Australia have a relatively low population with 26.7% of the total population living outside the Adelaide statistical division (ABS, 2003e). Unemployment rates in rural South Australia are similar to that seen in Adelaide at approximately 7%, and the rates of those receiving income support are also similar, but with pockets of variation due to industry and mining (ABS, 2003e).

**Characteristics of rural populations in Australia**

The rural and remote populations in Australia differ from those in metropolitan areas in terms of population distribution, socio-economic factors and the strength of social cohesion and health in the community, known as social capital. Reports on health status and social trends in Australia, including the Australian Bureau of Statistics publications on Australia’s Health and Australian Social Trends provide useful information for comparison of populations in different geographic locations and are drawn on heavily in this section.

**Population distribution**

As previously noted, the population distribution in Australia is uneven, with most Australians living in urban areas. There are trends of movement between areas, for example between 1991 and 2001 there was a 14% increase in population in Inner Regional areas while the numbers in Remote areas remained relatively stable (ABS, 2003b, p7). This type of population change occurred due to activities such as expansion in mining activity in some areas and resort development in coastal areas (Hugo, 2002). Additionally, there was a trend for retirees to move away from metropolitan areas to Inner Regional areas in order to take advantage of lower cost of living but remain within an accessible distance to services (ABS, 2003b). At the time this contributed to the Inner and Outer Regional areas having the highest number of residents aged 65 years and over (14% and 13%), with the lowest being in Remote and Very Remote areas (10% and 8%) (ABS, 2003b).

Overall though, over the past decade to 2006 the population in major cities grew faster than the rural areas – the Australian population increased by 2.4 million people to 20.7 million, with 68% living in Major Cities in 2006 (ABS, 2008a). The growth rate in Major Cities was 1.6% and 0.8% in Inner Regional areas compared with a stable population in Outer Regional areas and a slight decline in Remote (0.4%) and Very Remote (0.3%) (ABS, 2008a).
The Indigenous population of Australia is unevenly spread. Indigenous peoples constitute 2.5% of the total population, with many (26%) living in Remote or Very Remote areas (ABS, 2008a). Due to the low numbers overall living in Very Remote areas, Indigenous people comprise 48% of this population. In contrast, the number of overseas born Australians tends to be lower in rural and remote areas (approximately 83% of those born overseas were living in major cities in 2001). This is due to immigrants choosing to live in metropolitan centres for better access to other people who speak their language and multi-lingual and other services (ABS, 2003b).

It can be seen that as well as the spread of population in Australia being uneven, the demographic characteristics of populations within the regions also differs. This adds to the complexity of health care delivery for those in non-urban areas.

**Socio-economic factors**

The activities of specific industries in rural and remote areas of Australia have changed significantly over recent decades. In the 1960s agriculture provided approximately 12% of the gross domestic product, whereas in the 1990s this dropped to approximately 2.5% (Larson, 2002a) with a corresponding drop in farming related employment. Thus, while rural Australia is commonly thought of as being used primarily for farming, this is not necessarily so. There was also a 22% decrease in the number of farming families in Australia between 1986 and 2001, contributed to by the introduction of new technologies, greater efficiencies in farming methods and increases in the sizes of farms (ABS, 2003a). The reduction in agriculture employment has been balanced by increases in areas of manufacturing, trade, finance, property, business services, public administration, defence, community services and recreation (Hugo, 2002). However, overall there has been a downward trend in the socio-economic health of rural communities and a corresponding drop in services.

The report on social trends in Australia by the Australian Bureau of Statistics identified lower levels of education and qualifications and lower incomes in non-metropolitan areas (ABS, 2003b). It also highlights an increasing inequity in levels of income between major cities and regional areas. In 2001 the average weekly equivalised gross household income in Major Cities was 7% higher than the national average while in Outer Regional areas it was 16% lower (ABS, 2003b).

Inequities in education levels have been echoed more recently. Despite improvements nationally in the proportion of Australians aged 25-64 years with a non-school qualification
from 46% in 1990 to 59% in 2006, the largest improvements were in Major Cities (from 44% in 1996 to 57% in 2006) and smallest in Very Remote areas (from 30% in 1996 to 36% in 2006) (ABS, 2008a). The lower levels of skilled employment available is likely to be an influential factor in the lower levels of education and lower household incomes seen in rural populations (Hugo, 2002). These trends are likely to be influenced by migration of population groups, such as young adults moving to major cities seeking employment and as previously mentioned those on a low income, including retirees, moving to regional areas where there are lower living costs (Larson, 2002a). Industry related employment creates some exceptions to these overall trends, such as mining in remote areas which has seen many mining towns double in population as well as having sharp increases in population due to the ‘fly in, fly out’ miner population (ABS, 2008a). However the overall picture is of inequity in relation to socio-economic health when rural and metropolitan populations are compared.

**Social capital of rural communities**

Another indication of the health of a community or society is the social capital of the group concerned. This is a term used to measure the value of social and community relationships with a purpose of identifying ‘the norms and networks that enable collective action’ (The World Bank Social Capital Homepage, undated). Social capital is becoming more broadly used to measure the level of social cohesion and the quality and quantity of social interactions (ABS, 2003b). The report by the AIHW ‘Rural, regional and remote health: Information framework and indicators’ (AIHW, 2005b) identifies social issues that may indicate the health of rural populations such as:

- hours spent volunteering or engaged in community projects;
- levels of violence in the community and within the family;
- rates of property crime;
- membership of clubs;
- some measure of community empowerment;
- sole parenting; and
- truancy rates. (AIHW, 2005b)

These items measure social cohesion rather than the ability to enable collective action on a community level as suggested by the World Health Organisation’s definition of social capital.
However, markers of participation in community activity are important as an indication of the social health of a community. They are also useful to predict the level of assistance and support available to and provided by community members when individuals are in need, for example when diagnosed with cancer and undergoing treatment. Some of these indicators can also be used to show how involved individuals are in their community and their subsequent likely ability to be able to draw on support when needed.

The choice of living in a rural area
Living in a rural or remote area will reduce the level of access to some services and it is therefore worthwhile to consider why people choose to live in these areas. Rural dwellers may have been born and raised in the country and choose to continue living in rural areas, or may be metropolitan dwellers making a lifestyle or employment choice in moving to a rural setting. Those choosing to move to a rural area may be influenced by the perceived advantages commonly associated with living in rural areas, including clean air and environment, lower stress levels and stronger community networks (Dixon and Welch, 2000). Certainly it is generally true that living in the country means living in a less densely populated area, with more space and more access and exposure to a natural environment. People living in rural areas tend to report lower levels of stress and a higher overall quality of life (AIHW, 2002b). But the choice to live in a rural area can also be seen as a decision entailing 'trade-offs', for example a reduction in services, counter-balanced by a more rewarding lifestyle and as discussed in the next section, overall poorer health outcomes for the population.

Health of rural populations in Australia
There are differences between urban and non-urban populations in relation to socio-economic and social capital factors with disadvantages likely to impact on the health of the community concerned. Perceptions of health may also differ between populations living in rural and metropolitan areas. For example, those living in rural areas often believe that health and productivity are linked, which can affect their response to illness or injury (Elliott Schmidt and Strong, 1997). Such a belief can lead to minimisation of symptoms that do not impair the ability to work. Research has also shown that rural populations can tend to reject the 'sick role', which can lead to delays in diagnosis and treatment (Lee, 1993, p24). This can further exacerbate the effect of health system barriers to health care services. There are also specific risk factors in rural populations that contribute to overall poorer health outcomes.
Health related risk factors in rural populations

Adverse health outcomes in rural populations are generally due to risk factors associated with living in a rural area. These factors include:

- geographic isolation and problems of access to care;
- shortage of health care providers and access to primary health care services;
- socio-economic disparities;
- greater exposure to injury, in particular for those employed in farming and mining;
- lower road quality; and
- Indigenous health needs. (AIHW, 2008a)

Other factors identified in rural populations are a higher level of sedentary behaviour, a greater proportion of overweight people, a higher level of risky or high risk alcohol consumption (long term), and a higher number of smokers (AIHW, 2008a). In combination with this, there may be restrictions in access to healthy food in rural and remote areas (Simmons and Hsu-Hage, 2002). These together with the risk factors above put those living in rural and remote areas at greater risk of poor health in many areas.

Mortality rate differentials

Increased mortality rates are also seen in rural and remote areas, as identified in the recent report on rural, regional and remote health by the AIHW (AIHW, 2007b). Overall, Australian mortality rates have decreased from 2002-2004, however this report shows that the relative differences between Major Cities and regional areas remained. In Inner and Outer Regional areas there were an ‘excess’ of 3,723 deaths (i.e. the additional number of deaths beyond that expected if the metropolitan experience was replicated in the rural setting) and in Remote and Very Remote areas there were 695 ‘excess’ deaths (AIHW, 2007b). The major contributors to the excess deaths varied according to sex and Indigenous status. Table 1.1 shows the differences in mortality according to degree of rurality from four major causes of death.
Differences can be seen in all four major causes of death and significant differences in death due to cancer are also consistently seen in regional areas. These demonstrate that although some surveys of rural and metropolitan populations have shown no significant differences in the reported perception of health status (Glover, Harris et al., 1999) there are some important adverse health outcomes in rural populations.

**Indigenous health**

Higher mortality in the Indigenous population is also illustrated when mortality rates are analysed for correlation with remoteness of residency, socio-economic deprivation and Indigenous status across the Australian statistical divisions (Wilkinson, Ryan and Hiller, 2001). In this study by Wilkinson et al, the strongest correlation was seen between Indigenous
status and all causes of mortality \((r = 0.69, \ p < 0.001)\) and the three variables together accounted for 13% of the variability in mortality.

Life expectancy for the Indigenous population in the period 1996-2001 was 59 years for males and 65 years for females compared with an average life expectancy for the period 1998-2000 of 77 years for all males and 82 for all females in Australia (AIHW, 2008a). Levels of disability are also high in the Indigenous population with approximately 65% of all Indigenous people and 97% of those aged 55 years and over reporting at least one long term health condition (AIHW, 2006). In addition, common indicators of health and poor health risks such as infant mortality, diabetes, oral health, nutrition status, having low levels of physical activity and smoking are all worse in the Indigenous population (AIHW, 2008a). Access to specialist health services by Indigenous populations is poor particularly for those living in non-urban communities but outreach visiting services can be used to overcome barriers and increase availability (Gruen, Weeramanthri and Bailie, 2002). The poorer health status of the Indigenous population has relatively little impact on overall health status in metropolitan areas due to the low percentage of Indigenous people living in these areas but impacts more significantly on indicators of health status in remote areas.

**Access to health care**

Accessible health care is defined as the ‘ability of people to obtain health care at the right place and right time irrespective of income, cultural background or physical location’ (AIHW, 2005b, p49). It may be argued that those living in rural and remote areas have in effect decided to sacrifice their ability to access an equivalent level of health care services to that provided in metropolitan areas. However, a commitment to social justice means that health inequalities or differences in health status due to circumstances out of individual control, for example differences attributable to race, religion, place of residence or gender, should be addressed where possible (Leeder, 2002).

In recent decades there has been a trend towards redistribution of services including health care from rural areas to regional centres on the basis of economic effectiveness. This is inconsistent with a commitment to equity of access to health care services (Larson, 2002a). While the provision of highly specialised health care services in rural or remote areas may not be possible at an equivalent standard due to the relatively low density of population in Australia it can still be argued that the outcomes of cancer care in rural and metropolitan areas should be of the same standard as far as possible, including early detection, prompt
intervention, ability to access the appropriate treatment as determined by current research and practices, and survival. The challenge is to achieve this in a cost effective manner, acceptable to those diagnosed with cancer.

This is somewhat difficult in Australia as the ongoing rationalisation of health care services and weakening of the economic base in rural communities (Humphreys, 1998) combined with significantly lower numbers of health care professionals per head of population in rural areas (AIHW, 2008a) leaves the rural population potentially disadvantaged in relation to access to health care. The number of doctors in Australia has doubled over the past 30 years and is currently 287 per 100,000 population (AIHW, 2008d) but the geographic distribution of doctors across Australia is uneven. Approximately 80% of Australia’s doctors were living in major cities in 2005 compared with 68% of the general population (ABS, 2008a). As might be expected, the number of doctors tends to decrease with increasing remoteness. This discrepancy in distribution between rural and metropolitan areas increased between 1986 and 1996 (Johnston and Wilkinson, 2001), with the consequence that rural and remote areas became increasingly comparatively underserved during this time. One advantage of medical care provision in rural and remote settings that has been argued is that those in rural areas have a greater capacity to have general practitioners working in the role of case managers with an associated greater degree of continuity and consistency of care (AIHW, 1998). However, such advantages are only of importance when realised in the form of access to medical care.

Access and delivery of health care in rural and remote regions has been addressed through the development of a framework to improve health care in rural and remote areas (National Rural Health Alliance, 1999). This framework is intended to provide direction for Commonwealth, State and Territory governments in the development of strategies and allocation of resources to improve the health and well-being of people living in rural, regional and remote areas. This policy document was then reviewed and revised in 2003 to ensure currency (Australian Health Ministers' Advisory Council and National Rural Health Alliance, 2003).

The priorities identified in the revised ‘Healthy Horizons’ provide an overview of current issues in rural health care in Australia, describing seven interdependent goals to focus activity and planning on areas of high priority (see appendix 1). This plan states that for the successful development and implementation of national strategies for health improvement in rural, regional and remote Australia a focus on the following principles is required:
• The use of a primary health care approach to provide opportunity to keep people healthy in the community setting and to intervene early to maintain good health.

• Using public health programs to support health care provision decisions, such as the location and number of services, informing and educating people about changes needed, and fostering innovation in service delivery.

• Ensuring social capability and physical capacity to plan and implement local health programs.

• Ensuring community participation in determining local health priorities and programs.

• Ensuring access to culturally sensitive health care programs.

• The establishment of effective partnerships in the delivery of services.

• Ensuring safety and quality in health services and programs.

(Australian Health Ministers' Advisory Council and National Rural Health Alliance, 2003)

These principles provide an understanding of priorities in optimising health for rural and remote residents. For the purpose of this study it is notable that breast cancer is specified as an area of priority and that the delivery of health care including those coordinated by metropolitan services such as cancer care is also a priority. Rural health issues receive such policy attention appropriately as a reflection of health as a human right for those living in rural areas (Sidoti, 1999), however the policies formed to support rural health need to be accurately and appropriately informed. Identifying trends and changes in the health care policy context is important to ensure policy development and subsequent health care service delivery is appropriate and informed. A commentary on health care policy has identified the following trends:

• the individualisation of risk and responsibility;

• narrow budget accountability (moving away from a broader accountability to the public interest);

• short-termism (focusing more on the immediate future than long term);

• bucket funding (for local programs rather than central, national initiatives);
• the loss of program or service integrity, quality, and ‘time to care’;
• capture by the acute sector (where community programs become part of acute care); and
• the dominance of market values and economic efficiency.

(Hancock, 1999, p3).

These trends have the potential to have an adverse effect on health care provision in rural areas, particularly in relation to access to care. This occurs when changes in policy trends impact on care delivery through changes in the nature of programs funded. For example, moving health care towards a format of individual responsibility and economic efficiency may result in loss of public services in rural areas.

The current federal Labor Government National Platform and Constitution 2007, on which it was elected in 2007, includes a commitment to ‘provision of quality health care for all Australians’ (Australian Labor Party, 2007, p153). There is no specific mention of access to specialist health care for non-metropolitan residents and a statement of developing tele-health access is mentioned in relation to support for health care professionals rather than to support direct patient care. This in a sense reflects the inevitability of rural residents needing to travel to cities in order to access most specialist care.

**Patient cost reimbursement schemes for specialist care**

Another barrier to accessing health care, particularly specialist care, is the cost involved. It is self evident that when specialist care cannot be provided outside the specialist centre, for example radiotherapy treatment, the patient must travel to the treatment centre. This then requires the patient to incur costs associated with travel, accommodation if needed, and associated time away from work. The most common way in which access to specialist care is financially supported is through state based schemes that provide reimbursement of some of the costs incurred by the patient whilst accessing treatment (National Rural Health Alliance Inc., 2005).

Reimbursement schemes are government-funded and accessed via an application by the patient concerned, which must be authorised by health care professionals. Criteria developed by the States and Territories are then used to determine eligibility for the schemes. There are many differences between the criteria applied across Australia as seen in table 2.3, although all are developed based on the principle of ensuring that the general population is able to access
specialist health care as required. There are some recognised difficulties with the schemes and their administration. In general, they are criticised for being bureaucratic, inflexible, inadequate in meeting the expenses related to travel and accommodation, and poorly marketed (Larson, 2002a). The differences between the schemes are also problematic for patients accessing treatment across a State border, for example patients in Western Victoria being treated in South Australia. These differences can lead to confusion for patients and where differing levels of reimbursement are available, may lead to inequitable outcomes in terms of accessing care. The schemes are often poorly promoted, sometimes due to staff turnover and lack of knowledge in rural and remote areas, which can lead to patients being unaware of the financial support available until after they have presented for treatment (National Rural Health Alliance Inc., 2005).
Table 2.3: Summary of isolated patients’ travel and accommodation assistance schemes in Australia.
(Adapted from: Clinical Oncological Society of Australia, The Cancer Council Australia et al., 2003, pp116-7).

NOTE:
This table is included on page 28 of the print copy of the thesis held in the University of Adelaide Library.
How reimbursement schemes are accessed

Access to the South Australian scheme can be used as a practical example of how the schemes work (South Australian Department of Human Services, 2002). Initial access to the scheme typically occurs when a patient presents to a general practitioner in a rural area with symptoms that require further investigation in a regional or metropolitan area. In order to make a claim for reimbursement for travel and accommodation, completion of a form is required of the referring practitioner and specialist and all receipts for the transport and accommodation costs incurred must be kept (see appendix 2). Any need for an escort must be authorised by a medical officer, usually on medical grounds. Without this, costs incurred as a result of the escort are not eligible for reimbursement. The patient is also required to complete the form with details of travel and accommodation and associated costs. The completed application is forwarded to the relevant office with all receipts attached. This form must be filled out for each trip to the specialist, and costs incurred are paid for up front by the patient, with reimbursement forwarded when approved.

The success of this system is reliant upon the general practitioners and specialists making the scheme accessible to the patient through provision of information and through accurate completion of the forms by all involved. It is also, and possibly more importantly reliant on the patient understanding the scheme and its purpose and presenting the form to the general practitioner and specialist during their appointments. Research conducted in Queensland with clerks responsible for administering the schemes found that they are inconsistently administered and confusing to the clerks and that patients applying for funds frequently need explanation of the process of reimbursement and what amount they are entitled to (McGrath, 1999b). While the reimbursement schemes are an important source of support for accessing care these issues need attention to assess the effectiveness of the schemes in different States and Territories and the degree to which the support is accepted by the patients concerned.

Non-government support

Government support is frequently supplemented by support from non-government agencies for rural patients with cancer. For example, patients with a haematological cancer diagnosis can access support from the Leukaemia Foundation, including free accommodation and transport and access to disease and treatment related education sessions (Leukaemia Foundation of Australia, 2008). Similarly, Cancer Council Australia offers support to those affected by
cancer, through eight State and Territory based member organisations which may offer subsidised accommodation, information materials such as pamphlets and videos and education and peer support programs coordinated through the Cancer Council Helpline, a telephone support service which provides access to a local Helpline through a national number (Cancer Council Australia, 2008). Support offered by these charitable organisations complements the Government schemes and forms an important part of cancer management.

**Summary**

This section has shown that although there are many definitions of rurality, there are common characteristics of rural populations that differentiate them from their urban counterparts. These include being geographically isolated, being comparatively smaller in population and having a poorer socioeconomic status and limited access to health care, both contributing to poorer health care outcomes. Factors such as social capital may demonstrate positive outcomes associated with living in rural areas, but this has yet to be definitively researched in the Australian setting. Thus, access by rural residents to specialist health care is potentially compromised by a number of factors.

While those choosing to live in rural areas may be choosing to accept disadvantage resulting from this choice, for example reduced access to specialist care, advantages related to differing social capital factors offsetting this are not yet clearly understood or known. This includes outcomes of relevance to rural residents with cancer, for example access to supportive community networks. Reimbursement schemes designed to ensure equitable levels of access to specialist health care are criticised and need investigation at the point of implementation and use by rural residents. The use of non-government support also needs investigation to determine how this is implemented and accessed by rural residents.
Cancer in Australia

Introduction

To gain an understanding of the significance of cancer in rural settings, it is important to consider the significance of cancer across Australia as well as specifically in rural areas. Consideration of the incidence (number of new cases occurring during a given period (AIHW, 2008a, p557), most common types of cancer, current methods of prevention and screening, trends in incidence and differences between rural and metropolitan settings provides a context to discussion of the issues that groups of patients diagnosed with cancer face. This section describes how epidemiological cancer information is derived and presents current cancer information.

Epidemiology of cancer in Australia

Cancer was categorised as a notifiable disease in Australia in 1982 in all States and Territories except the Australian Capital Territory which was subsequently included in 1994 (AIHW & AACR, 2007). The required reporting of a cancer diagnosis together with a strong network of cancer registries means that the incidence of cancer is accurately and consistently coded and reported. Incidence and mortality rates are calculated per 100,000 of population per annum and standardised rates are typically calculated using the World Standard Population. There are a number of organisations involved in the production of cancer statistics in Australia, as outlined briefly below. These organisations work cooperatively to produce reports of current cancer statistics.

The collection of cancer information in Australia

The cancer registries in Australia play an important role in collecting cancer related information. All newly diagnosed cases of cancer and cancer related deaths are reported directly to cancer registries in Australia as required by the legislation relating to notifiable diseases (AIHW, 2002a). As well, all deaths registered in Australia are coded according to the 10th revision of the International Classification of Diseases (ICD-10). Data on deaths attributed to cancer are obtained by cancer registry staff from the Registrar of Births, Deaths and Marriages. The collation of information from State and Territory registries is coordinated by the National Cancer Statistics Clearing House, which is in turn supervised by the
Australasian Association of Cancer Registries. The recording of cases is virtually complete and loss to follow up is small (AIHW, 2003b). Australia is thus in the enviable position of having access to reliable and accurate information on cancer incidence, mortality and trends. These statistics are used for monitoring and comparison purposes, to inform and educate health professionals and the general public and to inform cancer control measures.

**Cancer in Australia**
Cancer is a disease that directly or indirectly affects one in three Australians. In 2003 there were 93,194 new cancer cases and 37,907 deaths from cancer in Australia (excluding skin cancers other than melanoma) (AIHW & AACR, 2007). Gaining an understanding of which groups are most commonly affected by which cancers helps in gaining an understanding of the needs of these groups when examining their experiences of cancer and cancer treatment. The most common cancer among all persons in Australia in 2003 was prostate cancer which accounts for 15% of new cancer cases (see table 2.4). Prostate cancer was the most common cancer in Australian men, accounting for 26% of all new cancer cases. Breast cancer was the leading cause of cancer related deaths in women with 16% of all cancer deaths.
Table 2.4: Most common cancers in Australia, 2003 (AIHW & AACR, 2007, pp8,44 a), b)).

<table>
<thead>
<tr>
<th>Cancer site</th>
<th>New cases</th>
<th>Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>% of all new cancer cases</td>
</tr>
<tr>
<td><strong>Males</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>13,526</td>
<td>26.3</td>
</tr>
<tr>
<td>Colorectal</td>
<td>6,857</td>
<td>13.3</td>
</tr>
<tr>
<td>Melanoma</td>
<td>5,535</td>
<td>10.8</td>
</tr>
<tr>
<td>Lung</td>
<td>5,281</td>
<td>10.3</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>2,297</td>
<td>4.5</td>
</tr>
<tr>
<td><strong>All cancers</strong></td>
<td>51,418</td>
<td>100.0</td>
</tr>
</tbody>
</table>

| **Females** |           |                     |        |        |               |        |                     |        |        |
| Breast      | 11,788    | 28.2                | 111.8  | 89.0   | 1 in 11       | 2,710  | 16.3                | 24.6   | 18.2  |
| Colorectal  | 5,679     | 13.6                | 51.1   | 36.2   | 1 in 27       | 1,990  | 11.9                | 17.2   | 11.4  |
| Melanoma    | 3,989     | 9.5                 | 37.9   | 31.0   | 1 in 34       | 382    | 2.3                 | 3.4    | 2.5   |
| Lung        | 2,968     | 7.1                 | 27.1   | 19.3   | 1 in 49       | 2,482  | 14.9                | 22.4   | 15.5  |
| Lymphoma    | 1,832     | 4.4                 | 16.9   | 13.0   | 1 in 80       | 693    | 4.2                 | 6.0    | 4.1   |
| **All cancers** | 41,776  | 100.0               | 386.5  | 294.8  | 1 in 4        | 16,669 | 100.0               | 146.9  | 101.2 |

| **All persons** |           |                     |        |        |               |        |                     |        |        |
| Prostate      | 13,526    | 14.5                | -      | -      | -             | 2,837  | 7.5                 | -      | -     |
| Colorectal    | 12,536    | 13.5                | 61.3   | 43.4   | 1 in 22       | 4,372  | 11.5                | 21.3   | 14.3  |
| Breast        | 11,889    | 12.8                | -      | -      | -             | 2,720  | 7.2                 | -      | -     |
| Melanoma      | 9,524     | 10.2                | 46.9   | 37.1   | 1 in 29       | 1,146  | 3.0                 | 5.6    | 4.0   |
| Lung          | 8,249     | 8.9                 | 40.4   | 28.2   | 1 in 33       | 6,988  | 18.4                | 34.2   | 23.5  |
| **All cancers** | 93,194   | 100.0               | 456.8  | 339.1  | 1 in 3        | 37,907 | 100.0               | 184.9  | 125.1 |

a) Rates are expressed per 100,000 population and age standardised to the Australian 2001 Standard Population (ASR (A)) and to the World Standard Population (ASR (W)).

(b) Skin cancer other than melanoma, known to be the most common cancer type, is excluded from this list as it is not a registrable cancer.
Cancer and age

The average age of first diagnosis of cancer was 66 years in 2004 (AIHW, 2007a) and the risk increases with age – for men in 2003 the risk of a diagnosis of cancer was 1 in 3 before age 75 and 1 in 2 before age 85. For women the risk was 1 in 4 before age 75 and 1 in 3 before age 85 (AIHW & AACR, 2007). This is an important factor when considering issues of supports and services for those diagnosed with cancer. When the incidence and mortality for age groups are viewed in graph form (see figure 2.2 below) the differences in age groups can be clearly seen with the peak incidence and mortality occurring in the 75-79 year age group.

NOTE: This figure is included on page 34 of the print copy of the thesis held in the University of Adelaide Library.

Figure 2.2: Incidence and mortality of all cancers (excluding non-melanocytic skin cancer) in Australia by age (2004), from (AIHW, 2007a).

Trends in cancer incidence
Changes in the incidence of cancers demonstrate evolving trends over time. These may reflect alterations in lifestyle, for example population smoking habits, or other factors such as developments in methods for early detection. For example, the incidence of prostate cancer was relatively stable until 1989 but increased rapidly between 1990 and 1994. This was thought to be because of the introduction of the prostate specific antigen test (PSA), which led
to the detection of cancers before symptoms were present. The rate then declined towards the pre-existing level and the mortality rate between 1990 and 1999 decreased by 1.4% (AIHW & AACR, 2002). More recently there have again been significant increases, from 12,003 cases diagnosed in 2002 to 13,526 cases in 2003, a rise of 12.7% (AIHW & AACR, 2007). This is thought to be related to a sharp rise in PSA testing, with a 42% rise from 492,147 in 2001-02 to 698,828 in 2005-06 (AIHW & AACR, 2007).

In another example the increase in incidence of breast cancer of 1.8% between 1990 and 1999, highest in the age group 50-69 years, was thought to have occurred as a result of the introduction of the national breast cancer screening program. This rise was balanced by a fall in the associated mortality rate during the same period by 1.9% per year (AIHW & AACR, 2002). Since then the screening rates have remained steady at 55-57% of women in the target age group and the incidence has likewise fluctuated only slightly (AIHW, 2008b).

Improvements in cancer detection can have a seemingly dramatic effect on incidence but these tend to be short term before settling to indicate a truer picture of incidence. Alterations over the long term are more likely to reflect changes in risk factors, including lifestyle changes.

**Cancer survival**

Earlier detection and improvements in treatment have had significant influence on the five year relative survival rates for cancer (taking into consideration the crude survival in the cancer population and the expected survival in the general population). For the diagnostic periods 1982-1986 and 1992-1997 the five year relative survival rates in males rose from 43.8% to 56.8% and in females rose from 55.3% to 63.4.5% (AIHW, 2001b). This increase in the number of people living with cancer for longer periods of time means that cancer is likely to affect almost all Australians at some time in their lives, either through direct personal experience or through the experience of a family member or friend.

**Cancer prevention and screening in Australia**

The approach to managing cancer in Australia has shifted from being traditionally treatment orientated to having an increasing focus on prevention and early detection. This is partly due to the growing understanding that many common cancers are preventable through lifestyle modification and screening choices (The Cancer Council Australia, 2007). The control of
cancer in Australia is one of seven National Health Priority Areas, along with arthritis and musculoskeletal conditions, asthma, cardiovascular health, diabetes mellitus, injury prevention and control, and mental health. These seven areas account for nearly 80% of the total burden of disease and injury in Australia (National Health Priority Action Council, 2005). Within cancer control there are eight specific cancer sites targeted for attention, lung cancer, melanoma, non-melanocytic skin cancers, colorectal cancer, prostate cancer, non-Hodgkin’s lymphoma, cervical cancer and breast cancer. These were chosen on the basis that improvements in early detection or treatment are likely to bring the greatest benefit to the highest number of people (AIHW, 2000).

The development of cancer prevention and early detection programs is informed by data collected from cancer registries throughout Australia as described previously. This information is used to identify areas of highest need and widest significance to the community and to direct educational and research efforts to minimise the incidence and impact of cancer in the community. Both government and non-government bodies are involved in the development and implementation of prevention and early detection programs.

The Cancer Council Australia (TCCA) emphasises prevention in its National Cancer Prevention Policy 2007-2009 and advocates an approach incorporating primary prevention and early detection, including strengthening the role of the general practitioner (The Cancer Council Australia, 2007). This policy outlines strategies for management of risk factors such as tobacco, sun exposure, nutrition, physical activity, overweight and obesity and alcohol intake, and describes these risk factors as all being lifestyle choices which can be modified to reduce risk of developing cancer. As an example, in relation to colorectal cancer the clinical practice guidelines prepared by the National Health and Medical Research Council indicate that approximately half of all colorectal cancers can be attributed to dietary factors and that modifiable dietary and lifestyle factors may account for 70% of the risk for colorectal cancer in Western populations (Australian Cancer Network Colorectal Cancer Guidelines Revision Committee, 2005).

Identifying the impact of lifestyle is an important step in modifying habits in the general population. In South Australia, Cancer Council South Australia has facilitated cancer prevention campaigns, including the Quit SA program, a government funded program supported by the National Heart Foundation aimed at reducing tobacco use in South Australia.
and the Cancer Council SunSmart Schools Program, which aims to reduce the incidence of skin cancer in the future (The Cancer Council South Australia, 2007b).

**Screening in rural and remote areas in Australia**

Population based screening is another strategy used to reduce the incidence and burden of cancer through the early detection of cancers, as well as the detection of pre-cancerous lesions (The Cancer Council Australia, 2007). Currently in Australia, screening programs are conducted for breast, cervical and colorectal cancer.

In rural populations, the ability to access screening may be compromised due to limited availability and access. This has the potential to affect both the prevalence of the cancer concerned and the stage at which it is diagnosed, for example the use of mammography to detect breast cancer at an early and pre-malignant stage. It is difficult to determine the actual numbers of women accessing breast screening as mammography services provided privately are not included in BreastScreen reports. The most recent report on breast screening rates of the target population showed that women in Outer Regional (59.5%), Inner Regional (58.0%) and Remote (57.8%) areas were significantly higher than rates in Major Cities (54.7%) and in Very Remote (45.9%) areas (AIHW, 2008b). Major City rates are likely to be under-reported as there are many more private mammography services available in metropolitan areas (AIHW, 2008b).

Data on cervical screening rates are more complete and show that in 2005-2006, participation rates were 62.1% for Major Cities, 59.3% for Inner Regional, 57.8% for Outer Regional, 56.9% for Remote and 53.0% for Very Remote regions (AIHW, 2008c). These reports demonstrate that population screening rates in rural and remote areas are likely to differ according to rurality, leading to potential differences in morbidity and mortality outcomes.

Research into screening differences in rural areas has focused on developing an understanding of attitudes towards screening and optimising participation in these areas. For example, a survey of 127 women attending for breast screening in rural New South Wales and 185 who had not attended showed that barriers to attendance included the degree of health consciousness, the awareness of the effectiveness of mammography in reducing the risk of developing severe breast cancer and concern about the procedure itself (Speedy and Hase, 2000). This study did not include a comparison with urban groups so it is difficult to determine the influence of rurality on the findings, but the description of factors influencing
the decision to participate in screening in a rural population provides insight into rural attitudes in this area. The influence of medical advice is also important in the decision for screening. Women in rural areas are more likely to undergo mammography based on a medical recommendation but less likely than urban dwelling women to receive this advice (Bryant and Mah, 1992).

Specific interventions have been used to increase the level of participation in rural populations. A community based intervention in rural Australian towns was shown to be effective in increasing the participation rates through the use of community based committees and mobilisation of screening at key community access points (Hancock, Sanson-Fisher, Perkins, Corkrey, Burton and Reid, 2001). This study also showed that participation rates by over-screened women were significantly reduced. These findings are not generalisable beyond the small rural town setting but provide an example of effective screening promotion in this setting.

Reports of breast screening demonstrates disadvantage in the Indigenous population, with participation by the target population (aged 50-69) at 36.2% (95% CI 35.3-37.0) in the Indigenous population compared with 56.9% (95% CI 56.8-57.0) in the non-Indigenous (age standardised to the Australian population) (AIHW, 2003a). Indigenous populations also have poorer screening outcomes than non-Indigenous. Recent data from New South Wales, Victoria, Queensland, Western Australia and the Northern Territory show that incidence of cervical cancer in the target population (aged 20-69 years) during the period 2000-2004 (age standardised per 100,000 population) was 16.9 in the Indigenous and 7.1 for the corresponding period in non-Indigenous (AIHW, 2008c, p34).

A number of barriers have been identified in relation to breast screening in the Indigenous population including lack of knowledge of screening, cost of treatment and availability of support for access (McMichael, Kirk, Manderson, Hoban and Potts, 2000). Research investigating patterns of cancer in Indigenous communities in Queensland identified significantly higher rates of cervical, lung and other smoking related cancers than in the general population and concluded that health care interventions should include those targeted at improving participation in cervical screening, reducing the prevalence of smoking and improving follow up of abnormal test results (Coory, Thompson and Ganguly, 2000).
Screening is an important part of cancer prevention, and the knowledge of health care professionals and the community, health beliefs and cultural and literacy factors are all important influences on the level of participation. Differences in participation rates are seen in minority groups such as the Indigenous population and rural residents and may have an adverse effect on the incidence and outcomes of cancer.

**Cancer in rural populations in Australia**

Information on rural cancers in Australia is not routinely, systematically reported, although some reports include information on rural figures and comparison with other geographic areas. Overall a higher incidence of cancer is seen in metropolitan areas than in rural or remote areas in Australia, possibly as a result of better diagnostic and screening facilities and easier access to these. For example, the incidence of prostate cancer is significantly lower in Very Remote areas than in Major Cities, probably due to higher use of prostate specific antigen blood tests in Major Cities (AIHW & AACR, 2007). However it is difficult to determine statistically significant differences in cancer incidence due to the relatively low numbers of people living in rural and remote areas.

The higher incidence of some cancers in metropolitan areas does not necessarily translate to poorer outcomes for these populations. The AIHW has analysed data from the ABS to determine differences in mortality according to degree of geographical remoteness (AIHW, 2003c). Specific types of cancers contributed to a higher number of deaths in populations outside Major Cities. Of these, prostate cancer was responsible for an increased annual average of 131 deaths, colorectal cancer for 117 and lung cancer for 52 deaths for the period 1997-1999 (AIHW, 2003c, p10). However, unfortunately this report does not analyse survival following a diagnosis of cancer, which may be an area of greater significance for the non-metropolitan population due to issues of access to early diagnosis and treatment. A more recent report confirms that prostate, colorectal and lung cancers contribute significantly to the higher rates of death outside Major Cities, with differences in Remote and Very Remote areas likely to be heavily influenced by the high Indigenous populations in these areas (AIHW, 2007b) (see table 1.2).

Cancers overall are responsible for up to 25% of all excess deaths in regional areas (AIHW, 2007b). There are some important differences in the average death rates in non-metropolitan
areas according to cancer diagnosis. Table 2.5 shows the average annual deaths and ‘excess’ deaths of the top four cancer diagnoses.

Table 2.5: Average annual deaths (per 100,000, age standardised) and ‘excess’ deaths, by type of neoplasm, 2002-04 (AIHW, 2007b)

Information on a State rather than national level provides more detail of the incidence and impact of cancer in relation to rurality. A report by the New South Wales Cancer Council analysed incidence, mortality and survival rates from 1992 to 1996 according to the degree of accessibility and remoteness to general and health care services (Jong, Smith, Yu, Goumas, O'Connell and Armstrong, 2002). This analysis showed a lower five-year survival in both
male and females living in remote and very remote areas when compared with those from accessible and highly accessible areas (see table 2.6).

Table 2.6: Five-year relative survival (%) and relative risk of excess death by five years from all cancers by ARIA category in residents of NSW 1992-1996 (Jong, Smith et al., 2002).

In addition to the poorer survival seen, the incidence of smoking related cancers (kidney, oesophagus, liver, stomach, pancreas, lung, uterus, cervix, bladder and cancers of the head and neck) was higher in residents of less accessible areas. The highest incidence rate for these cancers was 202.1 per 100,000 in very remote areas, compared with 142.2 per 100,000 in the moderately accessible areas. Analysis of the stage of disease evident at diagnosis showed there was a greater likelihood for residents in non-highly accessible areas to have non-localised disease at presentation for those with head and neck cancer, stomach cancer, lung cancer and prostate cancer (shaded rows in table 2.7). This has important implications for treatment and survival as the later a diagnosis of cancer is made the poorer the prognosis is likely to be. Differences in the spread of disease at diagnosis may be a factor in the poorer survival rates seen, however patterns of care following diagnosis may also be important and may differ according to the degree of rurality.
Risk factors, such as sun damage prevention behaviours and pre-existing conditions clearly influence outcomes of incidence and mortality but for some diseases differences in risk factors alone do not explain the discrepancies seen. The overall poorer survival level in remote and very remote groups presented in this report is a concern and requires further investigation to determine why this is so to ensure rural populations are as minimally disadvantaged by geographic location as possible.

Some differences in cancer and cancer outcomes in rural and remote areas in Australia may be due to access issues in relation to screening, level of awareness, early diagnostic procedures and treatment. Closer focus on these areas on a national level could determine differences in
survival outcomes in these groups compared with their metropolitan counterparts, and ascertain whether targeted interventions are needed to ensure not only equitable access but also equitable outcomes.

**Cancer in South Australia**

Cancer incidence in South Australia is reported using cancer registry data as described earlier in this chapter. The most common cancers in South Australia are similar to those reported for Australia overall, with prostate, colorectal, breast, lung and melanoma being the five most common (see table 2.8). In 2005, a total of 4,760 cancer cases were diagnosed in males and 3,696 in females (South Australian Cancer Registry, 2007).

Table 2.8: Most common cancers in South Australia 2005 (South Australian Cancer Registry, 2007)

Prevention and early detection screening programs are well established in South Australia and have contributed to a reduction in the incidence of some cancers such as cervical cancer and an increase in survival rates in others, such as breast cancer (South Australian Cancer Registry, 2007). The cervical screening program has been associated with a decrease in the incidence of cervical cancer of 40% in South Australia over the last 25 years and a fall in mortality rate by 69% (South Australian Cancer Registry, 2007).
Other changes in incidence of specific cancers in South Australia over the past 25 years include:

- a decrease in lung cancer in males of 25% but an increase in females of 65% due to corresponding changes in smoking patterns;
- an increase in prostate cancer in males, due to the increased use of PSA testing;
- an increase in melanomas (probably due to exposure to excessive sunlight in the 1960s) and more recent levelling off of incidence, possibly related to greater awareness of the importance of exposure to sunlight; and
- an increase in colon cancers of about 20% in males and 6% in females, possibly due to recent increasing use of faecal occult blood testing and colonoscopy.

(South Australian Cancer Registry, 2007)

Cancer related deaths in South Australia are detailed in table 2.9 below and show a similar pattern to the national statistics.

Table 2.9: Deaths from cancer in South Australia - 2005
(South Australian Cancer Registry, 2007)

NOTE:
This table is included on page 46 of the print copy of the thesis held in the University of Adelaide Library.
In summary, the overall pattern of cancer in South Australia is well known, however there is limited information on the comparison between rural and urban areas. As was shown in the national data, differences may arise from a number of factors and can lead to significantly different outcomes. Assessment of the impact of cancer in the rural population requires investigation into any differences there may be in incidence and mortality as well as examination of the impact on patients with cancer.

This section has presented epidemiological data relating to cancer in Australia including incidence, most common cancers, patterns of screening and prevention. Cancer is a significant health care issue and is a disease that affects the lives of many Australians. The overall increase in cancer relative survival times in Australia is positive, however this increase means that more people in Australia are affected by cancer for longer and hence that there is an overall higher burden of cancer in the community. In rural and remote areas, there are no significant differences seen in cancer incidence overall, but there is limited data on screening and the outcomes in terms of survival. It is important to understand the incidence and the trends in cancer when examining the question of the experiences of rural cancer patients receiving treatment in the metropolitan setting.
Cancer and cancer treatment

Cancer treatment is traditionally divided into the sub-speciality settings of medical oncology, surgical oncology, radiation oncology and haematology. The common treatment types used are surgery, chemotherapy including bone marrow transplantation, and radiotherapy. This section addresses cancer as a disease and the impact that a diagnosis of cancer may have on the person and their family as well as common cancer treatments and how these may affect the individual. Two common types of cancer in Australia, colorectal and breast cancer are discussed, as well as the leukaemias as this group of diseases frequently requires prolonged relocation to metropolitan treatment centres. Cancer care for rural and remote patients is also addressed including the provision of treatment for rural residents in South Australia.

Cancer diagnosis

Cancers generally present as a new lump or a lesion that does not heal and require a biopsy to confirm the diagnosis of cancer, its histopathology and the type of treatment to be used (Griffin-Brown, 2000). Other tests may be used to assess whether the cancer has spread from the original site. These include biopsy of surrounding lymph nodes, chest X-ray, bone scans, computerised axial tomography (CAT) scans and positron emission tomography (PET) scans, a combination of which may be used in the process known as ‘staging’ the cancer (i.e. determining where the cancer is, other than the site of origin (Griffin-Brown, 2000)).

The impact of a cancer diagnosis

A diagnosis of cancer is likely to be a traumatic event for the person concerned as well as for their family and friends. Responses are influenced by factors such as the person’s experiences leading up to the diagnosis, perception of the meaning of cancer, cultural background, knowledge of treatment and treatment effects, how they coped with traumatic events in the past and individual coping styles (Wells, 2001). Thus it is important not to make assumptions about ‘cancer patients’, but to understand that there may be a range of responses to a diagnosis of cancer for different reasons.

Fear and panic may be experienced on a level that may be similar to that felt when faced with a disaster or catastrophe. This may be accompanied by loss of a sense of control, leading to anxiety and withdrawal (Wood, 1996). In the initial stages, uncertainty of the causes, the
treatment and the likely outcomes of the cancer is likely to be stressful for the person diagnosed and their family and friends. Any difficulties in communication with the health care team are likely to exacerbate this and make it more difficult for the family to feel that they have control of the situation (Germino and O'Rourke, 1996).

The rural patient is often faced with the added pressure of learning about the diagnosis and treatment options away from home and family members. Furthermore, diagnosis of malignant disease may be made with few warning signals beforehand, so the person may have little time to prepare for the possibility of the existence of a serious illness. The impact of diagnosis may therefore be significant and is a time when there are likely to be strong needs for support and information.

The treatment of cancer

The main treatments used of surgery, radiotherapy and chemotherapy each carry with it predicted and potential side effects. Knowledge of these helps provide some understanding of the situation of a rural person receiving treatment in the metropolitan specialist setting.

Surgery

Surgery is the most common cancer treatment used and offers the best chance of long term remission or cure when used early in the history of the cancer (Hansen Frogge and Cunning, 2000). Surgical interventions for cancer differ from the cyclic patterns of chemotherapy and radiotherapy courses as they are more likely to be performed as 'one off' procedures. Decisions as to whether to use surgery, the type of procedure required and whether adjuvant treatment is also needed are influenced by the health status of the patient including co-morbidities and age, the tumour type and behaviour and the stage of disease (Hansen Frogge and Cunning, 2000). For rural and remote patients, the duration of time required to be in the metropolitan setting for surgical therapy is shorter than for other forms of cancer treatment and fewer visits are required. The immediate and rehabilitative recovery period, however, may need to be spent in the vicinity of the treatment setting.

Surgery is the treatment of choice to definitively treat a cancer if it has not spread beyond the tissue of origin, however if it is considered likely or even possible that the cancer has spread, surgery may be supplemented or replaced by other modes of treatment, such as chemotherapy and/or radiotherapy.
Chemotherapy

Chemotherapy, hormone therapy or the more recently seen biological or targeted therapies are used as systemic forms of treatment, either alone or in combination with others. The term chemotherapy means use of chemicals for the treatment of disease (Collins Australian Compact Dictionary, 2002), but common usage has led to this term being used primarily to refer to cytotoxic (i.e. damaging to cells) agents used for cancer treatment (The Cancer Council South Australia, 2007a).

Chemotherapy is commonly administered in regular cycles, with the number and duration of cycles varying according to the treatment regimen. For example, breast cancer may be treated with six cycles over a period of approximately five months (Royal Adelaide Hospital Cancer Centre, 2002b), whereas the regimen to treat an acute leukaemia may continue for over two years (Royal Adelaide Hospital Haematology/Bone Marrow Transplant Unit, 2003).

There is a range of side effects commonly associated with the use of cytotoxic agents and the severity and duration of effect can vary according to the agent used as well as patient and dosage factors. However there are common side effects which are likely to affect the majority of patients to some degree. The most immediate potential effects are hypersensitivity reactions to the chemotherapy agents and extravasation injuries, where chemotherapy leaks from the vein into the surrounding tissue. Acute post chemotherapy nausea and emesis may also occur within the first 24 hours.

A group of toxicities commonly occurs between 10 and 14 days after the administration of chemotherapy. The side effects experienced during this time can cause considerable distress and may put the patient at risk of serious morbidity. Immunosuppression is frequently a dose-limiting factor in cytotoxic treatment. The blood counts fall as the cells which were destined to become white and red blood cells and platelets have been damaged by the chemotherapy. The counts then recover within a few days as cell replacement occurs. Patients are advised to take precautions throughout this period to minimise complications of immunosuppression, such as maintaining good personal hygiene to minimise their risk of infection (Wujcik, 1999).

Oral mucositis, or inflammation of the oral mucosa, is a common, debilitating complication of cancer chemotherapy and radiotherapy, occurring in occurring in approximately 40% of patients receiving standard dose chemotherapy (Graham, Pecoraro, Ventura and Meyer, 1993).
and in the majority of patients undergoing high dose chemotherapy (Armstrong, 1994). Other gastro-intestinal side effects of diarrhoea and constipation are treated symptomatically.

Nausea and vomiting may be the most distressing side effects experienced by patients undergoing cytotoxic therapy and are managed primarily using pharmaceutical agents (Wickham, 1999).

Fatigue is an insidious and under-recognised effect of cancer and cancer treatment, which can have a major impact on the quality of life of the patient (Winningham, 1999). Fatigue is worsened by chemotherapy treatment and may be experienced by over 90% of patients (Stasi, Abriani, Beccaglia, Terzoli and Amadori, 2003).

Alopecia or hair loss occurs due to cytotoxic effects on the dividing hair follicles and is ‘one of the most tangible, difficult, emotionally painful side effects’ experienced by patients (Reeves, 1999, p275). Hair usually re-grows when treatment is finished, however alopecia can be experienced for a prolonged period.

**Radiotherapy**

Radiotherapy may be defined as ‘the use of ionising radiation for therapeutic purposes’ (Churchill's Illustrated Medical Dictionary, 1989, p1571), where radiation is used to lethally damage cells in a specified treatment area. Radiotherapy treatment is commonly administered on a daily basis (excluding weekends) over a period of one to six weeks although this is influenced by treatment dose and intent. A variety of treatment administration methods are used, such as external beam radiotherapy using a machine such as a linear accelerator, with the type of treatment used influenced by the location, size and type of tumour (Haas and Kuehn, 2001).

Radiotherapy may cause both localised and systemic effects, such as skin reactions, fatigue and loss of appetite. Review of research in this area suggests that the degree of fatigue experienced is influenced by the type of malignancy (highest in patients with cancer of lung, breast and prostate) and the type of treatment used (highest in patients receiving both radiotherapy and chemotherapy) (Jereczek-Fossa, Marsiglia and Orecchia, 2002).

Site-specific side effects include bone marrow suppression, hair loss, diarrhoea, mucosal inflammation and ulceration, and nausea and vomiting (Maher, 2000). These can have a significant effect on the patient’s health, for example, patients undergoing radiotherapy to the
head and neck region experience xerostomia (loss of saliva), mouth ulcers, sore throat and
taste changes, impacting on their ability to eat and drink and significantly affecting their
quality of life (Rose Ped, Bellm, Epstein, Trotti, Gwede and Fuchs, 2002).

Management of radiotherapy specific side effects such as severe mucositis and skin reactions
can be problematic due to the lack of access to specialist staff, particularly as reactions usually
develop approximately three to four weeks after commencement of therapy and resolve some
three to four weeks following completion of treatment (Saunders and Dische, 2002).

Summary

Treatment related complications are important for patients from rural and remote areas as their
distance from the specialist centre places them at greater risk if there are delays in detection
and treatment of complications. Patients from rural areas who travel to and from home for
treatment not only have the concern of being distant from specialist care should any
complications arise, but also have to deal with the physical challenges of travelling between
home and the treatment centre. Travelling after chemotherapy is likely to exacerbate any
feelings of nausea experienced and when driving between towns and there are few options for
managing nausea and vomiting should this occur (McLinden, 2001). Also, should
complications arise between treatment cycles the patient is more likely to be seen by a general
practitioner or community nurse rather than specialist health care staff. Effective
communication between specialist and community staff is essential so that the staff managing
the complications have the information they need to be able to provide appropriate and
effective care.

This brief outline of anticipated and expected side effects reinforces that chemotherapy and
radiotherapy are specialised forms of treatment that can have serious adverse effects, which in
the rural population may be problematic particularly if travel to and from treatment is
required. The specialised nature of these treatments and the potential and anticipated effects
seen related to their use reinforces why these treatments are rarely available in rural areas,
particularly the more complicated or complex treatments, or those requiring specialised
equipment such as radiotherapy. Patients undergoing these treatments from rural areas may
return home, for example between chemotherapy cycles, and be managed by their general
practitioner in the first instance should complications arise. This indicates a need for strong
communication between the treatment centre and the rural health care staff, and for the
patients and families concerned to have a clear understanding of who they should contact if needed.

