Dying In The Margins: Understanding the needs and capacities of a lower socioeconomic population for end of life care

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Thesis submitted in fulfilment of the degree of

Doctor of Philosophy

University of Technology Sydney
Certificate of Original Authorship

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged in the text.

I also certify that the thesis has been written by me. Any help I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition I certify that all information sources and literature used are indicated in the thesis.

Signature of student
Acknowledgments

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Anthology of Publications Associated with

Thesis


Abstract

Increased disease burden and unmet health care needs are defining features of lower socioeconomic groups, both in Australia and internationally. In Australia, there is limited understanding of the needs of lower socioeconomic groups for end of life care. At the end-of-life, health disparities are often more pronounced for both patients and their caregivers. Globally, there has been scant attention on the needs of individuals from socially and economically disadvantaged groups at the end-of-life. As gaps between the rich and poor widen and the emphasis on community-based care increases, this research area is of growing significance.

The research objectives of this study were to (i) provide a snapshot of the impact of socioeconomic status on place of death and after-hours crisis service utilisation by comparing outcomes of areas of high and low disadvantage; (ii) explore and describe the socioeconomic demographics, needs, capacities and experiences of patients and/or carers from a disadvantaged area focusing on (ii a) the social, economic and care outcomes and capacities at individual, community and government levels, (ii b) the nature and impact of social capital outcomes, (ii c) the experience of access for a specialist palliative care service; and (iii) describe the appropriateness, acceptability, and feasibility of self-report tools for capturing wellbeing, consumption, health literacy, social capital and palliative care needs and capacities in this population.

This study used a concurrent embedded mixed method design with a qualitative emphasis and explicit use of social determinants of health framework and social capital concepts. The conceptual framework determined selection of self-report tools which additionally structured interviews. Integration of the quantitative and qualitative data was achieved through the study design, data collection and discussion. Four years of administrative data from a single palliative care service, located in a socioeconomically disadvantaged area was collected and analysed. Place of death and after-hours crisis service data were compared for a most and a least disadvantaged area compared over a twelve month period. Semi-structured interviews were conducted with 14 patients and/or carers from a lower socioeconomic area and five key informants who provided formal care for this group. Demographic data and outcomes of self-report tools were collected from patient and carer participants during interviews. Semi-structured interview responses to self-report tools were evaluated for appropriateness, acceptability and feasibility of these measures.
The findings demonstrate that a lower socioeconomic group experienced end of life care within margins of social and economic resources and care networks. Social margins were shaped by limited community trust, engagement and deficiencies in social policy (public housing). Economic margins reflected income loss, healthcare spending on co-payments and economic disparity in aged care facility access. Care network margins were defined by limited informal and formal care support. Patients from the disadvantaged area had fewer home deaths and greater home care needs warranting facility admission. Capacities within the end of life care experience were demonstrated by trust and engagement with government organisations, potential for community club, neighbourhood and friendship support, access to financial support programs and benefits, and examples of supported home care networks. Recommendations for research, clinical practice and policy to address these issues are discussed.

This thesis has provided a unique and novel contribution to the literature. Specifically, it has demonstrated the needs and capacities for a lower socioeconomic group not previously described in the Australian literature, and in particular, it has advanced conceptual and theoretical issues in investigating social and economic issues in end-of-life care.
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<td>ABS</td>
<td>Australian Bureau of Statistics</td>
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<tr>
<td>ASCAT</td>
<td>Adapted Social Capital Assessment tool</td>
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<tr>
<td>CNC</td>
<td>Clinical Nurse Consultant</td>
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<tr>
<td>CNS</td>
<td>Clinical Nurse Specialist</td>
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<tr>
<td>COAG</td>
<td>Coalition of Australian Governments</td>
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<tr>
<td>CSDH</td>
<td>Commission for Social Determinants of Health</td>
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<tr>
<td>HILDA</td>
<td>Household Income and Labour Dynamics in Australia</td>
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<tr>
<td>IRSD</td>
<td>Index of Socioeconomic Disadvantage</td>
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<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
</tr>
<tr>
<td>OECD</td>
<td>Organisation of Economic Co-operations and Development</td>
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<tr>
<td>OOP</td>
<td>Out of Pocket</td>
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<tr>
<td>PCA</td>
<td>Palliative Care Australia</td>
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<td>PCOC</td>
<td>Palliative Care Outcomes Collaborative</td>
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<td>SDH</td>
<td>Social Determinants of Health</td>
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<td>SEIFA</td>
<td>Socioeconomic Indexes for Areas</td>
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<td>SOCAT</td>
<td>Social Capital Assessment Tool</td>
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Advanced care directive: Documents containing instructions that consent or decline specific medical treatments and/or specify care and lifestyle preferences in anticipating future situations or circumstances. These directives are activated in situations where the person is no longer able to make decisions. As legal documents, advanced care directives are distinct for legislative requirements in each State and Territory in Australia.

Bulk Billing: The process by which a practitioner sends the bill for services directly to Medicare, so that the patient receiving the service pays nothing.

Consumption survey: A self-completion 21-item survey which identifies approximate weekly, monthly, and yearly household expenditure and additional items for costs of medications and medical consumables and equipment hire/purchase costs.

End of life care: Combines the broad set of health and community services that care for the population at the end of their life. Inclusive of networks between specialist palliative care providers, primary generalist providers, primary specialists and support care providers and the community.

Home care services: The Home and Community Care (HACC) Program is a joint Australian Government, State and Territory initiative to provide community care services to frail aged people, younger people with a disability and their carers.

Index of relative Socioeconomic Disadvantage (IRSD): The Index of Relative Disadvantage uses indicators of low socio-economic wellbeing as a general measure of disadvantage. Its use is appropriate for users interested in the relative disadvantage of people in an area (lower deciles), and the relative lack of disadvantage of people in an area generally (upper deciles).

Medicare: Australia’s government-funded health care system that subsidises the costs of personal medical services for all Australian Medicare card holders and aims to support affordability of medical care.

Needs assessment tool: Progressive disease Cancer (NAT:PD-C): A sixteen-item, multiple section assessment tool administered by health professionals to assess levels of need in patients and carers in specialist and generalist health care settings and match these needs to specialist palliative care services as necessary.
**Personal Wellbeing Index (PWI):** An 8 item, 11 point self-report end-defined response scale, which assesses a person’s subjective quality of life across eight domains (‘standard of living’, ‘health’, ‘achieving in life’, ‘personal relationships’, ‘safety’, ‘feeling part of the community’, ‘future security’ and ‘spirituality or religion’).

**Pharmaceutical Benefit Scheme (PBS):** A publicly funded insurance scheme in Australia aimed at providing universal affordable access to prescription medicines.

**Primary care providers:** In the context of end of life care, a primary care provider is the first contact medical, nursing or allied health professional who undertakes an ongoing role in the care of a patient and their family or carer.

**Rapid Estimate of Adult Literacy Medicine-Revised (REALM-R):** An eight item instrument designed to rapidly screen adult primary care patients for low health literacy.

**Social Capital Questionnaire (SCQ):** The questionnaire is a researcher-designed tool to measure the quality and quantity of individual, community and societal relations and networks for the patient or their carer. The questionnaire has 16 questions with multiple item responses to 5 questions.

**Socioeconomic Index for Areas (SEIFA):** A measure of socioeconomic status in Australia used to define levels of disadvantage within and across areas. SEIFA scores are indicators of socioeconomic status and are the most widely used measure of socioeconomic status (SES) in Australia. They are based on international research and information collected in the census reflected in the Australian Bureau of Statistics (ABS) data.

**Specialist palliative care services:** Specialist palliative care services are provided by an interdisciplinary team of specialist palliative care professionals whose substantive work is with patients who have an eventually fatal condition. Specialist palliative care services are provided in care settings including community, home, hospitals, aged care, homes and hospices and palliative care units.
Chapter 1

11.1 Introduction

The increasing demand for palliative care services globally has placed huge demands on services to meet the needs of palliative patients, their families and carers during a highly vulnerable phase. Australia is not exempt from these demands for service. The capacity of Australia’s health system to provide access to quality end of life care for all Australians who would benefit from it is questioned (PCA 2008). The end of life care needs of a broad range of groups has been considered by Palliative Care Australia, who have emphasised the importance of a population needs-based approach to service delivery rather than on the basis of diagnosis or postcode (Glover & Hanson 2009). Yet, despite a firm commitment of government and non-government organisations to equity, there remains little understanding of the reasons for unmet palliative care needs and acceptability of palliative care services for marginalised populations, such as lower socioeconomic groups in Australia (Glover & Hanson 2009).

It is necessary to address gaps in understanding of the needs of lower socioeconomic groups for end of life care in Australia. Palliative care patients and carers from lower socioeconomic groups are likely more vulnerable, by nature of their illness, care giving demands and limits of social and financial resources. Therefore, specifically understanding palliative care needs, social, economic and system issues that may contribute to this vulnerability is imperative. This study has developed and refined methods for investigating care to socioeconomically deprived populations and understanding the experience of death, dying and palliative care access within this context. This study has sought to understand the needs of individuals and their care givers when navigating the end of life care experience.

This chapter provides an overview of socioeconomic disadvantage in Australia, and issues in palliative care delivery. This is followed by discussion of the significance of this study, the research objectives and an outline of the structure of the thesis for each chapter.

11.2 Background and context

11.2.1 Dimensions of socioeconomic disadvantage

Understanding the nature of socioeconomic disadvantage requires an appreciation of the dimensions that make up this complex entity. Poverty and social exclusion are two indicators of socioeconomic disadvantage most recognised in the Australian discourse (Saunders 2011) and are discussed below.
11.2.1.1 Poverty

Definitions of poverty have sparked debate in Australia. Disagreement around the definition and measurement of this construct has been central to any social and political discourse (Serr 2006). Key to any poverty debate is discussion of the incidence of poverty according to descriptions of ‘poverty lines.’ The Henderson poverty line, established in the early 1970’s was a measure of both absolute and relative poverty and was Australia’s first, widely accepted measure of this construct (Scutella, Wilkins & Horn 2009). The usefulness of the Henderson Poverty Index is debated. There is lack of consensus on the different measures used to estimate the poverty rates, such as income and housing costs, and limits of the index to account for welfare support payments and concessions (Willis et al. 2009).

Poverty lines set at 50% of the median income are often used as estimates of poverty in Australia (Wilkins 2008). Poverty estimates based on measure set at 60% of median incomes are also described in government and academic reporting. These are particularly important for poverty outcomes in Australia, because many welfare recipients’ incomes fall between the more austere measure of 50% median income and the 60% median income measure (Saunders 2011). The reporting of these two poverty line measures provides insight for the financial risks faced by certain groups in Australian society.

Income-only measures of poverty based on poverty lines are considered narrow measures of economic wellbeing, as they do not consider other economic factors, such as wealth and consumption, which can extend or limit earnings. Income-only measures also fail to measure non-cash income, such as rental and healthcare subsidies. Measures of consumption and wealth, in addition to income measures, are now considered more appropriate in supporting a broader picture of economic capacity which captures living standards (Headey 2008). Living standards are more likely to reflect the nature of financial resources and therefore, describe the capacity for an individual, couple or family to secure a standard of living that is reasonable in an Australian context.

Measuring income, wealth and consumption individually is difficult because of significant measurement errors for these items. Therefore, directly measuring each of these compensates for many of these errors (Headey, Krause & Wagner 2009). Development of the poverty literature in Australia has been enhanced by longitudinal household data sets, such as the Household Income and Labour Dynamics Australia (HILDA) survey. HILDA has measured consumption specifically through weekly expenditure diaries and produced findings that
support this broader understanding of income poverty features for an Australian context (Headey & Warren 2008)

11.2.1.2 Social exclusion

Social exclusion is considered a more comprehensive definition of disadvantage and proposes to address the limitations of other concepts (Barry 2002). The limitations of financial poverty are well-described in the literature, but are no longer considered to be adequate as stand-alone measures. The limits of income poverty are considered, because although broader descriptions, as described above, consider standards of living, they are unable to adequately identify whether these living standards are acceptable (Saunders 2011). The concept of deprivation supports a broader framework for living standards through identifying the outcomes of financial poverty and providing an operational definition of poverty. However, the social exclusion concept extends this further to describe non-participation in society arising from constraints rather than choice (Burchardt, Le Grand & Piachaud 2002). Social exclusion can be described in terms of its measurement:

Measure of social exclusion attempt to identify not only those who lack resources, but also those whose non-participation arises in different ways: through discrimination, chronic ill health, geographical location, or cultural identification, for example. Lack of material resources remain a central and important cause of non-participation, but it does not exhaust the possibilities (Burchardt, Le Grand & Piachaud 2002)

Australia has been a latecomer to the discourse of social exclusion. Attempts to understand the nature of this concept in Australian populations were initially dominated by a focus on employment and welfare reform (Saunders, Naidoo & Griffiths 2008). The broadening of the concept in Australian political and policy discourse did, however, occur, and was followed by development of social exclusion indicators identified in the Australian research and policy arenas (Saunders, Naidoo & Griffiths 2008). A framework for social exclusion used most recently in Australian research identified 3 domains and 27 indicators. The three domains and broad descriptors include:

- **Disengagement**-lack of participation in the kinds of social activities and events which are customary and widely practiced by members of the community.

- **Service exclusion**-restricted access to the kinds of services that meet basic needs, whether they are publically funded, subsidised by government (healthcare, disability, mental health and aged care services) or are predominately provided privately and subject to extensive user charges (dental treatment, child care, basic household utilities and financial services).
- **Economic exclusion**—those with low economic capacities and restricted access to economic resources. (Saunders 2011)

The British and European experience, which has much longer recognised that the nature of disadvantage, is an outworking of social needs for relationships, engagement and choice to name a few, and cannot be ameliorated by economic development alone, has prompted impetus for Australian governments to address poverty more effectively from a social exclusion platform (Saunders 2011).

### 11.2.1.3 Resilience, adversity and vulnerability

Resilience, adversity and vulnerability feature in the literature examining socioeconomic disadvantage and are considered important for understanding social problems from an equally valid strengths perspective (Ahmed et al. 2004). Resilience is considered to be created in the presence of adversity and is defined as the internal assets of a person’s constitution and external assets of the environment, that allow that person to buffer against the effects of adversity (Lindstrom & Eriksson 2010). Resilience was not a fixed, but a dynamic attribute changing with life circumstances, accumulation of adversity and presence of other resilient outcomes (Willie & Ravens-Sieberer 2010). Adversity depicted a range of risk factors which increased a person’s vulnerability to negative outcomes (Ahmed et al. 2004). Vulnerability was cumulative over a life course and sources included poverty, and race, social networks, lack of social support, personal limitations of impairment in health and cognition and poor physical environments. Support for vulnerability, whether in an individual, community or society, required intervention aimed at any of the sources of vulnerability (Mechanic & Tanner 2007). Resilience and adversity are important for acknowledging the nature of capacity in disadvantage and also for contending that deprivation is dynamic and shifted by persons and contexts (Mechanic & Tanner 2007).

### 11.2.1.4 Socioeconomic Index For Areas (SEIFA)

The Socioeconomic Index For Areas (SEIFA) score is a measure of socioeconomic status in Australia used to define levels of disadvantage within and across areas. SEIFA scores are indicators of socioeconomic status and are the most widely used measure of socioeconomic status (SES) in Australia. They are based on international research and information collected in the census reflected in the Australian Bureau of Statistics (ABS) data (2006). Census collection districts in Australia are assigned a score representative of levels of disadvantage or advantage compared with other areas (ABS 2006). The Index of Relative Socioeconomic Disadvantage (IRSD) is one of four SEIFA scores compiled by the ABS and captures information beyond
income and unemployment to include access to material and social resources and ability to participate in society (ABS 2006). The conceptual methodologies of SEIFA, which identify disadvantage as a social construct, are considered appropriate in exploring disadvantage as a multidimensional concept (Pink 2006).

Criticism for the use of geographically-based SEIFA scores, are that area-based measures were not necessarily sensitive to individual variations in an area and most particularly age-related variations that are unable, for example, to account for differences in function and employment opportunities (Walker & Becker 2005). Care in interpretation of SEIFA scores from an area level to an individual level are highlighted by the ABS (2006).

11.2.2 Outcomes for socioeconomic disadvantage in Australia

11.2.2.1 Poverty and social exclusion outcomes

Poverty rates in the Australian population, according to the Organisation for Economic Co-operation and Development (OECD), are 12% (50% median); that is, 20% (60% median) higher than the OECD average of 10.1% and 16.8%, respectively, for 50% and 60% medians (OECD). Variations in poverty across groups are noted and indicate that those people relying on social security payments are at greater risk for poverty generally (Saunders 2011). The most recent report from the Australian Institute of Health and Welfare (AIHW) gives a broad outcome measure of poverty in Australia indicating that in 2009-10, 1 in 8 Australians or 2.6 million people were living in a low income household (AIHW 2012a).

Outcomes for social exclusion in Australia identify that 20-30% of the population over the age of 15 years are described as being ‘marginally excluded’; 4-6% of the population are considered to be ‘deeply excluded,’ and less than 1% of the population were ‘very deeply excluded’ (Kostenko, Wilkins & Scutella 2010). Deep exclusion exists whereby individuals experience a number of different forms of exclusion simultaneously. The groups most likely to be deeply excluded in Australia include the unemployed, public renters, lone parents, Indigenous Australians and private renters, closely followed by those caring for a child or adult with a disability and those persons with an ongoing disability. The deeply excluded are over represented by persons relying on welfare (Scutella, Wilkins & Horn 2009).

11.2.3 Socioeconomic status and health inequalities

11.2.3.1 Social gradients and health outcomes

The evidence linking lower socioeconomic status and increased morbidity and mortality is strong and consistent and has been reported for over one hundred and seventy years (Davey
Smith & Krieger 2008). Regardless of the conceptual model used to understand and measure the impact of the social environment on disease and illness, the association between socioeconomic position and all-cause mortality is maintained (Rosvall et al. 2006). The increased incidence for late diagnosis for lower socioeconomic groups are found and contribute to both disease burden and increased mortality in this group (Dalton et al. 2006). Both incidence and shortened duration of disease are identified for lower socioeconomic groups and further highlight inequalities in poorer health outcomes (Mackenbach et al. 2008). The evidence for the relationship between socioeconomic status and health is therefore observed globally, is persistent over time, is evident irrespective of measurement and exists across nearly all disease states.

Health inequality research is a broad area of inquiry and the work of Michael Marmot and the Commission on the Social Determinants of Health (CSDH) has developed strong action in this area (Marmot et al. 2008). According to Marmot (2005), absolute deprivation seen in developing countries is established by profound levels of material deficit. Relative levels of deprivation in developed countries describe social gradients which are largely determined by limits in social functioning and capabilities.

Some of the most prominent studies on social gradients in developed countries are those from the Whitehall study which began in 1967 in the United Kingdom and measured the association between social class and mortality in British civil servants (Marmot et al. 1991). The follow-up Whitehall II studies found little change in socially graded mortality 20 years later (Marmot et al. 1991). The relationship between social gradients and health is clear. Research and historical findings support the need to understand that the capacity for social processes to determine ill health is not irreversible or inevitable, but overwhelmingly requires solutions which are socially derived.

11.2.3.2 Social determinants of health (social capital)

Socially derived health inequalities have laid the foundations for the Social Determinants of Health (SDH). The SDH identify the socially determined conditions that create ill health and poor wellbeing and also consider the outcomes of the degree of protection provided from disadvantage due to ill health (Marmot 2007). More broadly, the SDH framework outlines inequalities in health from the context of structural and individual (intermediary) elements of society; more specifically, the socio-political environments, social stratifications, community circumstances and individual conditions. The impact of social conditions on health realises the inadequacy of medical care alone to address the health needs of a population. The evidence
that health policies have failed to reduce the gaps in health between the privileged and disadvantaged, is such that broader social measures are required to achieve equality in health (CSDH 2008). Recognising the capacity of the SDH to shift the impact of disadvantage, requires that government social policy, not just health policy, is important as limited social status discrimination and exclusion lie at the heart of inequalities in health (Bell, Taylor & Marmot 2010).

Bridging the broader social and political policies of SDH with the individual and community health and wellbeing outcomes is the social capital concept. Social capital describes the individual, community and political networks or relations which inhere resources (Kawachi, Subramanian & Kim 2010). The concept focuses more specifically on the social and community elements necessary for health and wellbeing; balancing the broader socio-political consideration of social determinants elements. The SDH framework and social capital concept will be discussed in detail in Chapter Three, as they inform the conceptual framework of this study.

11.2.4 Socioeconomic disadvantage and health inequalities in Australia

Life expectancy in the Australian population has now risen to a point where it competes with Switzerland for the second ranking internationally (Ring & O’Brien 2007). Disability-adjusted life years (DALY), which estimate the overall year(s) of ‘health life’ lost to disease and injury, have been reduced as a result of improved health outcomes in Australia (AIHW 2012a). Despite these significant advances in mortality and health outcomes, health inequalities in Australia have persisted most particularly for Aboriginal and Torres Strait Islander groups, lower socioeconomic groups, persons with a severe or profound disability and those Australians living in rural and remote areas (AIHW 2012a).

The health outcomes for lower socioeconomic groups in Australia describe lower life expectancy, higher levels of disease risk factors and lower use of preventative services. The reasons for differences in health outcomes in this group are many and include, but are not limited to, lower income, lower housing standards, reduced access to medical services, lower levels of education and/or health literacy, and chronic stress (ABS 2010). Australian Bureau of Statistics (ABS) data reported the incidence of long term health or chronic conditions and found a distinct gradient for these conditions across quintiles of disadvantage (ABS 2010). Figure 11.1 demonstrates that people living in a most disadvantaged area were more likely to have arthritis, mental health problems, diabetes, ischaemic heart disease and cancer, compared with those living in the least disadvantaged area. The relationship between other
poor health outcomes and increased levels of disadvantage included poorer self-assessed health outcomes, higher proportions of disability and a higher prevalence of health risk behaviours (ABS 2010).

The links between socioeconomic disadvantage with poorer health outcomes is well supported (Coalition of Australian Governments COAG 2012). Conversely, the inverse relationship between socioeconomic status and resulting ill-health leading to reduced socioeconomic status is also described in the Australian literature and is explained in terms of a cycle of poor health leading to income loss, healthcare costs and poverty (Jan, Essue & Leeder 2012). This is of particular concern in a country like Australia, which funds a universal public healthcare system and social security support arrangements. Costs for medical spending outside of the public hospital service are a likely contributor to financial burden in healthcare populations in Australia. Australia has some of the highest out of pocket (OOP) costs for health care in the world at 21%, which is only behind the United States at 35% and Switzerland at 25% (Jan, Essue & Leeder 2012). These large OOP costs represent co-payments for medical care and pharmaceutical costs and although supported by a safety net scheme, these costs remain high and the impact for lower socioeconomic groups is likely to be most significant (Jan, Essue & Leeder 2012).

The health care needs of lower socioeconomic groups in Australia are described in a context of higher rates for mortality, poorer health outcomes, less reports for preventative management.
and greater vulnerability to economic consequences of illness (COAG 2012). Lower socioeconomic groups, in particular, are more likely to require management of more advanced disease (Schwartz et al. 2003) and likely have more complex social and economic needs which would entail different demands for end of life care (Dzul-Church et al. 2010; Giorgi Rossi et al. 2007; Hanratty et al. 2007; Kramer & Yonker 2011).

11.2.5 Palliative care in Australia

11.2.5.1 Palliative care service delivery and funding

Palliative care is delivered across a range of health care settings which include private or public hospitals (with or without designated beds), inpatient palliative care units or hospices, residential aged care facilities, the home and other community settings. Palliative care in Australia is identified by its philosophy, practice of care, service provision and service providers:

Palliative care is care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure, and for whom the primary treatment goal is quality of life...Palliative care is interdisciplinary care, delivered by coordinated medical, nursing, allied health and social services and integrating the physical, psychological, social and spiritual aspects of care. It recognises the patient and family as the unit of care, and respects the right of each patient to make informed choices about the care they receive. (PCA 2005)

The model of palliative care delivery varies across and within a range of settings because of different funding and support arrangements across the States and Territories (Gordon et al. 2009). The majority of generalist palliative care service delivery in Australia occurs in the home and community and aged care settings (AIHW 2012b)

Palliative care services and funding are understood within Australia’s health care funding model. Australia has a universal healthcare system, the Medicare scheme, which provides universal coverage for health care services. Australia also has a significant private health care sector supported by funding from both government and private health insurance schemes (Palangkaraya et al. 2009). Public hospital inpatient services are fully funded services and constitute 31.2% of health care spending, private services account for 8.6% of funding and community health services constitute 5% of health care funding in Australia (AIHW 2012a).

Funding for palliative care services is mainly through public funding, provided through a combination of funds from state and territory budgets (AIHW 2012b). Primary care services,
which include community nursing, general practitioner and home care services are funded solely by the Federal government (home care services, since July 2012) or by a mix of Medicare, state and territory-based programs, local government programs, patient/client contributions, private services and non-government organisations and charitable groups (AIHW 2012a). Residential aged care facilities receive a mix of state and federal funding and co-payments provided by clients and families through means tested schemes or pension contributions.

11.2.5.2 Palliative care service provision

Palliative care service provision is coordinated through linkages which are established through specialist palliative care services and primary care providers (PCA 2005). Specialist palliative care services are invariably provided by a multidisciplinary team whose role is to care specifically for patients with terminal conditions and their carers and families; the provision of inpatient and consultative services is for patients and carers with complex end of life care needs (PCA 2005). Primary care providers are informal and formal and include family, friends or community, community nurses, general practitioners, staff from residential aged care facilities and hostels, and staff from other specialist services and acute care hospital staff. The substantive role of these primary care providers is not palliative care and specialist palliative care services are engaged by these providers on an ‘as needs’, referral basis (PCA 2005).

11.2.5.3 Population-needs based model of care

A needs-based model of care has been proposed by Palliative Care Australia (PCA), to ensure a population-based services planning approach. This was a shift from a traditional patient-centered service plan to a model that recognised needs of whole populations at planning stage and could lead to improved outcomes for both whole populations and individuals (PCA 2005). This model of care is considered to be based on population needs and considered three subgroups of the population with terminal illness (PCA 2005). As seen in Table 11.1, these three subgroups are distinguished by population size, needs and service provision. Access to specialist palliative care services is based on complexity and intensity of need and dependent on referral by formal care providers and ideally should also have mechanisms to support self- or family and carer referral (PCA 2005).

Expected deaths in Australia are currently estimated to be around 100,000 per year (ANZSPM 2011). As noted above, PCA identifies that not all patients for whom death is expected require specialist palliative care services, but there remains uncertainty about whether patients receiving care from these services have the greatest need and/or whether those not receiving
specialist care have their needs adequately addressed by generalist services or primary care providers (PCA 2005).

**Table 11.1 Palliative care service provision by subgroup populations**

<table>
<thead>
<tr>
<th>Sub-group</th>
<th>Population size</th>
<th>Population needs</th>
<th>Description of service provision</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Group A</strong></td>
<td>Two thirds of all expected deaths</td>
<td>Do not require access to specialist palliative care; majority have a diagnosis of non-malignant disease</td>
<td>The largest of the three groups identifying a population with limited end of life care needs, which are met by their own resources or with support from primary care services and/or other specialist services.</td>
</tr>
<tr>
<td><strong>Group B</strong></td>
<td>A proportion (unknown) of one third of all expected deaths</td>
<td>Specialist consultation and advice but receiving ongoing care from primary care providers</td>
<td>A population which present with intermittent exacerbations of pain or other symptoms and may experience social or emotional distress, which requires generalist services/primary care services which are supported by access to specialist palliative care services as necessary.</td>
</tr>
<tr>
<td><strong>Group C</strong></td>
<td>The smallest of the three sub-groups. Proportion unknown</td>
<td>Needing highly individualised care plans from specialist palliative care providers in partnership with primary care providers</td>
<td>A population with complex care needs for physical, psychological, and/or spiritual which cannot be managed effectively by established care processes and who therefore require specialist palliative care services in inpatient or community settings. This specialised care occurs in partnership with primary/generalist services.</td>
</tr>
</tbody>
</table>

*Source: A Guide to Palliative Care Service development: A population based approach (PCA 2005)*
11.2.5.4 Hospital palliative care and specialist palliative care service provision for lower socioeconomic groups in Australia

Hospital palliative care service provision for lower socioeconomic groups

Understanding of the utilisation of palliative care services by lower socioeconomic groups is challenged by variations in service provision and use, knowledge of needs, and location of care. Patterns of service use are described in the health service data and answer some outcomes for palliative care populations and lower socioeconomic groups, in particular, in Australia.

The report by the AIHW on ‘Trends in Palliative care in Australian hospitals’ provides an overview of the nature and extent of palliative care separations in Australian hospitals (AIHW 2011). The report identifies data for episodes of admitted patient care for palliation, identified by palliative care ‘care type’ or diagnosis information, which may have been delivered in a hospice, a dedicated palliative care unit or in another, admitted patient bed in a hospital. The AIHW reported an overall increase in palliative care separations of 56% in the 10 years from 1999-2009 and that the length of stay for palliative care separations was nearly 4 times longer than other non-palliative separations (AIHW 2011). The increasing requirements for palliative care service provision are therefore likely demonstrated by this data.

Outcomes for palliative care separations for socioeconomically disadvantaged groups were also identified in this AIHW report, some of which are outlined in Table 11.2. The data reports that persons living in areas classified as having the lowest socioeconomic status had a higher percentage of palliative care separations (23.4%) than those living in other areas. Different requirements for palliative care separations across socioeconomic gradients are reported here and indicate increased demand for lowest socioeconomic groups.

<table>
<thead>
<tr>
<th>SEIFA Quintile</th>
<th>Total separations</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (lowest)</td>
<td>12,235</td>
<td>23.4</td>
</tr>
<tr>
<td>2</td>
<td>10,450</td>
<td>20</td>
</tr>
<tr>
<td>3</td>
<td>10,600</td>
<td>20.2</td>
</tr>
<tr>
<td>4</td>
<td>9,331</td>
<td>17.8</td>
</tr>
<tr>
<td>5 (highest)</td>
<td>9,585</td>
<td>18.3</td>
</tr>
<tr>
<td>Not reported</td>
<td>146</td>
<td>0.3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>52,347</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Source: AIHW, Trends in palliative care in Australian hospitals (AIHW 2011)
The AIHW report for trends in palliative care in Australian hospitals also described other differences by socioeconomic status. The report identified data reflecting differences across average length of stay (ALOS) in hospitals according to socioeconomic status groups, whereby proportions of overnight stays were lower than average for palliative patients living in the lowest socioeconomic areas (AIHW 2011). Additionally, among cancer patients who died in admitted patient care, those cancer patients living in areas in the highest socioeconomic status group were more likely (75%) than those living in the lowest socioeconomic group (67%) to be admitted as a palliative care patient during the hospitalisation that ended in their death (AIHW 2011).

The differences across socioeconomic gradients in provision of services and utilisation of services for patients admitted as palliative care patients were demonstrated in Australian hospital data. Variations in the elements of end of life care episodes between the lowest and highest socioeconomic groups were described at a population level and therefore causes and outcomes of these differences in end of life care for lower socioeconomic groups cannot be gleaned from this data.

**Specialist inpatient palliative care service provision for lower socioeconomic groups**

An estimated three quarters of specialist palliative care service data for inpatient and community/ambulatory care services in Australia is reported by the Palliative Care Outcomes Collaborative (PCOC). The most recent report of this nationally collated data was reported in the AIHW report; *Palliative Care Services in Australia* (AIHW 2012b). Outcomes of specialist palliative care services use for different socioeconomic groups showed that the lowest socioeconomic group accounted for the smallest proportion of episodes for specialist palliative care services at 9.5% with the highest proportion of episodes recorded for the highest socioeconomic group at 31.7%; little difference was demonstrated in these proportions for ambulatory/community settings (AIHW 2012b ). This is the first national report of specialist palliative care service utilisation across socioeconomic gradients and demonstrates distinct disparity of specialist service use for lower socioeconomic groups. A recent study by Currow and colleagues (2012) on referral patterns and locality of palliative care services, reported complex outcomes on the basis of socioeconomic variations for specialist palliative care service use and additionally found lower uptake of specialist services for least disadvantaged groups, better proximity to these services and longer lengths of stay in these facilities for this same group. The outcomes of this study suggest that there are different patterns of referral
and different care patterns across socioeconomic groups for specialty palliative care outcomes in Australian populations (ibid).

11.2.6 Significance of the research

It could be contested that current models of end of life care are based on the needs of the least disadvantaged and therefore service provision for lower socioeconomic groups may not be adequate. The prevalence of socioeconomic disadvantage in Australia is not insignificant. Limited evidence in the literature, particularly in the Australian context, that investigates socioeconomic disadvantage and end of life care, indicates that the needs of lower socioeconomic groups are poorly described in the context of health service planning.

Health inequities between socioeconomic groups in Australia further depict the need to consider access to essential health care services, such as end of life care services for this group. The outcomes of a terminal diagnosis for an individual and their family, is such that an added layer of socioeconomic deprivation likely requires resources and capacities beyond those available (Lin et al. 2008). This study seeks to understand the palliative care needs for this group and elucidate evidence for inequity in service provision based on access. Understanding capacity within this group that is likely to buffer some or several of the effects of disadvantage is also a component for inquiry. Moreover, this study seeks to investigate a range of measures to describe these constructs.

Measuring the social and economic needs and social networks and relations of support is essential for identifying relevant outcomes, but is also likely to be significant for a palliative care population broadly, who have increasing demands placed on these resources. The usability and acceptability of tools to measure social and economic needs and capacities in a lower socioeconomic population is important to understand these needs and capacities, which have had limited measurement in a palliative care population. It is also important to ensure these tools are appropriate for use in such a vulnerable population.

This study is significant as it investigates the needs of the vulnerable which have, to date, been largely ignored in the palliative care context (Glover & Hanson 2009). Understanding the experience of the ‘dying poor’ in Australia is important in establishing a stronger direction for policy, practice and research in the inadequately explored area of health disadvantage and end of life care.
11.2.7 Chapter summary

Questions about inequity and unmet need for lower socioeconomic groups for end of life care in Australia currently remain unanswered. The outcomes for poverty and social exclusion in Australia are not insignificant. Globally, lower socioeconomic groups have persistently demonstrated greater disease burden and more limited access to necessary health care resources. Recent palliative care utilisation and care episode data from AIHW found some consistent differences in palliative care service use between socioeconomic groups, suggesting disparity in access for lower socioeconomic groups (AIHW 2011, 2012a). Further description of health service context is necessary. Moreover, understanding the experience of end of life care for lower socioeconomic groups and research focussing on these elements of process and outcomes are required.

11.2.8 Research objectives

The research objectives of this study are to:

1. Provide a snapshot of the impact of socioeconomic status on place of death and after-hours crisis service utilisation by comparing outcomes between a most disadvantaged and a least disadvantage area.

2. Explore and describe the socioeconomic demographics, needs, capacities and experience of end of life care for patients and/or carers from this most disadvantaged area evidenced by:

   2a. The social, economic and care outcomes at individual, community and government levels.
   2b. The nature and impact of social capital outcomes.
   2c. The experience of access to a specialist palliative care service.

3. Describe the acceptability, feasibility and appropriateness of self-report tools for capturing wellbeing, consumption, health literacy, social capital and palliative care needs and capacities in this same lower socioeconomic population.

11.2.9 Structure of this thesis

Chapter One described the prevalence of socioeconomic disadvantage in the Australian population, as well as health and wellbeing of lower socioeconomic groups globally and in Australia. The details of palliative care service provision, funding and care models were
outlined. Additionally, some reporting and discussion for outcomes of disparity in palliative service use across socioeconomic groups in Australia were discussed. Furthermore, the significance of this study and the research objectives have been outlined in this chapter.

**Chapter Two** provides an integrative review of the literature for lower socioeconomic groups and end of life care using the key terms ‘socioeconomic disadvantage’, ‘socioeconomic’, ‘poverty’, ‘poor’ paired with ‘end of life care’, ‘palliative care’, ‘dying’, and ‘terminal illness’. The review describes the outcomes for the international and Australian literature separately within the domains of access. It describes the economic impact of a terminal diagnosis and care, access disparity, service acceptability and specific communication needs for lower socioeconomic groups.

**Chapter Three** discusses the rationale for the use of the Social Determinants of Health (SDH) framework and the social capital concept for the conceptual framework of this study. The constructs of these conceptual frameworks that describe the range of social contexts and circumstances and their utility for this study are also discussed.

**Chapter Four** provides a description and justification of the methodology of this study. Implementation of the study and ethical issues are also discussed in this chapter.

**Chapter Five** provides a broad context for the study and reports the outcomes and analysis of administrative data for place of death and after-hours service utilisation for a single palliative care service in Western Sydney, Australia, through a comparison of outcomes for a most and a least disadvantaged area.

**Chapter Six** reports the patient, carer and key informant participant demographic details, self-report tool outcomes and qualitative outcomes from semi-structured interviews with patients and/or carers and key informants.

**Chapter Seven** reports semi-structured interview outcomes of patient and/or carer for appropriateness, acceptability and feasibility of self-report tools.

**Chapter Eight** discusses the findings of the study within the elements of the Conceptual framework and further integrates the quantitative and qualitative data. Strengths and limitations of the study are also discussed. Conclusions of this study and implications for policy, practice and research are presented.
11.2.10 References


Glover, J. & Hanson, S. 2009, 'Access – does socio-economic background make a difference?', Palliative Care Australia.


PCA 2008, *End of life care is everyones affair-tackling the challenges of end of life care: Palliative care Australia submission to the National Hospital and Health Reform Commission*, Canberra.


Chapter 2

Literature Review

12.1 Introduction

As outlined in chapter one, socioeconomic disadvantage in Australia, described in terms of income poverty and social exclusion, is a pressing issue. The most recent reports identify that one in eight Australians are living in a low income household (AIHW 2012). The health outcomes for lower socioeconomic groups are such that they are likely to die younger, have a higher disease burden and present at a more advanced stage of their disease (Mackenbach et al. 2008). The needs for lower socioeconomic groups at the end of life are likely to be impacted by the physical demands of their disease burden and additionally, by their social and economic circumstances. This chapter presents an integrated literature review to investigate issues of poverty and access. A paper reporting the developed world literature in this area has been published in the *Journal of Pain and Symptom Management* (Lewis et al. 2011) (Appendix 1)

Research investigating the end of life care needs of lower socioeconomic groups has been driven by the increasing concern for improving equity of access to palliative care services. Variation in the use of these services is often attributable to patient characteristics such as age, ethnicity, socioeconomic status and gender (Walshe et al. 2009). To date, there has been limited understanding of equity and the concept of access in palliative care discourse. Variations in service use require a more detailed and systematic exploration of access elements (Burt 2011). The definitions and theoretical underpinnings of access elements are outlined in this Chapter.

The definition of equity of access in health care is defined as ‘equal access to health care for equal need’ (Goddard & Smith 2001; Oliver & Mossialos 2004). Access is a summary of factors that influence the level of service usage or resources and is conceptually distinct from utilisation. Utilisation refers to objective evidence that access has been achieved (realised access), but says little of the need for the service and does not describe the reasons why the service was not used (Fielder 1981). Overall, theories of access are described consistently for themes of supply and demand (Goddard & Smith 2001; Gulliford et al. 2002). Supply describes provider contexts; the distribution of resources which include variations according to population size, service costs, health care needs, and income where it impacts variation in service use (Oliver & Mossialos 2004). Demand primarily considers preferences and
acceptability of the user; costs, knowledge, information and beliefs (Oliver & Mossialos 2004). The fit between these provider and user elements is most important for distinguishing between the issues impacting access. The grouping of these elements across five dimensions of access availability, affordability, accessibility, accommodation and acceptability was described by Penchansky and Thomas (Penchansky & Thomas 1981):

1. **Availability**: the volume of health resources fit with the volume and type of user need

2. **Affordability**: the costs of services fit with users’ income and ability to pay;

3. **Accessibility**: the location of supply fit with the location of clients;

4. **Accommodation**: the organization of health care fit the clients’ demands;

5. **Acceptability**: the characteristics of the health service fit with the users’ attitudes and characteristics.

These five access domains identify the range of elements that determine the distinct supply and demand outcomes; however, the interdependence of these domains for access is equally important. Equating availability of a service with access fails to acknowledge the other barriers to services (McLaughlin & Wyszewianski 2002). Each of the dimensions of access plays a critical role in determining access to health care services. The objectives of the literature review were to describe the experience and outcomes of end of life care and how these relate to access outcomes. Literature that could describe these elements includes survey, secondary data analysis, and qualitative and mixed method studies. This is, therefore, a broad review of the literature to understand the overall science of end of life care outcomes for patients, families, and/or carers from lower socioeconomic groups.

**12.2 Literature review method**

The literature search was conducted using databases Medline, CINAHL, Cochrane library, EMBASE, and PsychINFO for the period 1991-2012 as it was considered that this period was sufficient to cover the range of changes in palliative care and hospice services and economic shifts globally. Search terms were “socioeconomic disadvantage”, socioeconomic”, “poverty” and “poor” paired with “end-of-life care”, “dying”, “palliative care” and ‘terminal illness”. In addition, reference lists of relevant articles were hand searched. The grey literature was searched for the same key terms described above.
12.3 Literature review outcomes

The outcomes of the search are outlined in Table 2.1. A total of 75 peer-reviewed publications and three grey literature documents were identified. The grey literature documents included two Palliative Care Australia publications; one report on access for disadvantaged and underserved groups, and one research report for the social impact of informal care giving; and a US report on access to hospice care. These documents were included in the review as they specifically addressed needs of disadvantaged groups and/or social and economic hardship in palliative care populations. The majority of publications were excluded because the socioeconomic variable was either not distinctly described from other variables in the research or outcomes for this variable were not discussed in the results of the study. Similar numbers of publications were excluded because they had a developing world focus or described non-palliative care or end of life populations or interventions. Literature that had a developing world focus was excluded because the context of this study was a developed world inquiry.

<table>
<thead>
<tr>
<th>Publications for inclusion/exclusion</th>
<th>Number of publications</th>
<th>Grey literature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Identified</td>
<td>181</td>
<td>3</td>
</tr>
<tr>
<td>Excluded: developing country context</td>
<td>23</td>
<td>0</td>
</tr>
<tr>
<td>Excluded: not relevant to palliative care (oncology and/or treatment focus)</td>
<td>22</td>
<td>0</td>
</tr>
<tr>
<td>Excluded: socioeconomic variable not described distinctly from other variables in analysis.</td>
<td>61</td>
<td>0</td>
</tr>
<tr>
<td>Total in review</td>
<td>75</td>
<td>3</td>
</tr>
</tbody>
</table>

12.4 Results

12.4.1 Description of studies

A summary of included publications is provided in Table 12.2. The studies represent research from a range of countries and therefore consider the different contexts of health funding, welfare systems and variations of service provision across these regions. The majority of studies identified in the review were from the United States (US). In particular, the US studies reported outcomes for the financial impact of care giving and utilisation of end of life care services for uninsured and underinsured groups. Moreover, other countries with universal access to health care services and welfare resources also reported outcomes for financial hardship.
The studies in the review mainly used income and/or education as proxies for socioeconomic status. The literature in the review revealed that research in this area was predominantly of a retrospective design, using administrative, population or health service data. Retrospective data analysis studies in the review measured a broad range of outcomes including utilisation of palliative care services, referral to services, costs, service availability, place of death and symptom outcomes. Studies of secondary analysis of linked data sets measured several social, clinical and service utilisation outcomes.

The prevalence of secondary data analysis for research in the area of equity in palliative care is reported and considered to be efficient for describing utilisation outcomes of large samples. Conversely, the adequacy of retrospective research for describing the reasons for the variations in demand for the service, patient and/or carer outcomes is limited (Burt 2011). A small number of publications in the review with prospective, survey, qualitative and mixed method designs did report variation in service use. Overall, the literature described range of access dimensions outlined above and are reported under these headings. The Australian literature is described separately to facilitate comparison with outcomes of the international literature.
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Study sample/sample size</th>
<th>Study method</th>
<th>Study outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ahmed et al (2004) UK</td>
<td>References [40]</td>
<td>Systematic literature review [symptoms, issues of access and referral barriers]</td>
<td>Lack of timely referral to palliative care services included minority ethnic groups, older persons, patients with non-malignant illness and socially excluded groups.</td>
</tr>
<tr>
<td>Becaro et al (2007) Italy</td>
<td>Informal carers (n=1271)</td>
<td>Survey</td>
<td>Carers with higher education levels were statistically more likely to have received services for their family member at home (p=0.01) and in the hospital (p&lt;0.01).</td>
</tr>
<tr>
<td>Bergman et al (2009) USA</td>
<td>Decedents (n=57)</td>
<td>Secondary data analysis</td>
<td>Hospice enrolment for low income uninsured men with prostate cancer was associated with a trend in fewer mean emergency room visits made by men enrolled in hospice care than by those not enrolled.</td>
</tr>
<tr>
<td>Born et al (2004) USA</td>
<td>Low income African Americans (n = 26) and Latinos (n = 27).</td>
<td>Qualitative study-focus groups</td>
<td>Participants reported low utilisation of hospice due to lack of awareness and cost. Latino groups particularly reported language barriers and African American groups highlighted issues of mistrust of services. African Americans and Latinos in this study were highly receptive to end-of-life care that would provide relief for patients and caregivers.</td>
</tr>
<tr>
<td>Burge et al (2005) Canada</td>
<td>Decedents (n=7212)</td>
<td>Secondary data analysis-linked population data</td>
<td>Odds of receiving one home visit was significantly higher among subjects from middle to high income neighbourhoods (for highest income quintile, adjusted odds ratio [OR] = 1.37, 95% confidence interval [CI] = 1.15, 1.64)</td>
</tr>
<tr>
<td>Burt et al (2010) UK</td>
<td>Patients (n=252) and carers (n=137)</td>
<td>Cross-sectional survey</td>
<td>Age, gender, deprivation, living alone, current or recent treatment, number of co-morbidities and carer stress were not associated with receipt of specialist palliative care services. The outcomes suggest that receipt of palliative care is on the</td>
</tr>
<tr>
<td>Authors</td>
<td>Study Population</td>
<td>Methodology</td>
<td>Findings</td>
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</tr>
<tr>
<td>Cardenas-Turanzas et al (2006) USA</td>
<td>Adult cancer patients (n=866)</td>
<td>Retrospective chart audit</td>
<td>Lower household income per zip code of area was marginally associated (p=0.06) with hospital deaths.</td>
</tr>
<tr>
<td>Chao et al (2008) USA</td>
<td>Elderly adults general population (n=1143)</td>
<td>Secondary data analysis (Asset and Health Dynamics Amongst the Oldest of Old (AHEAD): Health and Retirement Study (HRS))</td>
<td>Elderly would hypothetically recommend forgoing costs of end-of-life treatment if it would deplete savings; where treatment costs were covered by Medicare respondents would opt for treatment even if survival was low.</td>
</tr>
<tr>
<td>Chini et al (2007) Italy</td>
<td>Caregivers (n=2000)</td>
<td>Two point questionnaire (4 and 12 months)</td>
<td>When comparing educational level and socio-economic status only the later showed a significant association with the outcomes &quot;difficulties&quot; in sustaining the costs of treatment and &quot;use of entire savings for the illness&quot;.</td>
</tr>
<tr>
<td>Chochinov and Kristjanson (1998) Canada</td>
<td>References (n=69)</td>
<td>Literature review [examining the costs of end of life care]</td>
<td>Costs of end of life care are considerable and increase with the distance from the home setting. Literature reports a two-tiered system of palliative home care which allows families with higher incomes to afford help in supporting home deaths.</td>
</tr>
<tr>
<td>Cinnamon et al (2008) Canada</td>
<td>Palliative care services in British Columbia (n=29)</td>
<td>Geographical Information systems analysis of census data</td>
<td>Disparities in access to palliative care services based on geographical location.</td>
</tr>
<tr>
<td>Curtis et al (1999) USA</td>
<td>HIV /AIDS patients and clinicians (n=57)</td>
<td>Prospective cohort questionnaire</td>
<td>SES and ethnicity were associated with more limited occurrence and quality of communication. Lower income groups reported lower quality of communication (P = 0.05).</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Sample Description</td>
<td>Methodology</td>
<td>Findings/Highlights</td>
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<tr>
<td>Decker et al</td>
<td>Deaths from cancer. London (n=59,604) and New York City (n=51,668)</td>
<td>Secondary data analysis-death registrations in London and New York</td>
<td>Lower SE status reduced the odds of a home death by 22% in London and 39% in New York.</td>
</tr>
<tr>
<td>Dumont et al</td>
<td>Patients (n=248) and carers (n=243)</td>
<td>Prospective survey design</td>
<td>The public health care system, the family, and not-for-profit organizations (NFPO) sustained end of life care mean costs per patient respectively of 71.3%, 26.6%, and 1.6%.</td>
</tr>
<tr>
<td>Dzul-Church et al</td>
<td>Palliative care patients from underserved population (n=20)</td>
<td>In-depth interviews</td>
<td>Interviews with underserved palliative care patients in an urban public hospital found that difficult life events shaped relationship outcomes, concepts and concerns about care and dying. Lack of social support for this group meant that formal care providers were significant sources of support.</td>
</tr>
<tr>
<td>Emanuel et al</td>
<td>Patients (n=988) and informal carers (n=893)</td>
<td>Survey interviews</td>
<td>Outcomes reported that 34.7% had substantial care needs and were more likely to report subjective burden (P = 0.005); spend 10% of their household income on health care (P &lt; or = 0.001); and that they or their families had to take out a loan or mortgage, spend savings, obtain an additional job (P = 0.004); more likely to consider euthanasia (P = 0.001); have depressive symptoms and report caring interfered with lives (p=0.01.)</td>
</tr>
<tr>
<td>Evans et al</td>
<td>Older persons (n=457)</td>
<td>Longitudinal retrospective study (self-reported outcomes)</td>
<td>Low income older persons were more likely to be bereaved, have extensive care giving demands, be more social isolated and live in government housing</td>
</tr>
<tr>
<td>Felder et al</td>
<td>Decedents (n=415)</td>
<td>Secondary data analysis(Swiss Sick Fund)</td>
<td>Health care expenditure increased closer to death and the costs of dying was higher for younger than for elderly persons. Less health care expenditure incurred by lower income groups than higher income groups</td>
</tr>
<tr>
<td>Authors</td>
<td>Sample Description</td>
<td>Methodology</td>
<td>Findings/Outcomes</td>
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</tr>
<tr>
<td>Fernandes et al (2010) USA</td>
<td>Patients (n=46); primary caregivers (corresponding) (n=45)</td>
<td>Prospective survey of self-reported outcomes and secondary data analysis for an underserved population</td>
<td>Outcomes of home-based palliative care (HBPC) service in a low-income migrant community demonstrated that satisfaction with the service was high and discussions of end-of-life wishes increased from 50%-90% (p&lt;0.01). There was a decrease in hospitalizations (p = 0.002) after HBPC admission.</td>
</tr>
<tr>
<td>Gallo et al (2001) USA</td>
<td>Decedents (n=6813)</td>
<td>Secondary data analysis (place of death)</td>
<td>Multivariate analysis indicated demographic characteristics (being married, female, white, and residing in a higher income area), disease-related factors (type of cancer, longer survival post diagnosis), and health-resource factors (greater availability of hospice providers, less availability of hospital beds) were associated with dying at home.</td>
</tr>
<tr>
<td>Giogi Rossi et al (2007) Italy</td>
<td>Caregivers post bereavement (1900)</td>
<td>Survey</td>
<td>To cover the costs of care 26% of families used most or all of their savings. Economic difficulties were greater in the south of Italy, for women and for disadvantaged groups.</td>
</tr>
<tr>
<td>Givens and Mitchell (2009) USA</td>
<td>Adults, general population (n=786)</td>
<td>Secondary data analysis (General Social Survey)</td>
<td>70.6% of respondents approved of euthanasia for terminal illness. In adjusted analyses, respondents with concerns about emotional demands of decision making on family members, economic burden, and poor health care due to lack of insurance were significantly more likely to support euthanasia.</td>
</tr>
<tr>
<td>Goldsmith et al (2008) USA</td>
<td>US adult hospital palliative care program data (n=1294)</td>
<td>Primary and secondary data analysis</td>
<td>Prevalence of hospital palliative care was 52.8%. Public and sole community provider hospitals are the only option for remote communities and uninsured patients. The lack of palliative care services in these hospital was described as underscoring disparity in access for these vulnerable groups.</td>
</tr>
<tr>
<td>Goodridge et al (2011) Canada</td>
<td>Administrative data clients receiving home care services (n=700)</td>
<td>Secondary data analysis</td>
<td>Inequalities in allocation of home care services was seen for age (&gt;80 years), diagnosis of dementia or strokes and those who were single, but not for material deprivation.</td>
</tr>
<tr>
<td>References</td>
<td>Secondary data analysis</td>
<td>Secondary data analysis of linked population register data (Sweden)</td>
<td>Secondary data analysis (linked mortality and hospital activity data)</td>
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<tr>
<td>Grande, et al. (1998) UK</td>
<td>Literature review [patient characteristics and home death]</td>
<td>Patients from higher SE groups were more likely to die at home and access home services. Patients with informal carer support were both more likely to die at home and to access palliative home care. Provision of home care did not remove the dependence on informal carers in achieving home death.</td>
<td>Patients referred to hospital at home were younger and came from less deprived areas and were less likely to have been diagnosed within a month of death.</td>
</tr>
<tr>
<td>Authors</td>
<td>Study Details</td>
<td>Data Analysis</td>
<td>Findings</td>
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<tr>
<td>Higginson et al</td>
<td>Death registrations in England 1984-1994 (+1.3 mil)</td>
<td>Secondary data analysis (death registrations)</td>
<td>Social deprivation was inversely associated with a home death. The proportions of home deaths for deprivation were: 0.30 (low), 0.27 (middle) and 0.24 (high).</td>
</tr>
<tr>
<td>(1999) UK</td>
<td>Secondary data (n=1.5 mil). Meta-analysis of 20 studies</td>
<td>Meta-analysis-secondary data analysis</td>
<td>Distribution of palliative care services across Europe was described as being inequitable, not located in areas of need.</td>
</tr>
<tr>
<td>(2008) UK</td>
<td>Medicare decedents and survivors, 1993-1998 (n=19,500)</td>
<td>Secondary data analysis from 3 patient level databases</td>
<td>End of life care costs were higher in high poverty areas. Spending in high poverty ZIP codes was 43% higher than in ZIP codes with the lowest poverty rates.</td>
</tr>
<tr>
<td>Hogan et al</td>
<td>Decedents from chronic diseases eligible for palliative care(n=3672)</td>
<td>Secondary data analysis (death certificate data)</td>
<td>Non-cancer patients, patient with a carer and residents from areas with higher SES were more likely to have a home death.</td>
</tr>
<tr>
<td>(2001) USA</td>
<td>References (n=34)</td>
<td>Literature review [Poverty and palliative care in the US]</td>
<td>Limited literature to understand the experience of the urban poor at the end of life. Identification of the role disadvantage environment plays in contributing to illness and disease burden and additionally limited access to services.</td>
</tr>
<tr>
<td>Hughes et al</td>
<td>Patients from a poor urban area (n=14)</td>
<td>Qualitative study-in depth interviews</td>
<td>Experience of advanced cancer occurred in a context of deprivation and challenges. Identification of resilience in survivorship, mistreatment by the health system and the challenges posed by an overburdened health service.</td>
</tr>
<tr>
<td>(2007) USA</td>
<td>Palliative care home patients(n=192) and informal caregivers (n=200)</td>
<td>Survey interviews and second week weekly follow-up phone survey</td>
<td>Survey outcomes for expenses and absences from work during the palliative phase demonstrated that 9% of families incurred income losses in excess of 10%; low income status increased from 27% to 40% during this phase.</td>
</tr>
<tr>
<td>Authors and Year</td>
<td>Study Design &amp; Population</td>
<td>Methods</td>
<td>Findings</td>
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<tr>
<td>Kessler et al (2005) UK</td>
<td>Surveys of decedents (n=960) and carer interviews(n=10)</td>
<td>Mixed methods study</td>
<td>Survey identified that patients from lower classes were less likely to die in a hospice. Inequality for lower classes was associated with passivity in seeking information. Carers from lower social classes received more regular and reliable support from their families than other social classes.</td>
</tr>
<tr>
<td>Koffman et al (2007) UK</td>
<td>Oncology outpatients (n=252)</td>
<td>Cross-sectional interview based survey</td>
<td>The term ‘palliative care’ (p =0.002) and understanding the role of Macmillan nurses (p &lt;0.0001) was more likely for highest socioeconomic groups compared with poorest.</td>
</tr>
<tr>
<td>Kramer et al (2011) USA</td>
<td>Social workers (n=121)</td>
<td>Mixed methods study</td>
<td>Family conflict was significant predictor of perceived success for addressing patient needs (p≤0.01) and addressing carer needs (p≤0.001) needs in low income older adults.</td>
</tr>
<tr>
<td>Kwon et al (2009) South Korea</td>
<td>Persons from general population (n=1019)</td>
<td>Phone survey</td>
<td>In the absence of economic burden 62.3% specified the patient as decision maker and 21.7% the family, when asked ‘who is the appropriate decision maker, in terms of EOL decisions’. In contrast, the numbers were 44.9% and 49.1%, respectively, if substantial burden was assumed.</td>
</tr>
<tr>
<td>Kvale et al (2004) USA</td>
<td>Medically underserved population in Alabama, US</td>
<td>Report on demonstration project supporting end of life care needs.</td>
<td>Report identified the capacity for palliative care programs to overcome socioeconomic and cultural barriers and is dependent on models of palliative care which include community partnerships.</td>
</tr>
<tr>
<td>Lin et al (2008) USA</td>
<td>Patients (n=299)</td>
<td>Survey -patient barriers to services and service times</td>
<td>Poor and underserved patients required significantly more resources to address barriers to care. Financial barriers were the most reported. Patient navigators spent significantly more time helping uninsured than insured patients.</td>
</tr>
<tr>
<td>Authors</td>
<td>Sample Description</td>
<td>Methodology</td>
<td>Findings</td>
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</tr>
<tr>
<td>Lyckholm et al (2010) USA</td>
<td>Patients (n=29); unmatched caregivers (n=15); Health care Professionals (n=34)</td>
<td>Pilot study description and literature review</td>
<td>Carers and health providers thought hospice was discussed more often than patients (&gt;90% vs 57% patients), 48% patients had an advanced care directive and 72% enjoyed life most of the time. Barriers in the literature described limited access to pain, hospice, literacy, communication and understanding of palliative care.</td>
</tr>
<tr>
<td>Maddison et al (2012) Canada</td>
<td>Decedents (n=3,501)</td>
<td>Secondary data analysis</td>
<td>Patients with incomes of $45,000 were 2.74 times more likely to be registered with a palliative care program than those with incomes under $30,000.</td>
</tr>
<tr>
<td>Masucci et al (2010) Canada</td>
<td>Patients and informal caregivers (n=110)</td>
<td>Mixed method longitudinal study</td>
<td>Women and those patients living with others were more likely to have a home death (p&lt;0.05). Socioeconomic deprivation did not present as a barrier to a home death.</td>
</tr>
<tr>
<td>Matsuyama et al (2011) USA</td>
<td>Patients [non-Hispanic white and African American] (n=133)</td>
<td>Survey-awareness of Hospice and Palliative care</td>
<td>Participants reporting having heard of palliative care were more likely to have a high school education (P = 0.01), to have higher income (P = 0.001), and to be white (P = 0.01). There were no significant differences for sex or age.</td>
</tr>
<tr>
<td>Mc Garry et al (2005) USA</td>
<td>Decedents (n=271) and survivors (n=3550) aged ≥ 70 years</td>
<td>Secondary data analysis - national panel survey (2 waves)</td>
<td>Out of pocket medical expenses in the last 2 years of life were 30% of a couple’s annual income and for couples in the bottom income quartile OOPE were 70% of annual income.</td>
</tr>
<tr>
<td>Mc Quillan R and Van Doorslaer (2007) Ireland</td>
<td>Interviews/focus groups service providers and patients (Irish Travellers) (n=16); staff questionnaires (n=81).</td>
<td>Mixed method study</td>
<td>Low use of palliative care services by Irish travellers. Concerns by travellers and staff about travellers’ education, literacy, role of family and expression of grief. Open discussion and communication in palliative care posed communication and cultural difficulties for travellers.</td>
</tr>
<tr>
<td>Reference</td>
<td>Study Type</td>
<td>Setting</td>
<td>Findings</td>
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<tr>
<td>Motiwala et al (2006) Canada</td>
<td>Population cohort study</td>
<td>Decedents (≥ 66 years)(n=56,689)</td>
<td>Half (49.2 %) of all patients died in hospital, 30.5 per cent died in a long-term care facility, 9.6 per cent died at home while receiving home care, and 10.7 per cent died at home without home care. Co-morbidities were the strongest predictors of place of death (p &lt; 0.0001). Higher socio-economic status was associated with greater probability of dying at home.</td>
</tr>
<tr>
<td>O'Mahony et al (2008) USA</td>
<td>Literature review</td>
<td>References[32]</td>
<td>Barriers to end of life care for lower socioeconomic groups included limited access, care costs, limited services, mistrust of services and low uptake of healthcare benefits.</td>
</tr>
<tr>
<td>Parker et al (2009) USA</td>
<td>Literature review</td>
<td>References [59]</td>
<td>Information needs were more pronounced for patients who were older, of lower socio-economic class and from differing cultural backgrounds and likely to impact on communication and decision making.</td>
</tr>
<tr>
<td>Rosenzweig et al (2009) USA</td>
<td>Qualitative (grounded theory)and quantitative survey study</td>
<td>Women with metastatic breast cancer (n=47)</td>
<td>Low income African American women experienced greater physical and social distress and more uncertainty about treatment. Economic status was more influential for distress.</td>
</tr>
<tr>
<td>Silviera et al. (2005) USA</td>
<td>Secondary data analysis</td>
<td>Decedents (n=2604)</td>
<td>25% in the lowest income quartile experienced 5–6 symptoms while only 18% and 15% of those in the two highest income quartiles experienced these symptoms (p=0.004).</td>
</tr>
<tr>
<td>Silviera, et al. (2006) USA</td>
<td>Secondary data analysis</td>
<td>Decedents (n=351,110)</td>
<td>Likelihood of home death increased with local wealth (OR=1.04 ; 95% CI=1.02, 1.06), decreased with hospital bed availability (OR=0.96 per 1000 beds; 95% CI=0.95, 0.97).</td>
</tr>
<tr>
<td>Silviera, et al. (2011) USA</td>
<td>Secondary data analysis-observational geographic study</td>
<td>US census data for U.S. Counties (n=3140)</td>
<td>Counties with a median household income of $30,000 had an average supply of 0.53 hospice programs, whereas counties with a median household income of $60,000 had an average supply of 1.42 hospice programs.</td>
</tr>
<tr>
<td>Citation</td>
<td>Study Population</td>
<td>Methodology</td>
<td>Findings</td>
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<tr>
<td>Slutsman et al (2002) USA</td>
<td>Patients (n=988) and 893 informal carers (n=893)</td>
<td>Survey</td>
<td>Enrolee in Managed Care Organisations (MCO) and Fee for service (FFS) found that MCO patients were more likely than their FFS counterparts to use an inconvenient hospital (P = .02), spend more than 10% of their income on medical care (P = .02), and have been bedridden more than 50% of the time during the last 4 weeks of life (P = 0.03).</td>
</tr>
<tr>
<td>Song et al (2007) Taiwan</td>
<td>Homeless persons (n=53)</td>
<td>Qualitative study (In-depth interviews)</td>
<td>Participants expressed concerns about discrimination and stigma and barriers to end of life care services. Homeless expressed unique fears of dying anonymously undiscovered.</td>
</tr>
<tr>
<td>Volandes Paasche-Orlow et al. (2008) USA</td>
<td>Primary care patients (n=144) African American (n=80) and white (n=640)</td>
<td>Pre and post survey (verbal description and video of advanced dementia patient)</td>
<td>Health literacy and not race was an independent predictor of end-of-life preferences following verbal description of dementia. Subjects with low or marginal health literacy were more likely than subjects with adequate health literacy to have preferences for aggressive care after the verbal description, OR 17.3 (95% CI 6.0-49.9) and OR 11.3 (95% CI 4.2-30.8)</td>
</tr>
<tr>
<td>Walshe et al (2009) UK</td>
<td>References [48]</td>
<td>Literature review [Access to community palliative care services]</td>
<td>Patients who were older, male, from an ethnic minority population, not married, without a home carer, socioeconomically disadvantaged, and who did not have cancer were less likely to access community palliative care services. The studies did not identify the reasons for variable access. Authors reported that studies needed to move beyond description of utilization patterns, and examine whether such patterns are inequitable for broader access outcomes.</td>
</tr>
<tr>
<td>Williams (2004) USA</td>
<td>Terminally ill patients from lower SE group (n=33)</td>
<td>Qualitative-in depth interviews</td>
<td>Identified 'dying too soon', exposure to illness trajectories of others, social isolation and social death contributed to existential suffering. The limited assessment of social factors was considered to contribute to suffering for this group.</td>
</tr>
<tr>
<td>Authors</td>
<td>Sample/Sample size</td>
<td>Study method</td>
<td>Study outcomes</td>
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<tr>
<td>Wilson et al</td>
<td>Literature review[qualitative studies; patient finances and cancer]</td>
<td>Patients had difficulties understanding welfare and health benefit systems and problems negotiating these systems. Special criteria rules and limited financial advice were some of the barriers identified.</td>
<td></td>
</tr>
<tr>
<td>Wood et al</td>
<td>Census wards in North West England (n=1019)</td>
<td>Geographical Information systems analysis of census data</td>
<td>Longer drive times to services and increased demands for services at the end of life were more likely in areas with higher deprivation scores. Non-malignant disease groups were found to have similar symptom burdens but more limited access.</td>
</tr>
<tr>
<td>Currow, et al.</td>
<td>Respondent carers (n=1069)</td>
<td>Population health survey</td>
<td>Respondents with an income of &gt;AU$60,000 were more likely to report that specialist palliative care services had been used.</td>
</tr>
<tr>
<td>Currow, et al.</td>
<td>Respondents (n= 18, 224)</td>
<td>Population health survey</td>
<td>Uptake of Specialist Palliative care Services (SPCS) was significantly lower in people with a non-cancer diagnosis (40% versus 62%; P = 0.0001), lower income (56% versus 61%; P = 0.0006) and people born where English was not the first language (52% versus 58%; P = 0.0096). Lack of service uptake did not necessarily represent unmet needs except for non-cancer diagnosis</td>
</tr>
<tr>
<td>Currow, et al.</td>
<td>National inpatient and palliative care services (n=10,064 patients)</td>
<td>Geo-coding study for spatial access and referral patterns to socioeconomic status</td>
<td>People from the highest socioeconomic group (least disadvantaged) were significantly less likely to be referred to a specialist palliative care service, likely to be referred closer to death and to have more episodes of inpatient care for longer periods. Physical proximity to specialist inpatient for the lowest socioeconomic group (43.3 km) compared to medium (29.9 km) and highest (14.6 km) demonstrated spatial disparity</td>
</tr>
<tr>
<td>Study Authors and Year</td>
<td>Participants</td>
<td>Methodology</td>
<td>Findings</td>
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</tr>
<tr>
<td>Lewis et al (2011) Australia</td>
<td>References [67]</td>
<td>Literature review</td>
<td>Knowledge of access to palliative care services for low socioeconomic populations in a developed world context is limited in the literature. The review identified levels of inequity in access for low socioeconomic groups at the end of life and particularly described disparities for home death.</td>
</tr>
<tr>
<td>McGrath, et al. (2006)(i) Australia</td>
<td>72 interviews. Patients(n=10), carers (n=19), Aboriginal health workers (n=11), Health worker (n=30), and interpreters (n=2)</td>
<td>Qualitative study-interviews</td>
<td>Lack of local respite services for Aboriginal patients in Northern Australia was found to place undue financial pressure on family and carers</td>
</tr>
<tr>
<td>McGrath, et al. (2007)(ii) Australia</td>
<td>72 interviews. Patients(n=10), carers (n=19), Aboriginal health workers (n=11), Health worker (n=30), and interpreters (n=2)</td>
<td>Qualitative study-interviews</td>
<td>Practical and financial obstacles for terminally ill Aboriginal people in remote communities were identified and included equipment, essential services, transport and remoteness of location</td>
</tr>
<tr>
<td>McGrath, et al. (2007) (iii) Australia</td>
<td>72 interviews. Patients(n=10), carers (n=19), Aboriginal health workers (n=11), Health worker (n=30), and interpreters (n=2)</td>
<td>Qualitative study-interviews</td>
<td>Lack of appropriate palliative care services for Aboriginal people in Australia reflects those of Indigenous groups worldwide. Use of acute care services for end of life care was identified in this group and found to be inadequate.</td>
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### McGrath (2007)(iv) Australia

72 interviews. Patients (n=10), carers (n=19), Aboriginal health workers (n=11), Health worker (n=30), and interpreters (n=2)

Qualitative study-interviews

Strong cultural reasons for preference to die at home, with 'country' and family. Lack of palliative care services in rural and remote communities were barriers to supporting preferences for a home death.