**Cancer treatment provision in rural settings**

**Access to cancer treatment**

The level of access to cancer control measures, including screening and treatment, can be assessed directly through measuring time from investigation to diagnosis and treatment, or indirectly through monitoring of the stage of disease at presentation (for example, the effectiveness of screening may be seen on a population basis by the number of cases diagnosed at earlier stages). Once diagnosed the patient’s access to the different modalities of treatment, for example the distance from a radiotherapy unit or whether chemotherapy can be administered in the local region, can be measured through assessing the effectiveness of cancer treatment using the five year survival rate following diagnosis.

It has been estimated that approximately 50% of patients should receive radiotherapy treatment (Kenny, 2000), however this figure varies according to diagnosis and stage of disease. A review of the indications for radiotherapy treatment of colorectal cancer applied to an estimation of the incidence of each indication in the population showed that 7.1% +/- 0.8% of colon cancer patients would require radiotherapy at some point in their illness, whereas 72.3% +/- 1.0% of those diagnosed with rectal carcinoma would require this type of treatment (Foroudi, Tyldesley, Barbera, Huang and Mackillop, 2003). For breast cancer, a similar approach estimated that for all patients with breast cancer, 83% (95% CI, 82-85%) would have radiotherapy treatment recommended (Delaney, Barton and Jacob, 2003). For this level of treatment to occur, access to treatment, infrastructure and equipment must be available to those for whom the treatment is indicated. An analysis conducted of radiotherapy workforce and equipment coverage in Australia for the period 1986-1999 identified that these were insufficient to support treatment at an overall access level of 50% (Wigg and Morgan, 2001). This leaves rural patients vulnerable to issues of access in a system that may already be undertreating patients diagnosed with cancer.

Differences have also been identified in women receiving breast reconstruction surgery after treatment for cancer. Analysis of data from hospitals, cancer registry and death records in Western Australia identified differences in care according to rural status, socio-economic
status and membership of private health insurance (Hall and Holman, 2003). In particular, women from lower socio-economic groups and from rural areas were less likely to undergo breast reconstruction and women with private health insurance were more likely to undergo this procedure.

Access to chemotherapy treatment can also be influenced by socio-economic background. A review of case notes of 1314 patients in the North and North East of Scotland treated for lung and colorectal cancer showed that patients in outlying areas had an equivalent speed of access to treatment, and in the case of colorectal cancer a faster access time, but that patients with lung cancer from a deprived socio-economic background were less likely to be treated with chemotherapy, and patients from outlying rural areas with colorectal cancer were less likely to be treated with radiotherapy (Campbell, Elliott, Sharp, Ritchie, Cassidy and Little, 2002).

Rural residents with cancer may receive different treatment from urban patients and have different expectations and outcomes of care. A study conducted in France analysed data from 1445 cancer cases to determine differences in disease status and treatment according to rurality (Launoy, Le Coutour, Gignoux, Pottier and Dugleux, 1992). This showed that rural patients were less likely to be treated in a specialist health care centre (40.0%) than their urban counterparts (53.4%). This difference was chiefly explained by distance from the specialist centre.

In another study, four focus groups were held with 22 rural and urban patients and 10 family members in the United Kingdom exploring the perspectives of patients with colorectal cancer (Bain and Campbell, 2000). This study found that while key components of rural and urban patients’ experiences of care were similar, there were differences in expectations of care (rural patients being less demanding) and that rural patients experienced a greater number of barriers to accessing specialist care.

It is noteworthy that issues of rurality in two highly densely populated, developed countries such as the United Kingdom and France are identified as factors of significance. Issues such as access to specialist care and expectations of care are likely to be as, if not more important to patients in countries such as Australia where the degree of remoteness from services is greater and are also likely to be of importance in patients with other types of cancer.
Cancer treatment in rural South Australia

Comparison of rural and urban radiotherapy treatment levels has been conducted in South Australia in a study where access to radiotherapy by rural patients was assessed using a cohort analysis with data from the Cancer Registry (Luke, Chapman, Priest and Roder, 2003). This found that overall, 29.0% (95% CL: 28.5, 29.6) of cases had radiotherapy treatment prior to the census date in 1999, with 25.2% receiving this therapy within the first 12 months following diagnosis (p163). Rural residents, as determined through postcode, were less likely to receive radiotherapy than Adelaide residents, with a relative probability of 0.91% (95% CL: 0.86, 0.96) after adjustment for age, sex and country of birth. It is likely that issues of access play a part in this difference.

In South Australia the number of linear accelerators (used to deliver radiation therapy) is the highest per head of population in Australia (Clinical Oncological Society of Australia, The Cancer Council Australia et al., 2003, p84), however as the nine machines are all located in metropolitan Adelaide, access for rural and remote residents is more difficult than for urban residents.

Centralised, complete information on which treatments are offered at individual institutions is not currently available in published form but chemotherapy is offered at all public hospitals in Adelaide and a number of larger private hospitals. The more specialised treatments, such as autologous haematopoietic cell transplantation are offered at large public hospitals and in private hospitals with a specialist centre (approximately 4 hospitals in total) with highly specialist and costly treatment such as allogeneic bone marrow transplantation (using bone marrow from a related or unrelated donor) currently only offered at the two largest public hospitals.

Chemotherapy is routinely offered in major regional centres, such as Mount Gambier and Whyalla, but only in conjunction with a metropolitan specialist centre. The chemotherapy regimens that may be given are generally restricted to less complex protocols with a lower risk of complication and usually after planning and initiation of treatment in a metropolitan centre. Smaller rural and remote centres may offer chemotherapy treatment as required for individual patients with the support of the metropolitan centre, again, these being the less complex protocols. Administration of the chemotherapy drugs may be by the general practitioner or nursing staff.
General surgical services are available in major rural regional centres, with some visiting specialist services also provided such as urology. Centralised information is currently not available from the Department of Health as to which specialist services are available in what locations, however in general, access to cancer operations other than minor procedures such as skin cancer removal is limited in the rural setting.

In South Australia, information on the numbers of those from rural areas treated for cancer is not currently centrally available as data collected by the Department of Human Services and Health Insurance Commission records treatment episodes rather than the number of individual patients undergoing treatment. Therefore, it is currently only possible to calculate the numbers of patients involved by accessing data from all treatment centres. The majority of specialist cancer care for rural residents is coordinated, provided and supported by tertiary health care centres in the Adelaide metropolitan area.

**Patient education about cancer treatment and effects**

In order to participate effectively in decision-making, a considerable amount of information needs to be absorbed by the patient at the time of and shortly following diagnosis. This usually needs to be done quickly and in the context of making an adjustment to the diagnosis of cancer. Patients are frequently confused by the terms and language used by health care professionals and may initially have limited understanding of their diagnosis and prognosis (Lobb, Butow, Kenny and Tattersall, 1999). This highlights the importance of ensuring patients have access to accurate information, provided at an accessible level and at a pace at which the patient can absorb.

Patients diagnosed with cancer face the daunting task of concurrently learning about the disease and possible treatments, as well as making a decision about whether to undergo treatment or deciding between different, available treatment options. One of the most important roles of health care professionals involved in their care is to support the patient through this process. A guide to advocacy in health care identifies skills in communication, information gathering (including via the internet), decision making and negotiation as being important for health care professionals to possess in order to effectively support patients (Gomez and Gullatte, 2002).
Given the pressure and type of information to be learnt, it is not surprising that knowledge deficit has been frequently identified as an issue for patients with cancer (Galloway, Graydon et al., 1997; Treacy and Mayer, 2000; Feldman Stewart, Brundage and Mackillop, 2001; Jenkins, Fallowfield et al., 2001) and may persist for some time following diagnosis (Sainio and Eriksson, 2003). Repetition of information may be needed as patients may retain only a portion of the information provided, due to their emotional and psychological response to the diagnosis of cancer, any cognitive impairment, or a lack of desire to learn (Dodd, 1999). A number of strategies may be needed to maximise information learning, such as providing information in different ways to suit the learning needs of the person concerned.

The information needs of the patient’s family are also important as family members are frequently the primary carers for the patient and provide psychological and emotional support. This may involve them in communication that the patient has with the health care team. Interviews with adult family members of patients undergoing bone marrow transplantation showed that they have specific education needs, such as learning to advocate for the patient and to provide physical care. They also faced barriers in communicating with health care professionals, which created tension in their perceived need to protect the patient (Stetz, McDonald and Compton, 1996). Thus family members require information not only about the cancer and treatment, but also have specific information needs that differ from those of the patient.

**Examples of specific cancer treatments**

There are many different cancer treatment protocols, particularly in the range of cytotoxic drugs, however for specific cancer types particular drug or radiotherapy protocols are likely to be used. To gain an understanding of the issues involved for rural residents, two common types of cancer and typical treatments used are outlined as well as treatment for the leukaemias as these diagnoses often require prolonged periods of relocation to the metropolitan area.

**Breast cancer**

The treatment for localised breast cancer is surgery which involves removal of a portion only (lumpectomy), or lumpectomy with radiotherapy to the local area or removal of all the breast tissue. Depending on the established or possible extent of the cancer and the histopathology,
surgical treatment may be followed up with radiotherapy (for four to six weeks) to improve local control, and/or chemotherapy (for six months) or hormone therapy to reduce the chance of distant relapse (iSource National Breast Cancer Centre, 2001).

The availability of the two treatment options of lumpectomy and radiotherapy or mastectomy means the woman concerned is required to make a decision about how the breast cancer will be treated. For rural women the need to relocate to access a specialist radiotherapy treatment centre for the duration of radiotherapy could be a factor in this decision. In an assessment of factors affecting treatment decision in urban and rural women in Western Australia, of 160 women diagnosed with breast cancer, 46 women in urban areas opted for modified radical mastectomy only, and 83 for breast conserving treatment, in contrast with those in rural areas, 22 of which underwent modified radical mastectomy and 9 breast conserving surgery (p=0.00) (Mastaglia and Kristjanson, 2001). This was the only significant difference identified between the rural and urban groups.

The factors identified as influential in decision making in both groups were: having information on the lack of difference in long-term survival between treatment groups; the degree of involvement in decision-making; access to a general practitioner as an information source; and the adequacy and sufficiency of time for decision-making. This study identified that geographic location of residence may have an influence on treatment decision-making by women with breast cancer and that further work needs to be done to determine which aspects of rurality are important.

**Colorectal cancer**

Colon cancer may be cured by surgery if detected early when it is confined to the bowel wall. The natural course of bowel cancer is to spread through the bowel wall and into the adjacent lymph nodes. If this has occurred, chemotherapy is likely to be used in addition to surgery, as surgery alone is unlikely to remove microscopic cancer cells (Australian Cancer Network Colorectal Cancer Guidelines Revision Committee, 2005). Radiotherapy is not usually used as first line treatment but may be used for palliative effect in both colon and rectal cancer.

**Leukaemias**

Leukaemias (malignancy of the white blood cells) are classified as acute or chronic depending on their course and are further classified as either myeloid or lymphatic depending on their cell of origin. Patients with acute leukaemia are treated with intensive chemotherapy to
eliminate the leukaemic cells from the bone marrow. This is administered as induction chemotherapy followed by a maintenance regimen (Callaghan, 1996), leading to a prolonged period of treatment for most patients of up to two years, with varying periods of intensity (Royal Adelaide Hospital Haematology/Bone Marrow Transplant Unit, 2003).

Chronic myeloid leukaemia typically has a chronic phase that usually lasts some years and may be treated using oral chemotherapy or biotherapy agents, then develops into an accelerated phase followed by what is known as a blast crisis when it transforms into acute leukaemia (Callaghan, 1996). Bone marrow transplantation may be used to attempt cure, which requires a prolonged period of time for rural residents to be spent in the vicinity of the hospital. Chronic lymphatic leukaemia usually has a more indolent course with chemotherapy used for palliation of symptoms when required. Rural residents are not only faced with the issues of relocation, but also the need to adjust on the return home, with emotional, medical and practical support needs (McGrath, 2000b).

Discussion of these diseases and their treatment demonstrates the arduous nature of cytotoxic treatment and the specific difficulties faced by patients from rural and remote areas. The management of patients undergoing these types of treatment requires specialist skills and knowledge, as well as understanding by patients to minimise the risk of serious complications.

Cancer outreach programs

It is well recognised that barriers to cancer treatment exist for those living in rural and remote areas, including lack of local specialist services, transport to metropolitan centres, financial costs and access to supportive care (Launoy, Le Coutour et al., 1992; Wilkinson, 1996; Guidry, Aday, Zhang and Winn, 1997; National Rural Health Alliance, 1999; Lehman, Hedges et al., 2002). This can result in reduced access to treatment, lack of evidence based treatment provision and differences in outcomes (Launoy, Le Coutour et al., 1992; Hatzell, Ricketts, Tropman, Paskett and Cooper, 1999; Tropman, Hatzell, Paskett, Ricketts, Cooper and Aldrich, 1999; Tropman, Ricketts, Paskett, Hatzell, Cooper and Aldrich, 1999). The three main types of strategies used to provide specialist care in rural and remote areas have been to:

- ‘share care’ using electronic media (for example through consultations via video link up);
- educate and train rural health care professionals; and
• facilitate outreach visits by metropolitan specialist staff on a regular basis.

(Campbell, Ritchie, Cassidy and Little, 1999).

Share care using electronic media

Tele-medicine, or in its more generic sense tele-health, refers to the delivery of health services via remote telecommunications, including interactive consultative and diagnostic services, (CancerWEB, 1998), thus avoiding the need for the patient to travel. Diagnostic radiology and pathology information may be simultaneously viewed by all parties involved in the link up. Tele-health has many potential applications in health care and may also be used to support education of rural and remote staff (Doolittle and Allen, 1997).

Publications focusing on the use of tele-health in the oncology setting have focused mainly on patient and staff satisfaction with the technique, rather than clinical outcomes (Allen and Hayes, 1995; Mair, Whitten, May and Doolittle, 2000; Olver and Selva, 2000; Currell, Urquhart, Wainwright and Lewis, 2001). Evaluations indicate that tele-health can be used effectively to facilitate access to specialist oncology opinion and is satisfactory from the patient’s and health care professional’s perspective. One potential concern is that this method would be seen as unsatisfactory by patients who had previously had face-to-face consultations with specialist staff however, a pilot study of 39 such patients found that they continued to be satisfied with the tele-health service (Allen and Hayes, 1995).

Another study of 16 patients being informed of chemotherapy treatment via video conferencing assessed their retention of information when questioned the following day (Sezeur, Degramont, Touboul and Mosnier, 2001). Participants correctly answered 80.5% of the questions, demonstrating a high level of knowledge retention but this was not a comparative study so was not able to be used to demonstrate advantage or disadvantage to patients.

Tele-health is used in South Australia to provide specialist care through regular video consultations between the Cancer Centre at Royal Adelaide Hospital and Royal Darwin Hospital in the Northern Territory (Olver and Selva, 2000). An evaluation of this service was conducted with eight patients and 20 health care professionals involved in the consultations. Of the eight patients, three were able to avoid travelling to Adelaide for treatment altogether.
(approximately 3000km distance) and it was of interest that one of these would have preferred to go to Adelaide for treatment (the reasons for this were not given).

All three who needed to travel despite the consultation felt that the consultation before travelling had influenced their care and shortened the time that they needed to stay away from home. They also found it reassuring that a specialist had reviewed their case before they attended for treatment. The health care professionals identified benefits in relation to peer review, better support and communication, decrease in travelling time and participation in multi-disciplinary case discussions. Some concerns were identified in this evaluation by both patients and health care professionals. These included the impersonal nature of the meeting, technical difficulties (such as movement artifact) and issues around confidentiality during the conferences.

There is limited research into tele-health in its application to the management of patients with cancer and advantages and disadvantages associated with its use that warrant further investigation. While it is helpful for patients to avoid travel and still receive input from specialist staff, tele-health should not necessarily be viewed as an equivalent service to a face to face consultation at this point in time.

**Internet use**

The internet is increasingly being used as a medium through which cancer information and services can be obtained and may be particularly useful for the provision of information to patients and health care professionals from rural and remote areas. There has been little overall evaluation of such services specifically in relation to the needs of rural patients with cancer.

Lieberman et al evaluated the impact of participation in an electronic support group for women with breast cancer (Lieberman, Golant, Giese-Davis, Winzlenberg, Benjamin, Humphreys, Kronenwetter, Russo and Spiegel, 2003). This study involved 32 women with breast cancer from across America (49% from rural areas) who participated in a weekly on-line ‘real time’ support group facilitated by an experienced group leader that ran for a total of 16 weeks. In addition, the participants had 24 hour access to a dedicated newsgroup where they could chat and share pictures and stories. The impact of this intervention was assessed through use of questionnaires measuring coping and adjustment, depression, post-traumatic growth, suppression of affect, personality traits and pain. Qualitative interviews were also held
following completion of the support group. Significant improvements were identified in two of the 12 areas measured, i.e. degree of depression and reaction to pain, and when interviewed, 67% of the participants felt participating in the group had been beneficial. The impact of this intervention was not compared with a face to face support group or a control group, but it is of note in relation to rural populations that women were willing to commit to an on-line support group and that a positive impact was seen.

Before implementing internet based interventions, it is helpful to determine the level of interest that patients and health care professionals have in participating in and using this type of media. A descriptive study of 319 patients and caregivers in America assessed the level of interest and feasibility of providing internet based cancer services (Monnier, Laken and Carter, 2002). This study showed that more than half the participants had internet access at home (57%) and stated their preparedness to use the internet to access information and services. There was specific interest expressed in home health care strategies, such as use of computers for daily email contact, replacing a face-to-face visit by nursing staff. This type of intervention is unlikely to suit all though, as the study showed that participants from a minority ethnic background were less educated, were older and were less likely to have used the internet before and to be knowledgeable about use of this technology.

Rather than being a barrier to the use of such strategies, this may be more of a reason to develop internet access strategies targeted to the needs of the groups concerned. Thome et al in their research into the experience of older people with cancer identified the health care professional’s role as one of advocacy through supporting the involvement of the person in decision-making and affirmation of their treatment choices (Thome, Dykes, Gunnars and Hallberg, 2003). Any intervention which assists information provision and involvement of the person concerned is likely to be useful in maximising empowerment of the patient and carer.

**Education and training of rural health care professionals**

Another strategy used to provide specialist care in rural and remote areas is to provide education in order to expand the role of rural health care professionals in areas usually considered specialist. The two main groups of health care professionals who are likely to undertake specialised training are general practitioners and nurses.
Nurses based in rural areas have a traditionally broad practice base and are often required to be skilled in a number of areas due to the relatively small and therefore non-specialist population of patients involved, for example nurses may work in both an inpatient area and in an accident and emergency department, even during the same shift (Hegney, 1996). Any expansion of cancer treatment into rural areas means that nurses involved in the care of these patients may be required to administer specialist treatment such as chemotherapy and hormone therapy and/or may be responsible for caring for patients undergoing such treatments. While being technically straightforward, the side effects and toxicities associated with cytotoxic treatment are serious, as discussed earlier and it is important that nurses have the appropriate knowledge and skills in order to provide best care for the patients concerned (Humphreys, 1998; McLinden, 2001). Minimum education requirements have been developed for nurses involved in the care of patients undergoing treatment with cytotoxic agents, including the development and ongoing maintenance of knowledge in areas of cancer biology, principles of safe administration, handling and disposal, adverse effects, education and support of the person undergoing treatment and ethical and legal issues associated with the treatment (Cancer Nurses Society of Australia Position Statement, 2003).

Education courses can be used to support generalist staff through offering information on both general oncology concepts and chemotherapy administration (Stansfield and Brighten, 1998). Specialised post graduate education courses have also been developed to educate rural health care professionals and enable them to care effectively for patients receiving specialist treatment, for example courses in breast care for those caring for women diagnosed with breast cancer (National Breast and Ovarian Cancer Centre, undated).

Following initial education and training, ensuring ongoing maintenance of skills and knowledge is important to maintain the level of care provided. This can be problematic in rural areas due to the small numbers of staff working at a given time, difficulty accessing specialist staff, low number of patients being treated, limited education budget and the number of specialities which demand this type of ongoing education. Lifelong learning principles and the development of links between specialist and rural centres may be helpful for the support of general practitioners (Norington, 1997). Indeed the ability to access ongoing education has been shown to be a key influence in the length of practice in rural areas, in contrast with
degree of rurality which was identified as the least important factor (Humphreys, Jones, Jones and Mara, 2002).

Ongoing and specialist education used to inform providers of cancer treatment in rural areas are not without problems, particularly in influencing change in the way that cancer treatment and care are delivered. The Lake Superior Rural Cancer Project was conducted in the North Central United States over four years to evaluate strategies intended to improve rural physicians’ cancer practice (Elliott, Elliott, Regal, Renier, Haller, Crouse, Witrak and Jensen, 2002). Interventions trialled in one part of the study were preceded by strategies to increase knowledge of rural cancer providers and were intended to achieve earlier diagnosis of cancer and improved outcomes in staging and treatment. The interventions included educational activities for health care professionals involved in the management of patients with cancer, strategies to achieve better communication with the regional cancer centre, and identification and training of clinical opinion leaders. These were evaluated in six rural communities and compared with 12 control rural communities. However, despite a number of strategies being used, the findings showed that few of the outcomes measured showed significant improvement in the intervention communities (5 of the 37 outcomes measured). While an increase in knowledge was demonstrated in this study, this was insufficient to improve outcomes for rural patients. This indicates the degree of complexity and difficulty in improving care for patients in rural areas.

Other support provided to local practitioners includes the development of written protocols and the use of electronic media for education sessions (Curtiss, 1993). However, the lack of information on current care delivery to patients with cancer in rural areas by rural staff, preferred interventions and impact of these types of interventions means that it is difficult to assess the effectiveness of this type of intervention. Adding to this is the difficulty that with increasing remoteness comes increasing complexity of care delivery by rural health care professionals, meaning the need for specialist education becomes greater yet more difficult to implement (Humphreys, Jones, Jones, Mildenhall, Mara, Chater, Rosenthal, Maxfield and Adena, 2003).
Outreach visits by metropolitan specialist staff

Another strategy used to provide specialist care in rural and regional areas is through provision of a regular visiting service by specialist health care professionals. The frequency of the visits is important as it determines the level of care available to rural residents, for example a fortnightly visit may mean that chemotherapy can be administered entirely by visiting specialist staff. Both nursing and medical staff may be involved in visiting services, with nursing staff often taking on coordination and management roles as well as providing clinical care (Watson, 1993). When the distance and time required to travel are not extreme visiting specialists may be an effective way to deliver cancer care, particularly chemotherapy (Curtiss, 1993).

Curtiss provides an overview of issues related to various models of rural oncology care and argues that communication and continuity of care are the key factors to be considered when considering treatment away from home (Curtiss, 1993). It is important to be clear about the advantages and disadvantages of treatment and the option of no treatment, which may be preferred by the patient when all factors are taken into account. This can be a difficult assessment for non-specialist rurally based practitioners to make, as they may not be aware of current research and developments, particularly in relation to specific diseases. This highlights the importance of communication methods such as tele-health consultation.

Another variation on the model of visiting specialists is to have ‘mobile care units’ which travel from site to site on a regular, cyclic basis, providing phone contact between visits (Given, Given and Harlan, 1994). This is a strategy that enables current and detailed information to be made available in rural areas. It is important however, to link these and other services to the local staff and structures in order to strengthen communication, to ensure the program is meeting the needs of both parties and to aid the professional development of rural staff.

Visits by specialist staff to rural areas help in extending the provision of care to settings that are more accessible to patients. One cautionary aspect that should be considered when discussing extension of care is that it is advantageous to patients to be treated in a centre that treats a large volume of similar patients (Selby, Gillis and Haward, 1996), which is not feasible in a rural area. However there are many important factors to consider in health care
provision for rural residents, including ensuring access to care, health care professional competence and confidentiality and privacy (Lyckholm, Hackney and Smith, 2001). Avoiding the need to relocate is also a powerful argument in favour of extending cancer treatment availability into rural, if not remote, areas. However, given the proven benefits of being treated in a specialist centre for some cancers, it could be argued that no patients should be entirely diagnosed and treated in a non-specialist setting, without access to specialist input.

As has been seen from the discussion of treatments and new therapies, cancer treatment is a constantly evolving specialty area, which can make it difficult for those not specialised in the area to remain current. This is an issue that requires ongoing input from patients to determine their needs and preferences and further information about the risks and benefits involved.

Specialist health care, such as often required for the management of those with cancer, is usually centred in metropolitan settings and hence is less accessible to those in rural areas than generalist health care. Despite the use of strategies to support the extension of specialist cancer care to rural settings, highly specialised and sophisticated procedures such as haematopoietic cell transplantation and radiation therapy as used in cancer treatment are generally provided by specialised units at metropolitan treatment centres and this is unlikely to change in the near future. It is important to determine the impact on patients of having reduced access to health care, both general and specialist.

**Summary**

This overview of cancer and cancer treatments and issues for rural residents has shown that cancer treatment frequently involves the use of toxic therapies, which have significant associated risks. A considerable amount of information is needed by the patient and the treating team in order to make a decision about the optimal treatment method. There are also a number of health care professionals involved in treatment delivery. The patient receiving treatment is therefore likely to receive substantial amounts of information from a number of different people, which can add to the overwhelming nature of cancer treatment. Other areas to be considered in relation to cancer and cancer treatment for rural residents are:

- The requirement for most patients to attend treatment centres in urban areas for some if not all of their treatment. Due to the specialist nature of the treatments, this is unlikely to change.
• Strategies developed to aid education on the treatment, and strategies to extend care into rural areas may be used to help minimise the impact of living in a rural area and being treated in a metropolitan centre but these are currently implemented on an ad hoc basis and evaluation is limited.

• The development of such strategies is likely to be constrained by the lack of data available on rural residents and their access to treatment locally – it is difficult to evaluate such strategies without a clear understanding of how treatments are currently delivered.

• Health care professionals agree on the central issues for rural residents, including having access to high quality care and the need for treatment to be coordinated, but there isn’t clear consensus on how this is to be achieved.

• There are gaps between current government policy, health care providers’ assessment and consumer needs and satisfaction with cancer treatment.
Chapter summary

This chapter has provided information in three areas relevant to this thesis: health care in rural and remote areas of Australia; the current state of cancer in Australia; and cancer treatment, its impact and the implications for rural and remote residents. A third of Australia’s population is considered ‘rural’, characterised by factors such as geographic isolation and largely adverse health care outcomes, which are contributed to by reduced access to general and specialist health care services. Rural and remote populations also experience greater health care needs than urban populations to due to the factors associated with their lifestyle and attitude towards illness. While barriers to access to health care may be expected for those living greater distances from metropolitan areas, inequities in health care outcomes should not be accepted. Understanding of the needs of rural populations is required in order to develop appropriate strategies to overcome barriers.

It is also clear that cancer is a significant issue in Australia due to the large numbers of people diagnosed with this disease, combined with higher percentages of survivors. Screening to achieve prevention and early detection of cancer is used to reduce the overall burden of cancer in the population. There are knowledge deficiencies in rural populations of current screening recommendations, however overall, screening programs are effective in rural areas and have similar or better levels of participation than in metropolitan areas.

After cancer is diagnosed, treatments may be offered in a variety of forms with varying levels of toxicity, complexity and risk. The treatments are usually offered in metropolitan settings for at least some of the prescribed regimen. There are particular disadvantages and risks for patients from rural and remote areas, such as isolation from specialist staff in the event of complications arising, physical impact of travelling for treatment and the practical obstacles imposed due to the need to travel and stay in the metropolitan setting. Some strategies have been developed to ameliorate these disadvantages, such as shared care, but while they assist in the provision of treatment, have not been demonstrated to ensure an equivalent quality of care.

This background information is provided to assist an understanding of the particular influences, advantages and disadvantages of the rural context for patients with cancer. A diagnosis of cancer is an event that is likely to bring a unique set of stressors for the individual concerned. The issues of access to specialist treatment in rural township populations,
exacerbated by a reduction in numbers of regional health care centres, combined with the growing complexity and level of technology in health care means that equitable delivery of care is becoming increasingly difficult. This is an issue that needs attention to ensure rural patients who are diagnosed with cancer have equitable access to treatment or at least, equivalent outcomes from a diagnosis of cancer, and support during treatment which is appropriate for their needs as identified through research.
Chapter 3 - Methods

Introduction

Three phases of investigation were applied to answer three interrelated questions in this study. The first question addressed was:

1. Are there differences in the incidence, risk factors and mortality of cancer in rural and urban populations in South Australia? An analysis of cancer registry and government survey data was undertaken to identify this.

The second question was to explore possible reasons for differences identified, hence:

2. What is known about the challenges faced by rural residents who are diagnosed with cancer and does the management of their treatment meet their needs? A focused literature review was undertaken to identify and summarise current knowledge, opinions and issues.

The information and knowledge identified in this review and the gaps that became apparent led to the third question:

3. What is the extent and relative importance of these issues for rural patients undergoing cancer treatment in the metropolitan setting in South Australia? A survey tool was developed and used in interviews with patients to answer this. Interviews with health care professionals were used to further examine these issues with those responsible for care delivery.

The information from the three phases were outlined and then integrated in a discussion of the findings and implications for practice and current policy. This chapter details the methods used in each phase and why they were chosen, including discussion of methodological considerations relevant to this study. The chapter is divided according to the three study phases, depicted schematically in figure 3.1. How the data from all three phases is used to examine the situation of rural residents with cancer accessing treatment in the metropolitan setting is presented in the final section of the chapter.
A focused literature review was conducted to identify and summarise current knowledge, opinions and issues on this topic.

Secondary data analysis

Data from the South Australian Cancer Registry and government surveys were analysed to determine differences in cancer risk behaviour and incidence between rural and metropolitan patients.

Focused literature review

Participant survey and health care professional interviews

96 participants were interviewed using a questionnaire and asked to identify issues of priority to them. Six participant case studies were developed to present this information. Interviews with health care professionals were used to further examine these issues with those responsible for care delivery.

Figure 3.1: Schematic presentation of study phases
Phase 1 Method: Secondary data analysis

Introduction

It was shown in chapter one that there are what are termed ‘excess’ deaths (i.e. above what is expected) in rural and remote areas in Australia due to the diagnosis of some cancers. To investigate this on a state level, data was analysed from reports of the Department of Human Services and the Cancer Registry in South Australia to determine differences in risk factors for the development of cancer as well as the incidence of cancer types and mortality outcomes.

Design

Analysis of pre-collected and analysed data is known as a secondary analysis and is useful in determining the potential value of research in a given area in a time and cost effective manner (Williamson, Karp and Dalphin, 1977). Use of secondary data means that caution should be taken to ensure that enough is known about the data collection methods and limitations to ensure the data are sufficiently reliable and valid for the purposes of the secondary analysis. The data analysed were derived from surveys conducted under the auspices of the Centre for Population Studies in Epidemiology of the Department of Human Services of the South Australian Government.

Procedures

Data sources and analysis

Data were obtained from two main sources, a South Australian cancer registry report (South Australian Cancer Registry, 2000) that included data from 1977 to 1999 and three survey reports from the Centre for Population Studies in Epidemiology (Department of Human Services of the Government of South Australia).

Data that reported on cancer incidence and survival were extracted from the cancer registry report (South Australian Cancer Registry, 2000). As outlined in this report, cancer incidence was defined as the number of cases first notified for a given population during a specified period. Mortality was determined from reports to the registry of cancer deaths in hospitals as well as information from the Registrar of Births, Deaths and Marriages. Incidence and
mortality rates were calculated per 100,000 using the estimated South Australian population by age for 1999. The standardised rates for South Australia were based on the world standard population. Information on survival was informed by reports of death registrations from South Australia and national and interstate organisations. Life table, proportional hazards regression and allied methods were used to show trends in case outcomes. The cancer registry data of cases and deaths are reported by the postcode of usual residence at diagnosis. Place of residence was classified as Adelaide or country using regions corresponding to the Australian Bureau of Statistics Statistical Subdivisions.

Relative risk of case fatality (using 95% confidence limits) were calculated at age at diagnosis and diagnostic period and where appropriate by sex, sub-site and histological type. Relative survivals were estimated by subtracting the numbers expected from the total deaths using the age-sex and calendar-year specific death rates.

The data sets that were used to inform the survey reports were:

- The Social, Environmental and Risk Context Information System (SERCIS). This is a telephone survey system designed to provide health data of high quality on large samples of the population in South Australia. It is a source of information on health, health services and health care outcomes and can be administered to suit the needs of the survey focus. For example, SERCIS has been used to evaluate health care service provision in rural regions of South Australia, using a stratified random sample of telephone numbers for the health care regions (Wilson, Dal Grande and Taylor, 1996).

- The Health Omnibus Survey is a survey shared by several organisations that contribute questions and share the cost of the survey. The goal of this survey is to ‘collect, analyse and interpret data that can be used to plan, implement and monitor health programs and other initiatives’ (Population Research and Outcome Studies, 2003b). Several organisations can participate in this survey and thus share the costs involved. The survey is of 4,000 households and the response rate has been 70% or higher since its inception in 1991.

- The Health Monitor is another phone survey conducted on the South Australian population supplementing the Health Omnibus Survey (Population Research and
Outcome Studies, 2003a). This is conducted on 2000 households three times a year at other times of the year than when the Health Omnibus Survey is conducted. This is also a user-pays survey and generates information for use in health care planning and intervention.

These data were extracted and tabulated using the Statistical Package for Social Sciences (SPSS) version 10.0 to identify differences between rural and non-rural populations in South Australia. When comparing urban with rural rates, differences were considered to be statistically significant if the 95% confidence intervals (or standard errors) for the respective rates did not overlap.

**Conclusion**

Analysis of the data from these sources was used to examine differences between health outcomes for rural and metropolitan residents in South Australia. Information confirming differences in a number of areas was then used in the development of a focused literature review on the support of rural residents treated for cancer in the metropolitan setting.
Phase 2 Method: Focused literature review

Introduction

The literature review was conducted in 2002 to identify and summarise knowledge, opinion and issues in this area. A comprehensive search of the literature was conducted through electronic databases using key search terms. This section provides a brief background of health literature searching, the search methods used to identify research relevant to this study and the selection criteria used for inclusion of articles in this review.

Design

Literature searching in health care research has evolved to become a science and a research method in its own right. Historically, literature reviews were not conducted using standardised techniques, which created a risk of bias that would not be acceptable in primary research (Glass, McGaw and SMith, 1981). The methods used to conduct reviews were also not generally made explicit making assessment of review quality and comprehensiveness difficult (Jackson, 1980). At the same time, there has been a massive increase in the amount of health care information published. This, combined with the growing awareness of the limitations of traditional literature reviews, has led to the development of new techniques to manage research information, such as systematic literature reviews. Systematic reviews are used to both ensure that all appropriate and relevant papers are identified and where possible the findings are analysed as one, providing a more powerful analysis and making it more likely that the findings reach statistical significance (Bandolier: Evidence based thinking about health care, 2004). For these reasons it is increasingly accepted and becoming expected that an explicit and systematic approach should be used when a research review is conducted. The use of such an approach allows the identification, appraisal and synthesis of relevant studies in a systematic and hence defensible and reproducible manner (Mulrow and Cook, 1997). A structured systematic search strategy also maximises the searcher's ability to identify relevant papers and minimises the identification of unrelated documents (Critical Reviews Advisory Group, 1996).

Conventional systematic reviews have focused on evidence of effect although not exclusively. At the time this project was commenced, the methods for reviews of effect were well
developed, but for other forms of evidence this was not the case. The necessity to review broad types of evidence led to the decision to conduct a focused literature review using as structured and systematic approach as possible, but as will be apparent, not using all the methods of an orthodox systematic review. A combined statistical data analysis, or meta-analysis, was not required as this review aimed to provide a comprehensive description and summary of articles researching and addressing issues for rural and remote patients undergoing cancer treatment in a metropolitan area.

**Procedures**

**Search strategy**

The search strategy used for this literature review was developed in conjunction with staff from the Joanna Briggs Institute for Evidence Based Nursing and Midwifery. The search results were then reviewed by a librarian working in health care literature to ensure that appropriate methods of search refinement were used and that the search terms used were complete and appropriate. The search was conducted using the following steps:

1. **Initial search:** this determined the appropriate databases which should be searched and the search terms and fields to be used for each database. A health care librarian’s advice was also sought on which databases should be searched.

2. **Database search:** seven databases in total were searched using terms specific to the database (see appendix 3 for detailed search terms and findings). Databases were searched for literature for the time period available on the database. Databases with the facility of extended searches were searched using an adaptation of that described by the Cochrane Collaboration (Mulrow and Oxman, 1997). In this type of targeted search method the search is begun using a range of terms describing the disease or condition using the Boolean 'or' operator and is then narrowed by combining these terms with an intervention using the operator 'and'. For example, in the searches for this study, terms such as ‘cancer’, ‘neoplasm’ and ‘oncology’ were used as well as terms indicating specific cancer treatments, then these results were combined with terms indicating the research population of interest, such as rural, remote and frontier.

The databases searched were selected on the basis of their relevance to rural and cancer health care research. These were:
**AustHealth**: comprises seven Australian health databases covering medical journals, Indigenous and rural health and information on social, political and economic areas.

**CancerLit**: covers information relating to cancer and cancer treatment, hosted by the National Library of Medicine.

**CINAHL**: a database of nursing and allied health literature.

**The Cochrane Library**: consists of a number of databases into which articles and abstracts are divided according to the type of research. These include the Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effectiveness, Cochrane Controlled Trials Register, and Cochrane Review Methodology Database.

**Current Contents**: indexes over 7,500 research journal articles, covering all disciplines, hosted by the Institute for Scientific Information.

**MEDLINE**: comprises primarily medical research literature and also covers many nursing journals, policy issues, general health care and clinical practice, hosted by the National Library of Medicine.

**PsycINFO**: focuses on articles relating to psychosocial issues in health care, hosted by the American Psychological Association.

3. Contact with experts in the field: contact was made with colleagues who have research experience in this area to identify current research.

During initial searches, the term ‘frontier’ was found to be used in some literature, particularly of North American origin and the search was subsequently widened to include this term.

Altogether, 1949 articles were identified for initial assessment, however approximately half of the articles were identified in more than one database.

**Selection criteria**

When the initial search was conducted, selection of the articles to be retrieved and formally appraised was made based on the apparent relevance of the article as indicated by the title, key words and abstract, or title alone if an abstract was not available. Hard copies of relevant articles were then obtained.
Selection criteria were.

- The population of this review was restricted to adult subjects, as it was felt that many issues relating to the treatment of paediatric oncology patients were likely to be specific to the paediatric population.

- The population was likewise restricted to those diagnosed with a neoplastic disorder, as although there may be many issues in common with those diagnosed with other chronic illnesses, this thesis was focused on cancer related issues.

- Studies and papers describing or assessing issues related to treatment in a metropolitan setting for rural patients diagnosed with cancer were included.

- Studies and papers describing outcomes relating to rural patients with cancer receiving treatment in a metropolitan setting were included.

- Articles from any year of publication were included. The search period covered 1973 to April 2002.

**Exclusion criteria**

Non-English articles were excluded from this search as translation was beyond the capacity of this project. Additionally, articles relating to research in developing countries were not retrieved. While research from a variety of countries across the world may offer important ideas and insights in health care (NHS Centre for Reviews and Dissemination, 1996), research findings from substantially dissimilar areas are less likely to be of use than those from similar settings. This study focused on issues in developed countries.

**Critical appraisal**

At the time of this review, formal critical appraisal tools were not available to deal with the range of literature identified. Selected papers were critically appraised, summarised and are presented as themes. A summary of the review findings is presented in table format and a narrative synthesis of findings is provided.

**Conclusion**

The focused literature review identified a body of work related to rural residents, the need for travel and cancer treatment. The information arising from this review was used to inform the development of a questionnaire to investigate the impact of relocation.
Phase 3 Method: Survey, illustrative biographies and health professional interviews

1. Survey

Introduction
Information from the focused literature review was used in the development of a questionnaire to investigate rural residents’ experience of undergoing treatment in the metropolitan setting. The purpose was to develop an understanding of the issues involved and to determine the importance of issues identified. The survey tool was developed de novo but was informed by the findings of the literature review.

Design
The survey was conducted using convenience sampling in metropolitan settings. This sampling technique was chosen as an effective way of recruiting participants. Convenience sampling reduces the generalisability of study findings, but allows efficient recruitment of participants with the characteristics of interest (Schneider, 2003). Structured interviews were also used in the development of the survey. Structured interviews follow a set format and consistent set of questions, and are used when the topic area is known, but the answers cannot be anticipated (Field and Morse, 1985). This technique helps to ensure that information is gained in the areas of interest, and gives the informant freedom to answer using their own words to provide a description of the phenomenon of interest. The survey development was planned and piloted in order to minimise the influence of factors such as misunderstanding and bias (Bowling, 2003).

Procedures
Development of the questionnaire
The development of the questionnaire involved four main strategies:

1. review of the literature;
2. exploratory interviews with patients;
3. consultation with health care professionals; and

4. pilot testing.

The focused literature review was conducted to determine the main issues for rural patients having cancer treatment. The review revealed a number of potential issues, including the financial impact of treatment, having access to information about the cancer and treatment, having access to services, the psychosocial impact of treatment, the physical impact of treatment and issues of accommodation.

A series of structured, exploratory interviews was also conducted with eight rural residents undergoing cancer treatment to determine the concerns of the population to be studied. These interviews were conducted beginning with the open ended question ‘what is it like staying in Adelaide for cancer treatment?’, and following with questions intended to explore the answer given, such as ‘why is that so?’. The interviews then followed a question format to seek information in the areas identified in the literature review.

The interviews were all conducted at the first two intended recruitment settings, Royal Adelaide Hospital and Greenhill Lodge (a description of the research setting is given later in this chapter). All interviews were audio-taped and notes were taken by the investigator during the interview. All taped interviews were reviewed by the investigator within 48 hours to transcribe the major issues identified. The interviews were stopped when eight had been completed as no new major issues were arising.

The issues arising from these interviews were incorporated into a draft survey form that included the key areas of:

1. the modes of travel to and accommodation in Adelaide;

2. communication with health care professionals;

3. access to information on cancer and on support services;

4. the impact of undergoing cancer treatment in Adelaide; and

5. the priority of the issues identified.

The draft survey was reviewed by cancer care experts, including an expert cancer nurse researcher, a rural liaison nurse in a teaching hospital, a patient support officer from the Leukaemia Foundation, a breast cancer project officer, and an expert cancer nurse clinician in
a teaching hospital. Feedback was also sought from a rural consumer representative in relation to the appropriateness of questions, wording and structure of the questionnaire. Minor changes were made in wording and the sequencing of questions was changed. The section dealing with financial aspects of treatment and employment was moved to the end of the questionnaire, as it was felt that asking these questions at the beginning of the interview before a rapport had been established could have created embarrassment for the participant and would be better placed towards the end of the interview.

**Piloting process**

The draft survey form was piloted in three settings, including Royal Adelaide Hospital Cancer Centre, Greenhill Lodge and with three patients in their home in rural areas. Minor changes were made following the pilot of the survey to simplify questions and their wording and to remove jargon. For example, one question in the pilot survey was ‘what is your diagnosis?’ which some participants had difficulty in understanding. This was reworded to ‘what type of cancer do you have?’. Piloting continued until there was confidence that no further changes were needed, with a total of 23 pilot participants interviewed.

The final draft of the survey form was then reviewed by a rural cancer consumer representative, an expert in cancer nursing, a rural liaison nurse, a director of nursing in a teaching hospital and a professor of rural health. No further changes were made to the final version, which is included as appendix 4. A summary of the steps in the development is presented below in table 3.1.

Table 3.1: Summary of survey tool development steps

<table>
<thead>
<tr>
<th>Steps in survey development</th>
<th>Rationale</th>
<th>Rigour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review of the literature</td>
<td>To identify key issues.</td>
<td>Used to inform the survey tool development.</td>
</tr>
<tr>
<td>Exploratory interviews with patients</td>
<td>To determine the concerns of the population to be studied.</td>
<td>Training and advice gained from expert interviewer. Interviews were continued until there were no new major issues.</td>
</tr>
<tr>
<td>Review of a draft survey tool</td>
<td>To ensure the survey tool covered major issues from clinical perspective, to check wording and language.</td>
<td>Changes were made to the sequencing and wording of questions.</td>
</tr>
<tr>
<td>Pilot testing</td>
<td>To ensure appropriate wording, language, time taken to complete. Tested with patients undergoing treatment in Adelaide and with patients in their home setting.</td>
<td>Changes were made to the wording and language.</td>
</tr>
</tbody>
</table>
Types of questions and measurement scales used
Open and closed ended questions as well as a modified Likert rating scale was used in the questionnaire. The original Likert scale was developed to assess the strength of agreement or disagreement to a statement, for example ‘chemotherapy makes me feel sick’ with a response selection such as ‘strongly agree, agree, undecided or neutral, disagree, strongly disagree’ (Bowling, 2003). This approach enables the strength of responses to be compared across different concepts and thus gives an indication of the issues participants feel most strongly about.

Modified scales of semantic differentials were used in this study, as they allow greater flexibility in question construction as participants are asked to rate the concept in question along a scale between two extremes, rather than the less direct ‘agree’, ‘disagree’ scale (Murray, 1999). An example of a semantic differential scale from this study is ‘how satisfied are you with the convenience of transport to and from Adelaide?’ with the response scale ranging from very satisfied to very dissatisfied. The use of this modified scale allowed the construction of direct questions relating to specific issues, thus providing answers likely to give information most relevant to the survey. A limitation of this approach is in the difficulty comparing strength of responses to questions when different terms are used to describe concepts, rather than a consistent rating of strength of response. This limitation was minimised by consistently using a numerical rating between one and five in combination with the descriptive terms.

Open-ended questions were also used throughout the questionnaire to provide participants with the opportunity to comment on the scaled questions, for example ‘has the need to travel delayed your treatment in any way? Please comment.’ They were also used to request further description of an answer, such as ‘how much of a physical effect do you feel from travelling to treatment? Please list the effects you feel and/or give examples’.

Questionnaire content
The questionnaire was divided into nine major sections, in order to clearly structure the content in a logical sequence and to delineate the topics. The first four sections addressed issues identified as being important from the literature review and were not specifically related to the participant’s diagnosis of cancer. These questions were asked early in the survey.
interview as they were less likely to be emotionally upsetting to answer and hence were used to establish a sense of rapport and trust with the participants.

1. Firstly, demographic information was requested, such as age, country of birth, level of schooling and qualifications received and marital status.

2. The second section included questions on the participant’s place of residence and distance from the nearest town if the participant was a farm dweller, and distance from Adelaide. All distances were checked against those published by the Royal Australian Automobile Association (Royal Automobile Association of South Australia Incorporated, 2001).

3. Travel and parking were the subjects of the next section. Questions were asked in relation to how the participant most commonly travelled to the treatment centre, the length of travelling time taken, how convenient this was, how the participant travelled once in the metropolitan area (i.e. from the place of accommodation to treatment) and the convenience of parking. These were asked in order to identify travel related issues and their importance.

4. The fourth section focused on the participant’s place of accommodation in Adelaide and their satisfaction with that accommodation.

5. Section five included questions on the cancer and treatment that was being used. Specific information was asked for in relation to the method of treatment, length of time treatment was predicted to last, the treating hospital/s, and other details such as whether they had received any treatment in their local area. Participants were also asked about the health care professionals they had seen during treatment and satisfaction with treatment.

6. Section six addressed the areas of information and communication, asking where the participant had received information about their treatment and the support services available while they were undergoing treatment. Satisfaction levels with communication and any differences between the level of metropolitan and rural information provision were assessed.

7. In section seven, the impact of having treatment in the metropolitan setting on the participants and their family and friends was investigated. This was intended to determine both the extent and nature of practical arrangements needed as well as psychosocial and support arrangements, for example the participant arranging to have a companion present during treatment. To further explore the support network available to and used by the
participants they were asked about their degree of participation in community organisations and to describe any support they had received during treatment.

8. The eighth section addressed issues of employment and financial costs. It was considered important to determine the level of financial support available to and used by the participants, whether from employers, government schemes or other sources. Those who were on a variable income (i.e. self employed, employed on a casual basis, farmers) were asked to estimate an annual income and this was used to calculate the weekly income.

9. The last section was used to determine how the participants ranked the issues covered in the survey according to degree of importance. They were asked to identify the top three issues in order of priority and state their overall level of satisfaction with the issue concerned. For example, if the issue identified was having a support person, they were asked to state their level of satisfaction with their experience of this issue. To further establish the key priorities from the survey, participants were asked what advice they would give someone else travelling to the metropolitan area for treatment. The aim was to demonstrate where the participants felt there were important gaps in care or support. This section also provided opportunity to comment on any other issues that had not been covered in the survey.

The survey finished with an invitation to indicate interest in receiving a summary of the survey results when these were available. Ninety three of the 96 participants supplied their name and address to receive this feedback.

Recruitment settings
Recruitment took place between March and September in 2002 in four settings. Initially only two recruitment sites were accessed, Royal Adelaide Hospital and Greenhill Lodge. The recruitment process was extended to four settings after three months due to low numbers as described later in this chapter.

1. Royal Adelaide Hospital (RAH) is a public quaternary teaching hospital with some 1100 inpatient beds on three campus areas providing a range of speciality and general health care. RAH provides tertiary cancer care to South Australian and adjoining interstate residents on an inpatient and outpatient treatment basis. Services provided include radiotherapy, bone marrow transplantation, chemotherapy and surgery (Royal Adelaide Hospital Cancer Centre, 2002a).
Rural patient attendance in the outpatient department of this centre averaged 315 per week during 1999 - 2000 (Royal Adelaide Hospital, 2001).

2. Greenhill Lodge is a motel owned and operated by Cancer Council South Australia providing subsidised and commercial accommodation to rural and remote residents with cancer (The Cancer Council South Australia, 2003). The motel has 55 units and the usual length of residence ranges from days to seven weeks with an average occupation rate of over 90% (The Cancer Council South Australia, 2002). Residents of the units may be receiving treatment at any of the metropolitan health care facilities.

3. The Queen Elizabeth Hospital (TQEH) is a public tertiary teaching hospital that provides inpatient and outpatient treatment, including chemotherapy, surgery and stem cell transplantation as well as a metropolitan home care service (The Queen Elizabeth Hospital, 2000). For radiotherapy treatment, patients are referred to other specialist centres.

4. Calvary Hospital is a private hospital providing a range of diagnostic, treatment and support cancer services (Calvary Health Care Adelaide, 2001). For transplantation and radiotherapy treatment, patients are referred to other specialist centres.

Recruitment
The exact recruitment methods used at the sites differed slightly according to the needs and suitability of the setting as determined in consultation with staff in the area. Information sheets were made available to all potential participants before consent was obtained.

Posters were distributed in the RAH in inpatient wards, a chemotherapy outpatient treatment centre and the radiotherapy treatment centre. Nursing staff provided information sheets (see appendix 5) to interested potential participants and contacted the researcher as needed.

At Greenhill Lodge the poster was placed at the reception area and supplied to incoming residents. Motel staff provided information sheets to interested potential participants and contacted the researcher as needed.

At TQEH and Calvary hospital the staff identified potential participants and provided them with information, then contacted the researcher as needed. The posters and information sheets also provided the researcher contact information, so potential participants could contact the researcher directly for more information or to arrange an interview time.
When recruitment began, the rate at which participants were able to be recruited was significantly slower than seen in the pilot phase of the study. This was primarily due to a change in senior personnel at Greenhill Lodge and the subsequent need to renegotiate the recruitment method. Initially, all eligible participants for the pilot phase were approached by a staff member and given information about the study. When the pilot phase had ended and the study started, the recruitment method was negotiated with the new staff. Placement of a pamphlet in each patient’s room yielded fewer participants than previously. After a period of three months, it was decided to extend recruitment to two further sites in order to access greater numbers of potential participants, these being The Queen Elizabeth Hospital and Calvary Hospital.

Sample
In total 96 participants were interviewed. The total number of patients at recruitment sites eligible to participate in the study during the survey period was not able to be determined, as the total number of rural patients and cancer treatments were not routinely reported by the treatment centres.

Participants were interviewed over a period of six months, between March and September in 2002. Initially, the eligibility criteria to indicate rurality was residence at least 100km distance from Adelaide. However, during the piloting and literature phase of the survey, it became evident that some people living closer than 100km to Adelaide considered themselves to be ‘rural’ and that there was no defensible ‘standard’ distance used to delineate ‘rural’ residents. However as rurality implies some distance from the metropolitan setting and hence services, a distance of 75km was used for selection of participants.

Eligibility criteria
Eligibility criteria used were that the participant was:

- adult (over 18 years of age);
- with a diagnosis of cancer;
- requiring temporary residence in Adelaide for radiotherapy or cytotoxic chemotherapy treatment;
- able to converse in and read English; and
- living at least 75km from Adelaide.
Investigator interview training
How competently and appropriately the research interviews were conducted throughout all phases of research was critical as information gained from the interviews informed subsequent directions of the study and the development of the questionnaire used in the survey. Bowling suggests that interview technique training is important to manage the process of navigating the interview in a consistent and accurate manner and obtain the information needed, while being able to develop and maintain a rapport with the participant (Bowling, 2003).

The investigator in this study was an experienced oncology nurse with clinical interview experience but without specific research interview training. To ensure that the interviewing technique was appropriate and conducted with a level of skill sufficient for the purposes of this study, advice and training was sought from an anthropologist who lectures in interview technique. Tapes of two pilot interviews were listened to and critiqued by the anthropologist with participant permission and constructive feedback on interview techniques was given.

Interview technique
How a relationship is established is dependent on the participant and researcher concerned. For some, disclosure on the part of the researcher may build a sense of trust, for others, information provided through the consent process may provide sufficient information. For the purposes of this research, the investigator used a flexible approach to the interview that was responsive to the needs of the participants. The introduction by the investigator was simply that the investigator was a researcher in this area. Some participants assumed a cancer background on the part of the researcher due to the nature of the study and raised questions regarding their treatment and cancer. Participants who asked for more information about the investigator’s background were told that she had experience as an oncology nurse. This at times led to participants asking for clinical or treatment advice. They were referred to the appropriate service or health care professional in these instances. Other questions were also raised, such as regarding the natural history of cancer and effectiveness of treatment, for example,

‘maybe if we have got it in the early stages, but then, seeing you’re a nurse, how long does it take, this chronic myeloid leukaemia must have been building up, over years wouldn’t it?’ {participant 36, male, 64 years}. 

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Such questions about cancer and cancer treatment of a general nature were answered if they were within the researcher’s domain of practice as an oncology nurse, otherwise the participant was referred to the treating team of health care professionals.

**Resolving differences between interviewer and participant needs**

The needs of the participants were felt to be a particularly important consideration in the conduct of this study. People undergoing cancer treatment in a setting away from their home environment are in a particularly vulnerable position and to question them and ask them to talk about their treatment experience has the potential to cause distress. It was anticipated in this study that the risks associated with asking participants to discuss potential distressing issues were mitigated and counterbalanced by the potential benefits of being an informant and sharing experiences with the investigator. Referral to psychosocial support services was made available but no participant made use of this.

It is also important to acknowledge the potential tensions between the investigator’s and the participant’s needs. It was predicted that issues related to the researcher’s area of interest such as accommodation difficulties were likely to be less important to the participant than, for example, an upcoming disease staging assessment to determine the effectiveness of treatment. This had the potential to create tension between the researcher’s need to gather data and the participant’s need to voice their concerns and fears about their disease and prognosis. Again, a flexible approach was used, and participants raising such issues were listened to actively and encouraged to voice their concerns, however detailed information on the treatment stage and intent was not actively sought.

Another issue was the difficulty interviewing participants who were currently undergoing treatment and potentially feeling unwell. None of the participants ended an interview prematurely for this reason. What proved more difficult was managing to schedule the interview between multiple appointments during a finite period in Adelaide. One participant terminated the interview approximately half way through to attend a clinical appointment, but completed the interview within a week.

**The interview settings**

The interviews were conducted in a place of the participant’s choosing. At times, participants were receiving treatment for a short period only and chose to be interviewed in the treatment area, as they wished to be involved in the research, but did not wish to spend longer in the
health care centre and metropolitan area than needed for the treatment, which limited
opportunity for the interview. When this occurred, participants were interviewed in privacy.
The interviews took between 40 and 100 minutes to conduct. Otherwise, the interview was
conducted at a negotiated time and date according to the participants’ preferences and
availability. This included planning the interview for the next trip to Adelaide, or where the
participant was staying during treatment, such as a private home or a motel.

**Ethics procedures**

The research proposal for this study was initially assessed and approved by the internal
Research and Higher Degrees Sub-Committee of the Department of Clinical Nursing (The
University of Adelaide). The proposal was then submitted to and approved by the Research
Ethics Committee of the Royal Adelaide Hospital, The Cancer Council South Australia, the
Ethics Committees at the Calvary Hospital and the North Western Adelaide Health Service
(incorporating TQEH) (see appendix 6) for recruitment at these sites.

**Confidentiality and anonymity**

The ethical considerations included the need for confidentiality or anonymity. All participant
data was entered into the database using coded numbers as identification. Hard copies of the
questionnaires were kept under locked conditions. All participants were provided with an
information sheet about the study including contact details of the researcher and a person from
the University of Adelaide independent from the study.

**Consent**

Guidelines on the ethical conduct of research developed by the National Health and Medical
Research Council identify risks associated with research among vulnerable people or groups,
such as those highly dependent on medical care (National Health and Medical Research
Council, 1999). The guidelines outline principles to guide such research, including ensuring
the participant’s capacity to give informed consent is not impaired by reliance on medical
care, and further ensuring that any research involving people in dependent or unequal
relationships (such as patients and health care professionals) gains voluntary and informed
consent from participants. The participant should also be made aware that refusal will not
adversely affect the quality of care provided.
The use of a clear consent process outlining the rights of participants including their ability to withdraw without compromising their treatment was used to ensure minimum risk to the participants in this study. All potential participants in this study were informed that involvement in the study was voluntary, that refusal would not affect their care in any way and that the researcher had no involvement in their care. They were also informed that they could terminate the interview at any point or refuse to answer any of the questions in the questionnaire without their care being affected. Written informed consent was gained from all participants (see appendix 7). Most of those approached were enthusiastic about the study and expressed willingness to participate.

Approximately 10% of those provided with information by staff at the cancer centres and invited to participate refused. They were not asked why they preferred not to participate, but reasons proffered included that the person was feeling unwell, felt that he or she had insufficient experience or credibility to comment on the area of study, lack of time during the visit to Adelaide or that being treated for cancer was the priority at the time and they preferred not to add to the requirements of time and energy imposed by the treatment. One of those who refused commented that he realised his life span was now limited and he had decided to be selective in how he spent his time. Most of those approached, whether consenting or refusing, commented that they felt the issue of rural residents undergoing cancer treatment was important and warranted attention.

**Survey data analysis**

Completed survey forms were assigned a code number to allow analysis without identification. Data were entered into a database and analysed using descriptive statistics. The analysis was conducted using the Statistical Package for Social Sciences (SPSS) version 10.0. The results are presented using frequency distributions. Possible associations between variables were tested using Chi Square analyses. Significance was taken at the 5% probability (p) value.

**Measurement of place of participant residence remoteness**

The accessibility and remoteness index of Australia (ARIA) was used to determine the participants’ degree of accessibility to health care and services (0 = highly accessible, 12 = very remote) (Commonwealth Department of Health and Aged Care, 2001). Table 3.2 provides a description of the terms used.
Feedback to participants
Participants in this study were asked if they would like a summary of the survey results to be mailed to them, which most did (n=93, 96.9%) (see appendix 8). Six participants contacted the researcher, mainly with thanks for the feedback, but some also took the opportunity to provide an update on their situation.

Conclusion
The survey questionnaire provided a comprehensive overview of the issues important to rural residents undergoing cancer treatment in a metropolitan setting. As information was gathered on a wide range of issues, illustrative biographies were then developed with individual participants to describe key issues in a way that did justice to the human situation of individuals and to complement the summary of data gathered. The biography method is described in the following section.
2. Focused interviews and development of illustrative biographies

Introduction

To complement and extend the information arising from the survey, focused interviews were conducted to examine key themes arising from the survey. Information from the interviews was used to develop illustrative biographies to demonstrate and describe issues from the questionnaire. Description of individual situations or cases is a well-established qualitative research method commonly used to investigate ‘how’ and ‘why’ questions (Yin, 1989). This is a useful technique to investigate issues of interest in ‘real time’ situations, with the purpose of clarifying key characteristics of the phenomenon of interest (McMurray, 1994). Yin argues that case studies are useful in evaluation research to explain causal links, to describe the context of the area of interest and to explore situations of complexity, particularly in relation to interventional research, when the intervention effect is complex (Yin, 1989).

This type of approach may be used in any health care setting, however Keyzer argues it can be particularly useful in rural nursing research due to the applicability of case studies in both qualitative and quantitative research methods, the flexibility of this research strategy, the ability to incorporate data from different sources, the usefulness for both novice and experienced researcher and because they can be used to develop understanding of complexities of health care in the context in which they are studied (Keyzer, 2000). In this study, illustrative biographies were used adapting case study technique to show some individual situations and responses of survey participants.

Design

Follow up interviews were conducted with selected participants and used to discuss key issues in depth. The purpose was to focus attention on individual participant situations to gain an understanding of the importance of issues identified in the broader survey population, to provide rich description of the issues concerned and explanation of participant responses.
Procedures

Participants were selected purposively in order to interview those with particular characteristics or knowledge in the area concerned (Morse, 1991; Bowling, 2003).

Selection criteria
The criteria used for selection of illustrative biography participants were that they or their situation demonstrated themes that emerged from the survey, they were able to articulate their opinions or knowledge and were willing to be reinterviewed.

Interview settings and process
A total of six participants were re-interviewed in depth at least once. The interviews were conducted at the participant’s principle place of residence and in the case of one participant, at the rural hospital where he was undergoing chemotherapy. All interviews took between 40 to 100 minutes to conduct. The interviews were audio-taped, listened to within 24 hours and key comments were transcribed.

Interview technique and structure
Each participant was asked what issues were of greatest importance to them when they were undergoing treatment in Adelaide and were asked to reflect on their experience of undergoing treatment in Adelaide. They were also asked about the areas of concern identified in the study, including having a support person, accommodation in Adelaide and separation from family and friends. The interviews were focused in topic but unstructured in format. Identifying features of the participants were changed and pseudonyms were used in order to maintain confidentiality. The biographies were not intended to be used for comparison between participants but rather to allow a greater breadth and depth of description of the complex issues in this study topic.

Focused interview data use
In depth analysis of the transcripts was not undertaken as the interviews were considered supplementary to the survey data and primarily for use in explicating data from the survey. The survey response data from participants re-interviewed were described in the presentation of the biographies. The information presented in each biography includes a full description of the person and their domestic situation and identification and description of the key issues arising from the survey. The biographies are presented following the survey findings.
Conclusion

The illustrative biographies described the human perspective of the survey and enhanced understanding of the issues identified and summarised in the questionnaire findings. Health care professionals were also interviewed to complete the examination of the situation for rural residents undergoing cancer treatment in the metropolitan setting, as outlined in the following section.
3. Health care professional interviews

Introduction

The care of rural patients with cancer involves contribution from many health care professionals, mainly the disciplines of nursing, medicine and allied health. As the providers of care, the opinions of health care professionals were sought in order to determine their views of the needs of rural residents with cancer and how their management could be improved. In this sense, the health care professionals acted as a complementary source of information for the study on the provision of cancer treatment and care. It was felt the health professionals’ perspective would complement the survey findings and provide contextual information on health care provision for rural residents with cancer. Examination of treatment from the patient’s perspective alone has the potential to reveal information relating to satisfaction of the treatment rather than information on the quality of treatment itself. Indeed, it can be argued that evaluation of care based on patient satisfaction alone negates the importance of health professional knowledge, particularly on the part of nurses as ‘hands on’ care providers (Rankin, 2003).

Design

Health professionals were interviewed to gain their views on the care and support provided to rural patients receiving cancer treatment. It was intended that the interviews would assist in the development of recommendations for policy and practice.

Procedures

Sample

A convenience sample of key informants was interviewed, including a medical oncologist, two clinical nurse consultants from medical oncology and haematology, a social worker specialising in working with patients diagnosed with cancer, a general practitioner working in the rural setting, and a rural liaison nurse based in a metropolitan public hospital. These were selected in their roles as health care professionals currently involved in caring for rural residents diagnosed with cancer.
Interview settings and process
The interviews were conducted at the person’s place of work or by telephone as preferred by the participant and took approximately an hour. The interviews were conducted in a conversational manner, with the purpose of exploring the complexity of the issues identified in the survey (Rice and Ezzy, 1999). All participants were provided with an information sheet and explanation of the study objectives before written consent was obtained (see appendix 5).

The health care professionals were asked to describe their role in caring for rural and remote patients receiving cancer treatment to establish the extent of their involvement and experience with these patients. The interview questions were initially two broad questions ‘What are the priority care needs for this group?’ and ‘How do you think care could be improved for this group?’. They were then asked to identify which issues they thought were important in relation to areas covered in the patient survey, as follows:

- travel and accommodation;
- communication and access to information;
- psychosocial impact;
- physical impact;
- financial costs incurred; and
- access to services.

The interview was concluded with an invitation to comment on any other issue. The interview responses were documented by the researcher. A summary of the interview was then provided to the interviewee to confirm the major points made. No major changes were made but interviewees clarified points made as needed.

Ethics procedures
The ethical considerations included the need for confidentiality and anonymity and procedures were followed as for the survey participants. Hard copies of the interview findings were kept under locked conditions. All participants were provided with an information sheet about the study including contact details of the researcher and a staff member from the
University of Adelaide independent from the study. All health care professionals approached to take part in the study consented.

**Conclusion**

The health care professionals provided information on the context for the study participants. Their expert opinions on issues of importance for people with cancer provided a more complete picture of the needs of rural residents as they support numbers of rural residents. The interviews with health care professionals completed phase 3 of the study. The following final section of this chapter discusses the management of information arising from all three phases of the study.
**Integration of the three phases of study**

As outlined previously, sources of data for the study included databases, literature and participants with each providing complementary perspectives of the key issues in this research, the experiences and management of rural residents with cancer. The integration or making sense of data from different sources into a meaningful whole poses both practical and theoretical challenges. Practical challenges exist in the sense that ‘marrying’ two different types of data, particularly quantitative and qualitative data, is inherently difficult and even contradictory as the processes of data collection and analysis are different (Pearson, 1997).

In this study different methods were not used to reach the one, confirmed conclusion, but rather to form complementary, overlapping pieces of a puzzle. Data from the different phases of the study were used in two ways: to inform the development of the study method, and through the integration of the data into the study findings from other phases. Specifically, the data from phase one, the secondary data analysis, gave an indication that outcomes differed between rural and urban populations in relation to cancer, confirming the need for research to investigate this area. The literature review then conducted explored the issue further and was used to develop the third phase, the participant survey. Finally, interviews with health care professionals were also used to examine recommendations for change. Information from all phases was used to describe the complex situation for people from rural areas with cancer and issues of importance.
Chapter summary

This chapter has detailed the methods used in the three phases of this study. A multi-method approach was used to ensure that a comprehensive view of the issues was achieved. These methods were used to identify key issues and previous research in the literature, to determine key issues for a number of participants with a range of cancer diagnoses, to further investigate key issues from survey participants, and then to consider these issues from the perspective of health care professionals involved in the care of rural patients with cancer. The following chapter presents the results arising from the study.
Chapter 4 - Results

Introduction

The situation for people with cancer is complex and incorporates aspects of prevention, diagnosis, treatment and palliation. Rural residents experience cancer in a different culture and context from urban residents possibly resulting in different outcomes in important areas of incidence and mortality as well as access to treatment and supportive care. The results of the three phases of this study investigating the situation and outcomes for rural residents with cancer are presented sequentially in this chapter.

Initially, data were collected from cancer registry and government reports to determine differences in cancer related outcomes in rural versus urban populations. A focused literature review was then conducted to examine research in the area of rural residents accessing metropolitan cancer treatment. Finally a survey was conducted of rural residents with cancer who were accessing cancer treatment in Adelaide. The survey findings were complemented by selected illustrative biographies and interviews with health care professionals. The chapter is structured in three major sections, according to the order of phases described in the previous chapter:

- Analysis of registry and government survey data.
- Focused literature review.
- Survey of patients, presentation of illustrative biographies and interviews with health care professionals.

A summary of the findings is presented at the end of each study phase, leading to integration and discussion of the findings in the next chapter.
Phase 1 Results: Analysis of cancer registry and population survey data

Introduction

The question addressed in phase 1 was whether there were differences in the incidence, risk factors and mortality of cancer in rural and urban populations in South Australia. Data were extracted from a South Australian cancer registry report and from reports from the Department of Human Services and analysed to determine differences in health outcomes for rural residents.

Cancer registry - incidence

The cancer registry data comprised over 100,000 new cases of invasive cancer, reported using age-standardised annual incidence rates for the period 1977-1996. When these data were compared between urban and rural residents the incidence rate was approximately 4% lower for rural residents (265.2 per 100,000 vs. 274.9 per 100,000) compared with metropolitan cases.

However, significant differences were identified in some specific cancers. Cancers that had incidence higher in urban residents were stomach, colon, liver, lung, bladder, kidney, thyroid and non-Hodgkin’s lymphoma (see table 4.1). Those that were higher in the rural populations were buccal cavity, lip and pharynx cancer. The incidences of the remaining 20 cancers reported in the cancer registry were not significantly different between urban and rural residents.
Table 4.1: Mean annual age standardised cancer incidence per 100,000 population (95% confidence intervals) for South Australia, comparing Adelaide with rest of state, 1977-1996

<table>
<thead>
<tr>
<th>Cancer site</th>
<th>Adelaide (urban)</th>
<th>Rest of state (rural)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Buccal cavity</td>
<td>9.5, 9.1-9.8</td>
<td>16.0, 15.2-16.7 *</td>
</tr>
<tr>
<td>Lip</td>
<td>5.9, 5.6-6.2</td>
<td>12.3, 11.6-13.0 *</td>
</tr>
<tr>
<td>Pharynx</td>
<td>1.8, 1.7-2.0</td>
<td>2.4, 2.0-2.7 *</td>
</tr>
<tr>
<td>Oesophagus</td>
<td>2.9, 2.7-3.1</td>
<td>3.2, 2.8-3.5</td>
</tr>
<tr>
<td>Stomach</td>
<td>8.7, 8.3-9.0 *</td>
<td>7.2, 6.7-7.8</td>
</tr>
<tr>
<td>Small intestine</td>
<td>0.7, 0.6-0.8</td>
<td>0.6, 0.4-0.8</td>
</tr>
<tr>
<td>Colon</td>
<td>24.0, 23.4-24.5 *</td>
<td>22.1, 21.2-23.0</td>
</tr>
<tr>
<td>Rectum</td>
<td>14.6, 14.2-15.1</td>
<td>14.0, 13.2-14.7</td>
</tr>
<tr>
<td>Liver etc</td>
<td>1.4, 1.3-1.5 *</td>
<td>1.1, 0.9-1.3</td>
</tr>
<tr>
<td>Gall bladder etc</td>
<td>2.3, 2.1-2.5</td>
<td>2.4, 2.1-2.7</td>
</tr>
<tr>
<td>Pancreas</td>
<td>5.9, 5.6-6.2</td>
<td>5.6, 5.2-6.1</td>
</tr>
<tr>
<td>Larynx</td>
<td>2.7, 2.5-2.9</td>
<td>2.3, 2.0-2.6</td>
</tr>
<tr>
<td>Lung</td>
<td>31.7, 31.0-32.3 *</td>
<td>27.0, 26.0-28.1</td>
</tr>
<tr>
<td>Pleura</td>
<td>1.3, 1.1-1.4</td>
<td>1.1, 0.9-1.3</td>
</tr>
<tr>
<td>Bone etc</td>
<td>0.8, 0.7-0.9</td>
<td>0.8, 0.6-1.0</td>
</tr>
<tr>
<td>Connective tissue etc</td>
<td>2.8, 2.6-3.0</td>
<td>2.6, 2.3-3.0</td>
</tr>
<tr>
<td>Melanoma</td>
<td>22.3, 21.7-22.9</td>
<td>22.2, 21.2-23.2</td>
</tr>
<tr>
<td>Breast</td>
<td>64.7, 63.4-66.1</td>
<td>63.2, 60.9-65.6</td>
</tr>
<tr>
<td>Cervix</td>
<td>8.7, 8.2-9.2</td>
<td>8.9, 8.0-9.8</td>
</tr>
<tr>
<td>Uterine body</td>
<td>11.4, 10.9-12.0</td>
<td>12.1, 11.2-13.2</td>
</tr>
<tr>
<td>Ovary</td>
<td>9.0, 8.5-9.5</td>
<td>8.1, 7.3-9.0</td>
</tr>
<tr>
<td>Prostate</td>
<td>58.3, 57.1-59.6</td>
<td>57.4, 55.3-59.4</td>
</tr>
<tr>
<td>Testis</td>
<td>4.0, 3.7-4.4</td>
<td>3.9, 3.3-4.6</td>
</tr>
<tr>
<td>Bladder</td>
<td>8.2, 7.9-8.5 *</td>
<td>7.0, 6.5-7.6</td>
</tr>
<tr>
<td>Kidney etc</td>
<td>7.0, 6.6-7.3 *</td>
<td>5.8, 5.3-6.3</td>
</tr>
<tr>
<td>Brain</td>
<td>6.0, 5.7-6.4</td>
<td>5.4, 4.9-5.9</td>
</tr>
<tr>
<td>Thyroid</td>
<td>2.8, 2.6-3.0 *</td>
<td>2.3, 1.9-2.6</td>
</tr>
<tr>
<td>Non Hodgkin's lymphoma</td>
<td>10.6, 10.2-11.0 *</td>
<td>9.6, 9.0-10.2</td>
</tr>
<tr>
<td>Hodgkin's disease</td>
<td>1.8, 1.6-2.0</td>
<td>1.7, 1.4-2.0</td>
</tr>
<tr>
<td>Leukaemias</td>
<td>9.8, 9.5-10.2</td>
<td>9.4, 8.8-10.1</td>
</tr>
<tr>
<td>Other</td>
<td>17.3, 16.9-17.8</td>
<td>16.8, 16.0-17.6</td>
</tr>
</tbody>
</table>

* indicates statistically significant difference as 95% confidence intervals do not overlap.

Cancers with a significantly different incidence are shown in figure 4.1.
Figure 4.1: Mean annual age standardised cancer incidence per 100,000 population (95% confidence intervals) for South Australia, comparing Adelaide with rest of state, 1977-1996, showing cancer types with statistically significant differences.

**Cancer registry - survival**

Analysis of data from the cancer registry showed the five-year survival rates for the period 1977-1993 were 52% for both urban and rural residents, however there were statistically significant survival differences in 10 types of cancer (following age and sex adjustment) with survival higher for Adelaide residents in all of these (see table 4.2). These include breast and colorectal cancer which are among the five most commonly diagnosed cancers in South Australia (South Australian Cancer Registry, 2001).
Table 4.2: Five-year cancer survival rates (+/- standard error) for Adelaide and rest of state residents, South Australia, 1977-1993, showing cancer types with statistically significant differences.

<table>
<thead>
<tr>
<th>Cancer site</th>
<th>Adelaide</th>
<th>Rest of state</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salivary glands</td>
<td>75.0%, +/-4.5</td>
<td>47.9%, +/-8.5</td>
</tr>
<tr>
<td>Stomach</td>
<td>22.3%, +/-1.1</td>
<td>18.7%, +/-2.0</td>
</tr>
<tr>
<td>Colon</td>
<td>54.0%, +/-0.9</td>
<td>49.3%, +/-1.6</td>
</tr>
<tr>
<td>Rectum</td>
<td>55.5%, +/-1.2</td>
<td>50.4%, +/-2.0</td>
</tr>
<tr>
<td>Bone etc</td>
<td>61.1%, +/-4.5</td>
<td>44.8%, +/-8.0</td>
</tr>
<tr>
<td>Female breast</td>
<td>76.7%, +/-0.7</td>
<td>73.3%, +/-1.3</td>
</tr>
<tr>
<td>Bladder</td>
<td>63.7%, +/-2.0</td>
<td>55.7%, +/-3.5</td>
</tr>
<tr>
<td>Kidney etc</td>
<td>48.7%, +/-1.7</td>
<td>44.9%, +/-3.0</td>
</tr>
<tr>
<td>Multiple myeloma</td>
<td>34.0%, +/-2.1</td>
<td>25.6%, +/-3.7</td>
</tr>
<tr>
<td>Chronic lymphatic leukaemia</td>
<td>79.5%, +/-2.5</td>
<td>75.6%, +/-4.2</td>
</tr>
</tbody>
</table>

Data from 1977 to 1996 were used to compare four rural regions of the state. When all cancers were analysed (following age and sex adjustment) the relative risk of case fatality was significantly higher for two rural sub-regions compared with Adelaide north (the urban reference region). The relative risk was 1.10 (95%CI 1.04-1.17) for the Lower South East and for the region of Whyalla, Port Pirie and Flinders Ranges the relative risk was 1.11 (1.07-1.16). In addition, there were 11 cancers in which the relative risk of case fatality varied significantly when rural and urban sub-regions were compared. In stomach, colon, bladder and multiple myeloma the relative risk was higher in all four rural sub-regions than in all urban sub-regions, although the smaller numbers involved mean that these differences may not be statistically significant. In breast, prostate, lung and rectal cancer the risk was higher in three of the four rural sub-regions than in all urban sub-regions.

**Cancer registry - early detection**

The proportion of melanomas diagnosed in situ in rural areas of South Australia (31.2%) was higher than in Adelaide (27.8%, p<0.001), and the proportion of invasive melanomas classified as Breslow A (thickness <0.75mm, indicating an earlier stage) was lower in rural areas (50.9%) than in Adelaide (54.6%, p=0.006).

No significant differences were identified in the proportion of breast cancers diagnosed in situ in rural and metropolitan areas but the stage at diagnosis was different. The proportion of invasive cases diagnosed under 20mm in size was 26.5% in 1980-1986 in rural areas and 28.1% in Adelaide (p=0.57). This proportion increased to 50.2% in 1997-98 for the rural areas.
and 54.5% in Adelaide (p=0.17), suggesting higher rates of early detection in urban areas over time.

Population survey data analysis

This analysis investigated differences in cancer risk factors in relation to sun protection behaviours, smoking status, rate of alcohol intake and mammography and cervical screening. As shown in table 4.3 the incidence of risk factors were similar overall except for an apparently higher rate of participation in Pap smear screening in rural areas, greater protection against sun damage and a higher rate of smoking.

Table 4.3: Selected results from various Health Monitor, SERCIS, and Health Omnibus surveys conducted between 1997 and 2000 in South Australia

<table>
<thead>
<tr>
<th>Question</th>
<th>Variable</th>
<th>Adelaide no. (%)</th>
<th>Rest of State no. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you ever had cancer?</td>
<td>Yes</td>
<td>82 (5.6)</td>
<td>23 (4.4)</td>
</tr>
<tr>
<td>Derived smoking status</td>
<td>Current smoker</td>
<td>298 (20.1)</td>
<td>128 (24.7)</td>
</tr>
<tr>
<td>Derived alcohol risk</td>
<td>No risk</td>
<td>1361 (91.8)</td>
<td>466 (89.8)</td>
</tr>
<tr>
<td>If in the midday sun for more than 1 hour how often do you wear a hat?</td>
<td>Never</td>
<td>538 (36.2)</td>
<td>171 (32.8)</td>
</tr>
<tr>
<td>Have you ever had a Pap smear?</td>
<td>No</td>
<td>168 (16.4)</td>
<td>50 (11.8)</td>
</tr>
<tr>
<td>Have you ever had a mammogram?</td>
<td>No</td>
<td>609 (61.6)</td>
<td>258 (61.5)</td>
</tr>
</tbody>
</table>

Summary

The analysis of registry data showed significant differences in the incidence of specific cancers with an overall 4% lower incidence for rural residents compared with metropolitan residents. Survival differences were shown, with a significant survival advantage demonstrated for urban residents in 10 types of cancer. Two of the cancers where rurality was associated with lower five-year survival rates were breast and colorectal cancer which are among the five most commonly diagnosed cancers in the State.

The population survey data showed differences in the prevalence of some risk factors that appeared to favour the rural population, with rural residents indicating a higher participation in Pap smear screening and greater use of precautions against sun damage. The rate of smoking was higher in the rural population.
It is evident there are some discrepancies between rural and urban populations in terms of risk factors and survival outcomes. These findings indicate that there are differences between rural and urban populations that may adversely affect rural residents. A literature review was then conducted to assess research findings in relation to cancer treatment in metropolitan areas for rural residents and is presented in the following section.
Phase 2 Results: Focused literature review

Introduction

Having identified that there were survival disadvantages seen in South Australian rural residents for a range of cancer diagnoses as well as differences in risk factors, a focused literature review was conducted to investigate the situation for rural residents diagnosed with cancer. Specifically, the literature was reviewed to identify articles relevant to rural residents being treated in metropolitan areas. This section summarises and critiques the findings from the review and presents them in order of: a brief description of how the studies were conducted including definitions of rurality; the outcomes or phenomena of interest; and a synthesis of findings.

Search results

A total of 1949 articles were identified through the electronic search (see appendix 3). From these, 48 were identified for potential inclusion. The full articles were assessed and 25 were identified that included or addressed issues of rural patients with cancer accessing treatment in metropolitan settings. On further assessment, 15 were excluded and 10 studies were included in the review. A table summarising the articles included in the review is in Appendix 9.

Study methods and definitions of rurality

Articles were identified from Australia (six articles), the United Kingdom (two articles) and the United States of America (two articles). There were a mix of methods and methodologies used in the studies, including exploratory studies using qualitative data analysis (four studies), mixed methods with qualitative and quantitative data (four studies) and empirical analysis using quantitative data (two studies). The qualitative studies involved relatively small numbers of participants with cancer (10-22), quantitative studies involved 80-204 and mixed method 28-197. The numbers of carers involved varied but was usually the same or lower than the number of people with cancer.

A comparative study by Bain and Campbell in Aberdeen used focus groups with 22 patients and 10 spouses to compare urban, rural and remote patients’ priorities and attitudes in rural and urban areas (Bain and Campbell, 2000). Of the 22 patients, 11 were from urban areas, 11
from rural areas and none were living in a remote area. Transcripts from the focus groups were analysed using qualitative methods.

Sullivan et al analysed survey findings from a sub-sample of 290 participants who had provided written comments in response to an open-ended question from a survey of 420 families affected by cancer in rural and remote areas in the USA (Sullivan, Weinert and Fulton, 1993). The respondents were asked to comment on any issues that they felt were not addressed in the study. The responses were analysed using qualitative methods in order to assess their needs and the impact of the illness. At the time of the study, almost half of the participants (number not specified) were undergoing treatment, necessitating an average travel distance of 224km.

An exploratory study by McGrath investigated the financial impact of relocation by analysing transcripts of interviews with 10 patients and 10 carers using interpretive techniques (McGrath, 2000a). All participants were staying in dedicated housing provided free of charge for those affected by a diagnosis of a haematological disorder. The specific methodology underpinning the research was not identified. It may be considered that the use of an interpretive approach to investigate financial issues was unusual as the findings cannot be quantified or be generalised to a wider population, however McGrath justified the use of an interpretive method by citing the lack of previous research in this area and the need for a beginning description of the issue.

Payne et al used a mixed method approach to assess the impact of separation from family and usual social supports as a consequence of receiving treatment in a metropolitan centre (Payne, Jarrett, Jeffs and Brown, 2001). This comparative study involved 42 patients from Guernsey Island who needed to relocate for treatment and 42 Southampton patients who were undergoing treatment in their local area (Payne, Jarrett et al., 2001). A structured interview schedule was used which included both closed and open response format. All 84 participants were receiving either radiotherapy and/or chemotherapy treatment in Southampton. Identification of the Guernsey patients took place via their application for financial reimbursement but it was not made clear whether all patients apply for this assistance, possibly excluding those who were not aware of the reimbursement scheme. All participants from Guernsey stayed in dedicated accommodation, whether this was in a hospital during treatment or in accommodation dedicated to the support of patients. A combination of
structured interviews and standardised surveys was used to gather data to compare the two groups.

McGrath also investigated the situation of those diagnosed with haematological malignancies and their families or carers in relation to their usual need for accommodation away from home while undergoing prolonged treatment (McGrath, 1998). A secondary analysis of registration data from an accommodation centre was conducted to develop a demographic profile of residents.

An exploratory study of women with breast cancer was conducted in Kentucky (USA) in order to evaluate responses to the diagnosis and initial management of breast cancer (Dunaway, Hueston and Clevinger, 1995). It was anticipated that the information from the study could be used to inform physicians and enhance their ability to anticipate patients’ reactions and their relationship with patients. Ten women participated in structured interviews, all having completed treatment between 12 and 24 months previously. The transcripts were analysed using a thematic, content analysis.

McGrath and Seguerra (McGrath and Seguerra, 2000) surveyed 197 patients with a haematological disorder to assess whether those not accessing dedicated accommodation facilities were aware that the facilities and government reimbursement schemes were available. Closed and open ended questions were used and were analysed using descriptive statistics and thematically.

Clavarino et al (Clavarino, Lowe, Carmont and Balanda, 2002) investigated the needs of cancer patients and their families from rural and remote areas in Queensland. Twenty-eight patients undergoing radiotherapy treatment and 19 carers were interviewed. Survey scales measuring elements of supportive care needs, family functioning and anxiety and depression were used. Semi-structured interviews were also conducted and analysed using qualitative methods.

McMichael et al carried out a thematic analysis of interviews with 101 Indigenous women to identify factors associated with detection and subsequent treatment and support of breast cancer (McMichael, Kirk et al., 2000). The study reported on issues of awareness of breast cancer symptoms, breast self-examination and attitudes to breast screening services as well as the areas of diagnosis and treatment.
Definitions of rurality
The definitions and assumptions around rurality varied and were often not explicit, making direct comparison of studies and results difficult. An article by Davis et al presented the results of a needs assessment conducted and for this purpose defined rural as an area of residence outside the metropolitan area in which the treatment centre is located (usually greater than 100km) (Davis, Girgis et al., 1998).

Rurality was defined quite differently in a study from the UK by Bain and Campbell, with a rural area considered to be outside the city boundary but within one hour’s drive from the cancer centre and remote considered to be greater than one hour’s drive from the cancer centre (Bain and Campbell, 2000). The reason for the use of these definitions is not provided.

Rurality as a term or concept was not specifically defined in the remaining eight articles as investigation of rurality as a context or culture was not the purpose of most of these, rather issues of relocation or travel for specialist treatment.

Outcomes and phenomena of interest
The main interest of the studies included in this review was to assess and in some way measure the needs of rural residents affected by cancer or to explore areas of importance as beginning research in the area of rural cancer care. The studies varied in purpose but were mostly conducted to assess the needs of the specified population (five studies) or to explore the impact of travel or relocation (three studies). Furthermore, of the 10 studies included in this review, seven were investigating a specific diagnosis or diagnostic group, including haematological malignancies (three studies), breast cancer (three studies) and colorectal cancer (one study).

Cancer treatment and expectations of care
Few differences in priorities and attitudes were identified between rural and urban patients in Bain and Campbell’s study, with important aspects of care such as speed of referral and issues of communication viewed similarly by both groups (Bain and Campbell, 2000). However, the rural participants displayed lower expectations of care, including a greater acceptance of problems with transport and delays in treatment. The authors hypothesise whether such acceptance of delays could impact on the stage of the disease at presentation and prognosis. It is difficult to generalise the information from this study to the situation for patients in other
settings, particularly in Australia, where those living within a one hour drive from a specialist cancer centre are unlikely to be considered typically rural. Research using local definitions of rurality would be useful, identifying stage at diagnosis and time to treatment to further investigate this area.

An exploratory study by Dunaway described the responses of women diagnosed with breast cancer (Dunaway, Hueston et al., 1995). There was a sense of shock and disbelief experienced in response to the cancer diagnosis, with many resenting that the cancer was not detected earlier. The commencement of treatment was seen as an urgent requirement by some, partly as it was perceived that this would restore some feeling of control. In relation to treatment, the loss of control perceived by the women appeared to be somewhat mitigated by good communication and information on the part of the treatment team.

Some participants received treatment locally while others travelled to a university centre but the number of participants in each group was not specified. Data from the participants who travelled for treatment were not analysed independently, but one difference was reported in the findings. In general, those treated in a local (rural) setting expressed more positive views about their treatment than did those who travelled for treatment in a tertiary setting. The main issue appeared to be the manner of communication, with care providers in the tertiary setting described as being somewhat unapproachable.

This study highlighted the traumatic impact that a diagnosis of cancer can have and identified potential concerns in relation to satisfaction with care provided away from the home region. It is difficult to judge the importance of the findings in relation to the time of diagnosis and early management as all participants had completed their treatment some time previously and were describing issues as remembered some time afterwards. The focus on breast cancer also makes it difficult to determine whether the issues identified are applicable to those with another diagnosis.

**Being rural/Indigenous and diagnosed with cancer**

Sullivan et al’s analysis of survey responses from rural and remote families affected by cancer examined how the patients and families managed the cancer experience overall (Sullivan, Weinert et al., 1993). The results showed that the experience of coping with the cancer and the need to adjust to changes the diagnosis brought were expressed as challenges by 59 (20%) of the participants. Comments were also made by 26 participants (9%), on the need for
information, specifically in relation to coping with emotions, finances, interpersonal relationships, treatment and side effects, the cancer diagnosis and support services.

Only one study was identified that focused on issues of rurality and Indigenous status in relation to cancer diagnosis and treatment. This study covered the broad areas of screening through to treatment, but in relation to the treatment period showed that a lack of understanding of the diagnosis and treatment options by the participants was perceived as a barrier to treatment (McMichael, Kirk et al., 2000). The complex and unfamiliar medical language used and the speed with which treatment was often carried out also contributed to the overwhelming nature of the diagnosis of breast cancer. The treatment experience itself was perceived as alienating and the need for relocation perceived as a barrier as this required the woman to put her needs ahead of those of her family’s. The study did not discriminate between forms of treatment, such as surgery and chemotherapy and it appeared that any relocation period was potentially problematic, as one woman from a remote area commented:

*If a person who has cancer has to go away for treatment, it not only affects the person, but the whole family. There are a lot of factors impacting on that decision to go away to Brisbane for a week of treatment – looking after elderly people in the family, looking after other people in the family with problems.* (p518)

This study provides valuable information on the needs of Indigenous women in relation to treatment for breast cancer. The broad focus of the study provides useful description of general issues, but makes it somewhat difficult to quantify which issues are important and to whom. The barriers to treatment identified appear to be related to a lack of appropriate support to attend for treatment and further research into this area would be valuable.

**Accommodation and living arrangements**

McGrath’s secondary analysis of accommodation data from patients with haematological malignancies showed that of the 184 patients from within Queensland, 53% needed to travel more than 500km to the treatment centre (McGrath, 1998). Most in the sample (n=183, 90%) were accompanied by an escort, usually female and (n=132, 66%) indicated that they were receiving some form of government benefit. The results were used to speculate about the impact of relocating for treatment and the likely needs of the 204 residents concerned. McGrath comments on the dislocation that is likely to be experienced by patients using the accommodation, and the need for families to be separated from each other if not all are able to
stay away from home during treatment. However, it is difficult to determine how this description of accommodation usage can be reliably used to extrapolate information on patients’ needs, beyond their access of accommodation.

**Psychosocial and support needs**

Supportive care needs of cancer patients and their families were investigated in rural and remote areas in Queensland (Clavarino, Lowe et al., 2002). A total of 19 supportive care needs were identified as having a high level of unmet need, with nine of these considered to be in the psychological domain, such as fears about the disease and uncertainty about the future. Family functioning was adversely affected by changes in routine and problems with changes in social roles in the family. Anxiety or depression was experienced by eight patients (29%), however this study excluded those within three months of diagnosis, and psychological needs may have been greater closer to diagnosis. The authors conclude that there is a significant adverse effect on rural patients and carers when cancer is diagnosed and treated. Further work is needed to establish the needs of rural patients closer to diagnosis, in the context of relocation for treatment.

Payne’s comparative study of Southampton and Guernsey patients showed few differences in psychosocial stresses imposed through being away from home, although their perceptions of social support differed (Payne, Jarrett et al., 2001). From the interview findings the Southampton patients were more likely to report problems with intimate relationships (p=0.032) and supportive relationships (p=0.044). Interestingly this finding was not echoed in the survey data, which showed similar levels of social support, so it is difficult to determine the importance of this finding. For the Guernsey patients issues related to being away from home were offset by the benefits of contact with other patients in similar situations. The Guernsey patients also reported greater levels of support and intimacy with family and friends than participants from Southampton, which Payne et al postulated may be due to the nature of the isolated community they come from and a stronger expression of support while they were away from home. It was also noteworthy that the participants from Guernsey appeared to be ‘liberated from day-to-day domestic duties and concerns about travelling arrangements’ (p278) in a way that the Southampton patients didn’t report.

Overall, the comparison of both qualitative and statistical data showed ‘no significant differences in psychological pressures and concerns between the two groups’ (p280). It is
interesting that the psychosocial impact of travel and residence away from home in this study was not identified as being a significant barrier. However, it is difficult to know how generalisable these results are to other rural/urban settings and populations. This study excluded patients choosing not to travel to Southampton for treatment, and may therefore not have identified barriers preventing access to treatment. It is also a relatively unique, isolated community involved in the study, being an island population of approximately 60,000 residents, with a dedicated health care service that is contracted to private practitioners rather than being part of the United Kingdom National Health Service. This may provide a level of care that is more closely tailored to the community’s needs compared with other communities. The apparent advantages related to travel may also have been mitigated were patients not accommodated in purpose provided facilities. However, the study does demonstrate that assumptions should not be made about the hardships imposed by being away from home.

**Information and communication**

Another study by McGrath and Seguerra (2000) investigated whether those who were not accessing subsidised accommodation were aware of these facilities for patients with a haematological disorder as well as government reimbursement schemes. The findings showed that 72% were aware of the reimbursement schemes and 61% knew of the accommodation facilities (McGrath and Seguerra, 2000). Responses to open-ended questions in the survey conducted indicated that financial hardship was experienced for a range of reasons, including the need to support young children, the need to make health care gap payments for those using private health cover and lack of reimbursement for costs. This study demonstrates the importance of financial support schemes and the need to ensure that the target population is aware of these. It would be interesting to compare these findings with patients with a broader range of diagnoses.

**Impact on the financial situation**

Examination of the financial impact of relocation by McGrath identified seven areas of increased costs borne by patients and carers (McGrath, 2000a). These were:

- shopping;
- telephone calls;
- loss of the support of usual community based voluntary organisations;
• additional medical costs;
• accommodation;
• cost of maintaining home during absence, including costs of pet care; and
• incidental related costs, such as unsubsidised travel home for personal reasons.

A positive effect of sample bias was anticipated, as those staying in dedicated housing may be more likely to have special needs associated with their cancer diagnosis catered for than those staying in private accommodation. However, the possibility that those choosing to use free accommodation may have done so due to financial constraints creating the possibility of a sample bias is not addressed. No information on the income of the participants or the costs incurred was included, except to identify that eight of the patients were receiving government benefits and three had private health cover. This research identifies areas of potential financial impact for patients who relocate by investigating their perceptions of financial impact. Further work to quantify the impact in a representative sample would be useful.

Davis reported on an assessment of the needs of 80 women travelling to the city for breast cancer treatment (Davis, Girgis et al., 1998). The distances that participants lived from treatment centres were not reported in detail, but 82.5% needed to stay away from home and 17.5% travelled for treatment daily. All had completed treatment recently at the time of the study, which was conducted using a telephone survey. It was identified that financial concerns were a high priority and that 48 of the women (60%) did not receive the financial assistance they were eligible for. The reasons for this were that they were not aware of its availability (29%) or found the application process too complicated (13%). Additionally, 19% of the women who did receive financial assistance reported difficulty in claiming the money. This study identified problems and barriers in accessing support to undertake cancer treatment, despite the existence of clear needs in this population and schemes to provide this support. It is unclear at what point in time during their treatment the women in this study became aware of the existence of financial support and were able to access support and how much this impacted on the amount of financial support they received. Further research on the financial support for rural residents undergoing treatment is needed to identify whether barriers exist across all diagnostic groups.
Review synthesis

This literature review showed that there was limited research into the needs of rural residents with cancer who need to travel significant distances or relocate for treatment and no research in South Australia. What was available, including that from overseas suggests that there may be significant additional issues for rural residents with cancer to face when undergoing treatment in a metropolitan setting. There appeared to be a set of core issues which needed further investigation, including concerns around the treatment itself and access to treatment, transport and travel arrangements needed, accommodation and living arrangements required when staying away from home, psychosocial supports needed, information and communication in relation to treatment and supports and the impact on the patient and family’s financial situation.

Differences in attitudes towards treatment were seen in the lower expectations of care held by some rural residents and an accompanying tolerance of difficulties with transport and treatment delays. Evidence for psychosocial difficulties associated with separation and isolation while undergoing in the urban setting was mixed. Studies focusing on rural populations identified significant levels of psychosocial support needs due to problems such as loneliness and isolation, yet a comparison study of an island population with an urban group failed to show significant differences in psychosocial needs. The unique nature of the island population means that this finding should not be generalised, but indicates a need for further investigation.

The situation for rural Australians has been investigated mainly in patient groups with a specific diagnosis, such as breast cancer. These showed that supportive information needs, particularly in relation to financial information and support, were often not met. These needs may be exacerbated by the increased financial costs associated with relocation while maintaining the home residence. Rural residents with leukaemia were identified as being high users of accommodation even when living within 125km of the treatment centre and it would be of interest to determine whether this is unique to patients with leukaemia due to the demands of the treatment regimens used. Indigenous people may experience barriers to cancer treatment due to cultural factors, for example difficulty women may experience in putting their own needs ahead of those of their family’s in order to access breast cancer treatment.
Articles excluded from the review

Details of the 15 articles excluded from the focused literature review are included as appendix 10. The two most common reasons for exclusion were that five articles were a discussion rather than primary research (Given, Given et al., 1994; Wilkinson, 1996; Hawkins and Curtiss, 1997; Lehman, Hedges et al., 2002; Rodger, 2002), and four articles focused on issues arising for patients some time after their treatment had ended (McGrath, Patterson, Yates, Treloar, Oldenburg and Loos, 1999a; McGrath, Patterson, Yates, Treloar, Oldenburg and Loos, 1999b; McGrath, 2000b; McGrath, 2001). The reasons for exclusion of the remaining articles were: three articles didn’t have a rural focus and looked at travel generally for patients with cancer (Junor, Macbeth and Barrett, 1992; Guidry, Aday et al., 1997; Payne and Jarrett, 2000); one article provided a description of accommodation profile and use which was accessed by rural patients (McGrath, 1999a); and one paper compared the needs of rural and urban patients with cancer generally (Girgis, Boyes, Sanson Fisher and Burrows, 2000).

Summary

In summary, while some areas have been identified as problematic for rural residents undergoing treatment in a metropolitan setting, such as travel and the effects of separation from family and friends, the situation for rural residents in Australia with a diagnosis of cancer travelling for the common forms of treatment is under-investigated. This is a concern because of the prevalence of cancer in the Australian population, the relatively high percentage of residents living in regional and remote areas, and the potential for significant inequity in access to specialist health care services and support.

Most of the literature reviewed came from relatively densely populated countries, for example the United Kingdom, using definitions of rurality that were not directly comparable with the Australian context. Many articles reviewed also focused on disease specific patient groups, making it difficult to determine generic issues of importance to rural residents. Some research reported on qualitative aspects of larger studies and did not specifically address issues of rurality but included rural residents in the research population.

The main findings of the review are as follows:

- Travelling imposes a barrier and a burden for some rural residents.
• There are psychosocial concerns associated with being away from home (such as isolation) however the degree and importance of these concerns has not been fully established.

• Some rural residents may receive a greater level of support than those from metropolitan areas while undergoing treatment, however this is influenced by the type and location of the community in which they are living.

• There is limited research on information and communication in relation to the specific needs of rural patients.

• Financial costs of treatment are an important issue for rural patients. Reimbursement schemes were criticised as not meeting the needs of rural residents with cancer and require investigation to determine how these can be improved. Patients who are financially vulnerable (for example, with dependent children) are at highest risk of experiencing hardship.

• Purpose built accommodation in metropolitan areas provides an important support for rural residents.

The review showed that rural residents found dealing with cancer to be challenging in a range of areas outside of their direct medical concerns, however the inclusion of patients who had completed treatment some time past in many of the studies made it difficult to determine which needs were of significance to patients when undergoing treatment. There was little research investigating the nature of support provided and its acceptability to patients and families. Although Australian papers were comparatively well represented in the articles reviewed (six of the 10), overall the research in the Australian setting was particularly limited and mostly conducted with disease specific groups. It was evident that a comprehensive description of the factors affecting the care of rural residents undergoing treatment in the metropolitan setting would help to develop understanding of their needs and knowledge of how treatment can be improved.

Findings of the survey of rural residents with cancer and interviews with health care professionals in phase 3 of this study are presented in the following section.
Phase 3 Results: Survey, illustrative biographies and health professional interviews

Introduction

The focused literature review presented in the previous section confirmed a lack of research into the impact of relocating for cancer treatment on rural residents, particularly in diverse rural regions in Australia. The results of the survey that was then undertaken of rural residents having treatment in Adelaide are presented in this section. Illustrative biographies are described to highlight the findings of the survey, followed by the outcomes of interviews with health care professionals.

The results from the survey are presented grouped under major topic headings. The ordering of the presentation of the results is:

- demographic and disease characteristics;
- cancer treatment in Adelaide;
- transport and travel;
- accommodation and living arrangements;
- psychosocial and support issues;
- information and communication;
- impact on the financial and employment situation;
- priority of issues; and
- other issues.

Direct quotes from participants are included to provide description and better understanding of the responses.