### Mc Grath et al (2009) Australia/India

12 interviews. Patient (n=5), Health care professionals (n=4), Physician (n=1), Social worker (n=1) and Nurse (n=1)

Qualitative study-interviews

Identified poverty outcomes and needs for Australian patients which were not currently met by palliative care services. The needs for financial and material support in Australian populations were highlighted.

### Rosenwax, et al. (2006) Australia

Decedents (n=27,971)

Secondary data analysis (3 linked data bases)

Identified broader measures of disadvantage for disparity in specialist palliative care access (Single, widowed, divorced, >85 years and living in an area other than a major city)

### GREY LITERATURE

<table>
<thead>
<tr>
<th>Authors/Editors</th>
<th>Title</th>
<th>Institution</th>
<th>Description</th>
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<tr>
<td>Jennings, B, Ryndes, T, D’Onofrio, C, Baily, M (2003) USA</td>
<td>Access to hospice care. Expanding Boundaries, overcoming Barriers</td>
<td>Hastings Centre</td>
<td>Report describes the many factors which limit access to and utilization of hospice services with governmental policies and professional practices especially significant. Appropriate steps to increase access to and utilization of hospice care require that the mission of hospice not be defined narrowly and be inclusive of an ethical (access) framework.</td>
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<tr>
<td>Glover, J. Hanson, S (2009) Australia</td>
<td>‘Access – does socio-economic background make a difference?’</td>
<td>Palliative Care Australia</td>
<td>A report with contributions across the health sector identifying reasons why certain population groups do not receive needs based end of life care. The report proposes strategies to guide policy and debate and examines equity in five key areas; income, location, social or cultural background, age and</td>
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<tr>
<td>Aoun, S. (2004) (prepared by) Australia</td>
<td>‘The hardest thing we have ever done’; The Social Impact of Caring for Terminally Ill People in Australia, 2004</td>
<td>Palliative Care Australia</td>
<td>Report comprises a literature review on unpaid carers in Australian society and analysis of public submissions from individual carers and/or their support organisation or providers. Outcomes identify that carers need better access to resources and support, that the work of carers is undervalued and marginalised, and that support for this vital role for unfamiliar and complex care for the terminally ill requires policy response and resource allocation.</td>
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12.5 Dimensions of access literature review outcomes: international literature

12.5.1 Affordability

12.5.1.1 Income loss and health care costs

The care giving demands for patients at the end of life placed significant strain on financial resources for costs and use of savings (Emanuel et al. 2000). Difficulties sustaining costs of treatments, out of pocket (OOP) costs and bridging care costs were identified as the main financial issues for lower socioeconomic groups (Lin et al. 2008; McGarry & Schoeni 2005; Slutsman et al. 2002). The relationship between financial burden for lower socioeconomic groups and medium or longer term poverty issues were also identified in the literature, with forgone employment income, use of savings and superannuation identified as negative financial outcomes of a diagnosis of terminal illness and caregiver demands (Chochinov & Kristjanson 1998; Evans et al. 2008; McGarry & Schoeni 2005; Wilson & Amir 2008). Lower socioeconomic groups were particularly vulnerable to end of life care costs as the percentage of their incomes taken up by these costs was proportionately higher than other groups. A study by McGarry and Schoeni (2005) investigating the impact of out of pocket expenses spent on dying spouses found that for couples in the bottom quarter of income distribution, health care costs accounted for 70% of their income, compared with an average of 30% for couples in middle and higher income groups. According to McGarry and Schoeni (2005), one of the main risk factors for poverty in the elderly was being a surviving spouse.

Government health and welfare benefits demonstrated more limited uptake amongst lower socioeconomic groups despite the propensity for financial burden associated with end of life care and the capacity for these programs and benefits to support costs for this group (Hanratty, Jacoby & Whitehead 2008; Wilson & Amir 2008). A literature review of qualitative studies of patient finances reported that the reasons for low uptake were patient difficulties negotiating health and welfare systems and strict criteria and rules for accessing benefits (Wilson & Amir 2008). Overall however this was an area that had limited investigation in the literature.

Financial difficulties for lower socioeconomic groups were described in many of the publications in the review with the largest proportion of these studies from the United States (US). Hanratty and colleagues’ systematic review of financial stress in patients dying of cancer found that the largest proportion of US studies reported on the financial impact illness and
caregiving, but that investigation of this evidence in studies outside of the US was limited (Hanratty et al. 2007b). The financial burden of end of life care in the US was considered to reflect the high costs of healthcare in the US overall, due mainly to low availability of public funded healthcare services and welfare support (ibid).

### 12.5.1.2 Affordability within universal healthcare systems

Studies reporting financial difficulties for patients and families in countries with universal health care services were also identified in the review. Several Canadian studies described financial difficulties in the palliative care phase. A survey study by Dumont and colleagues found that the public health system bore 71.3% and families 26.6% of the mean cost of patient care during the palliative care phase of an illness and as such the impetus to increase community care would further shift financial burdens to patients and carers in Canada (Dumont et al. 2009). In another Canadian, a survey of economic loss in home care giving reported that families caring for palliative care patients at home incurred income losses that were significant for nearly 10% of the population and additionally reported large shifts in socioeconomic status with an increase from 27% to 40% in the proportion of low income status families in the palliative care phase (Jacobs et al. 2011). The impact of income loss and out of pocket care expenses were identified as the main financial burdens in these studies and highlighted the limits of healthcare funding arrangements and social policy.

Studies from Sweden described some mixed outcomes of financial burden for lower socioeconomic groups. These outcomes were most interesting because of the context of Sweden’s world renowned, comprehensive health and welfare system. One study of linked population data in Sweden found that lowest income groups experienced the highest increases in income and highest decreases in income, three years before death, potentially reflecting variability in the availability or utilization of health and welfare programs for this group (Hanratty et al. 2007a). Another study from Sweden, a secondary analysis of health care insurance data, found that health care spending on lower socioeconomic groups was less than for other groups and was considered to be due to variations in funding programs across socioeconomic groups (Felder, Meier & Schmitt 2000). These outcomes demonstrated that despite reasonable support for health care and living costs in Sweden there were gaps in insurance and funding models for lower socioeconomic groups.

### 12.5.1.3 Risks for limited affordability

Several articles in the review described limited affordability of services which considered the risks of restricted access or choices for end of life care services for lower socioeconomic
groups. Several studies in the review specifically described the impact of limited affordability on utilization of services. Hanratty and colleagues (2007b) in their systematic review found that patients with greater financial burdens were likely to make different treatment choices. A focus group study with low income African Americans and Latinos reported that participants identified low utilization of hospice services due to the costs of these services (Born et al. 2004). Other literature reported hypothetical and proxy responses to questions about choice between economic loss and palliative treatment, demonstrating particular the risks for patients in these contexts. A secondary data analysis of preferences of elderly adults in the general population in the US, found that the elderly would hypothetically forgo costs of end of life care treatments for a loved one if these treatments would deplete savings (Chao, Pagan & Soldo 2008). Another study of a general population in the US, which assessed support for euthanasia, found that respondents who described social needs, economic burdens and limited health insurance were more likely to support euthanasia (Givens & Mitchell 2009). Where carers described economic burdens they were less likely to support patient decision making (Kwon et al. 2009). The risks for limited financial resources or the perception of loss maintained choices for patients which likely described poorer end of life care outcomes.

12.5.2 Accommodation

12.5.2.1 Home death

Accommodation of lower socioeconomic patient demands for home death outcomes were described broadly across the literature in this review. The literature confirmed that home deaths were less likely for patients from lower socioeconomic groups (Coupland et al. 2011; Decker & Higginson 2007; Higginson et al. 1999; Silveira, Copeland & Feudtner 2006) despite the preference for home death consistent across all socioeconomic groups (Decker & Higginson 2007; Higginson & Costantini 2008). A large secondary data analysis study by Decker and Higginson (2007) identified outcomes for place of death in New York and London found that the likelihood of a home death for lower socioeconomic groups was reduced by 39% and 22% respectively, in these countries. A review by Chochinov and Kristjanson (1998) maintained that lower socioeconomic groups were less likely to achieve a home death because they were unlikely to sustain the costs of end of life care in the home setting. Therefore, the literature reflected a two-tiered health system demonstrating different end of life care outcomes across socioeconomic groups. This was further supported by other secondary data analysis and population cohort studies that identified an association with area, individual wealth and the
increased likelihood of home death (Houttekier et al. 2009; Silveira, Copeland & Feudtner 2006)

Not all studies in the integrative review reported disparities in home death outcomes for lower socioeconomic groups, but instead described the impact of other elements within the context of deprivation (Masucci et al. 2010). Higher levels of co-morbidities in lower socioeconomic groups were considered likely to contribute to outcomes for an institutional death; care needs and symptoms beyond the capacities of home care networks. A study by Motiwala and colleagues (2006) reported the outcomes of administrative data for association between deprivation and place of death which demonstrated statistical significance until adjusted for co-morbidities. The complexities of lower socioeconomic contexts make it difficult to determine specific outcomes for variations in service use. Variations in service use were further described by studies which measured or reported on specific outcomes for service demands by lower socioeconomic groups.

12.5.2.2 Increased service demands

Increased physical and social needs for lower socioeconomic groups likely accounted for variations in service use (Higginson et al. 1999; Wood, Storey & Clark 2007). One study reporting on symptom variations, in particular, found that patients in the highest income quartile had fewer symptoms and less pain than patients in the lowest income quartile (Silveira, Kabeto & Langa 2005). Increased functional impairment in lower socioeconomic groups was also noted (Slutsman et al. 2002) Different patterns of hospital use for lower socioeconomic groups likely underscored increased health care needs. This was demonstrated in a UK study using linked data sets which found that patients from lower socioeconomic areas with end stage heart failure and cancer had more admissions to hospital than higher socioeconomic groups (Hanratty et al. 2008). Increased assistance for personal care and activities of daily living for lower socioeconomic groups placed greater demands on formal care providers (Lin et al. 2008).

12.5.2.3 Increased social demands

A small number of studies in the review identified that social isolation and social marginalisation in lower socioeconomic groups necessitated specific social strategies to meet these needs (Hughes, Gudmundsdottir & Davies 2007; Williams 2004). A qualitative study by Dzul and others (2010) explored the experience of social needs for a group of socioeconomically disadvantage palliative care patients in the US. Participants in this study described difficult past histories and isolation from both family and community networks.
which prompted them to seek social and relational support from their formal care providers (ibid). The contexts of social relationships and engagement for lower socioeconomic groups were somewhat distinct for poorer social relations which limited the capacity in these relations to support end of life care needs (Hughes 2005; Kvale et al. 2004). A longitudinal case study identifying the outcomes of successful end of life home care, found that family conflict and crisis was detrimental to the success of home care for low income elderly patients (Kramer & Yonker 2011). The nature of increased social needs and fragile family relations for lower socioeconomic groups meant that accommodation of specific needs required distinct resources and likely determined limitations in home care giving outcomes.

12.5.3 Accessibility

12.5.3.1 Disparity in service location

Location and distance to palliative care and hospice services could enable or limit service utilization (Cinnamon, Schuurman & Crooks 2008). The often rapid development of palliative care services and facilities has meant that the location of services has been somewhat unplanned and does not necessarily support populations in areas of greatest need (Beccaro et al. 2007). The literature identified variability in the geographic distribution of palliative care or hospice services and this was demonstrated inequitable for lower socioeconomic groups (Goldsmith et al. 2008; Higginson & Costantini 2008; Silveira et al. 2011; Wood, Clark & Gatrell 2004). A geo-coding study measuring demand and supply of inpatient palliative care services in Northwest England identified longer drive times to inpatient palliative care services and increased demands for services (Wood, Clark & Gatrell 2004). Broader descriptions of palliative care service location across countries also maintained that there were issues of spatial disparity with the distribution of palliative care services across Europe found to be inequitable for lower socioeconomic groups (Higginson & Costantini 2008). Primary and secondary survey analysis and census data in the US found limited numbers of palliative care services in public and sole provider hospitals and limited geographic access to these services that served uninsured and remote communities (Goldsmith et al. 2008). Geographic location of palliative care services is an important identifier of equity and requires further attention in the literature for lower socioeconomic groups.

12.5.3.2 Costs of disparity in service location

The barriers posed by limited geographical access for lower socioeconomic groups and the impact of transportation costs to attend facilities likely extended financial burdens of end of life care for this group (Emanuel et al. 2000). A literature review by Chochinov and Kristjanson
(1998) examining the costs of end of life care described increases in costs were associated with distance of services from homes. The literature did not describe the extent of limited spatial access for lower socioeconomic groups nor the degree to which transportation costs impeded service use.

12.5.4 Acceptability

Acceptability referred to ‘goodness of fit’ between the providers and expectations or attitudes of patients and was described as being poorly considered as a barrier to health care services (McLaughlin & Wyszewianski 2002). Expectations and attitudes to palliative care or hospice services were reasonably well considered in the literature and reported in particular levels of mistrust, misconceptions of palliative care, communication needs and health literacy.

12.5.4.1 Mistrust of palliative care/hospice services

Mistrust of palliative care services for lower socioeconomic groups, was identified in the literature, particularly in African Americans and other US minority groups (Ahmed et al. 2004; Born et al. 2004). Race and culture were often considered inclusive of lower socioeconomic status in the literature and the difficulties separating them was emphasised (Born et al. 2004; Rosenzweig et al. 2009; Seale 2000). The report from the Hastings Centre (2003) reviewing access and justice issues for palliative care in the US outlined the concerns of minority ethnic groups around the separation of palliative care and hospice services from the broader health care system. Misconceptions of palliative care practice and concern for the lack of curative or life-prolonging intent, further compounded an established mistrust of healthcare services for lower socioeconomic groups in the US (O’Mahony et al. 2008).

Prejudicial treatment of marginalised groups was identified as an additional barrier to seeking out palliative care services and likely further supported levels of mistrust (McQuillan & Van Doorslaer 2007; Song et al. 2007). A qualitative study by Song et al (2007) which explored needs of homeless persons for end of life care found that mistrust of services was described in a context of prejudicial treatment within these services. In contrast, a survey of a low income migrant population in the US found satisfaction for a home based palliative care service and described high levels of satisfaction with the service, reduction in emergency admissions and increased discussions of end of life care preferences for this population (Fernandes et al. 2010). The literature demonstrated limited measurement of satisfaction for lower socioeconomic patients for palliative care services overall.
12.5.4.2 Understanding and awareness of palliative care

Inadequate awareness and understanding of the principles and practice of palliative care in lower socioeconomic groups was identified as a factor associated with lower levels of service utilisation (Curtis et al. 1999). Dissatisfaction concerning information received and high levels of unmet information needs were highlighted in the literature for lower socioeconomic groups (Parker, Aaron & Baile 2009). A study on the meaning of ‘palliative care’ and knowledge of a well renowned specialist palliative care nursing service (Macmillan nurses) in the UK reported more limited knowledge in lower socioeconomic groups (Koffman et al. 2007). Lower socioeconomic groups were also reported as less likely to actively seek out information for palliative care services than advantaged groups (Kessler et al. 2005; Walshe et al. 2009), thus requiring service providers to be more proactive in information provision for this group.

Communication barriers, particularly concerning discussions of diagnosis and prognosis, impacted particularly on lower socioeconomic groups negotiating end of life care services (Hughes, Gudmundsdottir & Davies 2007; McQuillan & Van Doorslaer 2007; Volandes et al. 2008). One study reporting the experience of Irish travellers for palliative care services described cultural and literacy difficulties for this group in engaging in the complexity of communication in palliative care (McQuillan & Van Doorslaer 2007).

12.5.5 Communication and health literacy

Degrees of unaddressed inadequate health literacy and a limited understanding of palliative care services and vernacular characterised barriers to access, according to a US report (Jennings et al. 2003). Concerns for the complexity of communication in palliative care and communication and literacy needs required for complex end of life decision making were further highlighted in the literature (Lyckholm et al. 2010; Volandes et al. 2010) Overall, the literature failed to adequately describe health literacy needs of this group (Lewis et al. 2011). A survey of patients found that individuals with limited health literacy were more uncertain about making end of life care decisions and were more likely to have made decisions for aggressive treatment choices (Volandes et al. 2008). The imperative for further research in this area is underscored by the limited evidence and the complexity of end of life care interventions and discussions. Moreover, the risks for patients having limited understanding of health care environments warrants attention.

12.5.6 Availability

The literature identified variations in the availability of palliative care and hospice services in lower socioeconomic areas and for lower socioeconomic groups. Limited palliative care
resources and increasing demands for these services were highlighted in the literature, with concerns that patients in greatest need did not necessarily receive these services (Higginson & Koffman 2005).

12.5.6.1 Referral and service variations

The availability of community services demonstrated disparity in referral to homecare services or other community services for lower socioeconomic groups (Campbell et al. 2010; Grande GE 2002; Walshe et al. 2009). These variations in referral were likely underpinned by both service practices and individual patient preferences for palliative care referral however there was limited exploration of reasons for referral disparity in the literature (Campbell et al. 2010). Walshe and colleagues (2009) described broad findings of referral variations in their literature review, which found disparity in access to home palliative care services with referral patterns favouring more advantaged groups. These authors posited reasons for these referral patterns, suggesting that community referrers were more likely to prioritise groups who could be supported for palliative home care and that groups who were socioeconomically advantaged were more likely to seek out community referrals (Walshe et al. 2009). A study of primary care medical support for palliative care patients in Nova Scotia, Canada, also demonstrated outcomes for disparity, with home visits to palliative care patients by family physicians more likely in middle and higher income neighbourhoods than low income (Burge, Lawson & Johnston 2005). The authors suggest that these outcomes reflected limits in the capacity of lower socioeconomic groups to remain at home and provider capacity or bias in service delivery to this group (Burge, Lawson & Johnston 2005). Patterns of variation in referral rates for services and treatments for lower socioeconomic groups required further investigation which included understanding of the nature of these disparities at provider and patient levels.

12.6 Australian literature depicting outcomes for lower socioeconomic groups

The evidence of Australian research for lower socioeconomic status and palliative care was somewhat limited, yet reflected several of the access domains identified in the international literature. The impetus to understand equitable access for lower socioeconomic groups in an Australian context was highlighted as a priority by Palliative Care Australia suggesting that despite services being shaped by the needs of the least disadvantaged, there was capacity within regions and services to capture outcomes for this group (Glover & Hanson 2009).
The Australian literature has been dominated by several papers from a single qualitative study exploring the needs of Aboriginal palliative care patients and their carers in a remote area in central Australia. Geographic isolation, mistrust and stigma were cited as barriers to end of life care (McGrath 2007; McGrath, Holewa & McGrath 2007). Levels of poverty and social exclusion were consistently described for this group and were considered to further contribute to their palliative care needs. The additional burden of disease for this population emphasized the increased need for end of life care services in rural and remote areas and sensitive cultural support for this population in hospitals and palliative care services (McGrath, Holewa & Kail-Buckley 2007; McGrath, Holewa & McGrath 2007; McGrath et al. 2006).

The literature describing outcomes for lower socioeconomic groups in the broader Australian population described mainly variations in utilisation specialist palliative care services. A study by Rosenwax and McNamara (2006) reporting analysis of linked data sets from Western Australia for specialist palliative care service outcomes found disparity in access to services for disadvantaged groups, based on socio-demographic indicators. Similarly, a study by Currow and colleagues (2008) conducted as part of a large population survey, found a statistically significant difference in uptake of specialist palliative care services for lower income groups (56% vs. 61% for higher income groups). This study also found that lack of uptake of specialist services did not equate to unmet needs for lower income groups according to carers, although the authors discussed that greater awareness of availability and aim of palliative care services may have altered perceptions of need in this group (Currow et al. 2008). Findings from an earlier population study by Foreman and others (2006) identified a relationship between poor knowledge of palliative care, low socioeconomic status and limited specialist service use, potentially supporting this concern.

A single study described the impact of financial burden in lower socioeconomic, non-Aboriginal groups in the Australian literature. McGrath and others (2009) in a comparative qualitative study of palliative care needs and service provision in an Indian and an Australian community, identified unrecognised and unmet needs related to poverty in the Australian community. The Palliative Care Australia report (PCA 2004 Pg 44) confirmed significant financial hardship for this group which included medication and equipment costs, income loss, taxation burdens, limited access to welfare support and financial burden of co-payments for private health care services. Beyond this study and report, outcomes describing financial hardship for patients and carers, and affordability of end of life care services and longer term financial outcomes were limited in the Australian literature.
Most recent outcomes for increased palliative care service demands and disparity in generalist and specialist palliative care service utilisation by lower socioeconomic groups, discussed in Chapter One, demonstrate inequitable palliative care service use for this group in Australia (see 11.2.5.4). The disparity in specialist palliative care service use described in this health service data is underscored by the outcomes from the study by Currow and colleagues (Currow et al. 2012) which described more limited geographical access to formal care networks and length of inpatient stay outcomes for lower socioeconomic groups. Understanding the experience of end of life care for lower socioeconomic groups in an Australian context is therefore necessary to both describe outcomes for this group and because the impetus of palliative care in Australia is to engender a needs based model of palliative care to manage equity of service provision. Most importantly, access to palliative care makes a difference for patients and carers; the outcomes of palliative care service utilization are significant for symptom management, quality of life (Temel et al. 2101), caregiver wellbeing (Higginson et al. 2003), increased likelihood of a home death (Higginson & Costantini 2008; Vassal et al. 2010) and are purposed to address holistic needs inclusive of social and economic and care giving domains.

12.7 Conclusion

This chapter has provided an outline of the theoretical underpinnings of access elements and a review of the literature demonstrating the experience of lower socioeconomic groups at the end of life within the dimensions of access to health care services. The review has demonstrated variations in service use; social and economic needs, service acceptability and awareness; and communication and literacy needs and outcomes between lower socioeconomic groups and others. More evidence of palliative care outcomes and experience for lower socioeconomic groups is necessary.

This review has identified the range of social, economic, care giving and health service outcomes which shape experiences of lower socioeconomic groups at the end of life. The need for a broad social and economic framework to investigate the needs, capacities and potential inequities for this group is required. A conceptual framework informed by social determinants of health is necessary for defining individual and structural elements necessary for health and wellbeing and advancing research, policy and practice. The next chapter describes the conceptual framework that underpins this study and informs its methodological approach.
12.8 References


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Chapter 3
Conceptual Framework

13.1 Introduction

The needs and capacities of lower socioeconomic groups at the end of life have been minimally discussed in the literature (Lewis et al. 2011). Disparities in access to end of life care services by lower socioeconomic groups provides understanding of the processes by which needs of this group are met by services or otherwise. Understanding the nature of these variations in populations and whether they are underpinned by inequity is necessary. The underlying social conditions that underpin outcomes for lower socioeconomic groups are explained within the conceptual and empirical literature for societal determinants of health (SDH) outcomes (Raphael 2003). The conceptual framework of this study engages two such social frameworks embedded in empirical literature to ensure that individual, social, economic and political determinants are described. This chapter summarises conceptual issues for SDH and social capital concepts as a conceptual framework for the Dying in the Margins study. This work represents an important step in developing a framework for investigating social capital in palliative care and has been published in the Journal of Pain and Symptom Management (Lewis et al. 2013) (Appendix 1).

The SDH framework has been well considered in the population health literature and research and provides a useful framework for addressing aspects of equity. The framework, as discussed in Chapter One, outlines the socioeconomic-political elements and conditions of daily life which can create inequality among groups. The social capital concept is an element of the SDH framework which additionally considers issues of equity, specifically focussing on social relations and networks. The explorations of these two conceptual approaches are discussed in this chapter.

13.2 Social determinants of health (SDH) framework

Population health researchers acknowledge the influence of SDH to the health of individuals and populations (CSDH 2008; Raphael 2006). The fundamental aim of social determinants inquiry is to understand the pathways which led to differences in health outcomes (Braveman 2010). These differences are identified for populations in developed and developing nations and describe individual links for each determinant to a range of health outcomes (Raphael 2006). The Commission on Social Determinants Health (CSDH) was set up by the World Health
Organization in 2005 to foster a global movement on the social determinants of health (CSDH 2008). The Commission has developed a comprehensive SDH model which draws on the work of several researchers, particularly that of Diderichsen’s model of “Mechanisms of Health” which considers that social stratification creates differential exposure, vulnerability and health outcomes (CSDH 2008). Many of the approaches of Diderichsen’s model have been integrated in the CSDH framework and are summarized in the final report by the Commission (CSDH 2008).

The CSDH framework (Figure 13.1) outlines the major categories of social determinants of health and the pathways by which these impact on health and wellbeing. The framework is considered distinct in its emphasis on socioeconomic and political contexts. Structural determinants describe the main socioeconomic and political elements and which are considered to generate social stratification, class divisions and define hierarchies of power, including income, education, occupation, social class, gender, race and ethnicity (CSDH 2008). Despite the evidence for the influence of structural determinants on health, there remains little discourse on these determinants among policy makers and researchers in many developed countries, including Australia (Raphael 2006).

Figure 13.1 Commission Social Determinants of Health Framework (final form)
The socioeconomic and political context of the framework describes societal structures of public policies reflecting the distribution of resources, services, and welfare benefits to its citizens. The organisation of health is considered a direct outworking of the policy decisions made by governments and therefore political context is an important determinant of health and needs inclusion in the SDH framework (Raphael 2006).

Socioeconomic position, distinct but integrated with the socioeconomic/political context in the Structural determinants, was considered a primary determinant of health, as it discerned the likelihood of experience and exposures in environments which impacted health and wellbeing. Positioning in societies was considered to be determined by levels of education, income and types of employment; which in turn could influence the quality of one’s housing, need for social welfare support, employment stability across a life course, and the incidence of social exclusion (Raphael 2006). A large study by Mackenbach and others (2008) comparing mortality data according to education and occupational class across 22 European countries, confirmed that inequalities in health were strongly associated with socioeconomic status. The structural determinants considered the differential conditions and consequences for groups with more disadvantages (ibid).

*Structural determinants* in the CSDH framework were seen to operate through *intermediary determinants* or the specific social circumstances or circumstances of daily life within communities. The *Intermediary determinants*, located on the right side of the framework, emerged from the outcomes of socioeconomic/political contexts and social stratification of *structural determinants* which could determine levels of exposure and vulnerability (CSDH 2008). *Intermediary determinants* are identified by categories of material circumstance, psychosocial circumstance, behavioral and/or biological factors, and health system factors. These were particularly relevant for issues of access, which accounted for some of the patterning of health outcomes (CSDH 2008). The intermediary determinants described the causal pathways to risk and vulnerability in health and wellbeing, which were nearer to the individual and their health experience.

The final element of the CSDH framework is the social capital/social cohesion item. Social capital/social cohesion or specifically social capital as it was described is considered to be a cross-cutting social determinant in the CSDH framework, identified by the situation of the concept across the structural and intermediary elements. The social capital concept was described as a concept which linked the interaction of structural and intermediary
determinants and additionally, because social capital was considered as a property of individuals, networks and communities it related these elements and this was communicated in the framework (CSDH 2008). The social capital concept will be discussed in more detail later in this chapter.

The inclusion of the SDH framework in the conceptual framework of this study was necessary to ensure that the range of social and economic resources and environments which impact on a population’s health and wellbeing were considered. The elements of the SDH framework were important for considering the interrelation of social and public policy, socioeconomic positioning and individual daily circumstances which may impact on the end of life care needs and capacities of socioeconomically disadvantaged populations. The challenge for understanding the impact of the SDH is therefore valuable but is challenged by the distance of the elements from the individual and their health experience (CSDH 2008). The linking of the elements of social capital discussed earlier were likely to manage this distance and were considered an important asset for promoting understanding of the social determinants (Baum 2010).

13.3 Social capital concept

Social capital is broadly understood to be a relational resource; defined as the individual and collective resources held in and produced by social relations (Lin 2001). It describes social networks, social norms, behaviors and values, levels of reciprocity, trust, and shared resources. The concept of social capital has had over 100 years of conceptual development; re-invented many times during the twentieth century within the terms ‘social cohesion’, ‘community’ and ‘civic virtue’(Putnam 2000 pg 19). The volume and diversity of empirical evidence of social capital has generally demonstrated an association with wellbeing (Sarracino 2010; Yamaoka 2008; Yip et al. 2007); quality of life and health-related quality of life (Bowling et al. 2002; Drukker et al. 2003; Kim & Kawachi 2007; Usher 2007; Wahl, Bergland & Loyland 2010); mental health (Aihara et al. 2009; Almedom 2005; Fitzpatrick et al. 2005); and the capacity to buffer effects of hazardous environments (Andrew 2005; Fitzpatrick et al. 2005). As described by Raphael (Raphael 2006), social capital was considered to be a capacity in a population that potentially balanced vulnerability and managed inequity.

Social capital has been defined across a range of disciplines including public health, where it is described extensively, education, economic development, community development and employment. The nature of these multiple definitions and variations of measures of social capital has driven much criticism of the concept (Kawachi, Subramanian & Kim 2010).
Criticisms mainly center on the over-flexibility of its use rather than the quality of its application as a framework for understanding the value, or otherwise, of social relations and networks to health. As a multifaceted concept, it drives complexity in theoretical and conceptual understanding. Literature and debate on social capital, particularly in public health, highlights strong concerns that the concept negates the responsibility of the state for the welfare of its people by considering community and individual factors out of context (Pearce et al. 2003). There is, however, consideration of macro-level influences within much of the social capital discourse and this is further described below.

13.4 Social capital framework

Despite the complexity of the concept of social capital concept, consensus in the literature for elements and functions of social capital have been identified (Kawachi, Subramanian & Kim 2010). The interrelation of the components, levels and domains of social capital are outlined in Table 13.1

13.4.1 Social capital components

The two main components of social capital are Structural and Cognitive. The Structural social capital component, also labeled in the literature as ‘network’, considers the formal and informal networks and relations of ‘What people do.’ The Cognitive social capital component, also termed ‘social cohesion’, describes values, perceptions, and norms or the quality of relationships or ‘What people feel’ (Harpham 2010). The distinction between these two components was important as they were seen to have different relationships with health outcomes. Harpham (2010) described that where there were large networks (structural), of limited quality (cognitive) there was an association with poor mental health outcomes.

13.4.2 Social capital levels of analysis

Table 3.1 depicts the micro, meso and macro societal levels of analysis of social capital. Micro reflects the level of the individual and refers to the network to which the individual belonged as well as aspects of ethnicity, neighbourliness, acceptance or presence of diversity (Raphael et al. 2001). Meso refers to community level of co-operative structures or organisations, responsive community institutions and citizen coalitions (Franke 2005; Raphael et al. 2001). Macro describes the government and policy making level that enable resources for responsive communities (Raphael et al. 2001; Veenstra & Veenstra 2005). These levels of analysis describe the context and composition of social capital across social delineations.
Table 13.1 Social capital framework: components, analysis domains and differentials

<table>
<thead>
<tr>
<th>Social capital components</th>
<th>1. Structural component</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(i). Formal networks</td>
</tr>
<tr>
<td></td>
<td>The behavioural expression of social capital (What people do)</td>
</tr>
<tr>
<td>2. Cognitive component</td>
<td>Attitudes, values and perceptions of the quality of the relationship (What people feel)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Levels of analysis (societal levels)</th>
<th>Micro</th>
<th>Meso</th>
<th>Macro</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of the individual. Individual aspects include ethnicity, neighbourliness acceptance/presence of diversity</td>
<td>Structures within a community that enable cooperation. Responsive community institutions and citizen coalitions</td>
<td>Government and policy making domains of community. Enables community institutions to be responsive</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Social capital domains (interactions)</th>
<th>Bonded social capital</th>
<th>Bridged social capital</th>
<th>Linked social capital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Degrees of diversity of members of a network</td>
<td>Strong ties of homogenous (values, relations and resources) groups; close family networks.</td>
<td>Weaker ties between like-minded individuals and groups of different social relations and resources</td>
<td>Ties connecting relations across authorities and power gradients. Enables entitlement to material needs and capabilities</td>
</tr>
</tbody>
</table>

| Differentials | Socioeconomic status, gender, cultural diversity |

13.4.3 Social capital domains

Further distinctions of social capital are the three domains which include bonded, bridged and linked social capital. These domains describe the interactions of relations within each of the social levels (Kawachi, Subramanian & Kim 2010). These domains describe the degrees of diversity of the member in these networks and are important for understanding the value of these relations and networks for resources. Bonded social capital is characterised as close vertical homogenous relations and networks of family and close friends. Bridged social capital refers to the formal and informal looser relations and networks of different individual and community groups. Linked social capital describes the ties to representatives of authority demonstrating connections across power gradients (Baum 2010).
13.4.4 Social capital differentials

The distinctions of the bonded, bridged and linked domains have contributed significant evidence to understanding how social capital can be both an asset and a liability. Social capital, considered a metaphor for advantage, has demonstrated valuable contributions for understanding the influence of social structures as hierarchies and proponents of inequality (Lin 2001). Lower socioeconomic groups, racial groups and women were considered to be at risk for limited social capital, as they potentially had differential access or outcomes, a shortage of relations or networks and/or these were of limited quality (Berry & Welsh 2010; Bouchard et al. 2006; Caperchione et al. 2008). Access to social capital was related to the strength of an individual’s positioning in society with the higher the positioning, the greater the access to resources (Lin 2001). Bonded networks were important for identity and collective action (Kawachi, Subramanian & Kim 2010) and bridged networks and relations were largely identified in the literature as being invaluable for social leverage (Lin 2001). Linked networks and relations enabled a capacity to cut across power gradients in relationships of respect and trust (Szreter & Woolcock 2004). These linked networks were considered important for the creation of cohesion in a society and also demonstrated access to persons or organisations with larger resource collections and/or links to other social networks (Lin 2001).

13.5 Social capital for lower socioeconomic groups

The outcomes of social capital for lower socioeconomic groups have had reasonable discourse in the literature describing the nature of resources and access for this population. The literature has specifically described limited social networks and lack of social support (Mechanic & Tanner 2007), limited neighbourhood contexts for services and facilities for this group (Cattell 2001), and poor community trust (Kawachi 1999). Social capital research in the area of disadvantage has been criticised for its limitations in describing the influence of macro-level influences such as social, welfare and housing policy, which are considered more necessary for supporting needs in this group than social and community networks (Pearce et al. 2003). Szreter and Woolcock (2004) who are two of many proponents of the social capital approach to understanding inequality and needs of disadvantaged health populations, acknowledge the impact macro level contexts but emphasise the contribution of relationships and networks. Building of networks of trust is of significant value in lower socioeconomic groups because without attention to the quantity and quality of relationships, networks will not develop across societal levels to alleviate social exclusion and achieve access to resources (ibid).
13.6 Social capital and care giving contexts

The social capital domains of bonded, bridged and linked networks and relationships are useful for understanding the resources of different domains for care giving contexts and outcomes. The outcomes of these different social capital networks have been described in care giving contexts (Derose 1008; Keating & Dosman 2009). Whereby bonded social capital was good for ‘getting by,’ bridged social capital was good for ‘getting on’ (Harpham 2010 pg 52). Bonded networks in disadvantaged groups were important for survival but extracted a cost to the providers of support, straining limited mental and financial resources (Kawachi, Subramanian & Kim 2010). Where bonded networks were particularly strong, other networks of bridged relations were more likely to be limited and therefore limiting for these groups to access other resources (Keating & Dosman 2009). Bridged social capital enables access to new resources and information and has potential to leverage to linked social capital networks of authority.

Despite the complexity and contested nature of the social capital concept, it holds great capacity for understanding the nature of relations and networks, individual, community and institutional, for providing resources for wellbeing and health outcomes. As the intersection between health and social circumstances is becoming increasingly recognised, it is necessary to understand these conceptual underpinnings. Recognising what types of networks and relations are best for generating necessary resources requires the capability to describe them, and in doing so, the social milieu of need and capacity for individuals and groups can be both understood and supported. The value of a social capital approach for lower socioeconomic groups negotiating end of life care is, therefore, fundamental for equity, wellbeing and sustaining care networks and relations.

13.7 Conceptual framework for the Dying in the Margins study

The SDH framework describes the social, political and economic conditions which determine outcomes for equity for vulnerable populations (Raphael 2006). The ability of the SDH framework to outline the range of societal conditions that can determine these outcomes is important for describing the needs and capacities of lower socioeconomic groups at the end of life. The SDH framework has been criticised for being limited to understanding the impact of economic and social policy (Raphael 2003) and for being distant from the health and wellbeing experience of individuals and communities (CSDH 2008). It therefore requires greater promotion of elements that can achieve understanding of the impact of these broader conditions at an individual and community level.
Social capital importantly considers the individual and community resources necessary for buffering the effects of vulnerability and for bridging the structural and community elements of societal conditions. Social capital, as stated previously, has been criticised for being restricted in its capacity for describing the limits of material needs or resources and focusing on the creation of resources in relations and community (Cattell 2001). Baum (2010), however, argues that when social capital is measured well, considerate of all forms for bonded, bridged and linked networks and relations, it is most useful in describing, among other things, the distribution of material resources.

The combination of the two theoretical/conceptual models, the SDH framework and the social capital concept, into a single framework is seen in Figure 13.2. This framework illustrates both the broad socioeconomic conditions and the resources of relations and networks necessary for describing the complexity of needs for socioeconomically disadvantaged groups. The application of the two frameworks ensures that the range needs and capacities of this group are made explicit through describing conditions and relations of support or inequity. Additionally, the limitations of one framework are likely balanced by strengths of the other.
The application of the framework to a lower socioeconomic palliative care population is necessary to investigate the resources (economic and social) necessary for this group. The outcomes of social and health policy and the impact of socioeconomic positioning describe the fundamental elements necessary to support lower socioeconomic patients and their families and carers at the end of life. The structural, physical, and social resources created by social and health policy necessary for this group include but are not limited to assets such as health care infrastructure, housing, education, welfare infrastructure, civic engagement and employment. Daily living conditions which may include psychosocial factors, access to health services, community cohesion, literacy, income adequacy, living costs, housing conditions and tenure are essential for health and wellbeing. These conditions of daily living describe the impact of structural conditions and influence on equity. Where conditions of daily living are positive, patients, families and carers will be supported for many end of life care needs.

Figure 13.2 Conceptual model for this study
Networks and relations of bonded, bridged and linked domains describe the contribution of societal support as resources for lower socioeconomic groups at the end of life. The support provided at these distinct levels matter very much to the quality and sustainability of care at the end of life (Lewis et al. 2013). The bonded social capital networks depicted the relations and networks necessary to support the intensity of care needs at the end of life. The resources derived from these relationships included practical care and support often delivered in the home by close family members. Bonded networks were revered by palliative care models (Parker Oliver et al. 2005) and yet, the quality and capacity of resources within them was poorly understood. Outcomes of bonded networks and relations for lower socioeconomic groups were described as overall poor (Cattell 2001). Bridged networks, however, often represented resources within communities, the informal and formal relations necessary for social inclusion, and trust and information. The additional and complementary nature of support provided by these networks and relations was considered essential for best outcomes for patients and carers (Keating & Dosman 2009). Linked networks and relations enabled the availability of and access to the social and financial resources described in the structural conditions of support in the SDH framework.

13.8 Conclusion

Conceptual frameworks or models have heuristic value in generating questions for significant research studies (Teddlie & Tashakkori 2009). The conceptual model of this study considers the needs of a lower socioeconomic population at the end of life and situates the questions for this study within a hybrid model of the SDH framework and social capital concepts. This new framework represents an exciting development in palliative care research and is a unique contribution of this thesis. These two interrelated frameworks drive understanding for individual, community and societal level factors that impact on persons utilising health care contexts at the end of life. The conceptual framework for the study defined the selection of social, economic and wellbeing assessment tools, the development of a social capital questionnaire, and an interview guide informed by access domains to explore descriptions of the experience of end of life care in a socioeconomically disadvantaged population.
13.9 References


Berry, H.L. & Welsh, J.A. 2010, 'Social capital and health in Australia: an overview from the household, income and labour dynamics in Australia survey', *Social Science & Medicine*, vol. 70, no. 4, pp. 588-96.


Cattell, V. 2001, 'Poor people, poor places, and poor health: the mediating role of social networks and social capital', *Social Science and Medicine*, vol. 52, no. 10, pp. 1501-16.


Raphael, D. 2003, 'Barriers to addressing the societal determinants of health; public health units and poverty in Ontario, Canada', *Health Promotion International*, vol. 18, no. 4, pp. 397-405.


Chapter 4

Research Methods

14.1 Introduction

As discussed in Chapter 2, previous studies investigating the experience and outcomes for lower socioeconomic groups and end of life care are limited, particularly in an Australian context. The purpose of this chapter is to describe the study’s epistemology, methodology and research design.

14.2 Epistemology

The postmodern theoretical approach of social constructionism is a philosophical world view that aims to provide an alternative to positivist-empiricist philosophy which is according to Hibberd (2005), long grounded in the pursuit of psychological knowledge and is to be criticised for the ‘illusion of objectivity’ it proposes. Hibberd (2005) explains that social constructionism instead:

...emphasises the historicity, the context-dependence, and the socio-linguistically constituted character of all matters involving human activity. The psychological processes of human beings are, it is said, essentially social, and are acquired through the public practice of conversation (page viii).

Meanings held by social constructivists are many and varied, and are subjective in nature; they therefore lead to the creation of complex views rather than limited meanings (Creswell 2009). The goal of the research within the social constructivism world view is to rely as much as possible on the participants’ view of the situation being studied (Creswell 2009). Social constructivism is an appropriate philosophy for this study, as its emphasis on multiple realities within the legitimacy of context and social milieu is likely to support understanding of the experience of end of life care; opening up new meanings and perspectives to be explored for this population.
14.3 Methodology

Transparency of the philosophical and theoretical positioning of a study are essential to ensuring that the researcher’s worldview is informed to the reader (Creswell & Plano Clark 2007). The longstanding debate between the inquiry paradigms of quantitative and qualitative methods has established a dichotomy of fact versus understanding of human experience. Patton (2002) suggests another paradigm; a pragmatic strategy that considers an inquiry approach which extends beyond the two established paradigms, to include the option of strategically mixing them to match specific research questions.

Pragmatism considers that social inquiry should have multiple realities of subjective and objective knowledge, which is both constructed and based on the reality of the world that is experienced and lived in (Onwuegbuzie, Johnson & Collins 2009). The pragmatic world view is concerned with ‘what works’ and focuses on the research problem, approaching and addressing the problem from a pragmatic stance (Creswell 2009). “Truth” and “reality” are debunked in the pragmatist worldview with the research questions under investigation influencing the truth (Teddlie & Tashakkori 2009). Pragmatic research is motivated by “anticipated consequences”; choices about being open to all avenues of inquiry and a vision for the consequences (Cherryholmes 1992). Cherryholmes writes:

Pragmatists also believe that we would be better off if we stopped asking questions about laws of nature and what is really “real” and devoted more attention to the ways of life we are choosing and living when we ask the questions we ask (Cherryholmes 1992).

The pragmatist paradigm is particularly appealing to the mixed methods design, as this paradigm rejects the notion of the incompatibility thesis; which states that integration of quantitative and qualitative methods is impossible due to the contrast of their underlying paradigmatic positions (Teddlie & Tashakkori 2009). Research that has important societal consequences lends itself well to the pragmatist paradigm because it supports the interactive relationship of qualitative and quantitative methods which are required to answer complex questions (Teddlie & Tashakkori 2009). The experience of dying in a lower socioeconomic context is most likely complex and multifaceted and therefore, will yield complex questions, which are best framed in a pragmatist paradigm.
14.4 Research design

A mixed methods research design was considered most appropriate to address the research aims. The aims of the study were to explore the experience of a lower socioeconomic population for end of life care; describe socioeconomic demographic characteristics and measure wellbeing, consumption, health literacy and social capital; and assess the impact of socioeconomic status on place of death and service utilisation outcomes for care giving. A mixture of qualitative and quantitative approaches was necessary to align with the research objectives outlined in Chapter One.

Mixed methods research integrates both qualitative and quantitative methods and has emerged over the last 20 years as an alternative to the single qualitative and quantitative traditions of inquiry (Teddlie & Tashakkori 2009). Mixed methods has had broad appeal in social sciences research because it has the ability to combine both methods to support strengths and overcome weaknesses of individual methods alone and also has the capacity to broaden the understanding of issues from these two perspectives (Halcomb & Andrew 2009).

Mixed methods approaches in palliative care contribute to understanding the complexity of interventions and challenges of assessing and determining suitable outcomes for this group due to the complexity of care needs (Farquhar, Ewing & Booth 2011). Patient and carer satisfaction with current service provision is a key consumer movement in health and this is certainly true for palliative care, where quality of life is aligned to satisfaction with care. A mixed methods approach is considered appropriate in measuring patient satisfaction to elucidate broadly, ratings of the quality of care, and manage the limitations of tools and scales to accurately measure satisfaction, beyond the ceiling effect (Andrew et al. 2011). Mixed methods are also useful in questionnaire or instrument design by means of providing context to quantitative analysis and demonstrating tool acceptability (Farquhar, Ewing & Booth 2011).

This study seeks to address the social complexity of end of life care from both a process and an outcome perspective and additionally, to test the appropriateness, acceptability and feasibility of social, economic and palliative care self-report tools in this population. Addressing these factors will contribute to the science of decreasing health disparities in palliative care access and participation.

14.4.1 Types of mixed methods

Mixed methods research provides unique and specific methods for research design, conduct, analysis and interpretation (O’Cathain, Murphy & Nicholl 2007). The four aspects that influence the design of procedures for a mixed methods study are timing, weighting, mixing
and theorising (Creswell 2009). Timing considers the schedule of quantitative and qualitative data collection; weighting refers to the priority of quantitative and qualitative emphasis; mixing represents the process for combining the two data sets; and theorising depicts whether a larger theoretical perspective is explicit or implicit (Creswell 2009). These four aspects of mixed method design help shape the procedures of a mixed method study and are outlined in Figure 14.1.

<table>
<thead>
<tr>
<th>TIMING</th>
<th>Concurrent</th>
<th>Sequential</th>
<th>Quantitative first</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Qualitative first</td>
</tr>
<tr>
<td>WEIGHTING</td>
<td>Equal weight</td>
<td>Unequal weight</td>
<td>Quantitative emphasis</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Qualitative emphasis</td>
</tr>
<tr>
<td>MIXING</td>
<td>Merged</td>
<td>Integrated</td>
<td>Embedded</td>
</tr>
<tr>
<td>THEORISING</td>
<td>Explicit/ Implicit</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Figure 14.1 Aspects of mixed methods research design* (Adapted from Creswell, 2009)

A concurrent embedded design of mixed methods is defined as one type of data embedded in another and both data types are collected simultaneously. This model of mixed methods is useful in gaining a broad prospective with a primary method guiding the study and a secondary data method having a supportive function; addressing different questions or seeking information at another level of investigation (Creswell 2009). The mixing of the data in embedded design can serve two purposes: to integrate and compare the information; and not be integrated, but exist as parallel perspectives of a composite evaluation of the issue (Creswell 2009).

The mixed methods research design of this study was a concurrent embedded design, see Figure 14.2. The concurrent embedded design was a qualitative emphasis (QUAL/quant) and explicit use of social determinants of health/social capital conceptual framework. The ‘QUAL’ strand of the mixed methods design included in-depth semi-structured interviews for patients and carers, during which self-report assessment tools and questionnaires were administered. In addition, semi-structured interviews with key informants were conducted. Two ‘quan’ episodes included; (i) quantitative data generated in the structured interview component through delivery of a sequence of outcomes tools to measure social, economic, health literacy,
wellbeing and palliative care needs, and (ii) reporting and analysis of afterhours palliative care crisis service utilisation and outcomes data; and place of death data for two disparate socioeconomic areas. The qualitative method, the primary method guiding the study, aimed to explore ways in which lower socioeconomic groups experienced end of life care. The quantitative method was important for answering specific questions about the outcomes of social and economic needs and capacities in this same group. Broader descriptions of palliative care service utilisation and death outcomes were reported from health service data.

14.5 Study setting

14.5.1 Study population

This study was conducted in a single palliative care service in Western Sydney Local Health District (WSLHD) of which service provision across the service is overall consistent and includes inpatient beds, outpatient services, generalist and specialist community nursing and after-hours crisis service. The provision of palliative care services for this area juxtaposes regions of both high and low socioeconomic status. WSLHD comprises eight Local Government Areas (LGAs): Auburn, Blacktown, The Hills Shire, Holroyd, Lemongrove, Lawson, Blue Mountains and Parramatta. All of these LGAs are supported by this single palliative care service. Administrative data for after-hours crisis service utilisation and place of death data was collected and reported for The Hills Shire (Hills) and the Mt Druitt Precinct, which is located in the Blacktown LGA. Socioeconomic indexes for areas (SEIFA) scores, which include and index of relative socioeconomic disadvantage (IRSD) were discussed in Chapter One, and are widely used measures of socioeconomic advantage and disadvantage in Australia. The IRSD score for Mt Druitt Precinct is 885, and for The Hills Shire is 1116.5 (ABS 2006b). Relatively disadvantaged areas have lower index values. The average SEIFA score is approximately 1,000 and the middle two thirds of scores fall between 900 and 1,100 with relative disadvantage associated with a number below 1,000 (ABS 2006a).
14.5.1.1  **Study population: Mt Druitt Precinct**

Mt Druitt Precinct is located in the Western suburbs of Sydney and is situated 43 kilometres west of the Sydney Central Business District, occupying a land area of 6.489 hectares. It is predominantly a residential area, with some industrial and commercial land use (2011). The Mt Druitt precinct has had slow population growth since 2001 with fewer dwellings being built and a decline in the occupancy of existing dwellings (2011). Mt Druitt was an area developed in the mid-1960s as a public housing program known as the Broadacre scheme. This program was a post-war initiative which relocated poor inner-city Sydney residents to specific areas on the city’s boundaries (Peel 2003).

The Mt Druitt palliative care unit is located within the suburb of Mt Druitt and is a purpose-built facility within the Mt Druitt Hospital campus. It is the second largest inpatient facility in the Western Sydney palliative care service. It is an entirely public-funded service with 16 inpatient beds, outpatient services and after-hours crisis service. The service houses and manages the after-hours crisis service and a patient registration data base for the Western Sydney palliative care service.

14.5.1.2  **Study population (comparison): The Hills Shire**

The Hills Shire is located in Sydney’s north-west and is 30 kilometres for the Sydney Central Business District, occupying a land area of 40,059 hectares. It is predominantly a rural and residential area, with some commercial and industrial land use (2009). The Hills Shire is one of the fastest growing Local Government Areas in Sydney (2009).

The greatest population density of the Hills Shire is located approximately 12 to 25 kilometres from the Mt Druitt palliative care inpatient facility and is in proximity (4 to 10 kilometres) to another palliative care inpatient unit, an 8 bed publically funded facility located at Westmead Hospital. Health service utilisation data from Western Sydney indicates that 30% of Hills Shire residents are likely to utilise private health services (WSAHS 2002) of which three are in proximity to this area.

A summary of the Australian Bureau of Statistics (ABS) data (2006) for Mt Druitt Precinct and The Hills Shire, shown in Table 14.1 details the socioeconomic characteristics for these two areas.
Table 14.1 ABS data for Hills and Mt Druitt areas

<table>
<thead>
<tr>
<th>Key Statistics</th>
<th>Hills Shire</th>
<th>%</th>
<th>Mt Druitt</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Population</strong></td>
<td>158,737</td>
<td>100</td>
<td>97,067</td>
<td>100</td>
</tr>
<tr>
<td><strong>Indigenous population</strong></td>
<td>438</td>
<td>0.3</td>
<td>4,190</td>
<td>4.3</td>
</tr>
<tr>
<td><strong>Overseas born population</strong></td>
<td>47,285</td>
<td>30</td>
<td>33,053</td>
<td>34.2</td>
</tr>
</tbody>
</table>

**Households and dwellings**

<table>
<thead>
<tr>
<th></th>
<th>Hills Shire</th>
<th>%</th>
<th>Mt Druitt</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Owned</td>
<td>18,036</td>
<td>35.3</td>
<td>5,688</td>
<td>18.8</td>
</tr>
<tr>
<td>Purchasing</td>
<td>22,944</td>
<td>44.9</td>
<td>11,513</td>
<td>38.1</td>
</tr>
<tr>
<td>Renting-Government</td>
<td>346</td>
<td>0.7</td>
<td>4,607</td>
<td>15.2</td>
</tr>
<tr>
<td>Renting-other</td>
<td>7,416</td>
<td>14.5</td>
<td>5,822</td>
<td>19.3</td>
</tr>
<tr>
<td>Single person household</td>
<td>5,750</td>
<td>11.50%</td>
<td>5,524</td>
<td>15.7</td>
</tr>
</tbody>
</table>

**Proficiency in English**

<table>
<thead>
<tr>
<th></th>
<th>Hills Shire</th>
<th>%</th>
<th>Mt Druitt</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>English only</td>
<td>19,318</td>
<td>40.9</td>
<td>8,392</td>
<td>25.4</td>
</tr>
<tr>
<td>Speaks another language and English not well or not at all</td>
<td>3,463</td>
<td>7.3</td>
<td>3,253</td>
<td>9.8</td>
</tr>
</tbody>
</table>

**Income (Household quartiles) 2006**

<table>
<thead>
<tr>
<th></th>
<th>Hills Shire</th>
<th>%</th>
<th>Mt Druitt</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lowest group (0-$31,066)</td>
<td>5,869</td>
<td>13.3</td>
<td>7,442</td>
<td>29.6</td>
</tr>
<tr>
<td>Medium lowest ($31,067-$59,985)</td>
<td>8,394</td>
<td>19</td>
<td>7,771</td>
<td>30.9</td>
</tr>
<tr>
<td>Medium highest ($59,986-$107,006)</td>
<td>12,082</td>
<td>27.3</td>
<td>6,861</td>
<td>27.2</td>
</tr>
<tr>
<td>Highest group ($107,007+)</td>
<td>17,857</td>
<td>40.4</td>
<td>3,107</td>
<td>12.3</td>
</tr>
</tbody>
</table>

**Highest level of schooling**
| Year 8 or below | 3,893 | 3.2 | 5,690 | 8.2 |
| Year 9 or equivalent | 6,521 | 5.3 | 6,647 | 9.5 |
| Year 10 or equivalent | 28,390 | 23 | 18,658 | 26.7 |
| Year 12 or equivalent | 70,103 | 56.8 | 25,387 | 36.4 |
| Did not go to school | 646 | 0.5 | 835 | 1.2 |

### Employment (occupation)

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Count</th>
<th>%</th>
<th>Subtotal</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managers</td>
<td>14,316</td>
<td>17.2</td>
<td>2,238</td>
<td>6.2</td>
</tr>
<tr>
<td>Professionals</td>
<td>21,761</td>
<td>26.1</td>
<td>3,726</td>
<td>10.3</td>
</tr>
<tr>
<td>Technicians/trades</td>
<td>9,581</td>
<td>11.5</td>
<td>5,112</td>
<td>14.2</td>
</tr>
<tr>
<td>Community workers</td>
<td>5,604</td>
<td>6.7</td>
<td>3,005</td>
<td>8.3</td>
</tr>
<tr>
<td>Clerical/admin</td>
<td>14,838</td>
<td>17.8</td>
<td>6,482</td>
<td>18</td>
</tr>
<tr>
<td>Sales</td>
<td>8,796</td>
<td>10.6</td>
<td>3,358</td>
<td>9.3</td>
</tr>
<tr>
<td>Machinery</td>
<td>2,740</td>
<td>3.3</td>
<td>5,592</td>
<td>15.5</td>
</tr>
<tr>
<td>Labourers</td>
<td>4,153</td>
<td>5</td>
<td>5,586</td>
<td>15.5</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2,789</td>
<td>3.20%</td>
<td>3,750</td>
<td>9.4</td>
</tr>
</tbody>
</table>

### 14.6 Participant population and recruitment

The patient and/or carer participants selected for interviews for this study were palliative care patients over the age of 25, who mainly resided in the Mt Druitt area and identified that they had needs related to social and economic hardship. Participants were recruited through the Mt Druitt inpatient palliative care unit and through outpatient clinics across the WSLHD and the Mt Druitt community health centre. Patients either self-recruited after responding to the study recruitment flyer (Appendix 2) located in these areas or were approached to participate by formal care staff to which they had revealed social and economic hardship needs. Details of patient and/or carer characteristics and demographics are outlined in Chapter Six.
Key informants were selected for the study if they were involved in the care of palliative care patients and/or carers from the Mt Druitt area. These were individuals who cared for a broad range of palliative care patients or those who demonstrated more limited access to specialist palliative care services, which included patients with non-malignant diseases and Indigenous groups. Key informant details are tabled in Chapter Six.

14.7 Sampling methods

The methods described for sampling in research vary according to the type of research that is being conducted. In mixed methods research, the purpose of sampling is to address all research questions. Probability sampling is used to answer the quantitative research questions and purposive sampling to answer the qualitative research questions (Teddlie & Tashakkori 2009 pg180). Parallel mixed methods sampling was used in this study whereby simultaneous (parallel) probability and purposive sampling procedures occurred. This sampling technique does not require one strategy to ‘set the stage for the other’ (Teddlie & Tashakkori 2009). Teddlie and Tashakkori (2009) identified two basic parallel mixed method sampling procedures that were both used in this study. In one, the sampling procedure occurs independently, with probability sampling used for the quantitative component and purposive sampling used for the qualitative component (Teddlie & Tashakkori 2009 pg 187). In the other, parallel sampling design, a single sample generates both quantitative and qualitative outcomes through purposive sampling. Figure 14.3 outlines the sampling schema for items and participants in the study.

Probability sampling is characteristically aligned with quantitative analysis. Probability sampling focuses on breadth of information and therefore needs to ensure that the sample is large enough to establish population representativeness; usually with at least 50 items (Teddlie & Tashakkori 2009 pg 178). Purposive sampling, which is associated with qualitative analysis, aims to select a small number of units which provided valuable and specific information related to the research question (Teddlie & Tashakkori 2009). The deliberate selection of participants in purposive sampling ensures that information rich cases are selected for study and as such, the researcher can learn broadly of the issues being examined (Liamputtong 2009).
14.8 Qualitative data sample and collection

In this study, a total of 19 interviews were conducted with patients and/or carers (n=14) and key informants (n=5). One carer participant who self-recruited to the study was interviewed 18
months following the death of her 19 year old daughter. In all other interviews, the patient was still alive at the time of the interview.