Interview settings

Most interviews (n=77, 80.2%) were conducted at Royal Adelaide Hospital, Greenhill Lodge and Calvary Hospital (see table 4.4).
Table 4.4: Place of interview

<table>
<thead>
<tr>
<th>Setting</th>
<th>Number of participants</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Royal Adelaide Hospital</td>
<td>35</td>
<td>36.5</td>
</tr>
<tr>
<td>Greenhill Lodge</td>
<td>32</td>
<td>33.3</td>
</tr>
<tr>
<td>Calvary Hospital</td>
<td>10</td>
<td>10.4</td>
</tr>
<tr>
<td>Private home</td>
<td>6</td>
<td>6.3</td>
</tr>
<tr>
<td>The Queen Elizabeth Hospital</td>
<td>5</td>
<td>5.2</td>
</tr>
<tr>
<td>Motel</td>
<td>3</td>
<td>3.1</td>
</tr>
<tr>
<td>Residential wing (Royal Adelaide Hospital)</td>
<td>2</td>
<td>2.1</td>
</tr>
<tr>
<td>Seaview Lodge</td>
<td>2</td>
<td>2.1</td>
</tr>
<tr>
<td>Leukaemia Foundation Unit</td>
<td>1</td>
<td>1.0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>96</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

**Demographic characteristics of the study population**

Most participants were male (n=61, 63.5%) aged between 50 and 69 years old (n=57, 59.4%) (see table 4.5). When male and female ages were compared the male participants were older by an average of seven years. Of the seven participants who stated they were never married or were single, six were male and one was female.

In this sample, 11 participants (11.5%) finished schooling before or on completion of seven years primary school. There was no association between years of schooling and gender (chi squared =5.1 dof=4, p=0.27). After leaving school, 33 participants (34.4%) achieved trade or certificate qualification and a further 16 (16.7%) received a tertiary qualification.
Table 4.5: Characteristics of the study population (n=96)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years) (61.8, 35-88, SD11.5)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;50</td>
<td>16</td>
<td>16.7</td>
</tr>
<tr>
<td>51-65</td>
<td>43</td>
<td>44.8</td>
</tr>
<tr>
<td>66-80</td>
<td>31</td>
<td>32.3</td>
</tr>
<tr>
<td>&gt;80</td>
<td>6</td>
<td>6.3</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>61</td>
<td>63.5</td>
</tr>
<tr>
<td>Female</td>
<td>35</td>
<td>36.5</td>
</tr>
<tr>
<td><strong>Education – school level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Up to year 7</td>
<td>11</td>
<td>11.5</td>
</tr>
<tr>
<td>Year 8-10</td>
<td>49</td>
<td>51.0</td>
</tr>
<tr>
<td>Year 11-12</td>
<td>36</td>
<td>37.5</td>
</tr>
<tr>
<td><strong>Education – tertiary level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>47</td>
<td>49.0</td>
</tr>
<tr>
<td>Apprenticeship/diploma</td>
<td>35</td>
<td>36.5</td>
</tr>
<tr>
<td>Bachelor degree or higher</td>
<td>14</td>
<td>14.6</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or living with partner</td>
<td>72</td>
<td>75.0</td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>5</td>
<td>5.2</td>
</tr>
<tr>
<td>Widowed</td>
<td>12</td>
<td>12.5</td>
</tr>
<tr>
<td>Never married/single</td>
<td>7</td>
<td>7.3</td>
</tr>
</tbody>
</table>

**Employment and income**

Most participants (n=59, 61.5%) had an income of $500 (gross) or less weekly (see table 4.6). The relatively low incomes seen were largely due to the fact that most were not currently working (n=68, 70.8%). Of those not working, 44 (45.8%) were on the aged pension and 14 (14.6%) received an invalid pension. One participant refused to answer this question as he felt it was too personal. Another eight participants (8.3%) did not answer as they could not estimate their average income.
Table 4.6: Employment, income and health insurance

<table>
<thead>
<tr>
<th>Employment Status n=96</th>
<th>No.</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>28</td>
<td>29.2</td>
</tr>
<tr>
<td>Unemployed</td>
<td>68</td>
<td>70.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment type</th>
<th>No.</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full time</td>
<td>15</td>
<td>15.6</td>
</tr>
<tr>
<td>Part time</td>
<td>6</td>
<td>6.3</td>
</tr>
<tr>
<td>Self employed</td>
<td>7</td>
<td>7.3</td>
</tr>
<tr>
<td>Total</td>
<td>28</td>
<td>29.2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Unemployment type</th>
<th>No.</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aged pension</td>
<td>44</td>
<td>45.8</td>
</tr>
<tr>
<td>Invalid pension</td>
<td>14</td>
<td>14.6</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>7.3</td>
</tr>
<tr>
<td>Unemployed</td>
<td>3</td>
<td>3.1</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>70.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Income n=87</th>
<th>No.</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; $300 per week</td>
<td>22</td>
<td>23.0</td>
</tr>
<tr>
<td>$300 - $500 per week</td>
<td>37</td>
<td>38.5</td>
</tr>
<tr>
<td>$500 - $800 per week</td>
<td>12</td>
<td>12.5</td>
</tr>
<tr>
<td>&gt; $800 per week</td>
<td>16</td>
<td>16.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health insurance n=96</th>
<th>No.</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private cover held</td>
<td>31</td>
<td>32.3</td>
</tr>
</tbody>
</table>

Country of birth

Australia was the country of birth for 78 (81.3%) of the participants with a further 11 (11.5%) born in the United Kingdom. Additionally, there was one participant from each of the following countries: Austria, Canada, Greece, India, Italy, the Philippines and Yugoslavia. All participants born in other countries had lived in Australia for longer than 20 years. Of the 18 participants born in a country other than Australia, 15 were male. No Indigenous participants were recruited during the study period.
Household members
Most participants (n=72, 75.0%) were currently living with a marital or defacto partner (see figure 4.2) and 16.7 % (n= 16) were living alone. The remaining six participants were sharing accommodation with other relatives or in share, rental or hostel accommodation.

Figure 4.2: Members of participant’s households

Place of residence
Most participants were residents of a rural town (n=86, 89.6%). The remaining 10 participants (10.4%) were living on a farm or block of land outside a township. Participants came from all health care regions in South Australia as well as interstate (n=24, 25.0%) (see table 4.7).

The postcodes of participants were used to determine their ARIA remoteness rating. This showed there were 5 participants living in highly accessible areas, 59 in accessible, 16 in moderately accessible, 13 in remote and 3 in very remote areas. The ARIA scores of all participants according to place of residence are included in appendix 11.
Table 4.7: Participant place of residence - health care region

<table>
<thead>
<tr>
<th>Health Care Region</th>
<th>No.</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Australia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eyre</td>
<td>10</td>
<td>10.4</td>
</tr>
<tr>
<td>Hills, Mallee &amp; Southern</td>
<td>6</td>
<td>6.3</td>
</tr>
<tr>
<td>Mid North</td>
<td>7</td>
<td>7.3</td>
</tr>
<tr>
<td>Northern &amp; Far West</td>
<td>11</td>
<td>11.5</td>
</tr>
<tr>
<td>Riverland</td>
<td>9</td>
<td>9.4</td>
</tr>
<tr>
<td>South East</td>
<td>14</td>
<td>14.6</td>
</tr>
<tr>
<td>Wakefield</td>
<td>15</td>
<td>15.6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>72</td>
<td>75</td>
</tr>
<tr>
<td>New South Wales</td>
<td>7</td>
<td>7.3</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>12</td>
<td>12.5</td>
</tr>
<tr>
<td>Victoria</td>
<td>5</td>
<td>5.2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>96</td>
<td>100</td>
</tr>
</tbody>
</table>

**Disease characteristics**

Most participants (n=72, 75.0%) were diagnosed with a solid tumour (see table 4.8). Other types of cancer were adenocarcinoma of unknown primary site (n=3, 3.1%), multiple myeloma (n=3, 3.1%), primary peritoneal omental (n=1, 1.0%), ovarian (n=1, 1.0%), Hodgkin’s disease (n=1, 1.0%), uterine (n=1, 1.0%), bladder (n=1, 1.0%), brain (n=1, 1.0%), liver (n=1, 1.0%), melanoma (n=1, 1.0%) and sarcoma (n=1, 1.0%).

Table 4.8: Type of cancer participants were diagnosed with

<table>
<thead>
<tr>
<th>Cancer type</th>
<th>No.</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colo-rectal</td>
<td>17</td>
<td>17.7</td>
</tr>
<tr>
<td>Prostate</td>
<td>14</td>
<td>14.6</td>
</tr>
<tr>
<td>Non-Hodgkin's lymphoma</td>
<td>11</td>
<td>11.5</td>
</tr>
<tr>
<td>Head and neck</td>
<td>11</td>
<td>11.5</td>
</tr>
<tr>
<td>Breast</td>
<td>10</td>
<td>10.4</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>9</td>
<td>9.4</td>
</tr>
<tr>
<td>Lung</td>
<td>9</td>
<td>9.4</td>
</tr>
<tr>
<td>Other</td>
<td>15</td>
<td>15.6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>96</td>
<td>100</td>
</tr>
</tbody>
</table>
Treatment settings
Royal Adelaide Hospital (RAH) was the treatment site for most participants (n=65, 67.7%), with the remaining 31 treated at private hospitals and other public hospitals (see figure 4.3).

Figure 4.3: Treating hospital in Adelaide
Cancer treatment

In total, 65 participants were receiving chemotherapy, 56 radiotherapy, 24 surgery and five were receiving some other form of treatment such as hormone therapy. The treatment combinations used are presented in table 4.9 below. In this sample, 43 participants (44.8%) were receiving adjuvant (combined) cancer treatment (e.g. radiotherapy and chemotherapy). Thirty patients were receiving chemotherapy as the sole form of treatment and 20 were being treated with radiotherapy alone.

Table 4.9: Combination of treatment types received

(√ indicates participants underwent the treatment)

<table>
<thead>
<tr>
<th>Radiotherapy</th>
<th>Chemotherapy</th>
<th>Surgery</th>
<th>Other treatment</th>
<th>No. participants</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>√</td>
<td>√</td>
<td>√</td>
<td></td>
<td>9</td>
<td>9.4</td>
</tr>
<tr>
<td>√</td>
<td>√</td>
<td></td>
<td>√</td>
<td>2</td>
<td>2.1</td>
</tr>
<tr>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td>17</td>
<td>17.7</td>
</tr>
<tr>
<td>√</td>
<td></td>
<td>√</td>
<td></td>
<td>7</td>
<td>7.3</td>
</tr>
<tr>
<td>√</td>
<td></td>
<td></td>
<td>√</td>
<td>1</td>
<td>1.0</td>
</tr>
<tr>
<td>√</td>
<td></td>
<td></td>
<td></td>
<td>20</td>
<td>20.8</td>
</tr>
<tr>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td>5</td>
<td>5.2</td>
</tr>
<tr>
<td>√</td>
<td></td>
<td></td>
<td>√</td>
<td>2</td>
<td>2.1</td>
</tr>
<tr>
<td>√</td>
<td></td>
<td></td>
<td></td>
<td>30</td>
<td>31.3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>√</td>
<td>3</td>
<td>3.1</td>
</tr>
</tbody>
</table>

Most participants were receiving treatment as outpatients (n=75, 78.1%) and 21 were being treated as inpatients (21.9%).

Length of treatment

There was a large variation in the length of treatment time, from five days for a participant with oesophageal cancer receiving radiotherapy to 900 days for a participant with acute lymphocytic leukaemia (mean 160.0, SD 161.4). Participants were interviewed at differing points in their treatment course, ranging from the first day of treatment to through 620 days treatment, with 35 participants (36.5%) interviewed within 30 days of treatment commencing.
Nine participants (9.5%) did not answer the question ‘approximately how long is your treatment planned to last?’ as they did not know. Ten participants were interviewed after their treatment had finished, however all survey interviews were conducted within three months of the treatment ending.

There were two distinct groups seen in relation to the length of treatment. As can be seen in figure 4.4, the length of treatment peaked at 50-100 days and again at 200-250 days. This corresponds with common patterns of radiotherapy (six weeks) and chemotherapy (six months) protocols.

![Figure 4.4: Treatment length (days)](image)

Std. Dev. = 161.44, Mean = 160, N = 87.00

The box plot following provides a comparative representation of the length of treatment time in days according to the category of diagnosis (see figure 4.5). This shows that participants with leukaemia had a substantially longer length of treatment when compared with all other types of cancer, with a minimum length of 100 days and maximum of 900. Three participants with leukaemia did not know how long their treatment would last and did not answer this question.
Figure 4.5: Length of treatment time according to diagnosis category

- O indicates outlier, * indicates extremes.

The middle line in the boxes represents the median values. The upper and lower sides of the boxes indicate the median values of the upper and lower halves of the data. The lines extending from the boxes show the range of the data values.
Appointments

Despite delays experienced by some participants in making appointments with specialists most were satisfied with the availability of appointments for treatment in Adelaide (n=89, 92.7%) and the time of day the appointments were available (n=84, 87.5%) (see table 4.10). Participants were also asked if they were able to coordinate different appointments while in Adelaide and 81 were able to do this as needed (84.4%). Participants receiving inpatient treatment commented that arrangements were usually made for them to see health care professionals during their stay of admission in hospital.

Table 4.10: Satisfaction with appointments in Adelaide (no.).

<table>
<thead>
<tr>
<th>Appointment availability</th>
<th>Appointment availability</th>
<th>Appointment time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfied</td>
<td>89</td>
<td>84</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Not applicable</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>96</td>
<td>96</td>
</tr>
</tbody>
</table>

Health professionals seen and contact with Adelaide staff

Most participants stated that they were satisfied that they had seen appropriate health professionals in relation to their treatment and that they did not need to see any other health professionals (see table 4.11). Some also felt it was the responsibility of the doctor to determine who they should see, for example when asked whether there were any other health professionals she would like to have seen, one responded:

*Not really, you’re in the hands of the doctors, they know.* {participant 13, female, 59}

Some of the 15 who identified a need to see a health care professional said that this was for a non-cancer problem, for example one would have liked to have had the opportunity to see a podiatrist while in Adelaide {participant 43, female, 59}. 

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Table 4.11: Health professionals seen during treatment and desired referrals

<table>
<thead>
<tr>
<th>Health professional seen</th>
<th>Number of participants</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social worker</td>
<td>48</td>
<td>50.0</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>6</td>
<td>6.3</td>
</tr>
<tr>
<td>Psychologist/counsellor</td>
<td>8</td>
<td>8.3</td>
</tr>
<tr>
<td>Dietician</td>
<td>41</td>
<td>42.7</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>2</td>
<td>2.1</td>
</tr>
<tr>
<td>Other</td>
<td>22</td>
<td>22.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Desired referral to health professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social worker</td>
</tr>
<tr>
<td>Physiotherapist</td>
</tr>
<tr>
<td>Psychologist/counsellor</td>
</tr>
<tr>
<td>Dietician</td>
</tr>
<tr>
<td>Occupational therapist</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

Other allied health personnel seen by participants were a rural liaison nurse (6), chaplain/church visitor (4), chronic pain unit staff (2), palliative care staff (2), district nurse (2), diabetes nurse (1), stomal therapy nurse (1), dentist (1), trials coordinator (1), Returned Services League representative (1), and volunteer support visitor (1).

Role and impact of health insurance

Private health insurance was held by 31 participants (32.3%), but not all of these were receiving treatment on a private basis, with 22 of the 31 (70.9%) being treated privately, eight treated in the public setting (25.8%) and six unsure whether they were being treated privately or not (19.4%). Five participants (5.2%) did not have private cover, but were receiving treatment in a private hospital as this was where they were referred for treatment. These participants were unsure as to whether they were receiving treatment on a private health cover basis or not. They were unsure as to what costs would be charged for their treatment and found this a source of concern.

There was a significant association found between having private health cover and not having an appointment with allied health care professionals. Twenty nine percent (n=9) of participants with private health cover had an appointment with a social worker compared with 60.0% (n=39) of public patients (p=0.005).
Similarly in relation to having an appointment with a dietician, 25.8% (n=8) of participants with private health cover saw a dietician, compared with 50.8% (n=33) of patients treated in the public setting (p=0.021).

**Satisfaction with treatment**

In relation to treatment received in Adelaide, most participants were satisfied or very satisfied (n=93, 96.9%), with only one participant expressing dissatisfaction (1.0%) (see figure 4.6). Some found it difficult to rate their satisfaction with treatment received. Reasons given for this were that they had nothing to compare their experience with, for example:

*Well I suppose satisfied would be the most appropriate, because you’ve nothing to compare it with, you know I’m having this treatment and I don’t know whether you could have better treatment or less better treatment, ‘cos you’ve nothing to compare it with.* {participant 10, male, 71}.

![Figure 4.6: Level of satisfaction with treatment in Adelaide](image)

Additionally, two participants felt unable to answer this question as their sole criterion for satisfaction with treatment was survival and they felt this could not be determined for some time following the completion of treatment.
**Treatment received in rural areas**

Some participants (n=23, 24.0%) were receiving cancer treatment in a rural area as well as in Adelaide (excluding general supportive care, such as antibiotic therapy or analgesia). At least one participant from all health care regions in South Australia was receiving treatment in a rural area (see table 4.12), most commonly chemotherapy (n=16, 69.6%). Additionally, six were treated with surgery, two with hormonal therapy and one received immunoglobulin therapy. Participants had to travel an average of 27km from their home to receive local treatment (range 1-360, std. dev. 75.7).

Table 4.12: Local treatment received per health region.

<table>
<thead>
<tr>
<th>Health Care Region</th>
<th>Rural treatment, no. participants (% of region)</th>
<th>Number in region</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Australia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eyre</td>
<td>1 (10%)</td>
<td>10</td>
</tr>
<tr>
<td>Hills, Mallee &amp; Southern</td>
<td>1 (16.7%)</td>
<td>6</td>
</tr>
<tr>
<td>Mid North</td>
<td>2 (28.6%)</td>
<td>7</td>
</tr>
<tr>
<td>Northern &amp; Far West</td>
<td>4 (36.4%)</td>
<td>11</td>
</tr>
<tr>
<td>Riverland</td>
<td>3 (33.3%)</td>
<td>9</td>
</tr>
<tr>
<td>South East</td>
<td>4 (28.6%)</td>
<td>14</td>
</tr>
<tr>
<td>Wakefield</td>
<td>2 (13.3%)</td>
<td>15</td>
</tr>
<tr>
<td>New South Wales</td>
<td>1 (14.3%)</td>
<td>7</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>3 (25.0%)</td>
<td>12</td>
</tr>
<tr>
<td>Victoria</td>
<td>2 (40.0%)</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>23 (24.0%)</strong></td>
<td><strong>96</strong></td>
</tr>
</tbody>
</table>

**Satisfaction with treatment in rural areas**

Participants who had received treatment locally were overall very satisfied with this treatment (see figure 4.7). The one participant who was very dissatisfied stated that he had been given the incorrect dose of hormone therapy for his prostate cancer in the local hospital {participant 42, male, 61}. 
Most participants (n=67, 69.8%) stated that they would prefer to receive treatment in their local area, however, most commented that this was with the proviso that local treatment should be supported by experienced, expert cancer care staff. Participants acknowledged that the possibility of having such staff available in their local area was limited:

> Well yes and no....yes had it been safe but I think p’raps Royal Adelaide’s better set up than Port Augusta, so it’s a yes and a no there. {participant 63, female, 65}

A compromise situation of shared care appeared to be preferred by most participants and those receiving care in both settings were satisfied with the arrangement, even seeing themselves as privileged, as one commented:

> I’ve been lucky, I’ve been having treatment in between times at Port Broughton. {participant 19, female, 52}.

Some participants commented that they were offered the option of having treatment locally but preferred to continue with the treatment in Adelaide. The primary reason commented on by participants was a lack of confidence in the local medical officer, for example:
(The) local doctor offered to do the chemo for me over there, he reckoned that once they worked out the recipe he could do it, but we figured that I probably had one shot at this, and I opted to come back to the specialist. {participant 32, male, 63}.

There was often an accompanying realism and acceptance of the difficulty in providing specialist care outside the specialist setting. One participant commented:

I think Adelaide's the best place to be for this particular disease (acute lymphocytic leukaemia). {participant 9, male, 58}.

The waiting time to see specialists in rural areas was also cited as an issue, as stated by one

Oh no, I’d rather come down here, you get specialist treatment down here, otherwise if you have to wait for a specialist to come up there you might be waiting quite a while. {participant 89, male, 72}.

This participant also appeared to believe that specialist preference for continuity was a factor:

I think I’d have to come down here, because ah, the specialist that started the treatment off I think he’d really want to..... continue it. {participant 89, male, 72}

Most preferred to return to Adelaide for follow up checks (n=55, 57.3%), with the main reason for this being a preference to be seen by the specialist prescribing treatment, and/or cancer specialist staff.

**Treatment delays**

Some participants experienced treatment delays (n=17, 17.7%). Delay was sometimes experienced around the time of diagnosis, for example one participant waited from October to January to see a radiation oncologist following the diagnosis of lung cancer, when the radiotherapy was the sole modality of treatment used {participant 4, male, 77}. Other delays experienced were: delays obtaining an appointment with the specialist (n=5, 5.2%); treatment or appointment cancellation without communication and the need to either wait in Adelaide or return home until this was rescheduled (n=4, 4.2%); delays in obtaining flights (n=2, 2.1%), delays in seeing the general practitioner (n=2, 2.1%); delays in undergoing diagnostic tests (n=2, 2.1%); delays in initiation of treatment (n=2, 2.1%); the need to undergo a second biopsy in Adelaide (n=1, 1.0%); misdiagnosis (n=1, 1.0%); lack of bed availability in Adelaide (n=1, 1.0%); and problems with chemotherapy delivery to the rural area (n=1, 1.0%).
Some participants experienced more than one type of delay. One participant (1.0%) diagnosed with breast cancer had an appointment made for one month later to start radiotherapy and chemotherapy following surgery, then delayed this for a further month so that she could make arrangements for work and family {participant 59, female, 46}. This was endorsed by the surgeon, however when she attended her appointment with the oncologist to make arrangements for the chemotherapy, he arranged for her to undergo chemotherapy treatment that afternoon to avoid any further delay.

One hospital required patients undergoing chemotherapy treatment to phone and check bed availability the day before their planned admission. Two participants being treated at this hospital who needed to book flights to travel for treatment commented on the difficult process of waiting for blood tests to ensure their treatment could go ahead and then checking bed availability at the treatment centre before booking flights.

In contrast with the above delays experienced, some participants received what they believed to be faster service in the rural setting than they would have in the city. For example, one participant in a remote town was diagnosed with a recurrence of bowel cancer on the day the specialist was visiting (who normally visits every three months) and was able to see him on the same day {participant 49, male, 55}. 
Transport and travel

There was a wide variation in the distance participants had to travel to Adelaide with a mean distance of 624km (75-3048, SD 811.3). Figure 4.8 below shows the spread of participant’s place of residence across Australia, and particularly the distance that is needed to travel by those living in the Northern Territory.

![Map of Rural and Remote Australia](image)

Figure 4.8: Participants’ place of residence

When the interstate participants were excluded, the distances for South Australian participants travelling to Adelaide for treatment was an average of 318km, however this varied according to the health care region they lived in (see table 4.13). Participants from Eyre travelled an average of 655.5km in contrast with those from Hills, Mallee and Southern, who travelled an average of 101.7km.
Table 4.13: Distances from Adelaide for South Australian residents according to health care region

<table>
<thead>
<tr>
<th>Health Care Region</th>
<th>Number</th>
<th>Distance from Adelaide (km)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Minimum</td>
<td>Maximum</td>
</tr>
<tr>
<td>Eyre</td>
<td>10</td>
<td>500</td>
</tr>
<tr>
<td>Northern &amp; Far West</td>
<td>11</td>
<td>290</td>
</tr>
<tr>
<td>South East</td>
<td>14</td>
<td>229</td>
</tr>
<tr>
<td>Riverland</td>
<td>9</td>
<td>147</td>
</tr>
<tr>
<td>Mid North</td>
<td>7</td>
<td>203</td>
</tr>
<tr>
<td>Wakefield</td>
<td>15</td>
<td>75</td>
</tr>
<tr>
<td>Hills, Mallee &amp; Southern</td>
<td>6</td>
<td>78</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>72</strong></td>
<td><strong>75</strong></td>
</tr>
</tbody>
</table>

**Travel methods**

As seen in figure 4.9 most participants used a private car to travel to Adelaide (n=59, 61.5%). The average time taken to travel to Adelaide ranged from one to thirteen hours, with an average of four hours (SD 2.223). Most participants commented that they were using their own car but some made arrangements with friends or relatives to meet and drive the rest of the way in the relative’s car to reduce the burden of driving on the participant and/or partner. Other methods of travel used include the Royal Flying Doctor Service (n=3, 3.1%), taxi (n=2, 2.1%) and train (n=1, 1.0%).
Most participants perceived that their method of transport to Adelaide was convenient or very convenient (see table 4.14). This was despite some participants describing travel that sounded arduous and time consuming, particularly for those living outside a town. One participant, for example, had to drive 12km to the nearest town, then take the bus to Darwin (4 hours), stay overnight, then take the plane to Adelaide (4 1/2 hours), yet called this method of travel to Adelaide ‘convenient’ {participant 37, male, 57}.

Table 4.14: Convenience of method of travel to Adelaide

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>very convenient</td>
<td>49</td>
</tr>
<tr>
<td>convenient</td>
<td>36</td>
</tr>
<tr>
<td>neutral</td>
<td>6</td>
</tr>
<tr>
<td>inconvenient</td>
<td>4</td>
</tr>
<tr>
<td>very inconvenient</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>96</strong></td>
</tr>
</tbody>
</table>
The inability of some to drive in the city restricted their choices of how to get to Adelaide, yet their very ability to access some form of travel was viewed positively, for example, as one commented

My husband can’t drive in the city, so I’m reliant on the bus to get here, ‘cos he’s scared, and you know, it’s good, I can get here {participant 13, female, 59}.

One participant from a remote area commented on the deterioration in regional flight schedules since the collapse of Ansett Airlines in 2001, with less choice and availability of flight times {participant 8, female, 55}. Some participants who would normally travel to Adelaide by air due to the distances involved chose to drive to Adelaide instead so they could bring supplies with them, such as linen, food and clothes.

**Public transport**

Although few participants used public transport, they were also asked how convenient their access to public transport to Adelaide was as a secondary means of transport. The majority responded that this was very convenient or convenient (see table 4.15). This was again despite some describing schedules and services which did not sound convenient, such as needing to travel to the pick up point and travelling times which allowed little flexibility in the time spent in Adelaide, for example:

We only have two buses a day, seven o’clock in the morning and it gets here at 10, then it leaves again at two in the afternoon, so you only have four hours. {participant 18, male, 65}.

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>very convenient</td>
<td>20</td>
<td>20.8</td>
</tr>
<tr>
<td>convenient</td>
<td>31</td>
<td>32.3</td>
</tr>
<tr>
<td>neutral</td>
<td>12</td>
<td>12.5</td>
</tr>
<tr>
<td>inconvenient</td>
<td>13</td>
<td>13.5</td>
</tr>
<tr>
<td>very inconvenient</td>
<td>18</td>
<td>18.8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>94</strong></td>
<td><strong>97.9</strong></td>
</tr>
</tbody>
</table>

There were also perceived drawbacks to using public transport, such as the lack of transport on arrival and during the stay in Adelaide. A lack of knowledge of the public transport available
was demonstrated, with two participants stating that they could not respond to this question as they had never used public transport to travel to Adelaide and were unsure what was available, and others aware that it was available but not of the schedules. There appeared to be a perception by some that public transport was used due to lack of other alternatives, for example:

First and foremost before I even answer, I’ve never ever in my life, had to rely on public transport. {participant 23, male, 67}.

Some participants commented on the physical challenges of negotiating public transport while unwell, for example one with a colostomy commented:

No, it wouldn’t be convenient, because I’ve got a bag on, suffering with diarrhoea. {participant 25, female, 61}.

**Travel within Adelaide**

Participants used a variety of travel methods once they were in Adelaide (see figure 4.10). Transport in a private car was the most common method of travel used (n=41, 42.7%), however this was difficult for those not used to driving in the city. Those who chose not to use private transport, even when they had a car in Adelaide, did this to avoid parking and the need to drive in the unfamiliar environment, as described by one:

You’ve got a lot on your mind, the last thing in the world you want to do, is be a green city driver. {participant 62, male, 53}

Most participants staying at Greenhill Lodge used transport provided by Cancer Council South Australia (at a nominal charge) even when they had driven to Adelaide in their own car, to avoid the need to park. Some travelled by public transport, but were unused to this, which led to some difficulties. For example, one participant described not knowing which bus to take:

They say catch 161, I wouldn’t have a clue if it went to Oodnadatta or Melbourne, it doesn’t mean nothing to me, and we got into all sorts of strife. {participant 23, male, 67}.

Public transport was also used to access entertainment while staying in Adelaide, with one using the tram to go out for dinner and bingo {participant 14, female, 45}.  

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On the whole, participants stated that the method of travel they were using to travel within Adelaide was either very convenient or convenient (see table 4.16). Two participants remained in hospital for the duration of treatment and did not answer this question. There were seven participants (7.3%) staying in motel accommodation who used taxis to travel within Adelaide.

Table 4.16: Convenience of method of travel in Adelaide

<table>
<thead>
<tr>
<th>Convenience</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>very convenient</td>
<td>55</td>
<td>57.3</td>
</tr>
<tr>
<td>convenient</td>
<td>34</td>
<td>35.4</td>
</tr>
<tr>
<td>neutral</td>
<td>1</td>
<td>1.0</td>
</tr>
<tr>
<td>inconvenient</td>
<td>3</td>
<td>3.1</td>
</tr>
<tr>
<td>very inconvenient</td>
<td>1</td>
<td>1.0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>94</strong></td>
<td><strong>97.9</strong></td>
</tr>
</tbody>
</table>

**Number and length of visits to Adelaide**

Some participants (n=13, 13.5%) were unsure how many trips they would need to make to Adelaide for treatment. The main reason for this uncertainty was that the ongoing treatment plan was influenced by response to current treatment which was yet to be determined. There
was a wide variation in the predicted number of visits needed by the other participants and the average number of days per visit (see table 4.17).

Table 4.17: Number and length of visits to Adelaide

<table>
<thead>
<tr>
<th></th>
<th>No. participants</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Std. Dev.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Predicted number of visits</td>
<td>83</td>
<td>1</td>
<td>50</td>
<td>7.1</td>
<td>9.3</td>
</tr>
<tr>
<td>Average days per visit</td>
<td>85</td>
<td>1</td>
<td>365</td>
<td>36.5</td>
<td>59.7</td>
</tr>
</tbody>
</table>

**Effects of travel**

A range of physical effects was experienced by participants as a result of travelling to and from treatment. Some respondents (n=10, 10.4%) did not respond to this question, as they were remaining in Adelaide for the entire treatment period. Of the remaining 86 participants, 63 (73.2%) experienced at least some effect. Fourteen participants (14.6%) felt they experienced a large or extreme physical effect from travelling to and from Adelaide for treatment (see figure 4.11). The effects felt were tiredness, shortness of breath, nausea, pain and general debilitation.

![Figure 4.11: The physical effects of travel perceived by participants](image-url)
A range of responses was received in relation to the issue of parking (see figure 4.12). Those who did not need to park a car did not answer this question (n=37, 38.5%). These non-respondents included those staying with friends and relatives and those staying at Greenhill Lodge, which provides a bus service to selected hospitals. Of the remaining 59 participants answering this question, 32 (54.2%) answered neutral, inconvenient or very inconvenient in relation to the issue of parking. As identified previously, some participants preferred to use public transport from where they were staying rather than their own car because they perceived parking to be problematic. Others found parking to be most difficult on the first visit to Adelaide for example:

_I haven’t tried to park down here, I came past in my car and couldn’t work out where to go so I went to someone’s house and caught a taxi back._ {Participant 80, female, 56}

![Figure 4.12: Convenience of parking in Adelaide (n=59)](image)

However, those who had a parking permit found this to be of great help, with the only difficulty being again, lack of knowledge of this service on the first visit.
Accommodation and living

Motel accommodation was used by 52 (54.2%) of participants while having treatment in Adelaide (see figure 4.13). Only 22 percent (n=21) stayed in a relative’s home. Two participants travelled back and forth to Adelaide on a daily basis and hence did not answer this question. Other places of accommodation include a caravan park, friend’s home and the residential wing of the Royal Adelaide Hospital.

![Figure 4.13: Place of accommodation in Adelaide (n=94)](image)

<table>
<thead>
<tr>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>GHL/SVL</td>
</tr>
<tr>
<td>Relative</td>
</tr>
<tr>
<td>Hospital</td>
</tr>
<tr>
<td>Motel</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Leukaemia Unit</td>
</tr>
</tbody>
</table>

GHL – Greenhill Lodge, SVL – Seaview Lodge

On the whole, participants were satisfied with their accommodation in Adelaide (see figure 4.14), with only one indicating he was dissatisfied. This participant commented that he was staying in a relative’s home for a protracted period (weeks at a time), which became wearing, due to lack of privacy and freedom to carry out daily activities as desired. One of the positive aspects of staying with relatives identified by some participants was that it provided an opportunity to catch up and spend time with family members.
Although most participants had found their accommodation to be satisfactory during their treatment in Adelaide, ensuring that accommodation was available to them was identified as a high source of concern.

*We knew about PATS, but we didn’t know about their assistance when you have long term situations in Adelaide, we knew about the travel side of it, that we could claim for travel, but we didn’t know that you could have long term accommodation.* {participant 35, female, 52}

Some, although indicating overall satisfaction, commented on specific issues of concern in relation to accommodation. For example, the residential wing at Royal Adelaide Hospital has shared facilities including shower, toilet and kitchen areas and one participant was advised that he should have a high intake of dairy products, including ice cream as he had a sore throat following radiotherapy for head and neck cancer. This proved impossible to manage as any dairy products left in the fridge were stolen {participant 72, male, 52}.

Three participants staying at Greenhill Lodge described their discomfort and anger that the non-smoking policy was not enforced, for example:
Somebody needs to do what’s required there and make sure that people don’t smoke anywhere on the premises, a total ban, and that should be signposted and enforced, otherwise it’s an imposition for me to be staying at Greenhill Lodge and have cigarette smoke coming in through the window... I got to shut the whole place up, I can’t even air the place, I can’t even leave the door open ‘cos the guy next door comes out and smokes and all cigarette smoke comes in the room, stinks, the room stinks  {participant 94, male, 51}.

Concerns were also expressed by one participant in relation to hospital accommodation, due to being physically confined in the hospital room. He described his distress:

I was in there for 3 days, and I was just about at the limit of just smashing the windows, I was just, absolutely rocked in the head, and I had to get out, and I just told the doctors look I’ve gotta get out, I’ve just gotta go, and they said you can’t go and I said I’m going, I don’t care, I’ve gotta get out, now they said well, I said well I’ll get somebody else to look after me, palliative care or somebody, I said I don’t care if I’ve gotta pay for it. I said I can’t stay here, in this little room, I said I’m bushed, me windows all locked up there, you can’t even open up the window to have a look outside, I’m not used to it, in this little room, I was absolutely boiling! and you believe me, I was shaking! Anyway, they said we’ll let you go home for a while, bit of time every day, I walked out of that hospital, I came back to the unit here, and I just felt myself go boof like that, just levelled out, went calm as a cucumber, and everything just changed like that, within a few hours. Now that night, I went back to that hospital that night after 5 hours, and that room was a different place, it just opened up. I just had to get out, I just couldn’t stay there no longer, just that little time, to get out, otherwise I’d’ve went crazy, I’d’ve just, nobody, nobody would’ve stopped me, nobody would’ve stopped me, nobody could, I was just that way that no-one was gunna stop me getting out of there.  {participant 37, male, 57}.

Levels of satisfaction were compared between those staying at Greenhill and Seaview Lodge (n=45) and relatives’ residences (n=21). Figure 4.15 below shows that while overall the satisfaction levels are high for both types of accommodation, the percentage is higher for those staying in Greenhill Lodge.
Alteration in usual living arrangements

As another example of the lengths some people went to in order to adjust to the need for ongoing treatment in Adelaide, a patient interviewed during the preliminary stages of the study had moved to Adelaide within the last week. She and her husband had recently retired and moved from where they had lived for 40 years in Adelaide to a seaside town approximately one and a half hours drive away. They had been living there for 20 months when she was diagnosed with cancer, and advised to receive treatment on a current trial protocol, which required attendance at a metropolitan hospital three times a week. Another factor influencing their decision to move was the lack of a close network of friends and family – they explained that they had met many people in the town they had moved to, but were not on a ‘drop in for a cup of tea’ basis with most of them. These were the two key triggers that prompted them to
move back to Adelaide. Although they had only moved the week before, she described it as the best move they had ever made.

Similarly one of the participants had altered many of the normal family arrangements. His seven year old son was being boarded with family friends, a friend was living in their family home to look after the animals and garden and his wife had arranged a transfer to an Adelaide branch of her employing company. All of these changes were perceived as necessary for him to undergo treatment in Adelaide.
Psychosocial and support issues

Psychosocial and support issues were significant for most participants, with separation and time spent away from home proving one of the most difficult parts of treatment. The length of time that participants needed to spend in Adelaide was also a concern, particularly in relation to being away from family members.

Many participants felt there was a moderate to extreme effect of separation from family and friends (n=68, 74.7%) (see figure 4.16). This was despite sixty three percent of participants being accompanied by a spouse or partner while in Adelaide (n=60). Five participants did not answer this question, as they did not feel as though they were separated from family and friends. The effect of separation was often expressed in strong terms, for example:

_Bloody terrible. {participant 2, male, 77}_.

![Figure 4.16: Effect of separation](image-url)
Being away from normal routines was also seen as hard, as described by one participant:

To be quite honest I’m a little bit sick of it. I’ve got no complaints about it, but the fact that you’re away from home, and there’s nothing like home really and that fact that you’re away from home and you haven’t got access to p’raps things you’d like to have, that you sort of p’raps should have brought with you, because you always forget something, and I would say large I think you could put for that, because I mean everything’s nice here, but the fact is that you’re here for 24 hours every day and there’s hardly anything to do and it gets very boring, I’m used to sort of doing things around the place and doing something a bit useful but here, you know, you have radiotherapy, and that’s about 20 minutes of the day and that’s all there is to the day and you’ve got to fill in time. I’ve found it very hard, I’m not much of a television watcher and that sort of thing and you get sick of reading. If I’d been home, and I’d been able to go home every night it would have made it 100 to 90 percent better, but that’s not to be of course, because they don’t do this sort of treatment in the country hospitals. {participant 67, male, 77}

Those with children also felt the impact of being away from them, as one commented:

It affects me big time..... my baby is five, and I'm missing out on time with him.
{participant 6, male, 40}

There was no correlation seen between the length of time of each visit to Adelaide and effect of separation from family and friends (Spearman rank correlation =0.087, p=0.4). However, some commented that separation from family and friends caused a level of concern enough that they would not go through treatment in Adelaide again, for example:

If any doctor in Whyalla says I’ve got to come back down here again, there’s no way I’m coming back down here again, I’ll leave it...... It’s such a long time to be away from your family and friends and everything like that you know, it’s so lonely here, I won’t do it again. {participant 10, male, 71}

When those who were within a month of treatment starting were compared with those who had been receiving treatment for longer, there was no significant difference (Chi-Square 9.2, df4, p=0.057), but a lower percentage of those within a month of starting perceived there was no effect of separation and a corresponding higher percentage indicated an extreme effect (see figure 4.17).
However in contrast to these findings, some viewed the time in Adelaide positively, as a break from the normal routine. One farmer made the comment that being away from home was:

*Bloody terrific. {participant 23, male, 67}*

He explained that this was because he had put all his stock on agistment and felt that he didn’t need to worry about them while he was away.

Being in Adelaide was also viewed as a necessary part of receiving treatment for those from rural areas, for example:

*Yeh, well, it’s not the best really, you know, but um, can’t do much about it, except if they could treat me over there, so um of, course they probably can’t have haematology ward and things like that over in Lincoln, it would be just too expensive, can’t, cough up that much. {participant 36, male, 64}*

Figure 4.17: Effect of separation by length of time through treatment (percent)
Having a companion travelling to treatment and in Adelaide

Seventy seven percent (n=74) of participants stated that having a companion with them while receiving treatment in Adelaide was very or extremely important (see figure 4.18). This was particularly so for some in a long term relationship, for example:

*We’ve been married 53 years and it’s the first time we’ve ever been apart.*

{participant 11, male, 78}

Of the 24 not currently in a spousal relationship, five were accompanied by a family member or friend. There was no significant correlation found between the importance of having a companion during treatment and time point in the treatment period (Spearman rank correlation 0.063, p=0.5). However, comments by participants indicated that the time point the participant had reached in the treatment period was important, with some commenting that it was extremely important to have someone with them when attending Adelaide for the first cycle of treatment, and less important for subsequent cycles, for example:
I tried to get someone to come with me on the first run, but nobody wanted to come down….but now it doesn’t matter, I know the ropes. (participant 72, male, 52).

Those who did not have a spouse or partner also identified having a companion as important, with 12 of the 24 not currently in a spousal relationship identifying having a companion as very or extremely important. As one put it:

It would have been really lovely if I could have had someone here, like a carer or somebody, would have helped a lot. (participant 25, female, 61)

When analysed by how far the participant was through the treatment, a higher percentage of those who were more than 30 days through identified having a companion as very or extremely important (n=50, 82.0%) compared with those who were less than 30 days through treatment (n=24, 68.6%), however this was not statistically significant (Chi Square 4.9, df4, p=0.29 (see figure 4.19).

![Figure 4.19: Importance of companion by length of time through treatment (percentage)](image)

When asked what role a companion would play 71 participants responded that this would be a mixture of emotional and practical roles. The types of support identified are shown in table 4.18.
Table 4.18: Key role of companion

<table>
<thead>
<tr>
<th>Key role</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comfort, company, moral support, team approach.</td>
<td>50</td>
</tr>
<tr>
<td>Physical support and care.</td>
<td>32</td>
</tr>
<tr>
<td>Advice, memory assistance, second pair of ears.</td>
<td>10</td>
</tr>
<tr>
<td>Help with navigation and driving in Adelaide.</td>
<td>18</td>
</tr>
</tbody>
</table>

The importance of having a mix of practical assistance with psychosocial support available was reinforced by some participants’ comments that they believed it should be advised or even required that those undergoing chemotherapy treatment have support, due to safety reasons:

_They don’t specify that, but I …. I think it’s safer for me to get somebody to come with me._ (participant 54, male, 69)

A minority of participants (n=18, 18.8%) said that having treatment in Adelaide had had an impact on their personal relationships or friendships, for example:

_I’ve got a very tight group of friends and they’re probably suffering as much as me._ {participant 61, female, 62}

The impact of leaving employment at short notice was also identified by some as important:

_As a teacher I had to desert six classes._ {participant 5, female, 60}

The impact on the students was seen as significant as well as on colleagues who had to pick up teaching extra classes at short notice.

Some stated that there was a positive impact, from strengthening family bonds and communication:

_It’s had an impact on the fact that people seem to care a lot more._ {participant 96, male, 53}

However most of the 18 respondents found that there was a negative impact due to the pressure and strain imposed by the situation they were in.

**Local organisations and support**

Many participants (n=47, 49.0%) belonged to a local group or club, such as social club, church group, sporting club or elderly citizen’s group. However, only a third of these (n=16, 34.0%) described receiving support from the organisation and of all participants, only 20 (20.8%)
reported receiving support from a local organisation. The main form of support received was reported as being moral or emotional \( (n=10) \), with four accessing some form of community transport, two receiving household help and four receiving information or assistance from a local organisation, including a support group \( (n=1) \), a local branch of Cancer Council South Australia \( (n=1) \), Rotary \( (n=1) \) and domiciliary care \( (n=1) \).

Privacy was identified as an issue for some in their local community. Some commented that they preferred their neighbours not to know that they were sick and went to some lengths to disguise the fact that they were having treatment, with one going to the local community health care centre rather than have a visiting nurse, even though she felt unwell. She commented:

\[ I \text{ sneaked up there rather than them come to me, but not every day, and I thought I’ll go up to them and that way, it’s not so conspicuous, but they know now…… they see a car coming every day and the nurse and they say oh Jill’s sick, I finally told them, the other neighbour after a long time. } \{ \text{participant 13, female, 59} \}. \]

Four participants reported receiving support in the form of access to community care or domiciliary care and only one participant reported participating in a cancer support group.
Information and communication

Participants received information from a number of sources in relation to the cancer and its treatment and the practical aspects of receiving treatment such as arranging transport, financial reimbursement and accommodation. Overall, participants recalled receiving information from a greater number of sources in relation to their cancer and treatment, rather than issues such as finance, travel and accommodation (see figure 4.20). Participants most often received information regarding their cancer and treatment from the specialist in Adelaide (n=91, 94.8%) and/or literature (n=81, 84.4%), but in relation to support, such as finance and accommodation, were more likely to learn about this from a social worker in Adelaide (n=40, 41.7%) or another source, such as staff from government-run transport assistance offices either locally or in Adelaide (n=21, 21.9%). Conversely, fewer participants received information about support services from the specialist in Adelaide (n=17, 17.7%), local general practitioner (n=18, 18.8%), with a similar number receiving information from family and friends (n=19, 19.8%).

Some participants (n=14, 14.6%) had received information about the cancer and treatment from the internet and few (n=2, 2.1%) had received information about accommodation and support services from this source. However few used the internet themselves, the information coming instead from relatives (usually younger) who had searched on their behalf. An equal number (n=14, 14.6%) had gained information from books, but these were all obtained by the participants themselves, from libraries or shops. Few participants used the Cancer Council Helpline, with three (3.1%) using it to obtain information about cancer and treatment, and one (1.0%) using it for service and support information.
Some participants’ lack of knowledge about accommodation options such as Greenhill Lodge led them to make arrangements for accommodation to suit their situation and budget that would not have been needed had they known they could access the Lodge. For example, one participant with leukaemia and her husband brought their caravan to Adelaide as they were concerned about the cost of motel accommodation:

*Even though you get supported by the PATS scheme, if you don’t know it, we didn’t know any of that existed before we came down, we brought our caravan down.* {participant 35, female, 52}

When they were informed about Greenhill Lodge they moved there after taking the caravan home.

**Most helpful source of information**

The sources of information perceived to have been most helpful varied widely. The Adelaide cancer specialist was seen to be most helpful in providing information about cancer and treatment (see figure 4.21), and the social worker or other source, such as transport assistance office staff, most helpful in providing information about supports and services.
The ease with which participants felt they could access information about their cancer and treatment varied (see table 4.19), however three quarters of the participants perceived finding information to be easy or very easy (n=72, 75.0%).

Table 4.19: Ease of obtaining information about the cancer and treatment

<table>
<thead>
<tr>
<th>Number of participants</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very easy</td>
<td>37</td>
</tr>
<tr>
<td>Easy</td>
<td>35</td>
</tr>
<tr>
<td>Neutral</td>
<td>15</td>
</tr>
<tr>
<td>Difficult</td>
<td>7</td>
</tr>
<tr>
<td>Very difficult</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>96</strong></td>
</tr>
</tbody>
</table>

A total of 40% (n=39) recalled contacting specialist centre staff following treatment in Adelaide, with the most common reasons given to change appointment times and to check treatment and/or side effect information.
**Accessing information from local health services**

In relation to information on cancer and cancer treatment in the local rural area, forty participants (41.7%) felt they had sufficient information available locally, 21 (21.9%) felt there was insufficient information available and 35 (36.5%) did not know, as they had not attempted to access information locally, as one participant commented:

*I don’t know, I haven’t looked.* {participant 34, female, 47}

Providing information on the cancer and treatment did not appear to be seen as the role of the general practitioner, with one saying:

*I know he had big fat books sitting there, and he had to look up about lymphoma, because there’s so many cancers, and that’s not their job, I mean that’s why you’ve got professionals, this is, these are one off jobs, and ah…. leave it to the people that know, but the local doctor, he all, he’d really want to know is what, is what one, is what cancer his patient has actually got.* {participant 62, male, 53}

**Satisfaction with level of communication**

Overall, most participants were very satisfied or satisfied with communication with and between health care professionals (see figure 4.22). The highest level of satisfaction was recorded for communication with cancer nurses with 88 of 89 participants satisfied or very satisfied. Seven participants did not answer this question in relation to nursing staff as they felt they had insufficient contact to judge their satisfaction with communication (for example those receiving outpatient radiotherapy only).
Figure 4.22: Satisfaction with communication with and between health professionals

**Perception of treatment provider**

As can be seen in figure 4.23, most participants saw the Adelaide cancer specialist as being the main treatment provider. Three percent of participants (n=3) believed that the radiation therapist (administering the radiotherapy) was in charge of their treatment and was the first point of call for questions relating to treatment.
Figure 4.23: Perceived main treatment provider

**Issues of communication**

Although there was a high level of satisfaction with communication with health care professionals overall, significant issues were raised during the interviews, such as the need to question the specialist to get sufficient information:

> Well she’s not very forthcoming, let’s put it that way, you’ve got to pry all the information out of her, you’ve got to keep asking her questions, and she’ll answer them, but it’s like, cursory answers. {participant 10, male, 71}

Some also experienced difficulty in getting forms signed as authorisation to receive reimbursement for travel and accommodation:

> It’s an effort for Jim to sign the PATS form. {participant 24, female, 42}

Issues of communication with general practitioners were largely focused on lack of continuity due to staff changes and associated delays. As one participant put it, in relation to her local practice:

> The clientele stay but the personnel change. {participant 5, female, 60}
Another believed that being rural, and having a culture of rurality, played a part in delaying his diagnosis:

_You know, I suppose all of us take things a bit for granted at times, you know, you get cuts and knocks and wounds and you know everybody does, in the bush I suppose you don’t just run off to town because you get a little lump or a cut or something like that, you persevere with it, and a week later it goes away and hunky dory. I suppose that in this new modern world, we’ll call it, I suppose people get things treated at the drop of a hat, soon as it appears and that’s probably cost me a fair bit of time in here by not doing the right thing……if I had to do it again I’d be a bit more dubious……but what are you going to do about it, I mean it’s over and done now._ {participant 62, male, 53}

Areas for improvement were identified by 20% of participants (n=21) (see table 4.20).

Table 4.20: Identified areas for improvement in communication

<table>
<thead>
<tr>
<th>Area for improvement</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>More information and better coordination (eg all information at first contact, identifiable case manager).</td>
<td>9</td>
</tr>
<tr>
<td>Improve communication between GP and patients.</td>
<td>4</td>
</tr>
<tr>
<td>More local information (eg pamphlets).</td>
<td>3</td>
</tr>
<tr>
<td>Ensure treatment information is consumer orientated (eg plain language).</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
</tr>
</tbody>
</table>

Many participants commented on examples of both poor and excellent communication, for example some participants were given the personal mobile phone number contact for the specialist, yet were unable to contact their GP after hours. Knowing they would be put through to the person on call who may not be familiar with their situation was off putting. What seemed to be valued highly was the willingness of health care professionals who made themselves available for personal contact, for example one participant commented on valuing communication with the GP as very good:

_...because he actually came out to the house to tell me I had leukaemia._

(participant 74, female, 60)

One described early difficulties in communicating with the specialist by saying

_We weren’t singing off the same hymn sheet for a while._ {participant 34, female, 47}.
The majority of responses on how to improve communication focused on the provision of information and coordination of care. Participants commented that receiving more information earlier in the treatment would be helpful, to the point of receiving this information before arriving in the metropolitan area.