Interviews with patients and/or carers were semi-structured to explore responses to the self-report tools and to discuss social, economic and palliative care needs and capacities, with use of an interview guide (Appendix 3). Interviews with key informants explored perceptions and experiences of access and social and economic needs, for palliative care patients and carers.

14.8.1 Interview Guide

The interview guide for participants was developed around the themes emerging from the literature review. These themes broadly outlined barriers to access for lower socioeconomic groups at the end of life and were described as key dimensions of access: acceptability, affordability, accessibility and availability (Peters et al. 2008). In addition, elements from the SDH framework and social capital concepts were included in the interview guide. The interview guide facilitated in supplementing responses regarding social, economic, palliative care and access needs and capacities assessed via self-report tools. The interview guide formed the key themes for discussion in the key informant interviews.

14.9 Quantitative sample and collection

14.9.1 Administrative data: Afterhours crisis service utilisation

The quantitative sample for the after-hours crisis service utilisation and outcomes data were collected for a 12 month period (1 March 2011 – 29 February 2012). A total of 1,017 call episodes to the after-hours service were recorded during this period and of these, 206 calls were for patients registered with the service from the Hills area and 160 calls were for patients registered with the service from Mt Druitt area.

Administrative data for crisis call episodes were collected from a central after-hours crisis service located at the Mt Druitt palliative care unit. Data on after-hours crisis service calls were collected from hard copy call sheet reports, filed, and stored at the Mt Druitt Palliative care inpatient facility. All calls to the service were documented on these forms following completion prospectively by the afterhours nursing staff. The call sheets were completed by Registered Nurses receiving calls to the service who documented calls for palliative care patients registered with community health centres in Western Sydney Local Health District (WSLHD). The items recorded from these call data sheets included community centre, caller details, patient and carer details, diagnosis, call details and call outcome(s). Data from Mt Druitt and Hills area calls were compared.
14.9.2 Administrative data: Place of death

The quantitative sample for the place of death data were reported for patients registered from the Hills and Mt Druitt areas during the period January 2008 to December 2011. Place of death data for the Hills area was obtainable for 471 (95%) patients registered and 293 (98.5%) registered Mt Druitt patients.

Place of death data were recorded for palliative care patient registrations collected from a central electronic palliative care database located in the Mt Druitt Palliative care Unit, WSLHD. Data analysis items included community centre (postcode), diagnosis, sex of patient, place of death and year of death. Missing data were managed by additional searching of hospital and community health data bases and cases were removed from analysis if data was unavailable following additional searching. A comparison of data were made between Mt Druitt and Hills community health centres to identify whether there were differences in place of death on the basis of area and the impact of sex and diagnosis.

Patients are registered with the palliative care service by primary health care providers (community nurses and general practitioners), health care professionals from acute care facilities and non-government organisations. Patients are registered with the service if they have a diagnosed terminal illness (malignant or non-malignant) and may or may not be having further treatment.

14.9.3 Self-report tools and socio-demographic data

A total of 16 patients and/or carers completed self-report tools and completed the socio-demographic information sheet. Two patient participants requested only to complete the tools and socio-demographic data sheet and declined to be interviewed for the study. Four patients with carers were unable to complete the self-report tool due to incapacity or death. In these cases, if tools were patient-specific, they were not completed.

Administration of a battery of patient and/or carer self-report outcomes tools and collection of additional socio-demographic information generated quantitative data for the study which was intentionally limited in sample size and was used to illuminate and quantify aspects of qualitative analysis. Self-report tools used in this study are discussed below.

14.10 Patient and/or carer self-report tools

The selection of the self-report tools for this study was based on the social determinants and social capital elements. The tools included in the study were the Personal wellbeing Index (PWI), a consumption survey, Social Capital questionnaire (SCQ), Palliative care needs
assessment tool (NAT:PD-C), Rapid Assessment of Adult Literacy Medicine Revised (REALM-R) tool. The self-report tools were administered verbally to patients and/or carer participants to semi-structure patient and/or carer interviews, to quantify aspects of qualitative outcomes and to capture outcomes for appropriateness, acceptability and feasibility of the tools through semi-structured interview outcomes.

The psychometrics of the self-report tools are described below. As the intention was to primarily scope the utility and acceptability, the sample size and limits of sampling methods in this study negate statistical analysis beyond descriptive statistics.

14.10.1 Socioeconomic-demographic and clinical data collection sheet

This is an investigator-developed data collection sheet that collects information on clinical diagnosis, age, income, sex, marital status, level of education, income, health insurance, work history and carer details (see Appendix 4).

14.10.2 Needs assessment tool: Progressive disease Cancer NAT:PD-C

The Needs assessment tool is a one page, sixteen-item, multiple section assessment tool administered by health professionals to assess levels of need in patients and carers in specialist and generalist health care settings and match these needs to specialist palliative care services as necessary (Appendix 5). Twelve items on the needs assessment tool were verbally assessed following discussion with patients (6 questions) and carers (6 questions) where available, as outlined below. Psychometrics of the tool reflected high face and content validity, acceptability and feasibility of the tool for patients with advanced cancer and their carers. Inter-rater reliability was found to be adequate for most domains. Patient spirituality and caregiver physical and family relationship domains demonstrated low reliability. (Waller et al. 2008). The NAT:PD-C also contained items for referral to services and further information which were not completed by patients and/or carers in this study. These questions were not included in the assessment as assistance in accessing services was not an objective of the study. Patients were verbally assessed with questions 1-6 in section 2 and caregivers were verbally assessed with questions 1-5 in section 3 and question 1 in section 4. The final question in section 4: ‘Is the caregiver or family experiencing grief over impending or recent death of patient that is interfering with their wellbeing or functioning?’ was not verbally assessed with caregivers as it was deemed that this question was too sensitive to be discussed in the presence of the patient. This tool was selected for the study because it assessed needs in palliative patient and caregiver contexts.
14.10.3 Consumption survey: Personal, Household Finances and Consumption Questionnaire
(Household spending- Wave 5 version)

These questionnaires are a self-completion (verbally administered in this study), 21-item survey which identifies approximate weekly, monthly, and yearly household expenditure (Melbourne Institute, Household, Income and Labour Dynamic Australia, HILDA) (Butterworth & Crosier 2004). Two additional items added to the survey by the investigator included costs for medications and medical consumables and equipment hire /purchase costs (Appendix 6). Yearly costs were converted to monthly costs following data collection to improve comparative analysis. Measurement of consumption was necessary in this study for two reasons. Firstly, to describe consumption outcomes as a component of income poverty outlined in Chapter One and secondly, to describe out of pocket costs for medical expenses and other costs in the study population.

14.10.4 Personal Well-Being Index (PWI)

The personal well-being index (PWI) is an 8-item, 11-point end-defined response scale, which assesses a person’s subjective quality of life across eight domains (‘standard of living’, ‘health’, ‘achieving in life’, ‘personal relationships’, ‘safety’, ‘feeling part of the community’, ‘future security’ and ‘spirituality or religion’). The domains share both unique and shared variance, with domains representing a deconstruction of satisfaction with ‘Life as a whole’, which is also an optional question in the tool (2006) (see Appendix 7). The scale demonstrates a correlation of .78 with the Satisfaction with life scale; reliability Chronbach’s $\alpha$ of between .70 and .85 and good test re-test reliability (ibid). The construct validity for ‘safety’ and ‘spirituality or religion’ has been found to make no unique contribution in Australian studies but have been retained because of their contribution in other countries (ibid). The normative PWI mean range for Australia is 7.34-7.64 (without inclusion of the spirituality and religion domain) however the unemployed and low income, home alone groups have described levels well below this range(Cummins et al. 2007). The PWI was chosen for this study as it was a subjective measure of people’s feelings about themselves and, in particular, it measured outcomes for satisfaction with standard of living, personal relationships, community connectedness and safety that were important for illuminating economic, social and community aspects of participants in this study.

14.10.5 Rapid Estimate of Adult Literacy Medicine-Revised (REALM-R)

The REALM-R is an eight item instrument designed to rapidly screen adult primary care patients for low health literacy (see Appendix 8). The instrument is a quick reading recognition
test that measures a person's ability to pronounce eight common medical words and two lay terms which are included to establish confidence in the respondent but are not included in the score outcome (Davis et al. 1991). The correct pronunciation of six or fewer words from the list indicates inadequate or ‘at risk’ for low health literacy. The REALM-R instrument has demonstrated validity and reliability in cognitively intact adults (ibid). A correlation of the REALM-R and the WRAT-R (Wide Range Achievement Test Revised), an accepted recognition test in health literacy which has extensive validity and reliability testing, demonstrated a Cronbach’s $\alpha$ of 0.91 (Bass, Wilson & Griffith 2003). The REALM-R was selected for this study because of rapid completion time of less than three minutes.

14.10.6 Social Capital Questionnaire (SCQ)

This questionnaire was developed by the researcher (see Appendix 9). The questionnaire was designed to measure the quality and quantity of individual, community and societal relations and networks for the patient or their carer. The questionnaire has 16 questions with multiple item responses to 5 questions. The questionnaire takes approximately 15 minutes to complete and details of the tool design and testing are discussed below in 4.11.

14.11 Social capital Instrument design and description

The main elements and functions of the social capital concept, outlined in Chapter Three, informed item generation for the social capital questionnaire used in this study. The social capital questionnaire includes questions derived from the World Bank’s Social Capital Assessment Tool (SOCAT) (2003), the Adapted Social Capital Assessment Tool (ASCAT) (Harpham, Grant & Thomas 2002); the Household Income and Labour Dynamics Australia (HILDA) survey (Berry & Welsh 2010) and the ABS General Social Survey (ABS 2002). Questions, social capital domains and sources of the SCQ are outlined in Table 14.2.

<table>
<thead>
<tr>
<th>Table 14.2 Social capital survey items</th>
</tr>
</thead>
<tbody>
<tr>
<td>#</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>1a</td>
</tr>
<tr>
<td>Spouse/partner</td>
</tr>
<tr>
<td>Family</td>
</tr>
<tr>
<td>Neighbours</td>
</tr>
<tr>
<td>Friends who are not neighbours</td>
</tr>
<tr>
<td>Pet/Animals</td>
</tr>
<tr>
<td>------------</td>
</tr>
<tr>
<td>Religious organisation</td>
</tr>
<tr>
<td>Community Health groups/centres</td>
</tr>
<tr>
<td>Community clubs</td>
</tr>
<tr>
<td>Politicians</td>
</tr>
<tr>
<td>Government representatives</td>
</tr>
<tr>
<td>Charitable organisations</td>
</tr>
</tbody>
</table>

1b **In the last 12 months have you received any help from any of the following?**

<table>
<thead>
<tr>
<th>Help Type</th>
<th>Support Type (Bonded/Bridged, Structural SC)</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional help</td>
<td>Emotional support</td>
<td>ASCAT; ABS 2002 General Social Survey</td>
</tr>
<tr>
<td>Help to do things</td>
<td>Instrumental support</td>
<td>ASCAT; ABS 2002 General Social Survey</td>
</tr>
<tr>
<td>Help to know things</td>
<td>Informational support</td>
<td>ASCAT; ABS 2002 General Social Survey</td>
</tr>
<tr>
<td>Companionship</td>
<td>Emotional support</td>
<td>ASCAT; ABS 2002 General Social Survey</td>
</tr>
<tr>
<td>Financial help</td>
<td>Instrumental support</td>
<td>ASCAT; ABS 2002 General Social Survey</td>
</tr>
<tr>
<td>Spiritual help</td>
<td>Emotional support</td>
<td>ASCAT; ABS 2002 General Social Survey</td>
</tr>
</tbody>
</table>

2 **What was the quality of these relationships?**

<table>
<thead>
<tr>
<th>Quality</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>No relationship, excellent, good, fair or poor</td>
<td>Bonded/bridged/Linked, Cognitive SC HILDA (2001)</td>
</tr>
</tbody>
</table>

3 **In the last 12 months have you been an active member of any formal groups?**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Breadth/frequency of participation; community integration/isolation (Bridged, Structural SC)</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never, occasionally, sometimes or all the time</td>
<td>HILDA (2001), Australian community participation Questionnaire (ACPQ); ABS 2002 General Social Survey</td>
<td>---------------------------------------------</td>
</tr>
</tbody>
</table>
### 4 What are some of the reasons for not attending a formal group?

<table>
<thead>
<tr>
<th>Reason</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not interested in this group; not interested in any group; already a member; too busy; negative experience with this/other group, transport problem; don’t have access to this group; too ill; and family don’t want me to attend.</td>
<td>Perceptions of ABS 2002 General Social Survey, HILDA (2001)</td>
</tr>
</tbody>
</table>

### 5 What are the reasons for being part of a formal social group?

<table>
<thead>
<tr>
<th>Reason</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional support</td>
<td>Social participation (Bridged/Linked, Cognitive SC) HILDA (2001)</td>
</tr>
<tr>
<td>Spiritual support</td>
<td>Social participation (Bridged/Linked, Cognitive SC) HILDA (2001)</td>
</tr>
<tr>
<td>Financial support</td>
<td>Social participation (Bridged/Linked, Cognitive SC) HILDA (2001)</td>
</tr>
<tr>
<td>Help to do things</td>
<td>Social participation (Bridged/Linked, Cognitive SC) HILDA (2001)</td>
</tr>
<tr>
<td>Help to know things</td>
<td>Social participation (Bridged/Linked, Cognitive SC) HILDA (2001)</td>
</tr>
<tr>
<td>To have fun and enjoyment</td>
<td>Social participation (Bridged/Linked, Cognitive SC) HILDA (2001)</td>
</tr>
<tr>
<td>To feel connected to the community</td>
<td>Social participation (Bridged/Linked, Cognitive SC) HILDA (2001)</td>
</tr>
<tr>
<td>To have companionship</td>
<td>Social participation (Bridged/Linked, Cognitive SC) HILDA (2001)</td>
</tr>
</tbody>
</table>

### 6 In the last 12 months have you participated in activities for your community (eg. Worked in a community garden or have been a member of a committee)?
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>7</strong></td>
<td><strong>In general most people in the community can be trusted?</strong></td>
</tr>
<tr>
<td><strong>8</strong></td>
<td><strong>Most people in the community get along well?</strong></td>
</tr>
<tr>
<td>Agree/Disagree</td>
<td>Community cohesion</td>
</tr>
<tr>
<td><strong>9</strong></td>
<td><strong>I feel part of the community?</strong></td>
</tr>
<tr>
<td>Agree/Neither agree nor disagree/Disagree</td>
<td>Social inclusion (Cognitive/structural SC)</td>
</tr>
<tr>
<td><strong>10</strong></td>
<td><strong>I feel that people would take advantage of you if they got the chance?</strong></td>
</tr>
<tr>
<td>Agree/Disagree</td>
<td>Generalised trust (Bonded/Bridged, Cognitive)</td>
</tr>
<tr>
<td><strong>11</strong></td>
<td><strong>In the last 12 months how often have you helped neighbours?</strong></td>
</tr>
<tr>
<td>Never, rarely, sometimes, frequently or all the time</td>
<td>Community participation (Bridged, Structural SC)</td>
</tr>
<tr>
<td><strong>12</strong></td>
<td><strong>People in the community will act if something bad or illegal is happening?</strong></td>
</tr>
<tr>
<td>Agree/Disagree</td>
<td>Informal social control (Bridged, Cognitive SC)</td>
</tr>
<tr>
<td><strong>13</strong></td>
<td><strong>I don't have anyone to confide in?</strong></td>
</tr>
<tr>
<td>Agree/Disagree</td>
<td>Emotional and general support (Bonded/Bridged, Cognitive SC)</td>
</tr>
<tr>
<td><strong>14</strong></td>
<td><strong>I often feel lonely?</strong></td>
</tr>
<tr>
<td>Agree/Disagree</td>
<td>Social support (Bonded/Bridge, Cognitive SC)</td>
</tr>
<tr>
<td><strong>15</strong></td>
<td><strong>I have a friend who is a person in a government position?</strong></td>
</tr>
</tbody>
</table>
14.12 Pilot testing for self-report tools

A draft version of the SCQ was piloted twice with 20 academic university staff, to revise and clarify the wording of the questions, and for comment on the structure of the questionnaire. The staff, who responded specifically, did so by email and other than typographical errors, the comments clustered around issues of formatting, consistency of questioning and missing items. As the staff completed the surveys online it was possible to analyse patterns in missing data. Many of the staff who piloted the questionnaire commented that they found the questionnaire ‘interesting’ and ‘thought provoking’, and ‘easy’ and ’quick’ to complete.

All tools with the exception of the SCQ were pilot tested with two palliative care patients. The SCQ was not tested with these patients as ongoing revision of the tool was occurring at this time. The outcomes of pilot testing were used to revise the aspects of the semi-structured interview, including duration. The pilot study with the patient participants identified that fatigue was a limiting factor for interviews and as such the interview guide was revised to ensure that there was limited replication of questions that were answered following completion of the self-report tools in interview. Interview guide questions that asked specific questions about care networks were removed, as these were explored adequately in the SCQ. The participant data from the pilot testing were not included in the data analysis as the patient participants did not meet the criteria for inclusion because they had not identified social and economic hardship needs.

14.13 Implementation of the study

14.13.1 Interview process

The interviews with patients and/or carers were conducted in a private location in a palliative care inpatient facility or in the patient’s home. A preferred location was offered to all participants, with many agreeing to be interviewed in their current location. Two patients preferred different locations with one patient requesting to be interviewed at home and
another did not wish to be interviewed at home, but preferred to be interviewed in a health service facility. Key informants were interviewed individually in their office location.

The interviews began with a further introduction to the research aims and a brief discussion of the topics to be discussed and aims of tools and surveys. Discussion of the aims of the social capital items, in particular, was necessary to ensure that there was an understanding of the rationale for questioning around relationships and networks of support; and to draw focus to social contexts, shifting attention particularly from physical concerns which tend to dominate clinical interviews and discussions. Self-report tools were administered first during interviews with completion of the demographic data sheet followed by the shorter tools and then finally the SCQ. The interview guide was referred to by me as the interviewer, following completion of the self-report tools to ensure that the range of questions had been covered in the interviews.

14.13.2 Additional data

Field notes are important additional data as they describe the experiences and observations, perceptions and interpretations that the researcher makes while engaging with participants (Liamputtong 2009 pg 158). The researcher’s reflective account which is recorded in field notes places the interview into a larger context, providing additional information for speculation of themes and connections and records relevant items which may be evident before entering and after leaving the field (Minichiello et al. 1995). The bulk of field notes for the study were written within 24 hours of the interview taking place and identified reflective and descriptive reflections and observations from interviews. Some brief field notes were made during interviews and were often comments on survey and questionnaire items. The field notes were valuable to the analysis as they documented initial ideas about themes and concepts, details about the environment, non-verbal language and engagement between patient, carers and key informants. In addition to field notes, a ‘contact summary sheet’ was included for each interview. These notes served essentially as extended memos which suggested new or revised codes, included prompts if necessary for future contacts and supported a basis for data analysis (Miles & Huberman 1984).

14.14 Ethical considerations

Conduct of this study was approved by the Western Sydney Local Health District, Human Research Ethics Committee (Appendix 10 & 11) and University of Technology Sydney, Human Research Ethics Committee (see Appendix 12). Written consent was obtained from all participants and it was reiterated that participation was voluntary. Participants were
reminded they could decline to participate or withdraw from the study at any time, without concern about ongoing or future end of life care.

14.14.1 Vulnerable populations

Researching vulnerable populations highlight several ethical issues for consideration. Liamputtong (2009 pg. 227) describes the vulnerable as invisible populations, by the nature of their marginality and their lack of voice and stigma attached to their social condition. Persons from lower socioeconomic groups who are terminally ill are doubly vulnerable; firstly, by the nature of the potential stigma associated with their socioeconomic status and secondly, as a result of their serious illness and incapacity. NHMRC Ethical Guidelines for research outline merit and integrity aims of research which emphasise that the respect for the participant is not compromised by research aims, that there is no unfair burden to participants and that the study is designed to manage risk or harm to participants (NHMRC, 2007). Management of risks for this study population was addressed in several ways:

- Recruitment literature and participant information sheets avoided using the term lower socioeconomic and described social and financial hardships as criteria for inclusion.
- Patients who were too unwell, had significant symptom burden or were deteriorating were not recruited to the study.
- The administration of self-report tools in interviews reduced the time burden for participants.
- The use of the REALM-R health literacy assessment tool presented potential concerns for stigmatising persons with limited literacy/health literacy. Specific processes were implemented to manage some potential outcomes of stigmatisation. Participants were informed of the inclusion of this tool in the study and that the application of the tool was to assess recognition (familiarity) with some common medical terms; health communication knowledge which was important to ensure that medical personnel and documentation communicated information that was understood by the general population. Participants were informed that the tool required reading a short list of items and were asked prior to commencement of the interview if they were happy to do this. If participants declined, the tool was to be withdrawn from the interview.

Research methods such as in-depth interviewing are appropriate as they allow for marginalised groups to have a voice and demonstrate capacity, including the very ill who may otherwise not be able to participate in research (Liamputtong 2009). Trust and rapport building are necessary in conducting research with vulnerable groups and will also contribute to the rigour of the study. The researcher in the study had experience working within this community as a nurse for over ten years and had observed many of the challenges experienced by this group. Possessing some understanding of these profound challenges,
highlighted further, the responsibility the researcher had to safeguard the dignity and rights of this vulnerable group.

14.14.2 Confidentiality and informed consent

Confidentiality and informed consent are particular ethical issues that require greater consideration when researching vulnerable groups, as the unequal power relationship is heightened in the marginalised. Rendering these groups more vulnerable by compromising confidentiality is a great concern. Consciousness around gaining consent that is invalid because it was coerced or not understood, is particularly pertinent for marginalised groups (Liamputtong 2009).

Prior to commencement of the interviews, patients and/or carer participants were given a participant consent and information sheet (PCIS) (See Appendix 13) and asked if they wished to read this themselves or have it read to them; to ensure that literacy issues were not exposed. The PCIS stated the aim of the study, general content area to be discussed in the interview and content areas covered by the surveys and questionnaires. The sheet also discussed the length of the interview, risks for the participant, measures for anonymity and confidentiality of their identity and their data, and use of the data for academic and research purposes. Participants were asked to sign the consent form at the back of the PCIS to acknowledge awareness of the information contained in the information sheet. Permission to audio-record interviews was explicitly asked of all participants prior to data collection.

Prior to commencement of interviews key informants were given a PCIS (Appendix 14). The PCIS stated the aim of the study, general content area to be discussed in the interview. The sheet also discussed the length of the interview, risks for the participant, measures for anonymity and confidentiality of their identity and their data, and use of the data for academic and research purposes. Participants were asked to sign the consent form at the back of the PCIS to acknowledge awareness of the information contained in the information sheet. Permission to audio-record interviews was explicitly asked of all participants prior to data collection.

14.14.3 Data management, storage and retention

Management of data is an important aspect of maintaining ethical research outcomes through ensuring confidentiality of the participants. Interviews were audio recorded and transcribed for later analysis. Interviews were transcribed by a transcriptionist and the data were destroyed following this process. Where names were mentioned in interviews this data were de-identified by the researcher following transcription. The interview and administrative data
were only accessible to the researcher and her supervisors. Paper and digital forms of data were retained for a period of five years and hard copy data was secured in a locked cabinet in the University of Technology, Sydney Campus; in keeping with the University of Technology Sydney Human Research Ethic Committee guidelines and Australian National Ethics guidelines (NHMRC 2007).

14.14.4 Positioning of the researcher

The researcher is considered as an instrument for data collection and therefore has great potential to influence this data (Pezalla, Pettigrew & Miller-Day 2012). Bott (2010) discusses the importance of reflexivity for managing the researcher’s position in the research and the risks for lack of reflexivity and proposes that qualitative researchers are to:

....remain in ‘flexible’ dialogue with their research subjects and contexts, in order to preserve a sense of the researcher’s own subjectivity within the process – and therefore avoid the tendency to become ‘absent’ from or ‘above’ our research contexts – and also towards the nurturing of relationships of mutual exchange (of information, secrets, disclosures and ‘truths’). (Bott 2010)

Understanding the positioning of the researcher within the interview is therefore of utmost importance and requires awareness of this stance, the influence and power that they bring to bear upon the interview, and how the other (the participant) is represented by them (Bott 2010). Interviewing people about sensitive topics, or vulnerable groups as is also the case in this study, is best suited to interview methods and therefore requires adherence to nurturing the research exchange (Elmir et al. 2011).

The NHMRC Ethical Guidelines (section 4.3) documents management of research for people in dependent unequal relationships and health care professionals and patients constitute such a relationship (NHMRC 2007). As a clinical nurse consultant (CNC) employed mainly in the inpatient setting for the study, there was a greater need for an awareness of researcher positioning. The CNC role in the Palliative care unit was mainly a community nurse liaison role and acute care consultancy, which meant that there was limited contact with inpatients or community palliative care patients on a daily basis. Although being in the CNC role had advantages in the development of rapport with the participants, as I was not seen as an outsider, the likely influence of the position on patients and carers decision to participate was understood. To ensure this influence was limited, several steps were taken and this was essentially important when approaching potential participants in the inpatient facility. Firstly, during first contact with inpatient participants, I introduced myself as a PhD student, outlined
the study and discussed my part-time role as a CNC within the facility to ensure honesty and transparency. Highlighting that these roles were distinct and again reiterating that consent to the study was purely voluntary was made very clear to potential participants. Secondly, patient interviews were scheduled to take place in the inpatient facility on my non-work days only. I wore casual clothing and refrained from wearing my identification badge or any other items that might identify a position of influence. Where possible, interviews in the palliative care facility took place outside in the garden in an area away from staff and other patients, to ensure privacy. This was done also to avoid a bedside interview which could reflect the dependent (and submissive) relationship of the patient to the researcher. As a white middle class woman, who had not experienced socioeconomic hardship, I needed to be aware of my specific values and biases that I would bring to the research field.

14.15 Research analysis

14.15.1 Qualitative analysis

The interviews were transcribed externally from the audio recordings to assist analysis. Transcripts were checked for accuracy by reading them simultaneously as interview recordings were played and listened to carefully for words that were not recorded on the transcript due to unintelligibility, background noise or quite/mumbled voice. Inflection in voice, mumbles, sighs, grunts and pauses were recorded at this time also, if they had been omitted from transcription.

Qualitative data sets can be analysed by manual coding procedures or computer program analysis. The use of manual transcript analysis was considered to be appropriate for this study due to the small data set. The quality of analysis outcomes for these two methods are similar, however manual analysis allows the researcher to become more familiar with the data. The framework approach to qualitative data analysis, developed by Jane Richie and Liz Spencer, is similar to thematic analysis yet it particularly enables the researcher to manage the qualitative data and undertake analysis in a systematic way (Smith & Firth 2011). The framework approach was particularly useful in this study of diverse groups (patients and carers, and formal carers) as it was appropriate in analysis of cross-sectional descriptive data. It also ensured that there was transparency of the researchers’ interpretation of participants experience and explicitly described the process through interconnected stages (Smith & Firth 2011). The strength of the framework approach is that it is systematic and disciplined, but allows for ‘both a jumping ahead and returning to rework earlier ideas’, which is where actual
analytical thinking occurs (Richie & Spencer 2002). Smith and Firth (2011) incorporate Richie and Spencers five key stages under three headings:

- **Data Management**: familiarisation with the data through reading and re-reading; identifying themes/categories; developing a coding matrix; and assigning data to these themes and categories in the matrix.

- **Descriptive accounts**: summarising and synthesising the data by refining initial themes/categories; identifying associations between themes for a ‘whole picture’; developing more abstract concepts.

- **Explanatory accounts**: developing associations/patterns within concepts and themes; reflection of the original data and analysis to confirm accurate representation of participant accounts; finding meaning and interpreting concepts and themes with wider application of concepts and themes.

The application of these stages for qualitative analysis in this study, are discussed here. Familiarisation with the data was achieved through reading and re-reading the transcripts. Reading familiarisation was concentrated at the beginning of the analysis but occurred throughout all the analysis stages where required. Comments for initial themes were recorded in the margins of the transcripts and a coding matrix was developed from selected data which represented a range of experiences for participants. Where aspects of the qualitative interviews explored the interview process, for appropriateness, acceptability and feasibility of self-reported tools, notes were made on these areas. Transcript excerpts were recorded in the first column of the matrix, with description (in-vivo codes) forming potential categories (Smith & Firth 2011). These categories were refined to preliminary thoughts of their meaning and from this, initial categories were developed and grouped. Coding matrices were reviewed by two experienced researchers to clarify codes and categories. Changes to the matrices by myself and expert reviewers (two experienced academics) were recorded in the margins for reference and transparency. An example of the coding matrix is seen in **Figure 14.4**

<table>
<thead>
<tr>
<th>Interview transcript</th>
<th>Description (in-vivo codes)</th>
<th>Preliminary thoughts (what is this about)</th>
<th>Initial categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>“You know your child is being sick whether they are poorly or not”</td>
<td>‘Know ...your child’</td>
<td>Knowing something is wrong.</td>
<td>Recognising when the child is ill.</td>
</tr>
</tbody>
</table>

**Figure 14.4 Example of coding matrix from Smith and Firth (2011)**
Initial themes, which were grouped from the coding matrices, were then formed into initial categories and were recorded in the ‘coding index’ which became an essential means of managing the whole data set (Smith & Firth 2011). The coding index was a dynamic document which was developed throughout analysis as new understandings emerged from the analysis.

Descriptive accounts of the data were developed through sifting and sorting of the data. Charts were devised with thematic headings from the coding index and were derived for each participant across all categories. This ordering and sorting enabled comparison of participants across themes and categories. Formal carers were recorded on separate charts to patients and carers to enable analysis of this distinct data. An example of a thematic chart is outlined in Figure 14.5.

Finally once data had been shifted and sorted there was development of explanatory accounts of the data which required that analysis returned to the original data of the participant accounts (transcripts) to ensure that these accounts were accurately represented in themes. Smith and Firth (2011) suggested asking ‘What are participants really trying to describe?’ when undertaking explanatory analysis. This technique was used to re-establish the relationship between ideas and participants accounts. Core themes were then developed and further refined for wider application.

Interpretive rigour in qualitative research is associated with attempts to achieve the broadest expression of the data (Kitto, Chesters & Grbich 2008). ‘Peer or expert’ checking of the data is a form of researcher triangulation to enhance rigour. Expert checking took place following initial analysis of the transcripts whereby two research experts and I analytically reviewed field notes and transcripts for emerging themes and clarification of current perspectives from the coding matrix (discussed above). Member checking which seeks clarification of the data from research participants, is another technique used to achieve rigour in qualitative research, but it was not used in this study as participants were either too ill or were deceased when transcripts
were available. It was also not considered appropriate for carers to review transcripts during this period of bereavement or care giving. Clarification of comments and statements by participants during interviews was achieved.

14.15.2 Reporting of Qualitative data

Qualitative data was reported in this study in a variety of ways to ensure that accuracy and representation of the data was reflected in the thesis manuscript. Reporting of data in ‘quotations’ was used in the manuscript to reflect participants’ own words. Where the authors own words were included, they were indicated by [square] brackets to ensure that they were differentiated from participant quotations. The use of (...) ellipses when reporting the data indicated that words from the interview transcripts had been omitted for inclusion whereby they did not contribute to the discussion and did not alter the analysis of that interview excerpt.

14.15.3 Evaluation of self-report tools

To understand the suitability of patient reported tools for this study and the study population, practical and relevant application of these tools was assessed for criteria of appropriateness, acceptability and feasibility; identified in semi-structured interview outcomes. The criteria for appropriateness, acceptability and feasibility are as follows:

**Appropriateness** captures the aims of application of the tool(s) and whether the content of the tool appropriately questions these areas; fits the purpose of the research, is relevant to the problem being investigated (Fitzpatrick et al. 1998).

**Acceptability** captures the extent to which the tool is acceptable to participants for completion time, completion burden, use of language or any other descriptions of unacceptability described by the participant; with the desire to minimise avoidable distress for participants (Fitzpatrick et al. 1998; Haywood, Staniszeska & Chapman 2012).

**Feasibility** is a criteria linked with acceptability which captures the ease of administration of an instrument and processing for the staff or researchers (Fitzpatrick et al. 1998).

14.15.4 Quantitative analysis

14.15.4.1 Self-report tools and demographic data

Data collected from the socioeconomic demographic data sheet, REALM-R, NAT:PD-C, consumption survey, SCQ, PWI were analysed using the Statistical Package for the Social Sciences (SPSS) version 15.0 with descriptive statistics for mean, standard deviation and range.
The intentionally small sample size precluded use of inferential statistics for these outcomes as this was not an objective of this study. Instead, my intention was to capture specific outcomes for these measures in this participant population to quantify the qualitative responses and to explore the appropriateness, acceptability and feasibility of tool use in this population.

14.15.4.2 Afterhours crisis service data and place of death data

Bivariate analysis was undertaken with after-hours crisis service data and place of death data to determine the contribution of factors such as place of residence to palliative care service utilisation and place of death. Data was entered into the SPSS version 15.0 for both data sets. Data cleaning occurred once all of the data had been entered and involved a check for outliers using frequency distribution and a second check for consistency of the data for terms and labels.

Missing values for the place of death data were maintained in the data set and the SPSS program recorded these missing values in each variable, to enable their exclusion where necessary for single analysis. All missing values for after-hours service utilisation were retrieved from health administration data bases and entered.

14.16 Integrating qualitative and quantitative data

Integration of the qualitative and quantitative data occurred within this study at several levels. Firstly, within the design of the study, the research objectives aimed for areas of inquiry which were for outcomes (quantitative) and processes (qualitative) of end of life care for a lower socioeconomic group. Secondly, integration was achieved through the essentially mixed qualitative and qualitative methods through the use of self-report tools, surveys and questionnaires within interviews. According to Teddie and Tashekori (2009) where there is a single source that gives rise to both qualitative and quantitative data, it is intrinsically mixed and therefore integrated. Finally it is in the writing up of outcomes of mixed method research where connections between the methods (integration) can be achieved (Bryman 2007). The discussions of the qualitative and quantitative findings of this study within the study’s conceptual framework draw together the quantitative and qualitative results for integration within this overarching structure. The integration of the methods in this study is therefore managed in the design, data collection and discussion of outcomes.

14.17 Conclusion

A concurrent embedded mixed method design with a qualitative emphasis was used in this doctoral study so that complexities of the experience and outcomes of end of life care for a
lower socio economic group might be described. The explicit use of Social Determinants of Health (SDH) and social capital concepts guided the design of the study for quantitative (administrative) place of death and service utilisation data collection, self-reported tool selection and interview guide. The quantitative results from the administrative data outcomes (place of death and service utilisation) are presented in the next chapter.
14.18 References


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CHAPTER 5

Results

Place of death and after-hours crisis service utilisation outcomes

15.1 Introduction

This chapter presents the results of place of death and after-hours crisis call utilisation data. These data were collected and analysed to specifically address research objective one:

1. Provide a snapshot of the impact of socio-economic status on place of death and after-hours crisis service utilisation, by comparing outcomes between a most disadvantaged and least disadvantage area.

As outlined in earlier chapters, the increased illness burden for the socioeconomically disadvantaged and reduced life expectancy means that, they are more likely to require management of advanced illness (Schwartz et al. 2003) and complex socioeconomic needs at the end of life (Dzul-Church et al. 2010; Kramer & Yonker 2011).

Socioeconomically deprived groups demonstrate a higher uptake of acute care service utilisation (Gallo, Baker & Bradley 2001; Hanratty et al. 2008; Kessler et al. 2005; Walshe et al. 2009). Lower usage of palliative care services by lower socioeconomic groups (Currow, Abernethy & Fazekas 2004; Currow et al. 2008). A recent study by Currow and colleagues emphasises the need for a greater understanding of specialist palliative care service utilization by these groups is required (Currow et al. 2012).

A report by the Cancer Institute NSW (2007) reviewed NSW Central Cancer Registry data on place of death for all NSW residents dying of cancer during the period 1972 to 2003. The report concluded that

“Although a home death is most often the preference of the sufferer, nearly two-thirds of cancer patients die in public hospitals. Fewer than 20% die at home, a statistic that falls well below some of the other states, most notably Queensland and Western Australia” (Tracey et al. 2009)

This report identified that the place of residence was the strongest predictor of place of death. After controlling for location of health services, socio-economic status, age at death and site of cancer, the next most important predictor of place of death was Index of Relative
Socioeconomic Disadvantage (IRSD) of the postal area of residence (Schuurman, Crooks & Amram 2010).

A study in the Western Sydney area by Lewis et al (Lewis et al. 2013), analysed palliative care use for Socioeconomic Indexes for Areas (SEIFA). Index for Relative Socioeconomic Disadvantage (IRSD) classifications were categorised and postcode comparisons were made between decile 1 (IRSD score on or below 900) for most disadvantage and decile 10 (IRSD score on or above 1,100) for least disadvantage: During the 12 month period, January 1st to December 31st 2006, there were 318 admissions to a specialist palliative care facility located in the most disadvantaged area, of which 21% were from the most disadvantaged postcode (n=68) and 15% were from the least disadvantaged postcode (n=50).

As discussed above, receipt of palliative care services is highly contextual and driven by a number of patient, provider and health system factors. It is often considered that access to specialist palliative care services, is a ‘postcode lottery’, and access to services is based upon where individuals live. Given the proximity of palliative care service to two socioeconomically disparate areas (Mt Druitt and Hills), the aim of reporting outcomes for place of death data and after-hours crisis service utilisation data was to provide a snapshot of the Mt Druitt population within the study setting with outcomes of service utilisation during the period of the study. A comparison of data for Mt Druitt and Hills areas, it is hypothesised, will demonstrate different outcomes for home death and after-hours crisis service utilisation.

15.2 Method

A detailed description of the method for collection and analysis of this data is described in Chapter Four. Briefly, data for place of death and after-hours crisis service utilisation outcomes were collected from a single palliative care service in Western Sydney Local Health district.

Place of death data were collected and analysed for the period January 2008 to December 2011 from a central database of the Palliative Care Network Western Sydney Local Health District (WSLHD). Data analysis items included community centre (postcode), diagnosis, and sex of patient, place of death and year of death. The two areas’ data were analysed to identify differences in place of death and impact of sex and diagnosis on outcomes.

Administrative data for after-hours crisis call episodes were collected from a central service located at the Mt Druitt palliative care unit. The after-hours crisis service was located in this facility and collected hard copy information on crisis after-hours service calls. The after-hours
crisis service data were collected and analysed for a 12 month period (1 March 2011 to 29 February 2012).

The items recorded from these call data sheets included community centre, caller details, patient and carer details, diagnosis, call details (purpose of call, assistance requested) and call outcome(s). Outcomes for calls to the service included phone assessment, management and/or home visit attendance; admission to a palliative care unit in Western Sydney LHD; or admission to an emergency department for assessment and management of an acute or unexpected event. Data were analysed to identify whether there were differences in outcomes for call demands, call outcomes and carer details between the areas.

15.3 Setting

The setting for this analysis was a palliative care service in Western Sydney and the central inpatient service located in the Mt Druitt area. The Mt Druitt palliative care service supports a number of local government and local precinct areas, of which Mt Druitt and Hills areas are two, that represent areas of highest and lowest scores for socioeconomic disadvantage, respectively.

15.4 Results

15.4.1 Place of death data

A total of 792 deaths occurred for Mt Druitt and Hills area patients registered with the Palliative Care service, Western Sydney Local Health District between January 2008 and December 2011. Outcomes for place of death rates are displayed in Table 15.1. Documentation of place of death was obtainable in 471 (95%) of cases registered with a Hills postcode area and 293 (99%) of Mt Druitt cases. Various forms of follow-up were undertaken to locate missing data including searching of community health records and administrative data sets in the Local Health District (LHD). As there was no record of hospitalisation, it can be assumed that individuals either died at home or were admitted to another Local Health District. Missing cases were excluded from the analysis leaving 764 cases for analysis.
Table 15.1 Place of death rates for Hills and Mt Druitt area service registrations

<table>
<thead>
<tr>
<th></th>
<th>Hills (n=471)</th>
<th></th>
<th>Mt Druitt (n=293)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>%</td>
<td>Frequency</td>
<td>%</td>
</tr>
<tr>
<td>Home</td>
<td>130</td>
<td>28</td>
<td>42</td>
<td>14</td>
</tr>
<tr>
<td>Palliative care unit (Mt Druitt)</td>
<td>97</td>
<td>21</td>
<td>187</td>
<td>64</td>
</tr>
<tr>
<td>Palliative care unit (other)</td>
<td>148</td>
<td>31</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Acute care public</td>
<td>19</td>
<td>4</td>
<td>38</td>
<td>13</td>
</tr>
<tr>
<td>Private hospital</td>
<td>44</td>
<td>9</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Oncology</td>
<td>20</td>
<td>4</td>
<td>14</td>
<td>5</td>
</tr>
<tr>
<td>Residential aged care facility</td>
<td>13</td>
<td>3</td>
<td>5</td>
<td>2</td>
</tr>
</tbody>
</table>

Data were re-coded into home death or no home death. Of the total sample, 22% (n=172) died at home. A total of 130 patients registered with the service from the Hills area (130/172; 76%) died at home, compared with 42 patients who resided in the Mt Druitt area (42/172; 24%) who died at home.

Chi square analysis revealed a statistically significant difference ($p<0.0001$) between those having a home death in the Hills area (130/471, 28%) compared with Mt Druitt area (42/293, 14%). Within a logistic regression model place of death remained statistically significant ($p<0.001$). Participants living in the Hills district had an Odds Ratio of 2.16 (CI 1.48-3.17) times more likely to die at home than those living in Mt Druitt. As shown in Table 15.1, those patients registered for the palliative care service from the Mt Druitt area were more than three times as likely to die in an acute care facility compared to those registered with the service from a Hills postcode (4% vs 13%), although this was not statistically significant.

Palliative care facility death for Mt Druitt patients registered with the service almost exclusively represented deaths in the Mt Druitt inpatient facility with only 2% (n=7) of patients dying in another inpatient facility. Death in other inpatient facilities for Hills area patients registered with the service represented the highest place of death rate for this group, with 31% (n=148) of deaths reported in other inpatient palliative care facilities.
Private facility death represented 9% (n=44) of all deaths for patients registered with the service from the Hills area during this period and Mt Druitt patients had no recorded deaths in private facilities during the same period.

<table>
<thead>
<tr>
<th>Table 15.2 Place of death rates for Hills and Mt Druitt area service registrations for sex</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hills (n=425)</strong></td>
</tr>
<tr>
<td>Male (%)</td>
</tr>
<tr>
<td>----------</td>
</tr>
<tr>
<td>Home</td>
</tr>
<tr>
<td>Palliative care unit</td>
</tr>
</tbody>
</table>

As shown in Table 15.2 male home deaths in the Hills area (83/130, 64%) were higher than female home deaths (47/130, 36%). Male home deaths in the Mt Druitt area (20/42, 48%) were less than female home deaths in the area (22/42, 52%). Similar numbers of male and female patients (56% vs 44%) registered from the Hills area died in a palliative care facility. Larger numbers of males from the Mt Druitt area died in a palliative care facility than female patients (75% vs 25%).

15.4.1.1 Place of death rates: non-malignant diagnosis

The majority of patients from Mt Druitt and Hills areas registered with the palliative care service had a malignant diagnosis (93%; n=712). A total of 52 (7%) patients registered with the service from Mt Druitt and Hills areas had a non-malignant diagnosis. A slightly higher percentage, 8% (n=24) of those patients with non-malignant disease were from the Mt Druitt area compared with 6% (n=28) of patients from the Hills area. As shown in Table 15.3, patients with a non-malignant diagnosis registered with palliative care from the Mt Druitt area were less likely to die at home (n=7, 29%) than they were in an acute care facility or palliative care unit (n=17, 71%). Patients registered with the service from the Hills area with a non-malignant diagnosis were more likely to die at home (n=17, 61%) than an acute care facility or palliative care unit (n=10, 32%). Private facility death for Hills area patients registered with the service represented 7% (n=2) of patients. Patients from the Mt Druitt area registered with the service with non-malignant diagnoses recorded no deaths in private facilities during this period.
### Table 15.3 Place of death for patients with non-malignant illness: Hills and Mt Druitt area registrations

<table>
<thead>
<tr>
<th></th>
<th>Hills (n=28)</th>
<th></th>
<th>Mt Druitt (n=24)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>%</td>
<td>Frequency</td>
<td>%</td>
</tr>
<tr>
<td>Home</td>
<td>17</td>
<td>61</td>
<td>7</td>
<td>29</td>
</tr>
<tr>
<td>Palliative care</td>
<td>6</td>
<td>21</td>
<td>8</td>
<td>33</td>
</tr>
<tr>
<td>Acute care</td>
<td>3</td>
<td>11</td>
<td>9</td>
<td>38</td>
</tr>
<tr>
<td>Private hospital</td>
<td>2</td>
<td>7</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

#### 15.5 After-hours crisis service utilisation outcomes

The after-hours crisis call data collected for the period totalled 1017 call episodes for all patients registered with the palliative care service in the Cancer Network, WSLHD. Hills and Mt Druitt area registrations totalled 366 call episodes or occasions of service for 170 patients during this period.

The Hills area averaged 141 patient registrations over this 12 month period and these patients recorded 206 calls to the service (average of 1.46 calls for each patient registered with the service). Mt Druitt area averaged 109 patient registrations that made a total of 160 phone calls to the service during this period (average of 1.47 calls for each patient registered with the service).

The sex of the caller to the service was recorded only for family and friendship callers (exclusive of patient callers and health professional callers). The majority of callers to the after-hours service were women. Male callers to the service for patients from the Hills area represented 29% (n=48) of calls and for female callers 71% (n=119) of calls. Male callers to the service from the Mt Druitt area were slightly less for male callers than Hills area and represented 20 % (n=28) of calls and for female callers these were higher comparatively than the Hills area representing 80% (n=106) of calls to the service.

#### 15.5.1 After-hours crisis service utilisation outcomes: relationship of caller to service

As seen in Table 15.4 persons calling the after-hours crisis service for Hills area patients were most likely to be a spouse/partner (n=78, 37.9%) and subsequently a child (n=63, 30.6%). Callers to the service for Mt Druitt area patients were most likely a child (n=52, 32.5%) and then a spouse/partner (n=49, 30.6%). Hills area patients were more likely than Mt Druitt area patients to have a call to the service from a health care professional (5.3% vs 0.6%) and
grandchild (4.9% vs 0.6%). Mt Druitt patients were more likely than Hills patients to have a call to the service from a parent (8.8% vs 2.9%) and other relative (8.8% vs 1%).

### Table 15.4 After-hours service utilisation relationship of caller to the service

<table>
<thead>
<tr>
<th></th>
<th>Hills calls (n=206)</th>
<th>Mt Druitt calls (n=160)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>%</td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>78</td>
<td>37.9</td>
</tr>
<tr>
<td>Child</td>
<td>63</td>
<td>30.6</td>
</tr>
<tr>
<td>Patient</td>
<td>29</td>
<td>14.1</td>
</tr>
<tr>
<td>Grandchild</td>
<td>10</td>
<td>4.9</td>
</tr>
<tr>
<td>Friend</td>
<td>7</td>
<td>3.4</td>
</tr>
<tr>
<td>Parent</td>
<td>6</td>
<td>2.9</td>
</tr>
<tr>
<td>Other relative</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Health care professional</td>
<td>11</td>
<td>5.3</td>
</tr>
</tbody>
</table>

#### 15.5.2 After-hours service utilisation outcomes: reason for service call

As seen in Table 15.5, calls for patients from the Mt Druitt area were more likely for ‘Medical and/or nursing intervention or treatment’ than Hills postcodes (70% vs 62%). Calls for patients from the Hills area were more likely for ‘technical support’ (equipment or patient device issues) than Mt Druitt (29% vs 20%). Calls to the service for phone call support were similar for Hills and Mt Druitt areas (9% vs 10%).

### Table 15.5 After-hours service utilisation reason for service call: Hills and Mt Druitt areas

<table>
<thead>
<tr>
<th></th>
<th>Hills calls (n=206)</th>
<th>Mt Druitt calls (N=160)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>%</td>
</tr>
<tr>
<td>Medical and/or nursing intervention for treatment</td>
<td>128</td>
<td>62</td>
</tr>
<tr>
<td>Support phone call for patient and/or carer</td>
<td>19</td>
<td>9</td>
</tr>
<tr>
<td>Technical support</td>
<td>59</td>
<td>29</td>
</tr>
</tbody>
</table>

#### 15.5.3 After-hours service utilisation outcomes: service provision and admission outcomes

As seen in Table 15.6, service provision and admission outcomes for calls for Hills and Mt Druitt area patients were similar for emergency department admission, with Mt Druitt area
patients having a slightly higher rate of referral to an emergency department than Hills area patients (8.8 % vs 7.8%). Mt Druitt area patients were more likely than Hills area patients to require a home visit following a call to the service (21.9% vs 17.5%). Mt Druitt area patients were twice as likely to be admitted to a palliative care unit following a call to the service than a Hills patient (15.6 % vs 7.8%) and Chi square analysis revealed that this was statistically significant (p<0.0001).

<table>
<thead>
<tr>
<th>Table 15.6 After hours service provision and admission outcome from call; Hills and Mt Druitt area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hills calls (n=206)</td>
</tr>
<tr>
<td>---------------------</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Home visit attended</td>
</tr>
<tr>
<td>Admission to palliative care unit Western Sydney</td>
</tr>
<tr>
<td>Admission to Emergency department for acute intervention</td>
</tr>
</tbody>
</table>

15.6 Strengths and limitations

It is important to consider the limitations of these data. The sampling frame minimises extrapolation of these data to other settings. Moreover, the administrative data set and level of ethical approval did not allow access to more in-depth characteristics that may have explained differences. As a consequence, this analysis did not include in depth clinical, social and psychological characteristics that may have explained variations in outcomes.

The limited sample size and number of variables available for reporting from the administrative data meant that inferential analysis was not possible. Recent findings of Currow et al (2012), that showed contradictory findings underscore the complexity of investigating social determinants of health and likely, the highly contextual nature for factors contributing to equitable access. In spite of these limitations, the study setting has provided a unique case study to explore socioeconomic differences and provided an important contribution to understanding differences in usage based on social determinants of health.

15.7 Conclusion

The results of the analysis of this data describe variations in palliative care outcomes across two disparate socioeconomic groups for place of death, care needs and crisis care networks. Patients registered with the palliative care service from the most disadvantage area (Mt Druitt)
were statistically less likely than those from the least disadvantaged area (Hills) to have a home death. Male patients in the Hills area were more likely to have a home death than female patients and had similar outcomes for a palliative care inpatient death compared with female patients. Male patients form the Mt Druitt area were slightly less likely to have a home death than female patients but were much more likely to have an inpatient palliative care death than a female patient.

Patients from Mt Druitt and Hills areas had similar utilisation for the after-hours crisis service, yet Mt Druitt patients were more likely to have a home visit following a call to this service and were statistically more likely than a patient form the Hills area to be admitted to a palliative care unit following a call to this service. Hills area patients demonstrated crisis care support from mainly spouse and Mt Druitt from predominantly children. Hills area patients were more likely to have crisis support from a healthcare professional than a Mt Druitt patient; and Mt Druitt patients were more likely to have crisis support from a parent than a Hills area patient.

15.8 Chapter Summary

This chapter reported the results from analysis of administrative data comparing place of death and after-hours crisis call utilisation for a most disadvantaged and a least disadvantage area. The outcomes for place of death find that patients from the Hills area (least disadvantaged area) are statistically more likely than patients from the Mt Druitt area (most disadvantaged area), to have a home death and were also more likely than Hills area patients to die in an acute care facility. Limited registrations to the service for patients with non-malignant disease was also identified from the data and the likelihood of a home death for Mt Druitt area patients with non-malignant disease was less when compared with Hills area patients. The implications of these data will be further discussed in Chapter 8. The following Chapter reports the results for patient and carer demographics, key informant characteristics, self-report tool outcomes for patients and carers and qualitative analysis of semi-structured interviews with patients, carers and key informants.
15.9 References


Lewis, J., DiGiacomo, M., Newton, P., Currow, D. & Davidson, P. 2013, 'Socioeconomic Status as a Marker of Specialist Palliative Care Service Access', BMC Health Services Research (submitted 15 Jan 2013).


Chapter 6

Results

Demographics, self-report tools and qualitative findings

16.1 Results

This chapter reports the findings of the study. Collection of this data specifically addresses research objective two:

2. Explore and describe the socioeconomic demographics and experience of patients and/or carers from this most disadvantaged area for end of life care evidenced by the social, economic and care needs and capacities at individual, community and governance levels; the nature and impact of social capital outcomes and the experience of access and acceptability for specialist palliative care services.

16.2 Participant characteristics

16.2.1 Socioeconomic characteristics: patients and carers

Overall, 16 patients and six carers participated in this study. Two patients declined to be interviewed, but provided socioeconomic demographic information and completed study instruments. Five additional patients and/or carers were approached for interviews and initially agreed to participate but withdrew or were withdrawn from the study. Two withdrew due to significant decline in health; one failed to be at home for interview on multiple occasions despite scheduling appointments; two couples were excluded by the researcher due to safety concerns and one couple withdrew because they did not wish to discuss financial circumstances.

The socioeconomic demographic information for the 16 patients and six carers are displayed in Table 16.1. These data provide a description of social determinants of health, in particular for socioeconomic position and material circumstances (see Chapter 3, Figure 13.1).

The social, cultural and health characteristics reported include age, gender, diagnosis, marital status, language and place of birth. The average age of patients was 66.3 (SD 17.9), slightly more patients were male, fewer than half were married, and they mainly had a malignant disease. Carers’ average age was 56.8 (SD 16.2), more carers were female, and all carers were married. Patients and carers spoke English language and were born in Australia or the UK.
Information on education, income, housing status and occupation characteristics of patients for socioeconomic position (education and occupation) and material circumstances (income and housing) were reported. Nearly one third of patients had completed school education for year 8 or below and year 9 equivalent and one third of carers reported completion of school education for year 9 or below, but did not report education for year 8 or below. Home ownership was high for the majority of patients and carers and the remainder of participants were living in government rental accommodation. The majority of patients reported household incomes in the lowest income group. The lowest income group represented those who were receiving a government pension (single or couple rate). The medium highest income group were represented by one patient who was still in paid employment and a patient whose carer was still in paid employment at the time of the assessment.
<table>
<thead>
<tr>
<th>Table 16.1 Patient and carer socioeconomic and demographic characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mean (SD)</strong></td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td><strong>Age</strong></td>
</tr>
<tr>
<td>&lt; 31</td>
</tr>
<tr>
<td>31-40</td>
</tr>
<tr>
<td>41-50</td>
</tr>
<tr>
<td>51-60</td>
</tr>
<tr>
<td>61-70</td>
</tr>
<tr>
<td>71-80</td>
</tr>
<tr>
<td>81-90</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
</tr>
<tr>
<td>Malignant</td>
</tr>
<tr>
<td>Non-malignant</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
</tr>
<tr>
<td>Married/partner</td>
</tr>
<tr>
<td>Widowed</td>
</tr>
<tr>
<td>Single</td>
</tr>
<tr>
<td><strong>Language</strong></td>
</tr>
<tr>
<td>English</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td><strong>Place of birth</strong></td>
</tr>
<tr>
<td>Australia</td>
</tr>
<tr>
<td>UK</td>
</tr>
<tr>
<td>Europe</td>
</tr>
<tr>
<td><strong>Education</strong></td>
</tr>
<tr>
<td>Year 8 or below</td>
</tr>
<tr>
<td>Year 9 or equivalent</td>
</tr>
<tr>
<td>Year 10 or equivalent</td>
</tr>
<tr>
<td>Year 12 or equivalent</td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
</tr>
<tr>
<td>Manual labourer</td>
</tr>
<tr>
<td>Secretarial</td>
</tr>
<tr>
<td>Trade/semiskilled</td>
</tr>
<tr>
<td>Business owner</td>
</tr>
<tr>
<td>Manager</td>
</tr>
<tr>
<td><strong>Housing status</strong></td>
</tr>
<tr>
<td>Home owner</td>
</tr>
<tr>
<td>Government rental</td>
</tr>
<tr>
<td><strong>Income(household)</strong></td>
</tr>
<tr>
<td>Lowest (0-31K)</td>
</tr>
<tr>
<td>Med Low (32K-59K)</td>
</tr>
<tr>
<td>Med High (60K-107K)</td>
</tr>
<tr>
<td>Highest (107.5+K)</td>
</tr>
</tbody>
</table>

16.2.2 Key informant characteristics

A total of five key informants were recruited for interviews and represented palliative care health care providers working in community settings, acute care settings and inpatient specialist palliative care settings. All key informants worked with palliative care patients and carers from the Mt Druitt precinct. Table 16.2 details the role and experience of key informants.
The outcomes of self-report tool completion for patients and carers are displayed in Table 16.3. Four patients were unable to complete the self-report tools due to incapacity (fatigue, lack of voice) and where these were patient-specific tools, the PWI and NAT:PD-C (Patient Wellbeing Section) were not completed. The REALM-R, consumption survey and SCQ were completed by four carers for patients who were unable, as the outcomes of these tools represented care giving contexts and not specific patient outcomes. Six carers completed the NAT:PD-C (Carer ability and wellbeing sections).

<table>
<thead>
<tr>
<th>Role title</th>
<th>Age</th>
<th>Sex</th>
<th>Years of experience (current role)</th>
<th>Care population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care CNC</td>
<td>53</td>
<td>F</td>
<td>4 years</td>
<td>Palliative care patients/carers-community and aged care facilities (Western Sydney)</td>
</tr>
<tr>
<td>Indigenous nurse Liaison</td>
<td>55</td>
<td>F</td>
<td>2 years</td>
<td>Indigenous patients with chronic and terminal illnesses (Mt Druitt)</td>
</tr>
<tr>
<td>Aged care Liaison nurse</td>
<td>49</td>
<td>F</td>
<td>5 years</td>
<td>Aged care and palliative care patients in public hospital and aged care facilities (Blacktown/Mt Druitt)</td>
</tr>
<tr>
<td>Palliative care CNS</td>
<td>57</td>
<td>F</td>
<td>8 years</td>
<td>Palliative care patients/carers-community (Mt Druitt)</td>
</tr>
<tr>
<td>Palliative care Social Worker</td>
<td>30</td>
<td>F</td>
<td>4 years</td>
<td>Palliative care patients/carers-inpatient and community (Mt Druitt)</td>
</tr>
</tbody>
</table>

### 16.3 Quantitative outcomes for self-report tools

(Psychometric characteristics of the test battery are provided in Chapter Four)
16.3.1 Personal Wellbeing Index (PWI)

The PWI is a short eight item response scale that measures subjective wellbeing. Along an eleven point scale (0-10), lower scores depict lower feeling of wellbeing and higher score reflect higher perceived wellbeing. The PWI was completed by 12 patients. Summary data is presented in Table 16.4. The highest wellbeing scores for this group reflected satisfaction with safety and personal relationships. The lowest wellbeing scores reflected health and feeling part of the community. The outcomes of PWI scores for this group indicate that patients described different feelings of wellbeing across these domains. The very low wellbeing outcome for health lowered the total mean score and would be an important consideration for the use of this tool in a palliative care patient population.

<table>
<thead>
<tr>
<th>Table 16.4 Personal Wellbeing Index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction with:</td>
</tr>
<tr>
<td>Feeling safe</td>
</tr>
<tr>
<td>Personal relationships</td>
</tr>
<tr>
<td>Achieving in life</td>
</tr>
<tr>
<td>Spirituality or religion</td>
</tr>
<tr>
<td>Standard of living</td>
</tr>
<tr>
<td>Future security</td>
</tr>
<tr>
<td>Feeling part of the community</td>
</tr>
<tr>
<td>Health</td>
</tr>
<tr>
<td><strong>Aggregated mean</strong></td>
</tr>
<tr>
<td><strong>Standard deviation</strong></td>
</tr>
</tbody>
</table>

16.3.2 Needs Assessment Tool: Progressive Disease-Cancer (NAT:PD-C)

16.3.2.1 NAT:PD-C (Patient wellbeing)

A total of 12 patients completed the patient wellbeing items (Table 16.5). The majority of participants stated that they had some/potential or significant concern with ‘experiencing unresolved symptoms,’ ‘problems with daily living activities’ and ‘psychological feelings interfering with wellbeing’. Approximately, one third of patients reported some/potential or significant concern regarding ‘financial or legal concerns’ and ‘health beliefs, social and cultural issues making care more complex’. One patient described some or potential concern for ‘spiritual or existential issues’.

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Table 16.5: NAT:PD-C Patient wellbeing

<table>
<thead>
<tr>
<th>Concern</th>
<th>Level of concern</th>
<th>No. of patients (n=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Unresolved physical symptoms</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Some/Potential</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Significant</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td><em>Problems with daily living activities</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Some/Potential</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Significant</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td><em>Psychological feelings interfering</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Some/Potential</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Significant</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><em>Spiritual /existential concerns</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Some/Potential</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Significant</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td><em>Financial or legal concerns</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Some/Potential</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Significant</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td><em>Health beliefs, cultural or social</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Some/Potential</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Significant</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

16.3.2.2 NAT:PD-C (Ability of carer or family to care for the patient)

A total of six carers completed the ‘ability of care or family to care for the patient’ section of the tool. The responses to this question are displayed below in Table 16.6. Carers reported that they were most concerned about distress for the patient’s symptoms and difficulties in providing physical care. Two thirds of the carers indicated some/potential or significant concern for these issues. Half of the carers stated that they had some/potential or significant concerns regarding ‘difficulty coping’, ‘financial or legal concerns’ and ‘problems interfering with their function or interpersonal relationships’.
### Table 16.6 NAT:PD-C Ability of carer or family to care

<table>
<thead>
<tr>
<th>Concern</th>
<th>Level of concern</th>
<th>No. of Carers (n=6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distress with patient physical symptoms</td>
<td>None</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Some/Potential</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Significant</td>
<td>3</td>
</tr>
<tr>
<td>Providing patient physical care</td>
<td>None</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Some/Potential</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Significant</td>
<td>1</td>
</tr>
<tr>
<td>Having difficulty coping</td>
<td>None</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Some/Potential</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Significant</td>
<td>1</td>
</tr>
<tr>
<td>Financial and legal concerns</td>
<td>None</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Some/Potential</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Significant</td>
<td>2</td>
</tr>
<tr>
<td>Problems with functioning or interpersonal relationships</td>
<td>None</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Some/Potential</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Significant</td>
<td>1</td>
</tr>
</tbody>
</table>

### 16.3.2.3 NAT:PD-C (Carer Wellbeing)

A total of six carers completed the carer wellbeing tool. Table 16.7 presents results for caregiver wellbeing for the question ‘Is the caregiver or family experiencing physical, practical, spiritual, existential or psychological problems interfering with their wellbeing or functioning?’ Nearly all of the carers participating in this study reported experiencing problems of this nature.

### Table 16.7 : NAT:PD-C Caregiver wellbeing

<table>
<thead>
<tr>
<th>Concern</th>
<th>Level of concern</th>
<th>No. Of carers (n=6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver experiencing problems interfering with their wellbeing</td>
<td>None</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Some/Potential</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Significant</td>
<td>1</td>
</tr>
</tbody>
</table>
16.3.3 Rapid Assessment Adult Literacy Medicine-Revised (REALM-R)

The REALM-R is a shortened version health literacy screening tool, which assess health literacy by pronunciation of some common medical words and was included in this study to assess health literacy outcomes. A total of twelve patients and four carers completed the REALM-R assessment tool in less than one minute. A quarter (n=4) of respondents demonstrated low health literacy (a score of six or less from a total of eight). All of the scores for low health literacy were patient responses. Three of the four patients with low health literacy outcomes scored six out of a total of eight and one patient scored zero on the assessment, unable to pronounce any of the words on the list.