Some participants also stated that both the information and treatment given should have a greater consumer focus and that information should be offered at a pace tailored to the patient concerned, in layperson language. The comment was also made that treatment should be provided in a way which took into account the needs of patients from rural areas, for example their need to stay in Adelaide for treatment should mean that treatment be offered over as short a time as possible and be coordinated to avoid delay. Other issues raised were that patients should see the specialist they had been referred to rather than a registrar, patients should have more time with the specialists during appointments, and communication should be improved between the Adelaide specialist and the GP so the local doctor could more effectively operate as the main care provider between treatment cycles.

Many participants needed to make special arrangements for their family while they were away (n=57, 59.4%), such as provision of pre-prepared food for their partner and/or children. Most also (n=65, 67.7%) indicated that they needed to make arrangements for their household (for example care of pets and/or garden). Neighbours frequently provided this assistance, however some participants commented that asking for this type of help was acceptable on a short-term basis but became problematic over time during the treatment period, as one commented

*You can ask neighbours for just so long.*  {participant 33, male, 54}.

There were some extraordinary descriptions of disruption to normal routines or arrangements. One participant’s parents gave up their rental accommodation of some 18 years to assist with care of the family. The participant’s mother accompanied her to Adelaide for treatment (of leukaemia) for over six months and the participant’s father took responsibility for the care of his grandchildren so her husband could continue working. Other participants described complex transport arrangements, with couples driving to meet relatives to share the driving for the rest of the way to Adelaide. This was frequently because the participant or his/her partner preferred not to drive in Adelaide. This also meant that the relative would accompany them during treatment or check ups. Simply being away from home was also perceived and
experienced as being difficult from both an emotional and a practical point of view, as one participant put it

This business of spending 6.7 weeks down here, it’s just too much, you’re away from your family, you got things to do at home you can’t do because you’re down here you’ve gotta rely on other people to, like we’ve got cats that ve gotta be fed, all that sort of thing, and you know, it’s so inconvenient, we’re running up ruddy phone bills, what was the last one, a hundred and twenty eight dollars, just for the quarter. {participant 10, male, 71}.

**Impact on finances and employment**

Of the 28 employed participants 18 (64.3%) stated that there had been an impact on their employment situation as a result of having treatment in Adelaide. The impact experienced was either a reduction in working hours (particularly for those working in casual employment) or loss of employment. Some participants were receiving income from a number of sources, for example armed services payments and pensions. One participant was employed part time as well as receiving an invalid pension. Other unemployment categories were carer’s pension (n=2), self funded retiree (n=2), partner’s disability allowance (n=1), military services pension (n=1) and widow’s pension (n=1).

Of the 21 participants who were employed (excluding the seven who were self employed), 17 were on some form of leave (paid or unpaid) and four were not. In addition, two participants were receiving income insurance protection. The types of leave that participants were receiving are detailed in table 4.21 below.

<table>
<thead>
<tr>
<th>Type of leave</th>
<th>Number of participants</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual leave</td>
<td>2</td>
<td>2.1</td>
</tr>
<tr>
<td>Sick leave</td>
<td>6</td>
<td>6.3</td>
</tr>
<tr>
<td>Unpaid leave</td>
<td>9</td>
<td>9.4</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>2.1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>19</strong></td>
<td><strong>19.8</strong></td>
</tr>
</tbody>
</table>

Only five participants knew how long their leave would last. The periods of time available for leave ranged from five to 180 days (mean 91, SD79).
Financial impact

Three quarters of the participants (n=71, 74.0%) felt that there had been an adverse financial impact on them as a result of receiving treatment in Adelaide. This was due to costs associated with treatment in Adelaide, such as food and transport and the cost of maintaining a primary household while staying elsewhere. Eighty three percent of participants (n=80) had received information about funding assistance, but fewer (n=76, 79.2%) reported that they had received some financial reimbursement related to their treatment in Adelaide.

A third (34%) of those who had received reimbursement stated that they had had some difficulty in accessing this assistance (n=25). These problems were related to filling out the forms, delays, or confusion over entitlements. This was a significant issue for many participants, with comments offered regarding the difficulty accessing reimbursement, their lack of knowledge as to the reimbursement they were entitled to, and the ambivalence with which many participants regarded what they perceived as financial ‘assistance’. One couple were receiving reimbursement for accommodation only. The participant’s wife was returning home frequently to check their house and commented:

{The} social worker was going to find out about that {financial assistance with transport} but that was a couple of months ago, she didn't actually get back to me and I didn't ask her, because I didn't think it would be........ I could just sort of foresee lots of forms, actually there was a form, and it was like, you had to lodge the form before you travelled, and I'm travelling about once a fortnight, to give the amount of petrol you'd use and that sort of thing and I just didn't quite know where to start. I know how much I'd use in the car which is half a tank. I suppose if it came to the crunch I could work it out, but I certainly wouldn't be exact, and then I'd be signing the form, and it could be perhaps a false statement, because I wouldn't be exact, and I think that's what deters me, I know they can come back at you.  {participant 9, male, 58}

Likewise, another participant commented that he found it a relief when he had established how financial costs would be covered

I think that’s what plays on everyones’ minds, how am I going to pay for accommodation and stuff like that, like I said, I found out about the PATS scheme straight away, and that like I said, just having that burden taken off you, it’s just, tremendous.  {participant 69, male, 35}

However not knowing the costs they were incurring from treatment was a source of confusion and stress for some. When asked about costs one commented:
Well I don’t know what it’s going to cost me, nobody’s mentioned paying.
{participant 66, female, 70}

A total of 29 participants (30.2%) said that they had a designated escort (i.e. a medically authorised carer whose travel and accommodation costs are eligible for reimbursement). However a further 31 participants (32.3%) were accompanied by a non-authorised spouse or partner during treatment. The costs of travel and accommodation for unauthorised companions are not eligible for reimbursement.

**Priority of issues**

A total of 22 issues were identified from the survey questions. The top five issues (identified by subjects as the most important to them) are shown in figure 4.24 below, as well as the total number of participants identifying the top five issues. Having a support person during treatment was ranked highest, followed by accommodation in Adelaide, separation from family and friends and financial costs. The quality of care in Adelaide was ranked sixth overall. The overall ranking of all issues is shown in appendix 12.

![Figure 4.24: Ranking of top five issues](image)

Figure 4.24: Ranking of top five issues
**Satisfaction with the most important issues**

Participants also allocated a satisfaction rating out of ten, for the most important issues they identified in relation to treatment in Adelaide (see figure 4.25). The overall satisfaction ratings that participants allocated to their top three issues of importance are listed in appendix 13. Participants rated the top two issues with high satisfaction overall (having a support person and accommodation in Adelaide), with ratings at five or higher out of a possible ten.

![Figure 4.25: Satisfaction rating for most important issues](image)

Figure 4.25: Satisfaction rating for most important issues
(0-very dissatisfied, 10-very satisfied)
Other issues arising from the survey

Recommendations for others having cancer treatment

Participants identified a broad range of recommendations which they would offer others having cancer treatment in Adelaide. These were grouped into the following categories:

- the need for information;
- the need for financial assistance and/or information;
- the need for a positive attitude;
- advice (accommodation, organisation);
- advice (health care insurance, treatment);
- recommendation to have treatment in Adelaide;
- the need for a support person; and
- general/other.

The transcribed verbatim recommendations are provided in appendix 14. Some participants did not answer this question. Some commented that they wouldn’t feel comfortable offering advice and others said that situations varied so greatly, advice from an individual’s point of view would be unlikely to be helpful.

Participants were also asked if they would like to raise any other issues affecting their care in Adelaide. Many identified ways in which the provision of cancer treatment in Adelaide for those from rural and remote areas could be improved. These recommendations were grouped according to the areas of health care services, support services, policy and education and are presented in full in appendix 15. Most of the recommendations were focused in the areas of care coordination, communication and easing the financial burden through specific strategies such as providing petrol vouchers. Other suggestions were to provide care coordination positions, and to provide respite to family carers. Practical considerations for the commercial accommodation included providing hand held showers as many having chemotherapy or radiotherapy may have movement impaired through use of a chemotherapy pump or skin reactions.
The data from the survey provides a comprehensive overview of the issues important to rural residents undergoing treatment for cancer in Adelaide and their priorities. This information was used to identify six participants for focused interviews to examine the most important issues in more depth. The illustrative biographies which are used to illustrate the issues identified and to provide understanding of why issues are important are presented in the following section.
Illustrative biographies

Introduction

Focused interviews were used to inform the development of illustrative biographies to demonstrate aspects of issues arising from the survey. Participants were selected based on the relevance of their situation to the issues in the survey and willingness to be reinterviewed. Interviews were conducted at their home or in the rural treatment setting. Areas from the survey that are highlighted by the biographies are in bold text.

Charlie

Charlie was a 77-year-old married man living in a town 150km north of Adelaide. He was born in a rural area and had lived in various places in South Australia, including Adelaide. Charlie had worked mainly as a wool classer and always in jobs involving farm livestock. He and his wife moved to his current place of residence from Adelaide 14 years previously in order to experience a better lifestyle. Charlie had no children. He was diagnosed with prostate cancer approximately two years previously, treated with surgery only and assured by the surgeon that the cancer had been totally removed. Prior to his diagnosis of recurrence, he described experiencing difficulty convincing the local surgeon that his urinary frequency was becoming significantly worse, and after some weeks of worsening symptoms was admitted to a local hospital and catheterised with recurrence of his cancer subsequently diagnosed.

Charlie’s situation exemplifies the difficulties some participants experienced in relation to accommodation and living arrangements that needed to be made to support patients to attend treatment in Adelaide and the isolation imposed when transport and travel are barriers to going home during treatment, particularly when the treatment outcomes are in doubt.

He initially stayed in Adelaide for eight weeks during radiotherapy and after this needed to return for monthly cycles of chemotherapy, staying for approximately five days each time. His wife travelled to Adelaide with him on his first visit, but stayed with her daughter while he stayed at Greenhill Lodge to spend time with her daughter and because her own health was somewhat frail. This proved difficult as neither Charlie nor his wife had transport and were reliant on the daughter to see each other, which happened rarely. On subsequent visits he travelled to and stayed in Adelaide by himself.
He was interviewed twice, two months apart, and during this time the focus of his treatment changed from an attempt to control his tumour to a palliative one. This created distress in its own right, but Charlie also identified the length of time he spent in Adelaide as a significant concern and source of regret. For this reason, he was relieved that he would not be offered more treatment:

*It seemed I was wasting good days down there when I could have been home cleaning up the weeds in the garden or doing something useful, but still I s’pose, at that stage I thought that they were probably going to do a lot more for me, but they did the best they could, it just didn’t really work. They didn’t give me a lot of encouragement, they told me it was a very nasty aggressive cancer that I had, in fact they went the other way, one of the doctors told me that I wouldn’t last very long at all, I don’t know what she meant, she said.... I only had months, she didn’t say how many months, I didn’t ask her, but she reckoned I only had months to go.*

During the initial eight weeks of radiotherapy treatment Charlie could have accessed a community car to return home for weekends, but didn’t ask about this, as he thought using the car for weekend trips would be an abuse of the resource. Charlie also commented on the boredom he experienced being in Adelaide:

*When I’m home I’m more contented, and I can do a few jobs and be a bit useful with me life, when you’re down there (Adelaide) you feel so useless.*

He was on the aged pension and his budget didn’t allow for any extra activities that would incur a cost. He was also restricted by his need to be able to find a toilet at short notice. However while in Adelaide, he enjoyed the weekends most as the day was his to spend as he wished.

**Wendy**

Wendy was a 46-year-old married woman with a teenage son from a regional centre 450km from Adelaide. She was originally from Adelaide and they had moved to the area five years earlier to accommodate her husband’s work. Her breast cancer was treated with surgery, six months of chemotherapy (monthly treatments) and six weeks of radiotherapy. She was re-interviewed at home a month after her treatment had finished. Wendy experienced the separation from family as traumatic and is an example of participants who did not use formal support measures despite having **psychosocial and support needs**. She also experienced side
effects from treatment and had difficulty with the management of these due to communication issues between metropolitan and rural health care professionals.

Wendy found the separation from her family and friends intolerable and flew home every weekend throughout the radiotherapy treatment at her own cost. The length of time Wendy was in Adelaide was extended by a week at the beginning of treatment due to a lack of coordination in planning treatment simulation, which angered her.

On their move to the country five years previously, she and her family established a community orientated approach to life that they had previously had when living in Adelaide and she commented that this helped their transition to the country environment. However, despite this, and despite her stated psychological distress, she did not use the community resources or her social network to manage her diagnosis and treatment. Wendy did not receive any community support, had not seen a breast care nurse at any stage in her treatment and had not attended any support groups, all of which were available. The non-involvement in a support group was in keeping with her attitude towards cancer, perceiving it as an acute illness requiring prescribed treatment, which once completed could be put behind her, as she commented:

_I can’t change the situation I’m in, and the whole process is, I’ve been told what has to be done and I’ve just got on with it and got it done, they’re the experts and I’ve just had to go and do what I’ve had to do and cope with it, and I mean, I’m a pretty strong sort of person in that way._

Also problematic were the side effects of treatment. Wendy described a severe skin reaction at the site of radiotherapy treatment, to the point where her skin, including the nipple area, was blackened and blistering and extremely painful. During radiotherapy, this area was dressed using creams, covered by temporary pads and netting. It was explained to her that longer lasting dressings could not be used as they may affect the level of radiotherapy penetration. However, on completion of treatment, the dressings weren’t changed to a longer lasting type before her return home. Her next appointment with a health care professional was on her return to Adelaide for chemotherapy treatment and it was not until the chemotherapy outpatient staff assessed the area that a more appropriate treatment was used. She told the radiotherapist of her misgivings about the management of her skin reaction and was concerned that this might have offended him.
**Barry**

Barry was a 54-year-old widower who was treated with a stem cell transplant for multiple myeloma. Barry was brought up in Adelaide and 17 years ago moved to a rural town some 200km from Adelaide to obtain work as a building inspector. Barry was re-interviewed approximately 2 months after his treatment had ended. He was required to make significant changes to his **living arrangements** to accommodate the requirements of treatment.

Barry was employed on a casual basis at the time of his diagnosis and subsequently began receiving an invalid pension. His daughter and her three children were living with him at the time of the first interview but had moved out by the time of the second interview. This was apparently done on the advice of the transplant treatment team in Adelaide, as his immune system would be suppressed for some time after the stem cell transplant and close contact with children was considered an infection risk.

The main problems Barry experienced in relation to going to Adelaide were difficulties with getting appointments to suit his need to travel and having to drive home afterwards. If attending for a single appointment he would try to return on the same day, so was restricted in the appointment times he could make. He also experienced distress around not being assured of accommodation in Adelaide when needed and in relation to the length of time he needed to stay in Adelaide. His daughter and grandchildren were the main focus of his social life and he found it difficult to be away from them. He also found driving to and from Adelaide physically demanding.

**David**

David was a retired farmer aged 72, married and living with his wife in a coastal town 160km from Adelaide. His two daughters were living in Adelaide and his son had taken over the farm (32km distant). He was involved in community groups including Probus (a social network organisation for people retired from a business or professional career) and the local church. David’s education was fewer than 3 years at high school as he left school to go farming. David was very clear about how he had set up his **communication** arrangements with his specialist and local GP and described strategies to develop a relationship with a GP to ensure he had access to continuity of care locally. He also was clear that while he would prefer **treatment** locally he would not opt for this unless he could be assured of an equivalent quality of care.
His normal pattern of treatment was to drive to Adelaide with his wife and alternate staying with each daughter. He was very happy with this arrangement and his daughters were happy to have the time with their parents. Following initial surgery, he was having monthly chemotherapy treatment for bowel cancer as a private patient in a private hospital. David had the option of receiving part of his chemotherapy treatment in a neighbouring town but refused this due to a belief that the staff would not have an equivalent or sufficient level of expertise. David did not apply for financial assistance as he thought the amount of reimbursement was not worth the time spent filling out the forms.

One of the most important aspects of treatment for David was that he was assured of 24-hour access to the Adelaide specialist. He did not discuss this arrangement with his general practitioner as he didn’t want to offend him. The arrangement made with the general practitioner was to phone the local hospital and speak to the on-call person if problems arose.

David also identified a need for an ongoing relationship with a general practitioner as important. This was problematic as the turnover in his region was high and his current doctor was due for retirement. He described his method of ‘fostering’ a relationship with a new general practitioner as follows:

See we’re getting doctors up there only stay two years, you like to get to know a doctor, you like the doctor to get to know you, but I’ve tried to foster one, ‘cos I’ll be under doctors now I’ve had this, I’ve tried to foster one a bit but I don’t know how long he’s going to stay, he said he’s going to stay. I’m trying to get used to one ‘cos I wanna wean myself off the old one, it’s awkward.

David also saw the support of his wife in attending for treatment as important and this remained as a top priority in both interviews, due to his perception that they were a team and for practical support.

**Darren**

Darren was a 46-year-old prison store clerk living in an inland town 185km from Adelaide. A follow-up interview was conducted with Darren while he was attending for chemotherapy at the local hospital and a third interview was conducted at his home. Each cycle of chemotherapy consisted of the first part of the chemotherapy administration in Adelaide, with follow up chemotherapy a week afterwards in the local hospital, for a total of six cycles over approximately six months. Darren’s situation demonstrates the importance that participants
placed on having a support person even when single and in having that **psychosocial support** and the alterations in **living arrangements** that were made by others to support him.

Darren’s parents stayed with him while he was undergoing each cycle of treatment and for the first week following to support him during this time. This entailed moving from their home in a coastal town some 150km away. Aged in their 70s, they found relocating a strain. They didn’t accompany him to Adelaide, as they were not confident about their ability to drive in the city environment. Darren had no other siblings or family members.

Darren identified his lack of a support person as being the most difficult aspect of undergoing treatment in Adelaide and commented on this in a review of his life situation.

*I think in my situation is being alone. It’s, you know, a choice thing, that you make years ago, and you really don’t know the consequences of it further down the track. That’s probably one thing, yeh, if I could have seen what was going to happen, probably would have gone out of my way to change…. put extra work in sort of thing…. But that’s probably about the only thing I’d change in the whole thing.*

Darren was happy with the model of shared care he was accessing, receiving treatment locally as well as in Adelaide. He received financial assistance to travel to and stay in Adelaide under a work place scheme developed to support employment in the region. Darren was advised of the scheme by a colleague and saw himself as fortunate in having access to this. However he still needed to drive himself to Adelaide and felt that he had no other option of travel available to him.

**Nigel**

Nigel was 55 years old, living in a small town 340km from Adelaide. He had been involved in various small businesses but at the time of the diagnosis of non-Hodgkin’s lymphoma was on sickness benefits for a back injury from some time ago. Nigel and his wife stayed in Greenhill Lodge and appreciated the convenience of its location near the hospital. Nigel was clear about the impact that relocating had on his **financial situation** and specified the extra expenditure they had incurred.

Nigel felt it was important that he had the advice of a social worker to find out what support was available. He commented that patients were not routinely informed that taxi vouchers could be used. Their spending habits changed while they were in Adelaide partly because they
were out of their normal routine. For example, they were more likely to buy a magazine to read and fill in time than they would if they were at home. They felt that they wouldn’t have been able to be in Adelaide for treatment had it not been for the subsidies they received. Difficulties in identifying what support he was entitled to were described and he and his wife had sought advice from a young person receiving government benefits on how to manage their situation.

Ad hoc acts of kindness by hospital staff were identified as making a difference to his care, as described below:

*I wasn’t too good the other day and I went up to W2 (hospital ward) and Lana (nurse) was there and she saw me and we got talking and she insisted that I have a taxi voucher and she even rung haematology and said oh you need a taxi, can you ring a taxi when he leaves, she’d kill you with kindness, yeh, it is good, cos I wasn’t feeling... I was pretty well bugged....I was very close to asking if I could have somebody push me in a wheelchair.*

In relation to his physical care, Nigel was on a transition diet that required the avoidance of uncooked (including fruit and vegetables) and unpasteurised food to reduce his infection risk. However, he was drinking unfiltered rainwater and had not been advised to test this for bacterial contamination or to boil it before drinking.

The illustrative biographies add an extra dimension to the presentation of descriptive statistics in the previous section by showing the impact of travelling to a metropolitan centre for treatment in the context of the individual’s and family situation. While many broad issues experienced were common to most participants, an understanding of their individual circumstance provides a more meaningful explanation of the importance of the issues.

Health care professionals were then interviewed to gain their perspective of issues in metropolitan based cancer care for rural residents. The following section presents the findings and recommendations from these interviews.
Interviews with health care professionals

Introduction

Health care professionals implement and deliver cancer treatment and care and through their role have experience and knowledge of the intent, process and outcomes of health care on a broader scale and from a different perspective compared with that of individual patients using the health care system. The health care professionals interviewed were clear about what they perceived to be the priorities for rural patients and based this on their experience of caring for numbers of such patients. This section of the chapter provides a summary of their responses. For the full list of comments and recommendations see appendix 16.

Findings – priorities identified

The priorities identified in relation to the care of rural residents were in the areas of travel and accommodation, communication and access to information, psychosocial impact and separation, the physical impact of the cancer and treatment, the financial costs involved, and access to services and treatment. The main priority was seen to be to achieve a level of care as close as possible to that received by non-rural patients through ensuring smooth access to specialist care. The main focus of recommendations and priorities for care was to facilitate aspects of transport to and accommodation in Adelaide, rather than to facilitate care in rural areas.

Travel and accommodation

It was felt important that patients had access to accurate and comprehensive information about the process of accessing treatment and accommodation in Adelaide and that these services were appropriate and accessible. For example, there should be hostel level accommodation available with some sort of health care support (e.g. a resident nurse) for patients. The limitations on escorts (family member or friend) were also felt to be unfair at times. It was felt that any rural person travelling to Adelaide for cancer treatment should be able to have the costs of a support person subsidised for travel and accommodation. The health care professionals identified a potential lobbying role by the hospitals in advocating for better patient support and accommodation.
There were also some advantages seen in staying in Adelaide if subsidised travel and accommodation was used, mainly that the patient may be able to combine their trip with other purposes and that they could meet other rural patients and families in the accommodation setting and thereby receive and provide mutual support.

The interviewees were also aware of the difficulties experienced by patients when navigating an unfamiliar environment and health care system, particularly when it was for the first time, and identified that there may be those with special needs for an escort aside from health care needs, such as those with a linguistically and culturally diverse background.

**Communication and access to information**

The general practitioner was seen as a key person in the support of rural patients with cancer. It was felt to be important that the general practitioner have specific information on the diagnosis and treatment but also the supports available to patients to help them to support the patient. Other rural health care professionals involved in supporting patients were also identified as needing access to information particularly if they were directly involved in caring for the patient. Extending use of electronic media such as the internet and teleconferencing was also identified as a useful strategy to support rural patients and health care professionals. It was acknowledged that although all the appropriate information was usually available, the difficulty was in ensuring that it was provided to the appropriate person at the time needed. Staff from treatment centres may also be focused on clinical information provision whereas patients also have a high need for information on the processes involved in accessing treatment.

Finally it was again identified that those from diverse backgrounds may have specific needs, for example interpreting the information provided. If health care professionals in metropolitan settings do not identify and provide for this need the situation of the rural patient is made more difficult as they are already separated from their usual environment.

**Psychosocial impact and separation**

The health care professionals reiterated the need for all rural patients with cancer to have the option of a support person accompanying them during treatment using the cost reimbursement scheme. The impact on the patient and family of a prolonged stay in Adelaide was identified
as an important issue, particularly if there were children in school, and it was seen to be important to have a possibility of a visit home during treatment or to have the option of completing treatment in the rural setting. Balancing the impact of psychosocial concerns was the belief that in general rural residents accept that the need to travel to access specialist treatment is a necessary part of living in a rural area.

A lack of psychosocial supports for rural residents were seen to be a potential problem, for example if the patient’s principal supporting health care practitioner in the rural setting is a general practitioner, provision of support for psychosocial concerns might be limited due to time constraints. Access to allied health services such as psychologists might also be restricted during treatment which may place extra strain on patients and families.

**Physical impact**

Specific concerns about the physical impact of some treatments and diseases were identified. Patients with leukaemia are advised not to use public transport due to infection risks so their options of travel are limited. Patients who have immunosuppressive treatments such as chemotherapy are at greater risk if they are unable to quickly access antibiotic therapy should they develop infection.

The burden of care that falls on the family was also identified and the potential difficulty in providing support through visiting health care services that are more readily accessed in metropolitan areas. Having a designated community person to be available for support in times of acute illness was felt to be an option. This may happen informally but not routinely. Health care professionals may assume that the physical care will be provided by the family but a comprehensive assessment of care needs and explicit mutual agreement on who will provide the care is important to ensure the patient and family are supported.

**Financial costs**

The impact on finances was seen to be a potentially problematic area as it may not be raised by the patient and family with health care professionals, and may be a hidden burden related to the diagnosis and treatment. Those who have been financially independent may find it difficult to discuss these issues with health care professionals or with financial services staff and it was seen to be important that health care professionals check whether finances are a concern.
Accessing PATS reimbursement was also seen to be daunting, due to paperwork requirements and complexity. Patients who are receiving benefits may also need support in dealing with government organisations.

Finally, if employment is lost by the patient or a supporting family member re-employment may be more difficult due to lower levels of employment in rural communities. It may be a particularly difficult situation if the patient is the primary wage earner for the family.

Access to services and treatment

Dealing with government services such as Centrelink was again identified as an issue, with the suggestion made that a welfare person be made available to support patients dealing with Centrelink who can link patients to the available supports. Centrelink in the past provided a visiting service to patients in hospital and it was felt that this should be reintroduced.

In terms of provision of treatment and support it was felt that whenever possible, treatments should be made available in the rural setting with support from the specialist metropolitan team. Patients being treated in the private setting were seen to have less access to allied health personnel, however it was also commented that rural patients have responsibility for ensuring they have access to health care and services.

There was felt to be a need for metropolitan staff to have understanding of the needs of rural patients, for example when organising appointment times and coordinating multiple appointments. The high level of tolerance that rural residents can have in understanding that access is likely to be difficult should be matched by efforts of health care staff to ensure that difficulties are minimised. Cultural issues specifically related to Indigenous patients were also identified as important, particularly related to ensuring they are given appropriate information and support to make decisions about cancer treatment.

Other comments

Other issues identified by the health care professionals included those of a more general nature. For example, one commented on inconsistencies in interstate schemes that create confusion for patients, with other states having different criteria than those used in South Australia. It was also identified that the hospitals providing treatment and charitable bodies providing support (such as Cancer Council South Australia) have complementary roles, with
the hospitals focusing on treatment delivery and charitable bodies focusing on support. Duplication of services is reduced because of the differing roles but the lack of direct communication between the organisations is a concern.

The reality that management of rural/remote patients is not able to be exactly the same as for non-rural patients was acknowledged. The choice of living in a rural area was perceived as a lifestyle decision, balancing positive and negative factors such as reduced access to some services. The rural population were felt to not necessarily expect or want health care to be the same and to have the right to decide how they would like to access treatment, rather than metropolitan based health care professionals making this judgement or decision. It was likewise identified that the needs of rural and remote residents were different and should be considered separately.

A need to rationalise rural support roles was identified, for example for one nurse to take on the responsibility for breast care nurse, chemotherapy nurse and counsellor as a full time position, rather than dividing this into several specialist positions with more than one nurse covering more than one town resulting in inefficiency of service delivery.

Potential problems with the general practitioner role were identified in relation to the time of diagnosis. The consultation that identifies a problem needing specialist input takes place before diagnosis and therefore cannot be used to provide all the subsequent information needed by patients. It was also considered questionable as to whether it is the role of the general practitioner to inform patients about metropolitan based support services or whether this is more appropriate coming from those in the metropolitan health care setting, particularly as rural general practitioners may not be able to answer questions about the services.

Many of the issues identified for rural residents were not necessarily cancer specific, however the treatment of cancer may require repeated or prolonged visits to the metropolitan setting and debilitation and risks associated with the treatment. This presents patients with demands related to the nature of their diagnosis that are not faced by all patients. The interviews with health care professionals revealed a detailed understanding of issues and barriers faced by rural residents in accessing cancer treatment.
Summary

The results of the survey conducted demonstrated that in general, satisfaction with the medical aspects of cancer treatment was high. Issues of psychosocial and practical support were the highest priority for participants out of all issues explored in the survey. Difficulties or issues were identified mostly in relation to the supportive needs aspects of undergoing treatment in Adelaide, such as information provision, psychosocial supports, financial costs and the practicalities of transport both to and within Adelaide. The main findings follow, grouped into topics.

Travel

The need to travel long distances was perceived by participants as an expected aspect of treatment, with an assumption that private means of transport would be used, rather than public. However, having access to alternative methods of transport in the city was important in order to avoid driving and parking especially if there was any lack of confidence in driving in the city.

A physical impact of travel was felt by three quarters of those who travelled back and forth from their rural residence between treatment cycles. This included fatigue, shortness of breath, nausea, pain and general debilitation.

Accommodation

Satisfaction with accommodation was high overall but less so for those staying in private accommodation compared with those staying at Greenhill Lodge and Seaview Lodge. Despite this, specific issues were raised in relation to accommodation provided by hospital and charitable bodies where the special needs of people undergoing cancer treatment were not catered for.

Treatment

Treatment delays were described due to diagnostic delay, communication breakdown and lack of appointment availability. Differences in access to allied health were identified between in
those treated in the public and private sectors, with treatment in the private setting associated with a reduced likelihood of seeing a dietician or a social worker.

Some participants were also receiving treatment in the rural area and were satisfied with this. Most participants preferred to have the option of treatment in the rural setting, but only if this was of equivalent quality.

**Psychosocial support**

Approximately half of the participants felt there was a large or extreme effect of separation from family and friends, regardless of whether they were accompanied during treatment. Having a companion during treatment was important to most participants, including many of those who did not have a spouse or partner. This was due to both practical and emotional needs. Few participants received practical support from local groups or organisations.

**Information and communication**

Information sources for accommodation and transport were different from those used for treatment and few participants used electronic media to access information about treatment or accommodation and transport.

Overall, participants were also satisfied with communication with and between health care professionals, however despite this, some provided anecdotes describing significant difficulties and breakdowns in communication. The role of general practitioners was criticised due to communication difficulties and a perception that they had insufficient knowledge of cancer and cancer treatment. For this reason they were usually not approached for information relating to treatment or used as a resource in the event of treatment complications.

**Financial impact**

Most of those in employment at the time of diagnosis experienced a detrimental effect on their employment and three quarters of all participants experienced an adverse financial impact of treatment. Lack of information about the reimbursement schemes was a significant issue with many not being informed about reimbursement schemes until after starting treatment in Adelaide. A third of participants who applied for reimbursement identified that they had experienced difficulties with this process.
From the range of issues discussed in this survey common concerns were identified for these participants with cancer undergoing treatment in Adelaide. It appeared that the treatment itself was less a source of concern than the process of undergoing treatment, including the need to come to and stay in Adelaide. Satisfaction with treatment was high, which contrasted with concerns related to psychosocial and practical support, rated as the highest priority of all issues by participants. Many of the concerns identified arose from the participants’ individual circumstances and situation, however it was also evident there were common themes identified, such as psychosocial concerns. Those without family support were left vulnerable to any gap in service and support provision.

**Illustrative biographies**

The illustrative biographies using in depth interviews illustrated the depth of need for support and assistance identified in the survey findings. The purpose of treatment, likelihood of success and length of time away from home may be important factors for rural residents when making decisions on whether to have treatment for cancer. Access to clear and accurate information is important to allow an informed decision to be made.

Family members can be an important source of support but those without family or friends who are in a position to assist can be vulnerable, particularly when access to treatment is physically and emotionally demanding. Tremendous upheaval can occur in family arrangements when rural residents receive treatment in the metropolitan setting, to the point of family members relocating residence. Participants with family support appreciated how important it was for them while undergoing treatment and those without or with limited support identified this as an issue impacting on their wellbeing.

Community involvement does not always translate through to community support during and following cancer treatment and may be limited to being a source of psychosocial support rather than practical assistance or information provision.

Differing lines of communication between patient, metropolitan health care staff and rural health care staff were set up to suit the preferences of those concerned. Barriers or breakdown in communication had a significant impact, for example when care was transferred to rural staff, demonstrating risk when responsibility for clinical care is transferred from specialist to general health care providers.
The biographies illustrate the types of pressures experienced by participants and responses made in order to adapt to these. The variation in personal circumstances and responses demonstrate the need for health care professionals to be aware of individual patient circumstances.

**Health care professionals**

The perspective of health care professionals involved in the care of rural residents with cancer was shown to be largely congruent with concerns expressed by patients in the survey. Areas of concern identified for rural residents included:

- Acknowledgement that rural residents have different needs from their metropolitan counterparts.
- The need to ensure accommodation is sufficiently available and suitable for patients’ needs.
- The need to ensure information about services is available to patients when needed.
- The importance of coordinating and linking care and support services.
- Prioritising the optimisation of the use of electronic media to improve communication with patients and rural health care professionals.
- Ensuring a degree of equity in psychosocial support by providing funding for escorts on a psychosocial as well a medical basis.
- Ensuring the needs of the Indigenous population are considered appropriately.
- Tailoring strategies to suit the needs of the patients from rural areas, with acknowledgement of their right to have input into the level of care they receive.

The health care professionals interviewed were able to clearly articulate specific concerns in relation to patients from rural areas undergoing cancer treatment. It was evident that some aspects were considered the responsibility of the treatment centre whereas others fell under the domain of government funding and charitable bodies.
Chapter conclusion

This chapter has presented the results from the three phases of this study and has provided description of cancer risks, outcomes and treatment and supportive care in South Australia for rural residents. The results of the phases in this study show that there are differences in rural and urban populations in relation to cancer risk factors, and cancer treatment and supportive care resulting in adverse outcomes for rural residents. The following chapter integrates and discusses the outcomes identified and draws on the literature to examine the reasons for these and to identify strategies for improvement where needed.
Chapter 5 - Integration of findings and discussion

Introduction

This study draws together a number of projects conducted over time which complement and build on each other to form a picture of issues relating to the cancer care of rural residents. The purpose of the study was to examine rural-urban differentials in cancer risk factors and outcomes, to assess literature on the cancer care and support provided to rural residents being treated in a metropolitan setting, and finally to determine the impact on rural residents when accessing cancer treatment in the metropolitan setting.

In this chapter the key findings of the study are reviewed, then the limitations of the various phases of the study are acknowledged and discussed, including those arising during the reality of conducting a research project in the ‘real world’. The risk factor, incidence and survival data findings are discussed and related to relevant literature, followed by discussion of the integrated survey findings. This includes information on the characteristics of the survey sample then the major findings in order of importance according to the participants. The final section presents the approach used for the discussion of the study including the description of a model of analysis which allows incorporation of the perspectives of patients and health care professionals in the context of the health care system.

Findings

The data analysis conducted in the first phase of this research identified lower survival rates for rural residents for some cancers. This was despite similar risk behaviours and similar or better participation in screening programs. The reason for this difference in the populations was unclear.

Factors of treatment and treatment access were then examined in the literature to assess the current knowledge in this area and determine if there were any gaps in the research, or factors that may be contributing to the poorer outcomes. The literature review indicated that the research conducted to date is not extensive and does not sufficiently describe the experiences of rural residents undergoing treatment. However the review did point to areas for further
investigation. These were primarily the need to describe the experience of and factors affecting treatment for rural residents, and to identify the impact of the barriers faced and the psychosocial issues involved in relocating temporarily or for prolonged periods to attend treatment.

The subsequent survey identified that participants were mostly born in Australia, older, male and undergoing a combination of cancer therapies for solid tumours. Most participants had a low income, were reliant on government pensions or casual or part time employment and had relatively limited schooling. The participants were satisfied overall with the management and treatment of their cancer. However, the impact of a cancer diagnosis, relocation over short and longer periods of time and treatment was perceived to be significant in a number of areas. These were largely in the areas of psychosocial and practical support and included:

- the psychosocial impact of being away from home during treatment;
- issues of communication with the health care team and access to information;
- the financial impact of treatment and access to reimbursement;
- the practical needs relating to travel to and from and staying in Adelaide; and
- the experience of the cancer treatment including access to specialist health care professionals.

Selected individual biographies illustrated the major areas of need and provided a more human picture of the experience of travelling to Adelaide for cancer treatment. Interviews with health care professionals both concurred with and complemented the survey findings.

This discussion will address all components of the research undertaken, focusing on the survey findings in relation to current literature and integration with the perspective of health care professionals and the health care system. The discussion is structured according to the topics of findings from the survey, with perspectives of patients, health care professionals and the health care system addressed in order to identify areas of importance and congruence.

**Strengths and limitations of the research findings**

Before discussing the findings of this study, the limitations of the study are acknowledged including comments about the context of the research conducted. Methodological limitations
are noted in chapter 3 in regard to the data collection and analysis during the development of the study phases. Limitations of the research as it was conducted are addressed by reviewing the purpose of the research phase and any major limitations, then discussing the limitations of data management and analysis.

**Analysis of cancer registry and population survey data**

The cancer registry data used for analysis in the first phase of the study was known to be reliable as case ascertainment is virtually complete and follow up is very high. Limitations for this phase of the study related mainly to the use of population survey data from the SERCIS, Health Omnibus and the Health Monitor surveys. Use of secondary data from health surveys means that there is no control over what has been asked in the survey and areas which may arise as potential areas for further investigation cannot be followed up at the time. Data on known risk factors such as smoking status, sun exposure, alcohol use, and whether Pap test or mammography had been accessed by the respondent were analysed. A more detailed scrutiny of factors such as age and frequency of use or exposure, such as the frequency of Pap test or mammogram were not possible in the context of this study. Follow up questions related to specific cancers identified to be of interest due to the different survival rates in 10 cancers were also unable to be addressed as this data was only available for some cancers. The data accessed was also the most recent available in this area at the time, but as it was drawn from published reports it was older data than it would have been had primary data been used.

**Focused literature review**

The literature review was focused in the area of research into support and management of rural residents with cancer receiving treatment in a metropolitan setting. A systematic approach was used to ensure that relevant articles were identified. An orthodox systematic review of effect was not deemed appropriate because of the broad nature of the review topic and at the time methods of review of qualitative data were not well developed.

A problem that can arise when searching databases for literature using qualitative methodology is that some articles may be difficult to identify as medical databases are more likely to use quantitative search terms to index articles (Evans, 2002). In this search both
medical and allied health databases were used to minimise the risk of failing to identify articles.

The findings of the studies were critiqued and summarised narratively due to their largely qualitative and descriptive nature. A possible disadvantage of using such a tightly focused review topic meant that research into other diseases that may have had useful information in other areas were not included. For example, strategies to support the care of rural residents may be used in other chronic diseases like heart disease and could have been of relevance in this study.

**Survey and interviews**

**Surveys**

Surveys have been criticised for being used to confirm the obvious (Bulmer, 1984) or making explicit what is assumed common knowledge. This could be said of the focus of this survey, in that the issues for rural residents undergoing cancer treatment in a metropolitan setting would seem to be predictably that it is a hardship, and that it would be preferable to have treatment available close to home. However assumptions can be misleading, particularly when made about a minority population with particular health care needs and should be challenged using research methods.

Surveys may be conducted face to face, or via telephone or mail. The use of mailed surveys is an unobtrusive method of gaining information from the population concerned, allowing the participant to answer the questions in their own time, at their own convenience, and expressing their opinion in an anonymous fashion (Parahoo, 1993). However, the drawbacks associated with mailed surveys include that the participant does not have convenient access to the researcher if they are unclear as to the questions, the response rate is likely to be relatively low (which can make it difficult to ascertain the significance of findings) and descriptive and explanatory responses written by the participants may be misunderstood by the researcher (Bailey, 1991). This survey was conducted face to face with all participants, which was costly in time but allowed in-depth description and explanation of responses.

Survey research is considered to be most useful when the sample is representative of the population in question (Mason and Bramble, 1989). This sample population was heterogenous, with participants receiving various forms of cancer treatment including surgery, different
chemotherapy protocols, radiotherapy and hormone therapy, at varying points in the treatment trajectory for a range of diseases. The common factors were: being diagnosed with cancer; receiving treatment for that cancer in the metropolitan setting of Adelaide; and having a principal usual residence in a rural or remote area. For these reasons the participants are considered to be representative of those who travel from rural and remote areas for cancer treatment in Adelaide. However, the large proportion of participants staying at subsidised accommodation (Greenhill Lodge) and receiving treatment at a major hospital (Royal Adelaide Hospital) means this group may have been over-represented in the sample.

The heterogenous nature of the sample also means that it cannot be used to state the needs of specific groups, for example those with a particular diagnosis. Instead it addresses issues more broadly representative of patients with cancer. The lack of an urban comparison also means that determination of the specific issues of ‘rurality’ impacting on the findings is difficult. The findings also cannot be used to make direct comparisons with other groups such as rural residents with other forms of chronic disease. The needs of Indigenous populations in rural and remote areas are not addressed so the findings of this study cannot be used to infer outcomes relating to Indigenous populations. Finally, the data in this study is largely drawn from rural residents in South Australia, which may limit the extent to which the findings can be generalised to other parts of Australia.

Interviews
The use of interviews for data collection has both advantages and disadvantages. Potential threats to the validity of information gained from interviews include technical issues such as participant memory recall, interviewer effects, response tendencies and dishonesty however these can be predicted and circumvented through planning, design and training (Fielding 1996). Use of the face to face interviews also meant that first hand information was accessed from the participants in real time, providing meaningful and accurate data. The place of interview was negotiated with participants to be conducted at a place and time as preferred by them, which was either in the treatment setting or in the participants’ place of accommodation in Adelaide. It is acknowledged that the interview setting may have influenced the interviews, for example, many of those interviewed at Greenhill Lodge may have focused on comments about their accommodation, whereas those interviewed in the hospital setting may have been more aware of aspects of treatment at the time of the interview.
This research did not include the perspective of patients diagnosed with cancer who had decided not to attend Adelaide for treatment. It is possible that those not attending had specific needs or perceived barriers that were not identified in this study. The information arising from this study can therefore only be used to comment on the situation of those who are aware of and access metropolitan cancer care.

The intent of this study was not to determine differences in the level or type of impact on the participants in relation to specific diseases, treatments or the time point in the treatment trajectory. These factors may well influence the experiences and processes of treatment and the quantitative analyses presented in the findings were conducted for descriptive purposes only.

**Integration of findings from the three phases**

Pulling together information from the three phases in a way that both provided meaningful information and did justice to the information arising from each phase was challenging. Similarly the situation for rural residents in relation to cancer prevention and treatment is also complex and challenging. Each phase was distinct and the findings were used to inform the development of the subsequent phase. The information was also used as building blocks in the development of understanding of the study area. One limitation that this created was that the study took a considerable length of time to complete and the data from the first two phases were from an earlier time. These may have been different if conducted concurrently with the third phase.

The information and understandings arising from within the three parts of the third phase required a more direct integration and proved more complex and difficult to manage. The information from survey participants and health care professionals identified many similar issues but the priority given to the issues differed. It was decided to consider the situation using a model that included the concerns of patients, health care professionals and the context of the health care institution and then to discuss the findings in relation to the major issues.
Patient centred discussion

The perspective of patients undergoing treatment was the main focus of this study, however it was also considered important to ensure that the patient perspective was not the only one considered. Potential limitations of only using patient data include:

- Patients may have nothing to compare their treatment with and therefore experience treatment from an individual perspective rather than having a view of treatment for a number of patients.

- Using data from patients only ignores the contribution that can be made by health care professionals who provide care for a number of patients and thus are able to assess and critique care on a broader basis.

- Patients are less likely to be critical of the treatment and care they are experiencing as they are dependent on the care they are receiving for recovery and/or survival, particularly with a diagnosis such as cancer.

- The outcomes of health care professional interventions are subject to quality assessment and accreditation programs, health care professionals are therefore likely to have a more critical and focused perspective on care.

- Both patients and health care professionals may have expectations and assumptions about what the health care system can provide which may be unrealistic.

It was also felt to be important that recommendations for improvements in health care should be: appropriate and preferred from the patient perspective; appropriate and indicated from the health care provider perspective; as well as feasible from the health care system perspective. The conceptual model developed by Stevens and Gabbay (Stevens and Gabbay, 1991) allows this broad approach by enabling analysis of the needs and demands in the health care system from multiple perspectives. This model was developed partly to assist more effective and greater levels of input by health care professionals into development of health care policy and planning and took place in the context of major revisions of the National Health Service in the United Kingdom at the time.
The model includes three overlapping areas of needs: patients’ demands for or expectations of health care interventions; the need for the health care intervention (based on the likely clinical benefit to be gained); and the supply or degree of availability from the health care system (see figure 5.1).

NOTE:
This figure is included on page 205 of the print copy of the thesis held in the University of Adelaide Library.

Figure 5.1: Need, demand and supply. Adapted from (Stevens and Gabbay, 1991, p21)

The model allows analysis of issues to incorporate the perspectives of patients, health care professionals and the health care system and to identify opportunities for improvement in overlapping areas. In this discussion the perspective of patients is privileged as being the key informants in this study and information from the epidemiological data, literature and health care professionals is incorporated, as depicted in figure 5.2 below.
Figure 5.2: Approach used for integration of findings
Risk factors, incidence and survival differences for cancers by rurality

Cancer registry data analysed for this thesis showed similar survival rates in rural and urban residents, however there were significant variations within this finding and some areas of difference from the national data. Data from the AIHW shows that there are higher numbers of deaths due to lung cancer, cervical cancer and cancer of the uterus in rural populations, but lower numbers of deaths related to breast cancer, leukaemias, ovarian cancer and stomach cancer (AIHW, 2003c) (contrasting findings in bold text). The SA Cancer Registry data identified a significantly lower 5-year survival associated with cancers of salivary glands, stomach, colon, rectum, bone, female breast, bladder, kidney, multiple myeloma and chronic lymphatic leukaemia. It is important that breast and colorectal cancer are among those with a survival advantage associated with being an urban resident in the SA Cancer Registry data, as these are among the five most commonly diagnosed cancers in South Australia (South Australian Cancer Registry, 2001). For some rural regions the relative risk of case fatality also varied and the reason for this is unclear, as data on usual referral and treatment patterns is not available.

The AIHW report notes that differences between rural and urban groups are likely to be influenced by population factors including the age structure of families, socioeconomic factors, diet and lifestyle factors, ethnicity and Indigenous status, environmental factors, access to treatment and screening services and levels of co-morbidities (p42). Residents of Major Cities had the lowest age-standardised average annual cancer death rate for all cancers from 1998-2002, lower than the national average and with no cancer rates significantly above the national average (AIHW, 2004). How the differences between rural and urban populations relate specifically to access to screening and treatment may influence these outcomes is unclear and therefore a focus of this thesis.

A cancer forum held in Darwin helped to identify specific issues related to the higher rates of cancer in the Indigenous population and ways that these could be addressed (Lowenthal, Grogan and Kerrins, 2005). These poorer outcomes contribute to an overall outcome where Indigenous people with cancer die at twice the rate of other Australians with cancer. An editorial piece in the Medical Journal of Australia (Lowenthal, Grogan et al., 2005)
commented on data gathered for the forum identifying factors of importance. This included the higher numbers of cancer types with poorer survival outcomes such as lung and head and neck cancers. Treatment factors also identified as likely to be relevant were delayed diagnosis and reduced likelihood of completing treatment. Investigation of the experience of treatment for rural and remote residents including Indigenous residents will contribute to an understanding of issues related to treatment and the part they play in poorer outcomes.

Other investigation into specific cancers has also identified differences in areas of screening and treatment, for example prostate cancer. There is currently no publicly funded and promoted screening program for prostate cancer however screening tests are widely available through general practitioners. A study using statistics from the Australian Bureau of Statistics compared data for men aged 50-79 years in regional and rural areas and those living in capital cities (Coory, 2005). This showed that while overall mortality from prostate cancer has been decreasing since 1993, excess or greater than expected mortality in regional and rural areas is increasing, and most recently (2000-2002) was 21%. In addition, rates of screening tests were found to be lower in regional and rural areas than in the capital cities. The authors concluded that the variances in expected mortality were most likely to be related to a combination of lower levels of screening and differences in management of men diagnosed with prostate cancer, postulating that reduced access to urologists may be a factor.

The population survey data analysis conducted for this thesis did not find lower rates of Pap test screening in rural populations and the literature suggests that rates of screening for breast cancer is higher in rural areas of Australia than in urban areas (AIHW, 2003a). The rates of screening for prostate cancer in rural areas may differ from those of cervical and breast screening, however it is difficult to accurately assess this as prostate cancer screening is not a funded program and the data available is limited and not routinely reported.

A recent study in NSW shows that people living in remote areas are 35% more likely to die as a result of their cancer in the five years following diagnosis than are those living in more densely populated areas with greater access to cancer services (Jong, Smith, Yu, O'Connell, Goldstein and Armstrong, 2004). A significant finding from this study is that although there were significant variations in stage of cancer at diagnosis for some cancers, including head and neck, when the stages were controlled for comparison the differences in relative excess risk were reduced for most cancers, suggesting that the differences may be partly due to
variation in cancer treatment. The analysis of cancer registry data conducted for this thesis showed a similar trend of poorer survival outcomes in rural residents, with differences able to be identified in some rural regions of South Australia. Stage of cancer at diagnosis was also shown to be later in rural residents than urban residents for melanoma and breast cancer. Risk factors were shown to be similar except for a possibly greater use of sun protection in rural residents, but a greater proportion of smokers. The differences in outcomes of mortality and survival may partly be ascribed to differences in screening and stage at diagnosis, but the degree to which differences in access to specialist care and treatment impacts is less clear.
Cancer treatment: The experience of participants

There are many aspects of rural life which impact on health and which are also important when individuals are accessing specialist cancer treatment. This section of the discussion chapter focuses on the process of cancer treatment in relation to the participant survey findings and focused literature review. The discussion of findings is ranked according to order of priority as identified by survey participants.

Survey participants – characteristics

The participants in this study were primarily from South Australia with most (68%) having treatment at Royal Adelaide Hospital (RAH). This is partially as a result of recruitment activity at this hospital, but also reflects the role of RAH as the largest hospital in South Australia and its function as a tertiary health care institution incorporating a specialist cancer care centre. Data are not available as to how many rural patients are treated for cancer at RAH, as episodes of treatment (such as chemotherapy) are collected, rather than individual cases. RAH is a major catchment hospital for South Australia, the Northern Territory and adjoining areas of other States.

The mean age of participants was 62 years, reflecting that cancer is primarily a disease of older people (AIHW, 2001a). Many had received relatively limited schooling, with 41% having left school by Year 10. The income of 59 participants (62%) as $500 or less weekly (gross) is in line with low incomes in the older population seen in the South Australian population (ABS, 2002). In terms of household members a total of 24% of the participants were either living alone or in a non-spousal situation, such as sharing a house. A third of all participants were living in areas designated as moderately accessible to very remote in terms of accessibility to services and general health care. These characteristics, combined with the elements of rurality such as being distant from the treatment centre, being unfamiliar with the metropolitan environment, and cultural differences impacting on the experience of accessing treatment all contribute to a picture of a relatively socioeconomically disadvantaged group in the context of accessing specialist cancer treatment.