16.3.4 Consumption Survey

The Consumption survey is an assessment of approximate weekly, monthly, and yearly household expenditure to identify consumption and outline medical spending and other cost burdens for this group. Twelve patients and four carers completed the consumption survey. The outcomes for numbers of participant spending, mean and range for weekly and monthly costs are presented in Table 16.8 below. Yearly costs were converted to monthly costs for reporting.

<table>
<thead>
<tr>
<th>Table 16.8 Weekly and monthly expenditure</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
</tr>
<tr>
<td>-----------------------------</td>
</tr>
<tr>
<td><strong>Weekly costs</strong></td>
</tr>
<tr>
<td>Groceries</td>
</tr>
<tr>
<td>Vehicle-fuel</td>
</tr>
<tr>
<td>Public transport</td>
</tr>
<tr>
<td>Meals eaten out</td>
</tr>
<tr>
<td>Alcohol</td>
</tr>
<tr>
<td>Cigarettes/tobacco</td>
</tr>
<tr>
<td>Entertainment</td>
</tr>
<tr>
<td>Medications</td>
</tr>
<tr>
<td>Gap payment for Doctors</td>
</tr>
</tbody>
</table>
The consumption survey outcomes reported that most participants’ were spending on essential items; groceries, vehicle-fuel, medications, telephone, general insurance and electricity/gas costs. Participants in the study described grocery costs with the exception of two participants who were completely unable to describe an estimate of these costs. All participants, with the exception of two, described electricity costs; one patient had this included in their business costs and another patient had these included in her government rental package, as were her medications.

Just under half of participants described expenditure on meals eaten out/takeaway, cigarettes/tobacco, clothing, car repairs, gap payments for doctors and maintenance on the home. Cigarettes/tobacco was the highest cost expenditure in this group. One carer identified a $200 weekly spending for her family on meals eaten out during the period of admission for her daughter in an inner city hospital.

Low numbers of participants, under one quarter, described expenditure on transport, alcohol, entertainment, medical equipment and consumables, private health insurance, repairs or maintenance on the home, holidays and education costs. Education costs were only described by one carer who had school and university aged children.

The large range of costs described for some items of expenditure (insurance and telephone costs) represented costs incurred by higher income participants (one patient and one carer). These two participants were both working at the time of the assessment and had dependents.
16.3.5 Social capital questionnaire (SCQ)

A total of 16 participants completed the SCQ; patients (n=12) and carers (n=4). The SCQ included items to measure the range of individual, community and state level relations and networks of support which are described in the conceptual framework (see 3.X; 4.7). The 16-item questionnaire provides multiple item responses to 5 questions. The reporting for the five multiple response questions (questions 1-5) are displayed and discussed distinctly. The descriptive statistics for the single item questions (questions 6-16) are collated and discussed under a single heading.

16.3.5.1 SCQ descriptive statistics:

Question 1 ‘In the last 12 months have you received help for any of the following?’

Responses to question 1 have been split into two tables; close relations and networks (bonded) and community/government (bridged/linked) relations of help (support) and engagement.

Question 1 close care relations and networks (Spouse/partner, family, neighbours, and pets/animals)

Table 16.9 displays responses from patient and carer participants for reporting on close relations and networks of support. The far right column reports total scores for support from close relations and networks. Most help for these participants was received from family and this help was identified as ‘help to do things’ and ‘emotional help’. Help from friends was the next highest source reported with the main help item being ‘companionship’. Help from neighbours was mainly reported as ‘help to do things’. Neighbour help responses recorded the highest score for ‘no help’ (n=5). Help from spouse/partner is limited in the sample due to low numbers of participants having a spouse or partner. Carer only completion of the tool (n=4) for patients with spouse/partner indicates that responses to spouse/partner help mainly demonstrated levels of support for the carer from the patient and this help was described consistently across the range of help items with the exception of ‘spiritual help’. Few participants had pets, but those who did described ‘emotional help’, ‘help to do things’, ‘companionship’ or ‘no help’, with one report for ‘spiritual help’ from a pet.

The bottom row in Table 16.9 displays total scores for each help item with ‘help to do things’ most frequently noted by participants. Overall responses for ‘financial help’ and ‘spiritual help’ were low across all groups and networks, with the exception of financial support from spouse/partner (n=4) which demonstrated that the majority of participants with partners
received financial help from the relationship and again this was likely reporting from mainly carers.

Table 16.9 Question 1 Close relationships and networks; “In the last 12 months have you received help from any of the following?

<table>
<thead>
<tr>
<th></th>
<th>N/A</th>
<th>No help</th>
<th>Emotional help</th>
<th>Help to do things</th>
<th>Help to know things</th>
<th>Compan’ ship</th>
<th>Financ. help</th>
<th>Spirit. help</th>
<th>Total score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse/partner</td>
<td>9</td>
<td>2</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>2</td>
<td>24</td>
</tr>
<tr>
<td>Family</td>
<td>0</td>
<td>1</td>
<td>14</td>
<td>14</td>
<td>11</td>
<td>12</td>
<td>2</td>
<td>3</td>
<td>56</td>
</tr>
<tr>
<td>Neighbours</td>
<td>0</td>
<td>5</td>
<td>5</td>
<td>9</td>
<td>6</td>
<td>7</td>
<td>1</td>
<td>1</td>
<td>29</td>
</tr>
<tr>
<td>Friends (non-neighbour)</td>
<td>0</td>
<td>2</td>
<td>9</td>
<td>9</td>
<td>10</td>
<td>13</td>
<td>3</td>
<td>5</td>
<td>49</td>
</tr>
<tr>
<td>Pets</td>
<td>7</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>0</td>
<td>5</td>
<td>0</td>
<td>1</td>
<td>14</td>
</tr>
<tr>
<td><strong>Total score</strong></td>
<td>36</td>
<td>41</td>
<td>31</td>
<td>42</td>
<td>10</td>
<td>12</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Question 1 community relations and networks (religious organisations, community organisations, politicians, government representatives, charitable organisations)**

Question one responses for community and government relations and networks are displayed in Table 16.10. The far right column contains total scores for support received from community and government organisations. Community health organisations were reported for the most help outcomes and likely demonstrated consistent contact with these organisations for all except one participant. The help most frequently reported from community health organisations was ‘help to do things’ and ‘help to know things’. Two participants described receiving ‘no help’ from their community health service. Religious organisations were the second highest score for total support received, mainly reporting ‘spiritual help’, despite low levels of participation indicated by nine participants reporting this network as ‘not applicable’. The help most frequently reported by participants from Government representatives was ‘financial help’. Community clubs were reported highest for ‘emotional help’ and ‘companionship’, and the help most frequently reported for politicians was ‘help to do things’. Engagement with charitable organisations was low and reported most frequently for ‘financial help’. The bottom row in Table 16.10 shows total scores for each help type mainly reporting support for ‘help to do things’ and ‘help to know things’.
Table 16.10 Question 1 Community and government organisations and networks; “In the last 12 months have you received help from any of the following?”

<table>
<thead>
<tr>
<th></th>
<th>NA</th>
<th>No help</th>
<th>Emotional help</th>
<th>Help to do things</th>
<th>Help to know things</th>
<th>Compa’ ship</th>
<th>Financ. help</th>
<th>Spirit. help</th>
<th>Total score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Religious organisation</td>
<td>9</td>
<td>1</td>
<td>4</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>19</td>
</tr>
<tr>
<td>Community health services</td>
<td>1</td>
<td>2</td>
<td>7</td>
<td>12</td>
<td>10</td>
<td>6</td>
<td>1</td>
<td>0</td>
<td>36</td>
</tr>
<tr>
<td>Community club</td>
<td>5</td>
<td>7</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Politicians</td>
<td>6</td>
<td>7</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Government reps.</td>
<td>3</td>
<td>6</td>
<td>0</td>
<td>3</td>
<td>5</td>
<td>0</td>
<td>4</td>
<td>0</td>
<td>12</td>
</tr>
<tr>
<td>Charitable organisation</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total score</strong></td>
<td>17</td>
<td>21</td>
<td>20</td>
<td>13</td>
<td>10</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

16.3.5.2 **SCQ: Question 2 ‘What is the quality of these relationships?’**

Question 2 in the SCQ asks participants to report on the quality of relationships with persons and organisations or groups which are identified in question one. Again, the responses are split into two tables separating close informal relations from community and government groups.

**Question 2: Close care relations and networks (Spouse/partner, family, neighbours, pets/animals)** .

Responses for quality outcomes of relationships with close relations and networks are displayed in **Table 16.11**. The quality of relationships was scored as highest for family and friends who were not neighbours. Nearly half of the participants with spouses described the quality of these relationships as fair. Scores for the quality of relations with pets/animals was described as excellent or good. Scores overall for relationship quality were generally positive, with some exceptions.
Table 16.11 Question 2 Quality of relationships with close relations and networks

<table>
<thead>
<tr>
<th></th>
<th>No relationship</th>
<th>Excellent r'ship</th>
<th>Good r'ship</th>
<th>Fair r'ship</th>
<th>Poor r'ship</th>
<th>Very poor r'ship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse/partner</td>
<td>9</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Family</td>
<td>0</td>
<td>9</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Neighbours</td>
<td>3</td>
<td>3</td>
<td>7</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Friends (non-</td>
<td>0</td>
<td>7</td>
<td>6</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>neighbour)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pets</td>
<td>10</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Question 2: Community relations and networks (religious organisations, community organisations, politicians, government representatives, charitable organisations)

Responses for the quality of relationships with community/government networks and relations are seen in Table 16.12. A small number of participants described ‘excellent’ relations with religious organisations, community health services, politicians and government representatives. Overall, the qualities of relationships with community health and government organisations were reported as positive. A small number of participants described poor relationships with community health services, community clubs and government representatives.

Table 16.12 Question 2 Quality of relationships with community and government networks and relations

<table>
<thead>
<tr>
<th></th>
<th>No relationship</th>
<th>Excellent r'ship</th>
<th>Good r'ship</th>
<th>Fair r'ship</th>
<th>Poor r'ship</th>
<th>Very poor r'ship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Religious</td>
<td>9</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>organisation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community</td>
<td>2</td>
<td>3</td>
<td>9</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>health services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community club</td>
<td>9</td>
<td>0</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Politicians</td>
<td>12</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Government</td>
<td>7</td>
<td>1</td>
<td>7</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>reps.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Charitable</td>
<td>13</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>organisation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
16.3.5.3 **SCQ: Question 3 ‘In the last 12 months have you been an active member of any formal groups?’**

Question 3 in the SCQ asked participants to describe their frequency or otherwise of participation in formal community groups. Responses to question 3 are seen in **Table 16.13**.

Low levels of formal group participation or activity for participants were reported in the previous 12 months. A small number of participants reported frequent (‘all the time’) and regular attendance (‘often’) to sports/recreational clubs and religious groups. The most frequently reported membership for participants was to sports/recreation clubs.

| Table 16.13 Question 3 responses for activity in membership of formal groups |
|-------------------------------|----------------|-----------|---------|---------|----------------|
| **Group**                     | **Never**     | **Occasionally** | **Sometimes** | **Often** | **All the time** |
| Community                     | 10            | 5          | 1       | 0       | 0              |
| Charity                       | 14            | 1          | 1       | 0       | 0              |
| Political                     | 15            | 1          | 0       | 0       | 0              |
| Sports/rec. club              | 6             | 6          | 1       | 2       | 1              |
| Cultural                      | 16            | 0          | 0       | 0       | 0              |
| Religious                     | 12            | 0          | 1       | 1       | 2              |

16.3.5.4 **SCQ: Question 4 ‘What are some of the reasons for not being an active member of a formal group?’**

Question 4 asked participants to identify reasons for not attending formal groups and the responses are displayed in **Table 16.14**. Participants, in general, reported that they were ‘not interested’ or were ‘too busy’ to attend or participate in formal groups. Limited transport was not described as a problem for formal group participation and only a small number of participants reported that their ill health limited their ability to attend a community group.
### Table 16.14 Question 4 ‘What are some of the reasons for not being an active member of a formal group’

<table>
<thead>
<tr>
<th>Group</th>
<th>Already member</th>
<th>Not interested (this grp.)</th>
<th>Not interested (any)</th>
<th>Too busy</th>
<th>Negative experience</th>
<th>Transport problem</th>
<th>No access to group</th>
<th>Too ill</th>
<th>Family discourage to attend</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community</td>
<td>4</td>
<td>4</td>
<td>1</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Charity</td>
<td>1</td>
<td>5</td>
<td>1</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Political</td>
<td>1</td>
<td>6</td>
<td>1</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Sports/rec. club</td>
<td>7</td>
<td>2</td>
<td>1</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Cultural</td>
<td>0</td>
<td>7</td>
<td>1</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Religious</td>
<td>4</td>
<td>4</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>

#### 6.2.5.5. SCQ: Question 5 ‘What are the reasons for being a member of a formal social group

Half of the participants reported the reason for being a member of a formal group was ‘to have companionship’ and just under half reported that they were members of formal groups ‘to feel connected to the community’ (Figure 16.1). None of the participants identified that being a member of a formal group was ‘not applicable to me’.

![Figure 16.1 Reasons for being part of a formal social group](image-url)
Questions 6 to 16 of the SCQ measured descriptions of community boundaries and participation; perceptions trust, cohesion, safety and reciprocity; and perceptions of levels of social and emotional support and positional influences. Responses are presented in Table 16.15.

Participants reported low levels of community participation 94% (n=15) and low levels of community trust with just over half of participants disagreeing that most people in the community could be trusted (56%, n=9). Nearly two thirds agreed with the statement that ‘people would take advantage of you if they got the chance’ (63%, n=10). The participants however generally reported good levels of community cohesion with 75% (n=12) identifying that most people in the community ‘get along well’; good levels of community inclusion, feeling ‘part of the community’(68%) were also reported. Two thirds of participants agreed that someone in the community would act if something bad or illegal was happening (75%, n=12). Reciprocity, defined as helping neighbours, was reported variably across the participant group with half reporting helping neighbours ‘sometimes’ in the previous 12 months, and 25% (n=4) reported that they had ‘never’ helped neighbours.

Social and emotional support was generally low for the participant group with nearly two thirds of participants (63%, n=10) reporting that they did not believe that they had someone they could confide in and over half responded that they ‘often felt lonely’ (56% n=9). Knowing someone in a position of authority was reasonably well reported with over a third of participants (37%, n=6) reporting that they had a friend in a government position.

The majority of participants reported their community boundaries as 20 kilometres or less and within this group 25% (n=4) reported their community boundaries as very small (one kilometre or less). Only one participant reported their community boundaries as larger than 50 kilometres.
### Table 16.15 Responses questions 6-15

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q6. In the last 12 months have you participated in activities in your Community?</td>
<td>Never</td>
<td>15</td>
<td>94</td>
</tr>
<tr>
<td></td>
<td>Occasionally</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Q7. In general most people in the community can be trusted?</td>
<td>Agree</td>
<td>6</td>
<td>38</td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td>9</td>
<td>56</td>
</tr>
<tr>
<td></td>
<td>Unable to answer</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Q8. Most people in the community get along well?</td>
<td>Agree</td>
<td>12</td>
<td>75</td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td>3</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>Unable to answer</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Q9. I feel part of the community?</td>
<td>Agree</td>
<td>11</td>
<td>68</td>
</tr>
<tr>
<td></td>
<td>Neither agree nor disagree</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td>3</td>
<td>19</td>
</tr>
<tr>
<td>Q10. I feel that people would take advantage of you if they got the chance?</td>
<td>Agree</td>
<td>10</td>
<td>63</td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td>5</td>
<td>31</td>
</tr>
<tr>
<td></td>
<td>Unable to answer</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Q11. In the last 12 months how often have you helped neighbours?</td>
<td>Never</td>
<td>4</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>8</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td>Frequently</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>All the time</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Q12. People in the community will act if something bad or illegal is happening?</td>
<td>Agree</td>
<td>12</td>
<td>75</td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td>4</td>
<td>25</td>
</tr>
<tr>
<td>Q13. I don’t have anyone to confide in?</td>
<td>Agree</td>
<td>10</td>
<td>63</td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td>6</td>
<td>37</td>
</tr>
<tr>
<td>Q14. I often feel lonely?</td>
<td>Agree</td>
<td>9</td>
<td>56</td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td>7</td>
<td>44</td>
</tr>
<tr>
<td>Q16. I have a friend in a government position</td>
<td>Yes</td>
<td>6</td>
<td>37</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>10</td>
<td>63</td>
</tr>
<tr>
<td>Q15. Overall would you define your community in terms of boundaries as being?</td>
<td>0-1 kms</td>
<td>4</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>2-4 kms</td>
<td>4</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>5-10 kms</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>10-20 kms</td>
<td>4</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>20-50 kms</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>50+ kms</td>
<td>1</td>
<td>6</td>
</tr>
</tbody>
</table>
16.4 Qualitative outcomes: Patients and carers

16.4.1 Introduction: themes and concepts

Semi-structured interviews with patients and/or carers aimed to focus on the experience of social and economic needs and capacities at the end of life. These data were collected to specifically explore research aims 2, 2a, 2b and 2c. In total, fourteen interviews with patients and/or carers were undertaken. Interview duration was an average of 37 minutes for each patient, or patient-carer dyad. Framework analysis of the interview transcripts (see Chapter 4) yielded themes and concepts which are outlined in Table 16.16. Initial themes and concepts of interviews are tabled in appendix 15.

The two themes in the left-hand column; *conditions of economic challenge* and *catalysts of social states* described the conditions of economic and social environments for this group. The three themes in the right-hand column; *bonded care conditions, breaches and capacities in bridged networks* and *realised specialist care* describe the formal and informal networks of end of life care for this group and the quality and accessibility of these networks of support. The economic needs and capacities were described by patients and/or carers in interviews and represented the theme of *conditions of economic challenge* with categories; *experiencing financial losses* and *managing uncertainty*.

<table>
<thead>
<tr>
<th>Socioeconomic needs and capacities</th>
<th>End of life care contexts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>16.4.2 Conditions of economic challenge</strong></td>
<td><strong>16.4.4 Bonded care conditions</strong></td>
</tr>
<tr>
<td>16.4.2.1 Experiencing financial losses</td>
<td>16.4.4.1 Fragile family networks</td>
</tr>
<tr>
<td>16.4.2.2 Managing and uncertainty</td>
<td>16.4.4.2 Opportunities for friends and neighbours</td>
</tr>
<tr>
<td><strong>16.4.3 Catalysts of social states</strong></td>
<td><strong>16.4.5 Breaches and capacities of bridged care networks</strong></td>
</tr>
<tr>
<td>16.4.3.1 Community milieu and margins</td>
<td>16.4.5.1 Consistency and discontinuity of primary care</td>
</tr>
<tr>
<td>16.4.3.2 Connectedness needs</td>
<td>16.4.5.2 Intersecting supports and barriers</td>
</tr>
<tr>
<td><strong>16.4.6 Realised specialist care</strong></td>
<td></td>
</tr>
<tr>
<td>16.4.6.1 Referral conditions</td>
<td></td>
</tr>
<tr>
<td>16.4.6.2 Aspects of acceptability</td>
<td></td>
</tr>
</tbody>
</table>
16.4.2 Conditions of economic challenge

The diagnosis of a terminal illness and consequent care needs challenged the economic resources of nearly all participants in this study. Loss of income, increased out of pocket (OOP) costs for medical and pharmaceutical items and the demands of complex financial decisions were the main financial concerns. For some participants these economic challenges appeared more pronounced, due to a recent loss in income to manage care needs for the patient or because of their terminal diagnosis and inability to maintain employment. The limits of wealth and savings posed problems for participants who were facing the likelihood of larger financial outlays.

The semi-structured nature of interviews permitted additional information to be sought regarding responses to patient socio-demographic, income, affordability and consumption questionnaire items (Socio-demographic questions, Consumption Survey and Interview guide). Outcomes of the Consumption Survey identified low expenditure overall beyond essential items, as reported in Table 16.8. Most participants were in the lowest income group which demonstrated income from government welfare payments. Analysis of interviews revealed that there were consistent financial challenges for participants and some contrasting characteristics of financial resources and contexts within this same socioeconomically disadvantaged group.

16.4.2.1 Experiencing financial losses

Financial losses were described by participants in terms of two distinct deficits; loss of income and increased expenses. Large financial losses were income losses described by a smaller number of participants.

Income loss

One participant particularly confirmed the impact of income loss. John, aged 55 years, was a full-time carer and described loss of income following his wife’s diagnosis with a primary brain tumour. John was employed as a consultant and his wife Lily a small business owner prior to her illness. Lily sold her business soon after her diagnosis because of rapid functional decline and John gave up employment to care for her shortly after. The changes in their financial circumstances were described by John as being quite profound.

“We had an income of probably a quarter of a million dollars a year and now we’re down to $25,000 a year so quite a devastating drop in income’. (Interview 1/Carer).
The impact of this income loss was mitigated by the sale of the ‘family home’. John and Lily sold their home shortly after ceasing employment and moved to the Mt Druitt area to access cheaper housing. They did this to ‘to relieve them of any debts’ which they could no longer sustain on a small income. John described the sale of the family home as a ‘traumatic’ event and he discussed the years of planning and building this home. John, however, also described strength in he and his wife’s’ combined decision to sell their home to ensure they could sustain the financial costs of care giving.

Another participant, David, a 56 year old man recently diagnosed with lung cancer, also described the impact of income loss following his diagnosis. David had been living and working as a mechanic in a rural area prior to his diagnosis and had relocated to Western Sydney for treatment and support from his family. He moved into the Mt Druitt area because of the cheaper rental costs and access to public housing, but still found it difficult to manage the costs of living with the income from a disability pension. David discussed the sale of household items to cover costs of living and to afford some travel, which had become a priority for him since his diagnosis.

‘I’ve been selling things... ‘I’ve got tens of thousands of dollars’ worth of tools and that at home which I’m not going to use again[so they are being sold] and they’ll only go to auction or something when I’m gone and then they’d get nothing for them.’ (Interview 6 /Patient).

Similar to John, David had made a decision to free up ‘wealth’ to sustain costs of living which were no longer affordable due to reduced income. David’s decision to sell his tools appeared to be both an easy decision and solution to his financial concerns and quite distinct from Johns’ distress at the sale of the family home. The sale of assets to manage income loss demonstrated distinct experiences for these participants which were both significant and insignificant.

A reduction in earning capacity to manage care giving needs also described income loss outcomes. A carer, Marion, discussed her experience of long term care giving and the impact this had on her and her family’s financial wellbeing. Marion, a nurse, had cared for three children who died from cystic fibrosis. In particular, Marion discussed the long term care of her youngest daughter who survived to age 19 and the financial impact of the caring experience for her and her husband.

‘... It certainly impacts on, gee where would my husband and I be at 57 if we had have had healthy children. You know? ... I still would have made the same wage
and that would have still been directed into family and... things. My husband would have stayed at probably a different job where he made more money rather than the job he took which suited the hours and the location because he had to work somewhere close. I could get her to school at 8.30 am... and Don had to have a job where he could finish at 3.30 pm to pick her up from school. So we never had the option for overtime ever in our lives or doing double shifts which is a common occurrence when you’re a nurse on the floor... He could never do overtime either. There was always the worry that you had to be within those hours. So our income was limited by our circumstances’ (Interview 4/ Carer).

Marion described circumstances of reduced earning capacity and limitations in job choices because of long term care giving demands. Income loss had occurred over an extended period and most particularly in the last 12 months of her daughter’s life when her husband stopped work to become a main carer. Marion’s financial circumstances were unique from many of the other participants as she and her husband were financially supporting dependents.

Income loss reflected a loss of wages earning capacity and shifts from employment income to a government pension income. In addition to income loss, other forms of financial loss were described by the participants and included losses due to spending on health care items and daily living costs.

**Health care spending**

Medication costs and issues of affordability were reported by all but one participant, an Aboriginal woman who had eligibility for free medications through a specific Aboriginal benefits scheme. Descriptions of medication costs by participants reflected the complexity of contribution payments, safety net provisions and separate costs for medications that were not covered by the Pharmaceutical Benefits Scheme (PBS). Medication costs were also described inclusive of the costs of medications for spouses and other family members. One carer confirmed the range of issues for medication costing.

“Well at the moment we’ve got the PBS. We reached the limit so they’re free at the moment but again it averages. Some months it could be about $40.00 if we weren’t getting any PBS thing. It depends if both of ours come together. It could average out to I suppose you could say $40.00 a month.... I have digesics for the pain for my ankles and they’re not on that. I have to pay for them which is $11.00 ‘ (Interview 7 /carer).

The higher costs for medications which were not subsidised by the PBS impacted on affordability of these items. The regularity of spending on medications was financially burdensome for some and considered to be one of the ‘main’ expenses during this period. Other complexities of the medication subsidy scheme(s) demonstrated other cost outlays. One
participant discussed a process to access subsidised medications which required attendance at a specialist pain clinic in order to receive a particular medication at a subsidised rate. The costs of attendance at the specialist service are highlighted.

‘I go through the Pain Clinic and that’s the Professor and it costs me nearly $300.00 to see him... I pay $3.60 for the medication, but without the Professor I’d be paying nearly $400.00’ (Interview 12 /Patient)

Specialist service costs were reported by several participants who described paying ‘gap payments’ for specialist doctors’ services. Participants did not describe paying ‘gap payments’ for services provided by general practitioners or for specialist palliative care doctors, but just under half of the participants described paying some gap payment for specialist medical services in the previous 12 months (Table 16.8). Many more participants however, described gap payment costs for specialist doctors’ services prior to the 12 month period while they were still in the treatment phase. The costs of these essential medical services and pharmaceuticals were described consistently by participants and highlighted some of the limitations of benefit schemes to manage affordability.

The availability of free consumable items and options for equipment hire at a small fee meant that spending on these health care items was low (Table 16.8). However although several participants reported that some community centres provided some consumables free of charge two participants appeared unaware of the availability of these items for free and had purchased them. Additionally, other consumable items necessary for patients during this care period incurred costs. Protein supplement drinks were one of the consumable items that were both expensive and not provided by health support services. A small number of patients reported that they were instructed to purchase these supplements by their general practitioner or specialist palliative care doctor. The high costs of supplements were described by one patient who reported these items as a weekly expense for her grocery budget.

‘I’ve noticed every time I’ve been to the shops lately, and it’s usually around every 8 days, that I’m spending between at least $100 to $170 or something. This is just for me….. Oh they’re expensive. Some of them are $20 or $26 depending on which ones I get.’ (Interview 12 /patient)

16.4.2.2 Managing and uncertainty

Analysis of interviews revealed that participants responded to conditions of economic challenge by managing finances and reducing spending because costs were uncertain and/or there was uncertainty in how to manage these costs with limited finances.
Managing and uncertainty described reduced spending or management of spending to limit the impact of few financial resources. Participants classified as being in the lowest income group maintained very limited or no access to savings or wealth and this impacted choices available to participants. Managing with limited financial resources meant that many participants did forgo spending on some items. Participants also described strategies to limit the impact of larger financial outlays and the impact of ambiguous future expenses.

One carer, John, highlighted the uncertainty of future costs and how this impacted future choices. He described the dilemma of making a decision to fund further treatments for his wife which were not covered by Medicare and managing the future costs of care.

‘Another thing you’ve got to think of too is the future. You know, you’ve got undoubted expenses that are going to come.’ (Interview 1/Carer)

Decisions to manage the costs of further treatment were weighed up against the costs of managing care and limited financial resources.

Limited financial resources also influenced decisions for spending on daily living expenses. Some participants discussed that they would ‘let expire’ insurance and private health care policies. Participants reported lack of spending on certain goods and services and in particular described forgoing payments for these services recently, following diagnosis and income loss. Others described that the decision not to purchase these items had been a long standing one.

Consistent financial concern for participants were the limited affordability of electricity costs and to a lesser extent the costs for other utilities. The rising costs of these services and therefore affordability was described as increasingly uncertain. Two participants reported paying large bills in arrears because they had been unable to keep up with payments (Interview 5/Patient and Interview 19/Patient). Several participants confirmed that they made regular fortnightly payments or contributed to payment plans to manage these increased costs, yet affordability remained a problem.

While several participants described pre-existing financial strategies which supported their financial means such as reduced spending, others described implementing new strategies to manage costs. One carer, Tom, a full time carer for his wife with end stage dementia, had taken on some part time work from home, laundering safety jackets for a small construction company. In doing so, he was able to supplement his and his wife’s pension and carer payment to afford uncertain future expenses for electricity and care costs.
‘...I keep the lights to a minimum and I think this bill [electricity] is going to be about a thousand dollars but I have a little job and it is official....It gives me a that extra leeway if Esther needs anything.’ (Interview 17 /Carer)

Several participants in the study also described concern for affording future expenses for funeral costs and several acknowledged that they had specific plans to fund these costs because of limited finances. One carer who had paid into a funeral plan for her and her husband commented that this was necessary because they didn’t ‘...have any big assets and big bank accounts and things’ (Interview 7/Carer). A patient, David, who had accessed his superannuation following his diagnosis with cancer declared that the small amount in the fund had been quarantined for funeral costs.

‘What’s left of my Super I’ve put half of it away just to cover my funeral costs.’ (Interview 6 /Patient)

One of the participants from the higher income group also described difficulties managing funeral costs. Marion maintained that she had not been able to pay into a funeral plan for her daughter with cystic fibrosis because of her daughters pre-existing illness and she emphasised the difficulties accessing several thousands of dollars at short notice.

‘We knew, at the very least, it was going to be a $10,000 bill at the end. And while you’re on one wage... It was like, if she died on Monday, by Friday I’d have to have $10,000... It’s not what you want to think about as you’ve got so many balls in the air doing all these other things, but it’s a reality. The reality of life is that at some point you’ve got to pay for death.’ (Interview 4 /Carer)

The ‘reality’ or certainty of funeral costs was therefore a likely driver for managing these costs forward. The ability for participants to cover the costs for funeral expenses out of savings likely demonstrated limited financial wealth across the group.

Beyond managing costs, participants described concerns for managing financial decisions. Levels of uncertainty around financial decisions were made by several participants in interviews and prompted requests for financial advice or support to understand and manage complex financial decisions. Mary, who had been caring for her mother and husband prior to her cancer diagnosis, raised significant concerns for how she should manage their finances and the impact of home ownership on hostel bond payment. She requested financial advice and support for these issues.
‘I’ve got everybody’s finances to try and work out. My mother. I’m looking after all her things and then there’s my husband I have to sort out and he’s never even had a bank account because he would spend it as quick as it poked him in the nose... But now I’ve got to work out what I can do with it [family home] so the Government doesn’t just say, well I’ll have it all and don’t you worry’ (Interview 12 / patient)

Two other participants also requested financial advice in interviews due to uncertainty in managing particular financial circumstances. One participant had concerns with managing a will and complex family dynamics (Interview 9/Patient) and the other had financial/legal concerns for the lack of progress of a prolonged compensation settlement from her previous employer (Interview 10/Patient). Requests for financial support and advice underscored the potential nature of financial dilemma and uncertainty for these participants.

Increasing costs, unknown expenses, future expenses and complex financial circumstances described a context of financial need and developed capacity for the patients and carers to manage these needs. Managing and uncertainty and experiencing financial losses reflected the overall theme of conditions of economic challenge for this group. The experiences were shaped by both the socioeconomic environment for participants and the impact of a terminal illness on financial resources.

16.4.3 Catalysts of social states

Catalysts of social states, was a theme which described the elements of participants structural and relational social experience. Analysis of the interviews found that there were catalysts for social states defined by particular individual social needs and capacities and community features. The interview outcomes for this theme and concepts, which will be discussed shortly, corresponded to the structured and semi-structured interview questions for social capital and personal wellbeing (SCQ, PWI and Interview guide). The social circumstances of participants impacted on the end of life context and vice versa. Two concepts which emerged described this relationship; community milieu and margins, and connectedness needs.

16.4.3.1 Community milieu and margins

The community milieu and margins described the perceptions and outcomes for participants of community trust and engagement in the Mt Druitt area. Community characteristics were described within descriptions of the origins of migration to the area and experiences of community. Community perceptions and networks, inherent in social capital conceptualisation, were expected to emerge from the analysis of interviews which were structured through questions on community area elements in the SCQ.
Origins of migration

Origins of migration were described by participants in response to the question ‘What brought you to live in this area?’ Many participants described moving to the Mt Druitt area as adults with young families or with their parents as dependents. Three participants relocated to the area following their own diagnosis of a terminal diagnosis or that of a loved one to be closer to family and/or to access cheaper housing. Participants who had been long term residents of the area confirmed that they moved there to access cheaper housing or were offered public housing in the area.

‘Well it was a Housing Commission grant that we got, that’s all we could afford. Everyone was coming out here.’ (Interview 12/patient)

‘My word because we used to live in housing commission and they were selling those houses. I didn’t have enough money to buy it. They were asking too much for it. It was a lot of money. Anyway this scheme came up so we snatched it up and this is what we got.’ (Interview 17/Carer)

Participants’ descriptions of the area following migration included comments on the isolation and sparseness of the region for homes or services. Three participants used the term ‘paddock’ to describe the area. Mary, a patient who moved into the area some 30 years earlier, describe the sense of isolation and abandonment she felt when she arrived in the area saying that she and her family were essentially ‘chucked out in a paddock’ (Interview 12/Patient). Mary commented on a lack of services in the area for young families, particularly health services and the difficulties she experienced caring for a child with cerebral palsy. Another participant who was a child when he moved into the area spoke positively about the wide expanses which were conducive for play, ‘real peaceful and real quiet. Birds, paddocks and we’d throw rocks at everything, mate.’ (Interview 19/Patient)

Community trust and cohesion

Most of the participants described living in the area for many decades, 20-50 years and made comment on their experience of the area over this period for levels of community trust and cohesion. Some participants described changes in their community over time which meant that they perceived their community to be no longer the same. When asked whether she believed ‘that most people in the community could be trusted,’ one, carer June, who lived in a neat government housing town house, commented that she would not be able to say that people in her community were trustworthy.
‘I wouldn’t. No, I wouldn’t, not today. Years ago, yeah, you could leave anything outside and nobody would touch anything but now, it’s shocking.’ (Interview 7 /carer)

Mary, a patient who was living in her own home in Mt Druitt, qualified that her community held up the appearance of being cohesive. In responding to the question of ‘most people in the community get along well?’ she discussed that her community appeared cohesive because residents did not necessarily engage with one another.

‘I’d like to believe that too but they really don’t communicate. When I look around there are no real problems in my street around me but I hardly know anyone either so I’d say, yeah, they generally get on well mainly because they just don’t communicate with one another.’(Interview 12/ Patient)

Another participant, Paul, who lived in a larger complex of government housing units, reiterated this experience of community disconnect. He explained that his relationship with neighbours was ‘alright’ because there was limited contact with them.

‘ Neighbours-Oh they’re there alright. They leave me alone and I leave them alone.’ (Interview 19/ Patient)

Participants were aware and able to describe the limits of safety and unity in their community through descriptive responses to the SCQ. Many described no particular problems in their community in terms of crime or unrest and some, like Mary, were thoughtful about the members of their community and engagement between them, believing that engagement was important in the creation of ‘community’. Descriptions of the nature of community boundaries which will be presented later, further underscore the participants’ understanding of their community identity.

**Increasing multiculturalism**

Several of the participants raised concerns about increasing multiculturalism in the Mt Druitt area. Concerns were raised by several participants in response to questions about community trust and cohesion. Joan, a carer, in response to questions about cohesion in her community, commented that her community was cohesive because it was somewhat exclusive, due to limited contact or engagement with people from different cultural groups.

‘Oh well we do [get on]. We don’t see much of the other people.’ The thing is, is that they don’t speak English. Some can but it’s very broken and it’s very hard to
Joan described the different racial groups in her townhouse complex and commented on ‘white’ people now being the minority. Paul, a patient in his early fifties who had lived in Mt Druitt for most of his life, described his concerns for increasing migrant numbers in his community. He offered that the area had changed in this time, that it had gone ‘from good, to bad, to worse’ (Interview 19/Patient). When asked what had happened to create this situation, he stated his concerns about the community having large numbers of Sudanese refugees.

‘Immigrants mate. There are dark people in there, Africans, and they won’t mingle. They stick with themselves. You go into Blacktown and they just hang in groups in the main street, two or three hundred of them, every day, just hanging in the main street. It’s no good!’ (Interview 19/Patient)

Paul reported that some Sudanese refugees were living in his housing complex and had not caused any real problems. He suggested that this was because there were only ‘one or two of them’, balanced by the majority of ‘white Australians’. Perceptions of being the minority group in a community and difficulties communicating with residents created fear for some participants, of persons from different cultural groups. The multicultural nature of the Mt Druitt area defined some issues for limited community cohesion and engagement for some participants.

**Community engagement**

Perceptions of community trust and cohesion were mainly low among participants. The arrangements of community engagement in this population were identified through the SCQ and questioned community contacts in the previous 12 months with several participants describing engagement outcomes prior to this time. Participants described the nature and quality of social contacts and, in particular, described community and or recreational club membership and church or religious connections. Social community connections were overall limited to religious groups and community clubs (community organisations such as tenancy groups, and sports and recreation clubs) and the majority of participants described never being involved in or members of other community groups. Only one participant described a previous volunteer role. Mary, a patient, spoke about working as a volunteer in her church as an aged care respite worker and additionally working in the girls’ youth group-'Girls brigade'. (Interview 12/Patient)
A small number of participants described religious group or Church ‘membership’ as being very important. One patient, Mary, considered her church groups as a source of ‘wonderful spiritual and social support’ and she described receiving many visits in hospital from her church friends (Interview 12/Patient). Ruth, also a patient, commented that her connections with her church group were important for meeting spiritual needs, describing that she could ‘call on them any time and meditate with them and that sort of thing’ (Interview 9/Patient). Many participants also reported no church or religious membership and questions for participation in these groups were qualified by comments about the irrelevance of religion and therefore engagement with these groups.

Nearly all participants identified that they had membership to a local sports/recreational club or a Returned Services League (RSL) club. Many patients and carers described attending these clubs recently and throughout the illness or care giving period. Membership described essentially access to a social venue for participants, whereby they could purchase a reasonably priced meal, entertain with family and play the poker or slot machines. A patient, Ruth, described going to the local RSL club as her ‘little bit of social activity’ (Interview 9 / Patient). However, apart from one patient, Winston, who described his social connections with other returned service men at the RSL club as a ‘connection with a band of brothers’ (Interview 8/Patient), participants did not confirm that they met with other club members or engaged with them during their visits to these facilities. Participants described these clubs as places they could bring their own families and friends. Membership to community clubs, therefore, did not appear to broaden community or social connections for this group, however membership for some reportedly met emotional and companionship needs. Therefore, this community network appeared more important than just the club location and amenities.

Community boundaries

Questions about community boundaries elicited a variety of responses about the size and the nature of the participants’ communities. Over half of the participants described their community as being just the local area of Mt Druitt and others considered their community boundaries as extending beyond this area. However further description of these boundaries offered by participants informed the nature of such boundaries for describing community.

One patient, David, who had recently relocated to the area, described himself as being very disconnected from his local community of Mt Druitt. David commented that he could not give a description of community boundaries as if he ‘had his way he would not even be living here’ and therefore his community boundaries were ‘zero’(Interview 6/ Patient). A patient, Cathy,
who had also more recently relocated to the area, did not describe the boundaries of her current community when asked but referred to her previous rural community and described these community boundaries as large ‘about 50 + kilometres’ (Interview 10/Patient). Other participants delineated their community boundaries not by size, but by physical locations of their social contacts or their reach of community engagement.

‘I would say the community would be the shops and down to the village’ (Interview 8/Patient).

Tom, a carer, felt unable to describe the size of his community because his perception of community did not fit his current circumstances. He did not believe that community was one like his own, which consisted of working people.

‘You see the thing is my conception of communities is people that are semi-retired or retired, not working people, You can’t have a community with working people.’ (Interview 17/Carer)

Tom conceived community to be about connections with people and without connection due to absences with employment, community was not possible. Questions about community boundaries therefore elicited participant comments about the margins for relationships in communities, and also the characteristics of the physical boundaries of their community.

Beyond community contacts, boundaries and relationships, participants were asked about their engagement or otherwise with members of local or state government. These were the ‘linked’ networks to groups or organisations in positions of authority. Participants were asked through specific questions in the SCQ about whether they had contact with a politician and to describe the quality of their relationship with this person. Several participants laughed when asked these questions and replied that they did not have such contacts, however a quarter of participants gave their response as affirmative (see Table 16.10). While some participants were acquainted with one local government member or state politician, others described having contact with several politicians and overall participants described relationships with these person(s) as being positive. They also perceived the potential for future support from these persons, if required.

‘I know quite a few as friends [politicians]. If I needed them, they’d be there, I know that.’ (Interview 10/Patient)
Participants described ease of accessibility to members of government and descriptions of support. One patient, David, commented that he had contacted his local member of parliament on one occasion to resolve a housing matter and this support had been given (Interview 6/Patient). Another patient, Paul, also took a dispute with the Department of Housing to his Local member of parliament and reported a positive outcome (Interview 19/Patient). Some participants acknowledged that they received support for resources from politicians because of support for social policy and welfare payments. Ruth, a patient, commented that she was not able to say that she didn’t receive help from a politician ‘because they do help by increasing our pensions’ (Interview 9/Patient). Overall, participants reported reasonable contact and levels of trust for persons in government positions and political members.

16.4.3.2 Connectedness needs

Relationships with close networks of family and friends were priorities for patients and carers. Connectedness needs were confirmed by patients and carers for close relationships and community relations. Connectedness needs were underscored by the outcomes for questions on ‘loneliness’ and ‘having someone to confide in’ from the SCQ (Table 16.15), which indicated that more than half of participants described loneliness and almost two thirds did not have someone to confide in. The majority of the patients interviewed in the study were living alone, without many external supports. Winston, a patient, who lived alone with limited family and community supports maintained that he was ‘...very lonely, yes, too often’ and stated that the only person he could confide in was myself (the interviewer) (Interview 8/Patient). A patient, Mary, who also reported limited family or community support, described some new and emerging family, neighbour and friendship contacts and networks since her cancer diagnosis and despite this discussed her needs for relationship connections.

‘Oh yes, I often feel lonely. Do you mean lonely or alone?...Because I can be in a big crowd and still feel lonely.’ (Interview 13/Patient)

Mary’s clarification of this question highlighted that wellbeing for her was more about the quality of relations, rather than the size of her close networks or contacts. Social states or conditions for support from friends and neighbours were clearly very important and valuable for self-esteem. Social connectedness remained a priority for many participants in the study.
**Limits of social engagement**

Illness and care challenged patients and carers capacity to maintain social roles and changed the nature of social engagement. For some participants, there was a sense of being ‘homebound’ and that outside of home no longer represented a place that they felt they belonged. John a carer described it in this way:

‘because it’s not the norm any more. It’s the exception rather than the normality of it. You feel uncomfortable outside of that cocoon I guess. If you need to go out you feel uncomfortable’ (Interview 1/Carer)

Mary, a patient with a head and neck cancer found social engagement difficult. She felt very self-conscious about social outings because of her facial disfigurement and so she tended to avoid these if she was on her own.

‘Well we used to go down the club. I don’t go on my own as I feel very self-conscious.’ (Interview 12/ Patient)

For patients who lived alone, the loss of social contact due to illness and disability appeared more pronounced in the absence of close family relations. Winston, an elderly patient living alone, described the inability to continue with regular visits to the local Returned Services League (RSL) club to meet friends, because he had been diagnosed with ‘this bloody malarkey’ (Interview 8/Patient). Winston also described valuable social connections within his local area, which were no longer possible due to his illness.

‘Before I got stuck with this bloody cancer we’d go across early in the morning and chat with the newsagent and some of the early people and we’d discuss everything that was going on. (Interview 8/ Patient’)

Where patients were separated from their ‘social environment’ due to hospital admission or relocation, alternate friendship contacts became particularly important. A patient, Steven described how he had connected with the nursing staff in the palliative care facility and considered them to be great sources of support. He described his feelings about receiving a visit from an acquaintance.

‘Someone came yesterday, a friend of the son’s, the bloke who does my gardening and I felt nine feet tall. I thought, fantastic, someone’s come to see me.’ (Interview 3/ Patient)
Cathy, a patient who had limited friendship or family contact due to relocation and multiple inpatient admissions, sought relationship with other patient’s relatives and friends. Cathy maintained contact with many of the people she had met during her treatment period and found this support and friendship connection to be ongoing during her palliative care admission. She described the reciprocal nature of the relationships she developed in the inpatient unit.

‘I’m doing alright and I’m chatting to people. Even here I notice a lot of the visitors will tap on my window and give me a wave and a big smile... Then there’s another one who waves to me and makes sure I see him when he goes past. That’s good for me and good for them.’ (Interview10/Patient)

New skills and challenges to achieve social connections were described by two participants following their diagnosis. David, a patient who, desired to travel and wished to do so with other people, explained his decision to call the Cancer Council to make enquiries about the possibility of travelling groups. He was told that these were not available and additionally was informed about the ‘social engagement norms’ for cancer patients.

‘She just said, people don’t want to do that, they just want to be with their families. I said that I wanted to be with the family but that I also wanted to travel.’ (Interview 6/ Patient)

Not deterred by this, David sought out advice to set up his own ‘blog site’ and did so to connect with other ‘travellers’ like him. He posted his contact details on the site so that he could offer support and encouragement to other patients who wished to travel and named the site “Living with Cancer” (Interview 6 /Patient).

A patient, Cathy, also made changes to accommodate her desire for social connection. Cathy, who had relocated to Sydney, kept in contact with her large friendship network through ‘Facebook’ and had also set up her own blog site to contact and provide support for other cancer patients and to connect with population groups to highlight the importance of regular pap smears (Interview 10/Patient). Both participants described connectedness needs beyond friendship networks through engaging with the wider community via their blog sites. In addition to offering support, they sought their own support through these networks. The desire to have a voice and affect change via these sites reflected capacity and need in these participants which were distinct from other participants.

Social conditions for the participants defined contexts of community, social need and engagement as the catalysts of social states for this group. Descriptions of community milieu...
and margins and connectedness needs considered more distinctly the community and personal contexts. The experience of community milieu and margins for this group reflected limited levels community trust and engagement, and conversely the capacity for positive civic contact. Needs for personal connections or connectedness needs were important, but were largely unmet due to levels of isolation and loss of social roles due to incapacity, care giving and community distrust. However, the ongoing desire in the group for social engagement and some descriptions of connection with the community more broadly defined social capacities in this group that were sustained despite illness and care giving demands.

16.4.4 Bonded care conditions

Bonded care conditions encapsulated the state and capacity of family and other close networks of support for end of life care giving and were the relationships that enabled care at home for patients. The two concepts which underscore the theme of bonded care conditions are fragile family networks and opportunities for friends and neighbours.

16.4.4.1 Fragile family networks

Family care networks are understood as the closest of bonded relations necessary to support end of life care for patients at home. These relations were described by most of the participants as limited in terms of the numbers of family members available to provide support and in terms of the quality of these relations. Family networks for support were small and relationships with family members for several participants were strained and fractured by past histories of family breakdown, violence, alcoholism and bereavement.

Small family networks

The majority of patients interviewed in this study lived alone with some external family or neighbour support for intermittent hands-on care and psychosocial support (Table 15.6). Two patients, Harold (Interview 2/Patient) and Winston (Interview 8/ Patient) lived alone with extremely limited family support due to family living some distance away. Patients with live-in family support received care from spouses/partners or children. Some patients described care support from other family members such as David, a younger patient, who described care support from his siblings and their children and his partner’s children (Interview 5/Patient). Overall, patients with full time carers reported that care was provided by a sole care giver with intermittent support from other family members. Some full time carers found the lack of support for care giving difficult. One daughter caring for her father described limited support from her brothers. Kylie stated that support from these siblings was ‘not very much...only if we need it’ (Interview11/Carer).
**Fractured relations**

Analysis of interviews described the quality of family relations for many participants as poor. The quality of the relationships gave a context for the likely capacity of these family relations to support patients and carers. For some participants, difficulties in family relationships were not described overtly in the interviews but were described in single and sometimes more obscure statements. John, when discussing the strain of being his wife’s full time carer, said that he would relieve this stress by going outside to dig in the garden and ‘curse the daughter’ (Interview 1/Carer). When asked about the quality of family relationships, Arthur, a patient and Joan, his wife and carer, who both had children from previous marriages, distinguished between these relationships and Joan commented that the relationship with family was good, then added ‘my family is good’ (Interview 7/Carer).

Some participants were more open and descriptive in disclosing relationship concerns in the interviews. A patient, Mary, laughed when given the options to describe the quality of the relationship with her spouse: ‘[laughing] It’s not excellent...fair’ (Interview12/patient). David, a patient, described very limited support from his partner and said ‘I am not even sure why I am even with her?’ (Interview 6/patient) The discussion of family relations for several patients heralded a description of larger contexts of previous crisis that had shaped the quality and nature of family relations for them. Some participants described relationships shaped by the impact of alcoholism and violence.

Ruth was one of the patients who described a past history of domestic violence. She had lived for many years in a violent and abusive marriage and she discussed her desire to live apart from her children even when her care needs were increasing. She emphasised her fears that her whereabouts would be known by her ex-husband.

> ‘Great lengths have been taken since the split and he doesn’t know where I live or even what area. The kids don’t ever, ever tell him where I am.’ (Interview 9/Patient)

Ruth’s daughters’ concerns for their mother living alone prompted requests for care to be provided in an inpatient setting. It appeared that neither Ruth nor her children or siblings discussed the reasons for this decision with the palliative care staff. Ruth described herself as independent and had decided to manage at home alone rather than put herself or her adult children at ‘risk’.
Mary was another patient for whom family relationships were shaped by previous experiences of crisis and trauma. Mary described a difficult life for her two children growing up with an alcoholic father and also coping with the death of their younger sister after a prolonged illness.

‘Very, very tough, they had a drunken Dad to listen to all the time.... They got so close to her and then she wasn’t there anymore.... It was so hard on them... they couldn’t handle losing their little sister. We were only in our 20’s and we didn’t have any support whatsoever not even from our families. Everywhere I went I had to drag along two other kids that didn’t want to go. So it was a tough life..... We made all the wrong choices I suppose but what else can you do? No one was helping us make the right choices. We didn’t have any support but that’s the way it goes.’ (Interview 12/ Patient)

Mary described very difficult relations with her adult children, feeling responsible for the difficulties they experienced in their childhood years. She confirmed the fractured relationship with her children recounting hurtful comments by them following her diagnosis, whereby they informed her that she needed to ‘just put the house on the market, Mum, and go into palliative care.’ (Interview 12/ Patient) Mary understood the context of her poor relationship with her children, but hoped that things could be resolved before her death. She revealed that her children were unlikely to become her carers, but was hopeful for some support.

In reviewing and analysing the field notes from this study, other outcomes of violence and traumatic life events were described by patients and carers who were not participants in this study. Two potential participants were not interviewed because their current personal relationships were violent and therefore, the risk for participation and disclosure of these circumstances in the study was too great. One female patient still living with her violent husband revealed her circumstances and declined to participate on understanding the nature of the questions in the study about relationships. Another elderly couple agreed to participate but when it was revealed that they had a violent and abusive live-in son, were agreeable to be withdrawn from the study.

16.4.4.2 Opportunities for friends and neighbours

*Opportunities for friends and neighbours*, is a concept which described the capacity and needs for close relations beyond families for support and resources. Friendship and neighbour relationships varied among participants with descriptions of established relationships, new relationships and loss of friendship and neighbour relations in this group.
Opportunities of support

Opportunities for support from friends and neighbours were evident through descriptions from participants despite limited contact overall for this group. Two patients who lived alone confirmed established neighbour networks which were invaluable for sustaining many care and social needs. In particular, these two participants, who lived in government housing complexes, described the support from neighbours increasing as they required it. One 83 year old gentleman, Harold, described his neighbours as ‘friends’ and needed their support at times to discuss outcomes from doctor’s appointments and to provide transport to these appointments (Interview 2/Patient).

Steven, a patient who lived alone without family support, had a very close relationship with his neighbour Peter and described Peter’s extended support during his inpatient admission:

‘He bought me pyjamas of course, paid the light bill, paid the phone bill and he pays my rent, so he does a good job.’ (Interview 3/Patient)

Steven made his neighbour Peter, Power Of Attorney and believed that although this would ‘turn the children on,’ he needed some practical support which he felt would be forthcoming from his neighbour.

For some patients, neighbours emerged as new sources of support. Participants described previously having limited contact with neighbours and following diagnosis this had changed. Ruth who lived alone, described limited contact with her neighbours but was ‘sure...that they would [help]’ if that was required, but had not requested any support (Interview 9 Patient). Ruth described practical support from neighbours stating that ‘...they do sometimes cut my lawn without asking for it and all that sort of thing’ (Interview/9 Patient). Another patient, Mary, described support and care from her neighbours where previously there had been limited contact.

‘Some of them have told me that they’ll do anything for me and one of them rang me up and I didn’t even know she had my phone number but she rings me up every week. Even though I haven’t spoken to the one across the corner for probably four, nearly five months, I was talking to her one day about the cancer and the next day she had a fruitcake for dinner and a bottle of something else on the doorstep when I got up.’ (Interview 12/patient).

Several participants described how important friendship networks were for support. A carer, Joan, described her and her husband’s phone contact with a small friendship group and as most people in this friendship group were also dealing with health problems they considered
them to be ‘very understanding and supportive.’ (Interview 7/ Carer) A patient, Paul, who lived alone, described his friendship network as most important declaring several friends who were not only great companions but also provided practical support. ‘I’ve got a couple of good mates who come up and see me all the time.’ (Interview 19/Patient) Paul’s friendship network was a younger group in reasonable health and their capacity to offer practical support was highlighted.

**Lost opportunities for friends and neighbours**

A smaller number of participants also described a loss of friendship and neighbour relations because of recent relocation to the area and emphasised limited contact with neighbours and friends in their new location. Steven, a patient, asserted ‘absolutely not’ to a question about receiving help from his neighbours (Interview 6/ Patient) and Cathy, in response to the same question about neighbour support said ‘up home I do’, referring to neighbour and friendship contacts in her previous residence (Interview 10/ Patient). Most participants described limited numbers of friendship contacts but nearly all described themselves as having at least one person who they could describe as a friend. One patient, Winston, however described having ‘no friends’, having lost contact with his friendship network at the RSL club and his local neighbourhood contacts because of his illness and physical decline (Interview 8/Patient).

The opportunity for friends and neighbours was a feature of bonded care conditions which characterised close relations beyond families and varied across participant descriptions. There were those participants who described well established friendship and neighbour networks from which they received ongoing support, some described new levels of support following diagnosis and finally others were without support from neighbours or friends. Patients who were living home alone were the group most likely to describe practical and ongoing support from neighbours and friends.

**16.4.5 Breaches and capacities of bridged care networks**

Analysis of interviews for responses to social capital and palliative care needs (SCQ and NAT:PD-C) of formal care outcomes generated the theme; breaches and capacities of bridged care networks. The limitations and capacities of formal community networks were described by participants and further analysed to the concepts of consistency and discontinuity of primary care and intersecting supports and barriers. The theme and concepts outlined the formal networks and relations community health care providers and networks of engagement with government agencies.
16.4.5.1 Consistency and discontinuity of primary care

Patients and carers discussed formal community care support as being somewhat inconsistent and unavailable for end of life care needs; overall they reported the experience in consistency and discontinuity of primary care. Formal home care needs for participants were mainly provided by generalist community nurses (to be referred to as community nurses) and general practitioners (GP’s). Two carers were receiving ‘home care packages’ for their spouses with longer term nursing care needs. This nursing care support was provided by personal care attendants employed by non-government organisations (NGO’s). These community care networks were supported in the community by some adjuvant specialist palliative care nursing and medical services. Some patients and carers described formal community care as solely a community nurse ‘that’s about the only thing’ (Interview 7/Carer).

Medical care networks

Patient and carer participants described medical support from GPs as essentially office visits for medical review without the availability of home visiting services. Participants overall did not describe care by a specific medical officer but attended local medical centres and saw different GP’s within these centres. Patients who were bed bound or too frail to attend GP clinics often did not receive any medical service in the community. This was particularly difficult for patients wishing to die at home and who required a death certificate to be issued by a local GP. One carer, Tom, described this situation for his wife and the availability of a palliative care GP in the community to manage this: ‘I have somebody in case anything happens from palliative care’ (Interview 17/Carer). Specialist palliative care nurses essentially had crisis support and consultative roles in the community, and often liaised between the community nurses and the medical staff ensuring that some home bound patients had a specialist medical review without having to ‘go through the logistical nightmare’ of attending a clinic (Interview 11/Carer). Specialist palliative care services were described as bridging some of the gaps in medical care services for palliative care patients in the community.

Community nursing networks

Community nursing services provided the general nursing care support for patients in the community and were being provided to all but one patient in the study. Descriptions of this support varied with several participants describing good levels of support and a small number describing ‘no help’ from this service Table 16.10. Participants overall described the quality of the relationship with community nursing services as mainly as positive and some participants
particularly enjoyed the social contact with community nursing services and considered the advice provided by the nurses as important.

Several participants were unsure about the level of support provided by community nursing services and although most described this support as ‘help to do things’ (SCQ),Interestingly they did not describe this help in practical terms. Mark, a patient whose main carer was his elderly mother, commented on the limited nature of this practical support describing only weekly visits and highlighted that the support provided by the nurse was ‘just advice’ (Interview 13/Patient). Other reports of limited visits featured, with one patient, Winston, describing his community nursing service as not operating ‘on any timetable’ (Interview 8/Patient). Another patient, David, described being unsure if he was still receiving the service.

‘I don’t know. The nurse I’ve got now I’ve never even met her because they keep changing them’ (Interview 6/Patient).

Descriptions of inconsistencies in home visits were confirmed by a few participants but it was the absence of practical hands-on support from community nursing services that was described most consistently across the participant group.

**Home care networks**

Essentially, only patients receiving a ‘home care package’ from a NGO described assistance with personal care or hands-on-care. One carer, Tom, whose wife was receiving a home care package described the challenges he experienced in gaining access to these services for his wife with end stage dementia. Tom’s wife, Esther, was receiving approximately 11 hours of home care services per week and the regular threats to reduce and withdraw some of these services were discussed by Tom. Tom declared that he and his daughter-in-law ‘had to fight’ for these services to be maintained. Tom contended that had it not been for his daughter-in-law who was ‘in the business’ of healthcare, advocating on his behalf, these services would not have been maintained (Interview 17/carer).

The restrictions on GP service provision, the absence of practical care support from community nursing services and the limited access to ‘home care packages’ for this group, demonstrated the confines of community care networks to support end of life care needs for participants. Additionally participants described support by specialist palliative care services in the community which managed gaps in medical care needs and overall positive relations with community nursing services for meeting social and informational needs.
### 16.4.5.2 Intersecting supports and barriers

The network of relations in the community for *intersecting supports and barriers* reflected the responses to the SCQ for availability and engagement with government agencies and the quality of these encounters. The broader conditions of community support which enabled access mainly to financial benefits and housing resources were important for the majority of participants who were receiving government welfare payments or reported loss of income. The relationships with inter-sectoral agencies were valuable in sustaining or gaining access to many of the broader resources required for care at the end of life.

**Intersectoral supports**

Nearly all participants described contact with government agencies which were mainly welfare support agencies (Centrelink) and housing departments. Most of the participants had been receiving government support benefits such as the aged or disability pension for long periods and described their engagement with these agencies as generally positive. Ongoing contact with these agencies was described by participants as being ‘oh yes very good’ (Interview 7/Carer). Some participants discussed that when they needed to receive extra payments or advanced payments, that these had been approved by Centrelink without too many problems. Direct face-to-face contact with Centrelink staff was possible and the staff was described as being ‘helpful’ (Interview 12/Patient). One patient, David, spoke very positively about his engagement with the Housing Department and their efficiency in finding him public housing at short notice. He knew the name of the person who had helped with his application and described regular support from this individual during the application process (Interview 6/Patient).

**Inter-sectoral barriers**

A small number of participants described less positive outcomes in their contact with government agencies. One participant, Marion, discussed her difficulties with Centrelink. She had not sought welfare payments previously and found the process of applying for carer payments for her husband time consuming and required a level of emotional energy that she didn’t have and she therefore decided not to pursue the application process.

*Don applied for the Carer’s Allowance but didn’t get it. We’re not really sure why now but we didn’t have the energy to chase that up. Once they said no or you need to do this or that or you can be reassessed at this point, we just went, forget it, the too hard basket. We just gave up on Centrelink. It’s hard enough when you’re emotionally well and stable but we weren’t.* (Interview 4/Carer)
Another carer John, who also had no previous experience accessing government benefits, described the service as overall ‘efficient’ but raised concerns about some inflexibility in the system. John described a reduction in he and his wife’s pension due to them not meeting the full pension eligibility criteria, because they had sold their home and were building a new home to accommodate his wife’s physical needs and their financial needs.

“The only problem I had is that the Government could probably change the fact that if you’re both on a pension and you’re building a house, your pension reduces to $130 each so you lose $260 a fortnight out of your pension because you don’t live in the house that you’re building because the Government sees that as an investment. So for 3 months, we lost that money because we were just stuck in that no-man’s land. It doesn’t seem like much, but it can be devastating.’ (Interview 1 /Carer)

Relationships with inter-sectoral organisations were described by many participants as positive for accessibility and forthcoming for support and most participants described having ‘no problems’ in engagement with these organisations. Participants who were less familiar with negotiating these organisations or described scenarios for eligibility which were more complex and outside of routine processes described difficulties in engagement with these services. These challenges appeared to describe however the inflexibility in the inter-sectoral policies rather than difficult relations with the representatives of these services.

The breaches and capacities of bridged care networks for supporting the care needs of participants were more alarming when considered in parallel to the fragile nature of informal family care contexts. Inflexibility in inter-sectoral policy arrangements were limiting for some participants in accessing in particular financial resources. Some capacities however within formal community networks were reported by participants and included perceptions by several participants of the overall quality of relationship with community nursing services and adjuvant support from specialist palliative care services. Descriptions of positive engagement with inter-sectoral agencies described access to financial and social resources and positive engagement with these service providers.

16.4.6 Realised specialist care

The analysis of participant responses for semi-structured questions from the interview guide for access domains to specialist palliative care services, underpins the theme, realised specialist care. Participants described their experiences of engaging with specialist palliative care services and how these services were attained, recognised and understood. The concepts within this theme were referral conditions and aspects of acceptability. These concepts further
describe the nature of accessibility and the appropriateness of specialist services for this group of patients and carers. All of the patients in the study were registered with the specialist palliative care service in the Local Health District.

16.4.6.1 Referral conditions

Specialist palliative care services, as described previously in Chapter One, define services provided by healthcare professionals who are specifically trained in the specialist area and work within a interdisciplinary team in dedicated inpatient units, community, acute hospital consultancy teams, day care or outpatient clinics.

Needs based referral

Analysis of the interviews for the experience of referral to specialist palliative care services, found that many patients were unsure about the process by which they came to receive services from palliative care. Gaining access to specialist palliative care services for participants was considered to be initiated through referral to these services by health care providers and mainly by their current treating specialist team. Harold, a patient, whose care had previously been managed by haematology services for his acute leukaemia, was referred to palliative care by his specialist haematology physician because of his sudden deterioration. Harold perceived that he came to access these services because he ‘went into hospital’ (Interview 2/Patient). A patient, Winston, described that his palliative care services ‘just came’ following what he perceived were some discussions in community regarding his needs (Interview 8/Patient). Another patient, Paul, stated that he was ‘just put into palliative care’, as his community nurse felt that he was ‘not looking real good’ (Interview 19/Patient). The perception that changed health needs had prompted palliative care service involvement or inpatient palliative care admission was common. Essentially these patients confirmed the capacity for health services (including palliative care services) to identify, refer and accept patients to palliative care services on the basis of need.

Referral trajectories

Other patients described referral to palliative care following discussions with their treating teams about no further treatments. Mark, a patient with liver cancer, had a long admission in a surgical ward and stated that the surgical team ‘threw’ him out to be cared for by palliative care when it was decided that further surgery was no longer possible (Interview 13/Patient). Mary, a patient, described her transfer to palliative care for pain and symptom management following discussion about the limitation of further surgery for her tongue cancer.
‘They said it was too much and would involve taking nearly all my tongue and they didn’t know how far down they’d have to go so they said that they could get me into some sort of palliative care where they would do the rest and maintain me as much as they could.’ (Interview 12/Patient)

Where patients described clear of trajectories of decline or cessation of further treatment for malignant disease, and following medical referral, transition to palliative services appeared to progress smoothly. These elements confirmed some key criteria outcomes necessary to gain access to specialist palliative care services.

**Seeking referral**

Where referral was sought outside of the parameters of medical referral, access to specialist palliative care services proved to be more difficult for participants. Carers seeking referral described some challenges for gaining access to palliative care services. Kylie a carer for her father described needing specialist palliative care input to manage her father’s pain issues, but was unable to access services due to the absence of a specialist palliative care referral.

‘Yeah, that was difficult because when we were having the community nurse come after our admission... because he had pain, we rang the Palliative Care nurse to come but because he hadn’t been reviewed or seen by a Palliative Care Specialist, she couldn’t do anything.’ (Interview 11/carer)

Kylie found self-referral to the service difficult, with barriers to access dependent on medical assessment. Another carer, John, through his experience of negotiating health care services for his wife, understood that there was a process that needed to be adhered to. He discussed that his prolonged experience in gaining access to palliative care services was because a sequence of events needed to occur before services would be available.

‘It took a while because it’s a chain reaction. It’s a networking thing. Once the network’s in place, anything can happen really.’ (Interview 1 Carer)

Once patients gained access to the service, these were described as being forthcoming. Limitations in access for patients and carers without medical referral to palliative care identified barriers to the service, ‘it was getting into the service which was hard’ (Interview 11/Carer).
16.4.6.2 Aspects of acceptability

Overall participants in the study described palliative care services as acceptable and appropriate for meeting the needs of patients, carers and families. They reported in particular communication and service acceptability.

Acceptable communication

Many participants valued the quality of communication in palliative care and several emphasised improved levels of communication for palliative care services compared to other health care services. One carer described her experience of palliative care for her and her partner; the distinction between palliative care and other health care services, the quality of communication and the focus on comfort.

‘It’s like they forget about the rest of the world and in palliative care everyone knows what’s going on and it’s comfortable.’ (Interview 13/Carer)

Co-ordination of services and communication between inpatient and community services and medical and nursing disciplines reflected an overall positive experience for this carer managing her father’s care at home with specialist palliative care nursing support.

‘They’re liaising with the community nurses and it has been very good... the palliative girls they talk to [the]Dr themselves and they know when to increase the dose and we have this Ghostbuster telephone number we just ring and it’s so great.’ (Interview 11/carer)

Many other patients also described palliative care as being a positive environment for open communication. They acknowledged being comfortable in asking questions where necessary, that health care language was not complex or difficult to understand. One patient commented that he asked questions ‘all the time’ and not only did he seek answers to questions, but also sought additional engagement and support from palliative care staff in the inpatient palliative care facility, to understand further.

‘Oh, I’ll have a question that’s been in my head until someone comes and can answer it. Then I ask for their support to work it all out.’ (Interview 3/patient)

Another patient, Harold, however commented that he preferred not to ask questions and that he wanted his treatment to be ‘whatever they (medical team) come up with’ (Interview 2/Patient). Trust and respect for palliative care health care providers was commonly described by participants in the interviews and was often discussed in a context of met communication.
needs; patients and carers felt encouraged and entitled to ask questions about care and treatment options and also described feeling comfortable in not asking questions, trusting the decisions made by health care providers.

**Service acceptability**

Some patients acknowledged that initially they had concerns about referral or admission to palliative care which were driven by fear of the service. Consistently, many of the patients and carers initially believed that palliative care was only end of life care; that a palliative care unit was synonymous with a ‘near-death unit’ (Interview 19/Patient). One patient described resisting admission to the service.

> ‘When I came down I went and saw the Doctor and she said I needed palliative care and I said, I don’t think so, I don’t want to be talking about that. She said ‘pain relief’ and I said ‘no, I don’t want to be talking about that either’...next day I finished up in here didn’t I? She jinxed me.’ (Interview 10/patient)

Following admission or contact with the palliative care service, many patients and carers welcomed that the service was broader than just end of life care and were pleased to have continued support from the specialist service and service providers. Participants described satisfaction with palliative care services but particularly commented on the focus of patient-centred care and communication. Paul, a patient who had a long acute admission, described his isolation and lack of care as a patient in a medical ward in a large public hospital stating that, ‘they just put you in a room and forget about you.’ (Interview 19/patient). Paul described the care he received in the inpatient palliative care unit as being responsive to his needs.

The interviews revealed acceptability for palliative care services which was perceived as coordinated and open to communication. Descriptions of access issues for participants were limited because patients and carers were already ‘in the system’. Those participants who described difficulties with access were carers who sought referral independently for their family member and reported delays by screening processes aimed at ensuring appropriateness of referral to the service. Broader descriptions of access to specialist palliative care services were discussed by key informants (Section 16.4.4).

**16.4.7 Conclusion**

Patients and carers described experiences of end of life care which maintained outcomes for limited social and economic resources at individual, community and policy or governance levels. Capacity for support across these levels was most evident in the potential for
community support and positive government level engagement. The most significant findings were descriptions of financial loss and social isolation for participants and the inadequacies of formal and informal networks for care giving support.

16.5 Qualitative findings: Key informants

16.5.1 Introduction to themes and concepts

Interviews with Key Informants were semi structured for questions in the interview guide for dimensions of access and domains for the social determinants of health, social capital elements. The qualitative interview outcomes for key informants (formal carers) additionally describe needs and capacities for patients and care givers in the most disadvantaged area and explore research objectives 2, 2a 2b and 2c. Interviews with key informants were an average interview time of 40 minutes per key informant.

Initial themes, concepts and categories for the framework analysis of these interviews are tabled in appendix 16. These categories and themes were synthesised (refined) further into key elements of the data and the themes and core concepts emerged. Resultant themes and core concepts originated from both a priori topics corresponding to the semi-structured interview questions as well as emergent concepts and categories otherwise unexpected.

Table 16.17 outlines the themes and concepts from the key informant interview analysis. The three themes which emerged from the analysis of the interviews were enabled care contexts, situations of vulnerability and negotiating the system. These themes described corresponding issues of social and economic needs and capacities, for those outlined in the patient and carer interviews. Themes from key informants additionally described broader outcomes for specific groups who were likely to have more limited utilisation of specialist palliative care services and also expanded on the experience of access to specialist palliative care services.

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16.5.2 Enabled care contexts

Analysis of the interviews with key informants demonstrated that there were contexts for patients and carers which were more likely to support palliative care needs in this lower socioeconomic population. The importance of informal and formal networks to support home care and the availability and accessibility of financial benefits and care programs were highlighted as features for enabling supportive care contexts. Enabled care contexts describe the key informants perception and experience of capacity for end of life care within this population. Two concepts within this theme which described these care contexts were families and communities of care, and programs and benefits.

16.5.2.1 Families and communities of care

Family, friends and neighbours were the networks of close care important for meeting home care needs and advocacy. The limits of these networks of support were described in interviews with patients and carers (16.4.4 bonded care conditions). The nature of close networks in this population, are expanded on by key informants who described their perceptions and experiences of these networks for enabling end of life care.

Families of care

Strong family support networks were identified by several key informants through descriptions of care in specific groups or family circumstances. One key informant, an Indigenous Liaison nurse working with Aboriginal patients and families in the Mt Druitt area, described the circumstances of cultural family networks for this group and how these impacted on care outcomes. This nurse detailed several descriptions of family support outcomes for Aboriginal patients with terminal illnesses and in particular acknowledged outcomes of support from large extended family networks who would travel from other locations and stay for extended periods to care for a terminally ill relative. She confirmed these outcomes in a description of the experience of family support for one Aboriginal gentleman.

‘He lived alone but when we visited there, there must have been 14 people there. His brother had come down from Bourke and he was actually sleeping in the same room because nobody left him alone for a minute so when his brother went to go and have a shower, somebody else would come into that room. There were people everywhere and they stayed there until he died so it was really beautiful to see that support.’ (Interview 14/Indigenous Liaison Nurse)

Family relations and networks were central to Aboriginal culture and the strength of these relationship ties would extend to care for terminally ill relatives and their families in critical
periods. The large size of Aboriginal kinship groups meant that the caring role was likely to be shared by many.

Other experiences of strong family networks were described for non-aboriginal groups also. These descriptions generally maintained circumstances of family cohesion, extended family support and often organised plans of care. The Clinical Nurse Specialist from the Mt Druitt Community Health Centre discussed circumstances of having a larger family who could organise a ‘roster system’ so everyone could offer support in some way as effective (Interview 16/ Palliative care CNS). This nurse described the situation for one particular young spouse who managed care giving for her husband with extended family support and organisation. The concept of good support described both the quality and quantity of informal care networks and relations.

‘She coped wonderfully and she had arranged everything but she had good support. She had her family and her mother-in-law and sister-in-law who were quite good.’ (Interview 16/ Palliative care CNS, Mt Druitt).

The palliative care social worker identified other features of family networks which enabled care for the terminally ill person. She described families who were very motivated to care for their loved one and also an awareness of what this care entailed.

‘...but they’re there and they’re doing the caring and understanding the system. I think maybe sometimes it just comes down to people’s own comprehension of what the situation is’ (Interview 18/Social Worker palliative care, Mt Druitt).

This key informant described the importance of families being prepared for managing the caring role, being aware of what was available within the system and working within these limits. These were considered important elements of care giving networks for this key informant and she confirmed these elements again, later in her interview.

Descriptions of family features to support care overall, included larger family networks, organisation to manage and distribute care giving demands, and understanding and knowledge of the formal care system and the care giving requirements. The quality of close family relationships and motivation to provide care reflected the basis of an enabled care giving context.

**Communities of support**

Key informants maintained that informal community support networks enabled end of life care contexts for patients and carers in this population. Contact and membership with community
groups and neighbour connections were described, in particular. One of the key informants identified church groups as an informal community group that supported spiritual and practical care needs for some patients and carers.

‘I’m sure different churches do it on different levels as people require them. A lot of them have their home visiting and that sort of thing so there is a fair bit and I think that it’s a largely unacknowledged group.’ (Interview 15/Aged Care Liaison nurse)

Neighbour contacts were also considered important networks of support in the community for patients and carers. The palliative care community CNS confirmed that informal community support for patients with limited family caregivers, included both practical support and security.

‘Surprisingly enough, people tell you that they’ve lived in their area for such a long time and they know the neighbours and some neighbours are just wonderful and they do lawns for them and they cook meals and they pop in and if they don’t see someone for a day or two, they’ll ring and say, are you OK?’ (Interview 16/Palliative care CNS).

Neighbours were also described as providing emotional support for carers. The palliative care social worker commented on the emotional needs of carers being met by neighbour relations.

‘Not so much hands-on care but it’s more that emotional support for the carer which is really important because they need that.’ (Interview 18/ Palliative care Social Worker, Mt Druitt)

Being accepting of and open to offers of community support was considered to be important for ensuring that end of life care at home was achievable and sustainable. The palliative care CNS described the experience of one carer for being willing to accept support.

‘She was receptive to any help whereas a lot of people try to do it on their own and a lot of people fail that way. I think it was her attitude and she was open-minded about a lot of things. I think it was her, the way she was.... A lot of people are proud and don’t want to accept help.’ (Interview 16/ Palliative care CNS, Mt Druitt)

The nurse described her experience with this carer contrasted with others who were less willing to seek and accept support and, therefore, were more likely to ‘fail’ in managing care at home. The nature of this carer stood out to this key informant as being distinct from the
experience of other carers who were described as bound by their sense of pride and non-accepting of community support.

16.5.2.2 Programs and benefits

Further to family and community networks of care, key informants identified programs and benefits as enablers which were potentially available to patients and carers for practical and financial support. The availability of these programs of support maintained important capacities to negotiate health systems and access financial resources.

System support

The Indigenous Liaison nurse discussed the increasing demands for understanding the complexity of treatment programs for patients with terminal illnesses. Many Indigenous people found negotiating the health system overwhelming and frightening. The availability of an Aboriginal health support program to fund, among other things, Aboriginal support persons to accompany patients to appointments and treatment clinics, enabled better understanding and negotiation of system processes for this group.

‘So what I did with her was that I referred her to Close the Gap and they actually have a staff member go with her for every one of her appointments and every time she has Chemo they go and sit with her while she has her Chemo so they’re able to support her through that process.’ (Interview 14/Indigenous Liaison nurse)

Other community support services, for assisting palliative care patients and families, included access to social work services to support patients and carers with more complex social needs and demands for financial support and advice. The recent introduction of volunteer program in the area aimed at supporting patients and carers by providing companionship and practical support and was endorsed as an important improvement to community services for this population. (Interview 16/Palliative care CNS).

Health care costs affordability programs

Programs and benefits to support financial wellbeing and enhancement were also tabled by key informants and included a range of benefits, most of which assisted the affordability of medications. The Indigenous Liaison nurse discussed an important funding program for Indigenous patients which entitled patients to receive medications for free or at a subsidised rate. The nurse emphasised the importance of such a program:
‘So if they’re on a health care card, it won’t cost them anything, provided it’s covered by the PBS, but if they’re working and they don’t have a health care card, they actually get their scripts for the price of a person who is on a health care card so I think it’s $5.00 or something. And what that does, of course obviously, is that it ensures that people take their medication.’ (Interview 14/Indigenous Liaison nurse)

The Palliative care CNS working in the Mt Druitt area also discussed a local program for medication affordability for palliative care patients in the area who were finding it difficult to afford medication costs.

‘We had this wonderful scheme run by Anglicare I think, where they had a pharmacist from Newtown who decided he was going to give free medications in this area to very low socio groups and so they had to go and visit him and he actually opened an Anglicare office in Mount Druitt and people would go there with their scripts and he would take some information from them and then he would actually post out their medications on a monthly basis. But there’s no more funding so that’s stopping.’ (Interview 16/Palliative care CNS, Mt Druitt)

The local palliative care service provided parenteral medications free to patients in the area, the costs of which were prohibitive for some patients as several were not PBS listed. The palliative care nurse discussed the importance of these free medications for a particular carer.

‘We used to get the medications (free) from the palliative care unit which was just wonderful as I was afraid they’d stop that but, that really helped and she just managed.’ (Interview 16/Palliative care CNS, Mt Druitt).

Medication affordability was a common concern raised by key informants and patients/carers alike (16.4.2.1 Experiencing financial losses). Programs and benefits schemes which supported medication costs were important for patients and/or carers to ensure cost containment of these essential medical consumables.

Costs of other consumables and equipment were considered less burdensome by patients and carers and often contained by provision of these items by community health centres and confirmed by key informants. Waiting times for hospital beds and other equipment items was considered to be short and the availability of consumable items for patients was considered to be particularly good for patients in the Mt Druitt area (Interview 16/Palliative care CNS).

The availability of specific local programs and benefits which supported the economic and psychosocial needs of this population reflected contexts that enabled end of life care for this population. Specialist palliative care services, NGO programs and Aboriginal health support
programs recognised specific economic and support needs of the population and sought to meet these needs through targeted local programs.

16.5.3 Situations of vulnerability

Key Informants described situations of vulnerability for their patients and carers that highlighted the potential of risk for them in an end of life care context which included care within facilities and the community. Situations of vulnerability were described for patients and carers in terms of limited care networks and margins of financial resources.

16.5.3.1 Limited care networks

Limited care networks were discussed in the analysis of responses from patients and carer interviews (16.4.4 Bonded care networks) and described the margins of informal care networks also identified by key informants. Further description of the risks posed for patients and carers with limited care networks were supported by key informant responses.

Informal care networks

Inadequate informal care networks and relations of family, friends and neighbours created environments of vulnerability whereby these relations were limited in size, quality and availability. Foundations of a home care network were established by the availability or otherwise of family care networks. These networks were described as being diminished for some families because of other demands on family member’s time for employment and child care demands limiting the availability of care giving hours.

‘We see quite a lot with families where the support is limited because people work. A lot of people are by themselves or until they reach the late stages of their illness are by themselves. Some have people at night-time or in the morning but during the day they’re just by themselves. That’s just the way it is, kids go to school and a lot of people haven’t got time or can’t take time off work.’ (Interview 16/ Palliative care CNS, Mt Druitt)

The difficulties of patients being ‘home alone’ without carer support for long periods during the day were highlighted as concerns. Further to this, the situation of patients at home without any resident care giver, were emphasised as the most vulnerable scenarios.

‘It’s pretty bad when you’ve got to go next door to get the key to get into someone’s house that might be in the early stages of palliation. Things like that we have had to do so I know that it happens. It’s a whole thing around blinds up, blinds down every morning and if the blind’s not up, I need to go over and knock
on the door to find out whether they’ve just slept in or whether they didn’t wake up, you know, all those sorts of things.’ (Interview 15/ Aged care Liaison nurse)

This key informant described a sad reality for some patients without informal carers managing end of life care home alone. Palliative patients without any family carers were considered by key informants to be a most vulnerable group, at risk for both physical injury and further social isolation.

The concern for patients without close care networks extended to include patients being cared for in facilities without family care givers. One nurse discussed her experience with a typical patient with end stage disease who presented to hospital with an acute condition. Without the availability of family, the option for discharge was not possible and therefore, an acute facility death was considered to be a likely and an ‘unpleasant’ outcome.

‘That scenario with the acute abdomen, with no family, well the medical staff may make that decision given that it’s made on a medical decision... at the end of the day she’s probably going to stay in hospital until she dies. Realistically, it could be very unpleasant given how we don’t always do those sorts of things well in an acute setting because that’s not really what we do, you know.’ (Interview 15/ Aged Care Liaison nurse).

Additional levels of vulnerability were described for socially isolated patients with limited English language proficiency. The palliative care CNC acknowledged the experience of one patient from a non-English-speaking background (NESB), without family, being cared for in an aged care facility despite her wish to return home.

‘Well she had no one except a neighbour ... and she had just been a newly diagnosed ovarian cancer and she was in the Nursing Home and she kept saying I want to go home. So they ... put bed rails up so she couldn’t get out of bed and then she climbed out of bed and then she had a fall. And she deteriorated and died quite quickly and in that space of time the neighbour backed off and said “look I can’t make these decisions, I’m just a neighbour” and not one living relative. No one. She was Latvian, or she was from overseas and her English wasn’t great.’ (Interview 5/ Palliative care CNC)

The risks of limited informal care networks are highlighted by this key informant. The nurse emphasised her concern that the patient’s preferences were neither understood nor met in this situation. Additionally, the neighbour’s withdrawal as a decision maker due to concerns about the legitimacy of her role meant that the patient had even less support and advocacy in this context.
Neighbours were a group of informal carers who were described by key informants as filling in some of the gaps for end of life care, when families were absent or the family relations or support were limited. The inclusion of these groups in decision making was considered important for patients who identified them as their carers and several patients in patient interviews described neighbours in this way (16.4.4.2 Opportunities for friends and neighbours). The Aged care Liaison nurse described situations where neighbours were the sole carers, where they ‘were the only contact...checking on the person and checking Webster[medication] packs’ and yet they could be excluded from being involved in consultation and decision making in the patient’s care.

‘... and I think that group is easily excluded because we just have the standard, “you’re not family we can’t tell you anything”, but in actual fact, if that person could talk, they would tell you that that’s the person who I want you to know or tell, or whatever, you know.’ (Interview 15/ Aged Care Liaison nurse).

The involvement of neighbours as support persons and decision makers potentially managed the risks for terminally ill patients without family care givers. The Aged care Liaison nurse discussed concerns for a lack of advanced care planning processes for these patients (Interview 15/ aged care liaison nurse).

**Formal care support**

Several key informants described the availability formal care support in the Mt Druitt community for palliative care patients as inadequate for meeting the care needs. These comments extended the responses from patient and carer interviews, documented previously, which also described insufficient formal care support in the community (6.3.5.1 consistency and discontinuity of primary care).

The palliative care CNS discussed her concerns for the lack of availability of personal care support in the community. She described this broadly and then through a recent example, the experience of a carer with no family support, seeking home care services.

‘...lots of people are elderly and don’t have a lot of support. I was talking to someone this morning who’s trying to get personal care. The man actually is palliative and his wife is elderly and they don’t have family and just trying to access services is hard. She was saying she tried about five agencies and there were just waiting lists. Years ago the nurses would actually go out and provide care but we can’t do that which is terrible. It takes away from us as well.’ (Interview 16/ Palliative care CNS, Mt Druitt).
Workforce changes meant that provision of personal care to palliative care patients was no longer part of the community nurse role. This had an impact on patients and carers and additionally impacted on the nurses’ desire to provide holistic care for patients.

Limited descriptions by patients and carers of the provision of personal care by NGO home care services for palliative care patients were also reinforced by key informant discussion. Key informants described barriers to these services in greater detail. The Palliative care Social Worker discussed her experience of the challenges and futility for accessing ‘home care’ services for personal care.

‘Home Care, if they don’t have a vacancy, they don’t even put you on a waiting list, it’s just the books are closed until they get new funding. So they say, try again in a few weeks if you want.’ (Interview 18/ Palliative care social worker, Mt Druitt).

The options for families without home care services were described as very limited.

‘I always give the families warning and say, look the chances are it will probably just be family caring for them at home or you can pay for private services but they’re expensive. They start at about $35.00 an hour. Mostly I think people just end up bouncing back into hospital.’ (Interview 18/ Palliative care social worker, Mt Druitt)

The end of life care choices for patients and families with few financial and human resources are described here, with a likely outcome for facility admission for patients with limited home care support.

Medical primary care services or GP services to palliative care patients in the Mt Druitt area were maintained by key informants as ‘good’, but they additionally highlighted the increasing demands for service from medical practitioners who were particularly experienced and knowledgeable in the area of palliative care.

‘We have some good GP’s who have the latest thinking but they’ve got a lot of patients.’ (Interview 16/Palliative care CNS, Mt Druitt)

The lack of home visiting capacity for GP services in the area was also discussed as problematic for palliative care patients who were no longer able to attend clinics.

‘I would like to say that we desperately need a GP who would do our visits. Advanced trainee in palliative care or even a Registrar.’ (Interview 16/Palliative care CNS, Mt Druitt)
The palliative care CNS designated to the Mt Druitt area found this lack of service provision for her patients most concerning and although she acknowledged some intermittent medical support from palliative care services, she thought this should be improved.

Key informants considered that the limits of informal and formal care networks which included family care givers, neighbours, community nursing services, home care services and GP services, underscored the vulnerability of this group for care at the end of life. The concerns for limited care networks reinforced the outcomes from patients and carer interviews but additionally broadened understanding of the impact of these care outcomes for this disadvantaged palliative care community.

**16.5.3.2 Margins of financial resources and inequity**

The margins of financial resources and inequity for patients in the Mt Druitt area were described by key informants in response to questions from the interview guide on affordability and equity issues. Responses for financial concerns reflected many of the cost concerns raised by patients and carers in the patient and carer interviews (16.4.2 conditions of economic challenge). Loss of income, longer term care costs, limited benefit uptake, medication costs and funeral costs were considered to be the main financial concerns and within these particular concerns for equity outcomes in this population. Key informants described the impact of income loss in this population and in particular described concerns for younger patients.

**Income loss**

The palliative care CNS from Mt Druitt community health centre was one of several key informants who identified that income loss was particularly dramatic for younger patients who had financial commitments with young children and mortgages.

‘...there are a lot of young people with cancer and mortgages and kids. A person might be in a very good position and have a very good salary and then they go from that to a disability pension, you know? I don’t know how they cope.’ (Interview 16/ Palliative care CNS, Mt Druitt).

The impact of income loss was described as being widely felt by younger patients and families, particularly if facing loss of both adult incomes following a terminal diagnosis. Income protection insurance, it was highlighted, was rarely owned in this population.
‘Only once can I recall that a young family had some income protection insurance. If one partner is unwell and the other partner’s taken time off to help them.’ (Interview 18/Palliative care Social Worker, Mt Druitt).

Accessing superannuation to manage the loss of income was considered to be a prolonged process. Limited employer support for carers taking time off work was an additional challenge.

‘I mean accessing Super takes time and then they have pressure from work. I don’t know how people cope. There’s not a lot out there for people.’ (Interview 16/ Palliative care CNS, Mt Druitt)

Younger palliative care patients and families were considered to be particularly vulnerable to financial pressures because of significant income loss and larger and ongoing financial commitments associated with greater consumption demands for these groups.

**Longer term care costs and inequity**

The financial impact for patients needing aged care placement and their carers were recognised and reported by key informants in interviews and these outlined other distinctions of limited financial resources in this population. The palliative care social worker reported co-payment cost concerns for palliative care patients requiring longer term care in an aged care facility. The significant income loss for couples in receipt of the aged care pension represented co-payment fees of 85% of a single pension.

‘It can be (an issue) if they’re on pensions and you’re losing half your pension. When they go into nursing homes their rates drop separately and they go on to single rates but the single rate doesn’t really go up to compensate as they still have to pay rates, rent, bills, even though they might reduce a little bit. So there’s an impact there, there’s a shortage there.’ (Interview 18/ Palliative care Social Worker, Mt Druitt).

The loss of pension income for this group was such that they were financially disadvantaged by needing longer term palliative care placement.

The Aged Care Liaison nurse identified equity concerns for the availability of concessional longer term aged care beds for patients without assets. The increased demands for these beds in a lower socioeconomic area meant that patients with longer term palliative care needs, were often required to relocate out of their community to access these beds.

‘...having built Department of Housing in special areas... might have been well and good while everyone was young, well it was never well and good ....you have concessional beds and they’re the beds for the person who might have lived in the
Department of Housing and so they’ve got nothing to sell. Where do all those people go?...given that most people don’t leave the area that they came from, they can’t. But also given that that’s where your core group of friends or whatever is, or your church is, you want to stay in your area.’ (Interview 15/ Aged care Liaison nurse).

The concerns for equity in accessing concessional beds were further underscored by this key informant with discussion of the potential financial inequity for accessing hostel accommodation, which required bond payments usually held against the equity available in the family home.

‘It’s problematic, but it also may limit your choices because it’s not a standard bond. It’s facility driven. This facility might charge $250,000 bond but this facility might charge a $400,000 bond so I can’t go there even though that facility will give me better care. I can only choose to go here because that’s all [the money] I’ve got’. (Interview 15/ Aged care Liaison nurse)

The impact of long term care placement on income loss and concerns for equity in accessing facilities were highlighted. Accommodation of longer term care needs for palliative care patients limited to aged care facilities in Australia signalled particular levels of disparity for lower income groups.

**Benefit and service uptake**

Key informants reported outcomes for limited understanding of the availability of benefit and service programs by patients and carers in the Mt Druitt area. The Palliative care CNS highlighted that more times than not, patients and carers commented that they ‘never knew’ that services and programs existed (Interview 16/ Palliative care CNS). The Indigenous Liaison nurse described an inaccurate perception that indigenous patients knew of and accessed many government benefits.

‘I actually spoke to somebody this morning and I said that when I first came into this position I was told that Aboriginal people know all the rules and they get everything for nothing and you know, I can honestly say to you that very rarely do people know the services that are out there for them or what they’re entitled to so they don’t know these services are out there and what can benefit them so what they’re doing is not taking their medication regularly because the bill came in and they can’t really afford those.’ (Interview 14/ Indigenous liaison nurse)

The risks for not accessing financial support programs for Aboriginal patient’s also included very limited use of specialist doctor services because of the large ‘gap payments’ for these services. Awareness of benefits programs which covered the costs services certainly made a
‘difference’ to the utilisation of these services for this group. (Interview 14/Indigenous liaison nurse).

**Medication costs**

Costs of medications again challenged affordability. Despite subsidies available for the majority of patients on health care concession cards, there were ongoing cost issues for this group. The Palliative care CNS maintained these issues as problematic and stated:

‘When you have multiple medications... it all adds up and for someone on a pension that’s quite a lot of money (Interview 16/ Palliative care CNS, Mt Druitt).

This nurse also described some practices by GPs that further exacerbated these costs. Some GPs required patients to attend doctor’s clinics weekly, rather than provide an authority script which meant patients were paying the same amount for a weekly prescription as the cost for a monthly prescription.

‘We get a lot of them who will not give authority scripts. They will make people come back every week.’ (Interview 16/Palliative care CNS, Mt Druitt).

The large numbers of medications and changes in doses and prescriptions for palliative patients were considered to increase medication costs for this group. Several key informants described that the burden of medication costs likely contributed to medication non-compliance. The palliative care CNS discussed her concerns for patients who may or may not reveal that they haven’t purchased prescribed medications because of costs.

‘You ask about the pain and symptoms but they’re telling you they’re taking medication but we really don’t know. Sometimes they will be honest occasionally but usually they’re not and you know.’ (Interview 16/ Palliative care CNS, Mt Druitt)

Medication costs were not limited to community settings but costs were also confirmed for patients in aged care facilities. The Aged Care Liaison nurse maintained that often little thought given to costs when prescribing medications for palliative care patients and whether these costs would be prohibitive for patients following discharge to a longer term aged care facility.

*We don’t actually tell you what that might cost you. Some of it will be covered and you might only pay $5.00 but still if it was Hyoscine, Morphine and Maxalon well there’s $15.00 just there and if you’re in a facility those costs do come back to you. (Interview 15/Aged Care Liaison nurse)*
Key informants overall highlighted that pharmacological management was a mainstay treatment of symptoms in palliative care and therefore appropriate access to this treatment, on the basis of affordability, required more careful consideration by governments and health care practitioners of these costs for patients with limited financial resources.

**Funeral costs**

Consistent with concerns raised in patient and carer interviews were descriptions of limited affordability for funeral expenses. These costs were reported as being beyond the financial resources of many patients in the area.

> ‘There are no substantial savings behind them. You know, the wholesale cost of a funeral is around $4,000. Sometimes even Funeral Directors have given them cost-price funerals... I think even if they’ve had warning that it’s going to happen, there’s just not the capacity of savings to support that or buffer that.’ (Interview 18/Palliative care Social Worker, Mt Druitt)

Families would approach the palliative care social worker to discuss options available to manage these costs which included contact with charities, funds from welfare agencies and coming to terms with the reality that they would just have to ‘go for a cheap funeral’. On other occasions, the options were limited to a state funded funeral or a destitute funeral which occurred ‘a fair few times a year’ for a variety of scenarios.

> ‘They might have family, but they may be estranged or the family will say, I can’t afford to pay...Or it could be that they’re isolated. We had a man recently, I think he’d come out from prison a few weeks ago because of his physical condition and went to stay with an old friend and had planned to donate his body to science but never got around to that but that was the plan. But he hadn’t organised anything and so she was left then to scramble and say, what do I do?’ (Interview 18/Palliative care Social Worker, Mt Druitt)

The *margins of financial resources and inequity* described by the key informants considered the limits of financial resources for lower socioeconomic groups and how this impacted on sustainability in costs of living, affordability of medications and funeral expenses. Additional concerns for equitable access to longer term care services were described.

**16.5.4 Negotiating the system**

Key Informants described the experience of patients and carers accessing services for end of life care which highlighted their outcomes for *negotiating the system*. Key informants described the features for patients and carers negotiating the specialist palliative care services
in the community and the specialist inpatient unit and the acceptability of these services for this group. The concepts describing this theme are *getting in* and *understanding the system*.

### 16.5.4.1 ‘Getting in’ to palliative care services

Access to palliative care services for patients and carers were described by key informants in response to questions from the interview guide for accessibility and availability. Analysis of interviews with key informants revealed that there were barriers to accessing palliative care services which were identified as the concept of *getting in to palliative care services*. Key informant interviews expanded on access issues described by carers, in patient and carer interviews (16.4.6.1 *Referral conditions*) as they considered challenges from the system’s perspective.

Several key informants described limitations of palliative care as a referral based system. Some of the reasons for limited referral were considered to be driven by referral teams who failed or declined to make referrals for patients. The Indigenous liaison nurse described the challenges of a referral system which was inconsistent in its referrals to specialist palliative care services.

> ‘It depends on the referral system here. That’s my biggest issue. This lady yesterday has been referred because she had her toes amputated and nobody has done anything about the fact that she’s got cancer. Nothing was done to address that. Some wards are really, really good at it and some are not and so sometimes people just literally fall through the cracks and that’s really hard, especially if people are starting to become almost end-stage by the time you get to see them and they’re getting symptoms.’ (Interview 14/Indigenous Liaison nurse)

The palliative care CNS for Mt Druitt described limited referral to palliative care from medical and or surgical teams following discontinuation of treatments. These patients were described by the nurse as being ‘in limbo’, not receiving treatment or palliation of symptoms (Interview 16/ Palliative care CNS). The risks for patients without timely referral to palliative care were considered to be poorly managed symptoms and gaps in management of care.

Other reasons for limited referral to palliative care services were determined by barriers within the specialist palliative care service itself which described particular barriers for patients with non-malignant disease. Getting in was easy if patients had a cancer diagnosis (Interview 5/ Palliative care CNC). Patients with no-malignant disease tended to have less defined access to specialist palliative care services and one key informant commented that gaining access to specialist inpatient beds for patients in the community was significantly ‘dependent’ on the patient’s diagnosis.
‘It depends. It depends if they have a malignancy or not... There are others who have end-stage liver disease or cardiac failure and we actually have to take their case to the meeting and plead their case.’ (Interview 16/Palliative Care CNS, Mt Druitt)

This key informant described the process of putting forward the case for patients with non-malignant diseases, having to confirm that these patients and carers had a clear understanding of the goals of palliative care and that patients were essentially in the end stage of their disease. This confirmed additional processes for patients with non-malignant disease to gain access to specialist palliative care services. Some key informants perceived that the limited resources of specialist palliative care services were considered to constrain access in particular for this group because of a perception that this group might overburden the service. The palliative care CNC discussed the potential for broadening the service to meet the needs of other illness groups as potentially ‘opening up a minefield.’ (Interview 5/ Palliative care CNC)

Barriers to service provision within the system were described. The palliative care CNS commented on the necessity for patients to be ‘known’ by a particular palliative care doctor for referral to proceed adequately.

‘A fellow was telling me yesterday who is under an oncologist, now he’s been seen by palliative care but there was nothing in the discharge summary who he was seen by ... Who’s going to claim him if there’s an after-hours call at night. He’s clearly palliative.’ (Interview 16/Palliative care CNS)

The lack of continuity and referral based system identified multiple barriers of access to specialist palliative care services. The outcomes for patients being delayed in gaining access to these services because of the complexity of referral processes and having limited pathways to access because of a non-malignant diagnosis were highlighted. The risks for limited access to specialist services in this lower socioeconomic population are likely more pronounced given limited informal networks of support, which normally engage advocacy in a system to overcome such barriers. The limits of informal networks for advocacy were discussed previously by key informants (see 6.7 situations of vulnerability).

16.5.4.2 Understanding the system

Acceptability of palliative care services was described in patient/carer interviews (6.3.6.2 Aspects of acceptability) with participants reporting positive and open communication and engagement. Key informants responses to questions on acceptability highlighted broader issues involving comprehension, communication and language. Analysis of interviews with key
informants revealed problems for patients and carers understanding and communicating in palliative care services; that is, **understanding the system**. Key informants consistently described the impact of limited health literacy in interviews.

The Indigenous liaison nurse described the experience and impact of limited health literacy for Indigenous people with advanced disease. Having a ‘really poor’ understanding of disease process meant that for this group of patients, hospital was often a very frightening place to be.

> ‘When they’re in a hospital situation they don’t understand what’s going on with them. Their understanding of their disease process is really poor and they get very frightened and they just want to go where they feel safe and that’s home.’ (Interview 14/Indigenous Liaison nurse)

This nurse additionally described an encounter with one patient who was having difficulties understanding questions posed in a routine health assessment. The patient revealed to the nurse that she was illiterate and requested that the nurse explain things more simply.

> ‘... she said to me, I’m illiterate, I can’t read or write, could you just use words that I can understand and I thought that was really brave of her to say that because normally they won’t say anything, they just leave it and they don’t understand what you’re talking about.’ (Interview 14/Indigenous nurse)

This key informant felt that patients with limited levels of literacy were generally unlikely to disclose this issue to health care providers and this posed risks for patients. The Indigenous liaison nurse raised these concerns in interviews highlighting that patients with limited literacy often lacked understanding of important health information and outcomes because ‘they’re the ones who don’t ask’.

Other key informants described the complexity of health information and the barriers this posed for patients and carers understanding of health, health care needs and treatment and care programs. The complexity of health information was seen to further compound difficulties in understanding the ‘language’ of health discourse and communication. Palliative care was also considered to have its own language.

> ‘I think a lot of it is their lack of understanding of the terminology that we use. I think that’s the biggest thing. I think the language is different and is more complicated.’ (Interview 16/Palliative care CNS).

The palliative care social worker described the shift in health knowledge that patients and carers had to make when transitioning to palliative care and that this new ‘concept’ of
palliative care was not well understood because it was distinct from the language of other health care domains.

‘Some people just aren’t [able to understand] and they go home and won’t take their medicine and really have no concept. I think that Palliative Care is a whole new concept for people even if they’ve had other conditions because it’s a different world really.’ (Interview 18/Palliative care Social Worker, Mt Druitt)

The complexity of health language also meant that negotiating appropriate care for a terminally ill patient within the healthcare system was also difficult. The aged care liaison nurse described the challenges of implementing advance care plans for patients in an acute care facility. She explained that ability to make informed choices about treatment options with limited health knowledge was likely to be very difficult and ‘if you were just Mary Smith from this community, you wouldn’t be able to negotiate through that.’ (Interview 15/Aged Care Liaison nurse)

The aged care liaison nurse summarised some of the key issues of the experience for palliative care patients with limited literacy in the health care system.

‘It’s all that education and understanding, health literacy and all those sorts of things. That makes it difficult given that you might have someone who doesn’t understand much of what the doctor said who would be well educated. Health language is difficult for anybody but obviously for someone who is illiterate.’ (Interview 15/Aged Care Liaison nurse)

The large population of patients from a NESB in the Western Sydney area likely prompted several key informants to describe particular difficulties for English language comprehension for these patients and carers. Limited use of interpreters and lack of interpreter availability was highlighted as being commonplace in both facility and community locations of care.

‘This concept of if you talk louder or yell at someone, you don’t need to use an interpreter because it works better and is less time-consuming. So I think it’s about having access to the appropriate people like the interpreters and all that sort of stuff because we have a big NESB population.’ (Interview 15/Aged Care Liaison nurse)

One key informant, a palliative care nurse, pointed out the difficulties in identifying limited health literacy for patients and carers from NESB who spoke English ‘well’, but demonstrated limited comprehension of health information.
‘I think it’s a really big issue, especially in my experience, with the clients...they speak English quite well but their comprehension is just not there and they come out from appointments not understanding what was actually said... I spoke to a lady the other day where Arabic was her first language but her English was very good but she didn’t understand. She actually had to read it to her son. I hadn’t booked an interpreter for the day as I was told she spoke quite good English.’ (Interview 16/Palliative care CNS)

Key informants described the risks for individuals with limited health literacy and their difficulties in recognising poor health literacy in this population. The margins of health literacy for this population were affirmed in key informant interviews with discussion on limitations for basic health literacy, to more critical interactive health literacy skills which enabled decision making in a complex healthcare system. Palliative care was described as having its own unique language and health communication demands which required capacity in the service to communicate complex medical information in an understandable manner.

16.6 Conclusion

Interviews with key informants described the experience of end of life care for a lower socioeconomic population in a broader context to patient and carer descriptions, but generally, reinforced many of the outcomes of limited social and economic resources for this group. Key informants reported findings for supportive and enabled care networks of larger, organised and engaged informal care networks. The risks for patients and carers with small or absent close informal care networks and reluctance to seek community support contrasted these enabled networks. Poor health literacy and literacy outcomes within complex health care and palliative care contributed further to risk for this population. Limited availability of formal primary care services, and inequitable access to longer term facilities and specialist palliative care services were reported by key informants and contributed to levels of vulnerability of a lower socioeconomic population at the end of life.

16.7 Chapter summary

The demographics of the patient and carer participant group reported markers of lower socioeconomic status for income, education and employment and homogeneity for place of birth language and limited spousal support. The social and economic tools reported outcomes of low wellbeing, particularly for health and community connectedness. Physical, daily living and psychological needs for patients were reported by patients and carers alike. A quarter of the patient groups indicated outcomes for evidence of low health literacy. Spending or consumption of goods and services was low with spending on essential daily items and
healthcare costs were consistently reported. Informal networks of care giving were reported as mainly family with limited community engagement. Low levels of community trust, yet reasonable levels of engagement with persons in political positions were reported.

Qualitative outcomes for patients and carers described the experience for limited social and financial resources. Social, community and social policy (public housing) outcomes defined distinct contexts for social isolation, limited community trust and inequity for this group. Some elements of community engagement described by participants suggested capacity to balance outcomes of disadvantage. Formal and informal care networks for care giving were overall limited for patients and carers.

Key informants described the experience of end of life care of this socio-economically disadvantaged population from a broader context of limited social and economic resources. The limits of these resources supported outcomes for vulnerability to financial hardship, risks for poor health literacy and literacy outcomes and inadequate informal care contexts. The lack of formal support by primary care providers and limitations of specialist palliative care service access constrained other essential networks of support for this population.

The following chapter presents the semi-structured interview findings reflecting appropriateness, acceptability and feasibility of the self-report tools used to evaluate dimensions of social and economic need and capacity for patients and carers.
Chapter 7

Review of Self-report Tools

17.1 Introduction

As outlined in earlier chapters, investigation of social and economic dimensions is limited in palliative care populations. Undertaking effective and rigorous research in this area is dependent on valid and reliable patient reported outcomes for palliative care populations (Granda-Cameron et al. 2009; Parker & Hodgkinson 2011). Beyond psychometric evaluations, assessments of acceptability, feasibility and appropriateness of these tools can and need to be investigated. The aim of this chapter is to address research objective three:

3. To describe the acceptability, feasibility and appropriateness of self-report tools for capturing wellbeing, consumption, health literacy, social capital and palliative care needs and capacities in this same lower socioeconomic population.

As discussed previously the small sample size used in this study preclude psychometric analysis of validity and reliability. As part of this investigation, instruments to assess wellbeing, consumption, health literacy, social capital and palliative care needs was undertaken. The highly emotive issues for research in end of life care are well-noted and many ethical review panels go to great lengths to avoid distressing participants (Cassarett, Knebel & Helmers 2003). Using tools to evaluate dimensions of social and economic need and capacity in terminally ill lower socioeconomic populations must therefore be both specific to measuring these elements and also sensitive to the particular risks of vulnerable populations to burden and distress (Liamputtong, 2009 #204).

This chapter will report on the appropriateness, acceptability and feasibility and implications for further research for each of the self-report tools (Personal Wellbeing Index, NAT: PD-C palliative care needs assessment tool, REALM-R health literacy tool, consumption survey and social capital questionnaire used in this study. As outlined in Chapter four (see 4.13.3), appropriateness considers whether the tool is appropriate to the research aims. Acceptability and feasibility reflect the suitability of tool completion for participants and researcher (Fitzpatrick et al. 1998).
17.2 Personal Wellbeing Index (PWI)

17.2.1 Personal Wellbeing Index: appropriateness outcomes

The PWI elicited response domains which were appropriate for understanding wellbeing for patient participants in this study. In particular, responses and scoring for ‘achieving in life’ demonstrated the importance of this domain for wellbeing and how integrated it was to relationship needs. Responses to the PWI item ‘How satisfied are you with what you are achieving in life’ elicited responses and scores from several patients which framed what was meaningful for them. Several participants initially dismissed the question believing it irrelevant, but then answered in the context of relationships and reported a high score for the domain. One patient stated ‘I’m not achieving very much at the moment.’ and then considered her relationship with her children and replied: ‘Yeah I’m satisfied I’d give it an 8’ (Interview 9, Patient). Another patient stated that she was achieving ‘nothing’ and then quickly recounted the value of new friendships in the palliative care unit and decided to ‘give it a big 10’ (Interview 10, Patient). The relevance of the ‘achievement’ PWI question for these patients described affirming outcomes; however, the same question also elicited responses of meaning and achievement for other participants which highlighted deficits. One patient responded to the question by describing a lack of achievement in not having had children in the past and gave a score of 4, stating that not having children was the ‘biggest’ issue for him to come to terms with at the end of his life because relationship with family had always been important (Interview 6, Patient). The patient’s responses highlight the utility of exploring questions for meaning of concepts such as achievement in this population group and how important family and social connections were for wellbeing.

Some of the terms used in the PWI were considered by patients to be somewhat incongruous with their terminal illness and included the words ‘health’ and ‘future (safety)’. Comments such as, ‘what health?’ and ‘I don’t have a future’ demonstrated limits of acceptability of these domains of the PWI for this population group. Other patients in the study scored these items above neutral and did not comment that the terms were irrelevant to their circumstances.

The complexity of community engagements and personal relationships meant that patients found it difficult to give a single score for diverse elements. One carer commented about the question for personal relationships ‘which ones...they’re different’ (Interview 12 Patient). Despite the difficulties for patients in reducing the complexity of items in this tool to a single score, they were able to give an overall score for these domains. The nature and complexity in
relations and networks were further described by other self-report tools in this study and highlight the challenge of describing these outcomes with a single numerical score.

The outcomes of wellbeing for 'spirituality or religion' in this study likely supported previous results that this domain demonstrated limited contribution to wellbeing measures in Australian populations (2006). Patients who discussed low or no interest or engagement in spirituality or religion consistently gave scores of (neutral) five and yet one patient who described satisfaction with this domain also scored a five; ‘I’m happy with that put down a 5 (Interview 6, Patient). Other patients who had strong religious or spiritual affiliations gave high scores. One patient gave a score for this wellbeing domain which appeared to reflect both denomination (membership) and non-attendance; ‘Church of England I am...Well about a six. I don’t go’(Interview 7, Patient). The appropriateness of the spiritual and religion wellbeing domain in the PWI was therefore limited in this study population.

17.2.2 Personal Wellbeing Index: Acceptability and feasibility

The completion of the PWI demonstrated acceptability for ease of completion. Patients appeared confident completing the 11 point (0-10) end defined response scale describing similarities with pain score scales for which many were familiar. The tool demonstrated ease for verbal administration and was completed by patients in less than five minutes. Feasibility of the PWI was demonstrated with ease of recording and reporting single item outcomes.

17.2.3 Implications for research and clinical practice

Overall, the PWI indicated reasonable appropriateness, acceptability and feasibility in this patient group with the exception of the use of the terms health and future, and the limited contribution of the spirituality or religious domain for describing wellbeing outcomes in this area. The ease of completion and short completion time of the tool for this group was important due to their level of ill health. The value of measuring wellbeing domains broadly provided valuable information for understanding personal need and capacity in this patient group. The use of such a generic wellbeing assessment tool is particularly helpful in enabling comparison of outcomes for wellbeing with other groups in health and the general populations. Understanding how the needs of this study population are situated in relation to other groups has important implications in comparing research outcomes for wellbeing and identifying interventions to address needs.
17.3 Needs Assessment Tool: Progressive Disease- Cancer (NAT:PD-C)

17.3.1 Needs Assessment Tool: Progressive Disease- Cancer (NAT:PD-C): Appropriateness

The NAT: PD-C demonstrated appropriateness for capturing palliative care wellbeing concerns and within the tool items, wellbeing concerns for financial and legal issues. The patient participants reported particular concerns for unresolved symptoms, daily living activities and psychological concerns in completion of the tool. The circumstances of advanced disease and functional impairment demonstrate that these concerns for wellbeing are not unexpected and therefore, the tool is likely appropriate for measuring these important dimensions of wellbeing in this population.

The symptom and physical needs captured by the tool were fundamental to wellbeing outcomes for patients and were represented by patient comments for symptom and physical needs that specified the impact of these needs on wellbeing. One patient stated that his concern for physical needs were significant because he found it ‘embarrassing’ to seek assistance with personal care and that he no longer ‘had a sex life’ (Interview 13, Patient).

Other comments made by patients during tool completion qualified the appropriateness of the tool for capturing financial need. A patient with significant financial concerns stated that he had some concerns for financial and legal issues because of trouble in affordability of some items (Interview 6, patient). Other patients reported concerns (some/potential) for financial and legal issues that related to their anxiety about wills and funeral costs.

Low scoring for wellbeing needs for spirituality and existential issues may not have represented low wellbeing concerns for this domain, but likely demonstrated descriptions of low reliability of the item discussed previously in Chapter Four (4.6.2). Low concerns for spiritual and existential issues were described by patients who also described issues of psychological symptoms which were related to concerns for having advanced incurable disease. The low reliability of this item therefore limits the appropriateness of the content of the NAT: PD-C tool for questioning the area of spirituality and existential issues.

The wellbeing outcomes of the ability of carers to provide care identified that there were reasonable concerns for this participant group in this area. These outcomes demonstrated particular concerns for patients’ physical symptoms which were consistent with patient concerns for unresolved physical symptoms outlined in Table 16.5. The NAT: PD-C (care giver ability) tool appropriately captured content for caregiver wellbeing related to care giver ability.
Care giver wellbeing outcomes indicated consistent concerns across the group for their own wellbeing and were qualified by semi-structured outcomes which identified interrelated concern for patient needs. Carers commented that their experience of wellbeing problems (physical, practical, spiritual, existential and psychological) were because of care giving concerns, physical needs for patient personal care, fear of patient falls, and the ‘physical stuff’ of care giving (Interview 7, Carer). The NAT: PD-C demonstrated general low wellbeing outcomes for this carer group that were integrated for particular concerns for patient physical and practical needs. The NAT: PD-C captured outcomes which were significant to the experience of caring for someone with a terminal illness.

17.3.2 Needs Assessment Tool: Progressive Disease- Cancer (NAT: PD-C): Acceptability and feasibility

The NAT: PD-C tool demonstrated ease of completion when administered verbally to patient and carer participants. Patients and carers required some questions to be repeated to enable understanding. Overall, this tool had a completion time of approximately five minutes and less when a carer was the only respondent. Patients and carers did not express difficulty with the language used in the tool. Feasibility of the tool was good in respect of ease of recording and reporting single item responses.

17.3.3 Needs Assessment Tool: Progressive Disease- Cancer (NAT: PD-C): Implications for research and clinical practice

The NAT: PD-C demonstrated appropriateness in capturing palliative care wellbeing needs, which are important concerns in a study of this population. The tool captured a range of symptom, daily living, psychological, financial and care giving needs which were necessary to understand specific needs around health outcomes and care giving for this group. These outcomes contributed to understanding of the specific elements of palliative care wellbeing. The inclusion of the financial and legal domain was most appropriate for a study of a lower socioeconomic population for whom financial resources were likely limited. The NAT: PD-C, is an appropriate and acceptable tool for inclusion as a measure of palliative care needs in this population as research informed by outcomes from patient and carer perspectives is increasingly important. The NAT:PD-C was created for use in clinical practice to assess need for specialist palliative care referral. The tool demonstrated measurement of factors significant to the experience of end of life care and caring for this study population. This demonstrates good application for use as a research tool in this group.
17.4 Rapid Estimate Adult Literacy Medicine- Revised (REALM-R)

17.4.1 Rapid Estimate Adult Literacy Medicine- Revised (REALM-R): Appropriateness

Health literacy is an important element of social determinants of health demonstrated the importance for inclusion of this tool in the study (Nutbeam 2008). The REALM-R tool measured risk of inadequate health literacy in carers and patients. The completion of the item in one patient demonstrated that measurement of literacy was also captured by the tool.

17.4.2 Rapid Estimate Adult Literacy Medicine-Revised (REALM-R): Acceptability and feasibility

The REALM-R tool demonstrated the acceptability for timeliness of completion with completion times for the tool of less than one minute. The outcomes of distress in completion of REALM-R tool for patients and carers had limited description from this study as participants were not specifically asked questions about distress in completion of the tools. The risk for distress in the measurement of health literacy (and literacy) was not understated in this study and processes to ensure this distress was avoided were discussed in Chapter Four (14.13.1).

Semi-structured interview outcomes for completion of the REALM-R demonstrated some differences in responses to completion between those patients and carers who reported adequate health literacy and those that didn’t. Several patients and carers who completed the test correctly, commented that they were aware that they had done so. One of these patients in particular smiled on correct completion of the tool and affirmed correct responses by stating ‘well I have had all of those’ (Interview 19, Patient). All patients who made errors in completion did not make comment on the test or outcomes. These differences potentially demonstrate awareness of the outcomes for tool completion and whether this caused distress to participants who made errors in pronunciation is not known.

Two patients potentially confirmed some concerns for distress in completion of the REALM-R tool highlighting potential limits for acceptability of the tool. One patient with adequate health literacy questioned at the end of the interview whether the REALM-R tool had in fact tested literacy and also wished to know the outcomes of the assessment. Another patient demonstrated outcomes for illiteracy; was unable to pronounce any of the words on the list including the three common words (fat, flu and pill) which are included in the tool to develop confidence in the respondent, prior to health literacy assessment. This patient had consented to the study having been informed that there was a short reading item, and appeared to read the participant information sheet and consent form.
The REALM-R tool demonstrated feasibility for completion. There was ease of completion with reading of the items achieved by the large print; font size of 18. Simple scoring of outcome for two items, ‘at risk for health literacy’ and ‘not at risk for health literacy’ demonstrated ease of collection and processing for the researcher.

17.4.3 Rapid Estimate Adult Literacy Medicine-Revised (REALM-R): Implications for research and clinical practice

Measurement of health literacy in lower socioeconomic populations is important to understand the risks for limited literacy for health knowledge and communication and how these circumstances can be improved (Paasche-Orlow & Wolf 2010). Identification of patients and carers with potential literacy problems is an imperative for a patient-centred health care domain such as palliative care and requires exploration of these outcomes in a population most vulnerable to limited health literacy outcomes. The application of the REALM-R tool in a small lower socioeconomic palliative care population demonstrated appropriateness for assessing risk of health literacy problems and also feasibility in application of the tool for timeliness, ease of completion, collection and processing.

Issue of literacy were challenging for some participants. The REALM-R and other health literacy assessment tools are linked closely with literacy outcomes (Nutbeam 2008) and therefore, the potential for the tool to be perceived as a literacy measure is to be noted for application of such a tool in research and clinical practice. Sensitivity to the stigma for literacy and health literacy problems must underscore the application of health literacy measures in research and clinical practice and is highlighted in the outcomes of this study.

17.5 Consumption survey

17.5.1 Consumption Survey: Appropriateness

The consumption survey is a single consumption (spending) assessment for household expenditure for daily living items and health care expenses. The survey demonstrated appropriateness for capturing outcomes for expenditure, limits of expenditure in this study population, and was easily adapted to include health care expenditure items appropriate for application in this study.

17.5.2 Consumption Survey: Acceptability and feasibility

The consumption survey demonstrated overall ease of completion by participants, being completed in approximately 5 minutes. Completion of fields for daily living items in the Consumption Survey was achieved with ease by participants with the single exception of
estimating weekly grocery expenditure. Difficulties in calculating grocery expenditure were described by the majority of participants in the study and two participants (one patient and one carer) were unable to give an amount for weekly grocery spending. The response to the question for weekly expenditure on grocery items elicited responses such as ‘It varies’ (Interview 7, Carer), ‘I don’t know, that’s really hard.’ (Interview 10, Patient), ‘I don’t know it’s hard to tell’ (Interview 6, Carer), ‘I wouldn’t have a clue’ (Interview 13, patient) and ‘I don’t know, how much do you spend?’ (Interview 11, carer) One carer justified these difficulties by explaining that he shopped intermittently and only when he could get respite care for his wife. Other participants described small and inconsistent expenditure on grocery items and therefore these costs were potentially not obvious and difficult to quantify.

Feasibility of the Consumption survey for ease of processing by the researcher was somewhat complex with multiple item recording required.

### 17.5.3 Consumption Survey: Implications for research and clinical practice

The measurement of consumption outcomes supported broader understanding of the implications of economic capacity for persons with limited income and wealth. The Consumption Survey demonstrated reasonable acceptability and feasibility with the exception of some limited responses to the question for grocery costs. The application of a consumption survey in a lower socioeconomic health population demonstrated important knowledge of spending and non-spending which captured the range of expenses for this group for essential items and non-essential items. The economic impact of illness and care giving is reasonably well described in the literature but understanding of more specific consumption outcomes for patients and families provided greater detail of financial need which can be addressed more specifically. The application of such a Consumption Survey in research and clinical practice will capture outcomes that can describe gaps in healthcare and welfare funding and therefore, can drive change in policy.

### 17.6 Social Capital Questionnaire (SCQ)

#### 17.6.1 Social Capital Questionnaire (SCQ): Appropriateness

The assessment of social capital items was essential to ensure that outcomes for individual, community and government or civic relations and networks were specifically described for the study population. The content of the SCQ captured the range of relations and networks for this population (structural social capital) and described outcomes for community trust, safety and cohesion, and connectedness outcomes (cognitive social capital). The SCQ demonstrated
appropriateness in capturing the extent and quality of relationships, the nature of care networks, connectedness needs and outcomes for civic or government engagement and support which were important elements of the end of life care experience for patients and carers. The resources gained from these relations and networks for practical, emotional, companionship, spiritual, financial and non-income welfare support (housing) were necessary for specific palliative care needs and the broader resources needed for social, spiritual and financial wellbeing. The SCQ outcomes reported complex elements of context for understanding the experience of end of life care in the participant group. It additionally was limited for some response items in capturing the range of complexity in relationships and outcomes for patients and carers in this study.

The inclusion of the item for relationship with pets demonstrated that these relationships had great value in creating resources for companionship, emotional, spiritual and practical support. One patient commented in particular that when she was feeling low her cat often got her out of bed in the morning (Interview 9, Patient). Several participants had needed to give up their pets in the previous 12 months as they had relocated or were unable to manage pet care due to illness. The SCQ item for relationship with pets captured the quality and resources held in this relationship. Semi-structured responses from participants reported the recent loss of these relations for several participants and the sadness this created for some.

The SCQ explored religious and spiritual networks, specifically identifying attendance and support from these groups and organisations. These outcomes for religious and church membership and support captured in the SCQ were distinct from the outcomes for the spiritual domain items captured in this participant group in the PWI and NAT: PD-C. The spiritual, existential and religious responses to the items on the PWI and NAT:PD-C reported inconsistencies between scores and semi-structured responses.

The outcomes of patient and carer scoring of community health organisations for ‘help to do things’ demonstrated that this response item was not adequate for describing hands on support. Semi-structured interview discussion of practical support by community health organisations contended that this support was not provided by these organisations and yet scoring of ‘help to do things’ was a consistent response from participants. The ‘help to do things’ response item therefore demonstrated limited application for describing specific hands on care and likely captured responses for general ‘help’.
17.6.2 Social Capital Questionnaire (SCQ): Acceptability and feasibility

The SCQ took approximately 10 to 15 minutes to complete and although there generally was ease of completion for the questionnaire, the complexity of the tool and language items created some problems for acceptability of completion for a small number of participants. The main difficulties were in quantifying complex social relations and acceptability of language in the questionnaire.

Some participants highlighted that the quality of relationships with family members differed and therefore this posed difficulties in providing a single response to questions such as ‘what is the quality of the relationship with your family?’ One participant replied in response to this question ‘my children or my brothers and sisters... they’re all different.’ (Interview 12, Patient) Broad questions on family relations presented difficulties for some participants to respond specifically. The complexity of community networks as being either local neighbourhoods or wider communities was highlighted by some participants in questionnaire responses, but appeared easily qualified by participants as being either their local or larger community contexts.

Acceptability of language in the SCQ was limited in some areas. Certain anchor terms such as ‘fair’ implied the connotation of fairness which for some participants did not adequately represent the quality of some of their close relationships, ‘I wouldn’t really describe them as fair’ (Interview 7, patient). Another participant requested further clarification of the response item ‘emotional support’ and when operationalised as understanding and caring, he recognised the applicability of the response for his relationship with his brother and replied ‘yeah he (brother) gives me a hug’ (Interview 19, Patient).

Overall, participants in the study described satisfactory acceptability of the questions on the SCQ for reporting the nature and meaning of their relations and networks and did not comment that questions in the SCQ lacked meaningful application to their experience. The exception to this was one carer who was unable to describe community relations because he declared that he did not feel part of a community because of his care giving demands. He stated, ‘...in regards to community, I’m not into it because I can’t get into it. It’s as simple as that’ (Interview 17, Carer). The question for community networks lacked meaning and relevance for this participant.

The application of the SCQ in interviews enabled both specific reporting on individual, community and civic networks and relationships, and more in-depth descriptions of these contexts through semi-structured responses. The application of a mixed method approach for
delivery of the SCQ supported acceptability of the tool for participants as the complexity of question items and social contexts and experiences may have limited response rates because of time burden and/or difficulty understanding and answering questionnaire items.

The feasibility of the SCQ is likely also to be limited by the complexity of the tool. As discussed above, verbal administration of the questionnaire improved acceptability of the tool but will require additional research and clinical staff time. Furthermore, the complexity of recording and multiple item scoring is likely to reduce feasibility of the tool, but was managed by a data processing computer program.

17.6.3 Social Capital Questionnaire (SCQ): Implications for research and clinical practice

The measurement and description of social capital elements in specific health populations remains limited and moreover consideration of these elements in a disadvantaged community is equally limited. The application of a social capital questionnaire in this study highlights that such a tool demonstrates reasonable appropriateness, acceptability and feasibility in such a population. The appropriateness of measuring social capital outcomes in this population has the greatest impact for research and clinical practice as the outcomes and experiences of relations and networks of individuals, community and government are essential to the quality and sustainability of end of life care for lower socioeconomic groups. Participants recognised the value of measuring and opening up dialogue for discussion of close relationships, community networks and community and government resources and they often acknowledged discussing these issues for the first time.

Further research to measure and explore social capital in lower socioeconomic and palliative care groups is warranted and will support interventions for this group from the patient’s perspective which is inhaled and understood in the social context of relationships and community. The inclusion of social capital assessments in clinical practice is important for understanding meaningful elements of social contexts and to ensure that resources can be directed to fill gaps in networks of support. The application of the SCQ in clinical practice is unlikely to be feasible as it currently exists, yet reduction of the items to increase acceptability for clinical practice is possible.
17.7 Chapter summary

The outcomes for appropriateness, acceptability and feasibility of self-report tools were captured in semi-structured interview responses by patients and carers. Importantly, this described whether these tools were able to specifically identify social and economic needs in this group, cause distress in the participant group, and to assess ease of application for researchers.