The proportion of participants who held private health cover was used as a point of comparison with the total population in South Australia. Private health cover was held by 31
participants (32%), which differed from the national average in the corresponding time period (September 2002) of 44% (Private Health Insurance Administration Council, undated). However, when the insurance coverage was analysed by age group, in the group with the largest number of participants (50-69 years, 57 participants) the percentage with private health cover was 30% which is similar to the percentage of 27% seen in the same age group in the South Australian population at the corresponding time (Private Health Insurance Administration Council, undated). This sample group of participants was therefore representative of patients in terms of: most common place of treatment in Adelaide; socioeconomic characteristics of the rural population in South Australia; and education level of the South Australian rural population.
Psychosocial impact of treatment for rural residents

It is becoming increasingly accepted that psychosocial and support issues can have an important influence on health care outcomes. For example, the way that significant news is communicated to patients and their family is important in the adjustment to the diagnosis and a higher level of social support aids in coping with the disease (National Breast Cancer Centre and National Cancer Control Initiative, 2003). Psychosocial needs were identified as the highest priority area by participants in this study, with three of the top six issues related to psychosocial issues and the impact of being away from home. This stands in contrast to the stronger focus on travel and accommodation by the health care professionals interviewed.

The need for companionship and support

Participants rated the need to have a support person with them during treatment as the highest priority out of the 22 issues covered in the survey. This is a concern, given that currently support is not routinely provided for a companion to travel and be with the patient during treatment. Many patients rely on close family or friends to support them during cancer treatment, and separation from them during the treatment itself is counter-productive to their support. The health care professionals also felt that all rural patients should have the option of a subsidised escort for support. Rural patients experiencing side effects from treatment particularly those receiving palliative treatment rely on support at home, and in the context of reduced access to local cancer health care professionals including psychosocial support (Wilkes and White, 2005) the need for a support person during treatment is evident.

Companionship during the cancer treatment period is also of importance as family members and friends at home are unlikely to have a full understanding of what the patient has gone through if they have not been present throughout treatment. This may be a factor in the assumption by participants in this study that their spouse would accompany them to treatment, indeed for many, going to treatment without their spouse or partner did not even appear to be a possibility. The focused literature review did not demonstrate differences in psychosocial needs between rural and urban patients but a lower expectation of care provision and higher tolerance for problems accessing support was identified in rural residents. It is possible that a higher tolerance may contribute to lack of identification of concerns.
Research by Atkinson et al which reinforces the importance of companionship identified that those with companionship at the treatment location, whether at the hospital with a fellow patient or by staying with someone while away from home, had a better experience, in a study conducted in Scotland (Atkinson, Kennedy, Goldsworthy and Drummond, 2002). The experience of support in patients undergoing radiotherapy treatment was also examined by Hinds and Moyer, with a view to identifying how patients perceive support from family and friends as well as from health care professionals (Hinds and Moyer, 1997). An issue identified as being important to patients who had relocated was that they were in an unfamiliar environment, which contributed to feelings of vulnerability. This reinforces the importance of having a companion during treatment.

Other Australian research has identified a different aspect of being away from home with a significant other, showing that unlike the survey findings presented it can actually create a burden as the person with cancer may feel responsible for the relocation and keeping their partner from home, or for leaving their partner at home by themselves, knowing that their absence is arduous (Martin-McDonald, Rogers-Clark, Hegney, McCarthy and Pearce, 2003). However, in this study companionship was a high priority for participants and the absence of companionship was viewed as an important difficulty which is less likely to be an issue for urban patients.

**Being away from home**

One of the main reasons psychosocial issues have been identified as a concern for rural patients is due to their isolation from usual networks while undergoing treatment away from home (Payne, Jarrett et al., 2001). Being away from home during treatment for cancer and the consequences of how that is managed is an additional burden that urban residents don’t experience. Likewise, on return home, social contact with others may be limited, again creating isolation during the experience of cancer, as commented by a rural woman ‘…cancer is, for rural people, a very lonely experience’ (Sullivan, Weinert et al., 1993, p41). Patients have a need for relatively simple support through what has been described as ‘ordinary’ conversation with others (McGrath, Patterson et al., 1999b) to alleviate concerns. In this study participants clearly indicated that being away from home was a burden and the formal supports available were not used as substitutes or to complement their existing sources of support.
Payne’s study comparing island and urban cancer patients showed that patients from isolated areas can receive equivalent, or in some cases greater levels of support in being away from home, in comparison with those who are able to remain at home during treatment (Payne, Jarrett et al., 2001). Her findings are supported by later work by Fitch demonstrating that a benefit of being away from home is the access to peers and their support (Fitch, Gray, McGowan, Brunskill, Stegges, Sellick, Bezjak and McLeese, 2003), however this cannot necessarily be said to wholly compensate for being away from home. Furthermore, it has also been shown that distress can be created if the patient with cancer becomes attached to friends made where they are staying who they then lose contact with (Gray, James, Manthorne, Gould and Fitch, 2004).

Research findings detailing the burden of being away from home have been used to support an argument for the establishment of a regional radiotherapy treatment facility, particularly as it was identified that some patients were making treatment decisions with the need to relocate being a factor in deciding to have surgery instead of radiotherapy (Martin-McDonald, Rogers-Clark et al., 2003). However, the population needs must be balanced with the assessment of what services can viably be offered, due to workforce issues, costs of offering specialist treatment outside the metropolitan centres, and also as centres offering care infrequently have less opportunity to develop specialist skills and experience at an equivalent level to major centres.

**Supports used**

Few formal supports were used by the participants in this study. The need for psychosocial support among rural patients diagnosed with cancer has been well established (Sullivan, Weinert et al., 1993; Burman and Weinert, 1997b; Burman and Weinert, 1997a; Silveira and Winstead Fry, 1997; Davis, Girgis et al., 1998; Davis, Williams, Redman, White and King, 2003; National Breast Cancer Centre and National Cancer Control Initiative, 2003). A common theme among these authors is of psychosocial support being an important issue for those undergoing cancer treatment, however the degree to which the support is provided and source of support differs. It was striking that in this group of participants, although nearly half reported feeling a large or extreme effect of separation from family and friends (n=46), the use of formalised psychosocial support mechanisms appeared low, with only one participant reporting participation in a cancer support group. Support groups can be difficult to organise.
and maintain in rural areas when compared with the urban setting (Gray, James et al., 2004) which may be a factor in this finding.

Of the 48 participants (50%) who had not seen a social worker, only four indicated that they would have preferred to receive this support. Similarly in a study by Davis et al (Davis, Williams et al., 2003) only 10% of the 204 women in the study of rural women with early breast cancer reported social workers to be a source of support. In relation to counselling support, none of the 88 participants (92%) who did not see a psychologist or counsellor felt they would prefer to see one. Half of the participants belonged to community organisations such as clubs and church groups. However, despite this relatively high level of membership, only 20 (21%) of all participants reported receiving some form of support from a local organisation. The finding of little use of formal supports is surprising, given how highly participants rated their psychosocial needs, but may indicate that their needs are largely met if they are able to use them as preferred, such as having a spouse or family member travel and stay with them during treatment.

Girgis et al also identified that most of the high priority needs were in the areas of health information and psychosocial needs in a needs assessment of women with breast cancer which compared rural and urban residents (Girgis, Boyes et al., 2000). Only one area of significant difference in the populations was shown, this being a greater perceived need for help in dealing with fears about cancer spread or recurrence by rural women. The lack of differences identified between the groups may have been limited by the category of rural used to delineate the urban and rural groups, as 60% of the rural participants lived within one hours travel time of chemotherapy treatment and therefore had a relatively high level of access to specialist care. However the findings echo research by McGrath showing that fear of recurrence is a significant issue for rural women who have completed treatment for breast cancer (McGrath, Patterson et al., 1999a). Fear of recurrence was not identified as a priority issue in this research but may reflect the different point in the disease trajectory that participants were at, with most receiving treatment at the time of participation in the survey.

In this study electronic communication methods were not used by participants to obtain psychosocial support. Few psychosocial interventions have been researched specifically in rural populations but there is increasing interest in interventions of electronic communication such as internet based support groups. A study conducted by Winzelberg et al (Winzelberg,
Classen, Alpers, Roberts, Koopman, Adams, Ernst, Dev and Taylor, 2003) of a web based cancer social support group demonstrated improvements in reducing depression scores, perceived stress, and trauma related to cancer. Although this study was not conducted with rural participants, it is potentially of use for rural patients as it overcomes the need for patients to travel to attend the group. However, the effectiveness of this type of intervention for rural populations depends on the accessibility of electronic telecommunication and it’s unclear whether this type of communication would meet the need for companionship identified in this survey.

**Changing needs over the treatment period**

Some participants identified differences in the psychosocial support needed between the experience of the first and subsequent cycles of treatment. There appeared to be a perception that it was more important to be accompanied when attending Adelaide for the first cycle of treatment when the participant needed to navigate to and within the hospital system and were unsure what effects the treatment would have and nervous of their ability to cope. Subsequent treatment cycles were seen as being easier to manage alone. This change in perception of need partly confirms McGrath’s findings (McGrath, 2001) in a study of the needs of patients who had returned home after treatment for haematological malignancies and disorders. Approximately a third of the participants indicated that their needs changed over time, mainly due to improvement or deterioration in their physical wellbeing. However in this survey it appeared that the needs of participants were also influenced by emotional changes. There seemed to be a growing confidence in the ability to cope with attending for treatment following the first treatment.

**Advocacy**

An important aspect related to companionship and psychosocial support is the role of advocacy assumed by the companion identified in the survey findings. Many commented on the importance of having an ‘extra pair of ears’ to hear what the health care professionals were recommending and in the companion being able to verbalise and ask questions on the patient’s behalf. These supports were seen as instrumental in overcoming difficulties in participating assertively in interactions with health care professionals.

Advocacy issues are known to be of great importance to patients with cancer due to the complexity of cancer care, the breadth of information available and the possibility of
discrimination against those with a diagnosis of cancer (Gomez and McHale, 2002). In Australia there is currently not a strong emphasis on the role of the spouse or partner as advocate in the information gathering and decision-making during the cancer journey. The health care professionals interviewed identified that a rural care provider focusing on supportive care needs could be useful for rural residents with cancer and could also incorporate an advocacy role. The survey participants did not identify this as a strategy, instead focusing more on communication with the cancer care providers they were already in communication with and the importance of having a companion for support.

**Other psychosocial interventions**

Some psychosocial strategies have been used in a research setting to test their effectiveness in mitigating the psychosocial impact of treatment on rural residents. The use of a workbook journal with stories, advice on coping strategies and messages of inspiration did not show a significant intervention effect, but the women using the journal reported feeling emotionally supported (Angell, Kreshka, McCoy, Donnelly, Turner-Cobb, Graddy, Kraemer and Koopman, 2003).

Psychosocial support has also been offered to rural residents through the use of teleconference sessions (Curran and Church, 1999). The topics for discussion were initiated by the participants and 11 of the 14 topics discussed by the authors were related to disease and treatment issues (p49), possibly indicating a higher need in this area.

These types of interventions were not used or recommended by participants in this study. Although they identified high needs for psychosocial support, the main preferred source of support was through being accompanied by a companion. Current psychosocial supports offered by the health care system do not financially support this option unless it is deemed medically necessary (South Australian Department of Human Services, 2002). This means that patients from rural areas face the potential barrier of cost while funding for an escort is provided on the basis of physical need only. The findings of this study affirm the importance of the psychosocial support of rural residents diagnosed with cancer and highlight specific needs in relation to being accompanied for treatment.
Summary: psychosocial needs

Psychosocial interventions have been shown to provide health care benefit to patients with cancer and the participants in this study clearly identified psychosocial needs as important. However they demonstrated minimal participation in what are considered standard interventions such as support groups or counselling by social workers and psychologists. It is unclear to what degree these services are currently available in rural and remote areas but also unclear to what degree such services would be accepted or used by patients with cancer. Participants appeared to obtain support through companionship of spouse/partner or family members rather than from professional services. It is therefore problematic that escorts of patients are not funded routinely on the basis of psychosocial support. The findings in this study indicate the importance of psychosocial concerns and also give rise to the question whether better provision of support may be an effective strategy to improve outcomes in this area.
Accessing information, communication with health professionals

Information and communication needs were identified as a high priority in this study, and specifically, a lack of coordination of care and lack of information on support services were identified as problematic. The focused literature review also showed that there is a lower use of cancer information services by rural residents but a greater need for information overall.

Information

Information needs fell into two main categories: firstly in relation to the cancer and its treatment; and secondly the practical and support aspects of treatment in Adelaide such as accommodation and transport. The sources of information used by participants differed according to these two broad categories. The main sources of information for cancer and treatment were health care staff, pamphlets and others undergoing treatment or with experience of cancer. Only 15% of participants obtained information from the internet, and of these, most commented that this was obtained by courtesy of a (usually younger) relative searching for information on their behalf.

Unmet needs for information was one of the few areas in this study where dissatisfaction was expressed by the participants in relation to both cancer and treatment and supports and services. Contrasting with the very high levels of satisfaction with care overall, 9% of participants found it difficult or very difficult to obtain information about the cancer and treatment and a further 16% were neutral on this issue.

Provision of information for patients has been identified as an issue of need in relation to cancer treatment (Wiggers, Donovan, Redman and Sanson-Fisher, 1990) including in rural populations (Gray, James et al., 2004) and it can be argued that there is nothing different about the needs of rural patients with cancer. However, participants commented on the greater amount of information available in Adelaide than in the local, rural areas, particularly in pamphlet form. This is important for participants receiving care in local areas, who therefore have reduced access to information. Furthermore, 36% of participants did not know what information was available to them locally. This is an important issue, given the moves over time to change the way that health care services are provided in rural areas, including the push to decentralise care and provide treatment in regional areas (Government of South Australia, 2003), and the current move to reduce acute services, including provision of chemotherapy, in
small country hospitals and provide these in four rural settings only (Government of South Australia, 2008).

The participants in this study appeared to have an expectation that they would be provided with the information they required at an appropriate level and time. When this expectation was not met, participants found this frustrating and had few other alternative sources from which to seek assistance. Participants rarely described making attempts to obtain information when an unmet need was identified, instead appearing to be relatively passive in this process. This is echoed in other Australian research with patients and families identifying an expectation that necessary and relevant information related to their need to travel for cancer treatment will be offered rather than them needing to seek this out (Wilkes, White, Mohan and Beale, 2006). This passivity compounds the difficulty associated with the limited amount of information being available locally. Information on cancer and cancer treatment is available through the national Cancer Council Helplines (Cancer Council Australia, 2008), however this resource was only used by a few participants.

Differences in use of information services are influenced by factors that also influence use of health care services, such as age, ethnicity, socio-economic background, employment status, health status and physician referral services. Evaluation of the use of a telephone information service showed that rural residents consistently used the service less than urban residents (Monroe, Ricketts and Savitz, 1992). Restricted access to services such as those which support information provision places rural residents at risk of poorer outcomes in understanding their treatment and compromises their ability to make informed decisions.

There is an increasing emphasis on the patient’s right to make decisions regarding their treatment, for example in relation to the treatment of early breast cancer where different treatment options of radiotherapy and surgery can be used without differences in survival outcomes (iSource National Breast Cancer Centre, 2001). The printed information provided to patients with cancer is an important source of information, however it is also known that women both are reliant on the surgeon for information regarding treatment options (Stafford, Szczys, Becker, Anderson and Bushfield, 1998) and perceive the surgeon’s preference or recommendation as important when making a decision (Mastaglia and Kristjanson, 2001). Access to specialist health care professionals is therefore important in the decision making
process, particularly for rural residents with cancer who perceive, as shown in this study, a lack of cancer information available locally.

The provision of information is also important as it empowers patients to participate in their care (Wilkes, White et al., 2000). Any barriers to accessing information compromise the patient’s ability to be actively involved in treatment decision-making. This is particularly important in cancer treatment that entails a wide range of anticipated and potential treatment effects. Ensuring patients have good knowledge and understanding of treatment effects enables them to better anticipate and safely manage these.

Information needs are high for rural residents with cancer and there is little evaluation of their needs and how strategies can be tailored to their use. This study has shown that the participants felt that information in rural areas was limited compared with that available in Adelaide and were not active in seeking out information. This leaves them vulnerable in decision making and under-informed in relation to sources of support available to them.

**Communication**

Issues of communication with health care professionals have been identified as an area of need in patients with cancer and their carers (Clavarino, Lowe et al., 2002). The majority of participants in this study were satisfied or very satisfied with communication, both with and between health care professionals. However there were many anecdotes of difficulties in communication and a lower level of satisfaction with communication with general practitioners than with other health professionals. It appeared to be important to be able to have direct access to a health care professional with knowledge of their disease and treatment from whom they could seek advice. Some participants commented that they could more easily have access to the specialist than their general practitioner and, given the general practitioner was meant to be their primary contact, their expectations were not met.

It was demonstrated through this that different systems and styles of communication were used in rural health settings compared with the specialist metropolitan centres. Some participants commented that they were given the direct mobile phone number of the specialist when starting treatment with encouragement to call should problems arise. It is not known whether this level of direct access was offered by specialists only to patients from rural and remote areas specifically to address their needs and not to patients in the urban areas. The strategy appeared to be valued by participants. In contrast, the health care professionals
interviewed felt that the general practitioner should form a key part of communication and continuity of care. This mismatch of expectation could lead to communication breakdown, leaving rural residents at risk if they are not in communication with their general practitioner.

Despite the overall satisfaction with communication, there was also some uncertainty by participants as to who their main treatment provider was, that is, who they should approach with questions regarding their treatment. While most identified the medical specialist as the main provider (78%), the remainder identified the nurse, the general practitioner or the radiation therapist (the person responsible for the actual delivery of radiotherapy) and one participant didn’t know who to go to. This could contribute to confusion and misunderstanding as to who is responsible for treatment decisions.

The number of sources of information was also problematic, for example, most participants received information from the specialist on their cancer and treatment, yet received information from different and varied sources in relation to accommodation, transport and finances. The role of the specialist and treating institution was not clear in relation to providing information on these aspects and many participants assumed that it was their responsibility to organise their own affairs so were unlikely to ask about support. However, this meant they were less likely to be informed about support services available, particularly those being treated in the private setting, who were less likely to see allied health care professionals.

Despite the high level of satisfaction with communication in relation to health professionals, 20% of participants identified areas for improvement in communication, mainly focusing on the provision of information and coordination of care. It was apparent that there were deficits identified in various aspects of care, such as problems with coordination of appointments. Some participants also believed that both the information and treatment given should have a greater consumer focus. For example, information given was not always in terms that the patient and carer could understand. In relation to treatment being patient-focused, one of the key issues seemed to be the lack of understanding of the situation of rural patients, such as travelling for some hours to attend an appointment and being told that there had been a mistake made and that they would have to return the following week.

Difficulties with communication of information can potentially be ameliorated or overcome through use of new technology. The volume of information available in rural and remote
areas, through electronic means such as tele-health and the internet is continually increasing. A framework published in 1999 reported on strategies to improve the health of rural, regional and remote Australians (National Rural Health Alliance, 1999). This report predicts that the development of electronic technology will be an important part of the dissemination of current health care information to those with limited local information services. However patients with cancer require information from both local health care bodies and metropolitan treatment centres. Strategies to maximise communication require consideration of both aspects.

Ultimately, in order for interventions aimed at improving communication and information provision to work it needs to be clear who is responsible for information provision. Currently, this falls between government bodies such as the Patient Assistance Transport Scheme office, the treating centre and the rural health care service. These issues of communication and information have a common theme relating to coordination of care. Patients from rural and remote areas are particularly vulnerable to deficits in care coordination as the impact of mistakes is so much greater than for those living in urban areas, in relation to time and travel. Participants in this study identified a need for greater clarity in communication and in receiving information in relation to both treatment and support services. Health care professionals demonstrated an understanding that lack of information and communication barriers have an adverse effect on the patient but are unsure as to what extent they are responsible. Rural residents with cancer are vulnerable to deficits in information provision and communication when this is unresolved.
The financial impact of treatment

The comparatively poorer health experienced by the financially disadvantaged (Beck, Jijon and Edwards, 1996) is likely to be exaggerated in the context of a diagnosis of cancer where the level of support and care required is high. Financial costs of treatment are greater for rural residents than metropolitan residents. This is due to travelling costs, whether by private or public transport, accommodation in the metropolitan setting, increased cost of food, the cost of maintaining contact with family and friends (for example by telephone), and the hidden cost of the patient usually being unable to work and spouse or partner also if they accompany the patient during treatment. These costs are on top of any associated with the treatment itself.

Most participants in the survey were on a relatively low income of $500 (gross) or less weekly. This was partly because in this sample, 71% were not in paid employment at the time of the study. Those with a lower income living in rural areas are less likely to access health care services and are more likely to have a poorer health status (Beck, Jijon et al., 1996; Barnett, Coyle and Kearns, 2000; Young, Dobson and Byles, 2000). Those on a low income have also been shown to perceive and experience more barriers to cancer care than those on a higher income (Burman and Weinert, 1997b; Davis, Girgis et al., 1998; Lehman, Hedges et al., 2002).

Most participants (74%) in the survey felt that there had been a financial impact on them as a result of receiving treatment in Adelaide. This is significant, given that 71% were not employed at the time of treatment, and hence would not have had their income reduced while staying in Adelaide for treatment. In this group, the cost of maintaining a household in the rural setting as well as paying for living and transport costs while in Adelaide was a concern. Additionally, the financial impact of treatment was rated highly in terms of importance by most participants. This is in line with research in Canada where unforeseen costs were identified as a significant issue, and was in addition to the more obvious costs of time away from work etc (Gray, James et al., 2004).

Reimbursement schemes

Financial reimbursement for travel and accommodation is the method used to facilitate equity of access to specialist health care for those living in rural and remote areas in Australia. The reimbursement schemes are administered by State and Territory government health services.
These schemes have been criticised because of the lack of awareness by the very patients who require or are eligible for this support, their complexity to administer and their insufficiency for patients requiring more intensive or prolonged treatment (McGrath, 1999b). Arbitrary boundaries of distance used to delineate eligible populations can also exclude patients with real needs who reside within the boundaries but are still distant from the treatment centre. These distances vary between 50 to 200km (Clinical Oncological Society of Australia, The Cancer Council Australia et al., 2003), which adds to the confusion and inequity seen.

There was a relatively high level of awareness of the availability of financial support in this sample as 83% reported knowing that support was available. This was likely to have been influenced by the high numbers of participants recruited from subsidised accommodation services including Greenhill Lodge, i.e. already accessing a support service for people in their situation. Problems arose for this group despite them having this knowledge though, as 10% did not receive any financial reimbursement and of those who did receive reimbursement, 34% reported difficulties in accessing this. Given that the reimbursement is offered in order to ensure access to specialist care, any barriers in accessing this means that the patients concerned are experiencing the process of reimbursement as a difficulty rather than a support. This is unacceptable given the barriers of time and distance that rural patients are already facing.

There were also differing perceptions of the purpose of the schemes as some participants commented that they had not applied for reimbursement as they were not in financial difficulty at the time. The reimbursement scheme is not means tested and is for reimbursement of costs rather than to assist those in financial need, so there appears to be a misconception about the purpose of the schemes resulting in those eligible for reimbursement of costs not receiving this. The requirement for patients to provide up front payment of costs and request reimbursement is also problematic, both for those on low incomes and because any delays in reimbursement add to the financial strain being experienced (Lehman, Hedges et al., 2002).

**Reimbursement for interstate patients**

Costs of patients attending the nearest interstate treatment centre are reimbursed by their home state, which has particular relevance for South Australia as the specialist centres in Adelaide provide a service to rural and remote South Australia, Northern Territory, western Victoria and western New South Wales. This means that the schemes used in Adelaide are the South
Participants staying in Greenhill Lodge frequently made contact with other patients from rural areas through their access to communal eating and entertainment areas. It was commented by some participants that confusion was experienced when discussing reimbursement issues and when advice conflicting with that provided by health professionals was given by fellow patients. Comments were also made that health care staff were unsure about reimbursement amounts and how to access them. Previous research has identified barriers to accessing reimbursement schemes, such as lack of knowledge and lack of flexibility in the schemes (Davis, Girgis et al., 1998; McGrath and Seguerra, 2000). Confusion relating to conflicting advice received from other patients has not previously been identified and may be a particular concern in South Australia given the wide catchment areas for specialist services in Adelaide.

**Reimbursement process**
Participants in this study were nearly all undergoing treatment at the time of the survey and may therefore have been particularly at risk of experiencing an adverse financial impact from treatment, as during the early stages of treatment patients are likely to be focused on the life threatening aspects of the diagnosis and treatment rather than the usually less urgent issues of cost related to travelling to Adelaide. The need to keep receipts and request signatures from medical officers may be either overlooked or not done and costs incurred cannot be reimbursed without these at a later date.

The early stages are not the only time that is problematic however, as the reimbursement process requires the patient or spouse/partner to go to the local hospital or medical officer, obtain authorisation for the form, then get the specialist to co-endorse the form, as well as filling in the necessary cost and receipt information. Patients who find filling out the forms difficult can ask for assistance from the treating institution but they are still responsible for completion of the form and obtaining the necessary signatures. It is questionable as to whether this complexity of process is necessary or appropriate for people undergoing this type of treatment. Usually the time allocated for a specialist appointment is limited and use of this time to fill out forms for authorisation of reimbursement of costs incurred is not necessarily in
the best interests of the patient and rather than providing support can conflict with the patient’s needs.

The health care professionals identified that the process of accessing reimbursement is burdensome and that patients may feel inhibited about raising issues of finance with health care professionals. They identified a need for health care professionals to raise the issue as part of an initial assessment to ensure that access to reimbursement was achieved by those eligible. It has also been argued that rural health care professionals should ensure that rural residents accessing specialist care are aware of support services including reimbursement schemes when they are referred to metropolitan services (Keleher and Ellis, 1996). This could be useful for standard services such as reimbursement but the rural health care practitioners may not be aware of all services available across the different specialties.

A minority of participants in this study accessed the reimbursement scheme by having the costs of an escort subsidised (30%). A slightly higher percentage of participants were accompanied by a non-authorised, i.e. non-funded escort (32%). Given the relatively low income of most participants and the increased costs incurred through travelling to and staying in Adelaide this is a significant finding as it contributed to the financial hardship experienced by participants.

Another Australian study focusing on rural women with early breast cancer identified that 53% of 240 participants reported not receiving financial assistance and of those who did receive assistance, 13% experiencing difficulty in claiming it (Davis, Williams et al., 2003). These findings are echoed in a study by Clavarino in which concerns about financial reimbursement for costs incurred was identified as an issue by 30% of the 28 patients interviewed (Clavarino, Lowe et al., 2002). In this study the participants were relatively well informed, however still experienced barriers and hardship related to costs incurred while undergoing treatment in Adelaide. The participants did not always see it as their right to be reimbursed, instead sometimes perceiving it to be based on need. Health care professionals may not perceive financial aspects of treatment to fall within their domain of practice, and as a result may not always take responsibility for ensuring patients are aware of supports available. The reimbursement schemes are presented as being non-means tested and relatively straightforward (Government of South Australia, undated), however this study has shown they are frequently experienced by patients as being complicated and burdensome.
It is clear that financial barriers can impede the use of health care services by rural residents, whether these are pre-existing or illness related. The barriers presented by cost of travel, treatment and accommodation may be exacerbated by the lower socio-economic status of residents in rural and remote areas. To what degree financial barriers impede access to care is unclear, however that they exist and are perceived as a concern for rural patients with cancer is well documented (Burman and Weinert, 1997b; Davis, Girgis et al., 1998; Clavarino, Lowe et al., 2002; Lehman, Hedges et al., 2002; Davis, Williams et al., 2003). This survey showed that knowledge of the schemes alone was insufficient to ensure that rural residents were able to obtain reimbursement for costs incurred.

**Health care insurance and related costs**

The cost of health care was a source of concern for many participants. Five participants did not have private health care insurance, but had been referred to a private treatment centre for their cancer treatment. They were unsure as to their financial liability for treatment, whether or not they were being treated as a private patient, and who to ask regarding this issue. This is despite hospitals having a process of routinely determining on admission whether patients are being treated on a private or public basis and discussing this with the patient concerned. Furthermore, six participants with private health cover were unsure if they were receiving treatment as a private or public patient so did not know what costs they were going to incur. Other research has also shown that patients being treated privately are not always aware that they can receive the same treatment free of charge as a public patient (Hegney, Rogers-Clark, Martin-McDonald and Buikstra, 2005). Such issues are a demand on patient’s attention when they are in a stressful situation involving cancer treatment and relocation and for the participants in this survey the uncertainly about costs, added to the known costs, created unnecessary distress.
Travel and accommodation
Specialist treatment is provided in Adelaide for patients from throughout South Australia, the Northern Territory and parts of New South Wales and Victoria. As discussed in the previous section, accommodation and transport reimbursement schemes operate in all States and Territories and are intended to ensure equity of access to specialist treatment (South Australian Department of Human Services, 2002). In South Australia these schemes are used to provide partial reimbursement of costs rather than the actual accommodation or transport. Accommodation is largely provided by charitable bodies such as Cancer Council South Australia and the Leukaemia Foundation, by hospitals, for example residential wings at major hospitals and commercial hotel accommodation can also be used. Public or private transport may be accessed by rural residents with cancer, but when they are in Adelaide, transport may be provided by Cancer Council South Australia if they are staying in the motel accommodation, or by the Leukaemia Foundation.

Participants were largely satisfied with their transport within Adelaide, which may have been influenced by the large numbers staying at Greenhill Lodge who therefore had access to their free bus service. Problems experienced were related more to their access to and use of transport from home and accommodation in Adelaide.

Those going by commercial plane to Adelaide needed to book flights but at times faced the uncertainty of bed availability at the treating centre, with some needing to cancel due to hospital bed shortages. This added to the stress of travelling to Adelaide and having treatment, as well as the difficulty with making arrangements for family and household. The distance participants lived from Adelaide was also important in terms of the method used to travel to Adelaide and whether it was possible for participants to return home for a break during treatment. One participant paid to fly to Mount Gambier each weekend throughout the six weeks of radiotherapy treatment so that she would not be separated from her family for this prolonged period of time. Others would have preferred to go home but were unable to due to cost or transport issues.

Public transport is one option which can be used by patients receiving cancer treatment in Adelaide, however 62% of participants in this study travelled by private car to their treatment and appointments. Public transport was not seen as a viable option by most, with 45% of participants stating that they felt their access to this form of transport was very inconvenient,
inconvenient or neutral. Two participants had no knowledge of what public transport to Adelaide was available to them. There also appeared to be a perception that public transport was there for the use of those who could not afford private transport, rather than being a viable option for common use. This perception creates a potential barrier for those who could benefit from the use of public transport.

**Impact of cancer treatment**

Another barrier to the use of public transport was the physical fitness of the participant concerned. A moderate to extreme physical effect of travel was felt by 47% of participants. There are many symptoms associated with the diagnosis and treatment of cancer, with fatigue the most commonly reported (Grant and Kravits, 2000). Factors influencing the degree of physical effect participants felt could have been related to the type of treatment, point of treatment they had reached, distance and method of travel. Metropolitan based patients also need to travel to receive treatment, but for rural and remote patients, the physical impact of long hours of travel after chemotherapy is likely to exacerbate or potentiate treatment-related side effects such as fatigue, nausea and vomiting. The physical impact of travel and treatment has been previously identified (Guidry, Aday et al., 1997; Payne and Jarrett, 2000; Hegney, Rogers-Clark et al., 2005) and is a particular concern for rural and remote patients who do not have a carer to travel with them. It has been identified that longer distances may have a greater impact on rural residents with cancer (Junor, Macbeth et al., 1992), but in this study it appeared to be more important that the patient have a support person with them and access to transport.

Participants also indicated that their travel and transport arrangements were convenient but there were many anecdotes of apparently difficult travelling situations using different forms of transport each time the person travelled to Adelaide, such as driving, catching a bus, flying and then travelling to the accommodation or hospital. This seemed to again reflect an acceptance of hardship expected from living in a rural area. Participants also accepted the need to drive instead of flying in order to bring supplies for the stay in Adelaide, even if they would normally fly. The importance of carers in providing practical support with travel was seen in the comments made by participants that it was important for their spouse/partner to accompany them to treatment so they could drive them home as they would not be physically able to drive themselves.
Difficulties with parking in the city and near the treatment centre did not emerge as a significant issue in this study, largely because parking was anticipated by participants to be a problem and avoided through the use of strategies such as friends and relatives providing transport, public transport and transport provided in the subsidised accommodation. Those who did not anticipate difficulties with parking and make arrangements to avoid the need to drive and park found parking was most problematic on the first visit to Adelaide due to the lack of knowledge about where to park and stress associated with travelling to Adelaide for treatment for the first time. Parking permits may be provided by hospital staff on request however, this usually meant that if the participant did not ask they did not receive a permit.

A systematic review to investigate the impact of travel on cancer patients’ experience of treatment found that there was a ‘perceived or actual influence of distance and travel to treatment upon the treatment outcome or compliance’ (p202), and that this was possibly related in part to the nature, mode and accessibility of travel including cost (Payne and Jarrett, 2000). The review provided confirmation that the requirement of travel is likely to be a burden for rural patients, but was not able to identify specific common issues and strategies to improve care for these patients. This study has found that companionship is a crucial factor in reducing the burden of travel for rural residents with cancer.

**Accommodation**

While participants were overall satisfied with their accommodation, the need to organise accommodation and food and payment for these was a source of concern in the context of undergoing cancer treatment. Those most at risk of being disadvantaged in accessing accommodation were those without support from family or friends in Adelaide or those who did not know of accommodation options and were not informed of these by the health care team. Only two participants used the internet to get information about accommodation and transport support, although this information is available at treatment centre websites (Royal Adelaide Hospital, 2003) and cancer support and information sites (The Cancer Council South Australia, 2003).

A secondary consideration less frequently addressed in the literature is the reliance of patients on subsidised accommodation. In this study, the main source of subsidised accommodation used by participants was Greenhill Lodge, owned and managed by Cancer Council South Australia. Greenhill Lodge was rated highly overall by participants staying there, but some
specific problems were identified, such as the cost of meals, difficulties with the transport provided, the cost of phone calls (residents were charged at commercial rates and phone cards were not available during the study period) and smoking by some residents in front of their rooms.

Some of the issues identified seemed to relate to a fundamental problem that the motel was not designed for the needs of the group using it, i.e. medium to long-term accommodation for patients with cancer and their carers. For example, one participant interviewed at the motel accommodation was found by the researcher to be hungry, physically unwell due to pain, appeared to be sedated by the codeine he was taking and without carer support. Food was not available at the accommodation over the weekend and the support personnel at the time of the survey was a social worker who was available four hours a day, Monday to Friday and accessed through request of the motel resident. This participant had been discharged from hospital on the preceding Friday afternoon. He was subsequently readmitted to hospital the following week. The absence of government or hospital funding for this type of accommodation and the current use of a charity organisation to provide this accommodation means that the development of specialised accommodation is unlikely.

Subsidisation of accommodation is an essential part of providing cancer care to rural patients to ensure equity of access to treatment in the metropolitan setting. Again, this is an area that does not appear to fall into any one organisation’s area of responsibility, which leaves the patients concerned vulnerable to deficits in support, particularly when they are not evaluated in relation to the specific needs of the patients. Since this study was commenced, evaluation of accommodation at Greenhill Lodge has been conducted with input from the preliminary findings of this study.

In contrast, a description of accommodation usage at facilities provided for patients in Queensland with haematological malignancies such as leukaemia demonstrates how housing dedicated for the use of patients from rural areas can be successfully used for their support (McGrath, 1999a). Many of the facilities for haematology patients in Queensland are purpose built, can be used by patients and their families for prolonged periods free of charge and located close to major metropolitan cancer treatment centres. The Leukaemia Foundation of Queensland also has a requirement that all using the accommodation facilities provided are
accompanied by a carer, due to the possibility that patients will become debilitated during treatment.

Not all patients have access to this type of dedicated accommodation, whether purpose built or otherwise. Many hospitals use buildings that were previously used to house hospital staff for general and patient accommodation (Lehman, Hedges et al., 2002). Evaluation of these forms of accommodation as to their suitability to rural residents with cancer is not available. Many patients choose to stay with relatives rather than staying in accommodation provided by the treatment centre or charitable body, however research evaluating these options is also limited. In this study the levels of satisfaction with subsidised accommodation tended to be higher than for private accommodation leading to the question of why this should be so.

The organisation of travel and accommodation may be overlooked by metropolitan based health care professionals as seemingly trivial and prosaic when compared with the issue of a cancer diagnosis and treatment. Research indicates that these are practical concerns of great importance to those undergoing cancer treatment (Guidry, Aday et al., 1997; McGrath, 1999a; Bain and Campbell, 2000; McGrath and Seguerra, 2000; Payne and Jarrett, 2000), but there are few studies focusing specifically on this area and fewer on interventions to improve management.

In this study, difficulties with cost, the time spent away from home and the lack of support for the spouse/partner to accompany the patient were issues perceived as barriers by many participants. The provision of travel and accommodation support was divided between government reimbursement schemes of and charitable bodies providing subsidised accommodation. This division of responsibility was further complicated by the multiple sources of information on support resources available from both rural and metropolitan health care providers. The health care professionals interviewed identified the complementary roles played by hospitals and cancer charities, with both having a key role in the support of rural residents with cancer but a lack of direct communication as a problem area leaving rural residents at risk if there were gaps in the support system. Patients require support to access specialised cancer treatment on an equitable basis. When the manner and degree of support is not consistently offered it leaves rural residents vulnerable.
Practical concerns

Support was often needed by participants in the home setting. Practical arrangements were made by 59% of participants for assistance with areas such as care for household members, pets and gardens. Neighbours frequently provided this assistance, however some participants commented that asking for help was acceptable on a short term basis, but became problematic over time during the treatment period. Support in these areas is rarely available for rural residents unless through friends and/or neighbours. The greater the degree of remoteness, the less likely it is that such support will be available (Buehler and Lee, 1992) and the more reliant the person with cancer is on a companion if they have one. In the survey, companions of participants were seen as a source of practical assistance across a range of activities, such as physical care, preparing food, driving and navigating in the city and assisting in communication with the health care team.

Practical support issues were of concern to participants, yet there were difficulties experienced in accessing supports and information about the supports available. As commented previously, there was no single source of information about supports and it was not even clear whether this type of support was the responsibility of patients, health care workers, or carers and families. Social workers in either the rural or metropolitan centres were identified by 48% of participants as having provided information on supports such as transport and accommodation, indicating this is a key function of their role. It is therefore a concern that 50% of participants did not see a social worker, particularly those being treated in the private setting. It is also a concern that for rural and remote participants, the information source for cancer treatment was clearly identified as the specialist and treating staff however, the information source/s for practical support which assumed greater importance to participants were less clear. This is another area of need which does not necessarily fall into any one organisation’s responsibility which may contribute to the lack of clarity. The health care professionals interviewed did not identify the practical concerns of rural residents with cancer as an issue, reinforcing that they may not view this area as their responsibility. If resources are needed yet not available, the greater the strain is likely to be on the carer (Buehler and Lee, 1992) and the consequences for the rural resident with cancer could be significant.
Cancer treatment

Most participants were very satisfied or satisfied with health care given. While it is tempting to take this finding on face value, it should not be accepted uncritically, particularly in view of the undemanding attitude towards health care that can be seen in those from rural and remote areas (Buehler and Lee, 1992; Keleher and Ellis, 1996). Participants also commented that they had relatively few expectations of cancer care in Adelaide, due to lack of knowledge, negative media portrayal and negative perceptions of cancer treatment generally. Focus group research has identified that lower expectations are held by rural patients when compared with metropolitan patients, together with a less demanding approach as health care consumers (Bain and Campbell, 2000). Coming from this frame of mind, any ‘positive’ aspects of treatment are also likely to be experienced in stark contrast. It also means that feedback from rural patients should be scrutinised and complemented with broader health care service evaluation where possible to assess the care and support provided.

Access to allied health care professionals

Referral to allied health support as required is important in the provision of comprehensive cancer care. Referral to these services is particularly important for rural and remote patients, as there may be limited local resources, depending on the size of the community concerned (Hegney, McCarthy et al., 1999). Two groups of allied health care professionals frequently involved in the support of cancer patients are social workers and dieticians. Patients may be referred to a social worker for general psychosocial support and advice on financial and employment issues. Patients from rural and remote areas may be referred for discussion and advice on managing their absence from home from both a psychological and a practical viewpoint. Patients may also be referred to a dietician for assessment of nutritional status and advice on maintenance of good nutritional intake while undergoing treatment.

Most participants were satisfied that they had seen appropriate health care professionals in relation to their cancer treatment, however those being treated in the private setting were significantly less likely to see a social worker or a dietician than those in the public setting. The reason for this was unclear. Possible factors may be that the needs of patients attending private health care setting were lower than those attending the public health care setting; that the associated financial cost to the patient precluded referral to allied health in the private
setting; that allied health care team members were less frequently employed in the private setting; or there was over-referral in the public setting.

Some participants demonstrated a pragmatic approach to their visits to Adelaide by indicating that they would have liked to have seen other health care professionals for concurrent, non-cancer health care needs, for example a physiotherapist, to make the most of their visit and to ensure the most effective use of health care resources. It demonstrates both a lack of flexibility in the health care system that access to other health care professionals was not possible but also that cost could have been a factor as physiotherapy services do not require referral from a general practitioner.

**Access to cancer treatment**

This study did not seek to directly evaluate the level of access to treatment or the effectiveness of cancer treatment provision in rural areas, but rather to describe the experience of accessing metropolitan cancer treatment and determine where the system has failings and can be improved and where it is working well. The survey established that chemotherapy treatments are being administered in all health care regions of South Australia and further showed that the participants were overall satisfied with the treatment received in both rural and metropolitan areas, but that there were issues of accessing care that presented significant problems. It was also clear that while participants would prefer to access treatment locally where possible, the care had to be high quality, they were not willing to compromise the quality of care to achieve greater accessibility. In fact some 70% of participants would have preferred to access treatment locally yet only 24% accessed at least some of their treatment in a rural setting.

Support for chemotherapy treatment through the use of video linkages and presentation of clinical data including X-Rays for discussion is available in South Australia (Olver and Selva, 2000). However the level of support on a policy level for treatment in rural areas is unclear. Although the ‘Generational Health Review’ of health care services in South Australia called for accessible provision of health care to South Australians based on justice and equity, it failed to identify people living in rural and remote areas as a population with specific needs (Government of South Australia, 2003). It is difficult to see how the system of care for this population can be improved without explicit identification of their needs and targeted interventions to address these. More recently in South Australia the Statewide Cancer Control Plan has been developed jointly by The Cancer Council South Australian and the South
Australian Department of Health. This identifies the need for all people to be able to access quality cancer care including multidisciplinary care, but does not address strategies to achieve this (The Cancer Council South Australia and the SA Department of Health, 2006).

The health care professionals interviewed identified a concern that the care provided to rural residents must be equivalent in quality as far as possible given the constraints imposed by their rurality. The greater the rurality or remoteness of the area, the more likely the general practitioner is to provide complex forms of treatment not commonly undertaken by their counterparts in metropolitan areas such as chemotherapy (Humphreys, Jones et al., 2003). This is also the case for the provision of nursing care (Hegney, McCarthy et al., 1999). There needs to be a balance between providing the specialist care needed for people diagnosed with cancer and the need to educate and train rural GPs who see relatively few patients with cancer but who are responsible for their care throughout the treatment trajectory from diagnosis to palliation (White, 2007). However the health care professionals interviewed in this study tended to focus on ensuring access to care was maintained rather than making specialised care more available in rural areas.

The type of treatment chosen, i.e. radiotherapy or surgery may be influenced by the degree of rurality or remoteness of the rural resident with cancer (Bettencourt, Schlegel, Talley and Molix, 2007). In this survey, participants who were already accessing metropolitan based treatment were recruited so any differences related to access to health were not able to be determined. However, some participants identified that the difficulty associated with travelling to Adelaide for treatment and staying away from home was such that if they were told that further treatment was required they would not accept this, regardless of the consequence in terms of prognosis. This prediction was not able to be tested in the current study but it gives an indication of how arduous some participants perceived the process of accessing metropolitan cancer treatment.

An unexpected finding in this study was that the treatment itself was not always available at the prescribed time. Participants from one of the public hospitals described having to make contact with the hospital to check bed availability before making arrangements to come to Adelaide. This included organising blood testing and flights, and put the participants concerned under considerable pressure due to uncertainty as to when they would need to
travel. This has not been reported elsewhere in the literature related to rurality and may be indicative of an increasing pressure in the public health care system.

Ensuring and improving access to specialist care is perceived to be an issue for rural residents, yet improving access to care is inherently problematic as this is not the direct responsibility of clinicians, but instead falls under government health care policy and the management of infrastructure and health care delivery. Health care professionals and consumers contribute to the process of health care reform by identifying areas of need and advocating or lobbying, for example, through consultative forums. A national meeting of cancer professionals and consumers held in 2001 titled ‘Cancer in the Bush’ focused on cancer care provision in rural areas. This resulted in a call for research into the disparities between urban and rural cancer care, particularly in the areas of access, psychosocial support and quality of life (Cancer in the Bush: Optimising clinical services, 2001). The South Australian Statewide Cancer Control Plan calls for all people to have equitable access to high quality cancer treatment and services no matter where they live and acknowledges the need for rural residents to have ‘frequent and easy access to their family and locally based support networks’ (The Cancer Council South Australia and the SA Department of Health, 2006, p33). The provision of support which is so crucial in enabling rural residents to access cancer care is not addressed specifically in this plan, except in the statement that cancer care service providers should be cognisant of rural residents’ need for access to family members and local networks when planning services. It is not clear how this is to be achieved and the important role that charitable bodies such as Cancer Council have in providing support to rural residents is not discussed. It is hard to see how services currently provided in a complementary fashion such as cancer treatment and accommodation services can be improved if these roles are not placed centrally in such a planning process as a state-wide cancer control plan and acknowledged.

**Rural or shared care**

Overall, participants who received part of their treatment in the rural setting were satisfied with this care. Some participants had been offered the option of receiving treatment locally and had decided against this. The reasons given for refusal were to ensure continuity of care when treatment had already started, a belief that the levels of experience, expertise and access to technological care were greater in Adelaide and a lack of trust in the ability of local health care professionals to provide specialist care. One strategy used to provide specialist care is
through the use of visiting specialist staff (Lyckholm, Hackney et al., 2001). This improves the accessibility of care, but can create problems with continuity of care, privacy (due, for example, to the likelihood that patients being treated in a chemotherapy day treatment area will know other patients being treated) and the lack of supervision when specialist staff are not present. These strategies were not used to provide treatment for the patients in this survey and could have reduced the number of times that some participants travelled to Adelaide.

Providing access to specialist health care professionals can also be achieved through phone support. This has been successfully piloted in NSW (Wilkes, Mohan, White and Smith, 2004) as a support to patients and families within a rural health care region with access to the palliative care team in the area, but could be extended to provide access to metropolitan based staff as well. While the nationally accessible Cancer Council Helpline can provide some level of support to those affected by cancer, this service does not provide medical advice so is of limited assistance. The recent development of a national health care advice phone service which is currently being implemented across Australia (Government of South Australia, 2006) is another potential source of support for rural residents. This will provide a source of general support available 24 hours a day which is valuable for residents in rural and remote areas but will not be a source of specialist information relating to cancer and cancer treatments.

Continuity of care has been identified as an issue of importance in the provision of rural cancer care (Curtiss, 1993; Wilkes and White, 1998). When rural residents feel confidence in their local health care services they are more likely to feel well supported during cancer treatment (McGrath, Patterson et al., 1999b). Furthermore, if general practitioners are involved in organising the cancer treatment including support services from an early stage, patients are likely to feel more supported and may have a better experience throughout their cancer journey than those who don’t have this support (Atkinson, Kennedy et al., 2002). While many participants in this survey would have preferred to receive treatment locally, they accepted that provision of specialist care in rural and remote areas was not feasible and focused on the medical specialist in Adelaide as being the main source of information about their treatment and effects. They also mostly focused on the metropolitan health care team for support to the exclusion of the general practitioner and local health care services and no participants appeared to view local and metropolitan health care personnel as a team working together. This creates potential issues in relation to lack of continuity of care both during treatment and
when treatment is completed and leaves a gap in care if the patient is relying on contacting the specialist when problems arise and then is unable to.

It is argued that improvements in primary care and better access to multidisciplinary services may help to reduce inequalities in cancer care and outcomes (Jong, Vale and Armstrong, 2005). This is supported by work by Wilson et al (Wilson, Oldenburg and Lopez, 2003) analysing trends in avoidable deaths in New South Wales from 1980-2000. The results showed that primary, secondary and tertiary prevention strategies could be targeted to prevent many potentially avoidable deaths including cancer. At the other end of the spectrum, while there can never be the equivalent access to expert treatment, arrangements such as shared care can be used to improve the ability of rural and remote residents to access expert care at critical points in the management of cancer, for example assessment at diagnosis and initiation of treatment.

**Use of tele-health**

The use of tele-health has been shown to be satisfactory from health care professionals’ view point (Kunkler, Rafferty, Hill, Henry and Foreman, 1998) but may not suit patients to the same degree and it is worth considering how it could have been used to support participants in this survey. Evaluation of tele-health clinics has showed that while the convenience was highly valued in eliminating the need for travel, the patients using the service believed that it was suitable only for routine, uncomplicated consultation and lacked the level of personal and clinical interaction that would be seen in a face to face setting (Mair, Whitten et al., 2000). The convenience of access also needs to be weighed against the limitations of this form of technologically supported care. For example, it is possible that patients may withhold information due to sensitivity and privacy concerns (Mair, Whitten et al., 2000). However, as outlined in the background chapter, it has been demonstrated that tele-health can be effectively used to provide patients with cancer with information about their diagnosis and treatment (Sezeur, Degramont et al., 2001) and patients can find its use satisfactory, even if they had previously had face to face consultations with the medical specialist (Allen and Hayes, 1995). Tele-health can also provide access to multidisciplinary care team consultation which would not be feasible to offer as a face to face service in remote areas (Olver, Shepherd and Selva-Nayagam, 2007). It is a concern that despite the positive outcomes that can be realised for rural residents through using this technology, it was not used to support the care of any of the
96 participants in this survey. The health care professionals interviewed noted that tele-health services can provide a useful adjunct to face to face specialist care but did not identify a need to extend or expand the current services. This is an area where greater attention and resources could greatly benefit rural residents with cancer.