The semi-structured interview outcomes for self-report tool completion demonstrated overall appropriateness, acceptability and feasibility of these tools for the study population. The PWI demonstrated important content for capturing general wellbeing outcomes and, in particular, for wellbeing in ‘achieving in life’; however complexity of relationship outcomes and language use in the tool presented some problems for acceptability. The NAT:PD-C captured a broad range of palliative care needs of which physical symptoms and activities of daily living were fundamental to wellbeing outcomes for patients and carers. Additionally, the NAT:PD-C tool demonstrated limited capacity for capturing spiritual and existential outcomes for participants. The REALM-R reported outcomes for health literacy problems and also demonstrated some limitations for acceptability, specifically related to the stigma and risks associated with literacy assessment. The consumption survey was effective in capturing consumption (spending) and absences of spending for everyday costs and health care spending. The SCQ captured context of relations for quantity and quality at individual, community and government levels. Some limited acceptability of the survey for relevance of some items and language was demonstrated. The SCQ specifically described the nature of spiritual and religious networks for participants beyond the PWI and NAT:PD-C.

The following chapter presents the discussion and conclusions of this research and details the implications for research, policy and practice, as well as the limitations of the study.
### 17.8 References


International Wellbeing Group 2006, *Personal Wellbeing Index-Adult*, Australian Centre for Quality of Life, Deakin University, Melbourne, Australia.


Chapter 8

Discussion

The findings from this study describe the experience of end of life care for lower socioeconomic groups. The study has identified the concept of *margins* illustrating the boundaries of limited social, economic and care giving resources. This approach has also described the capacities which support and protect against influences of socioeconomic disadvantage. In this chapter, the study findings are discussed in the context of the existing literature. The qualitative and quantitative outcomes are further integrated using the conceptual framework describe in Chapter Three. Structural conditions; conditions of daily living; and bonded, bridged and linked relations and networks necessary for end of life care have been identified. This chapter also discusses the study limitations and implications for policy, practice and research.

18.1 Social and community margins

To date, there has been limited discourse of the broad social (macro) contexts within which lower socioeconomic groups at the end of life are engaged. Macro level influences that support conditions of governance for equitable policy are essential to creating and maintaining support for communities and individuals (Almedom 2005). This study has described these constructs through patient and carer completion of the SCQ and discussion of network and relational elements by key informants. Descriptions of the impact of public housing policy and evidence of political engagement confirmed the importance of these factors at the vulnerable stage of end-of-life. Criticism of the social capital approach as limited for exploration of macro level influences, discussed previously in Chapter Two, were not supported by the outcomes of this study.

The risks for social isolation are most pronounced in lower socioeconomic groups. This group is more likely to be limited in social networks and additionally describe social needs which define the nature of long term limitations in social engagement and exchange (Williams 2004). The literature outcomes in Chapter Two identified the limited descriptions of social and community engagement and social isolation and exclusion in this population were not well described.

A qualitative study by Dzul-Church and others (2010) confirmed the experience of social isolation and marginalisation in a disadvantaged population and found that although this group had lived isolated lives, they ‘did not necessarily want similarly isolated deaths’. 

Understanding the social and community contexts for patients and carers is therefore necessary as community networks were important for connections of trust and social inclusion discussed previously in Chapter Three. The needs for social connection are likely no less important for this group and the results of this study confirm this through patient and carer responses to social needs.

Structural conditions of macro level outcomes, which include the impact of policy and political engagement, and daily living conditions of social isolation and community capacity are outlined and discussed below as they have particular salience for improving care at the end-of-life.

18.1.1 Structural conditions of public housing policy

18.1.1.1 Limited planning of public housing policy

The population profile of participants moving to the Mt Druitt area described both the nature of public housing policy in Australia in the 1960s and the continued capacity of the area to support cheaper housing. Mt Druitt, originally a semi-rural area until the mid-1960s, was developed under the Broadacre public housing program discussed in Chapter 4. Within ten years of the first home being built in Mt Druitt under the program, 9,000 homes with 45,000 residents were housed in the area.

Despite the stated intentions of the Housing Commission, the provision of amenities such as schools, health centres, churches and recreation sites were long held up with disputes over funding of infrastructure (Peel 2003 Pg 48). Mark Peel (ibid Pg 53), in his book based on conversations with people living and working in areas of disadvantage in Australia, described the impact of limited planning in public housing policy in Australia at this time and acknowledged consensus among respondents in his study that disadvantaged groups relocated under the Broadacre scheme were essentially ‘just dumped and left to get on with it’.

The isolation and limited resources of the Mt Druitt area was described by participants in my study, many of whom had relocated to the area three or four decades earlier with young families or as young children. A ‘paddock’ as the area was referred to by several participants likely described what the area looked like, a rural area of large open spaces and room to move. The area was considered distinct from the size and location of the inner western suburbs or inner city where this population had lived previously. These descriptions of the area also reinforced the limited planning of the public housing scheme in creating and supporting infrastructure in the area.
The lack of community, recreational or health services highlighted the sense of isolation. One participant described that her perceived inadequacies of the area was significant for defining her life course experience. She asserted that relocation to the Mt Druitt area was akin to being ‘chucked out in a paddock’; the lack of health and community services in the area impacted so significantly on the outcomes for her family following the death of one of her children decades earlier, that these relationships had never recovered.

The built environment of an area is an important social determinant of health and the ‘soft infrastructure’ of a community which includes access to community services, opportunities for community interaction and crisis services was dependent on relationships between people in the community and the investment of governments (Laverty & Callaghan 2011 Pg 182). The decision to concentrate public housing in the Mt Druitt area also impacted adversely on the resources accessible to this population prospectively. In particular, the concentration of public housing in a small local area placed demands in the area for aged care concessional beds. This meant that demand of these beds went beyond supply, requiring patients to move out of the area to access longer term care facilities for end of life care. A key informant declared her frustration at the failure of the ‘planners’ to consider the longer term health needs of this population.

The concentration of disadvantage in communities has long been seen as problematic and not solely as a concern for the socioeconomic characteristics of individuals within that community. The wider disquiet for the impact of the environment on these individuals over time underscores the inhered aspects of social exclusion in neighbourhoods of disadvantage (Cattell 2001). The effects of poor planning for public housing in the Mt Druitt area decades earlier had longer and immediate term impact for the residents, the effects of which were seen into their end of life care phase. Within this context however, other macro level outcomes defined support for this group at the end of life.

18.1.2 Positive political engagement

Communities of disadvantage often create their own capabilities for managing needs (Cattell 2001). The skills and desire for activism can develop in a context of deprivation and may be driven by the experience of being disenfranchised from other levels of social engagement (Cattell 2001; Peel 2003 Pg 158). Several participants in this study described their experiences of political engagement as actions motivated to maintain, in particular, housing and welfare entitlements. This clearly identified their need to advocate and lobby for support.
Decisions to engage members of local and state government in order to challenge entitlements achieved such positive outcomes for participants that several were confident of ongoing support at this level if necessary. As one patient stated ‘if I needed them they’d be there I know that’. This characteristic for political engagement in this group may have represented a response to disenfranchisement as discussed above by Cattell and Peel. Alternatively it may also have denoted a trend for social activism seen in disadvantaged populations as an outworking of compulsory electoral engagement (compulsory voting) (Scott 2011). It is valuable to note that there is capacity for political engagement to manage social exclusion in disadvantaged groups (Scott 2011). The outcomes for political engagement in this study demonstrated that lower socioeconomic groups at the end of life are not necessarily passive recipients of their political environment and are not limited in their capability for political engagement.

The political environment, in its capacity as being responsive to the needs of these individuals is also equally important and highlights the potential for Australian society as egalitarian. The nature of positive engagement with organisations at the macro level of linked social capital has particular advantages for social cohesion (Lin 2001), necessary for the wellbeing of individuals, communities and societies.

18.1.3 Daily living conditions of social isolation and community disengagement

18.1.3.1 Social isolation

Chapter two identified that the level and experience of social loss and isolation for lower socioeconomic groups is described inadequately in the literature. A qualitative study by Williams (2004) which explored the sociological experience of suffering for terminally ill patients from lower socioeconomic groups affirmed the social needs in this population discussing expectations of social contact within a shrinking social world due to physical incapacity and routines of care and treatment. The social needs for patients and their carers described in this study confirmed margins of social engagement and social contact which were impacted somewhat by limited physical capacities, care needs and through what appeared to be established patterns of limited family and social relations. The expectations or desire for social contact was a priority for many patients and carers, demonstrated by interview outcomes which affirmed connectedness needs for relationships with family and others. Outcomes for wellbeing responses from the PWI reported that meaning and achievement were most important for this group and were intimately linked to relationships and valuable for wellbeing. Participants described limited social engagement for reasons which included;
functional incapacity, the stigma of physical disfigurement or because the experience of social engagement was no longer comfortable or routine. Funk and others (2010) described the reluctance of caregivers to engage socially where there was a loss of social connections due to the intensity of care giving. A carer confirmed limitations in social engagement and loss of community by being unable to answer questions about community engagement because he couldn’t ‘get into it’ due to his care giving role. This experience of limited social engagement and perception of irrelevant community contexts highlighted outcomes of social isolation for this group.

Loss of contact with social networks following inpatient admissions created vulnerability to social isolation for patients with limited family or friendship support. These patients both emphasised and managed this loss by seeking out social contact with staff, patients and visitors within the inpatient facility. Dzul-Church and others (2010) described similar themes in their study for outcomes of social isolation in a disadvantaged population. They found that disadvantaged patients, with limited family and social networks, both yearned for social contact and sought it from care providers and others; these were considered most important connections as they likely represented the last relationships that would be experienced before death. The increased likelihood of a facility death for lower socioeconomic groups is reported in the literature (Decker & Higginson 2007; Houttekier et al. 2009) emphasised the importance of supporting the social needs for this group within an inpatient setting.

Not distinct from the experience of social isolation for inpatients in the hospital were descriptions of social loss for participants who were relocated in the palliative phase of their illness. Recent relocation to the Mt Druitt area from rural areas to access services, and/or from other areas of Sydney to access cheaper housing, adversely influenced the nature and quality social networks for a small number of patients and carers. These participants went on to describe limited social contacts in their new community. Social connections and social cohesion were particularly dependent on length of time in a residence with the creation new networks for friendship and community connections needing to withstand the loss of previous supports (Pearson et al. 2012). This likely posed significant challenge for an ill socioeconomically disadvantaged person. Patients who relocated to new areas during the terminal phase of an illness represented a group with a distinct vulnerability to social isolation.

Broader descriptions of social isolation were also demonstrated in the patient and carer participant group with over half of the participants in this study living alone. One third of participants had limited contact with neighbours and over half described themselves as being
lonely and without someone to confide in (Chapter 6, Table 16.15). Low levels of social and community activity beyond family and close friendship networks described in the previous 12 months likely emphasised established and limited community engagement in this population. Responses to the SCQ for community participation outcomes (Chapter 6, Table 16.14) identified that many participants did not consider themselves to be an active member of a group because they were ‘not interested in’ and/or ‘too busy’ for community membership. Several participants qualified their responses by stating that limited community membership was longstanding due to work commitments and ageing. The outcomes for the PWI for scoring on ‘satisfaction for feeling part of the community’ represented one of the lowest scores for the tool responses with a mean score of 5.3 (Chapter 6, Table 16.4). Limited community or bridged networks and relationships, were confirmed in the social capital literature as more prevalent in lower socioeconomic populations (Cattell 2001; Helliwell et al. 2004; Ravenera & Rajulton 2010). Low levels of community trust and additional pressures of socioeconomic disadvantage on status and material resources were seen to maintain the limited community networks in lower socioeconomic groups (Stephens 2008). Limited bonded networks of family and additionally small numbers of bridge or community networks and relations were described in this study population and further emphasised outcomes for social isolation.

18.1.3.2 Limits for community engagement, trust and cohesion

Low levels of community trust were demonstrated in many of the participants with over half responding negatively to the question in the SCQ, ‘Do you think most people in the community can be trusted?’ (Chapter 6, Table 16.15). Experiences of community engagement and levels of community trust and cohesion cannot be considered distinctly, according to Usher (2007), as the elements were interrelated. The imperative to build trust in communities for the creation of networks or engagement was noted in the literature (Szreter & Woolcock 2004). Patient and carer participants described the interrelation of community trust, cohesion and engagement in their responses contending that community cohesion only appeared to exist in their community because people did not necessarily engage with each other. These closed homogenous networks which described limited engagement in communities defined low levels of community trust (Cattell 2001).

Participant responses for limited community engagement reported concerns for increasing community diversity. The relationship between low levels of community trust and ethnic diversity is described in the literature (Putnam 2009). However, other outcomes for community disengagement suggest that it is in fact higher levels of deprivation in diverse
communities which are more or as likely to impact on low levels of community trust (Deminerva 2012). This evidence suggests complex causes for low levels of community trust in disadvantaged communities and emphasises increased vulnerability of these populations to limited community contexts.

Populations with low community trust (engagement and cohesion) are considered to be more likely to use personal coping strategies and attempt to manage in isolation of community supports (Payne & Williams 2008; Rogers et al. 2008). It is, however, these community (bridged) networks which were considered necessary to support the demands of illness and care giving (Keating & Dosman 2009), enable access to necessary health resources (Szreter & Woolcock 2004) and improve wellbeing (Sarracino 2010). Enabled contexts for care giving described in the key informant interviews included willingness to accept community support. Improving outcomes of community trust is therefore, invaluable for disadvantaged populations to encourage engagement more broadly within communities.

18.1.3.3 Understanding geographical boundaries and place

Social and geographic elements of communities are important for understanding place-based disparities and are considered in descriptions of neighbourhood or community boundaries (Coulton, Jennings & Chan 2012). Coulton and others (ibid), measured perceptions of community boundaries in low income communities finding that longer term residents, groups with higher education and income, and those engaged in community activities, maintained larger community boundaries. Physical impairment, which might be considered pertinent to perceptions of smaller community boundaries, was among other individual variables such as gender and employment status which were not found to impact on the size of community boundaries (Coulton, Jennings & Chan 2012).

Community boundaries were described by patients and carers in this study as generally being small with more than half of the participants having described their community as limited to their local area (Chapter 6, Table 16.15). Participant responses to the question on the size of their community or neighbourhood boundaries were inclusive for the social and geographic aspects. These two elements were often not distinguished as being different by participants. Descriptions of boundaries geographically, as they pertained to the reach of social supports, were provided. One patient described his community as landmarks for his social connections. He stated that his ‘community would be to the shops and down to the village’. Another patient confirmed the large boundaries of her rural community which she had lived in previously and still considered as ‘her’ community; and two participants in the study could describe no
boundary distances at all, because of what they perceived to be poor community relations. Descriptions of community boundaries therefore provided important insights into perceptions of the ‘place’ in which patients were dying and carers were providing care. Tunstall et al (2004), in their glossary of conceptual tools for place and health, defined ‘Place’ not as a description of an area within a context, but as the context itself. Descriptions of community boundaries as ‘places’ therefore provided important insights into what might define the context, and in particular, for a palliative care population, the likely preferences for place of care and/or place of death for an individual. Descriptions of small community boundaries supported the previous outcomes in this study for limited social engagement and community trust. Importantly, community boundary sizes identified implications for activities of daily living for this study population. These boundary descriptions confirmed the experience of community for patients and carers through the relational and physical elements that made up their community contexts.

Patient and carer participants in this study acknowledged the experience of social isolation and affirmed this through descriptions of limited community engagement, low levels of community trust and the absence or limited nature of community boundaries. Social isolation was exacerbated for some participants because of recent relocation to the area and inpatient admission. Understanding of social and community contexts for patients and carers was achieved in a systematic way, mainly through application of the SCQ. Aspects of social exclusion outlined in Chapter 1 (11.2.1.2) defined outcomes of community disengagement and non-participation in disadvantaged groups and although this is potentially a response to incapacity and caring demands in this study population, a lack of community identification was noted to be longstanding and supported by descriptions of loneliness in this study.

18.1.4 Daily living conditions of community engagement

Despite the limitations in social engagement and community group membership and participation for patients and carers, there were some essentially important community network outcomes described in this study. Membership and participation in community or recreation or sports clubs were reported broadly across the group. Limited membership with religious or church groups were also discussed with overall positive outcomes described. A small number of participants highlighted participation with online groups and networks and these identified particular opportunities for community and social connections.
18.1.4.1 **Community Clubs**

Nearly all of the patient and carer participants in this study described community recreation or sports club membership. Three quarters of participants described attendance at their local community recreation or sports club in the previous 12 months (Chapter 6, Table 16.13). Other participants who described non-attendance indicated that they had current membership for these clubs. The community or recreational club demonstrated a ‘community hub’ function for participants. Many described membership of these clubs as meeting places with family or friends; used restaurant facilities for cheaper meals and had a little bit of ‘social activity’. Community clubs supported mainly bonded networks of close relations but the potential for stronger community connections of bridged networks were evident. The broad membership and the nature of these clubs as local community networks demonstrated this capacity. These findings were overall consistent with those of an Australian study of licensed club use of older persons by Simpson-Young and Russell (2009), who identified that club use, predominantly for working class persons extended limited financial resources (cheaper meals, food raffles and entertainment); enabled entertainment in an appropriate environment (air-conditioned, safe and well appointed); and supported connections with the local community. Community clubs were described as having great capacity to extend social engagement for ill and disabled patrons and needed to be considered more as a resource for people in disadvantaged communities (Simpson-Young & Russell 2009). The possibilities for club membership to support a disadvantaged palliative care population are highlighted but require active engagement of these organisations to connect with the needs of this group.

18.1.4.2 **Religious and church groups**

Membership to a church group for participants represented the only other community group which had reasonable and active membership in the previous 12 months (Chapter 6, Table 16.13). Patients who described positive church membership discussed receiving a broad range of support from this group (Table 5.10). A key informant also described positive outcomes for patients and carers from religious and church groups in the area, for a range of practical and spiritual needs. The challenge of evaluating spiritual outcomes demonstrated in the PWI and NAT: PD-C have been described in Chapter Seven. Participants did not describe satisfaction or engagement with religious or church groups. The lack of engagement with these organisations did not necessarily equate to a lack of importance for these organisations (Kub et al. 2003) The outcomes of SCQ questions and semi-structured interview responses for these items however identified specific outcomes for the quality of relationship and engagement episodes with
religious groups that may have otherwise have been missed. The value of religious and church membership is dependent on the nature of the religious group for being exclusive or inclusive for members (Maselko, Hughes & Cheney 2011). Importantly, membership has demonstrated higher levels of social capital in communities (King & Furrow 2004) and in particular, important outcomes for disadvantaged groups as supportive environments to meet a range of needs (Maselko, Hughes & Cheney 2011). The capacity for religious and church group to meet needs of lower socioeconomic groups with faith contexts is highlighted in albeit, the limited outcomes of this study. Some unrealised potential for these religious and faith community connections is noted when they are described within a social capital framework of structural (networks) and cognitive (quality) social capital elements.

18.1.4.3 Internet and social media connections

The use of the internet to connect with known relations and to create new relations and networks described important capabilities of these technologies for social engagement for a small number of patients in this study. Two participants, who had recently relocated to the area, described using the internet to make and sustain social relations through Facebook and Blog sites. Internet and social media maintained and achieved connections with a wider community of persons with similar health and social needs that otherwise would not have been possible. These networks additionally enabled these participants to both receive and provide support within this context. Literature reporting outcomes for the use of the internet and social capital continues to emerge, but has already described some important outcomes for bridging networks. Studies that described the outcomes of internet and web group participation found that these connections had the capacity to enhance self-esteem (Steinfield, Ellison & Lampe 2008), create levels of advocacy and trust (Radin 2006) and were most appropriate for health populations. Importantly for this population these web connections were not limited by the constraints of time, location or physicality (Viswanath 2010). Lowered perceptions of loneliness and increased perceptions of social support were identified as positive outcomes for internet group connections (Shaw & Grant 2002). Web-based networks demonstrated the potential to limit levels of social isolation and create capacities for support and engagement with wider community networks for participants, who were likely, not possible otherwise.

18.1.5 Conclusion

The structure of the social environment and the nature of social isolation and exclusion in this study population outlined important contexts for understanding the experience of end of life
care in a lower socioeconomic group. Elements which shaped the experience of social isolation for this study population included broad socio-political contexts for the impact of poor public housing policy on end of life care outcomes; community contexts of limited networks and trust which defined limits of community engagement. Additionally individual contexts for loss of social roles and networks through illness, relocation and care giving were demonstrated. Social and community contexts also maintained social inclusion elements in this population. Participants described reasonable levels of positive political engagement to achieve housing and welfare entitlements; community club membership as a local community and social resource; and some positive outcomes of religious group membership for a range of needs. The use of the internet and social media to connect to a wider community and support existing and new social and community connections highlighted another capacity for social engagement for this group.

18.2 Economic margins

Limited affordability for medical and other health care costs for lower socioeconomic groups at the end of life was described in Chapter Two. Financial uncertainties and requests for financial support were requested by some patients highlighting ongoing financial issues into the palliative phase of illness. Difficulties sustaining care and treatment costs (inclusive of gap payment costs) and spending on OOP costs (Emanuel et al. 2000; Lin et al. 2008; McGarry & Schoeni 2005; Slutsman et al. 2002) were two of the main difficulties for affordability described in the literature. Income and wealth loss in lower socioeconomic groups negotiating end of life care described significant financial burdens for this group (Chini et al. 2007; Chochinov & Kristjanson 1998; Evans et al. 2008; Giorgi Rossi et al. 2007; Wilson & Amir 2008). The burdens of health care costs were demonstrated in countries with and without universal health care coverage and therefore, were not surprisingly described in this study population in Australia. Patients, carers and key informants discussed economic margins which were explained by the structural conditions of health care spending programs and policies, aimed at reducing health care costs. Despite these strategies co-payments for medical, pharmaceutical and aged care costs were still maintained by this group. Some benefit programs however which focused on specific community vulnerabilities closed these spending gaps for some patients and carers. The daily living conditions of low income, wealth and consumption in this group also highlighted the experience of limited financial resources.
18.2.1 Structural conditions of gaps too large

18.2.1.1 Medicare safety net and specialist service gaps

The introduction of the Medicare scheme in Australia in the 1984 was intended to ensure universal access to health care for all Australians. Yet, subsequent reforms to the system in recent years have led to an impaired and inequitable system (van Gool et al. 2009). Health care spending for OOP medical costs in Australia as a share of healthcare spending are at 18.2%, above the OECD median of 15.8% (AIHW 2012, Pg 475). The OOP costs for medical care in Australia include co-payments set by general practitioners and specialist doctors (Van Doorslaer et al. 2008). Pharmaceutical costs which include the costs of non-PBS medications and co-payments for PBS medications made by concession and non-concession card holders are held at different rates. OOP costs for medications borne by patients in Australia, accounted for nearly half of the funding of these items (47%, or $7.7 billion)(AIHW 2012). Attempts to address these large and rising OOP costs in Australia saw the government introduce safety net programs to manage both medical and pharmaceutical costs, which set thresholds for health care spending and could limit cost burden for groups with high health care expenditure (Korda et al. 2009). These medical safety net programs were, however, likely to have created greater inequities in Australia’s health care financing activities (van Gool et al. 2009).

A review report on the current Extended Medical Safety Net (EMSN) program, introduced in 2004 found that the program increased the affordability of high cost medical items, but had little impact on the affordability of medical services for low income groups, with Australians living in the wealthiest areas receiving 55% of benefits in the program and patients living in the poorest areas receiving less than 4% (Savage et al. 2009). This report additionally identified that safety net programs increased specialist providers’ capacity to increase fees and as such, entrenched specialist service provision for wealthier populations (ibid). The PBS safety net scheme is more regulated by the government with costs of PBS medications capped for concession (welfare recipients) and non-concession card holders and a safety net threshold established for these two groups (ibid). However, concession card holders are required to fill the equivalent of sixty scripts per year to be eligible to reach the safety net which negates the co-payment fee (ibid). Co-payment costs for individual scripts for concession card holders as of January 2012, is $AU5.80.

The impact of large OOP costs for medical services in Australia, are most significant for lower socioeconomic groups for whom this spending is disproportionately large compared to their income. The availability of safety net programs and subsidies were described by patient and
carer participants who explained costs for medical and medication gap payments. Patients and carers in this study did not describe OOP costs for GP services, but reported these costs for specialist doctor services. Bulk billing incentives for GPs is argued to have significantly improved access to these services for lower socioeconomic groups, having removed OOP costs, and yet high costs for utilisation of specialist care services is likely a major barrier to access (Korda et al. 2009). The consumption survey outcomes for this study identified that nearly a fifth of patients reported costs for specialist doctors in the interview period (Chapter 6, Table 16.8). Many more participants in the study described these payments earlier in their treatment period, which highlighted that the use and payment for specialist services was necessary for palliative care populations earlier in their diagnosis and to a lesser extent, into the later palliative care phase. Descriptions of the limited affordability of specialist services were noted in the study population. Limited utilisation of specialist doctor’s services by Indigenous patients confirmed that awareness of costs for these services in this group was a distinct barrier to utilisation. Specialist services represented a tier of health care provision in Australia that were largely unavailable for this study population.

18.2.1.2 Medication co-payments for patients

Medication expenditure was considered to be the main and most consistent OOP cost described by patients and carers in this study. OOP costs for medications were identified by participants despite the availability of the PBS safety net programs (Chapter 6, Table 16.8). This spending likely represented spending on co-payment costs prior to reaching the safety net and demonstrated that meeting this threshold may not be achievable throughout most of the year or at all for this group. The complexity of medication payments represented different costs for PBS and non-PBS items and also costs for specialist access medications which one participant described was only available at a subsidised rate when she attended a specialist medical doctor appointment for a large fee. The variability of medication costs and complexity of co-payment programs made it difficult for patients and carers to calculate total spending on these items. Therefore, medication costs described by participants in this study may not reflect the actual spending on these items. Managing the uncertainty of these costs is an added burden for spending on these items.

Key informants subsequently confirmed that medication costs were a significant financial burden for patients. The financial impact of co-payments for medications for low income groups was reported in formal carer interviews and these costs were considered to be significant despite medication subsidies, with multiple medications prescriptions making
affordability difficult. Key informants also confirmed non-compliance with medications in disadvantaged groups due to costs. Palliative Care Australia (PCA) in their federal government submission for budget priorities in 2010, recommended a waiver for palliative care patients to meet the PBS safety net thresholds, because of reduced incomes and increased care costs for the group (PCA 2010). The government is yet to take up the recommendation raised by PCA.

18.2.1.3 Inequity in payment for aged care placement

Key informants declared inequity in payment for aged care placements for palliative care patients and carers from lower socioeconomic groups. In particular, they discussed the negative financial impact for couples receiving the aged pension who required longer term care for one partner, ‘When they go into nursing homes their rates drop separately and they go onto single rates but the single rate doesn’t really go up to compensate...’. Furthermore, discussion of the inequity of access to aged care hostel facilities for patients with limited wealth (equity in their home) maintained that levels of wealth prescribed the quality of the hostel facility available to them. The Australian Productivity Commission report into aged care in Australia identified financial inequities in levels of consumer co-contribution for aged care facility access (2011). This report informed the government’s aged care reform package delivered in 2012, and highlighted concerns for access issues for patients from lower socioeconomic groups (DoHA 2012). This study described limits in equitable access to aged care facilities for longer term care for lower socioeconomic groups. Aged care funding policy which has more recently acknowledged some of these financial concerns does not however consider the financial impact of aged care placement for the spouses of low income couples, identified as an issue in this study.

Current health care arrangements in Australia which include co-payment for out of hospital specialist services, co-payment for medications and co-payment of aged care funding places has established costs which for lower socioeconomic groups are too great. This evidence from the study reports outcomes for service exclusion, a domain of social exclusion outlined in Chapter One (see 11.2.2.1). As ‘co-payments’ suggest, health care in Australia outside the public hospital system is not cost free and despite attempts to manage these costs through safety net programs, the costs for health care services and goods remain and are likely most burdensome for lower socioeconomic groups. The impact of health funding policies for patients and carers in this study were described both as costs for this group and also posed risks for non-use of services or medications necessary for managing end of life care needs.
Despite this, some specific support programs were described which negated OOP costs for this participant population and these are discussed.

18.2.2 Structural conditions of closed gaps

Programs which supported the full costs for medical and pharmaceutical spending were identified in this study. These specific programs had identified financial needs and risks for non-affordability within the Mt Druitt and Indigenous populations.

The Close the Gap campaign: Indigenous Health Equity, is a national program aimed at improving access to specialist services, pharmaceuticals and other health supports necessary to meet the needs of Indigenous patients with chronic disease (2009). Accessibility of the program for Indigenous patients with both chronic and terminal illnesses was described in this study and supported costs and compliance with medications, affordability access to medical appointments and advocacy support persons. Improving access to healthcare services for the large Indigenous population in the Mt Druitt area required such a program. The value of such a program to support the health care needs (palliative care needs) of a most vulnerable group in the Australian population highlighted. Healthcare policy which recognised and aimed to address the ‘gaps’ in access to health care services for this group, demonstrated outworking of policy at an individual and community level.

Local ‘programs’ of support for medication costs beyond government subsidies were also described and these programs were most significant whereby they provided medications without cost. The provision of free medications through the specialist palliative care service (unit) at Mt Druitt and through a scheme managed by an NGO (possibly Anglicare, a charitable arm of the Anglican Church), reported affordability of medications for palliative care patients in this community. The containment of these costs through these programs were considered to make a difference to how well carers ‘managed’ financially caring for patients at home. Recognition of some specific needs in this community for the financial burden of medication costs elicited a response from these organisations. Additionally it demonstrated some capacity in these service providers to both understand and extend resources to specific areas of need. The ability of palliative care services to respond to local needs, partnering with other community services to support disadvantaged groups in particular, has been demonstrated in some programs internationally (Kvale et al. 2004). Where palliative care services are located in areas of specific disadvantage, such as the setting for this study, the key service goals would be to understand needs of local populations and to be responsive to them.
18.2.3 Conditions of daily living for low income, low wealth and low consumption

The economic experience for patients and carers were understood in the context of mainly low income, low wealth and low consumption. The combinations of these three aspects of income poverty were described in Chapter One and were important as they outlined a broader description of economic experience and wellbeing. The aim of capturing financial outcomes in this study was to understand the experience of financial context for this group. The patients, carers and key informants confirmed similar economic outcomes for illness and care giving in a context of limited financial resources. Participants also maintained some variations for financial experiences which were accounted for by differences in income loss, spending and access to medical and pharmaceutical subsidies.

18.2.3.1 Low income and income loss

The circumstances of low income and income loss for patients and carers in the study more specifically represented experiences of the group for established low income. Overall low income represented receipt of government welfare benefits, recent income loss due to forgone employment (transition to government welfare benefit) or reduced income for those carers maintained in employment. Participants who reported recent income loss described and were reported as having main issues for financial burden in this study population.

A terminal diagnosis heralded income loss for a number of patients and their families in this study. The literature confirmed that loss of income for patient and family groups due to illness and care giving demands were so significant following a terminal diagnosis that this group were likely to shift to a lower income category in the palliative care phase of an illness (Hanratty et al. 2007; Jacobs et al. 2011). Some patients and carers in this study who were impacted by income loss described relocating to cheaper housing areas and selling assets to sustain costs. The literature confirmed the impact of care giving on income loss and described it as one of the single greatest financial burdens for family caregivers (Dumont et al. 2009; Giorgi Rossi et al. 2007).

The circumstances for younger patients and their families coping with a terminal diagnosis maintained distinct income losses in this group. The younger group were considered to have additional financial difficulties for higher costs of living and costs for supporting dependents. Key informants discussed concerns for this group in particular, highlighting limited income protection insurance, difficulties in accessing superannuation and low uptake of health and welfare benefits. The needs of this younger group demonstrated some distinct financial burdens which required specific approaches for financial support. The financial losses for
families caring for someone with a terminal illness are not considered to be adequately supported by government carer payments or pensions (PCA 2004). These financial burdens for income loss are not likely limited to lower socioeconomic groups but additionally are likely no less problematic for them and occur in the context of other limited social and financial resources.

18.2.3.2 Low consumption

Patterns of low consumption were described overall by patient and carer participants. The literature which is limited in describing consumption or spending outcomes for palliative care populations tended to exclusively describe medical and care costs (Dumont et al. 2009; Jacobs et al. 2011). Importantly, the consumption survey used in this study captured the range of spending for both daily living and care giving costs which revealed a broader picture of financial outcomes for this patient and carer group. The nature of economic needs for a lower socioeconomic population were likely beyond the costs of care giving, encompassing broader and pre-existing economic burdens which were specifically captured by the consumption survey.

The consumption of goods and services for patient and carer participants identified mainly spending for essential items of living; food, telephone, utility costs and healthcare costs (Chapter 6, Table 16.8). Spending on equipment and medical consumables was low with costs for these items maintained by subsidies and other local health facility hire programs. Several participants did not report spending for certain daily living costs such as home contents insurance, car repairs and maintenance, clothing, private health insurance, holidays and entertainment. Where there is low consumption of goods and services, it can reflect either forced low consumption or a willing low consumption or both. Forced low consumption due to low income is a marker of social exclusion and reflects persons and groups at the lower end distributions for income and wealth (Saunders 2011 Pg 46). Where low consumption is driven by choice, the outcomes for limited income and wealth may not be demonstrated (Headey 2008). Determining willing low consumption in the study population was difficult as several participants described lack of spending on items for a long period, and others reported no affordability for these daily living items. Understanding low consumption is considered important whereby it describes a limited capability to cope with unexpected or large costs (Saunders 2011). Such costs were described by participants in this study and were reported as financial difficulties.
18.2.3.3 **Low wealth and savings**

The capacity to buffer upward movement in consumption or income loss are managed by wealth in the form of savings or assets (Headey 2008). Home ownership which is often used as a measure of wealth was identified for over 60% of interview participants (Chapter 6, **Table 16.1**). Home ownership is not unusual in lower socioeconomic populations, with home ownership in Australia for this group reported as being higher than in any other country (Bradbury 2010). The home, however, is not an easily liquefiable asset and Australian data suggests that there is limited practice of selling home assets to manage costs of living in Australian populations (Bradbury 2010). Only one participant in this study reported the sale of a property to access wealth and support income loss; a couple who downsized the family home to a smaller, less expensive property. A survey study of caregivers for terminally ill persons in an Australian population found that nearly ten per cent of a full time caregiver population sold assets or used savings to manage end of life care (Abernethy et al. 2009). Sale of assets were described by one patient participant in the study who discussed the sale of tools and other items in his home to manage costs of living and to fund the costs of a holiday.

Patient and carer descriptions of wealth in the form of savings or assets were limited. Low consumption, previously described, demonstrated the limits of wealth and savings for participants. More specifically though, participants confirmed limited wealth by consistent concerns for the affordability of higher cost items such as the costs of electricity and other utility services and in particular, concerns for the affordability of funeral costs. Funeral costs were considered expenses which were unlikely to be managed because of the absence of ‘big bank accounts’. Patient and carer participants described paying into funeral plans or setting aside funds specifically to manage this cost. The palliative care social worker described the regularity of organising state funded or destitute funerals for patients in the area and that regardless of the preparation time families might have to organise funds, affordability was unlikely because there were ‘no substantial savings behind’ the population to manage these costs. The Australian government policy for early release of superannuation for funeral expenses enabled affordability of these costs for persons with superannuation (DHS 2011). Participants in this study overall described no superannuation.

18.2.4 **Conclusion**

The experience of economic need in the study population described margins of the economic resources for patients and carers. Broadly, Australia’s health care funding framework restricted access to services for this group which included private services and certain levels of aged care
service. The limited economic capabilities outlined the nature of economic exclusion, an element of the social exclusion framework discussed in Chapter One. The diagnosis of a terminal illness heralded a most significant economic shift for some study participants through income loss in particular for younger patients. For most of the participants, low incomes were established prior to the diagnosis of a terminal illness and the costs for care giving were supported by government programs and subsidies. In spite of this the impact of gap or co-payments on limited financial resources aggravated social circumstance. Low income and limited wealth defined spending for patients and carers which outlined the limits of financial resources to support spending beyond essential items. Lack of wealth or savings meant that necessary spending on high cost items such as utility costs and funeral expenses created significant concerns for affordability.

18.3 Margins of care networks

The quality and availability of formal and informal care networks significantly define the experience of end of life care (Grande, Addington-Hall & Todd 1998). The combination of close bonded family care networks and bridged networks of formal resources are both equally necessary for achieving and sustaining care giving (Keating & Dosman 2009; Ray & Street 2005). In Chapter Two the limits of informal care networks for lower socioeconomic groups for enabling home care and home deaths was identified. Some of this literature also described inequities for formal care networks around referral bias and geographical distribution of formal resources, but overall these areas had limited exploration in the literature. Discussion of the outcomes for care networks for patients and carers in this study and the capacity of these networks to support home care, inpatient care and home death outcomes will follow. Interviews, self-report tool outcomes and reporting and analysis of administrative data (after-hours crisis service and place of death) described the overall experience of end of life care networks for this study population.

18.3.1 Structural conditions of formal networks of inequity

Disparities in care support for lower socioeconomic groups from formal carers and variations in referral to palliative care formal services (Burge, Lawson & Johnston 2005; Campbell et al. 2010; Grande, Addington-Hall & Todd 1998; Grande GE 2002) and limited access to these formal services based on spatial or geographical disparity were identified (Goldsmith et al. 2008; Wood, Clark & Gatrell 2004). Disparities in formal care networks in the Australian literature identified limitations in spatial access to palliative care services for Indigenous groups in remote areas (McGrath, Holewa & Kail-Buckley 2007); limited specialist services use
by lower socioeconomic groups (Currow, Abernethy & Fazekas 2004; Currow et al. 2008); and inequitable distribution of specialist palliative care services across the country (Currow et al. 2012).

Formal networks of care are defined by palliative care funding and service delivery models discussed in Chapter One. These formal networks identify a mix of service provision from generalist health care services, primary health care services and specialist palliative care services (see 11.2.5.2). Australian health service data for palliative care service outcomes also outlined in Chapter One support some of the Australian literature outcomes summarised above, for service disparity across socioeconomic areas. This health service data (see 11.2.5.4) reported increasing demand for palliative care services in Australia finding that persons from lower socioeconomic areas accounted for a higher proportion of this demand; with disparity demonstrated in palliative care service provision in non-specialist and specialist inpatient and primary care services. The outcomes of this study affirm some of these limitations in access for patients and carers to primary care services, and to a more limited extent to specialist palliative care services. Additionally, some limitations in engagement with government agencies for welfare support as inter-sectoral formal support organisations are also described.

### 18.3.1.1 Community nursing services

Nearly all of the patients in this study reported support from a primary care nursing service (to be referred to as community nursing services). The quality of community nursing relationships was overall described as ‘good’ with descriptions of mainly met outcomes for support, social and informational needs. The SCQ reporting also confirmed that the quality of the relationship with community nursing services was positive and demonstrated a range of support outcomes (Chapter 6, Table 16.10 & Table 16.12). However, patients and carers consistently described limited support from community nursing services for hands-on (personal or practical) care. The needs for practical support were reported with nearly two thirds of patients describing problems with daily living activities (Chapter 6, Table 16.5) and four of the six carers participating in the study indicated some difficulty providing physical care (Chapter 6, Table 16.6). The palliative care CNS for the Mt Druitt area acknowledged that workforce changes meant community nursing roles no longer included provision of personal care. This nurse lamented the lack of practical support for patients and carers: ‘Years ago the nurses would go out and provide care but we can’t do that which is terrible’. The role for provision of personal care for patients had shifted to the domain of home care services and yet inadequate access to these services is described in this study.
18.3.1.2  **Home care services**

A limited number of carer participants in this study were receiving personal care support from home care services. Barriers in access to home care services were described by carers and key informants alike. One carer receiving these services for his wife acknowledged that retaining these services had been an ongoing challenge for him and his family. The experience of futility in accessing home care services due to the nature of waiting lists was emphasised. One key informant discussed the plight of an elderly carer as ‘she tried about five agencies and there were just waiting lists’. Inconsistent funding of these services meant that for long periods, no service availability existed and patients and carers were informed that the ‘books are closed’. The options for personal care support were then limited to family caregivers or payment for private services; a scenario which was financially beyond many families. According to one key informant, limited availability of practical home care support likely prompted facility admission. A study by Currow and others (2012) in Australia reinforced these concerns. The study reported higher levels of community-based care for lower socioeconomic groups when compared with other groups, which meant that the responsibility of care shifted to the population group who were least likely to afford to pay for home care services (ibid). Palliative Care Australia’s submission to the federal government highlighted concerns for lack of availability of home care services for palliative care populations and suggested policy and funding change in this area (PCA 2010).

18.3.1.3  **GP services**

GP services met the needs of patients in the study whereby they were able to attend clinics for medical review. Carers, who required a medical home visiting service for frail and ill family members, considered that they had no medical primary care service. Additionally problematic were comments by a key informant that GPs in the area who were experienced in palliative care were limited in number. Increasing demands for medical primary care services demonstrated inadequate availability. The Australian General Practice Network most recently highlighted concerns for the capacity and skills of GP’s to meet the primary care needs of palliative care patients (AGPN 2012). The network outlined a number of issues which included; the lack of appropriate remuneration for complex consultations and home visits, limited education and training in palliative care for GP’s and inequitable distribution of health care providers (ibid). These outcomes mirrored many of the concerns raised by patients, carers and key informants in this study. This report by the key medical stakeholder group highlighted their awareness of the issues of GP service availability for palliative care patients and demonstrated
organisational level concern and lobbying. These limits in access to general medical services based on availability are likely problematic for a broad palliative care population, however they most likely to impact lower socioeconomic groups who have demonstrated higher utilisation of these services when compared with other socioeconomic groups (Turrell et al. 2004).

### 18.3.1.4 Specialist palliative care services

#### 1.1.1.1 Access: Referral limitations and bias

Limitations in accessing specialist palliative care services, whereby the referral process defined barriers to access were discussed by carers and key informants in this study. Two carers described issues gaining timely access to specialist services because of medical gatekeepers and ‘network’ delays. Palliative care as a referral based service maintained barriers to access based on a system whereby the referrer, who may or may not be able to assess palliative needs, determined whether access to the service was necessary (Ahmed et al. 2004). Key informants confirmed these limitations of the referral process for palliative care services and considered two distinct groups, the first being patients who were not referred to the service by acute care teams and therefore, received poor symptom management, and other groups most likely the non-malignant group who had been referred but needed to meet specific criteria such as established palliative goals of care and demonstrated end stage status prior to admission.

Analysis of the place of death data reported limited referral to specialist palliative care services for patients with non-malignant disease, with only 7% of palliative care registrations (Hills and Mt Druitt postcodes) for patients with non-malignant diagnoses. Slightly higher percentages of non-malignant registrations were from Mt Druitt (8%) compared with the Hills area (6%) and may reflect the higher prevalence of chronic disease in the Mt Druitt area (NSW Health 2010). The outcomes of death for patients with non-malignant disease in an acute care facility, which remains a less than ideal place of death for patients (Parish et al. 2007) was demonstrated more distinctly in the Mt Druitt data with the likelihood of an acute care death higher for these patients (n=9, 37%) compared with patients from the Hills area (n=3, 10%). Similar numbers of Mt Druitt patients, however, had died in the palliative care facility (n=8, 33%). This outcome may confirm some level of access block to specialist inpatient beds for this group, whereby referral to the service did not negate the likelihood of an acute care death for a similar proportion of patients. The inequity of this referral bias was underscored for lower socioeconomic groups whereby the proportion of Hills area patients from the non-malignant group who died at home (60%), compared with the Mt Druitt area (29%) demonstrated more
limited capacity for patients with non-malignant disease from a disadvantaged area to have a home death.

1.1.1.1.2 Limited perceptions and understanding of palliative care

Many patients and carers described perceptions of palliative care which were limited to understanding the service as purely end of life care. Failure to appreciate the objectives of palliative care as a service which provided a broad range of support and treatment options for people with terminal illness, their carers and families constituted a barrier to access (Jennings et al. 2003). Lower socioeconomic groups were more likely to have a limited awareness of palliative care philosophy and practice (Born et al. 2004; Foreman et al. 2006; Koffman et al. 2007). Subsequently, where there was experience or awareness of the services provided by palliative care, lower socioeconomic groups were found to be most receptive to referral (Born et al. 2004; Fernandes et al. 2010). Patients and carers in this study who described concern and apprehension for admission to palliative care were most positive about the service following admission.

The difficult language of palliative care described challenges for patient and carer comprehension and key informants described evidence for limited patient and carer understanding of terminology and language that was peculiar to palliative care. Palliative care was considered to be ‘a whole new concept for people even if they’ve had other conditions...a different world really’. The language and concepts of palliative care which are not understood by different social groups supported concerns for palliative care as a middle class entity (Moller 2005). Strategies to engage lower socioeconomic groups external to and within palliative care services are necessary and require greater understanding of language and literacy needs for this group.

18.3.1.5 Policies of government welfare organisations

The limitations of inter-sectoral agencies of government welfare organisations were highlighted by a small number of participants. The main issues outlined a lack of flexibility in policies around processes to accommodate some distinct needs of this group. The complexities in the criteria for eligibility for welfare payments or concessional services were underscored by concerns which were essentially described by participants who had not previously used these services. A secondary data analysis study of survey outcomes for government benefit utilisation found limited uptake to be more common for groups experiencing financial burden, the study however did not report the reasons for lack of uptake in this group (Hanratty, Jacoby & Whitehead 2008). Another study from Sweden reported similar outcomes.
for limited uptake of welfare benefits and the authors highlighted the need to investigate the barriers to these programs for these patients, because financial burden for this group was particularly limiting (Hanratty et al. 2007). The outcomes of this study reinforced some the concerns identified in the literature which reported outcomes for limited access to welfare payments for this group. Additionally, this study described particular difficulties for patients and carers unfamiliar with negotiating welfare agencies and these may represent barriers to these programs which are policy and process derived. Capacities in government agencies for support and resource provision were also described by participants.

18.3.2 Structural conditions of organisational support

Structural conditions which described capacities in formal networks of care for the participant group represented positive engagement with representatives of government organisations for welfare and housing resource provision. These networks of formal government support were reported as being overall ‘good’ for many participants and were qualified by responses of support and trust in these agencies. In particular, patients and carers found the staff in these agencies to be helpful and receptive to their changing needs and these outcomes were considered to be longstanding for several participants. Many of whom had been engaging with these services for long periods. Participants described reasonable and/or respectful treatment by representatives of government organisations and did not describe being made to feel undeserving of their payments or housing entitlements. Welfare organisations, which are defined by positive outcomes of financial support and engagement, are important for creating norms of trust demonstrated in bridging social capital (Patulny 2005). The outcomes of positive engagement with welfare agencies demonstrated in this study highlighted levels of trust which encouraged engagement with these organisations, likely improving access to resources for this group.

18.3.3 Conditions of daily living for informal care giving margins

The availability and quality of informal care networks for lower socioeconomic groups were overall described in the literature as being inadequate for supporting end of life care needs (Hughes, Gudmundsdottir & Davies 2007; Kvale et al. 2004). The limits of informal care networks for this group additionally proved to be barriers to receiving formal care support from other services, namely home care services, which required informal caregiver availability and capability to sustain home care needs overall (Hughes 2005; Kvale et al. 2004). The impact of limited informal care networks underscored the experience of limited home deaths for lower socioeconomic groups (Grande, Addington-Hall & Todd 1998; Houttekier et al. 2009;
Seale 2000). This study identified that the informal networks for patients and carers were limited in quantity and quality. Additionally, descriptions of vulnerable contexts for some patients and carers whereby language, health literacy and isolation posed risks for poor end of life care outcomes were also described. Health service data for outcomes of utilisation of an after-hours crisis service and also place of death outcomes for the Mt Druitt palliative care population supported a broader picture of care giving margins. These highlighted disparities and risks for a socio-economically disadvantaged population.

18.3.3.1 Informal care giving contexts

Much of care giving role for patients at the end of life is the domain of family members (Rolls et al. 2011). Similarly family caregivers provided most of the informal care for patient participants in this study and overall these family networks were described as small with the majority of substantial care giving provided by a single family member. Many of the patients in this study lived alone with intermittent informal family or neighbour caregiver support. The literature, not surprisingly, highlights that overall, where there are greater proportions of family networks, greater numbers of care giving hours are provided (Keating & Dosman 2009). Outcomes from the NAT: PD-C for caregiver wellbeing needs identified that five of the six carers in this study reported that they were experiencing problems interfering with their wellbeing (Table 16.8). Small strained family networks were described as being unlikely to sustain the demands of home care giving for palliative care patients (PCA 2004).

The after-hours crisis service caller data reported some broader outcomes for informal care networks for lower socioeconomic patients from the Mt Druitt area, comparative to patients from the least disadvantage Hills area. This caller data (caller as proxy for care giver) reported distinctions between these two areas for informal care networks. This data reported that Mt Druitt area patients were less likely to have a spouse or partner call the service than a Hills area patients (30.6% compared with 37.9%) which may reflect the reduced likelihood of a live in carer for these patients. This same data also reported that Mt Druitt area patients were more likely than Hills area patients to have a call to the service from a child (32.5% compared with 30.6%), a parent (2.9% compared with 8.8%) or other relative (1% compared with 8.8%); but less likely to have a call to the service from a grandchild when compared to Hills area patients (0.6% compared with 4.9%). These outcomes of carer networks may indicate that Mt Druitt patients were a younger cohort with different care support availability. A study by Currow et al (2012) for specialist palliative care utilisation across Australia supports outcomes for disadvantaged groups being a younger cohort, finding that the average age of the most
advantaged groups utilising specialist palliative care services was higher. The care networks of lower socioeconomic groups therefore demonstrated some distinct circumstances of carer support characteristics.

The literature finds that palliative care needs for lower socioeconomic groups are greater than for other socioeconomic groups (Lin et al. 2008; Wood, Clark & Gatrell 2004; Worrall, Rea & Ben-Shlomo 1997). The outcomes for palliative care needs and demands for Mt Druitt area patients likely supported these literature results. The after-hours crisis service data reported increased needs and demands for this service for Mt Druitt area patients comparative to Hills area patients. Patients from the Mt Druitt area were more likely to require medical or nursing intervention or treatment than a support phone call or technical support (70% compared with 62%); more likely to require a home visit (21.9 % compared with 17%) and were statistically more likely to be admitted to a specialist palliative care unit than a Hills area patient (15.6% compared with 7.8%) following a phone crisis assessment (see Table 15.5 & Table 15.6). Mt Druitt patients therefore demonstrated greater palliative care needs or needs beyond the capacities of their home care giving networks, or both, when compared to those of patients from a least disadvantage area. These outcomes for contexts of home care giving for lower socioeconomic groups demonstrated likely barriers to home care in the palliative phase. Other outcomes for limitations in informal care networks were also described in the participant group.

1.1.1.3 Fractured relations and difficult histories

Patients in this study reported some significant outcomes for the limited quality of close relationships. A qualitative study by Dzul-Church and others (2010) described the propensity for poor quality relationships in a disadvantaged group, contending that interpersonal relationships were often described by these patients in a context of difficult social and financial circumstances. Descriptions of difficult or impaired relationships were discussed by several participants in the study who reported conflict with family members due to limited support for care giving and strained relationships due to divorce and other relationship conflict. Additionally, several patients discussed difficult life histories which shaped most significantly the contexts of family networks and invariably the end of life experience. Difficult life histories were described by patient participants in this study with reports of lives lived within contexts of alcoholism and domestic violence, in particular. Where family relationships were impaired by crisis, care giving was found to be most difficult (Holst et al. 2009) and unlikely to successfully support home care outcomes (Kramer & Yonker 2011). Several patients in this
study described relationship outcomes that defined end of life care choices whereby home was not a safe place emotionally or physically and therefore an unlikely option for care or dying. The quality of family relations in palliative care populations is underexplored and incorrectly presupposes that these relationships are overall positive and functional, which is problematic when family is central to care giving outcomes and little is understood of the nature of these relations (Fisher 2003). Understanding the dimensions of quality in close family care relationships is therefore an important duty of care for palliative care service providers as these networks are fundamental to achieving or impairing end of life care outcomes (Lewis et al. 2013).

18.3.3.2 Area disparity in place of death outcomes

Patients from lower socioeconomic groups are as likely as other groups to have a preference for a home death (Foreman et al. 2006). The outcomes of analysis of the place of death data for palliative care patients in the Mt Druitt area demonstrated that these patients were statistically less likely to have a home death when compared with a least disadvantaged Hills area patient (14% compared with 28%) (see Table 15.1). The outcomes for facility death also demonstrated differences across these two distinct socioeconomic areas which are telling for disparity in end of life care outcomes. Nearly two thirds of all Mt Druitt area patients died in the Mt Druitt specialist facility and a very small number (2%) died in other inpatient facilities. Hills area patient outcomes described similar specialist inpatient service utilisation for terminal care with 52% of deaths taking place in these facilities of which 21% were in the Mt Druitt palliative care facility and 31% were in other specialist palliative care facilities. Additionally, 9% of Hills area patient deaths occurred in a private facility. These outcomes demonstrate that patients from the least disadvantaged area accessed a greater range of inpatient facilities in the terminal phase. The outcomes for death in an acute care facility, which is least desirable, were higher for Mt Druitt area patients than Hills area patients (13% compared with 4%).

The place of death data reporting outcomes across these two areas for males and females also reported distinctions demonstrating different care networks for these groups. Male patients in the Hills area were more likely to have a home death than female patients (64% vs. 36%), whereas male patients in the Mt Druitt area were less likely than female patients to have a home death (48% vs. 52%). Variations in home death between male and female palliative care patients are reported in the literature (Gallo, Baker & Bradley 2001; Masucci et al. 2010) but are limited for describing the nature of these networks for supporting home deaths.
Mt Druitt area patients outcomes for death in the Mt Druitt palliative care facility likely demonstrated good spatial access to this service and the availability of inpatient beds is found to reduce the likelihood of a home death (Gallo, Baker & Bradley 2001). However this group with reasonable spatial access to a specialist service and established service links (registrations with the service) were also more likely to have an acute care facility death than least disadvantaged patients. A literature review by Lewis et al (2011) reporting palliative care access for lower socioeconomic groups identified that home death outcomes were dependent on a range of service, patient preference and informal care giver arrangements. The limitations in informal care networks discussed previously likely determined some of the place of death outcomes for this group. Additionally, the increased likelihood for an acute facility death for patients from the most disadvantaged area suggest other barriers for this group for meeting place death preferences which cannot be ascertained from the utilisation data captured in this study. Key informants, however, reported the likelihood of acute care deaths for patients without informal caregivers. The outcomes for vulnerability for this population with limited informal care networks were further highlighted by key informant descriptions.

18.3.3.3 Situations of vulnerability

Key informants described contexts of risk for palliative care patients in the Mt Druitt population which considered outcomes for limited informal care giver and social support. The contexts of vulnerability for these patients were defined by limited carers or advocates and, limited language and health literacy. According to key informants, many patients in the area lived alone or were alone for long periods during the palliative care phase. The socially isolated were of greatest concern to the key informant group and were described as increasingly vulnerable because of the absence of a carer in the community and also in acute care facilities, where there was risk for inappropriate treatment. In the absence of carers, some patients were being supported by neighbours; however advocacy by this group was limited because of their concern for becoming a medical decision maker. The limits placed on the decision making capacity by non-family caregivers by facilities further was also highlighted. This raised the broader issue of advanced care planning for these patients which is acknowledged as being inadequately considered in this population. Lower socioeconomic groups who were most at risk for limited advocacy and poor health literacy benefited significantly from advanced care planning (Sudore et al. 2010).

Limited English language skills and limited literacy and health literacy issues were described somewhat indistinctly by key informants. In particular key informants reported on the impact
of limited communication and comprehension capabilities for patients and carers to negotiate health systems, understand treatment plans and medication regimens. The challenge in understanding palliative care knowledge which has been discussed previously in this chapter, confirmed additional systems challenges for patients and carers with limited literacy and English language skills. Patient and carer participants in this study all spoke English as their first language and did not raise concerns for limits in language aptitude in interviews. The health literacy assessment outcomes did indicate limited health literacy in a quarter of the patient participants and one patient participant likely demonstrated outcomes for illiteracy. A key informant described the difficulties in managing both the stigma and risks for patients who were attempting to negotiate a health care system without basic reading or writing skills. Other key informants maintained the difficulties for some patients and carers in this community in understanding health treatments and results and in particular the concern was for patients and carers where English was not their first language. The association between education, literacy and health literacy are often demonstrated in the literature (Nutbeam 2009). Although limited health literacy is not confined to lower socioeconomic or cultural groups, it is more prevalent in these groups (Nutbeam 2009) A limited health literacy relates to poorer health outcomes, it is necessary to manage outcomes by simplifying healthcare language (Nutbeam 2008). Measuring health literacy in a most sensitive way in these populations is, however, essential. Health literacy is an important social determinant of health, an ‘asset’ which can limit inequity for disadvantaged populations (Nutbeam 2008).

18.3.4 Daily living conditions of capacities in informal and formal care networks

18.3.4.1 Capacities for families

In a context of good family relations and availability of support, lower socioeconomic groups are as likely as other groups to both desire and work towards meeting the care needs of family members at the end of life. Kessler and others (2005), in a mixed methods study to compare differences and experiences across social classes for specialist palliative care services, identified no differences in beliefs or desire for good care giving. Equally they did also find that lower social groups were more likely to receive reliable and more frequent support from other family members (ibid). Key informants described the experience of some patients for whom family support enabled home care and death. They acknowledged characteristics of these families which included large numbers, organised for reasonable distribution of care giving tasks and an awareness of care giving demands and resources.
Indigenous patients and the nature of their large family kinship ties were a distinct group for whom the demands of care giving were more likely to be achieved. The extended family ties of Indigenous cultures were broadly bonded because they intersected with other bonded networks and the roles of members were often highly obligated for social and financial support (Maru & Davies 2011). Other descriptions of informal care giving capabilities considered individual families who had not only ‘arranged everything’ but also ‘had good support’ and utilised services. The characteristics of these networks also considered personal characteristic of being open to support (trusting); understanding and being aware of care giving demands, the availability of services and the patient’s prognosis. All of these were all considered important for enabling care networks. Understanding capacities for care giving in groups with limited social and economic resources identified the most basic of requirements necessary for supporting care needs at the end of life. The desire and capability to sustain a patient at home for end of life care therefore, must be considered within the family networks that achieve these outcomes and achieve them well. The SCQ administered in interview format demonstrated outcomes for capturing these close relationships and the quality or otherwise which defined them. Additionally, these informal care relations within other broader networks of support were equally well described by the SCQ.

18.3.4.2 Friends and neighbours

Neighbour and friendship relations affirmed opportunities for the capacity of support from this group. Neighbour and friendship groups were not described as providing practical hands-on care giving support, but friends, in particular, were most important for meeting other emotional, companionship and help support needs (Chapter 6, Table 16.9). Emotional support determined how well some patients and carers ‘coped’ with the demands of illness and care giving. The limits of friends and neighbour relations for practical support was often balanced by the social and emotional support provided by these groups, considered to be equally important (Ray & Street 2005).

The distinction between neighbours and friends, who were not neighbours (SCQ), was not always clear for patients who described good support from this group, likely because they understood them to be both. Several patients without family relations or limited relations described stronger connections with neighbours and friends which maintained some care support outcomes for these patients. Patients and key informants described neighbours and friends becoming aware of need and then being forthcoming in providing support and resources. Where groups were disconnected from the close bonded network ties, other
bridged networks were more likely to occur with access to different resources and information (Lakon, 2010). The capacity for friendship networks to contribute to improved end of life outcomes was identified in a recent study by Burns and others (2010). Authors discussed that these friendship networks broadened the resources of this group, and additionally questioned whether these friendship networks for care giving might reflect the outcomes for shrinking family groups (ibid). The descriptions of capacity for friendship and neighbour care giving were small in this study, but responses from several patients suggested that there were possibilities for greater engagement with these groups. Importantly, Burns and others (ibid) in their study found that the outcome for care giver friends was positive, that they were affirmed in their care giver role and that the role created a new social cohesion. The creation of social cohesion in a disadvantaged area has many merits and would, in particular, likely balance some of the low levels of community trust and cohesion demonstrated in this study’s outcomes.

18.3.4.3 Specialist palliative care network equity

Patients, carers and key informants describe the structures of specialist palliative care services which enabled positive, formal care contexts for the participant group in the community and in the specialist inpatient facility. Many patient participants described the philosophy and practice of palliative care in their experience of the service). Patients and caregivers affirmed the outworking of palliative care as a needs-based holistic service, whereby their referral to the specialist service were based on palliative care needs which were considered to be beyond the resources and skills of generalist or other specialist services resources. Patient and carers described acceptability of specialist inpatient and specialist community services, whereby they endorsed the care as coordinated, focused on comfort, patient-centred and a positive context for communication for those who desired information and those who did not. Descriptions of trust underscored many of the discussions by patients, carers and key informants for engagement with these specialist services.

Comparisons of service outcomes for the utilisation of the afterhours service for Mt Druitt area and Hills area patients likely demonstrated equity in service provision between these two areas. The average numbers of calls to the service, per registered patient, were essentially the same for both areas. Consequently, the location of the specialist inpatient facility within the Mt Druitt area supported geographical access to this service for a lower socioeconomic population and demonstrated previous palliative care service development planning for the palliative care needs of a most vulnerable population.
18.3.4.4 Conclusion

The limitations of formal care networks to support the patient and carer population were demonstrated across the range of primary care providers and for a small number, government welfare organisations. The limits of these formal networks to support care needs of this group were underscored by limited access to formal care networks and limited capacities within these networks for practical home care support. Acceptability and geographical access to the specialist palliative care demonstrated some good outcomes for patient and carer needs. Limitations of the specialist palliative care service due to referral based barriers; misconceptions of palliative care practice and terminology was however highlighted. Accordingly, the limits of formal care networks are most alarming for this group for whom the margins of social and economic resources are unlikely to manage the gaps in these services.

Informal care giving contexts for patient and carer participants were limited in size and in their capacity to support home care and home death. Palliative care patients from the Mt Druitt area demonstrated different home care giving contexts and outcomes when compared with Hills area patients and were less likely to achieve a home death. Interview outcomes identified that patient participants had distinct characteristics for vulnerability; contexts of difficult life histories and a lack of family support networks or communication capabilities to negotiate health care systems. Mt Druitt area patients demonstrated greater palliative care needs and/or needs beyond the capacity of their informal care giving contexts which meant that outcomes of crisis were more likely to end in a facility admission.

Capacities in care giving contexts supported understanding characteristics of this participant group which managed or buffered the effects of disadvantage. Large family networks of persons who were prepared for, and willing to offer care and receive support; networks of friends and neighbours as new and developed support givers; and specialist services located locally and meeting the physical, crisis and communication needs of this group were maintained as the elements of quality end of life care outcomes.

18.4 Study Conclusion

The concurrent mixed method design of this study achieved the research objectives outlined. The quantitative approach compared secondary data analysis outcomes for place of death and after-hours service utilisation for a most disadvantaged and a least disadvantaged area (research objective one). The qualitative approach explored and described the experience of a lower socioeconomic group for end of life care with (i) patients and/or carers for semi-
structured interviews during which self-report questionnaires and tools were administered, and (ii) with key informants, formal caregivers for this group. This qualitative approach enabled the researcher to explore the experience of this patient and/or carer group for social and economic needs and capacities at individual, community and societal levels; social capital outcomes; and access to and acceptability of palliative care services (Research objectives Two a, b and c). The outcomes of socioeconomic demographics and the self-report tool outcomes were utilised for illuminating and quantifying qualitative outcomes. Semi-structured interview outcomes for self-report tool completion reported the appropriateness, acceptability and feasibility of these tools for this group (research objective three).

This study described the experience of end of life care for a lower socioeconomic group and is the first description of social and economic outcomes for such a group in an Australian context. The socioeconomic status of participants in this study defined outcomes for care and dying which although were somewhat distinct for each patient and care giver, shared many similarities for being within margins of social and economic contexts. The study of context in end of life care is important and this study demonstrated that where context is explored at individual, community and societal levels, descriptions are rich for a range of outcomes of the patient and/or carer experience at the end of life.

Social and community contexts are important for creating and supporting social exclusion or inclusion. The evidence from this research demonstrated that this lower socioeconomic group were most vulnerable to social exclusion because of deficiencies in social policy (public housing) and limited community trust and engagement. The impact of illness, care giving and relocation narrowed community and social networks further and likely further underscored the experience of loneliness and isolation by several patients and carers. Patients and carers ‘desired’ for community, evidenced by descriptions of concern for the absence of community within limited reporting of community engagement. Where connection and relations for community contexts existed, outcomes for social inclusion were demonstrated. The value of community and social engagement for patients and carers at the end of life is likely demonstrated but requires further exploration. The bridged networks of social and community engagement are important for lower socioeconomic groups in particular because of their potential to buffer the effects of disadvantage.

The margins of financial resources for a lower socioeconomic group at the end of life and the impact of managing with limited finances were demonstrated in this study. Persons who described income loss due to lost employment or transition to welfare income had the
greatest difficulties managing costs. Australia’s healthcare funding arrangements which necessitate co-payment for medical, pharmaceutical and long term care placement impacted on the limited financial resources of this population. This underpinned some disparities in health service utilisation and supported outcomes for service exclusion for this group. The elements of economic deprivation for low income, low wealth and low consumption defined the daily challenges of managing spending, of which large spending demands for funeral costs and utility costs were most difficult and caused the greatest concern for this group. Beyond spending on healthcare and end of life needs, the costs of essential items for daily living were difficult to manage financially and demonstrated the requirement to consider the financial difficulties experienced more broadly by these lower socioeconomic populations. Where local and federal government services recognised the particular financial needs for a lower socioeconomic health population, targeted programs to manage affordability of essential pharmaceutical and medical items and improve access were realised. These programs made significant differences to how this disadvantaged group managed these costs.

The study found that informal care networks were most important for sustaining home care and home death outcomes and yet they were significantly limited in size and quality in this lower socioeconomic group. Patients with limited or no informal care networks were most vulnerable to poor end of life care outcomes. These were most likely determined by their circumstances rather than preferences for home care and home death. The likelihood of a home death for this most disadvantaged population was reduced and episodes of need in home care demonstrated more intensive interventions such as home assessment and facility admission because care needs were either greater or were beyond the capacity of informal care giving contexts. The nature of these informal care giving contexts to sustain care giving for this group suggests that circumstances of large family networks were important. Where these large family resources were not available, other capacities such as organisation and utilisation of broader networks in community and preparation of families for care giving were important for supporting home care. Formal and informal community (bridged) networks are important for supporting close family care giving (bonded) networks. Broader resources are required for sustaining family care giving networks; valuable indeed for lower socioeconomic groups with limited family care networks, but also important for managing the changing nature of shrinking family networks which will impact on informal care giving capacities across a broad range of socioeconomic groups.

The outcome of this study also demonstrated that specialist palliative care services were accessible and acceptable for this lower socioeconomic population with the probable
exception of patients with non-malignant diagnoses. The location of the specialist inpatient service within a most disadvantaged postcode supported spatial access for this group and likely meant that the local community were more aware of the facility and services it provided. Despite these outcomes, the ‘language’ and terminology of palliative care and the understanding of palliative care goals remained limited overall and potentially defined some barriers to access. The location of the specialist service in a most disadvantaged area highlights the obligation of this service to promote palliative care literacy and health literacy for the most disadvantaged population it serves.

The limited availability of practical hands-on support in the community for patients and carers was an alarming outcome of this study. This recent workforce change in community nursing service provision to relinquish a practical care service impacted significantly on home care outcomes for this group and most particularly for those with limited informal caregiver support. Specialist palliative care services did not undertake practical care needs and home care service packages, provided by NGO’s, had very limited accessibility for this group. The limitations of informal care networks to provide this care and a lack of financial resources to support the costs for private home care services demonstrated gaps in informal networks of care for this group. What is required to meet the needs of lower socioeconomic groups at the end of life in the community domain is access to home care services which can manage practical hands-on support. Palliative care services are well positioned to advocate for these services for groups and most particularly those who demonstrate limited social and financial resources.

This study was effective in exploring and describing the experience of end of life care for this lower socioeconomic population through the application of a conceptual framework of social determinants of health and social capital. The individual and family connections and resources were described within broader contexts of community and government based actions and engagement, and demonstrated how these environments were able to support or impede end of life care. The use of a range of self-report tools and questionnaires defined by the conceptual framework elicited social, economic, wellbeing, palliative care and health literacy outcomes. Overall, these tools were acceptable, generated descriptions of context and were also able to elicit elements of inequity and capacity experienced by this group. The use of the self-report tools as the large component of the interview structure ensured that outcomes and processes of the end of life care experience for patients and carers could be captured simultaneously. Key informants provided a larger context for understanding access and health service outcomes for this population and analysis of health service utilisation and place of
death data enabled comparison of key palliative care outcomes between a least and a most disadvantaged area. The integration of this quantitative and qualitative data in a mixed method design was essential to exploring this complex phenomenon.

### 18.5 Strengths and limitations

One of the major strengths of this study is that it sought to explore the experience of end of life care for a lower socioeconomic population and in doing so, gave voice to the needs and capacities of a population rarely engaged for research. This study demonstrated that this most vulnerable of populations can participate in research; provide rich stories and complete a range self-report tools and questionnaires with relative ease. The layers of vulnerability for limited social and economic resources and the demands of illness and care giving requires sensitive research planning, but should not limit research in this group and this is demonstrated in this study.

The other major strength of this study is the innovation of the conceptual framework to capture the context of end of life care experience in a disadvantaged population. The complexity of end of life care, lower socioeconomic status and care giving is such that context is essential for understanding the elements of this experience for outcomes and meaning. The application of a framework of social determinants of health and social capital concepts was essential in achieving this aim and such a framework, which describes the nature of individual, community and societal elements, is a valuable tool for researching disadvantaged population groups.

The main limitation of this study was that despite attempts to recruit a broad range of participants with social and economic needs (purposive sample) the characteristics of the interview participant group demonstrated some limited cultural diversity. The interview participant group in this study were mainly Anglo-Saxon and English-speaking which did not reflect the more diverse nature of the community of Mt Druitt. Although qualitative research does not necessarily seek representativeness, the outcomes for interviewing participants from culturally diverse groups may have described different end of life care needs and capacities. However, some of the experiences of these more diverse groups were captured in key informant interviews and the sample of patients and carers described experiences which sufficiently answered the research questions.

Patients who described current circumstances of domestic violence were withdrawn from or not recruited into the study to maintain the safety of these patients and/or carers. The outcomes for the end of life care experience for this most vulnerable group are therefore not
described; yet, a number of patients in this study did report previous experiences of domestic violence. Researching vulnerable groups can present greater challenges in recruitment and require more careful consideration of safety for this group. Ensuring that vulnerable groups are not made more vulnerable by participating in research requires flexibility particularly in recruitment and the concerns for risk in this study required recruitment strategies which excluded participants ‘at risk’. This strategy ensured safety for patients, carers and myself, as the researcher. Although this strategy limited the participant group for certain characteristics, the ethical imperative to reduce risk for research participants was upheld.

The sampling frame of the after-hour’s crisis service data and place of death data had limited capacity to extrapolate these data to other settings. The limits of the administrative data set and ethical approval limitations did not allow access to more in-depth characteristics that may have explained differences for this population for other social and demographic characteristics beyond that which is described. The limited number of variables reported in the health services data negated the possibility of performing inferential analysis. The utility of these data was in demonstrating service utilisation and carer networks comparatively for two disparate socioeconomic areas.

18.6 Implications for policy, research and practice

The application of an individual, community and societal level framework to describe the needs of a lower socioeconomic group for end of life care identified interventions at these levels which generated evidence to engage policy makers and clinicians. The implications for policy, research and practice generated in this study therefore include the following:

- The Government’s primary healthcare reform agenda which aims to shift more care to the community sector may support greater access to home care services for palliative care patients. It is, however, necessary that palliative care peak bodies lobby for these services on behalf of all patients, but in particular, draw attention to the needs of groups such as lower socioeconomic groups who may have limited informal care networks and will not only require formal community support services, but require them to be tailored to specific needs. Research which utilises frameworks to identify socially excluded or marginalised persons in health populations are well placed to inform primary healthcare policy.

- The impact of income loss through illness and care giving and the costs of co-payments for medical and pharmaceutical goods and services are evident from this study and other literature. Further shifting of care giving to the community will exacerbate care giving
costs for patients and families and therefore co-payment costs should be waived for lower socioeconomic groups and those experiencing income losses. Additionally, an increase to carer payments to support income loss is also required. Financial and healthcare funding outcomes must be considered as part of any healthcare reform agenda which seeks to develop a primary care model. Otherwise, financial hardship will no doubt limit the capacity to achieve these aims.

- Community networks are important for supporting the care needs and the social wellbeing needs of an increasingly larger population needing home care. Support for socially isolated persons is imperative for their needs but also for the wellbeing of communities and societies, so this is an important direction for policy change. The potential for formal and informal community networks to care for its members is underdeveloped and more research in this area in Australia is required. Developing community resources is not a free or cheap option. Supporting end of life care preferences for lower socioeconomic groups requires interventions which target partnerships with local community services, groups (including web-based) and persons. Such models of community palliative care exists internationally developed within social capital frameworks and endorse the value of social capital to develop community partnerships.

- Social capital approaches are valuable for describing individual, community and government networks and relations which are essential elements of the end of life care experience. The capacity of a social capital questionnaire tool to describe context, quality of relations and religious and spiritual outcomes demonstrate great application in this population for research and clinical assessment of need and capacity. Further development and testing of this tool for greater acceptability and feasibility is warranted and will broaden knowledge and care needs for this and other health care populations.

- Palliative care services in Australia have demonstrated through policy and service models that meeting the end of life care needs of entire communities is an overarching principle. Yet, there remains limited research in the area of equity for palliative care services. Understanding the nature of needs for specific groups and the potential barriers that are created for these groups in accessing palliative care services is required. The limits for lower socioeconomic groups in terms of literacy and health literacy, understanding of palliative care practice and lack of informal care givers, reflected barriers to palliative care services and end of life care preferences and are priority areas for research and shifts in resource allocation. The outcomes of increased investigation of population needs have
benefits most likely which extend beyond lower socioeconomic groups to more broadly
describe the experience and barriers to services for other groups.

18.7 Concluding comments

The impact of a terminal diagnosis for those with limited social and financial resources is
profound. This requires specific interventions to support and manage the needs of this
vulnerable group for care at the end of life. Understanding the context for caring and dying is
critical for planning for palliative care on a population level. Based on the findings of this
thesis, the frameworks of social determinants of health and social capital will be useful to
inform policy, research and clinical practice to improve health outcomes and decrease health
disparities.
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Appendices
Appendix 1: Publications associated with this thesis

Review Article

Dying in the Margins: Understanding Palliative Care and Socioeconomic Deprivation in the Developed World

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Abstract

Context. Individuals from low socioeconomic (SE) groups have less resources and poorer health outcomes. Understanding the nature of access to appropriate end-of-life care services for this group is important.

Objectives. To evaluate the literature in the developed world for barriers to access for low SE groups.

Methods. Electronic databases searched in the review included MEDLINE (1996–2010), CINAHL (1996–2010), PsychINFO (2000–2010), Cochrane Library (2010), and EMBASE (1996–2010). Publications were searched for key terms "socioeconomic disadvantage," "socioeconomic," "poverty," "poor" paired with "end-of-life care," "palliative care," "dying," and "terminal Illness." Articles were analyzed using existing descriptions for dimensions of access to health services, which include availability, affordability, acceptability, and geographical access.

Results. A total of 67 articles were identified for the literature review. Literature describing end-of-life care and low SE status was limited. Findings from the review were summarized under the headings for dimensions of access.

Conclusion. Low SE groups experience barriers to access in palliative care services. Identification and evaluation of interventions aimed at reducing this disparity is required. J Pain Symptom Manage 2011;42:105–118. © 2011 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words
Socioeconomic deprivation, poor, end-of-life care, palliative care, dimensions of access, provider-patient interaction, health literacy
Introduction

Improved health outcomes and increased life expectancy in developed countries over the previous decades have done little to improve the disparity in health for low socioeconomic (SES) groups. Socioeconomic status (SES) remains a determinant for health and ill-health, with the risks associated with morbidity and mortality for low SE groups identified by robust and consistent evidence. The poor die younger; have a higher disease burden; are less likely to act to prevent disease; and are less likely to present early in the symptomatic phase. The poorer health outcomes of low SE groups extend across the lifespan. Understanding the experience of SE deprivation at the end of the lifespan is consequently important.

The collective experience of dying in poverty raises many questions around the nature, meaning, and outcomes for individuals and their families. Evidence supports the notion that the health care needs of the socioeconomically deprived are greater than those of the general health care population. Recognizing SE disadvantage as a significant factor in influencing health outcomes underscores the importance of focusing on the distinctive characteristics that the illness and death experience has for this group. As a multidimensional construct, SE disadvantage is complex in definition and measurement. Definitions of disadvantage and poverty although diverse are generally inclusive of income, societal arrangements such as social participation, health behavior, education, and occupational class. Understanding the impact of a terminal diagnosis in such a broad context is, therefore, challenging; however, despite a lack of consensus for understanding SE deprivation, it is consistently viewed in terms of constraints to make choices over health care.

The potential risks for limited utilization of specialist palliative care services is likely to impact on the quality of end-of-life care for low SE groups. With many competing for palliative care services and with those resources limited, there is strong uncertainty around whether end-of-life care services are accessed by those in greatest need. Access to palliative care services is dependent on referral, with constraints in referral to services being well described in groups such as the elderly and those with noncancer diagnoses. Broadly, referral patterns to palliative care are nonstandardized, are dependent on numerous patient and service provider characteristics, and are not necessarily dependent on need. Low SE groups are identified as being limited in their capacity to access needed health care services and are, therefore, at a distinct disadvantage for access, in a referral-based service.

Confidence that palliative care is well positioned to identify and meet the needs of the socioeconomically deprived is challenged by statements that suggest that it has middle-class underpinnings. Accessibility of palliative care services by low SE groups is not well understood. Evidence identifying needs for low SE groups at the end of life is limited, and the impact of social and economic deficits are unclear. The aim of this article was to identify evidence from the developed world literature that identifies issues of access to palliative care for low SE groups. Themes will be explored in the literature under the dimensions of access headings.

Dimensions of Access

Access to health care services is a topic that has been explored in the literature for many decades, with multiple definitions of the phenomenon identified across several disciplines. Many definitions of access do, however, identify common themes in supply and demand and realized need for service use. For the purposes of this review, access is defined as the ability to secure services; quality of service; inconvenience and cost; and the tenure of information. Concepts or dimensions of access are commonly described within the contexts of developing countries and rural and remote areas. These dimensions, as they are known, identify a set of specific areas that link the patient and their family and the health care service, essentially a supply demand relationship, which recognizes both service and user requisites. The four main dimensions of access include availability, affordability, acceptability, and geographical accessibility. The access dimensions identified by Penchansky and Thomas are summarized by Peters et al. as follows:
• Availability—the demand for services and the adequacy and appropriateness of service providers, facilities, and consumables.
• Affordability—the relationship between the price of services and the willingness and ability to pay.
• Acceptability—the relationship between the users’ attitudes and expectations and the characteristics of the health service.
• Geographic accessibility—the distance or travel time from the user’s location to the service location.

Methods

Electronic databases searched in the review included MEDLINE (1996–2010), CINAHL (1996–2010), PsycINFO (2000–2010), Cochrane Library (2010), and EMBASE (1996–2010). Publications were searched for key terms “socioeconomic disadvantage,” “socioeconomic,” “poverty,” “poor” paired with “end-of-life care,” “palliative care,” “dying,” and “terminal Illness.” Additional data were obtained by manual searches of bibliographies from articles identified in electronic searches. The gray literature was searched for published documents using the key terms listed. The topic of health literacy was included in the search, as it was an important link between the two concepts and considered a significant aspect of the provider-patient interaction.22

Inclusion and Exclusion Criteria

Literature was included in the review if it met one or more of the following criteria:

1. Described SE disparities in end-of-life care;
2. Described the experience of SE deprivation and palliative care;
3. Identified dimensions of access to palliative care for low SE groups;
4. Identified the relationship between SES and place of death; and
5. Identified issues of health literacy in end-of-life care.

Publications were excluded from the review if they met one or more of the following criteria:

1. Did not explore SES as a significant issue;
2. Had a developing world focus;
3. Were not relevant to palliative care, that is, had a treatment or oncology focus only.

The terms hospice, end-of-life care, and palliative care and poverty, poor, and low SE are used interchangeably in the review to ensure that none were excluded and to reflect the individual articles’ contexts correctly.

Results

A total of 67 articles were included in the review (Table 1). Forty-nine percent (49%, n = 33) of the articles originated from the United States (U.S.). Nineteen percent (19%, n = 13) originated from the United Kingdom (U.K.) (one article was a U.K./U.S. collaborative). Twelve percent (12%, n = 8) were from Europe. Seven articles originated from Australia (10%), three articles from Canada,
two from Asia (Japan and Taiwan), and a single article from Ireland. Only two articles were identified in a search on health literacy and palliative care; one was a short commentary and the other was included in the review. Three general health literacy articles were included. The gray literature documents included two Australian government documents, one Palliative Care Australia publication, one U.S. report on access to hospice care, and one U.S. report brief on health literacy. Key outcomes from articles in the review were summarized using the dimension of access framework headings: availability, accessibility, acceptability, and affordability (Table 2).

Availability

The limitations of the availability of palliative care resources were identified in the literature and found to be further exacerbated by the increasing aging population. The demands for palliative care services are such that many compete for limited resources, and those with the greatest need did not necessarily realize available services at the end of life. Two studies in the United Kingdom in 1998 and 2002 by Grande et al. found that referral to home palliative care services was less likely for low SE groups. Limited availability of hospice services in certain low-income urban areas in the United States and fewer home visits in poorer areas in a palliative care service in Canada emphasized the potential for disparity in service availability for these groups. The availability and use of palliative care services exerts an important influence on the patterns of care for the terminally ill; yet much of this systems level influence remains hidden. Adequacy of supply of palliative care services is an important factor in identifying limits in access for this group; however, discussion of this issue in the literature was limited to describing the relationship between low SE groups and potential service availability bias.

Service availability entails uptake and usage to satisfy access requirements. Low SE groups’ reliance on acute care services during illness progression and the likelihood of death in acute care facilities were identified by many authors in the review. A recent U.S. study identified that palliative care service registration reduced the likelihood of emergency department presentations in a cohort of low-income men. Limited or lack of awareness of services at the end of life highlights that the dimension of availability must include both the actual and the potential demand for service availability. Limited service utilization for this group was often considered in parallel with concerns for the acceptability of services. A lack of informed choice regarding the ability to decline end-of-life care services constitutes a barrier to access such services.

Preference for a home death was identified across all SE groups. Resoundingly, the likelihood of a home death was least likely for low SE groups in countries with and without universal health care programs. One study that compared factors affecting place of death in London and New York found that the odds of a home death for low SE groups were reduced by 22% and 39%, respectively. Overall, the literature in this area was limited in exploring the reasons for this disparity, but considered that inadequate palliative care resources, financial costs of home deaths, referral bias, limited informal care arrangements, and greater service demand by low SE groups were likely causes. Literature identifying limits for home deaths for low SE groups is outlined in Table 3.

Geographical Access

Location and distance of health services significantly determine service utilization and are strong determinants of access. A meta-analysis by Higginson and Costantini found that the distribution of palliative care services in Europe was inequitable and that services were not necessarily located in areas based on greatest need. In Australia, poor indigenous groups in rural and remote areas held very strong cultural and spiritual preferences for home deaths, but were least likely to achieve this aim, because of a lack of local services. A study by Wood et al. established that longer drive times to services and increased demand for those services were more likely in areas with high levels of deprivation in Northwest England. A geo-coding study in 2008, in a Canadian province of British Columbia, found that, overall, 20% of the population did not have reasonable access to a specialized palliative care service, and in
Table 2

Dimensions of Access/Literature Outcomes Summary

| Availability (demand for and adequacy of service) | Utilization of palliative care services was lower for low SE groups (Carrow et al., 2008; Freeman, 2004; Gallo et al., 2001)  
Home death was less likely for low SE individuals (Decker and Higginson, 2007; Gallo et al., 2001; Higginson et al., 1999; and 2000; Motiwal et al., 2006; Silveira et al., 2005)  
Referral to home palliative care services was more likely in less deprived areas (Grande et al., 1998; and 2002)  
Low SE groups were more likely to use acute care services at the end of life (Hanratty et al., 2008; Houettekier et al., 2009)  
Awareness of palliative care services was low among the least affluent (Hughes, 2005)  
Koffman et al., 2007)  
Lack of informal carers for low SE groups are barriers to home hospice services (Kvale et al., 2004; Hughes, 2005)  
Limited respite services in rural remote areas to support low SE groups (McGrath et al., 2007)  
Limited hospice services in low-income urban areas (O’Mahony et al., 2008)  
Emotional and financial concerns about EOL care were associated with support for euthanasia (Givens et al., 2009)  
Increased demand for palliative care services for low SE groups (Wood et al., 2004; Higginson et al., 1999; Worrall et al., 1997)  
Palliative care patients in poorer areas received fewer home visits (Burge et al., 2005)  
Cumulative vulnerabilities for low SE groups contribute to persistent health disparities (Meyers, 2007)  
Suboptimal recruitment of low SE groups into clinical studies (Sloane, 2009)  
Institutional care more likely for those without informal care arrangements (Scale, 2000)  
Houettekier et al., 2009)  
SE deprived groups required more resources to achieve the same level of palliative care (Clark, 1997) |
| Geographical access (accessibility) | Longer drive times to palliative care services for patients in SE deprived areas (Wood et al., 2004)  
Location and distances to palliative care services determines utilization and access, and can exacerbate disparity (Ginnamon et al., 2008; Hughes, 2005)  
Distribution of palliative care services was inequitable across Europe (Higginson and Costantini, 2008; Beccaro et al., 2007)  
Transportation costs were burdensome for patients and carers from low SE groups (Emanuel et al., 2000; McGrath et al., 2007)  
Lack of transportation was identified as problematic for patients in poverty (Hughes, 2005)  
Hospice enrollment reduced emergency room visits for low SE groups (Bergman et al., 2009)  
Patients from low SE groups reported lower quality of communication in EOL care (Curtis et al., 1999; Parker et al., 2009)  
Low-income residents in aged care facilities were less likely to have an advanced care directive (Dobilian et al., 2000)  
Palliative care is viewed as an inadequate substitute for aggressive treatment for the poor and disenfranchised (Gibson, 2001)  
Health service referrals for community palliative care services was lower in deprived areas (Grande et al., 1998; and 2002)  
Patients from the most deprived areas with heart failure spent more days in hospital and patients with cancer had more admissions to hospital, compared with those from other SE areas (Hanratty et al., 2008)  
Mistrust and stigma limits use of palliative care services for low SE groups (Born et al., 2004; O’Mahony et al., 2008; Houettekier et al., 2009)  
Fragile or nonexistent support systems common for the urban poor exclude access to palliative care services (Hughes, 2005)  
Limited education and literacy in low SE groups impaired the ability to negotiate palliative care services (McQuillan and Van Doorslaer, 2007)  
Low-income groups were more uncertain about treatment and goals of care (Rosenzweig et al., 2009)  
Limited data in the literature on the special needs of low SE groups (Sloane, 2009)  
Groups with limited health literacy were more likely to have preferences for aggressive treatment at the EOL (Volandes et al., 2008)  
The middle-class underpinnings of palliative care may not connect with the social experience of the dying poor (Williams, 2004)  
Elderly would hypothetically forgo EOL care if it would deplete savings (Chao et al., 2008) |
| Acceptability (characteristics of health service/user beliefs and attitudes) | (Continued) |
Affordability (costs of service and users willingness and ability to pay)  

SES was associated with difficulties sustaining costs of treatments and/or use of savings in caring for a terminally ill relative (Chini et al., 2007; Emanuel et al., 2000; McGraith et al., 2007; McGarry and Schoeni, 2005). Costs of EOL care can be considerable and were dependent on the model of care (Chochinov and Kristjanson, 1998). Income and health inequalities were identified in elderly, caregiver widows (Evans et al., 2008). Transportation costs were a significant burden for low SE groups (Chochinov and Kristjanson, 1998; Emanuel et al., 2000; Lin et al., 2008; McGraith et al., 2007). Out-of-pocket expenses for low-income groups negotiating EOL care were significant (Giorgi Rossi et al., 2007; Lin et al., 2008; Slutman et al., 2002). Limited literature outside the United States for financial stress at the EOL (Hanratty et al., 2007). Health care expenditure for higher-income groups at the EOL was greater (Feider et al., 2008; Hanratty et al., 2007). Financial strain in EOL care was common, yet benefit uptake was low (Hanratty et al., 2008; Wilson and Amir, 2008). Health care expenditure was higher for low-income groups (Hogan et al., 2001; Chochinov and Kristjanson, 1998). Primary care workload costs were higher with lower SE groups, reflecting increased workload and drug costs (Worrall et al., 1997). Patients in the highest quartile for net worth had fewer symptoms and pain at the EOL compared with others (Silveira et al., 2005).

| SE = socioeconomic; SES = socioeconomic status; EOL = end of life. |

one regional area, this was greater than 50%. The ad hoc nature in which palliative care services have developed worldwide has supported disparities in access based on geographical location.

In a review of the literature describing challenges to receiving palliative care in the United States, a lack of transportation was highlighted as a practical barrier for the poor wishing to access services. The poor were most vulnerable to transportation costs associated with location of services and this was described as a frequently reported barrier to treatment in poor populations. The current fragmentation of medical care, resulting in multiple outpatient visits for patients, was likely to further exacerbate the costs of transportation for this group. Costs were often paired in the literature with geographical access issues and these costs increased where distances to service locations were greater. The impact of transport costs for low SE groups is, therefore, most significant. Literature that specifically considered geographical access problems for low SE groups for end-of-life care services was overall inadequate in describing the extent of the problem for this group.

Acceptability

Absence of Informal Carers. The literature in the review identified concerns for the limits of informal care arrangements for low SE groups, and the subsequent impact this had on palliative care home services. Those most likely to be without an informal carer or those who had care arrangements that were tenuous were most likely to come from a low SE group. Lack of informal carers was identified as a barrier to home hospice services for low-income groups. Living alone often indicated an overall absence of informal care options, with this group unlikely to have children, siblings, or a spouse, and would invariably progress to institutional care. Barriers to discharging patients from low SE groups with appropriate hospice services in the United States, identified the basis for the Balm of Gilead project, a project to support terminally ill, vulnerable populations, who were at risk for poor end-of-life care. The report by Kvale et al. found that palliative care had the capacity to overcome SE barriers. Analysis of evidence in the United Kingdom of home nursing referral by Grande et al. identified that the relationship between low SE groups and limited home care referral was consistent and did not reflect the differences in need for referral.

Stigma and Mistrust. Issues of stigma and mistrust of palliative care are well considered in the literature and are often linked to culture.
and poverty. Race and culture were considered to run in parallel with SE deprivation, with the disentanglement of race and deprivation considered to be challenging. The large representation of African American groups in the U.S. literature, identified in the review, highlighted the relationship between culture and SES. Racial and ethnic minority groups in the United States were most likely to lack health care insurance; however, access to palliative care was not completely explained by income and insurance status of this group. Questions concerning how patients of marginal groups, invariably low SE groups, are viewed and how they view their health care providers, is important for understanding potential barriers to access. Mistrust of hospice or palliative care, arising from misconceptions of practice or concern at the absence of curative or life-prolonging intent, was an established theme in the international literature and reflected a lack of acceptability of palliative care services for this group. Prejudicial treatment was identified as a barrier to accepting palliative care services by homeless and transient groups.

The U.S. literature identified that low SE populations viewed palliative care suspiciously, considering it an inadequate substitute for aggressive, curative treatment. What was perceived as deprivation of technologically advanced services over supportive palliation further compounded an established mistrust of health care services for the poor in the United States. In a review of pilot programs to improve access to palliative care services for the poor and disenfranchised in the United States, recommended models of care for the dying poor, which incorporated both curative and palliative intent to treatment, in an attempt to modify perceptions that palliative care was not part of “mainstream” health care services.

Communication and Health Literacy. Mistrust in palliative care for the socioeconomically deprived was often paired in the literature with concerns around communication and the cultural implications for communication strategies in end-of-life care. Communication practices in palliative care were seen to facilitate further barriers to access for the poor. Limitations for socioeconomically disadvantaged groups to engage in communication required for open discussion around diagnosis and prognosis were highlighted in the literature. McQuillan and Van Doorslaer explored views of Irish travelers (“Gypsies”) toward palliative care in the United Kingdom and identified patient concerns associated with the openness of communication about death in palliative care, and the difficulties experienced by this group in understanding information delivered by palliative care service providers. The limited education and literacy levels of the travelers were considered likely barriers to palliative care services. Challenges in communicating with the socioeconomically disadvantaged at the end of life have received attention more recently in the literature. Vulnerable populations, which include the poor, the disenfranchised, and those with minimal education have high levels of unmet information needs and have expressed dissatisfaction with the information received from the providers. There has been little discourse in the palliative care literature, which acknowledges or seeks to address communication strategies for this group. This lack of investigation sits within the context of an impetus to address health literacy worldwide. Misinformation and misperceptions about end-of-life care, based on “unaddressed” poor health literacy, represent barriers to access.

Health literacy issues extend across all SE domains, yet are most profound in lower SE groups and are linked to education and general literacy levels, but are not exclusive of them. Health literacy is a requirement for a patient-centered health care system and the characteristics of that system can limit or promote access to the service based on its commitment to meeting health literacy needs. Health literacy is a measure by which an individual has the “capacity to obtain, process and understand basic health information, and use that information to access services and make appropriate health decisions.” Communication and education of patients and carers are foundational components of the palliative care and hospice domain; thus, attempts to improve health literacy should be highlighted as a priority. Yet, literature informing these issues is particularly limited. Volandes et al. identified that health literacy was an independent predictor of end-of-life preferences. Evidence for unmet communication needs in palliative care for low SE
groups highlighted limits in decision-making ability and uncertainty about treatment goals, all of which were considered to impact on quality of life for these groups. 50,60,62

Affordability

The affordability dimension of access describes the relationship between the cost of the service and the ability and willingness of the user to pay for those services. 10 High costs of end-of-life care for the uninsured and underinsured in the United States are well described in the literature. 51,53,56,67,68 Countries that have universal health coverage also identified financial burdens for the poor accessing end-of-life care services. 6,18,24,25,99–72 Expenses included bridging costs of the gap payments and costs of services and goods exceeding those provided by a government health service. These include the services and goods required to support a patient and their family through an advancing terminal illness and death. 53,73 Chochnov and Kristjanson 25 found that high-income groups were most likely to financially support home deaths. Givens and Mitchell 74 in their recent study in the United States, identified an association between social and economic concerns and support for euthanasia.

The impact of costs were not only significant in end-of-life care, but also on the survivor’s future financial position, with an Italian study identifying that 26% of families used all or most of their savings to cover the costs of care of a terminally ill loved one. 75 The impact of costs of end-of-life care for the elderly was particularly challenging, with the somewhat limited savings of this group depleted to care for a dying spouse. 76 One of the main risk factors for poverty and ill-health in the elderly was being a surviving spouse. 67,77 A national panel survey in the United States found that disparities in economic status that existed prior to widowhood, and as a result of medical expenditure, accounted for increased levels of poverty for elderly widows. 67 A U.S. study by Chao et al. 76 found that, hypothetically, the elderly felt spouses should forgo end-of-life care if it would deplete savings.

Health care expenditure on end-of-life care for low SE groups was identified in several studies as being higher than for other SE groups. 25,78,79 A meta-analysis by Higginson and Costantini, 43 to determine the effectiveness of palliative care services in Europe, found that more resources were required in low SE areas to achieve the same level of palliative care service. A U.S. study in 2001 identified end-of-life care costs based on the SES of ZIP codes. It found that end-of-life care expenditures for high poverty ZIP codes were 20% higher than for ZIP codes with the lowest poverty rates. 78 Higher health care costs for lower SE groups may reflect the costs of managing the health outcomes for late presentation with malignant disease, 79 the existence of multiple comorbidities, 78 lack of uptake of services and support payments, 70 the lack of attention to social factors, not amenable to current models of care, 80 the increased support required from primary care providers, 6,52,81 and a higher percentage of acute admissions and hospital deaths for low SE groups. 26 Two studies from Sweden contrasted these findings with Felder et al. 82 and Hanratty et al., 83 identifying increased health care expenditure for higher income groups at the end of life. Sweden’s comprehensive welfare state may account for these differences and investigation of this comparative phenomenon would certainly support understanding of the impact of appropriate social welfare strategies on health care expenditure for low SE groups.

Discussion

The United States and United Kingdom contribute the majority of evidence for low SE groups and access to end-of-life care services. Although the number of studies from Australia, Europe, and Canada were less, the issues were comparable. The literature identified in the review yielded themes for factors that impact dimensions of access; namely, accessibility, availability, affordability, and acceptability. The nature of SE deprivation and its influence on access to health services has the potential to contribute further to the disproportionate burden of suffering for this group. Literature identified in a developed world context finds challenges very similar to those experienced in the developing world. 84 These similarities indicate that supply or availability of a service is not sufficient for access. The pursuit of equity for access to palliative care services must be a central objective of health
Table 3
Limits in Home Death for Low SE Groups

<table>
<thead>
<tr>
<th>Limitations</th>
<th>Findings/Outcomes</th>
<th>Author, Date, Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inadequate palliative care</td>
<td>Relocation of Aboriginal patients to metropolitan hospitals for EOL care was due to a lack of local services.</td>
<td>McGrath et al., 2007 (Australia)</td>
</tr>
<tr>
<td>care resources</td>
<td>Lack of respite services in rural and remote areas to support Aboriginal groups</td>
<td>O’Mahony et al., 2005 (US)</td>
</tr>
<tr>
<td></td>
<td>Limited inpatient and community hospice services in low-income urban areas</td>
<td>Higginson et al., 2006 (UK, meta-analysis of European data)</td>
</tr>
<tr>
<td></td>
<td>Inequitable distribution of palliative care services across Europe</td>
<td>Gallo et al., 2001 (US)</td>
</tr>
<tr>
<td></td>
<td>Low-income communities had an increased likelihood of an institutionalized death, influenced by available health resources</td>
<td></td>
</tr>
<tr>
<td>Limited informal care</td>
<td>Lack of informal carers for low SE urban people in the United States were considered barriers to home hospice services</td>
<td>Kvale et al., 2004 (US), Hughes, 2005 (US)</td>
</tr>
<tr>
<td>care arrangements</td>
<td>Institutional care was more likely for those without informal care arrangements</td>
<td>Scale, 2006 (US, worldwide demographic review), Houttekier et al., 2009 (Brussels)</td>
</tr>
<tr>
<td></td>
<td>Fragile or nonexistent support systems common for the urban poor in the United States excluded access to palliative care services</td>
<td>Hughes, 2005 (US)</td>
</tr>
<tr>
<td></td>
<td>Patients without informal care support were less likely to die at home</td>
<td>Grande et al., 1998 (UK)</td>
</tr>
<tr>
<td>Referral bias</td>
<td>Fewer medical home visits for palliative care patients in lower SE areas</td>
<td>Burge et al., 2005 (Canada)</td>
</tr>
<tr>
<td></td>
<td>Patients in lower SE areas were less likely to access home palliative care services</td>
<td>Grande et al., 1998 and 2002 (UK)</td>
</tr>
<tr>
<td>Service demands</td>
<td>Demands for palliative care services were increased in low SE groups</td>
<td>Wood et al., 2004 (UK), Higginson et al., 1999 (UK), Worrall et al., 1997 (UK), Higginson et al., 2008 (UK, meta-analysis of European data)</td>
</tr>
<tr>
<td></td>
<td>More resources were required to achieve the same level of care for palliative patients in SE deprived areas</td>
<td>Hanratty et al., 2008 (UK)</td>
</tr>
<tr>
<td></td>
<td>SE deprivation influenced the use of hospital services in the last year of life</td>
<td></td>
</tr>
<tr>
<td>Costs of a home death</td>
<td>High-income groups were likely to support a home death</td>
<td>Chochinov and Kristjanson, 1998 (Canada)</td>
</tr>
<tr>
<td></td>
<td>Home care services incurred significant costs at the EOL</td>
<td>Hanratty et al., 2008 (UK)</td>
</tr>
<tr>
<td></td>
<td>Health care expenditures are high at the EOL and constitute a large proportion of the income of low SE groups.</td>
<td>McGarry and Scheoni, 2005 (US)</td>
</tr>
<tr>
<td></td>
<td>Prohibitive costs for power utilization at the EOL were incurred by Aboriginal groups in remote areas in Australia</td>
<td>McGrath et al., 2007 (Australia)</td>
</tr>
</tbody>
</table>

SE = socioeconomic; EOL = end of life; US = United States; UK = United Kingdom.

care services and should begin by engaging a need-based system of referral rather than the current referral-based system of access. The complexity of needs for disadvantaged groups at the end of life would be best supported in such a context.

The dimensions of access identified in the review are most broadly covered in literature from the United States. In particular, the U.S. evidence most strongly identifies themes around stigma and mistrust (acceptability), and costs or affordability of health care services. The limitations of health and social funding systems in the United States are certainly most likely to contribute to evidence for economic pressures for seriously ill people accessing health care services. Health insurance coverage for hospice services is available for the uninsured in the United States, but is limited in length of service provision and requires patients to forgo curative treatments to receive hospice benefits. The cultural and racial demographics of the United States, which include significant African American and Hispanic groups, describe a landscape of mistrust and disparity well understood in the literature. The financial separation of palliative care from a curative treatment option is likely to contribute to the skewed attitudes and beliefs of palliative care held by these groups.

Evidence from the United Kingdom contributed the second largest body of research in this area. Geographical dimensions of access and
place of death for low SE groups were well considered in the literature from the United Kingdom. Affordability was also identified strongly in a U.K. context. Despite a National Health Service funding model in the United Kingdom, the need for payment or gap payments for health care services was identified. Funding and service provision for hospice in the United Kingdom has the longest history and is a mix of charitable, not-for-profit and government-funded generalist care.\textsuperscript{88} Charitable and voluntary health funding models do potentially support a level of service disparity, whereby more affluent areas fund and support services locally and as such may be disconnected spatially and socially from areas of greatest need.\textsuperscript{27}

Access to end-of-life care services and resources, based on affordability, most profoundly impacts the socioeconomically deprived and although measured in several studies, exploration of the impact of financial hardship was limited in the literature internationally. The amount of income and net worth that was expended in caring for a family member at the end of life is proportionally higher and as such more significant in low-income groups. The capacity for low SE groups to both afford and recover from the costs of end-of-life care requires further investigation.

The small number of articles from other developed countries identified similar outcomes to the larger body of literature, with some contributing specific contextual variations. The Italian studies identified the variation of SES across the country and the impact of financial burdens for end-of-life care comparatively. The articles from Sweden not only contrasted the other literature, finding that health care expenditure in Sweden was greater for high SE groups, but also identified health care disparities for low SE groups. Both of these outcomes support further discourse on the impact of terminal illness for low SE groups in the context of the comprehensive, fully funded, social welfare and health system peculiar to Sweden. The Australian literature overall included a greater proportion of studies concerned with Aboriginal peoples’ access to services and the limitations of palliative care services in rural and remote areas. This is not surprising considering the large gap in health and health care outcomes between Aboriginal groups and other Australians, and the vast expanse of the Australian continent. Research investigating disparity in end-of-life care within countries contributes important contextual understanding that is likely to describe the problem(s) and highlight strategies for change. More country-specific research in this area is, however, required.

Disparities in home deaths based on SES and the limited discussion of health literacy in the palliative care literature were alarming outcomes of the review and compel exploration of novel and appropriate solutions. Literature that considered issues of choice and communication referred to the potential for a “two-tiered” health system, which provided different services and different quality of service, based on an individual’s SES.\textsuperscript{25,89}

Limits of informal care arrangements, most particularly for low SE groups, will provide increasing challenges for home-based palliative care services.\textsuperscript{90} The socially disadvantaged have a differential access to home care, which cannot be ignored.\textsuperscript{27} The necessity, therefore, to consider how best to accommodate the needs of patients without family support is imperative.\textsuperscript{11} The developed world is likely to be further challenged to provide care for those people from low SE groups for whom informal care is not an option. The increase in numbers of people living alone is contributing to a fall in the number of home deaths.\textsuperscript{27} and the needs of this group require that they receive specialized support and approaches to home care.\textsuperscript{90} The literature is limited in identifying impetus to address this current and likely future trend in health service disparity. Research evidence identifying individual level data in this area is imperative to ensure that the individual’s goals for end-of-life care are understood and shared at the policy and service provision levels.

Overall, the international literature was generally defined by population studies and research that considered the relationship between SES and challenges and risks for accessing end-of-life care services, and the trends for these over time. The determinants that underpin this relationship and the analysis of interventions to support access were poorly considered in the literature. This is certainly not a new criticism of the literature in the
area of health inequity, which has a tenacious history of definition without analysis. Further descriptive studies in this area are still very necessary to identify trends and the range of access issues. Research is required, however, to investigate the relationship that underpins low SES and access to palliative care and the outcomes of interventions that seek to reduce disparity in this area.

The increasing chronicity of certain cancer diagnoses presents a context not previously considered for this group and will require care that more appropriately reflects a progressive disease model. Patients with malignant disease have well-defined specialist palliative care service use and constitute a large consumer area of palliative care services. Longer periods of illness require resources beyond those previously considered necessary and will place greater demands on palliative care services and informal care arrangements. The impact of increasing chronicity of cancer and the appropriate demand for services by nonmalignant groups is, therefore, an area for concern and action. Future service provisions for palliative care will be required to acknowledge the increasing service demands and chronicity of its patient population, and the SE consequences this brings about. Future projections of palliative care service need have begun to call for urgent planning for the large increases in an aging population and deaths.27

The needs of the socioeconomically deprived, as a subgroup of this increasing population, must be considered in future palliative care service planning or they may “miss” the opportunity for appropriate care at the end of life.

**Conclusion**

Knowledge of access to palliative care services for low SE populations in a developed world context is limited in the literature. This review of the literature identified levels of inequity in access for low SE groups at the end of life. Further analysis and understanding of the experience of the dying poor and their families is required, with a focused commitment to research that both identifies and evaluates interventions aimed at modifying and eliminating disparity.

**Disclosures and Acknowledgments**

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Referral patterns and proximity to palliative care inpatient services by level of socio-economic disadvantage. A national study using spatial analysis

David C Currow1*, Samuel Allingham2, Sonia Bird2, Patsy Yates3, Joanne Lewis4, James Dawber2 and Kathy Edgar2

Abstract

Background: A range of health outcomes at a population level are related to differences in levels of social disadvantage. Understanding the impact of any such differences in palliative care is important. The aim of this study was to assess, by level of socio-economic disadvantage, referral patterns to specialist palliative care and proximity to inpatient services.

Methods: All inpatient and community palliative care services nationally were geocoded (using postcode) to one nationally standardised measure of socio-economic deprivation – Socio-Economic Index for Areas (SEIFA; 2006 census data). Referral to palliative care services and characteristics of referrals were described through data collected routinely at clinical encounters. Inpatient location was measured from each person’s home postcode, and stratified by socio-economic disadvantage.

Results: This study covered July – December 2009 with data from 10,064 patients. People from the highest SEIFA group (least disadvantaged) were significantly more likely to be referred to a specialist palliative care service, likely to be referred closer to death and to have more episodes of inpatient care for longer time. Physical proximity of a person’s home to inpatient care showed a gradient with increasing distance by decreasing levels of socio-economic advantage.

Conclusion: These data suggest that a simple relationship of low socioeconomic status and poor access to a referral-based specialty such as palliative care does not exist. Different patterns of referral and hence different patterns of care emerge.

Keywords: Palliative care, Socio-economic disadvantage, Service planning, Referral patterns.

Background

Specialist palliative care services in Australia have grown rapidly over the last 20 years [1]. The site and model of service delivery have commonly developed in a way which is defined by local initiatives and have been ad hoc. A fundamental question arises as to whether there is evidence of discrepancies in referral to, or proximity to specialist palliative care services [1,2]. Are services distributed across the community in a way that reflects the populations that they serve? [3] These concerns are supported by existing evidence for limited social and geographical access to palliative care services for certain groups in Australia [4].

Internationally, inequity in palliative care service provision has been demonstrated [5,6]. Previous research has suggested that lower socio-economic status has been associated with poorer utilization of palliative care services [7]. Inequity in the distribution of palliative care services in disadvantaged areas [5] and increased travel times to specialist palliative care facilities from low socioeconomic areas [8] have been shown to further exacerbate disparities in care for people from lower socio-
economic groups. Lower levels of palliative care service uptake by socioeconomically disadvantaged groups are considered to be driven by health and social service structures, and individual characteristics [9,10]. The relationship between the social determinants of health and well-being demands a commitment to address any inequitable access to services [11]. The foundations of Australia’s universal health care coverage, the established evidence for health service inequity and the vast geographical expanse of the continent confirms the need to ensure that utilisation of services is optimised for all people. To date, there are limited Australian data identifying any difference in access to palliative care services by socio-economic status.

Providing quality palliative care is not simply a social good. Emerging evidence demonstrates benefit to patients (better symptom control, better survival, better adjustment to the disease process, better support); [12-22] caregivers (improved survival and adjustment having relinquished the role, better support in the role); [19,20,23-25] health services (fewer inpatient bed days, few admissions, lower overall costs); [21,26,27] and health practitioners (better support) [28]. These benefits then would suggest that there needs to be an assessment of referral to and proximity to services in order to ensure these benefits are available to all the people with the most complex end-of-life needs.

The use of linked population and healthcare data with geographic information (geocoding) has contributed to understanding service coverage [29-31]. The aims of this study are to examine:

i. Referral to specialist palliative care services by socio-economic advantage and clinical phase [32]; and
ii. Proximity to, and utilization of inpatient services

Methods
Study setting
The Palliative Care Outcomes Collaboration (PCOC) is a national quality initiative to improve the clinical care of people with life-limiting illnesses. National coverage has grown rapidly since its inception in 2006 and, to date, more than 80% of all patients seen by specialist palliative care services in Australia have data collected at point-of-care from referral until death. As a collateral opportunity, PCOC has allowed the identification of services that provide specialist palliative care nationally, including non-participating services.

Data are divided into three levels: patient data are collected once at the time of referral to the services, episode data are recorded each time the physical place of care changes; and phase data are coded with changes in clinical condition [32]. The clinical classification of ‘phase’ has four divisions relevant to this study: ‘stable’, ‘unstable’, ‘deteriorating’ and ‘terminal’. Independently of diagnosis, these descriptors reflect the last months of life and, in PCOC, are recorded at least weekly (for inpatient care) or every clinical encounter (for community care) [32].

The Socio-Economic Index for Areas - Index of Disadvantage (SEIFA) based on data from the 2006 Australian Census is a summary measure of socio-economic conditions and is generated by the Australian Bureau of Statistics (ABS), and is updated after each census. The 2006 SEIFA score relates directly to the patient cohort reported here. This measure allocates a social disadvantage index to each postal area in Australia using census-derived variables including income, educational attainment, levels of employment and the number of households with a car [33]. In this study, the SEIFA index was collapsed into three SEIFA groups – low (most disadvantaged), medium and high (most advantaged) to represent three basic socio-economic levels. These three groups each represent approximately one third of the Australian population. The postcode of each patient’s residence could then be allocated to one of the three SEIFA groups.

To understand service utilisation, the proportion of referrals to specialist palliative care services from each SEIFA tertile and the clinical status (phase) at the start of palliative care episodes are compared.

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Analyses
Chi-square, t-tests and analysis of variance (ANOVA) were used to compare the different measures of interest across the three SEIFA groupings as appropriate. Bonferroni corrections were applied as appropriate. A linear regression model fitted to log transformed distances was generated to adjust for the effect on SEIFA of age of the population who are dying.

Ethical oversight of this program is provided by the Human Research Ethics Committee of the University of Wollongong. This is a secondary analysis of de-identified aggregated patient and service data.

Results
Study data
The study used data from July 1 to December 31, 2009 collected at referral to specialist palliative care services across Australia. For geocoding and for socio-economic
disadvantage, patient and service level postcodes data when first recorded were used in the analyses.

**Study setting**

In total, 91 of the estimated 179 palliative care services that existed at this time participated in the PCOC data collection during the period. (Table 1) Fifty percent of these services were in major cities, 32% in inner regional centres and 16% in outer regional or rural areas. While these 91 services represented 51% of palliative care services, it is estimated that they treated more than 80% of people referred to specialist palliative care services. These 91 services provided 751 (69.3%) of the estimated 1,084 specialist palliative care inpatient beds. Services provided various combinations of inpatient, consultative and community-based services (home visits and outpatient clinic appointments).

**Patient population**

In this period, 10,964 patients had data collected prospectively by PCOC. These people had 12,523 episodes of care (where an ‘episode’ changes each time the place of care changes). Overall, 54% of referrals were males (56% in the lowest SEIFA group; Table 2). The average age of the highest SEIFA group was significantly higher than the other two groups (p<0.002; Table 3). Eighty-two percent of those with a recorded diagnosis had cancer as their primary life-limiting illness and this proportion was the same for all three SEIFA groups (Table 2).

---

**Table 1 Socio-Economic Index for Areas (2006 Census data; SEIFA) group for services that are and are not participating in the Australian Palliative Care Outcomes Collaboration (PCOC)**

<table>
<thead>
<tr>
<th>SEIFA group</th>
<th>Low</th>
<th>Medium</th>
<th>High</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participating services (n=91)</td>
<td>47.3%</td>
<td>28.6%</td>
<td>24.2%</td>
</tr>
<tr>
<td>Non-participating services (n=88)</td>
<td>35.2%</td>
<td>37.9%</td>
<td>27.3%</td>
</tr>
</tbody>
</table>

---

**Table 3 Demographic and proximity data at a patient level for all people in the Australian Palliative Care Outcomes Collaboration database July 1 – December 31, 2009, by Socio-Economic Index for Areas of Disadvantage (2006 Census data; SEIFA)**

<table>
<thead>
<tr>
<th>Patient-level data</th>
<th>SEIFA Group</th>
<th>Low</th>
<th>Medium</th>
<th>High</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years) Mean</td>
<td>70.3</td>
<td>70.1</td>
<td>71.3</td>
<td></td>
</tr>
<tr>
<td>Median</td>
<td>72</td>
<td>72</td>
<td>73</td>
<td></td>
</tr>
<tr>
<td>IQR</td>
<td>19</td>
<td>20</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>Distance from inpatient care (kilometres) Mean</td>
<td>43.4</td>
<td>29.9</td>
<td>14.6</td>
<td></td>
</tr>
<tr>
<td>Median</td>
<td>9.9</td>
<td>9.4</td>
<td>8.1</td>
<td></td>
</tr>
<tr>
<td>IQR</td>
<td>25.8</td>
<td>14.6</td>
<td>9.9</td>
<td></td>
</tr>
</tbody>
</table>

1 Inter quartile range.
2 High SEIFA group significantly older than both other groups (multiple t-test; largest p = 0.0002).
3 Low SEIFA group significantly greater than both other groups (multiple t-test; largest p < 0.001).
4 SEIFA low = most disadvantaged; SEIFA High = most advantaged.

**Referral to, and care provided by specialist palliative care services by socio-economic status**

Using Chi-square, the distribution of referrals to specialist palliative care services was significantly lower for people from the highest SEIFA group (lowest 3744 (37.2%), medium 3466 (34.5%) and highest 28.3%; p<0.001). This was also reflected in a significantly lower number of episodes of care provided. As a marker of the time of referral, people from the highest SEIFA group were also significantly less likely to be hospitalized in the palliative care hospital (19.4% vs 22.6% (medium) and 24.2% (lowest); p=0.001) [31]. (Table 4) Episodes of care were significantly more likely to be in the inpatient setting for people from the highest SEIFA group (71% compared with 63% for the other two groups; p<0.001) with significantly longer mean inpatient lengths of stay (highest 13.9 days; medium: 11.6 days and lowest 11.5 days; p<0.001) (Table 5).

---

**Table 2 Demographic and referral data at a patient level for all people in the Australian Palliative Care Outcomes Collaboration database July 1 – December 31, 2009, by Socio-Economic Index for Areas of Disadvantage (2006 Census data; SEIFA)**

<table>
<thead>
<tr>
<th>Patient-level data</th>
<th>SEIFA Group</th>
<th>Low</th>
<th>Medium</th>
<th>High</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis Cancer</td>
<td>2,781</td>
<td>83%</td>
<td>2,580</td>
<td>81%</td>
</tr>
<tr>
<td>Non cancer</td>
<td>577</td>
<td>17%</td>
<td>614</td>
<td>19%</td>
</tr>
<tr>
<td>Gender Male</td>
<td>2,114</td>
<td>56%</td>
<td>1,869</td>
<td>54%</td>
</tr>
<tr>
<td>Female</td>
<td>1,660</td>
<td>44%</td>
<td>1,597</td>
<td>46%</td>
</tr>
<tr>
<td>Referral to specialist palliative care service</td>
<td>3,761</td>
<td>37%</td>
<td>3,470</td>
<td>34%</td>
</tr>
</tbody>
</table>

1 Significant difference in SEIFA groups (Chi-square p < 0.001).
2 SEIFA low = most disadvantaged; SEIFA High = most advantaged.
Table 4 Episode of care level data in the Australian Palliative Care Outcomes Collaboration database
July 1 – December 31, 2009, by Socio-Economic Index for Areas of Disadvantage (2006 Census data; SEIFA)

<table>
<thead>
<tr>
<th>Episode-level data</th>
<th>SEIFA group</th>
<th>Low¹</th>
<th>Medium</th>
<th>High²</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Place of care¹</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inpatient</td>
<td></td>
<td>2,819</td>
<td>63%</td>
<td>2,871</td>
<td>68%</td>
</tr>
<tr>
<td>Community</td>
<td></td>
<td>1,701</td>
<td>37%</td>
<td>1,663</td>
<td>37%</td>
</tr>
<tr>
<td>Phase at beginning of a patient’s palliative care episode</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stable²</td>
<td></td>
<td>1,076</td>
<td>24%</td>
<td>971</td>
<td>22%</td>
</tr>
<tr>
<td>Unstable</td>
<td></td>
<td>1,786</td>
<td>40%</td>
<td>1,639</td>
<td>39%</td>
</tr>
<tr>
<td>Deteriorating</td>
<td></td>
<td>1,246</td>
<td>28%</td>
<td>1,367</td>
<td>32%</td>
</tr>
<tr>
<td>Terminal</td>
<td></td>
<td>343</td>
<td>8%</td>
<td>326</td>
<td>7%</td>
</tr>
</tbody>
</table>

*Episode changes every time physical place of care changes. ¹ High SEIFA group significantly different from both other groups (multiple chi square: largest p = 0.001). ² High SEIFA group has a significantly lower proportion of episodes starting Stable (multiple chi square: largest p = 0.001).³ SEIFA low = most disadvantaged; SEIFA High = most advantaged.*

Proximity to inpatient services by socio-economic status
Using geocoding, for people who had at least one inpatient episode of care, there were significant differences between the proximity to that care by SEIFA. For the lowest group, distances were a mean of 43.4km compared to medium (29.9km) and highest (14.6km) (Table 3). Using a regression model with distance as the dependent variable, and controlling for SEIFA, rurality and age, the model demonstrated that older people were significantly more likely to be proximate to inpatient services (R² 0.78; for age, p<0.001).

Discussion
This study confirms that there are significant differences in the uptake of, and proximity to specialist palliative care services in Australia. These differences are associated with socio-economic status in a complex way. For the highest SEIFA category (those who were least disadvantaged) there was: lower uptake of specialist palliative care services; later in the course of the illness; with referral less likely to be in the stable phase; better proximity to inpatient services; and longer duration of inpatient care [34,35]. These data support previous population-based studies in the United States, Canada and Australia that observed disparities in access to specialist palliative care services by socio-economic disadvantage, although the patterns appear somewhat different to previous reports [36-38].

Not all studies on disparities on referral to specialist palliative care services have seen socio-economic differences [39]. Higher levels of community-based care in the lowest tertile shifts the responsibility of care to families and friends, including the financial cost of caring. Such differences in community-based care are amplified if the most advantaged SEIFA group are able to access a range of services including user-pays nursing and home care [34,40].

Proximity to specialist palliative care services may have significant implications for health service delivery more broadly. In an analysis of more than 28,000 people over the age of 65 who died of cancer within one year of diagnosis, while controlling for key demographic and clinical factors, physical proximity to hospice services was an independent predictor of less aggressive end-of-life care [41].

Needs based services
Do people from lower socio-economic strata have different needs? There is no evidence that needs in the most disadvantaged communities are any less and, arguably, given the social deprivation experienced across the life span, needs will be greater [42]. This challenges directly hospice and palliative services to consider how to provide needs-based care that genuinely serves the whole population in order to achieve equitable outcomes (not simply
equitable access] [34]. The patterns demonstrating higher levels of chronic illness and of earlier mortality for people from greater socio-economic disadvantage would suggest that there is an even greater focus required to ensure equitable outcomes at the end of life given, for example, the higher likelihood of dependent children given the age at which people are dying.

Limitations
These data also assume that for each SEIFA group the likelihood of death is equal. The discrepancy in access is likely to be greater given that socio-economic status at the end of life is going to be lower for a significant proportion of the population given diminishing disposable income for older people. The services not represented in the patient-level data were more likely to be rural where greater socio-economic disadvantage is also likely. Discrepancies in the way services are utilised are magnified in subtle ways — the costs of community-based care are borne largely by the family and the proportion of care provided in the community is greatest in the most disadvantaged group in the community. Likewise, the costs of travel to inpatient units will be disproportionately borne by those least able to afford it.

Limitations of the study (sample)
The study does not include all services in Australia, but the missing services tend to be smaller more rural services where poor proximity to care will add to disadvantage. Their inclusion would likely magnify the effects seen in the data presented. Coding has been done for the services that are missing, but the populations who access these services are not available in this data set.

People who already experience geographic isolation from services may simply never be referred and hence not represented in this sample further underestimating disparities. Only people who used designated inpatient palliative care beds form the basis of this analysis. This therefore underestimates the impact of distance for people who chose not to have inpatient care because the distances were too great, or had care at a hospital closer to home in a non-designated bed.

Limitations of the study (data)
The current studies refer only to distance not ease of travel which incorporates distance, mode of travel, costs and other factors that contribute to accessibility. Although absolute distances may be much shorter in metropolitan areas, travel time especially when relying on public transport may still be very challenging [43].

Using straight-line distances between the patient’s postcode and the postcode of the inpatient facility, it is likely that the travel distance is underestimated for patients living in regional and rural areas. This is because postal areas are not uniform in geographic size. Hence, patients living in the same postcode as a palliative care service in a regional area (assigned a travel distance of 0) may need to travel much further than a patient living in a major city who lives in the same postcode as a palliative care service. While straight-line distance travelled is not an exact measure of travel burden, it acts as a strong indicative measure of access.

Generalisability
These data refer to the Australian health and social systems, thus limiting generalisability to other settings. Further, there are differential rates of coverage for the services represented: 51% of all services; 69% of all designated inpatient beds; and approximately 80% of all patients referred to specialist palliative care services in the country. As noted in Limitations, this therefore probably underestimates the differences seen for the most socially disadvantaged rural patients.

Future research directions
Research in the future should look specifically at needs, complexity of care and outcomes at the end of life by socio-economic status. Given that one in two people with an expected death will not access palliative care in Australia, population-level studies are required to ensure that service delivery better incorporates needs-based access to specialist palliative care services across the community [44]. Accessibility to services needs to be geocoded for all predictable deaths accepting that only a sub-set would derive benefit from referral to specialist palliative care services.

Conclusion
Most palliative care services have had little jurisdictional or local planning. With few exceptions, this ‘organic’ process has been built around community interests and goodwill as well as the availability of existing hospital stock rather than sound principals of health service planning. Population-based service planning may require further affirmative action to overcome some of the geographical difficulties highlighted by this current study.

Better use of new models of care with emerging technologies such as video-conferencing for clinical consultations and family conferences may relieve some burden related to poor proximity to services. This becomes an overwhelming imperative for areas where long distances need to be travelled by caregivers, families and friends in metropolitan peri-urban and rural areas when inpatient services are dislocated from that person’s own environment.
Inpatient care needs to be accessible since much of it is required at short notice due to unexpected changes in condition. Inpatient care also needs to be physically proximate so that family and friends can continue to support patients.

Competing interests
The authors declare that they have no competing interests.

Authors’ contributions
Conception and design (DC,IE); Planning (DC,IE,JP); data acquisition (DC,JP,IE,KE); analysis (SAS,JP,IE); interpretation (KE,JP,DCU); drafting (DC,IE,JP); critical revision (DC,SA,JP,JDCU). All authors read and approved the final manuscript.

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Special Article

A Social Capital Framework for Palliative Care: Supporting Health and Well-Being for People With Life-Limiting Illness and Their Carers Through Social Relations and Networks

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Abstract

Context. Social relations and networks are vital for sustaining and enhancing end-of-life care. The social capital concept supports a framework to understand the association between social relations and well-being; yet, to date, there has been very limited investigation of social capital in the palliative care literature. A framework for understanding social contexts in end-of-life care is necessary.

Objectives. To summarize the literature on social capital, well-being, and quality of life for key outcomes to inform a model of social capital in palliative care.

Methods. The electronic databases MEDLINE (1997 to March 2011), Embase (1997 to March 2011), CINAHL (1997 to March 2011), and PsycINFO (1997 to March 2011) were searched using key/MeSH search terms of “social capital,” “palliative care," and “well-being” and/or “quality of life.” The literature was reviewed to identify key concepts to develop and inform a palliative care social capital framework.

Results. A total of 93 articles were included in the literature review, with only two articles identifying discourse on social capital and palliative care. Four key areas integrating the social capital outcomes informed a framework for palliative care.

Conclusion. The social capital concept provides a structure for understanding how the organization and meaning of social contexts can potentially enhance or hinder end-of-life care. Research that identifies specificity in application of social

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capital concepts is fundamental to issues of access to services, sustaining levels of care, quality of life, and well-being. The importance of “bridged” social capital relations and networks for improved resource acquisition and information flow was identified in the literature and outlined within the palliative care social capital framework. Differential access to social capital by disadvantaged groups provides further impetus to engage a model of social capital for palliative care.

Key Words
Social capital, palliative care, end-of-life care, well-being, quality of life, social relations and networks

Introduction
The health of individuals is partly dependent on the characteristics of their relationships and the social structures in which people live. The importance of social ties to health and well-being has been captured in the construct of social capital. The concept of social capital has been conceptually refined across nearly a century of work by sociologists, economists, and social theorists to understand how lives are made more fulfilling through social ties. Social capital research has demonstrated relationships between neighborhood/community characteristics and life expectancy, health and well-being, and health care access and health behaviors.

Palliative care is an approach to care that fundamentally seeks to optimize the quality of life for patients with life-limiting illnesses and their families and carers. This aim is achieved through the management of symptoms and support for psychological, spiritual, and social needs. Contemporary palliative care services are coordinated and provided by multidisciplinary teams that seek to support patient-centered care across levels of service, wherever possible in the environment of choice. Recognition of the family and carers as inclusive of the unit of care is central to palliative care philosophy and practice because their involvement is necessary to both enable patient-centered care and provide practical caring support. A greater understanding of social structures and relations is required to plan support for informal carers, who provide the vast majority of end-of-life care even in well-resourced countries. The needs of informal carers are significant but remain largely unmet. These needs are best understood in the context of relationships, yet the value of relationships as perceived by carers is underreported in the literature. Life-limiting illness is often isolating for patients and carers alike, many times leading to a burden of social loss. Disparities in accessing palliative care services and the overrepresentation of women as informal carers raise issues of justice, gender, and power gradients within social contexts of end-of-life care.