In summary, the actual treatment provided (i.e. chemotherapy, radiotherapy) was the least problematic of the issues the participants identified. In terms of priorities overall, it was ranked sixth which could reflect the participants’ overall satisfaction with treatment. However the delays experienced by some participants were a concern and were identified by these patients as unacceptable. Some participants also queried the value of their treatment when it resulted in them being away for so long. The lack of local cancer treatment was also problematic and could be addressed through use of technologies such as tele-health.
Conclusion

This study contributes to the body of research into rural Australian residents with cancer who are receiving treatment in the metropolitan setting. The international studies published are few in number, vary in methodological approaches used and use a wide range of definitions of rurality. Australian studies are also small in number and tend to focus on specific diagnostic groups. This study used a large sample of rural residents and drew information from a range of sources to investigate metropolitan provided cancer care for rural residents. The findings showed that the expectations of participants of treatment itself were largely met but their expectations or needs of support including practical and psychosocial aspects were not.
Chapter 6 - Conclusions

Overview

It is neither viable nor appropriate to offer highly specialised and expensive cancer treatments (such as bone marrow transplantation and radiotherapy) in regional areas. Hence the need for some rural and remote patients to travel to receive appropriate treatment is inevitable. This thesis has examined the situation of rural and remote patients with cancer including when they undergo treatment in the metropolitan setting and identified a number of key findings. Firstly there are some differences in cancer survival outcomes for rural residents in South Australia when compared with urban counterparts and this cannot be explained by differences in risk factors and incidence.

The literature search showed that research to date into the factors affecting rural residents undergoing cancer treatment in Australia was limited and focused mainly on patients in specific disease groups. While there is excellent data available in Australia to monitor the effects of cancer surveillance and prevention, this is not routinely used to focus on the health of rural Australians and does not provide information about the experiences of rural residents undergoing treatment.

The survey of participants undergoing cancer treatment in Adelaide was intended to be descriptive rather than comparative or explanatory and was not intended to differentiate between groups of participants. However, factors that may have been influential were identified where possible. Inclusion of patients undergoing different types of treatment for different cancers was also considered to be important to ensure the identification and description of issues was relevant to a broad range of patients.

The survey identified that overall patients were satisfied with the quality of treatment they were undergoing. While this is an important positive finding it is necessary to evaluate the health care system rather than rely solely on patient satisfaction in order to make meaningful change (Hiidenhovi, Laippala and Nojonen, 2001). The detailed description of their experiences showed that the circumstances of patients attending for treatment varied widely and that the support provided to attend for treatment did not always meet their needs. The highest area of need identified by participants was for psychosocial support, however the use of formal support strategies such as support groups and specialist allied health care
professionals was low. The support most commonly used by participants was the companionship of spouse or partner but two thirds of participants did not receive financial support for this despite most participants being on a relatively low income. The participants’ support needs also appeared to change over time but the support strategies available were not tailored to this change, for example greater support was not always available at the beginning of treatment in Adelaide. Participants also viewed the support of a companion as a virtually essential component of their ability to access treatment by providing practical as well as emotional support.

The provision of information was an area of difficulty for participants partly due to a lack of knowledge about where to access it, i.e. in the rural setting or in Adelaide. As there were a number of sources of information it wasn’t clear which should be used as a primary source. Some participants accessed the specialist directly for their communication needs while others used their local general practitioner. Information is a basic area of need for rural residents with cancer and the survey findings identified that there was a lack of coordination and no systematic approach used to provide them with information, leading to frustration and uncertainty.

It was also identified that processes of coordination of care were problematic with breakdown in communication resulting in difficulty for some due to the greater distances needed to travel to access care. This occurred partly as the responsibility for provision of treatment and provision of support to attend treatment were in the domain of separate staff or organisations. The separate responsibility for these areas created a risk that some were disadvantaged if they did not have access to the relevant sources of information.

The financial impact of having treatment in Adelaide is exacerbated by the low income of many rural residents undergoing cancer treatment as cancer is primarily a disease of the elderly. This makes it crucial that all rural residents eligible for reimbursement of costs related to treatment receive accurate information about the schemes and experience the reimbursement process to be as straightforward as possible. This study identified that there were issues with both participants being informed about the schemes and in accessing the support. For some the situation is complicated by cancer treatment being provided by both private and public health care institutions without having clear understanding of the costs that were being incurred.
In relation to travel and accommodation satisfaction with private accommodation was slightly lower than commercial accommodation, including subsidised accommodation provided by charitable organisations. This requires further investigation to ensure that rural residents who may prefer to stay in commercial accommodation but find the associated costs prohibitive are well supported while staying in Adelaide. There were also issues with subsidised accommodation primarily in areas where commercial interests overlapped with the needs of the rural residents with cancer. There is a delicate balance required to reconcile the need to offer a subsidised accommodation service that both meets the needs of the rural residents with cancer and achieves success as a business. The practical needs of rural residents need to be included in evaluation of the service provided.

The survey also showed that rural residents with cancer have practical needs to arrange while they are away from home that become increasingly difficult to achieve the longer they need to be away, such as care of pets. Currently there are few supports available other than making arrangements with friends and neighbours and this is unlikely to change.

An unexpected finding from the study is that the use of shared health care arrangements were minimal and few interventions were used to minimise the number of visits required by the rural residents with cancer. There is significant opportunity to improve the management of care through care coordination and use of technology such as tele-health. One finding not specifically related to rurality was the lower access to allied health care professionals by those having treatment in the private setting. This is a concern for rural residents however, as they may also have restricted access to allied health in the rural setting.

The health care policy from which the interventions are developed to support rural residents with cancer in accessing specialist treatment requires a broader input of data including information on supportive care outcomes. This study has shown that there is little data available on use of support systems and related outcomes for rural residents with cancer which makes it difficult to formulate targeted, effective interventions. For example the low use of formal support networks could place rural residents at risk of adverse psychosocial outcomes, however while information is not routinely gathered about psychosocial outcomes this will remain a silent problem.

There was congruence between the description of patients’ experiences undergoing treatment and the opinions of health care professionals responsible for providing care. Health care
professionals identified that there was sufficient information on treatments and services, but believed that the systems and processes of informing patients were variable in practice and in effectiveness. The low use of electronic forms of communication was noted as a potential area for improvement in information provision.

**Health care policy**

The development of health care policy is informed by analysis of data measuring health care outcomes and its implementation is only as effective and appropriate as the information it is based on. It is also difficult to identify deficiencies in care unless data is systematically collected and analysed with this purpose. Australia has excellent cancer registry data that have been used to measure the effects of prevention and early detection interventions as discussed in chapter 2. The same quality of data is not available for care delivery aspects for cancer including treatment and support.

The formulation of health care policy is somewhat complicated in Australia as federal and State and Territory governments all have a role in formulating health care policy but the State and Territory governments have a greater focus on the actual delivery and regulation of health care. Federal policy measures may be informed through work done by externally managed but government-funded groups. For example, the national ‘Optimising Cancer Care in Australia’ report (Clinical Oncological Society of Australia, The Cancer Council Australia et al., 2003) was prepared through the collaboration of three organisations in cancer control in Australia. These were:

- The National Cancer Control Initiative, an expert reference body that provided advice, identified initiatives and made recommendations to the government and key groups regarding the prevention, detection, treatment and palliation of cancer in Australia (funding ceased for this body in 2006).
- The Clinical Oncological Society of Australia, a multi-disciplinary group of cancer professionals.
- The Cancer Council Australia, a national cancer control body.
These groups used a process of consultation to identify key themes in cancer services, which were then developed into key issues and recommendations, with the intent of these being implemented by the Commonwealth Government.

More recently the National Health Priority Action Council prepared a national framework to identify opportunities for improving prevention and care in the national health priority areas including cancer (National Health Priority Action Council (NHPAC), 2006). This states that ‘people with cancer will have access to all relevant expertise and facilities regardless of where they live’ and that they will ‘experience the cancer journey as seamless and continuous care provided by one integrated service’ (p38).

State policy is developed with input from reports such as the Generational Health Review in South Australia (Government of South Australia, 2003). This report sought to rationalise and redefine health care service provision with a move towards primary health care. The subsequent Statewide Cancer Control Plan outlined a range of actions to optimise cancer care in South Australia and to reduce the impact of cancer (The Cancer Council South Australia and the SA Department of Health, 2006). Since this study was started, Cancer Australia has been established as the national government body providing leadership in cancer control (Cancer Australia, 2007). One of the strategies that has been implemented is the establishment of CanNET in all States and Territories as a demonstration project intended to link regional and metropolitan cancer services into comprehensive cancer networks. In South Australia one of the activities being undertaken is an audit to collect and analyse baseline data on the infrastructure used in the current provision of cancer services in South Australia (Cancer Service Networks National Demonstration Program, 2008). While this will be useful it demonstrates the current lack of comprehensive information available on cancer services, with even less available on supports.

So there is certainly no deficit in cancer care policy and recommendations for actions on state and national levels, and there are a number of ways in which the implementation of health care policy can be assessed and evaluated. Budget adherence is one indicator which may be used. Satisfaction surveys may be conducted by health care institutions, however these tend to evaluate perceptions of care rather than outcomes. Quality control measures may also be used by institutions, for example, assessing the incidence of readmission, intravenous infection and length of stay. However these are indicators of care rather than a comprehensive evaluation of
the overall care delivery. On a national level, information on health care service provision is available from the Health Insurance Commission, which is the body responsible for the administration of the Medicare Program. However, this does not include information on services provided for public patients in hospitals (Overland, 2000). Evaluation of care is therefore achieved primarily through budget reports, patient feedback and institutional indicators of care. However these are all indirect indicators of care. It is difficult to see how appropriate service planning and policy development can take place in the absence of centrally available and assessed data on current service provision. There are also difficulties in assessing the total treatment and support provided as a number of organisations are involved, such as cancer charities.

There is a current gap in the knowledge that policy is based on in South Australia as information on cancer service provision is not gathered in any systematic way. The findings in this survey suggest that rural residents with cancer are experiencing difficulties and barriers in accessing cancer care. This survey has identified that policy development and implementation should be underpinned by data which more accurately and appropriately progresses the outcomes for rural residents with cancer including issues of practical support.

**Policy implications**

Policy underpinning cancer treatment should be informed not only by patient preferences as to priorities but also input from health care professionals who have a broader perspective. Service delivery should be informed by patient priorities but in Australia the potential costs of fully supporting rural and remote patient preferences are significant and need to be weighed against affordability. Equally, health care professionals once armed with the information on what is preferred by patients have an obligation to advocate for service delivery improvements. Policy implementation can also promote partnership between consumer groups, cancer providers and support agencies and help to ensure ongoing collaboration. The current activities by CanNET SA are likely to provide a greater level of information on cancer health service provision. Supportive care needs are likely to remain largely invisible and as the responsibility for these is not owned by a single agency, this may not change.
Recommendations

Psychosocial support

Cancer treatment for rural residents is currently provided through either taking the specialist care to the patient or by taking the patient to the care. The further the patient lives from the tertiary health care centre the more problematic both options become. The strategy used to bring patients to the care from a government level is through subsidisation of transport and accommodation for the patient only except in cases where a companion is authorised on medical grounds. However this study has shown that in order to allow equitable psychosocial support and to avoid treating the patient in isolation from their family, subsidisation should include supporting escorts for patients based on psychosocial needs as well as medical.

Patients from rural and remote areas undergoing cancer treatment in metropolitan areas should be provided with flexible, patient orientated support that is informed by evaluation of the outcomes of care and support. Evaluation of these outcomes should be carried out collaboratively with health care providers and consumers. As a part of this, greater understanding is needed as to why local supports are not accessed and how support for patients can be optimised whether through local formal or informal networks.

Information provision

There appears to be a general understanding or assumption that the treating hospital has responsibility for ensuring patients have equitable access to specialist care, however the practical assistance for access is provided through government reimbursement schemes, which is not linked to their hospital care. Routine processes need to be implemented to ensure provision of information on reimbursement schemes to all patients who are eligible for reimbursement.

Given the number of health care staff involved in the care of patients with cancer, it is important that patients know who to contact and when, particularly in relation to complications of treatment. Involvement of multiple bodies in information provision also means that coordination of information requires cooperation between the organisations concerned. Coordination of the information and clarity over which body is accountable for its
communication increase the availability and provision of information. Case manager or rural liaison positions could be used to achieve this.

**Access to health care**

Lack of access to health care professionals in rural areas may have a significant impact on patients with cancer due to the intense and high risk nature of their treatment. It may not be sufficient that the patient is under the care of a general practitioner but also whether they are able to access care reliably on a 24 hour basis.

The option of tele-health for consultation on chemotherapy treatment options is likely to be acceptable and cost effective (Sezeur, Degramont et al., 2001) and could be used to support information provision for rural patients. Technology is available to share information among all health care professionals involved in patients’ care and could be used to facilitate shared-care arrangements (Mann, 2005) to better care for rural residents diagnosed with cancer. Visiting specialist staff did not provide treatment for the patients in this survey but may have been of benefit in reducing the number of times that travel to Adelaide was required.

**Financial support**

The assumption by participants in this study that they should not apply for reimbursement of costs if they were not in current financial difficulty indicates that clear information on the eligibility for the scheme needs to be provided to all rural patients. In this study the participants were relatively well informed of the existence of the reimbursement schemes, however still experienced hardship related to costs incurred while undergoing treatment in Adelaide. This highlights the need to assess the individual patient’s situation when providing cancer care, to maximise the quality and appropriateness of care given.

The situation where interstate patients attend for treatment and require reimbursement creates additional problems that need to be addressed by treatment centres caring for these patients and support agencies providing accommodation. Reducing the complexity of the reimbursement process would also improve the access to and equity provided by the schemes.
Care coordination and support

The impact of delays in treatment due to hospital bed pressures on rural patients in relation to their need to travel means that better coordination of care is warranted. It is clear from this study that greater coordination of care would benefit rural residents with cancer. The benefits of care coordination for people with cancer are becoming increasingly well recognised (Cancer Nurses Society of Australia, 2008) and would be of particular benefit in rural populations. It may also be useful for health care professionals to consider differences between the first and subsequent visit when making arrangements for patients with cancer as this study indicated that the needs of rural residents with cancer differ at these time points.

Hospitals providing cancer treatment to rural and remote residents and organisations providing their support should have linked systems of communication to ensure that patients have a smooth, well supported and informed journey.

Data gathering

Data to assess and monitor care delivery aspects of cancer treatment is needed to provide information on outcomes related to psychosocial and practical support.

Further research

Many issues identified in this survey are unlikely to be unique to patients with cancer. What creates special needs or pressures for patients with cancer is the life threatening nature of the diagnosis, the volume and frequency of visits and the side effects and complications of treatment. A comparative survey of cancer versus non-cancer patients in Australia would be useful to establish gaps in care and to ensure that all strategies currently being used to enhance patient care are considered for use in the broader health care context. In addition, a comparative analysis of treatment support outcomes with metropolitan residents would be useful to identify discrepancies in patient outcomes and possible reasons for these.

Investigating changes in perceptions of care and ability to cope over time may be useful to aid in tailoring support provision more appropriately to patients’ needs. A follow-up study to assess the effect on those who attended for treatment without being accompanied by a spouse
or partner to determine if their adjustment on the return home was affected would assist to clarify how important this need is.

Research is needed to assess the acceptability of private accommodation with relatives and friends and to determine how many patients were using this as an option due to ignorance of other options available.

The acceptability and feasibility of evolving interventions such as internet based interventions needs to be determined for rural residents with cancer.

Given that there was little use of support networks such as community groups by the participants even when they already belonged to such groups, it is hard to predict whether electronically accessed models would be acceptable and used. Research is therefore needed to determine acceptable interventions and their effectiveness.

Further investigation is warranted to discover why those with private health care were less likely to see allied health personnel.

Finally it would be useful to specifically examine whether there are any differences in the impact of travelling or relocating for cancer treatment according to the degree of remoteness.

**Conclusion**

This thesis has presented a series of investigations into the situation of rural residents diagnosed with cancer. It has not attempted to address the needs of rural residents with cancer while based in rural regions but rather as they are required to interface with metropolitan specialist centres. It has been shown that cancer treatment for rural residents is a complicated process. This research report has sought to rigorously examine the issue of cancer treatment for rural residents and thus be ‘a foundation for positive change’ (Rice and Ezzy, 1999, p29).

This thesis in total forms the report of an investigation into the needs and experiences of rural and remote patients undergoing cancer treatment in Adelaide. While it cannot be said that the sample in this study is representative of all those undergoing cancer treatment from rural and remote areas in Australia, the presentation of background information and description of the research process and findings allows the reader to gain an understanding of this area in the context of health care provision in Australia.
It is the argument of this thesis that to ensure an equitable and acceptable degree of quality of care and outcomes of cancer control activities, financial support for rural residents should be routinely provided to enable them to bring a support person when travelling to Adelaide. Investigation of the process of treatment itself is also needed to ensure that the supports designed to ensure access for rural residents are appropriate and suited to their needs. Cancer treatment is a complex process and this complexity combined with the needs of rural residents relocating to the vicinity of metropolitan specialist centres means that clear communication and coordination are paramount to ensure equitable patient outcomes.
Appendices
Appendix 1: Summary of seven interdependent goals to focus national activity and planning on issues of high priority for the health of rural, regional and remote Australians

(National Rural Health Alliance, 1999)

NOTE:
This appendix is included on pages 261-263 of the print copy of the thesis held in the University of Adelaide Library.
Appendix 2: Patient assistance transport scheme reimbursement form

NOTE:
This appendix is included on pages 265-269 of the print copy of the thesis held in the University of Adelaide Library.
Appendix 3: Search strategies of electronic databases

**AustHealth**

#1 cancer*  (4381 records)  
#2 chemo*  (528 records)  
#3 neoplas*  (4223 records)  
#4 oncolog*  (684 records)  
#5 #1 or #2 or #3 or #4 (7081 records)  
#6 rural  (7595 records)  
#7 remote  (1985 records)  
#8 #6 or #7  (8433 records)  
#9 #5 and #8  (222 records)

**Cancerlit**

#1 rural and treatment  210 records  
#2 remote and treatment  540 records  
#3 rural and chemo*  30 records  
#4 rural and rad*  215 records

**CINAHL**

#1 explode 'Neoplasms-' / all topical subheadings / all age subheadings in DE (20993 records)  
#2 explode 'Oncologic-Nursing' / all topical subheadings / all age subheadings in DE (4023 records)  
#3 'Oncologic-Care' / all topical subheadings / all age subheadings in DE (1253 records)  
#4 'Cancer-Patients' / all topical subheadings / all age subheadings in DE (3406 records)  
#5 explode 'Chemotherapy-Cancer' / all topical subheadings / all age subheadings in DE (1197 records)  
#6 'Cancer-Care-Facilities' / all topical subheadings / all age subheadings in DE (256 records)  
#7 #1 or #2 or #3 or #4 or #5 or #6 (26054 records)  
#8 'Rural-Health' / all topical subheadings / all age subheadings in DE (1209 records)  
#9 'Rural-Areas' / all topical subheadings / all age subheadings in DE (1827 records)  
#10 'Rural-Health-Services' / all topical subheadings / all age subheadings in DE (715 records)  
#11 'Rural-Health-Centers' / all topical subheadings / all age subheadings in DE (20 records)  
#12 'Rural-Health-Nursing' / all topical subheadings / all age subheadings in DE (636 records)  
#13 'Frontier-Nursing-Service' / all topical subheadings / all age subheadings in DE (128 records)  
#14 'Hospitals-Rural' / all topical subheadings / all age subheadings in DE (316 records)  
#15 'Rural-Health-Personnel' / all topical subheadings / all age subheadings in DE (33 records)  
#16 #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 (3872 records)  
#17 #16 and #7 and (English in la) (125 records)

In addition, more focused terms were used in the following search.  
#1 explode 'Neoplasms-' / all topical subheadings / all age subheadings in DE (22292 records)  
#2 therap* (133337 records)
#3 #1 and #2 (8067 records)
#4 radi* (25199 records)
#5 chemo* (5891 records)
#6 explode 'Bone-Marrow-Transplantation' / all topical subheadings / all age subheadings in DE (718 records)
#7 #3 or #4 or #5 or #6 (34658 records)
#8 rural (8430 records)
#9 remote (1276 records)
#10 frontier (769 records)
#11 #8 or #9 or #10 (9902 records)
#12 #7 and #11 (649 records)
#13 #12 and (English in la) and (DT=RESEARCH) (178 records)

Current Contents
Database: Current Contents Full <1993 - 2001 Week 35>
Search Strategy
#1 cancer.mp. (mp=abstract, title, author keywords, keywords plus) 218094
#2 neoplasm.mp. (mp=abstract, title, author keywords, keywords plus) 9637
#3 1 or 2 224426
#4 treatment.mp. (mp=abstract, title, author keywords, keywords plus) 555597
#5 3 and 4 56993
#6 rural.mp. (mp=abstract, title, author keywords, keywords plus) 21590
#7 remote.mp. (mp=abstract, title, author keywords, keywords plus) 19963
#8 6 or 7 41050
#9 5 and 8 216

Medline
1966-1992
#1 explode 'Neoplasms-' / all subheadings in MIME,MJME (861143 records)
#2 'Cancer-Care-Facilities' / all subheadings in MIME,MJME (995 records)
#3 'Oncology-Service-Hospital' / all subheadings in MIME,MJME (48 records)
#4 explode 'Medical-Oncology' / all subheadings in MIME,MJME (1702 records)
#5 explode 'Radiotherapy-' / all subheadings in MIME,MJME (38546 records)
#6 'Radiation-Oncology' / all subheadings in MIME,MJME (1 record)
#7 'Chemotherapy-Adjuvant' / all subheadings in MIME,MJME (844 records)
#8 explode 'Drug-Therapy' / all subheadings in MIME,MJME (78816 records)
#9 'Rural-Health-Services' / all subheadings in MIME,MJME (3 records)
#10 'Hospitals-Rural' / all subheadings in MIME,MJME (1007 records)
#11 explode 'Remote-Consultation' / all subheadings in MIME,MJME (0 records)
#12 explode 'Social-Isolation' / all subheadings in MIME,MJME (6005 records)
#13 #9 or #10 or #11 or #12 (7015 records)
#14 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 (937594 records)
#15 #13 and #14 (165 records)
#16 #15 and (English in la) (129 records)

1993 - October week 2 2001/10
In addition, more specific search terms were used in the following searches.

#1 14854 country
#2 8274 remote
#3 87276 regional
The Cochrane Library

#1 cancer*
#2 neoplas*
#3 chemo*
#4 oncol*
#5 hematology
#6 (cancer*) or (neoplas*) or (chemo*) or (oncol*) or (hematology)
#7 rural
#8 remote
#9 (rural) or (remote)
#10 (((cancer*) or (neoplas*) or (chemo*) or (oncol*) or (hematology)) and ((rural) or (remote)))

Search results
Search term: ((((CANCER* or NEOPLAS*) or CHEMO*) or ONCOL*) or HEMATOLOGY) and (RURAL or REMOTE)) (No restrictions)

<table>
<thead>
<tr>
<th>Database</th>
<th>Hits (Total)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Cochrane Database of Systematic Reviews</td>
<td></td>
</tr>
<tr>
<td>Complete reviews</td>
<td>53 (1081)</td>
</tr>
<tr>
<td>Protocols</td>
<td>11 (866)</td>
</tr>
<tr>
<td>Database of Abstracts of Reviews of Effectiveness</td>
<td></td>
</tr>
<tr>
<td>Abstracts of quality assessed systematic reviews</td>
<td>2 (1993)</td>
</tr>
<tr>
<td>Other reviews: bibliographic details only</td>
<td>0 (800)</td>
</tr>
<tr>
<td>The Cochrane Controlled Trials Register (CENTRAL/CCTR)</td>
<td></td>
</tr>
<tr>
<td>References</td>
<td>124 (307870)</td>
</tr>
<tr>
<td>Medical Editors Trial Amnesty</td>
<td>0 (2)</td>
</tr>
<tr>
<td>The Cochrane Database of Methodology Reviews</td>
<td></td>
</tr>
<tr>
<td>Complete reviews</td>
<td>0 (1)</td>
</tr>
<tr>
<td>Protocols</td>
<td>0 (4)</td>
</tr>
<tr>
<td>The Cochrane Methodology Register</td>
<td></td>
</tr>
<tr>
<td>References</td>
<td>0 (3407)</td>
</tr>
<tr>
<td>About the Cochrane Collaboration</td>
<td></td>
</tr>
<tr>
<td>The Cochrane Collaboration</td>
<td>0 (1)</td>
</tr>
<tr>
<td>Collaborative Review Groups - CRGs</td>
<td>0 (50)</td>
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<td>Fields</td>
<td>0 (10)</td>
</tr>
<tr>
<td>Methods Groups</td>
<td>0 (14)</td>
</tr>
<tr>
<td>Networks</td>
<td>0 (1)</td>
</tr>
</tbody>
</table>
Centres 0 (14)
Sources of support 0 (1)

Health technology assessment database (HTA)
Abstracts by INAHTA and other healthcare technology agencies 1 (2187)

NHS Economic evaluation database (NHS EED)
Abstracts of economic evaluations of health care interventions 6 (682)

PsycLIT

Search History
#1 explode 'Neoplasms-' in DE (8228 records)
#2 explode 'Drug-Therapy' in DE (45927 records)
#3 canc* (12485 records)
#4 'Radiation-Therapy' in DE (229 records)
#5 #1 or #2 or #3 or #4 (58359 records)
#6 'Rural-Environments' in DE (4775 records)
#7 rural (11160 records)
#8 remote (2298 records)
#9 #6 or #7 or #8 (13362 records)
#10 #5 and #9 (203 records)
Appendix 4: Survey form

Cancer treatment in Adelaide - A survey

This survey is being conducted to investigate issues arising for people living in rural or remote areas receiving cancer treatment in Adelaide. The results will form part of a PhD project to identify where services can be improved.

I appreciate that this may be a difficult time for you however your opinions and suggestions on what you have found beneficial and how to improve services are highly valued. Your responses will remain confidential. This survey form should take approximately 40 minutes to complete.

If you would like to receive information about the results of this study, please write your contact details in the space provided at the end of the survey, or contact the researcher directly, Kate Cameron ph 08 8303 3645, fax 08 8303 3594 or email kate.cameron@adelaide.edu.au

Thank you very much for your assistance in completing this survey.

Yours sincerely

Kate Cameron

Code  □□□□□
1. Demographic information

The following questions are used to ensure there is a representative sample of people surveyed in this study.

1.1 Gender (please tick) □ Male                □ Female

1.2 Age (years) __________________________

1.3 Country of birth ________________________

1.4 What is your current marital status? (please tick)
   □ Married
   □ Defacto/living with partner
   □ Divorced/separated
   □ Widowed
   □ Never married/single

1.5 Who are the current members of your household (the place you live) (tick all applicable)
   □ Marital/defacto partner
   □ Children
   □ Parents
   □ Siblings
   □ Live alone
   □ Other (please specify) __________________________
1.6 What is the highest level of school education that you have completed? (please tick)

- [ ] Did not complete primary school
- [ ] Completed 7 years of primary school
- [ ] Fewer than 3 years at high school
- [ ] 3 years at high school
- [ ] 4 years at high school
- [ ] 5 years at high school

1.7 Aside from school, what is the highest qualification that you have completed? (please tick)

- [ ] None
- [ ] Trade or certificate course
- [ ] Technical diploma
- [ ] Graduate degree or diploma
- [ ] Postgraduate degree or diploma
- [ ] Other (please describe) __________________________
2. Place of residence

2.1 Where do you currently live? (please tick)

☐ Town/city  (Please state name) ________________________________

OR

☐ Farm

Approximately how far is it to the nearest town/city _____________ (km)

Please state the name of the nearest town/city ______________________

2.2 Approximately how far do you live from Adelaide? ________________ (km)
3. Travel information

3.1 How do you most commonly travel from home to Adelaide for treatment? (please tick)

- Private car
- Plane (commercial)
- Train
- Bus
- Community car
- Royal Flying Doctor Service
- South Australian Ambulance Service
- Other (please specify) ________________________________

3.2 How convenient is this method of transport? (please circle the number which best describes how you feel)

1 2 3 4 5

Very convenient convenient neutral inconvenient very inconvenient

Please comment

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

3.3 Approximately how long does it usually take you to travel from home to Adelaide using this method? (hours)

________________________________________________________________________
### 3.4 How convenient is your access to public transport to and from Adelaide? (please circle the number which best describes how you feel)

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very convenient</td>
<td>convenient</td>
<td>neutral</td>
<td>inconvenient</td>
<td>very inconvenient</td>
</tr>
</tbody>
</table>

Please comment:

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

### 3.5 How much of a physical effect do you feel from travelling to treatment? (please circle the number which best describes how you feel)

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>small</td>
<td>moderate</td>
<td>large</td>
<td>extreme</td>
</tr>
</tbody>
</table>

Please list the effects you feel and/or give examples:

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

### 3.6 Has the need to travel delayed your treatment in any way? (please comment)

[ ] Yes  [ ] No

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
3.7 How do you most commonly travel within Adelaide? (please tick)

☐ Public transport
☐ Community vehicle
☐ Greenhill Lodge bus
☐ Private transport
☐ Other (please state) ___________________________________________

3.8 How convenient is this method of transport? (please circle the number which best describes how you feel)

1 2 3 4 5

Very convenient   convenient   neutral   inconvenient   very inconvenient

Please comment
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

3.9 How convenient for you is parking in Adelaide? (please circle the number which best describes how you feel)

1 2 3 4 5

Very convenient   convenient   neutral   inconvenient   very inconvenient

☐ Not applicable

Please comment
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
4. Accommodation

4.1 Where do you most commonly stay while in Adelaide (please tick)

- Hospital
- Relative's home
- Motel accommodation
- Own property
- Greenhill Lodge
- Not applicable
- Other (please specify) ________________________________

4.2 How satisfied are you with your accommodation? (please circle the number which best describes how you feel)

1 2 3 4 5

Very dissatisfied dissatisfied neutral satisfied very satisfied

- Not applicable

Please comment

_____________________________________________________________
_____________________________________________________________
_____________________________________________________________
_____________________________________________________________
5. Treatment and treatment delivery information

The following questions are about your cancer and treatment. If you have not yet finished treatment, please answer as correct at the time of completing this survey.

5.1 What type of cancer do you have? ______________________________

5.2 What type of treatment are you currently receiving? (please tick all applicable)

☐ Radiotherapy
☐ Chemotherapy
☐ Surgery
☐ Other (please specify) ______________________________

5.3 When did your current treatment start?

_______________________________________

5.4 Approximately how long is your treatment planned to last?

☐ Ongoing  OR  ________________________ (months)

5.5 At which hospital in Adelaide are you receiving most of your treatment?

_______________________________________

5.6 Are you receiving your treatment mainly as an inpatient or an outpatient?

☐ Inpatient  ☐ Outpatient

5.7 Do you have private health cover?

☐ Yes  ☐ No (go to Q 5.9)

5.8 Are you currently being treated as a private patient?

☐ Yes  ☐ No  ☐ Don't know
5.9 Approximately how many times will you need to go to Adelaide for treatment?

☐ Don't know  OR ________________________________

5.10 Approximately how long will you need to stay in Adelaide for each visit?

________________________________________

5.11 Have you received any of your current treatment from a local health care service?

☐ Yes  ☐ No (go to Q 5.15)

5.12 What treatment have you received locally? (please tick)

☐ Chemotherapy  ☐ Surgery  ☐ Radiotherapy  ☐ Other (please state) ________________________________

5.13 How far do you need to travel for this treatment? (km) ____________

5.14 How would you rate your satisfaction with treatment you have received locally? (please circle the number which best describes how you feel) (go to Q5.16)

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very dissatisfied</td>
<td>dissatisfied</td>
<td>neutral</td>
<td>satisfied</td>
<td>very satisfied</td>
</tr>
</tbody>
</table>

Please comment

______________________________________________________________

______________________________________________________________

______________________________________________________________
5.15 Would you prefer to have received any of your current treatment locally? (please comment)

☐ Yes (please state which) ☐ No ☐ Undecided

_____________________________________________________________

_____________________________________________________________

5.16 Would you prefer to have follow up appointments locally or in Adelaide? (please comment)

☐ Locally ☐ Adelaide ☐ Either

_____________________________________________________________

_____________________________________________________________

5.17 Are you satisfied with the availability of appointments in Adelaide in relation to your treatment? (please comment)

☐ Yes ☐ No

_____________________________________________________________

5.18 Are you satisfied with the time of day appointments are available? (please comment)

☐ Yes ☐ No ☐ Is not a concern

_____________________________________________________________

5.19 Have you been able to coordinate different appointments within the one visit to Adelaide? (please comment)

☐ Yes ☐ No ☐ Not applicable

5.20 During your current treatment, what health personnel have you seen (other than the doctors and nurses directly involved)? (please tick all applicable and indicate whether you saw them locally or in Adelaide)

☐ None _____________________ OR

☐ Social worker _____________________

☐ Physiotherapist _____________________

☐ Psychologist/counsellor ________________
5.21 **Are there any health care personnel that you would like to have seen in relation to your treatment?** (please tick all applicable, and whether you would have liked to see them locally or in Adelaide)

- None ______________________ OR

- Social worker ______________________
- Physiotherapist ______________________
- Psychologist/counselor ______________________
- Dietician ______________________
- Occupational therapist ______________________
- Other (please state) ______________________

5.22 **Have you contacted health care staff in Adelaide in relation to your treatment?**
(please state who you contacted, how many times and what it was about)

- Yes ______________________
- No ______________________

____________________________________________________________
____________________________________________________________
____________________________________________________________
5.23 How would you rate your satisfaction with treatment you have received in Adelaide? (please circle the number which best describes how you feel)

1 2 3 4 5

Very dissatisfied dissatisfied neutral satisfied very satisfied

Please comment

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________
6. Information and communication

6.1 From where have you received information about your cancer and treatment? (please tick all applicable)

☐ Have not received information

OR

☐ Local GP
☐ Local cancer doctor
☐ Local nurses
☐ Adelaide cancer doctor
☐ Adelaide nurses
☐ Cancer help line
☐ Internet
☐ Local social worker
☐ Adelaide social worker
☐ Friends and/or relatives
☐ Anti-Cancer Foundation pamphlets
☐ Information pamphlets from elsewhere (eg hospital)
☐ Others who have had cancer treatment
☐ Pharmacist
☐ Books
☐ The Cancer Care Centre
☐ Other (please specify) ________________________________

6.2 Which of these sources was the most useful to you?

______________________________
6.3 From where have you received information about practical support services in relation to your treatment (eg finances)? (please tick all applicable)

☐ Have not received information

OR

☐ Local GP
☐ Local cancer doctor
☐ Local nurses
☐ Adelaide cancer doctor
☐ Adelaide nurses
☐ Cancer help line
☐ Internet
☐ Local social worker
☐ Adelaide social worker
☐ Friends and/or relatives
☐ Anti-Cancer Foundation pamphlets
☐ Information pamphlets from elsewhere (eg hospital)
☐ Others who have had cancer treatment
☐ Pharmacist
☐ Books
☐ The Cancer Care Centre
☐ Other (please specify) _________________________________

6.4 Which of these sources was the most useful to you?

_________________________________
6.5 How easy was it to find information about your treatment and its effects? (please circle the number which best describes how you feel)

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very easy</td>
<td>easy</td>
<td>neutral</td>
<td>difficult</td>
<td>very difficult</td>
</tr>
</tbody>
</table>

Please comment

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

6.6 Do you feel you have enough access to information in your local area about your cancer and treatment?

☐ Yes  ☐ No  ☐ Don’t know

Please comment

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

6.7 How would you rate your satisfaction with communication between you and the cancer doctor in Adelaide? (please circle the number which best describes how you feel)

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very dissatisfied</td>
<td>dissatisfied</td>
<td>neutral</td>
<td>satisfied</td>
<td>very satisfied</td>
</tr>
</tbody>
</table>

Please comment

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
6.8 How would you rate your satisfaction with communication between you and the GP? (please circle the number which best describes how you feel)

1 Very dissatisfied  2 dissatisfied  3 neutral  4 satisfied  5 very satisfied

Please comment_____________________________________________________________
_____________________________________________________________
_____________________________________________________________

6.9 How would you rate your satisfaction with communication between you and the cancer nurses in Adelaide? (please circle the number which best describes how you feel)

1 Very dissatisfied  2 dissatisfied  3 neutral  4 satisfied  5 very satisfied

Please comment_____________________________________________________________
_____________________________________________________________
_____________________________________________________________

6.10 How would you rate your satisfaction with communication between the health professionals involved in your care? (please circle the number which best describes how you feel)

1 Very dissatisfied  2 dissatisfied  3 neutral  4 satisfied  5 very satisfied

☐ Don't know

Please comment_____________________________________________________________
_____________________________________________________________
_____________________________________________________________
6.11 Who do you see as your main treatment provider (ie, the person you would ask about treatment) (please comment)

________________________________________________________________________

________________________________________________________________________

6.12 Please comment on any improvements you think could be made in communication or access to information.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
7. You and your household
The following questions are about the impact of having treatment in Adelaide on you and your household.

7.1 How would you rate the effect on you of being separated from your family and friends during treatment? (please circle the number which best describes how you feel)

1 2 3 4 5
None small moderate large extreme

☐ Not applicable

Please comment

_____________________________________________________________
_____________________________________________________________

7.2 Have you had to make special arrangements for any members of your household or family while you are in Adelaide? (eg children, partner, parent)

☐ Yes (please describe)  ☐ No

_____________________________________________________________
_____________________________________________________________

7.3 Have you needed to make any special arrangements for the management of your household while you are in Adelaide? (eg garden, pets)

☐ Yes (please describe)  ☐ No

_____________________________________________________________
_____________________________________________________________

7.4 How important is it that someone (friend/partner) go with you to Adelaide during your treatment? (please answer this regardless of whether anyone has gone with you during treatment) (please circle the number which best describes how you feel)

1 2 3 4 5
not at all slightly moderately very extremely
7.5 What is (or would be) their key role?

_____________________________________________________________

7.6 Do you have a medically endorsed escort?

☐ Yes  ☐ No

7.7 Has someone gone with you during your treatment in Adelaide?

☐ Yes  ☐ No

7.8 Has the need to have treatment in Adelaide had an impact on any of your personal relationships? (please comment)

☐ Yes  ☐ No

7.9 Do you belong to any local community organisations?

☐ Yes (please list)  ☐ No (go to Q8.1)

7.10 Please describe any support you have received from community organisations during your treatment.

_____________________________________________________________

_____________________________________________________________

_____________________________________________________________
8. Current employment/costs

Please answer the following questions about your current employment and finances.

8.1 Which of the following best describes your employment situation? (please tick)

☐ Employed (go to Q8.2)  ☐ Unemployed (go to Q8.3)

8.2 How would your situation best be described? (please tick) (go to Q8.4)

☐ Full time employment
☐ Part time employment
☐ Self employed (eg own business, farming)

8.3 How would your situation best be described? (please tick) (go to Q8.7)

☐ Household duties
☐ Student
☐ Retired or Aged Pensioner
☐ Invalid Pensioner
☐ Other (please describe) _________________________________

8.4 Are you on leave while receiving treatment?

☐ Yes  ☐ No (go to Q8.7)  ☐ Not applicable (eg self employed)

8.5 What type of leave?

☐ Annual leave
☐ Sick leave
☐ Unpaid leave
☐ Compassionate leave
☐ Other (please indicate type) _________________________________

8.6 For how long is this leave available? (weeks) _______________________________
8.7 What is your current gross family income (ie before tax)? (please tick)

☐ Less than $300 per week
☐ Between $300 and $500 per week
☐ Between $500 and $800 per week
☐ Between $800 and $1000 per week
☐ More than $1000 per week

8.8 Has the need to have treatment in Adelaide had any effect on your employment situation?

☐ Yes (please describe) ☐ No

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

8.9 Has receiving treatment in Adelaide had any financial impact on you?

☐ Yes (please describe) ☐ No

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

8.10 Have you received information about any funding assistance schemes?

☐ Yes ☐ No ☐ Not eligible (go to Q8.12)
8.11 Have you received any assistance with costs related to your treatment in Adelaide? (this includes travel and accommodation costs)

☐ Yes (please describe) ☐ No

_____________________________________________________________
_____________________________________________________________

8.12 Have you had any difficulty in accessing financial assistance?

☐ Yes (please describe) ☐ No

_____________________________________________________________
_____________________________________________________________
## 9. Summary

### 9.1 Following is a list of issues in this survey. From these issues, please number the **three** most important issues for you, in order of importance and give each a satisfaction rating out of 10.

(0 = very dissatisfied, 10 = very satisfied)

<table>
<thead>
<tr>
<th>Issue</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact on employment</td>
<td></td>
</tr>
<tr>
<td>Transport to Adelaide</td>
<td></td>
</tr>
<tr>
<td>Accommodation in Adelaide</td>
<td></td>
</tr>
<tr>
<td>Transport within Adelaide</td>
<td></td>
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<tr>
<td>Parking in Adelaide</td>
<td></td>
</tr>
<tr>
<td>Financial costs</td>
<td></td>
</tr>
<tr>
<td>Difficulty accessing funding assistance</td>
<td></td>
</tr>
<tr>
<td>Physical effect of travelling</td>
<td></td>
</tr>
<tr>
<td>Treatment delay</td>
<td></td>
</tr>
<tr>
<td>Length of time staying in Adelaide</td>
<td></td>
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<tr>
<td>Availability of appointments in Adelaide</td>
<td></td>
</tr>
<tr>
<td>Accessing information about diagnosis and treatment</td>
<td></td>
</tr>
<tr>
<td>Accessing information about supports and services</td>
<td></td>
</tr>
<tr>
<td>Communication with health care professionals</td>
<td></td>
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<tr>
<td>Communication between health care professionals</td>
<td></td>
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<tr>
<td>Separation from family and friends</td>
<td></td>
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<tr>
<td>Having a support person while in Adelaide</td>
<td></td>
</tr>
<tr>
<td>Impact on personal relationships</td>
<td></td>
</tr>
<tr>
<td>Household management</td>
<td></td>
</tr>
<tr>
<td>Availability of local treatment</td>
<td></td>
</tr>
<tr>
<td>Quality of local care</td>
<td></td>
</tr>
<tr>
<td>Quality of care in Adelaide</td>
<td></td>
</tr>
</tbody>
</table>
9.2 What advice (if any) would you give someone else coming to Adelaide for cancer treatment?

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

9.3 Please comment here on any other issues which have not been covered in this survey.

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
Thank you very much for your assistance in completing this questionnaire. If you would like to receive information about the results of this questionnaire, please write your contact details below, or contact the researcher (see page one). Your details will remain anonymous.

Name:  ____________________________________________

Address: ____________________________________________

____________________________________________

____________________________________________
Appendix 5: Information sheets
Dear Sir or Madam,

I am a PhD candidate in nursing at Adelaide University. In providing cancer treatment, health care professionals try to ensure that patients from rural and remote areas of South Australia are provided with care according to their needs. My research involves investigating the needs of these patients, to ensure that the care we provide is appropriate and to identify ways to improve services.

If you were to participate I would like to hear about your experiences of cancer treatment and what it was like coming from a rural or remote area and staying in Adelaide for treatment, using a survey form to ask questions. You can refuse to answer any questions. Some participants may be asked to participate in another interview for further discussion.

Participating in this research will not affect your care now or at any time in the future. There are no immediate benefits to you from participating in the study, but it will help nurses and doctors to understand more about the needs of patients from rural and remote areas. The results of the study will be published, but any information that could identify you will remain strictly confidential.

If you have any queries regarding the study please contact Kate Cameron, Royal Adelaide Hospital on ph 8303 3645. This study has been approved by the Royal Adelaide Hospital Research Ethics Committee. If you wish to discuss aspects of the study with someone not directly involved, you may also contact the Chairman of the Research Ethics Committee, Royal Adelaide Hospital on ph 8222 4139.

Please accept in advance my thanks for your assistance.

Kate Cameron
Dear Sir or Madam,
I am a PhD candidate in nursing at Adelaide University currently undertaking research into the needs of patients with cancer from rural and remote areas of South Australia. The purpose of the research is to ensure that the care we provide is appropriate and to identify ways of improving services.
In the interview I would like to hear about your experiences as a health care provider for patients with cancer from rural and remote areas receiving treatment in Adelaide. There are no particular questions to be answered, but this will be the main topic of discussion.
You can withdraw from the study at any stage or refuse to answer any questions. There are no immediate benefits to you from participating in the study, but it will help develop greater understanding of the needs of patients from rural and remote areas. The results of the study will be published, but any information that could identify you will remain strictly confidential.
If you have any queries regarding the study please contact Kate Cameron, Royal Adelaide Hospital on ph 8303 3645. This study has been approved by the Royal Adelaide Hospital Research Ethics Committee. If you wish to discuss aspects of the study with someone not directly involved, you may also contact the Chairman of the Research Ethics Committee, Royal Adelaide Hospital on ph 8222 4139.
Please accept in advance my thanks for your assistance.

Kate Cameron
Appendix 6: Ethics approval letters
8222 4139

12 September 2001

Kate Cameron
DEPT OF CLINICAL NURSING
ROYAL ADELAIDE HOSPITAL

Dear Ms Cameron,

Re: "Experiences and needs of rural and remote South Australians receiving cancer treatment in Adelaide." Revised Patient Information Sheet & Consent Form (30 August 2001).

RAH Protocol No: 010706a

I am writing to advise that ethical approval has been given to the above project. Please note that the approval is ethical only, and does not imply an approval for funding of the project.

Human Ethics Committee deliberations are guided by the Declaration of Helsinki and N.H. and M.R.C. Guidelines on Human Experimentation. Copies of these can be forwarded at your request.

Adequate record-keeping is important and you should retain at least the completed consent forms which relate to this project and a list of all those participating in the project, to enable contact with them if necessary, in the future. The Committee will seek a progress report on this project at regular intervals and would like a brief report upon its conclusion.

If the results of your project are to be published, an appropriate acknowledgment of the Hospital should be contained in the article.

Yours sincerely,

Dr M James
Chairman
RESEARCH ETHICS COMMITTEE
7th of June 2002

Ms Kate Cameron
281 Carrington St
ADELAIDE 5000

Dear Ms Cameron

RE: EXPERIENCES AND NEEDS OF RURAL AND REMOTE SOUTH AUSTRALIANS RECEIVING CANCER TREATMENT IN ADELAIDE
ACF HREC protocol number: 2002/02

I am writing to advise you that ethical approval has been given to the above project.

Human Research Ethics Committee deliberations are guided by the Declaration of Helsinki and the NHMRC National Statement on Ethical Conduct in Research involving humans.

Adequate record keeping is important and you should retain at least all signed consent forms which relate to this project and a list of all those participating in the project to enable contact with them, if necessary, in the future.

The Committee will seek an annual review of this project and you are required to report, within 72 hours, any adverse events, including complaints, to the Chair.

Yours sincerely,

[Signature]
Chair, Research Ethics Committee
7 May 2002

Ms Kate Cameron
PhD Candidate
C/- Department of Clinical Nursing
Level 3, Eleanor Harrald Building
Royal Adelaide Hospital
Adelaide University SA 5005

Dear Kate

Application for Ethics Clearance - Project 26/0402
"Experiences and needs of rural and remote South Australians receiving cancer treatment in Adelaide"

I refer to your application for ethics clearance for the above project, and to correspondence between the Project Advocate, Ms Elizabeth Keam, and yourself.

I confirm that the Ethics Committee approved the above application in principle at its meeting on 2 May 2002, subject to resolution of the matters set out in Ms Keam’s letter to you dated 3 May 2002. I acknowledge receipt of your email dated 6 May 2002 and the revised patient information sheet and survey questionnaire attached thereto, which now satisfies the requirements of the Ethics Committee.

Please provide a copy of any publication that results from your study to the Chair of the Ethics committee and keep the Committee informed of your progress in this matter.

Should you have any queries, please do not hesitate to contact Ms Keam on 8239 9476, or myself.

Yours sincerely

Sr Thora Specht LCM
Chair
Ethics Committee
NORTH WESTERN ADELAIDE HEALTH SERVICE

Ethics of Human Research Committee

09 May 2002

Ms K Cameron
Department Clinical Nursing
Level 3 Eleanor Harraff Building
Royal Adelaide Hospital
SA 5005

Dear Ms K Cameron

Application Number 64/2002

The Ethics of Human Research Committee at the last meeting considered your protocol entitled:

"Experiences and needs of rural and remote South Australians receiving cancer treatment in Adelaide"

Approval Status Final

Where conditions require documents to be changed or submitted, final approval will not be given until sighting by the Chairman.

Protocols are approved for up to twelve months only and a report is required at the end of the study or 12 month period. Extensions will not be granted without a report to the Committee.

The Ethics of Human Research Committee must be notified should there be significant changes to a protocol.

Yours sincerely

_/Dr M Hobby
Chairman
Ethics of Human Research Committee
Appendix 7: Consent forms
Consent Form - Patients

**Project title:** Experiences and needs of rural and remote South Australians receiving cancer treatment in Adelaide.

**Researcher:** Kate Cameron

This is to certify that I, _____________________________________________________

(print name)

agree to participate as a volunteer in the above named project. I give permission to be interviewed and for the interviews to be tape recorded.

I agree that the information may be published, provided my name and any information which may lead to the identification of me or any other person or institution will remain confidential. I understand that I can withdraw from the study at any stage or refuse to answer any questions without prejudice to any further care I may require. I have been informed about the aims and purposes of this study by the researcher and have been given the opportunity to ask any questions I desire and all such questions have been answered to my satisfaction.

_______________________________________ ______________________________

participant researcher

Date _________________________
Consent Form - Health Professionals

Project title: Experiences and needs of rural and remote South Australians receiving cancer treatment in Adelaide.

Researcher: Kate Cameron

This is to certify that I, ________________________________

(print name)

agree to participate as a volunteer in the above named project. I give permission to be interviewed and for the interviews to be tape recorded.

I agree that the information may be published, provided my name and any information which may lead to the identity of myself or any other person or institution will remain confidential. I understand that I can withdraw from the study at any stage or refuse to answer any questions. I have been informed about the aims and purposes of this study by the researcher and have been given the opportunity to ask any questions I desire and all such questions have been answered to my satisfaction.

_____________________________________ ________________

participant researcher

Date _________________________
Appendix 8: Feedback to participants
12th December 2002

Dear Sir/Madam

Thank you very much for your participation in the research project ‘The experiences and needs of people from rural and remote areas receiving cancer treatment in Adelaide’. My apologies for the delay for those interviewed in the early stages of this project, as interviewing took place over six months between March and October. Attached is a summary of responses for your information. Please note that this is a summary only and that a full analysis will be carried out over the next six to twelve months.

If you would like to receive a copy of the full analysis, or would like any further information about the study please contact me on phone 08 8303 3645 or email kate.cameron@adelaide.edu.au Any feedback about the study would also be welcome.

Thank you very much for your valuable contribution to this study. I greatly appreciate your willingness to participate at a difficult time. When the full analysis is completed, recommendations will be forwarded to the relevant health care bodies, to help improve cancer care for those from rural and remote areas.

Yours sincerely

Kate Cameron
Cancer Treatment in Adelaide: Summary of survey responses

The purpose of this survey was to identify common issues for people from rural and remote areas when attending Adelaide for cancer treatment. This is a condensed summary of responses given by the participants.

A total of 96 people (61 male, 35 female) were interviewed over a period of six months, between March and September in 2002. The average age of participants was 62 years (youngest 35, oldest 88). Seventy two participants (75%) were in a marital or defacto relationship, 12 were widowed and 12 were single or divorced.