The concept of social capital enables understanding of both the capacities and limitations of social networks for improving health and well-being. The social capital literature provides a framework of causally related definitions, levels, and domains that provide insights into how benefits in the social milieu might be accrued. The public health approach is an emerging focus in the palliative care literature, and although social capital sits within this new discourse, it has had limited investigation specifically. Social capital is a distinct concept within public health, explicitly characterizing social systems and supporting a link between the structural (social stratification) and intermediary (social circumstance) social determinants of health, and offers new insights into community development and health promotion approaches. The mainstreaming of contemporary palliative care services, within the biomedical focus on physical care, has meant that end-of-life care is no longer well positioned in social contexts, a significant issue whereby the essentially social nature of dying is such that social context, social support, and inclusion are imperative for quality care at the end of life. The potential for social relationships...
and networks to buffer the effects of crisis and transition associated with a terminal diagnosis further underscores the need to understand and support social contexts for health and well-being. Palliative care, therefore, requires application of a distinct social framework such as social capital to engender a clearer understanding of the meaning of social context at the end of life. The aim of this article was to summarize the social capital literature as it relates to quality of life and well-being and apply this knowledge to a model of social capital for palliative care.

Social Capital Model Derivation

Social capital literature identifying outcomes for quality of life and well-being and palliative care were identified through electronic databases (MEDLINE, PsycINFO, Embase, and CI-NAHL) and through hand searching of reference lists for relevant publications and seminal authors’ works. Ninety-three publications were identified that reached conclusions about the impact of social capital for health and well-being. Two articles from the 93 publications identified specifically discussed social capital and palliative care. The conceptual model derived from this literature is shown in Fig. 1, and elements are discussed below.

Social Determinants of Health

The social determinants of health framework perceive social capital as one factor among many. Social capital also was identified as a compatible model within social determinants of health research, which considered the broader nonmedical determinants of health. In particular, the literature identified that the social capital construct outlined the impact of social networks and relationship factors, within the social determinants of health framework.

Major Theories of Social Capital

The expositions of major contemporary social capital theorists, Pierre Bourdieu, James Coleman, Robert Putnam, and Nan Lin, have contributed to the complexity of the construct of social capital through their varying approaches. Bourdieu and Wacquant defined social capital at the individual level as the “aggregate of actual or potential resources linked to the possession of a durable network,” particularly highlighting contexts of power relations and social inequalities. Both Coleman and Putnam defined social capital as individual and collective assets embedded in social relations and structures. One of the distinguishing features of Putnam’s theory was the assertion that social capital could generate not only

![Diagram of Social Capital Model](image-url)

Fig. 1. Social determinants of health. *Theories of social capital are situated in one or more of the levels of analysis.*
positive outcomes but also negative ones. Lin (p. 25) described social capital in terms of network theory: “resources embedded in social networks accessed and used by actors for actions,” also conceptualizing and measuring social capital as individual and collective assets. Broadly defined, then, social capital can be seen as the valued resources inherited within and as a result of social relations.

Levels of Analysis

Major theories of social capital are situated in one or more levels of analysis at the macro, meso, and micro levels relative to the levels of society. At the macro level, presentations of social capital identify state and government institutions, laws, and governance that support the capacity to enable community responsiveness at a structural collective level. Meso level structures accredit networks of formal and informal community institutions, services, coalitions, and groups that occur at adjacent hierarchical levels and enable differential access to resources. Micro level aspects, which are concerned with behavior at the individual level, relate to connectedness or linkage of members at similar hierarchical levels. As mentioned above, there has been some debate as to whether social capital should be understood and analyzed as an individual or collective property. In its broadest form, social capital has been defined as both individual and collective resources, held in and produced by social relations.

Social Capital Types

Following conceptual revisions of social capital in the late 1990s, functions of social relations and networks were further refined as “bonding” and “bridging” social capital with others also recognizing a third distinction of “linking” social capital. Bonding social capital was used to characterize the densely connected relationships of family and close friends, connections between people holding the same or similar values. Bridging social capital was contrasted with the “weaker” ties or relations of mutuality with individuals and groups across boundaries of social identity, age, ethnic group, and class. Bridging social capital was considered a form of social leverage that supported access to other levels of social capital. The third and less considered distinction of linking social capital described the capacity for relations and networks to cut across power gradients to connect with the representatives of formal institutions in respectful and trusting relations. Linking social capital was a distinction that more overtly introduced governance and macro level factors into the conceptual discourse.

Social Capital Components

Elements within these three social capital types have been developed in the health literature according to two distinct social capital components: structural social capital and cognitive social capital. Structural social capital is thought to be inclusive of social networks and access to goods and services, whereas cognitive social capital is characterized by shared values, trust, participation, belonging, cohesion, and decision-making capacity incribed in individuals, communities, and societies. Harpham described structural social capital as what people “do” and cognitive social capital as what people “feel.” These constructs were considered to be complementary to each other as they sustained the range of social attributes. Yet, despite the connectedness of these domains, it was important that they also were considered distinct, as they demonstrated different relationships with health outcomes and behaviors.

Positive and Negative Social Capital Outcomes

Social capital capacities and limitations are summarized from the literature under the headings in the levels of analysis in Table 1.

Social Capital Capacities

Broadly, the literature demonstrates a reasonable association between social capital, well-being, and mental health. The literature also finds that social capital research identifies empirical links between social support processes and the capacity to buffer the effects of hazardous environments and improve access to services and resources.

Arts, cultural, religious, and entertainment programs and organizations were found to augment social capital. Social ties, community involvement, and cohesion were fostered by programs that engaged individuals in community activities. These programs promoted trust,
Table 1  
Potential Social Capital Capacities and Limitations for Levels of Analysis

<table>
<thead>
<tr>
<th>Capacities and Limitations</th>
<th>Macro Level</th>
<th>Meso Level</th>
<th>Micro Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Potential capacities</td>
<td>Creation of resources</td>
<td>Information flow</td>
<td>Maintenance of resources</td>
</tr>
<tr>
<td></td>
<td>Development of networks to support opportunity at the micro and meso levels</td>
<td>Access to services and resources</td>
<td>Maintenance of functions for daily needs</td>
</tr>
<tr>
<td></td>
<td>Creation of civic trust and social cohesion</td>
<td>Promotion of social inclusion</td>
<td>Creation of trust and reciprocity</td>
</tr>
<tr>
<td></td>
<td>Creation of social and welfare policy</td>
<td>Creation of social leverage</td>
<td>Sense of belonging</td>
</tr>
<tr>
<td>Potential limitations</td>
<td>Macrostructures determine whether meso and micro transactions for resources and information can occur</td>
<td>Community cohesion</td>
<td>Adoption of negative group norms</td>
</tr>
<tr>
<td></td>
<td>Limited recognition of unfavorable macro level influences on social capital</td>
<td>Adoption of negative norms and behavior</td>
<td>Impact of damaging close relationships</td>
</tr>
<tr>
<td></td>
<td>Corrupt/nepotism</td>
<td>Disparity in pathways to social capital on the basis of social position, education, and gender</td>
<td>Demands of close relations particularly for females, cultural, and lower socioeconomic groups</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social exclusion because of structural barriers that limit access to networks and resources</td>
<td>Strength of individual ties limits links with community resources and networks</td>
</tr>
</tbody>
</table>

social inclusion, self-esteem, access to resources, and access to resource people. The use of information and communication technologies to generate social capital also was found.57-60 Social networking websites were acknowledged as being particularly successful at fostering broader social networks, in particular reducing the barriers to accessing networks for people with low self-esteem.57 The role of the Internet has been identified as an emerging area of interest in social capital.62 A study by Radin13 examining activities of an online support group for women with breast cancer found that this group developed effective action, media advocacy, and lobbied government through trust that was created in the virtual environment.

Negative Social Capital Outcomes

Negative effects of social capital were identified, demonstrating unequal transactions or gains, particularly in relation to vulnerable and marginalized groups such as the frail elderly, racially segregated groups,52,63,65,66 women,49,63 and also with regard to membership of certain clubs or groups.41 Social capital had the capacity to increase both social inclusion and social exclusion within its domains. Social position and networks, influenced by race, gender, and status within a continuum of differential access, were seen in formal social structures where exclusion and the criteria for exclusion were most explicit.20(p, 56)

Power relations, hierarchical structures, and differential access to social capital were identified,20,52,59,60,64 whereby power gradients potentially limited choices, influences, and access to resources.61 The failure to include power in the discourse on social capital was identified as a limitation in the social capital literature,20,64 with suggestions to incorporate Bourdieu’s theory in social capital inquiry to engage a consciousness of the dynamics of power in resources and access.20,65,66,60 Evidence from the literature on power relations is summarized as follows.

Dynamics of Power. Cultural aspects of social capital concerned with language and formal and informal networks were found to be biased toward the majority or dominant language group, who were invariably likely to be more educated and socioeconomically advantaged.66 Minority language groups were found to be at greater risk for poorer health and wellbeing, with an identified association to social disparities. Bouchard et al.25 examined the health determinants in a minority Francophone community in Canada and proposed that literacy issues were major barriers to social
integration and inclusion for this group, with ties to social networks potentially mediating access to resources and social, cognitive, and emotional support. The importance of minority language and racial groups establishing networks and partnerships to communities and government groups was highlighted.  

A gender perspective in examination of social capital was considered a valuable inclusion. Osborne et al. in a qualitative study of women’s experiences of social participation, identified that levels of participation imposed stressful demands on individual women because of the competing responsibility of family roles in addition to potentially negative social dynamics of relationships that led to harm. Outcomes of gender differences identified that forms of social capital operated differently for men and women and were positively and negatively associated with health. Community participation and club membership varied between genders, with females more likely to belong to clubs and participate in community organizations that fostered supportive community and family networks. In a study by Berry and Welsh that explored the relationship between social capital and health in Australia, women reported stronger associations with both structural social capital and cognitive social capital yet were simultaneously found to have worse mental health outcomes. The authors proposed that this could be the result of two particular issues: the first is that the relationship between social capital and mental health was gendered and, as such, limited the ability for women to convert social capital into opportunities, and the second is that women were more likely to possess the informal bonded close family ties, which tended to limit the potential for the greater and more diverse resources that were associated with bridged weaker ties of more external formal and informal networks.

Groups with lower socioeconomic status were identified as being at greater risk for having limited social capital. The pressures and outcomes of socioeconomic deprivation were likely to influence the structure and actions of relationships. These groups were more likely to have low levels of trust, particularly at a macro level. Reciprocity and trust were found to enhance access to economic assistance in the event of temporary financial difficulties, with limited trust in external agencies acting as barriers and reinforcing limited social capital.

Employment was found to be particularly important in the relationship between social capital and well-being, with the negative effects of unemployment surpassing that of income loss alone. The complex and apparently indissoluble relationship between economic deprivation and social deprivation is highlighted by this.

**Social Capital Framework for Palliative Care**

A social capital framework has the capacity to support health and well-being through connections, information exchange, and resource acquisition and leverage. Development and refinement of the social capital concept within research have failed to advance understanding of the application of this concept to specific health care settings. There remains capacity for a model of social capital to provide significant contributions to understanding the needs of patients with advanced incurable illness and their carers. Research aimed at improving outcomes in patients with life-limiting illnesses and caregivers is becoming increasingly important with an aging population; a focus is needed on the factors that contribute to well-being for this group.

Mechanisms of support for patients and informal carers in palliative care have generally concentrated on stress and crisis models when what is really required is a focus on strategies for recognizing strengths and resilience-building capacity and coping. Where models of care have failed to incorporate the broad experience of caring, practitioners remain unsure about how best to support carers in end-of-life care. The pressing priority to increase support for carers in the future mandates an understanding of models that can sustain capacity for informal care. These models will need to be inclusive of support for this group at the individual level and also will need to identify external links with formal services and networks and government agencies. The contribution of wider networks and supports is recognized for enhancing the capabilities of informal carers in palliative care.

The key outcomes identified in the social capital literature inform the proposed ABCD model in Fig. 2. The framework identifies four areas of
social capital facilitation in palliative care, which include: advocacy and support for bonded or bonding social capital (A), bringing about intra-community networks (B) and connection to intercommunity networks for bridging or bridging social capital (C), and drive for linkages with government and organizational groups for linked or linking social capital (D).

**Advocacy and Support for Close Networks and Relations**

Identification and support of bonded social capital through advocacy and support of close relations (A) ensures that there is understanding of the quality of the strong ties inherent in patient/carer networks and subgroups at risk for limited or negative outcomes within the context of the social capital available to them. Knowledge of networks and relations required for the intense level of care at the end of life is important, whereby this level of care is likely to be grounded in the close ties of family and friends. It is essentially these bonded ties that are formally acknowledged in palliative care philosophy and practice by the maxim that family and carers should be considered alongside the patient as the unit of care. However, the free “services” offered by informal caregivers are often exploited by health care systems, with limited alternatives for care and support for carers presented.

A study of carer relationships for the frail elderly found that the best outcomes for patients and carers were not solely inhered in close family relations and networks, which were found sometimes to be detrimental in their exclusivity. In addition to the nature of close relations and networks, the quality of these relations also is an important consideration. This was found to be inadequately considered in the palliative care literature, with the assumption that these relations and networks were essentially functional and cohesive. Where such relations were not positive, or where a terminal diagnosis altered the nature of the relationship and patient/family were unable to adapt, the quality of end-of-life care was likely to be impaired. Critical periods of care in the end-of-life trajectory require assessment of networks and relations required to ensure adequate support for patients and carers.

The capacity of strong bonded networks and relations to enhance well-being for patients and carers at the end of life is understood; however, what is required is support for and knowledge of the quality and nature of close relations for sustaining care and supporting the carer. Multidisciplinary palliative care teams are generally well positioned to assess relations and networks at this individual level.
Vulnerable Populations

Population subgroups within palliative care that are potentially at risk of limited or negative social capital were identified in the general social capital literature, finding that social capital operated differently in culturally diverse groups, lower socioeconomic groups, and women. This literature also identified culturally diverse and lower socioeconomic groups as low community participants, who possessed limited levels of trust. In particular, proposes that individuals with limited social resources demonstrate higher numbers of constraints and less opportunities to develop social capital. Mackinnon, in an application of feminist, multicultural, and social justice theory to palliative care female caregiving literature, found potential risks for social isolation, oppression, and unrealistic demands of care for culturally diverse female caregivers. Interventions, therefore, that target the needs of groups vulnerable to limited or negative aspects of social capital are required. These interventions are likely to reside in the domains of bridged and linked social capital, which have the capacity for social leverage to valued resources and information embedded within them. It is within a context of a long trajectory for caregivers providing end-of-life care, and the relationships required for that care, that the inclusion of external networks and wider community is valuable.

Connection and Generation of Intra- and Intercommunity Networks and Relations

Intracommunity and intercommunity services and relations characterize the bridged network domains of social capital, which are inclusive of wider friendship networks, health care agencies, community service groups, and intersectional service agencies (B and C). The meso- or community-level engagement of formal groups supports resource and information flow that is both complementary and important to the existing close relations of caregivers. Primary care providers are well positioned to ensure that these community links are offered; this was identified by Bernosky de Flores in a study of social capital in immigrant communities, where these formal care providers were invariably embedded in key networks for access and engagement. Identification of informal carer networks beyond immediate family is an important strategy to support broader supportive social networks. Friends and neighbors were considered good mediators between families and service providers in caregiving for the frail elderly, and it was these relationships that characterized some of the broader connections that remain underexplored in palliative care. Recent findings from an Australian study by Burns et al. highlighted the value of care networks beyond family caregivers. The study identified positive outcomes for friendship networks providing end-of-life care. The study findings identified that the rate of specialist palliative care use was higher, there was an increased likelihood of a home death for patients, and the friendship caregivers characterized their role as potentially creating a new social cohesion. Arts programs, community, religious and cultural groups, and social networking sites were further examples of bonded social capital, which supported social inclusion, trust, self-esteem enhancement, and safety. Communication media and social networking sites were identified in palliative care populations as particular pathways for trust, reciprocity, social cohesion, and a capacity for improvement in social policy. The importance of elements such as trust and norms of reciprocity highlighted cognitive social capital elements and requires exploration in a palliative care population, as trust in particular was of primary importance in informal caregiving.

The integration of “social prescribing” into some general practice/primary care models was a social capital innovation that aimed at empowering communities to address health and well-being needs that were unresponsive to biomedical therapies. A “social prescription” from a primary care provider (usually a general practitioner) outlined the socioeconomic and psychosocial needs of patients and linked these to locally relevant social opportunities in the community. Designation of nonhealth resources to a patient assessment was seen as part of the primary practitioners’ clinical work, supported through an awareness of a patient’s social needs and the community capacity to support these. Models of social prescribing can identify capacity through the use of a community network facilitator and volunteer support personnel.
specific community services and the creation of new community networks and groups was an extension of the primary care provider role within the scope of “social prescribing” practice. A study by Greene et al. piloted the use of a community facilitator in palliative care for the purpose of connection with community resources, among other support interventions. This study uniquely sought to engage support beyond immediate close networks to the person’s community, whereby such levels of support could not be achieved otherwise. The integration of “social prescribing” and community network facilitator concepts identifies examples for clinical applicability of the social capital model for palliative care practice at the community level.

**Links with Government Institutions and Organizations**

Linkages that drive connections with government organizations enable important relations with external sources of power and authority (D). Szreter and Woolcock, in grounding social capital theory in bonded, bridged, and linked levels, considered that power was made explicit by the inclusion of linking social capital in conceptual frameworks, with the delineation of linking social capital identified as especially important for disadvantaged groups where it was central to welfare and well-being. Partnerships for the development of infrastructure and social policy; communication of equity in government policy, programs, and laws; and provision of reliable resources for community services and organizations are essential to support well-being in advanced disease. Although according to Lin, at this macro level structural networks predominate, there is inhered a significant capacity for social cohesion through which palliative care peak service providers are well positioned to support community awareness, ownership, and responsiveness to end-of-life issues. Such peak service providers can inform governments, which invariably hold the resources and authority required to increase social support for people living with terminal illnesses and their informal carers. A society broadly responsive to the needs of this group will engage in understanding the potential for social isolation and stigma of disease, dying, and caring and seek to address these issues.

**Conclusion**

Despite the contested nature of social capital inquiry, it remains a concept that supports a broad framework for understanding the impact of social relations and networks on health and well-being. Social capital theory provides a structure for the organization of the social reality that can potentially enhance or hinder care at the end of life. Application of a social capital model into a specific care domain is important in both establishing the utility of the social capital concept and also identifying a social context of care for particular populations. Research that identifies specificity in application of social capital is fundamental to issues of access to services, sustaining levels of care, health, and well-being. A narrow focus on family obligations for care provision at the end of life has the potential to limit well-being for the patient and informal carer. Well-being for the patient and carer is best optimized by a combination of the close relations of family carers with informal nonfamily relations and networks of broader community relations. Partnerships with government organizations to support resources for community services, development of social policies, and programs also is required. The capacity of a social capital framework to support, in particular, female informal carers and marginalized groups is not yet well understood. Consideration of advocacy for these groups, identified in the integrated palliative care model, ensures that the particular needs of these groups are patent.

Palliative care must seek to extend its focus beyond health service development to understand and identify the broader resources that will enable communities to manage end-of-life care. Sustaining caring relationships requires an understanding of the needs and the complexities of networks and relations that support or impair them. Therefore, what is required for palliative care is an application of a model of social capital—well understood and evidenced, supporting interventions that will have a positive impact on the lives and deaths of patients and their carers. Creating a community and society that is responsive to the needs of the terminally ill and their family carers will ensure greater sustainability of the resources required to achieve good
end-of-life care and facilitate enabling environments of social advantage and inclusion.

Disclosures and Acknowledgments

The authors wish to acknowledge Sylvia Gray and Marie Rosenthal for their generous support with literature retrieval. Joanne M. Lewis is supported by an Australian postgraduate award scholarship. Michelle DiGiacomo is a postdoctoral fellow supported by NHMRC 533547. The authors declare no conflicts of interest.

References


Appendix 2: Recruitment flyer for patients and carers

Coping with financial and social hardships in Palliative Care?

How can I get more information about participating?

If you are willing to be contacted to hear more about this study, please give your details to the secretary. Alternatively you can telephone for more information:

Ms Joanne Lewis
Centre for Cardiovascular and Chronic Care
Curtin University of Technology
Telephone: 0430 219 922
02 8883 0202
Email: jo-anne.lewis@postgrad.curtin.edu.au

Centre for Cardiovascular & Chronic Care
Curtin University of Technology

This research project has been approved by the Sydney West Area Health Service Human Research Ethics Committee.

A study which aims to gain a better understanding of the experiences of palliative care patients and their families, who identify that they have insufficient financial and social resources to meet their needs.
<table>
<thead>
<tr>
<th>What is the purpose of this study?</th>
<th>Who is invited to participate?</th>
<th>What is involved in participating?</th>
</tr>
</thead>
<tbody>
<tr>
<td>The information gained from this study will assist us in identifying resources and programs in palliative care, to best meet the needs of these patients and their families.</td>
<td>Palliative care patients aged 25 and over who identify social and financial hardships.</td>
<td>A researcher will interview patients and families, asking about their experiences in managing care. The researcher will ask about social and financial concerns which you might have. You will also be asked to complete some short surveys relating to care needs and household spending.</td>
</tr>
</tbody>
</table>
Appendix 3: Interview guide patients and carers

<table>
<thead>
<tr>
<th><strong>Interview guide</strong></th>
<th><strong>Dimensions of access</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Acceptability</strong></td>
<td><strong>Health service</strong></td>
</tr>
<tr>
<td>1. What are your needs for end of life care, particularly for social and cultural needs? (P-W: What has changed since diagnosis?)</td>
<td>Characteristics of palliative care service to the social and cultural needs of the individual and care/family.</td>
</tr>
<tr>
<td>2. How well are these needs met by palliative care services?</td>
<td>Health service</td>
</tr>
<tr>
<td>3. Did and does the services provided meet your expectations?</td>
<td>Patient/carer</td>
</tr>
<tr>
<td>4. How do you feel (what do you think) of palliative care?</td>
<td>Attitudes and expectations of the service on the patient/carer; whether these are acceptable.</td>
</tr>
<tr>
<td>5. How did you come to be in palliative care?</td>
<td>Stigma of disease; ability to negotiate the service.</td>
</tr>
<tr>
<td><strong>Affordability</strong></td>
<td><strong>Health service</strong></td>
</tr>
<tr>
<td>6. What are the costs to manage care?</td>
<td>Costs and prices of service.</td>
</tr>
<tr>
<td>7. Are you able to sustain these costs?</td>
<td>Patient/carer</td>
</tr>
<tr>
<td>8. Are there things you do without because of care costs?</td>
<td>Sustaining costs of treatments, transportation, medications, other OOPE; uptake of gov’t benefit</td>
</tr>
<tr>
<td><strong>Accessibility</strong></td>
<td><strong>Health service</strong></td>
</tr>
<tr>
<td>9. How do you get to appointments etc?</td>
<td>Service location.</td>
</tr>
<tr>
<td>10. Are these services convenient to get to?</td>
<td>Patient/carer</td>
</tr>
<tr>
<td>11. What is the cost of transport for you?</td>
<td>Location of patient/carer and transportation resources, cost.</td>
</tr>
<tr>
<td><strong>Availability</strong></td>
<td><strong>Health service</strong></td>
</tr>
<tr>
<td>12. How accessible and available are services?</td>
<td>Volume and type of resources.</td>
</tr>
<tr>
<td>13. Reasons why you don’t use some services?</td>
<td>Patient/carer</td>
</tr>
<tr>
<td>14. What is needed for you to use some services?</td>
<td>Awareness of services and the impact of the limitations of services. Use of acute care services.</td>
</tr>
</tbody>
</table>

**Provider-patient interaction**

<table>
<thead>
<tr>
<th><strong>Health literacy and communication</strong></th>
<th><strong>Provider-patient interaction</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>15. How is communication with staff?</td>
<td>Difficulty understanding written materials- pharmacy medication charts, patient information sheets, doctor’s letters.</td>
</tr>
<tr>
<td>16. Do you have trouble understanding explanations for tests, treatments, medications?</td>
<td>Difficulty in conveying outcomes of tests and appointments to others; limited understanding of aim(s) of treatment.</td>
</tr>
<tr>
<td>17. Do you find it difficult to explain to other people what is happening with health plans?</td>
<td>Difficulty describing how medications should be taken or the action of prescribed medications.</td>
</tr>
<tr>
<td>18. Do you make mistakes with medications?</td>
<td>Take medications incorrectly; Do not understand questions to ask doctors/nurses/allied health.</td>
</tr>
<tr>
<td>18. Do you ask questions of staff if you don’t understand (response is understood)?</td>
<td></td>
</tr>
</tbody>
</table>

**Social capital**

<table>
<thead>
<tr>
<th><strong>SC-structural</strong></th>
<th><strong>Support from friends, neighbours, community, organisations.</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>20. How important is support and companionship from family, neighbours, community &amp; groups?</td>
<td>Membership formal groups. Community participation.</td>
</tr>
<tr>
<td>22. What brought you to live in this area?</td>
<td></td>
</tr>
<tr>
<td><strong>SC-cognitive</strong></td>
<td><strong>Feelings of trust and reciprocity, feelings of safety, feelings of social cohesion Social inclusion/exclusion</strong></td>
</tr>
<tr>
<td>23. Does this support impact how you feel/cope?</td>
<td></td>
</tr>
<tr>
<td>24. What is your community like?</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 4: Socio-demographic data collection sheet

Demographic Data Sheet

Name_________________________ Age_________

Income_____________________

Marital status______________ Place of Birth_____________________

Language___________________

Highest education qualification____________________

Housing status (Owner, mortgage, renting +/- rental support, renting-Gov.)_______

Employment status (previous and current)________________________

Diagnosis__________________________________________
Appendix 5: Needs assessment tool: Progressive disease-cancer (NAT:PD-C)

**NEEDS ASSESSMENT TOOL: PROGRESSIVE DISEASE CANCER (NAT: PD-C)**

**COMPLETE ALL SECTIONS**

**PATIENT NAME:**

**DIAGNOSIS:**

**DATE:**

**PATIENT/ADDRESS LABEL**

<table>
<thead>
<tr>
<th>SECTION 1: PRIORITY REFERRAL FOR FURTHER ASSESSMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Does the patient have a caregiver readily available if required?</td>
</tr>
<tr>
<td>2. Has the patient or caregiver requested a referral to a specialist palliative care service (SPCS)?</td>
</tr>
<tr>
<td>3. Do you require assistance in managing the care of this patient and/or family?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SECTION 2: PATIENT WELLBEING (Refer to the back page for assistance)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of Concern</td>
</tr>
<tr>
<td>None</td>
</tr>
<tr>
<td>1. Is the patient experiencing unresolved physical symptoms (including problems with pain, sleeping, appetite, nausea, bowel, breathing or fatigue)?</td>
</tr>
<tr>
<td>2. Does the patient have problems with daily living activities?</td>
</tr>
<tr>
<td>3. Does the patient have psychological symptoms that are interfering with wellbeing or relationship?</td>
</tr>
<tr>
<td>4. Does the patient have concerns about spiritual or existential issues?</td>
</tr>
<tr>
<td>5. Does the patient have financial or legal concerns that are causing distress or require assistance?</td>
</tr>
<tr>
<td>6. From the health delivery point of view, are there health beliefs, cultural or social factors involving the patient or family that are making care more complex?</td>
</tr>
<tr>
<td>7. Does the patient require information about (tick any options that are relevant):</td>
</tr>
<tr>
<td>The prognosis</td>
</tr>
</tbody>
</table>

**COMMENTS:**

<table>
<thead>
<tr>
<th>SECTION 3: ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT (Refer to the back page for assistance)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of Concern</td>
</tr>
<tr>
<td>None</td>
</tr>
<tr>
<td>Who provided this information? (please tick one)</td>
</tr>
<tr>
<td>Patient</td>
</tr>
<tr>
<td>1. Is the caregiver or family distressed about the patient's physical symptoms?</td>
</tr>
<tr>
<td>2. Is the caregiver or family having difficulty providing physical care?</td>
</tr>
<tr>
<td>3. Is the caregiver or family having difficulty coping?</td>
</tr>
<tr>
<td>4. Does the caregiver or family have financial or legal concerns that are causing distress or require assistance?</td>
</tr>
<tr>
<td>5. Is the family currently experiencing problems that are interfering with their functioning or interpersonal relationships, or is there a history of such problems?</td>
</tr>
<tr>
<td>6. Does the caregiver or family require information about (tick any options that are relevant):</td>
</tr>
<tr>
<td>The prognosis</td>
</tr>
</tbody>
</table>

**COMMENTS:**

<table>
<thead>
<tr>
<th>SECTION 4: CAREGIVER WELLBEING (Refer to the back page for assistance)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of Concern</td>
</tr>
<tr>
<td>None</td>
</tr>
<tr>
<td>Who provided this information? (please tick one)</td>
</tr>
<tr>
<td>Patient</td>
</tr>
<tr>
<td>1. Is the caregiver or family experiencing physical, practical, spiritual, existential or psychological problems that are interfering with their wellbeing or functioning?</td>
</tr>
<tr>
<td>2. Is the caregiver or family experiencing grief over the impending or recent death of the patient that is interfering with their wellbeing or functioning?</td>
</tr>
</tbody>
</table>

**COMMENTS:**

**IF REFERRAL REQUIRED FOR FURTHER ASSESSMENT OR CARE, PLEASE COMPLETE THIS SECTION**

| 1. Referral to (Name):  |
| 2. Referral to (Specialty):  |
| General practitioner  | Social worker  | Psychologist  | Specialist palliative care service  |
| Medical oncologist  | Radiation oncologist  | Haematologist  | Other  |
| 3. Priority of assessment needed:  |
| Urgent (within 48 hours)  | Semi Urgent (2-7 days)  | Non-Urgent (next available)  |
| 4. Discuss the referral with the client.  |
| Yes  | No  |
| 5. Client consented to the referral.  |
| Yes  | No  |
| 6. Referral from Name:  |
| Position:  |

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Appendix 6: Consumption Survey

Consumption survey

The following is a list of items that many Australians regularly spend money on, weekly, monthly and yearly. Cross YES or NO in the box to indicate if anyone in the household spends money on that item. If the answer is YES then write the best estimate of the average amount spent for that period. If you are unsure then please make your best guess.

<table>
<thead>
<tr>
<th>Weekly expenses</th>
<th>no</th>
<th>yes</th>
<th>How much per week?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Groceries (Include food, cleaning products, pet food, personal care products)</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Motor vehicle fuel (petrol, diesel, LPG)</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Public transport and taxis</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Meals eaten out</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Alcohol</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Cigarettes and tobacco products</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Medications/Supplements (Prescription and pharmacy)</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Doctors bills (Include only gap payment)</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 Entertainment (Movies, DVD hire, shows, bingo, lotto)</td>
<td>$</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Monthly expenses</th>
<th>no</th>
<th>yes</th>
<th>How much per month?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Men's clothing and footwear</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Women's clothing and footwear</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Children's clothing and footwear</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Telephone rent and calls</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Equipment hire/consumables</td>
<td>$</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Annual expenses</th>
<th>no</th>
<th>yes</th>
<th>How much per year?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Holidays</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Private health insurance</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Other insurance (Home, contents, motor vehicle)</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Electricity bills, gas bills and other heating</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Repairs, renovations and maintenance to your home</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Motor vehicle repairs and maintenance</td>
<td>$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Education fees paid to schools, universities and other education providers/child care fees</td>
<td>$</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 7: Personal Wellbeing Index (PWI)

Satisfaction with Life as a Whole and The PWI Scale (Verbal Format)

Instructions for Verbal Format (i.e. respond to test items verbally).

“I am now going to ask how satisfied you feel, on a scale from zero to 10.”

“(On this scale,) Zero means you feel completely dissatisfied. 10 means you feel completely satisfied. And the middle of the scale is 5, which means you feel neutral (i.e. neither satisfied nor dissatisfied).”

```
<table>
<thead>
<tr>
<th>Completely Dissatisfied</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>Neutral</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>Completely Satisfied</th>
</tr>
</thead>
</table>
```

“Would you like me to go over this again for you?” [If “yes”, repeat the above. If “no”, proceed to next statement]

“In that case, I will start by asking how satisfied you are with life. So,------------ (Refer to the test items below)”

Test Items

<table>
<thead>
<tr>
<th>Respondent’s Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>(0-10)</td>
</tr>
</tbody>
</table>

Part I (Optional item): Satisfaction with Life as a Whole

“Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?”

<p>| |</p>
<table>
<thead>
<tr>
<th></th>
</tr>
</thead>
</table>

Part II: Personal Wellbeing Index

“How satisfied are you with…….? ”

1. your standard of living?

2. your health?

3. what you are achieving in life?

4. your personal relationships?

5. how safe you feel?

6. feeling part of your community?

7. your future security?

8. your spirituality or religion?”

<p>| |</p>
<table>
<thead>
<tr>
<th></th>
</tr>
</thead>
</table>
Appendix 8: Rapid Estimate Adult Literacy Medicine-Revised (REALM-R)

REALM-R Examiner Record

Patient Name/ Subject # Date of Birth

Date Clinic Examiner

fat fatigue
flu directed
pill colitis
allergic constipation
jaundice osteoporosis
anemia

Fat, Flu, and Pill are not scored. We have previously used a score of 6 or less to identify patients at risk for poor literacy.

Score _____
Appendix 9: Social Capital Questionnaire (SCQ)

1. The Social Capital Questionnaire is designed to assess your social relationships and the resources derived from and incidental to them.

1. **In the last 12 months have you received any help from any of the following:**

<table>
<thead>
<tr>
<th></th>
<th>Not applicable</th>
<th>no help</th>
<th>emotional help</th>
<th>help to do things</th>
<th>help to know things</th>
<th>companionship/financial help</th>
<th>spiritual help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse/partner</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neighbours</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends who are not neighbours</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pets/Animals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Religious organisation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Health organisations</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Club</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Politicians</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Government representatives</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Charitable organisations</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. **What was the quality of these relationships?**

<table>
<thead>
<tr>
<th></th>
<th>No relationship</th>
<th>Excellent relationship</th>
<th>Good relationship</th>
<th>Fair relationship</th>
<th>Poor relationship</th>
<th>Very poor relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse/partner</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neighbours</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends who are not neighbours</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pets/Animals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Religious organisations</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Health organisations</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Club</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Politicians</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Government representatives</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Charitable organisations</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
3. In the last 12 months have you been an active member of any formal groups.

<table>
<thead>
<tr>
<th></th>
<th>never</th>
<th>occasionally</th>
<th>sometimes</th>
<th>often</th>
<th>all the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community organisation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Charity group (e.g. Anglicare)</td>
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<td></td>
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<tr>
<td>Political group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Sports/Community Club</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Cultural group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Religious group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. What are some reasons for not being an active member of a formal group?

<table>
<thead>
<tr>
<th></th>
<th>Not interested in this group</th>
<th>Not interested in attending any groups</th>
<th>Already a member</th>
<th>Too busy</th>
<th>Negative experience with this group or one like it</th>
<th>Transport is a problem</th>
<th>I don't have access to this group</th>
<th>Too ill</th>
<th>Family don't want me to attend</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community organisation</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Charity group</td>
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<td></td>
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<td></td>
<td></td>
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<tr>
<td>Political group</td>
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<tr>
<td>Sports/Community group</td>
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<tr>
<td>Cultural group</td>
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<tr>
<td>Religious group</td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

5. What are the reasons for being part of a formal social group

☐ not applicable to me
☐ emotional support
☐ spiritual support
☐ financial support
☐ help to do things
☐ help to know things
☐ to have fun and enjoyment
☐ to feel connected to the community
☐ to have companionship

Other (please specify) ____________________________________________________________________________

6. In the last 12 months have you participated in activities for your community (e.g. worked in a community garden or been a member of a committee)?

☐ never
☐ occasionally
☐ sometimes
☐ frequently
☐ all the time
7. In general most people in the community can be trusted?
   - agree
   - disagree

8. Most people in the community get along well?
   - agree
   - disagree

9. I feel part of the community?
   - agree
   - neither agree nor disagree
   - disagree

10. I feel that people would take advantage of you if they got the chance?
    - agree
    - disagree

11. In the last 12 months how often have you helped neighbours?
    - never
    - rarely
    - sometimes
    - frequently
    - all the time

12. People in the community will act if something bad or illegal is happening?
    - Yes
    - No

13. I don't have anyone to confide in?
    - Yes
    - No

14. I often feel lonely?
    - Yes
    - No

15. I have a friend who is a person in a government position?
    - Yes
    - No
16. Overall would you define your community in terms of boundaries as being
- [ ] 0-1 km
- [ ] 2-4 km
- [ ] 5-10 km
- [ ] 10-20 km
- [ ] 20-50 km
- [ ] 50+ km
20 September 2010

Dr Philip G Lee
Sydney West Cancer Care Centre
Westmead Hospital
WESTMEAD NSW 2145

Dear Dr Lee,

Study Ref: 10/28 - AU RED HREC/10/NEPEAN/70
Study Title: ‘Dying in the margins: Understanding the experience of socioeconomic deprivation and dying in an Australian context’

Thank you for your letter dated 15 August 2010 addressing the matters raised in the HREC’s letter dated 10 August 2010 following ethical review of the above project at its meeting held on 27 July 2010.

This HREC has been accredited by the NSW Department of Health as a lead HREC to provide the single ethical and scientific review of proposals to conduct research within the NSW public health system. This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Human Research and the CPMP/ICH Note for Guidance on Good Clinical Practice.

I am pleased to advise that the HREC has now granted ethical approval of this single site research project to be conducted by you at Mount Druitt Hospital.

The following documentation has been reviewed and approved by the HREC:

- NEAF application AU/2/OB96013
- Research Proposal Version 1 dated 17/5/2020
- Participant Information and Consent Sheet Version 3 dated 17/9/2010 for Patients/Careers
- Participant Information and Consent Sheet Version 2 dated 17/9/2010 for Consensus Group
Study Ref: 10/28 - AU RED HREC/10/NEPEAN/70 - cont’d

- Participant Information and Consent Sheet Version 3 dated 17/9/2010 for Formal Carers
- Consumption survey Version 1 dated 17/5/2010
- Interview Guide Version 1 dated 17/5/2020
- Demographic Data Sheet Version 1 dated 15/8/2010
- Study Flyer Version 2 dated 15/8/2010
- Consent to Approach Form Version 1 dated 17/5/2010

Please note the following conditions of approval:

- The coordinating investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project.
- Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, are provided to the HREC to review in the specific format. A copy of all proposed changes is also provided to the relevant research governance officer.
- The HREC must be notified, giving reasons, if the project is discontinued at a site before the expected date of completion.
- The coordinating investigator must provide an annual report to the HREC and a final report at completion of the study, in the specified format. HREC approval is valid for 12 months from the date of final approval and continuation of the HREC approval beyond the initial 12 month approval period is contingent upon submission of an annual report each year. A copy of the Annual/ Final Research Report Form is attached and can be obtained electronically from the Research Office on request.
- It should be noted that compliance with the ethical guidelines is entirely the responsibility of the researcher.

You are reminded that this letter constitutes ethical approval only. You must not commence this research project until separate authorisation from the Chief Executive or delegate of that site has been obtained. A copy of this letter and the approved listed documentation must be forwarded to the Research Governance Officer.

In all future correspondence concerning this study, please quote your approval number, ref. Study No. 10/28 – HREC/10/NEPEAN/70. The HREC wishes you every success in your research.

Yours sincerely

Dr. Jamshid Kalantar, Chair
Sydney West Area Health Service
Human Research Ethics Committee
1. Appendix 11: Amended Sydney West Area Health Service, Human Research Ethics Committee approval

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**HUMAN RESEARCH ETHICS COMMITTEE**

Court Building, Ground Floor
P.O Box 63
Penrith NSW 2751

Tel: 47 34 3441
Fax: 47 34 1385

Email: Ethics@nepean.nsw.gov.au or
Paula.Erasmus@npsc.health.nsw.gov.au

JK/pma

10 July 2011

Dr Philip Lee
Department of Palliative Care
Cancer Care Centre
Westmead Hospital

Dear Dr Lee

Study Ref: Study 10/28 – HREC/10/NEPEAN/70
Study title: “Dying in the margins: Understanding the experience of socioeconomic deprivation and dying in an Australian context”

Thank you for your letter dated 6 May 2011 together with a copy of the following documents for the above referenced study were reviewed by the Human Research Ethics Committee at its meeting held on 28 June 2011:

- Amendments Form dated 10/5/2011
- Updated Participant Information and Consent Sheet Version 4 dated 6/5/2011
- Social Capital Questionnaire (SCQ) 2
- REALM Questionnaire
- FWI Scale Questionnaire

On review the above documents were approved subject to the following changes being made to the study documentation (PS 2.2.3):

**Participant Information and Consent Sheets**

- In the first sentence of the last paragraph of page 2 of 6 of the PIS, it is stated that there will be 3 short assessment tools. (in brackets next to the word ‘tools’ the researcher should describe once only what an ‘assessment tool’ is.

- On the 2nd paragraph on page 3 of 6, at the end of the first sentence, the word ‘administer’ should be amended to read ‘administered every month for 3 months. Overall ......’
Study 10/28 – HREC/10/NEPEAN/70 - cont’d

• The last word of the last sentence in the 2nd paragraph should be changed from the word ‘same’ to read ‘study’.

• Any reference to Sydney West Area Health Service, SWAHS or SWAHS letterheads in either the PiS or the Consent Sheet should be replaced with the letterhead and words ‘Nepean Blue Mountains Local Health District’

• Spacing between paragraphs should be implemented.

• A tracked and non-tracked copy of the PiS updated as requested, should be submitted for the Committee.

Rapid Estimate of Adult Literacy in Medicine (REALM) ©

• The study participant’s details and the study participants study code should not be shown on the same document.

Scientific Protocol

• The Version No. and date on this document has not been updated and still shows the reference to 2010. This should be corrected.

You are reminded that this letter constitutes ethical approval only. A copy of this letter and the approved listed documentation must be forwarded to the Research Governance Officer for review and authorisation.

In all future correspondence concerning this study, please quote your approval number, Study Ref: Study 10/28 - HREC/10/NEPEAN/70.

Yours sincerely,

Dr. Jamshid Kalantar
Chair
Nepean Blue Mountains LHD
Human Research Ethics Committee

c.c. Ms Joanne Lewis
Centre for Cardiovascular and Chronic Care
Curtin University of Technology
Curtin House
39 Regent Street
CHIPPENDALE NSW 2008
Appendix 12: University of Technology Sydney, Human Research Ethics approval

Dear Patricia and Joanne,

Re: "Dying in the Margins: Understanding the experiences of socioeconomic deprivation and dying in an Australian context"
[External Ratification: Human Research Ethics Committee, Nepean HREC approval - 10/28-AUREDHREC/10/NEPEAN/70 - 01/06/2010-01/02/2013]

At its meeting held on 18/10/2011, the UTS Human Research Ethics Committee reviewed your application and I am pleased to inform you that your external ethics clearance has been ratified.

Your UTS clearance number is UTS HREC REF NO. 2011-372R

You should consider this your official letter of approval. If you require a hardcopy please contact the Research Ethics Officer (Research.Ethics@uts.edu.au).

Please note that the ethical conduct of research is an ongoing process.
The National Statement on Ethical Conduct in Research Involving Humans requires us to obtain a report about the progress of the research, and in particular about any changes to the research which may have ethical implications. This report form must be completed at least annually, and at the end of the project (if it takes more than a year). The Ethics Secretariat will contact you when it is time to complete your first report.
You must also provide evidence of continued approval from the Human Research Ethics Committee you originally received approval from.

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered
of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

If you have any queries about your ethics clearance, or require any amendments to your research in the future, please do not hesitate to contact the Ethics Secretariat at the Research and Innovation Office, on 02 9514 9772.

Yours sincerely,

Professor Marion Maas
Chairperson
UTS Human Research Ethics Committee

C/- Research & Innovation Office
University of Technology, Sydney
Level 14, Tower Building
Broadway NSW 2007
Ph: 02 9514 9772
Fax: 02 9514 1244
Web:
Appendix 13: Participant Information Sheet and Consent Form (PCIF): Patients and/or carers

PARTICIPANT INFORMATION SHEET AND CONSENT FORM
Patients/Carers

Study Title: Understanding the experience of social and financial hardship, and terminal illness in an Australian context.

Associate Investigator: Mrs Joanne Lewis
Department of Palliative care, Western Sydney Local Health District
University of Technology Sydney

Invitation
You are invited to participate in a research study to investigate the experience of end of life care for people experiencing social and financial hardship.
The study is being conducted by:

Ms Joanne Lewis
Centre for Cardiovascular and Chronic Care
University of Technology Sydney
Western Sydney Local Health District
Blacktown/Mt Druitt

Professor Patricia Davidson
Centre for Cardiovascular and Chronic Care
University of Technology Sydney

Dr Michelle DiGiacomo
Centre for Cardiovascular and Chronic Care
University of Technology Sydney

Dr Philip Lee
Western Sydney Local Health District
Sydney West Cancer Care Centre
Westmead Hospital

Dying in the Margins Study  Version 4  06/05/2011
PARTICIPANT INFORMATION SHEET AND CONSENT FORM
Patients/Carers

Study Title: Understanding the experience of social and financial hardship, and terminal illness in an Australian context.

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

What is the purpose of the study?
The purpose is to investigate the needs in end of life care for people who may be experiencing social and financial hardship, and whether these needs are currently being met by service providers.

Who will be invited to enter the study?
You are invited to participate in this study because you are a person with a life limiting illness, or are family member or informal carer of such a person, and may as a result be experiencing social and financial hardship.

Do you have a choice?
Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason. It may not be possible to withdraw your data from the study results if these have already had your identifying details removed.

What will happen on the study?
If you agree to participate in this study, you will be asked to sign the Participant Consent Form. This study will be conducted over 12 months. If you agree to participate in this study, you will then be asked to complete an interview lasting approximately 1 hour. The interviewer will ask questions to guide or prompt your thoughts and experiences around the impact of living with a terminal illness and receiving care for that illness.

Dying in the Margins Study  Version 4  06/05/2011
Study Title: Understanding the experience of social and financial hardship, and terminal illness in an Australian context.

A short questionnaire, 3 short assessment tools (single answer questionnaires) and a survey will also be given to you at this time. The questionnaire, tools and survey will ask questions about needs you and/or your carer might have. Topics will include physical symptoms, social, communication, caring and financial issues. This questionnaire, tools and survey will take approximately 30 minutes to complete. The survey asks about current financial needs, responsibilities, living expenses and costs associated with care and can be completed by a family member or carer if you wish. This survey asks you to identify financial needs and spending in the previous week, month, and 12 months. The survey will take approximately 15 minutes to complete. The other assessment tools ask questions about symptoms, wellbeing needs, social contacts and information/communication needs and will take approximately 15 minutes to complete.

Overall your participation in this study will take approximately one hour to complete.

The results of the interview, questionnaire and survey will be presented in an aggregated and summarised way and no details that might identify you will be made available.

Are there any risks?
The risks for participants in this study are very low. The study seeks to limit the amount of time and any emotional discomfort that may be experienced by the participants. The investigators will be available at all times to answer study questions. If you feel that you have suffered psychological distress as a result of this study, you should contact the researcher as soon as possible, who will link you to facility-based counselling units.

Are there any benefits?
The study aims to understand the impact of terminal illness on patients and their carers and/or families, who identify themselves as experiencing social and financial hardship. This study may impact on the needs of this group and thus improve the delivery of care, however, it may not directly benefit you. The knowledge gained will be used to inform service providers and peak Government and non-Government bodies of the resources required to care for such groups, requiring palliative care.

Dying in the Margins Study  Version 4  06/05/2011
PARTICIPANT INFORMATION SHEET AND CONSENT FORM
Patients/Carers

Study Title: Understanding the experience of social and financial hardship, and terminal illness in an Australian context.

Confidentiality / Privacy
Of the people treating you, only the principal researcher and possibly the staff involved in your care will know whether or not you are participating in this study. Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. The interviews will be audiotaped and transcribed into written form to ensure accuracy of the information. Only the researchers named above will have access to your details and results that will be held securely at University of Technology Sydney.

Will taking part in this study cost me anything, and will I be paid?
Participation in this study will not cost you anything. You will be reimbursed for reasonable travel expenses if you choose to attend for interview at somewhere other than your place of residence. You will not be paid to participate in this study.

What happens with the results?
If you give us your permission by signing the consent document, we plan to discuss the results with peak Government and Non-Government bodies and palliative care service providers. The results will be published through internal monitoring and in peer-reviewed journals, conference presentations and thesis writing. In any publication, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, if you wish.

Complaints
This study has been approved by Nepean Blue Mountains Local Health District (NBMLHD), Human Research Ethics Committee. If you have any concerns about the conduct of the study, or your rights as a study participant, you may contact:

The Secretary, NBMLHD Human Research Ethics Committee
Telephone No 47343441 or email Ethics@wahs.nsw.gov.au
You should quote Study 10/28-HREC/10/NEPEAN/70

Dying in the Margins Study  Version 4  06/05/2011
PARTICIPANT INFORMATION SHEET AND CONSENT FORM
Patients/Carers

Study Title: Understanding the experience of social and financial hardship, and terminal illness in an Australian context.

Contact details
When you have read this information, the associate researcher Joanne Lewis will discuss it with you and any queries you may have. If you would like to know more at any stage, please do not hesitate to contact her on 0430 219 922. If you have any problems while on the study, please contact:

Dr Philip Lee
Working hours Telephone No - 9845 5200
After hours Telephone No – Westmead Switch 9845 5555

Thank you for taking the time to consider this study.

If you wish to take part in it, please sign the attached consent form. This information sheet is for you to keep.
PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Study Title: Understanding the experience of social and financial hardship, and terminal illness in an Australian context.

CONSENT TO PARTICIPATE IN RESEARCH

Name of Researcher: Mrs Joanne Lewis

1. I understand that the researcher will conduct this study in a manner conforming to ethical and scientific principles set out by the National Health and Medical Research Council of Australia and the Good Clinical Research Practice Guidelines of the Therapeutic Goods Administration.

2. I acknowledge that I have read, or have had read to me the Participant Information Sheet relating to this study. I acknowledge that I understand the Participant Information Sheet. I acknowledge that the general purposes, methods, demands and possible risks and inconveniences which may occur to me during the study have been explained to me by (Mrs Joanne Lewis) and I, being over the age of 18 acknowledge that I understand the general purposes, methods, demands and possible risks and inconveniences which may occur during the study.

3. I acknowledge that I have been given time to consider the information and to seek other advice.

4. I acknowledge that refusal to take part in this study will not affect the usual treatment of my condition.

5. I acknowledge that I am volunteering to take part in this study and I may withdraw at any time.

6. I acknowledge that this research has been approved by the Nepean Blue Mountains Local Health District, Human Research Ethics Committee.

7. I acknowledge that I have received a copy of this form and the Participant Information Sheet, which I have signed.

I acknowledge that any regulatory authorities may have access to my medical records to monitor the research in which I am agreeing to participate. However, I understand my identity will not be disclosed to anyone else or in publications or presentations.

Before signing, please read 'IMPORTANT NOTE' following.

IMPORTANT NOTE:
This consent should only be signed as follows:
1. Where a participant is over the age of 16 years, then by the participant personally.

Name of participant: ___________________________ Date of Birth: ___________________________

Address of participant: ___________________________

Signature of participant: _________________________ Date: ___________________________

Dying in the Margins Study Version 4 06/05/2011
Signature of researcher ____________________________ Date: ______________________

Signature of witness ____________________________ Date: ______________________
Appendix 14: Copy of the Participant Information Sheet and Consent Form (PCIF): Formal carers

PARTICIPANT INFORMATION SHEET AND CONSENT FORM
Formal carers

Study Title: Understanding the experience of social and financial hardship and terminal illness in an Australian context.

Associate Investigator: Mrs Joanne Lewis
Department of Palliative care, Western Sydney Local Health District
University of Technology Sydney

Invitation
You are invited to participate in a research study to investigate the experience of end of life care for people experiencing social and financial hardship.

Ms Joanne Lewis
Centre for Cardiovascular and Chronic Care
University of Technology Sydney
Western Sydney Local Health District
Blacktown/Mt Druitt

Professor Patricia Davidson
Professor of Cardiovascular and Chronic Care
Centre for Cardiovascular and Chronic Care
University of Technology Sydney

Dr Michelle DiGiacomo
Post Doctoral Research Fellow
Centre for Cardiovascular and Chronic Care
University of Technology Sydney

Dr Philip Lee
Western Sydney Local Health District
Sydney West Cancer Care Centre
Westmead Hospital

Dying in the Margins study. Version No 4 Dated 09/05/2011
Page 1 of 9
PARTICIPANT INFORMATION SHEET AND CONSENT FORM
Formal carers

Study Title: Understanding the experience of social and financial hardship and terminal illness in an Australian context.

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

What is the purpose of the study?
The purpose of this study is to investigate the needs in end of life care for groups experiencing social and financial hardships and whether these needs are currently being met by service providers.

Who will be invited to enter the study?
You are invited to participate in this study because you are a formal carer for a population of palliative care patients from such groups, who have been identified as having limited access to specialist palliative care services.

Do you have a choice?
Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect your employment or your relationship with University of Technology Sydney and/or Western Sydney Local Health District now or in the future. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason. It may not be possible to withdraw your data from the study results if these have already had your identifying details removed.

What will happen on the study?
If you agree to participate in this study, you will be asked to sign the Participant Consent Form. This study will be conducted over 12 months. If you agree to participate in this study, you will then be asked to complete an interview which will last approximately 1 hour and is your total time commitment for this study. The interview will ask questions to guide and prompt your thoughts and experiences of caring for terminally ill patients from low socioeconomic groups.

The results of the interview will be presented in an aggregated and summarised way and no details that might identify you will be made available.

Are there any risks?
The risks for participants in this study are very low. The study seeks to limit the amount of time and any emotional discomfort that may be experienced by the participants. The investigators will be available at all times to answer study questions. If you feel that you
PARTICIPANT INFORMATION SHEET AND CONSENT FORM
Formal carers

Study Title: Understanding the experience of social and financial hardship and terminal illness in an Australian context.

have suffered psychological distress as a result of this study, you should contact the researcher as soon as possible, who will advise you of facility based counselling units.

Are there any benefits?
The study aims to understand further the impact of terminal illness on patients and their carers and their families, who identify themselves as having social and financial hardships. This study may impact on the needs of this group and thus improve the delivery of care. The knowledge gained will be used to inform service providers and peak Government and Non-Government bodies of the resources required to care for these groups, requiring palliative care.

Confidentiality / Privacy
Of the people treating your patient, only the principal researcher and possibly other staff involved in their care will know whether or not you are participating in this study. There will be no personal information collected on patients you discuss in the interview and identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. The interviews will be audio-taped and transcribed to ensure accuracy of the information. Only the researchers named above will have access to your details and results which will be held securely at University of Technology Sydney.

Will taking part in this study cost me anything, and will I be paid?
Participation in this study will not cost you anything. You will be reimbursed for reasonable travel expenses if you choose to attend for interview at somewhere other than your usual place of employment. You will not be paid to participate in this study.

What happens with the results?
If you give us your permission by signing the consent document, we plan to discuss the results with peak Government and Non-Government bodies and palliative care service providers. The results will be published through internal monitoring and in peer-reviewed journals, conference presentations and thesis writing. In any publication, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, if you wish.

Dying in the Margins study  Version No 4  Dated 00/00/2011
Page 3 of 8
PARTICIPANT INFORMATION SHEET AND CONSENT FORM
Formal carers

Study Title: Understanding the experience of social and financial hardship and terminal illness in an Australian context.

Complaints
This study has been approved by Nepean Blue Mountains Local Health District, Human Research Ethics Committee. If you have any concerns about the conduct of the study, or your rights as a study participant, you may contact:

Ms Sheryl Findlay, Blacktown Hospital Patient representative
Telephone 9881 8000. You should quote [Study10/28-HREC/10/NEPEAN/70.]

Contact details
When you have read this information, the associate researcher Ms Joanne Lewis will discuss it with you and any queries you may have. If you would like to know more at any stage, please do not hesitate to contact her on 0430 219 922. If you have any problems while on the study, please contact

Dr Philip Lee
Working hours Telephone No -9845 5200
After hours Telephone No –Switch Westmead Hospital 9845 5555

Thank you for taking the time to consider this study.
If you wish to take part in it, please sign the attached consent form.
This information sheet is for you to keep.
PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Study Title: Understanding the experience of social and financial hardship and terminal illness in an Australian context.

CONSENT TO PARTICIPATE IN RESEARCH

Name of Researcher: Mrs Joanne Lewis

1. I understand that the researcher will conduct this study in a manner conforming to ethical and scientific principles set out by the National Health and Medical Research Council of Australia and the Good Clinical Practice Guidelines of the Therapeutic Goods Administration.

2. I acknowledge that I have read, or have had read to me the Participant Information Sheet relating to this study. I acknowledge that I understand the Participant Information Sheet. I acknowledge that the general purposes, methods, demands and possible risks and inconveniences which may occur to me during the study have been explained to me by ____________________________ (Mrs Joanne Lewis) and I, being over the age of 16 acknowledge that I understand the general purposes, methods, demands and possible risks and inconveniences which may occur during the study.

3. I acknowledge that I have been given time to consider the information and to seek other advice.

4. I acknowledge that I am volunteering to take part in this study and I may withdraw at any time.

5. I acknowledge that this research has been approved by the Nepean Blue Mountains Local Health District, Human Research Ethics Committee.

6. I acknowledge that I have received a copy of this form and the Participant Information Sheet, which I have signed.

7. I acknowledge that any regulatory authorities may have access to my medical records to monitor the research in which I am agreeing to participate. However, I understand my identity will not be disclosed to anyone else or in publications or presentations.

Before signing, please read "IMPORTANT NOTE" following.

IMPORTANT NOTE:
This consent should only be signed as follows:
1. Where a participant is over the age of 16 years, then by the participant personally.

Name of participant_________________________ Date of Birth_____________________

Address of participant___________________________________________________________

Signature of participant_________________________ Date:__________________________

Signature of researcher_________________________ Date:__________________________

Dying in the Margins study. Version No 4 Dated 08/05/2011
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PARTICIPANT INFORMATION SHEET AND CONSENT FORM
Formal carers

Study Title: Understanding the experience of social and financial hardship and terminal illness in an Australian context.

Signature of witness ___________________________  Date: ___________________________
Appendix 15: Initial concepts and themes: Framework analysis (Patient and/or carers)

Concepts and themes: Framework analysis Patient and/or carer interviews

<table>
<thead>
<tr>
<th>Initial themes</th>
<th>Initial Categories</th>
<th>Refined categories</th>
<th>Core concept</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial loss/needs</td>
<td>Loss of income</td>
<td>Income/wealth loss</td>
<td>Financial impact</td>
</tr>
<tr>
<td></td>
<td>Loss of ability for cost savings</td>
<td></td>
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<tr>
<td></td>
<td>Loss of assets/limited wealth</td>
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<tr>
<td></td>
<td>Loss of superannuation/limited superannuation</td>
<td></td>
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<tr>
<td></td>
<td>OOPE (medications, gap payments, consumables etc)</td>
<td></td>
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<tr>
<td></td>
<td>Specialist/private costs</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Forgoing spending</td>
<td></td>
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<tr>
<td></td>
<td>Transport/parking costs</td>
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<tr>
<td></td>
<td>Funeral costs</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Daily living costs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial advice/support</td>
<td>Complexity of financial decisions</td>
<td>Financial risk/resilience</td>
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</tr>
<tr>
<td></td>
<td>Independent financial decisions</td>
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<td></td>
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<tr>
<td>Financial strengths/reduced consumption</td>
<td>Using assets and income to manage costs</td>
<td>Affordability and cost containment</td>
<td>Financial means</td>
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<tr>
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<td>Using and understanding entitlements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial themes</td>
<td>Initial Categories</td>
<td>Refined categories</td>
<td>Core concept</td>
</tr>
<tr>
<td>Relationship changes</td>
<td>New relations</td>
<td>Shift in care support</td>
<td>Terminal illness transitioning relations</td>
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<tr>
<td></td>
<td>Changed family relations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social changes</td>
<td>Social limitations, loss and transitions</td>
<td>Changes in social relations/engagement</td>
<td></td>
</tr>
<tr>
<td>Initial themes</td>
<td>Initial Categories</td>
<td>Refined categories</td>
<td>Core concept</td>
</tr>
<tr>
<td>Access</td>
<td>Key/entry point to access</td>
<td>Getting in</td>
<td>Negotiating the system</td>
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<tr>
<td></td>
<td>Barriers</td>
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<tr>
<td>Acceptability</td>
<td>Service suitability</td>
<td>Negotiating within</td>
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<tr>
<td></td>
<td>Communication acceptability</td>
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<tr>
<td>Social capital</td>
<td>Who’s available to care (networks)?</td>
<td>Family care relations</td>
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<tr>
<td></td>
<td>Who cares?</td>
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<td></td>
<td>Crisis shaped relations</td>
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<td>Neighbour &amp; friendship networks</td>
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<td>Quality of neighbour and friendship relations</td>
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<td></td>
<td>Community contacts</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Community trust /cohesion</td>
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<td></td>
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<tr>
<td></td>
<td>Community migration and boundaries</td>
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<tr>
<td></td>
<td>Government/institutional contacts</td>
<td>Societal conditions for support and resources</td>
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<tr>
<td></td>
<td>Government /institutional trust</td>
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2.
Appendix 16: Initial concepts and themes: Framework analysis (key informants)

Concepts and themes: Framework analysis key informant interviews

<table>
<thead>
<tr>
<th>Initial themes</th>
<th>Initial categories</th>
<th>Refined categories</th>
<th>Core concept/theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Services</td>
<td>Place of care; cultural and family preferences</td>
<td>Preferences for care</td>
<td>Spectrum of palliative care</td>
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<td>Challenges in the public health system</td>
<td>Using acute care</td>
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<td>Demands, acceptability and equity- long term beds</td>
<td>Long term care needs</td>
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<td>Initial themes</td>
<td>Importance of family relationships/care networks</td>
<td>Family care; advocacy</td>
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<td>Formal and informal community support persons and programs</td>
<td>Community relations</td>
<td>Means in end of life care</td>
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<tr>
<td></td>
<td>Understanding of and uptake of benefits/programs</td>
<td>Financial support/benefit uptake</td>
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<tr>
<td></td>
<td>Health service preferences; meeting care preferences and needs</td>
<td>Health service capacity</td>
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<tr>
<td>Initial themes</td>
<td>Language barriers; poor health literacy</td>
<td>Barriers for communication/poor health literacy</td>
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<tr>
<td></td>
<td>Acceptability of palliative care; death denying</td>
<td>Stigma of Palliative care/dying (consumer barriers)</td>
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<tr>
<td></td>
<td>Limited informal care networks(family; neighbours as carers)</td>
<td>Limited networks and vulnerability</td>
<td>Margins in end of life care</td>
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<tr>
<td></td>
<td>Limits of formal community support (home care services-NGO's, primary care services); availability and acceptability of inpatient services</td>
<td>Limitations in formal care availability/support</td>
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<tr>
<td></td>
<td>Limitations of referral system; limitations of referees ;referral bias</td>
<td>Referral limitations</td>
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</tr>
<tr>
<td></td>
<td>Financial support/benefit - no uptake. Financial costs and income loss</td>
<td>Costs of EOL care</td>
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