<table>
<thead>
<tr>
<th>Type of cancer</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Colo-rectal</td>
<td>17</td>
</tr>
<tr>
<td>Prostate</td>
<td>14</td>
</tr>
<tr>
<td>Non-Hodgkin's lymphoma</td>
<td>11</td>
</tr>
<tr>
<td>Breast</td>
<td>10</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>9</td>
</tr>
<tr>
<td>Lung</td>
<td>8</td>
</tr>
<tr>
<td>Head and neck</td>
<td>6</td>
</tr>
<tr>
<td>Oesophageal/throat</td>
<td>5</td>
</tr>
<tr>
<td>Adenocarcinoma (unknown primary)</td>
<td>3</td>
</tr>
<tr>
<td>Multiple myeloma</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
</tr>
</tbody>
</table>

Many were receiving more than one form of treatment (e.g. radiotherapy and chemotherapy). The length of time that treatment was planned for varied from 5 to 900 days. Nine participants were not sure how long their treatment was planned to last. Seventy five were receiving treatment as day patients, and 21 as inpatients. There was a wide variation in the number of visits to Adelaide needed, from one (for radiotherapy) to 50 visits. The average length of visit was 37 days.

**Residence**

The majority of participants were living in a town at the time of their treatment (86) and 10 were living on a farm or block of land outside a township. Twenty four participants were from interstate (Northern Territory, New South Wales and Victoria). The average distance participants were living from Adelaide was 624km (range 75-3048km).
<table>
<thead>
<tr>
<th>Participants town/city of residence (number)</th>
<th>South Australia</th>
<th>South Australia</th>
<th>Interstate</th>
</tr>
</thead>
<tbody>
<tr>
<td>American River</td>
<td>1</td>
<td>Lucindale</td>
<td>1</td>
</tr>
<tr>
<td>Barmera</td>
<td>1</td>
<td>Melrose</td>
<td>1</td>
</tr>
<tr>
<td>Beachport</td>
<td>1</td>
<td>Millicent</td>
<td>3</td>
</tr>
<tr>
<td>Berri</td>
<td>1</td>
<td>Moonta</td>
<td>3</td>
</tr>
<tr>
<td>Cadell</td>
<td>1</td>
<td>Mt Gambier</td>
<td>4</td>
</tr>
<tr>
<td>Ceduna</td>
<td>1</td>
<td>Penola</td>
<td>1</td>
</tr>
<tr>
<td>Clare</td>
<td>1</td>
<td>Port Augusta</td>
<td>3</td>
</tr>
<tr>
<td>Cleve</td>
<td>1</td>
<td>Port Elliott</td>
<td>1</td>
</tr>
<tr>
<td>Coober Pedy</td>
<td>1</td>
<td>Port Lincoln</td>
<td>7</td>
</tr>
<tr>
<td>Furner</td>
<td>1</td>
<td>Port Pirie</td>
<td>5</td>
</tr>
<tr>
<td>Gladstone</td>
<td>1</td>
<td>Renmark</td>
<td>1</td>
</tr>
<tr>
<td>Glossop</td>
<td>1</td>
<td>Riverton</td>
<td>1</td>
</tr>
<tr>
<td>Kadina</td>
<td>7</td>
<td>Roxby Downs</td>
<td>1</td>
</tr>
<tr>
<td>Kapunda</td>
<td>1</td>
<td>Swan Reach</td>
<td>1</td>
</tr>
<tr>
<td>Karoonda</td>
<td>1</td>
<td>Tailem Bend</td>
<td>2</td>
</tr>
<tr>
<td>Keith</td>
<td>2</td>
<td>Warrnambool</td>
<td>1</td>
</tr>
<tr>
<td>Kimba</td>
<td>1</td>
<td>Whyalla</td>
<td>4</td>
</tr>
<tr>
<td>Leasingham</td>
<td>1</td>
<td>Worrolong</td>
<td>1</td>
</tr>
<tr>
<td>Loxton</td>
<td>3</td>
<td>Yorketown</td>
<td>1</td>
</tr>
</tbody>
</table>

**Travel from home to Adelaide**
Fifty nine participants travelled to Adelaide in a private car, 18 by commercial plane, 8 by bus and 5 in a community car. The time taken to travel one way to Adelaide was from one to thirteen hours, with an average of four hours. Over 80% of participants stated that their transport was very convenient or convenient. Most also said that their access to public transport from home to Adelaide was very convenient or convenient, but some had never used public transport to Adelaide. Most felt that travelling to Adelaide had some physical effect on them (see graph). Ten respondents did not answer this question, as they were staying in Adelaide for the whole time of treatment (eg six weeks of radiotherapy).
Most used private transport to travel within Adelaide. Those staying at Greenhill Lodge generally used the Greenhill Lodge bus, rather than their own car. On the whole, participants stated that their method of travel within Adelaide was very convenient or convenient. Finding parking was seen to be most difficult on the first visit to Adelaide.

**Convenience of parking in Adelaide**

**Accommodation**

Most participants stayed in motel accommodation in Adelaide, subsidised by The Cancer Council South Australia or The Leukaemia Foundation. Twenty one stayed in a relative’s home and two participants travelled back and forth to Adelaide each day for treatment. Other places of accommodation included a caravan park, friend’s home and residential wing (at Royal Adelaide Hospital). On the whole, participants were satisfied with their accommodation in Adelaide.
Health cover
Thirty two percent of participants had private health cover at the time of treatment. Some participants commented that they were unsure as to what they would be charged for their treatment and found this a source of concern.

Treatment received in local regions
Twenty three participants were receiving chemotherapy treatment in their local region and were satisfied or very satisfied with this treatment. Participants had to travel an average of 27km to receive local treatment. Most participants (70%) said that they would prefer to have treatment in their local region. However, many commented that this would only be if treatment was supported by health care staff experienced in cancer treatment, and acknowledged that the possibility of having such staff available locally was small. A higher number (57%) preferred to have followup checks in Adelaide, so they could be seen by the treating cancer specialist.

Treatment in Adelaide
Most participants were satisfied with their appointments in Adelaide. Few participants stated that they would have liked to have seen a health professional other than those they had seen during treatment.

<table>
<thead>
<tr>
<th>Health professional seen</th>
<th>Number</th>
<th>Additional health professional participants would like to have seen</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social worker</td>
<td>48</td>
<td>Social worker</td>
<td>4</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>6</td>
<td>Physiotherapist</td>
<td>4</td>
</tr>
<tr>
<td>Psychologist/counsellor</td>
<td>8</td>
<td>Psychologist/counsellor</td>
<td>0</td>
</tr>
<tr>
<td>Dietician</td>
<td>41</td>
<td>Dietician</td>
<td>4</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>2</td>
<td>Occupational therapist</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>22</td>
<td>Other</td>
<td>3</td>
</tr>
</tbody>
</table>

Thirty nine participants needed to make contact with health care staff while in Adelaide, usually to change appointment times or to check treatment and/or side effect information. Finally, 93 participants (97%) were very satisfied or satisfied with treatment received in Adelaide.

Information and communication
The graph on the following page shows where participants obtained information about treatment and support, such as finance and accommodation. Participants most often received information regarding their cancer and treatment from the specialist in Adelaide and/or information pamphlets. Information on finance and accommodation was more often obtained from a social worker in Adelaide or another source, such as the Patient Assistance Transport Scheme (PATS) office.
Twenty one participants identified areas for improvement in communication as follows:

- Better coordination/information (eg all information at first contact, case manager).
- Improve communication between GP and patients.
- Improve communication between Adelaide specialist and GP.
- More local information (eg pamphlets).
- Ensure patients see referring doctor.
- Allow more time with the specialist.
- Ensure information is consumer orientated (eg plain language).
- Improve GP knowledge

**Household, relationships and support networks**

When asked how much of an effect being separated from family and friends during treatment had, there was a mixed response (see graph). Some participants stayed with relatives and hence did not feel that they were separated from their family.
Importance of having a companion in Adelaide
The importance of having a companion during treatment in Adelaide varied, but was seen by many to be more important at the beginning of treatment.
Having a companion was seen to be important mainly for the following reasons.

- Physical support and care.
- Comfort, company and moral support.
- Advice, memory aid (‘extra pair of ears’).
- Going together as a family and/or team.
- Help with navigation and driving in Adelaide.

**Financial impact**
Most participants (74%) felt that there had been a financial impact on them as a result of having treatment in Adelaide. Eighty three percent of participants had received information about funding assistance and 73% reported that they had received some financial assistance to receive treatment in Adelaide. However 34% of those who received financial assistance reported difficulty in accessing this assistance.

**Most important issues in the survey**
Participants were asked which three issues in the survey were of most importance to them. The top six issues (in order of importance) were:

1. Having a support person.
2. Accommodation in Adelaide.
3. Financial costs.
4. Separation.
5. Length of time in Adelaide.

The graph on the following page shows the satisfaction rating (out of ten) for the top six issues, with the darker colours indicating dissatisfaction (0 = very dissatisfied, 10 = very satisfied).
Participants were asked what advice they would give others having cancer treatment in Adelaide. The main areas of advice were:

- The need for information,
- The need for financial assistance and/or information,
- The importance of a positive attitude,
- Advice on areas of accommodation and organization of practical details,
- Advice on areas of health care insurance and treatment,
- A recommendation for others to go to Adelaide for treatment, and
- The need for a support person.

Finally, many participants also offered recommendations to improve cancer treatment for people from rural and remote areas. These recommendations are listed below.

**Health Care**

Ensure patients are aware of community support services, make respite care available.
Provide leaflets for rural/remote doctors to give patients re accommodation / financial assistance.
Introduce case managers, rural liaison (advising on applying for refunds, accommodation etc).
Make sure the system is consumer oriented, keep the consumers the point of interest.
Ensure access to psychological assistance.
Ensure communication with the treatment team continues after treatment is finished or that the patient knows what to expect.
<table>
<thead>
<tr>
<th>Transport</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improve inter-hospital transport (eg those having treatment at both QEH and RAH).</td>
</tr>
<tr>
<td>Provide petrol vouchers.</td>
</tr>
<tr>
<td>Make the Leukaemia Foundation car more available at short notice.</td>
</tr>
<tr>
<td>Organise weekend volunteers to help with activities while staying in Adelaide.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Accommodation/activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide hand held showers at motel accommodation (eg. for those with pumps).</td>
</tr>
<tr>
<td>Provide after hours reception phone access to Greenhill Lodge.</td>
</tr>
<tr>
<td>Ensure pamphlets have the correct Greenhill Lodge phone number on them.</td>
</tr>
<tr>
<td>Provide volunteers to go with patients to appointments (particularly when in Adelaide alone).</td>
</tr>
<tr>
<td>Don’t allow smoking at accommodation (eg Greenhill Lodge).</td>
</tr>
<tr>
<td>Make food available after hours at Greenhill Lodge (eg for patients discharged on weekends).</td>
</tr>
<tr>
<td>Provide secure refrigeration in accommodation (eg for those reliant on milk products).</td>
</tr>
<tr>
<td>Reduce the cost of meals at Greenhill Lodge.</td>
</tr>
<tr>
<td>Ensure private phone rates are available in accommodation (not commercial), phone access is easily available (eg Seaview Lodge), and phone cards are easily available.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Finance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cover the costs of private patients (they are saving money for the public health system).</td>
</tr>
<tr>
<td>Subsidise those staying in private accommodation.</td>
</tr>
<tr>
<td>Make PATS more proactive and transparent in providing financial reimbursement.</td>
</tr>
<tr>
<td>Monitor and ensure drug costs aren’t prohibitive and that patients know how to minimise costs.</td>
</tr>
<tr>
<td>Provide discount airfares for rural patients.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>General</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduce palliative care from the beginning.</td>
</tr>
<tr>
<td>Make warm clothing available for those from the Northern Territory.</td>
</tr>
<tr>
<td>Have an ID bracelet from St Johns in case of accident when travelling to and from Adelaide, as well as a medical information card.</td>
</tr>
<tr>
<td>Facilitate access to support groups for people from remote areas.</td>
</tr>
<tr>
<td>Supply an information pamphlet re coming to Adelaide (eg clothes, things to organise).</td>
</tr>
</tbody>
</table>

**Thank you**

Thank you again for your contribution and I hope you find this summary of the findings of interest. If you would like further information, please contact Kate Cameron on ph 08 8303 3645 or email kate.cameron@adelaide.edu.au Any further feedback you would like to make would also be welcome.
Appendix 9: Focused literature review findings
<table>
<thead>
<tr>
<th>Author, year</th>
<th>Country</th>
<th>Definition of rurality</th>
<th>Purpose</th>
<th>Subjects</th>
<th>Method</th>
<th>Topics/findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Sullivan, Weinert et al., 1993)</td>
<td>USA</td>
<td>Not formally defined, those in rural areas averaged 214miles (342km) travel, those in isolated averaged 296 (474km) travel.</td>
<td>Describe self identified needs and concerns of patients and carers.</td>
<td>166 patients with cancer, 124 carers.</td>
<td>Content analysis of written feedback from survey of whole sample.</td>
<td>Themes identified: Coping with stresses of illness and contingencies (eg travel). Information needs. Support Interpersonal relationships Effects of treatment Life view</td>
</tr>
<tr>
<td>(Dunaway, Hueston et al., 1995)</td>
<td>USA</td>
<td>Not defined</td>
<td>To explore issues faced by rural women diagnosed with breast cancer</td>
<td>10 women with breast cancer who had completed treatment 12-24 months before the study started</td>
<td>Face to face structured interview, content analysis</td>
<td>Those who were treated in a local setting expressed more positive views towards their treatment providers than those treated in tertiary settings.</td>
</tr>
<tr>
<td>(Davis, Girgis et al., 1998)</td>
<td>Aust.</td>
<td>Rural – residence outside the metropolitan area in which the treatment centre is located (usually more than 100km)</td>
<td>To assess the needs of rural women travelling to the city for treatment.</td>
<td>80 women with breast cancer</td>
<td>Phone survey, needs analysis (social and practical support issues)</td>
<td>80% were told of support services and 76% used these services. 39% received financial assistance, 19% of these experienced difficulty in claiming. Specific problems were identified by 89%, particularly a need for information about accommodation and transport.</td>
</tr>
<tr>
<td>(McGrath, 1998)</td>
<td>Aust.</td>
<td>Not defined</td>
<td>To use a description of demographic residence data to describe the needs of the sample concerned.</td>
<td>Records of 204 rural residents with haematological disorder</td>
<td>Analysis of secondary data (accommodation records)</td>
<td>36% of sample lived ≤125km of treatment centre, remainder ≥125km. 90% were accompanied by an escort. 11% had children staying with them.</td>
</tr>
<tr>
<td>(Bain and Campbell, 2000)</td>
<td>UK</td>
<td>Urban – within city boundary Rural – outside city boundary ≤ 1 hr of centre Remote &gt; 1 hour from cancer centre</td>
<td>To explore perspectives of patients receiving treatment for colorectal cancer</td>
<td>11 rural patients 11 urban patients 10 spouses</td>
<td>Content analysis of transcripts from focus groups.</td>
<td>Most issues were similar in rural and urban groups. There were lower expectations of care in rural/remote participants. Transportation was difficult for rural/remote but appeared accepted.</td>
</tr>
<tr>
<td>(McMichael, Kirk et al., 2000)</td>
<td>Aust.</td>
<td>Not defined, participants were geographically dispersed in</td>
<td>To identify factors associated with detection of breast cancer and</td>
<td>101 Indigenous women, the number having or had treatment not</td>
<td>Thematic analysis of interviews, according to</td>
<td>Women found attendance at regional centres difficult due to lack of knowledge of the hospital system and the alienating environment. The decision to attend for treatment was difficult as</td>
</tr>
<tr>
<td>Study Details</td>
<td>Location</td>
<td>Setting</td>
<td>Objectives</td>
<td>Methodology</td>
<td>Findings</td>
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<td>-------------</td>
<td>----------</td>
<td></td>
</tr>
<tr>
<td>McGrath, 2000a</td>
<td>Aust.</td>
<td>Not defined</td>
<td>To assess the financial impact of relocation for treatment of haematological malignancies.</td>
<td>10 patients, 10 carers</td>
<td>There were several areas of additional costs associated with treatment in Adelaide, buffering factors and long term potential adverse outcomes (e.g., the need to sell the family home).</td>
<td></td>
</tr>
<tr>
<td>McGrath and Seguerra, 2000</td>
<td>Aust.</td>
<td>Those living &gt;100km from the metropolitan centre.</td>
<td>To assess whether patients not accessing dedicated housing were aware of support available.</td>
<td>197 participants with a haematological malignancy</td>
<td>72% of participants knew of the reimbursement schemes. 61% knew of accommodation centres. The lack of knowledge led to practical and financial hardship.</td>
<td></td>
</tr>
<tr>
<td>Payne, Jarrett et al., 2001</td>
<td>UK</td>
<td>Not defined. Compared patients travelling daily for treatment (from Southampton) with those relocating (from Guernsey, 120km south of British mainland).</td>
<td>To identify the effects of receiving chemotherapy/radiotherapy away from home.</td>
<td>42 (15 men, 27 women) from Southampton 42 (20 men, 22 women) from Guernsey.</td>
<td>Non-travellers more likely to report problems with relationships (interview), no difference on survey data. Disadvantage of being away from home was offset by benefit of contact with other patients. Psychosocial impact of travel not identified as a barrier to treatment.</td>
<td></td>
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<tr>
<td>Clavarino, Lowe et al., 2002</td>
<td>Aust.</td>
<td>Not defined. Participants were eligible for inclusion if they were required to stay away from home to receive radiotherapy.</td>
<td>To determine the impact of travelling for treatment on patients and families.</td>
<td>28 patients (6 male, 28 female), 19 carers (11 male, 8 female)</td>
<td>High levels of unmet needs in patients and carers, highest in the psychosocial domain. Patient’s scores indicated problems in communication, problem solving, social roles and effective involvement. Two patients considered depressed (7%). Concerns about finances expressed by 32% of patients. Differences were identified in health care information needs and access to services (greater for carers). Lack of flexibility was problematic for patients with specific needs, e.g., single parent who needed support to bring young children to treatment.</td>
<td></td>
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### Appendix 10: Articles excluded from the literature review

<table>
<thead>
<tr>
<th>Author, year</th>
<th>Country</th>
<th>Purpose</th>
<th>Reason for exclusion</th>
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</thead>
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<tr>
<td>(Junor, Macbeth et al., 1992)</td>
<td>UK</td>
<td>Audit of travel and waiting time to determine impact on radiotherapy experience</td>
<td>Focused on those going back and forth to treatment on a daily basis rather than rural residents.</td>
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<tr>
<td>(Monroe, Ricketts et al., 1992)</td>
<td>Various – review</td>
<td>To identify differences in urban/rural cancer mortality, incidence and survival, use of health care services and to explore issues of urban/rural research</td>
<td>Not primary research, not focused on rural issues</td>
</tr>
<tr>
<td>(Given, Given et al., 1994)</td>
<td>USA</td>
<td>Examined issues in rural areas and barriers to accessing specialist treatment in regional centres</td>
<td>Discussion paper.</td>
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<tr>
<td>(Wilkinson, 1996)</td>
<td>USA</td>
<td>Discussion of barriers to cancer care for rural minorities.</td>
<td>Discussion paper.</td>
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<tr>
<td>(Guidry, Aday et al., 1997)</td>
<td>USA</td>
<td>To assess transportation as a barrier to treatment</td>
<td>Non-rural focus.</td>
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<tr>
<td>(Hawkins and Curtiss, 1997)</td>
<td>USA</td>
<td>Discussion of resources and strategies available to health care providers in rural areas.</td>
<td>Discussion paper.</td>
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<tr>
<td>(McGrath, 1999a)</td>
<td>Aust.</td>
<td>To provide a descriptive profile of accommodation available to patients and families with leukaemia.</td>
<td>Description of accommodation and usage profile only.</td>
</tr>
<tr>
<td>(McGrath, Patterson et al., 1999a)</td>
<td>Aust.</td>
<td>To identify personal concerns of rural women diagnosed with breast cancer</td>
<td>Focused on the issues for women some time after diagnosis at their place of residence, rather than related to a need to travel for treatment.</td>
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<tr>
<td>(McGrath, Patterson et al., 1999b)</td>
<td>Aust.</td>
<td>To identify post diagnosis support needs of women with breast cancer and evaluate supports.</td>
<td>Focused on the issues for women some time after diagnosis at their place of residence, rather than related to a need to travel for treatment.</td>
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<tr>
<td>(Girgis, Boyes et al., 2000)</td>
<td>Aust.</td>
<td>To assess the prevalence and predictors of perceived unmet needs among women diagnosed with breast cancer, comparing rural with urban women.</td>
<td>Does not include issues of patients travelling to the metropolitan area for treatment.</td>
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<tr>
<td>(McGrath, 2000b)</td>
<td>Aust.</td>
<td>Description of experiences of rural residents on return home after treatment for haematological malignancies.</td>
<td>Focusing on post treatment issues.</td>
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<tr>
<td>(Payne and Jarrett, 2000)</td>
<td>Various – review</td>
<td>To identify the impact of travel on cancer patients’ experiences of treatment.</td>
<td>Review of studies focusing on travel generally, rather than specifically related to rurality.</td>
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<tr>
<td>(McGrath, 2001)</td>
<td>Aust.</td>
<td>To describe the needs and support for rural residents over time on return home after specialist treatment for haematological malignancies.</td>
<td>Focusing on issues seen after treatment has finished.</td>
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## Appendix 11: ARIA ratings of participants’ place of residence

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<th>Health Care Region/Area</th>
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Appendix 12: Ranking of all issues in the survey

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<th>Issue</th>
<th>Number of people ranking as the top three issues of importance</th>
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<td>Separation (from family/friends)</td>
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<td>Quality of care (Adelaide)</td>
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<tr>
<td>Accessing treatment information</td>
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<td>Local treatment availability</td>
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## Appendix 13: Satisfaction rating for issues of importance

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### Appendix 14: Participant recommendations to others attending for treatment

#### The need for information

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<tr>
<th>Participant</th>
<th>Recommendation</th>
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<tr>
<td>3010</td>
<td>‘find out as much as you can before leaving home or, speak to someone who’s been through it, find out what goes on here’.</td>
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<tr>
<td>3011</td>
<td>‘well my advice would be to communicate as much as possible with the doctor that’s going to do the operation, don’t be afraid to ask any questions that come to mind that you’re not certain of’. Then – if you get a diagnosis and need treatment in Adelaide, get there as soon as possible to expedite the process.’</td>
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<tr>
<td>3012</td>
<td>get info from local anti-cancer unit in your home town.</td>
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<tr>
<td>3013</td>
<td>‘ask questions’</td>
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<tr>
<td>3026</td>
<td>Participant’s wife ‘get as much information as you can, ask lots of questions…. keep at them’.</td>
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<tr>
<td>3026</td>
<td>‘Get straight to the Adelaide hospital and bang on their door and rave on at them…. don’t go to a GP’.</td>
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<tr>
<td>7032</td>
<td>‘ask lots of questions until you understand’.</td>
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<tr>
<td>7034</td>
<td>get a second opinion, no matter how difficult.</td>
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<tr>
<td>1035</td>
<td>Participant’s husband ‘ask every question you can think of’…Participant ‘yeh to as many people as you can, don’t ask questions, you’ve gotta ask as many questions as you can to get all the information you can get, ‘cos the more information you’ve got, the more ready you are for your treatment when you have to have it’.</td>
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<td>8043</td>
<td>‘to try and find out more information before you leave home, you know from PATS or the welfare or somebody like that’, participant’s husband ‘you want to know everything that goes on before you leave, you don’t want to come up like us in the blind’…participant ‘it gets very scary when you don’t know what’s going on’….</td>
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<tr>
<td>1091</td>
<td>‘oh I’d pass on as much info. as I could’.</td>
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<td>1092</td>
<td>‘I couldn’t give em any more advice than what I’ve been given to me myself, and at times that’s not very much.’</td>
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<td>1035</td>
<td>‘I said (to another patient) well if you want to know an answer to a question you’ve gotta ask either the doctor or the nurse I said, otherwise I can’t tell you I said you can get books and read it but that can’t answer all your questions either, you’ve gotta talk to either a doctor or a nurse about it, and ever since then we’ve been that close because she reckons if it hadn’t been for me she wouldn’t have been able to get through it, but that’s the most important thing, if you can think of what questions you want to ask so you can ask them, then you get a lot more information from the nurses and the doctors and they explain it in the language that you can understand it, and that’s the advice I’d give anyone’.</td>
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<tr>
<td>3079</td>
<td>‘well to get information first, know what’s going on’</td>
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<td>1047</td>
<td>‘ask them if they could get the assistance (financial)’.</td>
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<tr>
<td>1069</td>
<td>‘I’d actually get them to um go see the social worker about financial things first, I think that’s what plagues on everyone’s minds, how am I going to pay for accommodation and stuff like that, like I said, I found out about the PATS scheme straight away, and that like I said, just having that burden taken off you, it’s just, tremendous’.</td>
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| 3039        | ‘Bring plenty of money’. Participant’s daughter ‘Think of finances, because, I mean everybody that I’ve spoken to around here can’t believe how much they’ve got to pay out, of their own pocket, to stay, in a place like this, or anywhere, to stay anywhere in Adelaide….you seem to be spending money every day practically! For
something! … social worker and finances, and stay at Greenhill Lodge…. because without Greenhill Lodge you’re buggered, putting it bluntly, without money you’re buggered.

9088 – ‘my biggest worry was thinking this is going to cost a lot, until I knew about PATs’.

9088 – ‘my advice would be to make sure that they got all the information on where they can stay and all the information they can get about, um, um support, or what do you call it? Financial support. I mean if somebody came on their own, they’d need somebody to wash their clothes’.

5016 – explain the process, tell them to contact Greenhill Lodge ASAP, advise them on the PATS scheme.

4024 – ‘I should be the social worker for Millicent… I’ve had 3 people this week ring up (seeking advice). Advice given was ‘to ring PATS, and stay at Gurney Lodge’.

1001 – ‘I would tell them about bus fares, PATS scheme’.

1015 – ‘I’d certainly tell them about the PATS scheme’.

3067 – ‘I’ve been a bit neglectful, bit negligent if that’s the right word (in not applying for travel expense refunds)…..some of the other things you’ve got to think about, getting your treatment, and getting your meals and having this and that and organising your accommodation, yeah, I need a manager’.

3084 – ‘Speak to social worker first’.

Attitude

7086 – ‘well, I would say to people, to ah seek treatment because if you don’t, you don’t know what you miss out on, and also to have an extremely positive attitude because you need to… if you want to live you’ve got to try hard’.

3078 – ‘to not be in a hurry, to um, how would you put it…… be respective of what your medical officers tell you, because a lot of people come down with set ideas, um, without really knowing what they’re in for, ah you know, and that’s the difference with me, I come down, when I started, I come down and that’s it, you know, I’m in their hands, they tell me what to do and I do it, whereas I’ve known people to come down and say no, I’m only here for 2 days and I’m going back, I’m not worried about them’.

(Told of a friend with myeloma who came down for treatment, had 2 cycles and refused further treatment and was dead within months, so he’ll stay as long as necessary).

3070 – ‘Well I’d tell them what they have to put up with, you know, a little bit of inconvenience, and that they’d have to put up with that, otherwise, you haven’t got much choice have you!’

3068 – ‘I would say take each day as it comes’.

1006 - ‘think like you're going to walk out of there and not get put in a pine box’.

1063 – ‘well I don’t know, bad luck really (laughs).. you’ve just got to accept it and make the best of it, once you’ve been told you’ve got it, that’s it, no good crying over spilt milk’.

1055 – ‘I’ve learnt to be patient’ I remember the first night I was here and the machine kept on beeping and I just kept on pressing the nurse’s button, all the time, and probably half or three quarters of the time there was just no need for it, cos they’d hear it anyway and come anyway, or your nurse was on lunch break or tea break, sort of thing, somebody else’s looking after you as well, just wait’.

1064 – ‘you’ve gotta do it, so you’ve gotta do it, so don’t whinge’.

9080 – ‘I’d just tell them they just have to cope with it… I guess my advice may be different in the future’.

Advice (accommodation, approach, organisation)

1094 – ‘I’d advise people to trust in the professionalism of the staff at Royal Adelaide Hospital, but at the same time, they need to make, people need to make decisions for their own well being, you know? It’s a twofold sort of thing, you know?.. trust them, but take steps to assist in self help’.

9085 – ‘listen to everyone, communicate with the doctors, communicate with the hospital staff, communication is the best thing….. talk it over with your partner, don’t leave him out’.

3090 – ‘you’re not a hundred percent free to do anything you want to do… nobody can alter that, times you’ve got to go over there (to radiotherapy) you can’t just say oh well I’ll jump on a bus today and go on a tour, you’ve always got that consideration, you’ve got to go for your treatment at 4 o’clock or 2 o’clock’.

1019 – Participant’s husband ‘talk about it, don’t hold it in’ (commented that they found talking about the situation helpful).

3070 – ‘well I come up here, and the place is strange to me, well I can’t venture too far cos I don’t know where I’m going do it? So the best thing to do is go along with the system. If you want to get groceries, there’s a bus takes you there and they make an appointment with you for to go back at a certain time, and you’re there at that certain time to get back in time, so really it’s a bit of a robot situation, you know what I mean? You’re you can’t say well look I’m away for a walk away round the town, you can’t ‘cos you don’t know the town, and you might get confused and get lost (laughing), but eh, I just stick to the system…..really you’re not sort of free, you’re tied to the system…… the system works all right, but you’re in bondage to that system, you can’t sort of relax’.

3059 – ‘I don’t like to give advice. I would probably advise in, I would give them the positives, in preference to anything else, I’d only ever try and put the positives and tell them come to here, to Greenhill Lodge, um, how great it is here, to get to, to talk to the people within the complex get friendly with people, don’t alienate yourself and sit
in your room and stay away from people, cos that’s been one of the best things for me here, is the friendships that I’ve developed now, from some of the people here, and the lady Kay who’s going to be leaving soon, I’m going to miss her terribly, the fact that she’s going before me, I’m glad for her, but I’m going to miss her friendship and her time here with me, that’s probably the most advice I would give, and the other little bits of, like um, you know, if you’ve got the same cancer as myself, much the same as the lady that I spoke to, get soft cotton bras, all those sorts of little tit bit things you know? That are a personal comfort.’ (in relation to information about treatment side effect) ‘that little bit of pre-warning is a good thing to hear, from someone that’s been there and done it, hearing it from a professional person, doesn’t have the same impact as hearing it from someone who’s been there and done it, and it does personalise it a bit more I suppose’.

7093 – ‘Always pack your bag and be on the ready’. Participant’s husband ‘prepare for the worst and hope for the best’.
6074 – ‘Organise accommodation and transport’. (This participant commented that he sees many other patients in the community car who don’t have these things organised and the pressure they are put under as a result.) ‘I’ve got the girls, there are a lot of people who haven’t got family, and they have to bunk down at a doss house or something, you know, I know there are these places round, like QEH have, apartments, but then that’s hard to get into, cos they’re always chocker….that’s the main thing I think, because you can’t do much about the other side of it, but that’s one thing you’ve got to do yourself’.
3007 - 'I'd advise them to get in early at Greenhill Lodge'.
4023 – ‘Stay at Greenhill Lodge…let the rural doctors know about Greenhill Lodge’. (This couple described meeting someone who had ‘spent a fortune’ and was only told about Greenhill Lodge on the last visit from Mt Gambier).
3090 – ‘Well I guess they couldn’t go any further or any better than going to Anti-Cancer people anyway, for transport and accommodation, for assistance’.
3018 – ‘Oh, I'd tell them to come here for accommodation’.
3022 – ‘Go ahead and get everything set out so that when you get here you got no hassles, no good getting here and then trying to figure out where you’re going to stay, what you’re going to do’.
6037 – ‘Buy a nanna trolley (market trolley on wheels). If you don’t have transport and you need to walk to shops you need the trolley, and it can be taken on the bus. Participant’s wife ‘if you come in winter, bring a bloody umbrella’.
3042 – ‘Greenhill Lodge. Radiotherapy not as bad as somebody shining a torch on you’. 
7048 – ‘Organise accommodation and transport’. (This participant commented that he sees many other patients in the community car who don’t have these things organised and the pressure they are put under as a result.) ‘I’ve got the girls, there are a lot of people who haven’t got family, and they have to bunk down at a doss house or something, you know, I know there are these places round, like QEH have, apartments, but then that’s hard to get into, cos they’re always chocker….that’s the main thing I think, because you can’t do much about the other side of it, but that’s one thing you’ve got to do yourself’.
4023 – ‘Stay at Greenhill Lodge…let the rural doctors know about Greenhill Lodge’. (This couple described meeting someone who had ‘spent a fortune’ and was only told about Greenhill Lodge on the last visit from Mt Gambier).
3071 – ‘Well I’d definitely advise them to come here, to Greenhill Lodge for their stay’.
1005 - 'Pack your own bag'.
4023 – ‘stay at Greenhill Lodge…let the rural doctors know about Greenhill Lodge’. (This couple described meeting someone who had ‘spent a fortune’ and was only told about Greenhill Lodge on the last visit from Mt Gambier).
3071 – ‘Well I’d definitely advise them to come here, to Greenhill Lodge for their stay’.
1005 - 'Pack your own bag'.
1066 – ‘Oh, I’d tell them to go out and do what I did, first off, go and collect all the leaflets they could find about things you can do, because suddenly you’ve got more time than you’ve ever had in your life, I spend an hour a day here (radiotherapy), and the rest of the day I have to fill in, so I’ve been to the art gallery twice, ‘cos the first time I was too tired to do the Burke and Wills as well as the main gallery, which is tremendous….. botanical gardens, oh yes, I’ll have to go back again’.
3090 – ‘Well I’d thoroughly recommend this place…. That’s for sure…. but I sort of hope I haven’t ever got to recommend for anybody else’s cancer ‘cos I hope that no-one else ever gets it!’.
1082 – ‘Come and see me’.
1083 – ‘That they should go to that Greenhill Lodge’ (has heard of it through other patients).
3068 – commented that she wished she had kept a photographic record of the time during treatment to help measure her improvement.
1004 – ‘Use Google as your main search engine’ (to get information about accommodation and treatment).
**Advice (health care insurance, treatment)**

1096 – ‘Treat the other people (health professionals) the way you’d like to be treated’.
1004 - Check availability of treatment and where accommodation, transport.
3027 – ‘I’d tell them to come here and do as they were told, by the doctors. That’s what I think you’ve got to do’.
Participant’s wife ‘you must listen to your specialist’.
7031 – ‘they need a full understanding of how the private medical cover works (eg ask their GP to refer them to a specialist who doesn’t charge a gap fee)….and you definitely need a carer or a companion, that’s a very important issue’. Participant’s wife ‘get all the costs sorted out before you start’.
7033 – Participant’s wife ‘arrange for the district nurse’. ‘Suss out the local health service as to what we could get’.
3071 – ‘now I cannot compare the treatment at Royal Adelaide against what I am receiving (at St Andrews Hospital), but ah, I’d definitely recommend the mob that I’m using’.
4056 – ‘to do it, yes, I would, and I would suggest that they go to um the people I had been to, although probably I would consider them having the same hospital (throughout treatment), having had my surgery at St Andrews, I would probably have suggested they just have their chemo there, only because of the convenience, um Harry Daniels referred me to Fred Jenkins (at RAH) simply, well he said he was very good, but he also said because he’s got an outreach clinic he thought it might be worthwhile for me he didn’t realize at the time that I was intending to stay down here, he thought I was going to go home’.
1089 – ‘I think a lot of it depends whether you’re in a health scheme or not….we always had hardly any waiting time at all….the biggest waiting time is once you get to the place (hospital) you have to wait down there to be seen, to go to your room and all the rest of it (admissions) just to see the man to tell you where you have to go, where we were waiting some were there for hours and hours, we were there waiting for more than an hour’. (Belonging to a health fund) ‘costs a lot of money, but it’s pretty good service though’.
7093 – ‘Have treatment under a doctor you are confident with, take packed bags’.

**Recommendation to go to Adelaide**

2036 – ‘To make sure that you come over (to Adelaide) straight away, you know, as soon as your doctor, like my doctor diagnosed over there’.
3039 – ‘Come here, for the treatment in Adelaide Hospital’.
1014 – ‘In hindsight I mean that is exactly what we’d say to anyone in Mildura that had something that they were not sure about, to just don’t buggerise around, to come straight here (Adelaide)’.
1057 – ‘Well we’ve found nothing but the best with what we’ve come into contact with’ (in Adelaide). If you’re up there (Loxton) and something goes wrong, you’ve still got to come down here’.
3030 – ‘Come to Adelaide and stay here for treatment’ (Greenhill Lodge).
1049 – ‘Come here ‘I reckon it’s the best they can get’.
1050 – ‘Do it because it’s gotta be done’.
8052 – ‘Come to Adelaide’
9053 – ‘Come here, you get the best treatment’.
1096 – ‘Go to Adelaide, nowhere else’.
1065 – ‘Well, if they’ve had as good treatment as I’m getting, well, I can’t see why they shouldn’t be alright!’.
1005 - Know that you will be receiving quality treatment from people who care about you as a person as well as a patient. ‘In those early days when I didn’t want to listen, I wasn’t just a patient, they cared about me’.
1014 – ‘Come, trust me they know what they’re doing. As soon as you know something’s wrong come here. You might not have anything done differently, but overall, come to one of the big cities’.
6037 – ‘It’s probably the best treatment I reckon that you get anywhere, anywhere at all….the hospital’s very thorough in everything they do I think, far as I’m concerned, it’s just the drama of going through it all’.
3042 – ‘It’s just something that you’ve gotta do.’
3028 – ‘It’s essential to come to Adelaide for treatment’.

**The need for a support person**

7093 – ‘I would say to bring some to support you. I would say that’s vitally important, because you’re so detached from family and friends anyway…um… it’s not a good idea to go through cancer on your own’. Participant’s husband ‘you couldn’t do it by yourself, not the way we’re doing it, there’s no way you’d drive yourself down and back, you can’t do it… it would be an impossibility for us’…. ‘it’s nice to have someone that’s either a very good friend or a very good spouse, because you’ve left your support group at home’. ‘have a strong support base’. ‘That’s like those days (when feeling down) I put a sad video on and watch that and if I get caught out I can always blame the movie’.
4073 – ‘Have someone with you so you’re not by yourself when you come back and forth’.
1061 - ‘(It’s) frightening, particularly because you’re away from your circle of friends’.
7046 – ‘Have a good wife as a support person’.
3058 – ‘Bring your daughter with you, so she can look after you’.

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<th>Page</th>
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<tbody>
<tr>
<td>1064</td>
<td>‘Have someone with you, um, and a pocketful of money!’</td>
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<td>3025</td>
<td>‘Have someone with you’</td>
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<tr>
<td>4073</td>
<td>‘Well I reckon try and arrange so they’ve got somewhere to stay before they come down and have someone stay with them’</td>
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<tr>
<td>1095</td>
<td>‘Work out your transport first, and ah try and work out to have some family member try and be here with you’</td>
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**General/other**

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<tr>
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<tbody>
<tr>
<td>1008</td>
<td>‘Run, don’t come!’</td>
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<tr>
<td>3009</td>
<td>‘Don’t catch A double L’ (acute lymphocytic leukaemia)’</td>
</tr>
<tr>
<td>1020</td>
<td>‘I think you got to make your own judgment’</td>
</tr>
<tr>
<td>1021</td>
<td>‘I don’t know that I’d give anyone any advice, everyone’s situation is different’</td>
</tr>
<tr>
<td>3028</td>
<td>‘Stay home’</td>
</tr>
<tr>
<td>7032</td>
<td>‘Don’t get cancer’</td>
</tr>
<tr>
<td>6074</td>
<td>‘Goodness me, um, well it depends on the circumstances in which they came’</td>
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<tr>
<td>1077</td>
<td>‘Don’t get cancer… while you’ve got cancer you’re in big shit and nothing’s going to be easy…end of story…that’s why I’m a bit dirty on the Cancer Foundation with their you know, cancer’s only a word, not a sentence, bullshit it’s a sentence’</td>
</tr>
<tr>
<td>9080</td>
<td>‘Stay home!’</td>
</tr>
<tr>
<td>1040</td>
<td>‘I don’t think I’d give them any’</td>
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# Appendix 15: Participant recommendations for improvement of cancer treatment

## Health Care Services

- Advise patients to attend Adelaide early to minimise doubling up of diagnostic tests.
- Introduce palliative care from the beginning.
- Provide leaflets for doctors in rural/remote areas to provide to patients advising of accommodation and financial assistance.
- Introduce and use case manager positions (advising patients on applying for refunds, booking accommodation etc).
- Increase rural - metropolitan liaison positions.
- Make respite care available for partners/family.
- Ensure access to psychological assistance.
- Ensure communication with the treatment team continues after treatment is finished or at least ensure the patient knows what to expect.
- Have an ID bracelet from St Johns in case of accident when travelling to and from Adelaide, as well as a medical information card.
- Health professionals should be aware that attending Adelaide is very time consuming (particularly frustrating if treatment is cancelled at short notice).

## Support Services

- **Accommodation specific:**
  - Provide hand held showers at accommodation (e.g. for those with intravenous pumps).
  - Provide after hours reception phone access to Greenhill Lodge (closes at 7.30pm and relatives might not know which room the patient is in).
  - Don’t allow smoking at accommodation (e.g. Greenhill Lodge).
  - Make food available after hours at Greenhill Lodge (e.g. for patients discharged on weekends).
  - Provide secure refrigeration in the Royal Adelaide Hospital residential wing (e.g. for patients on restricted, high calorie diets who rely on milk products).
  - Reduce the cost of meals at Greenhill Lodge.
  - Provide petrol vouchers.
  - Improve inter-hospital transport (e.g. for patients having chemotherapy at TQEH and radiotherapy at RAH).
  - Make the Leukaemia Foundation car more available at short notice.
  - Have volunteers available to accompany patients to appointments (particularly when they are in Adelaide on their own).
  - Organise weekend volunteers to help with activities while staying in Adelaide.
  - Make warm clothing available for those from the Northern Territory.
  - Facilitate access to support groups for people from remote areas.

## Policy

- Cover the costs of private patients (they are saving money for the public health system).
- Subsidise those staying in private accommodation.
- Ensure private phone rates are charged in subsidised accommodation, ensure phone access is easily available (e.g. Seaview Lodge), ensure phone cards are easily available.
- Discount airfares for rural patients should be made available.
- Make sure the system is consumer oriented, keep the consumers the point of interest.
- Provide information on available financial reimbursement more proactively (i.e. from PATS office).

## Information

- Ensure patients are aware of community support services.
- The availability of PATS funds should be transparent (i.e. shouldn’t depend on individual application).
- Monitor drug costs, ensure they aren’t prohibitive and that patients know how to minimise costs.
- Supply an information pamphlet re coming to Adelaide (e.g. clothes, things to organise).
## Appendix 16: Responses of health care professionals

<table>
<thead>
<tr>
<th>Key areas</th>
<th>Identified issues</th>
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| Travel and accommodation         | The need for more accommodation for families and hostel level accommodation for those who live alone. Hostel accommodation should have a nurse living in who is able to keep an eye on patients and be a resource should problems arise.  
The residential wing (at Royal Adelaide Hospital) needs to be improved, it is generally unclean, full at times, and the criteria for staying there should be more flexible (i.e. lower distance from Adelaide).  
Travelling to the metropolitan specialist centre has both up and down sides. The down side is that the patient is away from their family and unable to work. The up side is that they have a trip to town and are able to combine the visit with other purposes, such as visiting relatives, shopping etc. The visit is also less expensive due to the subsidy provided.
Information about the city should be provided to allay anxiety about the unknown environment (for example telling them it’s easy to get around).
Greenhill Lodge is successful in supporting patients. A degree of user pays should be retained for this type of support.
Greenhill Lodge is useful in bundling people together who have similar needs.
More accommodation options that are economical are needed.
There needs to be more recognition by the treatment site that patients need to stay somewhere and that this accommodation needs to be appropriate to their needs. Their primary function is as a treatment site, but there is a potential lobbying role for those providing accommodation and support to patients.
Patient Assistance Transport Scheme should increase the funding available for support of patients.
Any patient should be entitled to an escort – particularly as metropolitan patients are able to have an escort without the worry of associated costs of staying away from home.
The new information kit put out by The Cancer Council New South Wales may be of use.
Patients should be pre-warned, or warned as early as possible, of the need to relocate so they are prepared for this possibility (specifically those with leukaemia).
It can be difficult to arrange for family members to go with the patient. Some have particular needs for someone to go with them (eg Aboriginal patient) and it can be hard to ensure both appropriate accommodation and an appropriate support person (who speaks the same language etc).
An escort can be requested on the PATS form, but anecdotally, if the person is not a family member they may be asked to pay for accommodation costs.
It is particularly difficult for those who haven’t been to Adelaide before, as the treatment process in the metropolitan setting can seem incredibly complicated when beginning treatment.
Information needs would be assisted through good internet access. The focus must be on further development of electronic communication.
There is sufficient information available, particularly on diseases and treatments and duplication is not needed.
Information on how to navigate the metropolitan environment would be helpful.
Rural liaison nurses could coordinate the transfer of information from the metropolitan hospital to the rural one. The information is available, it is just a question of getting it there.
Video conferencing between health care practitioners via video/teleconferencing is useful. An advantage is that this gets around the medico-legal difficulty of not seeing the patient in person, but instead, talking with the medical person seeing the patient. Another advantage is the up-skilling of the rural practitioner.
There is a need for readable information for patients and for good levels of verbal communication with the doctors – they need to be more available for this.
This cancer centre produces guidelines for chemotherapy protocols, administration and support care. |
that are available from the internet and sent to outlying health care centres.

Clinical trials are listed on the hospital website, making this information available helps overcome barriers for rural patients.

It is really important that the GP receives information from the hospital, it is difficult to manage the patient without this.

Rural GPs don’t get enough information about what is available to support patients who are diagnosed with cancer.

When someone is diagnosed and starts treatment, copies of the information on supports should be sent to the GP as well as be provided to the patient (eg support groups) as a way of ensuring the GP gets targeted information at the time of treatment.

When a patient goes back to the community (particularly in remote areas) the registered nurse/health worker in the health clinic should have access to a phone contact, to be able to talk to someone about the patient should complications arise. People agree to medical treatment for cancer, but if something happens they don’t necessarily identify it as a treatment complication or problem that needs addressing. Lack of knowledge and education are influencing factors in this area.

There is a need for the GP to deal with associated treatment issues (accommodation, travel etc), as well as communicating news of the diagnosis. This complicates their role.

In the rural area the GP is the key point of contact should there be problems and needs to negotiate their management in the rural setting or in Adelaide as appropriate. GPs realise it’s not an area they are expert in and that specialist management is appropriate, but they are an integral part of the support for this person and need to understand the treatment.

Language is an important issue for some Aboriginal patients. English may be a second or third language. An appropriate interpreter would be helpful in this situation.

Health professionals should have an awareness of cultural issues. For example, it may not be appropriate for a female registered nurse to shower an Aboriginal male, or a male doctor to examine an Aboriginal female. It is important to remember to show respect to people. Patients like to have their name remembered and know that staff understand issues which are important to them. For example, that they live outside of Adelaide (and may have sat up on a bus all night to get to the appointment).

Psychosocial impact / separation

It is desirable to get patients home for a break or to finish the treatment in the rural setting to minimise the time in Adelaide.

Family and children should be supported and encouraged to accompany the patient.

Patients should have an escort funded to go to treatment with them on psychosocial grounds.

Families may have a child in school while mum or dad is away having treatment, which can have a huge impact. Having a diagnosis of cancer also has a huge impact.

People are resigned to the fact that this is what they have to do (i.e. travel) to get cured, they feel stoic and as though they have to cope. For example, those with a child in school have limited options in dealing with the situation (e.g. while one parent or carer goes away for treatment, the other may have to stay at home hundreds of kilometres away to care for the children).

GPs/health care professionals may not talk to patients enough about psychosocial issues or give them enough support. It places enormous strain on families, particularly when the wage earner is sick. These issues seem self-evident. It is unclear if or how that type of issue is identified while patients are in the metropolitan hospital and how they are addressed. Resources in the public health system to manage these issues are also limited.

Physical impact

Patients with leukaemia are restricted in travel options as they can’t go by bus due to risk of infection.

There is a need for more community buses for transport.

Once the patient goes home, the gap between them and specialist assistance is greater, potentially leading to delays in intervention (particularly in relation to patients who are febrile and neutropaenic). This puts them at greater risk of morbidity than non-rural patients.

There is a reality of needing to travel and little that is likely to be able to improve this.

There may be a burden on carer or the family to physically look after the patient. This can be an issue in
the acute stage or later if the person remains unwell, for example the patient can’t function at usual level. Communities often provide good support and families will help, but if nothing is set up, it is not clear whose job it is (possibly GPs).

A recent project by the Flinders and Far North Division of General Practice organised for a designated person to be available for doctors in times of crisis, eg acute illness. It would be good to have a similar thing available in the wider community. However, in a supportive rural community this does happen anyway – neighbours, friends and family will help at short notice.

**Financial costs**

The costs incurred relate to treatment, travel, accommodation and lost productivity.

If patients lose their job there are not as many options for re-employment (due to lower levels of employment in rural communities).

PATS needs reviewing.

PATS covers costs of transport and accommodation to a certain extent, however the paperwork can be off putting for the person.

It is a particular problem if the person who is sick is the wage earner.

Financial support is something that we need to discuss more, some are good at asking for help (for example, those who are on government assistance may be accustomed to discussing finances), others may not ask for help.

An example of an issue that can arise is for Centrelink to cut off payments as the patient hasn’t attended when due, as they have been unwell in hospital.

This issue differs according to family structure, treatments and communities.

**Access to services and treatment**

There needs to be a welfare person available to patients specifically dealing with Centrelink, a key person who can link patients to the available supports.

Centrelink staff used to visit patients in hospital (about 2 years ago) and this should be reintroduced.

Privately treated patients lack allied health support.

In other states they are overly concerned about administration of chemotherapy in rural areas, (for example, bolus chemotherapy given on day eight of some regimes). As long as the training, back up and support are available and the control of the treatment is through the specialist team, administration of selected chemotherapy agents in rural settings should be possible.

The differences in access to services for rural patients depends on how much the person concerned wants to take responsibility for and how much access they would like to ensure they have.

Rural patients tend to identify and get to know medical care providers who are sympathetic to the situation of rural people, for example if the patient says they have to drive eight hours the health care provider will be flexible.

It is a problem when health care staff are inflexible and think it’s not a problem for people to be waiting in Adelaide for one or two appointments or investigations. Patients will miss tests/procedures sometimes as they don’t want to stay, for example they’ll go home rather than wait to have the test. This may result in late diagnosis etc.

Aboriginal people are reported to have fewer referrals to specialist treatment, even though they have a significant burden of disease.

There are cultural issues particularly in relation to the Aboriginal population, such as isolation in the city environment. They may not understand treatment options and may not get the appropriate treatment.

The process of identifying the appropriate specialist may be influenced by whether the patient is in the public or private system. Rural patients may have limited choices as they are dependent on GP referral.

Rural patients are a tolerant group and will put up with a lot to get the treatment they need (abrupt doctors, inconvenient appointments, travel etc). It is more difficult for rural and remote people to access treatment for cancer. This needs to be considered when planning treatment.
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