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The experiences of socially isolated older people as they access and navigate the health system

A Dissertation submitted by

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ABSTRACT

This study explores the experiences and challenges of socially isolated older people in navigating and accessing the health care system. Understanding the specific issues confronting these individuals will inform the development of more appropriate models of community-based aged care. An extensive literature review identified many areas of research into social isolation of the older person, but minimal research was located that dealt specifically with how this cohort accesses and navigates the health care system.

Key words: social isolation, older person, aged, access health/medical services, aged care

Objective: This research reports findings from a study that explored the challenges experienced by socially isolated and unwell older people as they attempted to access the health care system.

Design: A longitudinal qualitative, interpretive study using a constructivist grounded theory approach with in-depth interviewing.

Setting: This study was conducted in metropolitan Brisbane, with frail elderly people who were accessed via their General Practitioner (GP) service.

Participants: Six participants who met pre-determined selection criteria were invited to participate in this longitudinal study and interviewed three times over an eighteen-month period.

Findings: Fear emerged as a common experience embracing aspects of daily life such as depletion of social networks, being dependent on others, loss of mobility and diminishing ability to drive. Inadequate or unreliable public transport resulted in extended waiting times to attend medical appointments. Disillusionment and anger were responses to ageist attitudes that engendered feelings of invisibility and powerlessness.

Conclusions: Through efforts to address the specific issues of older people living independently, this study highlights the suffering experienced by those who are socially isolated and lack the knowledge, skills, physical wellbeing and support to locate and access relevant health services.

CERTIFICATION OF DISSERTATION

I certify that the ideas, experimental work, results, analyses, software and conclusions reported in this dissertation are entirely my own effort, except where otherwise acknowledged. I also certify that the work is original and has not been previously submitted for any other award, except where otherwise acknowledged.

Signature of Candidate Date

ENDORSEMENT

Signature of Supervisor/s Date

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Nurses are often in a unique position to be closely involved with their patients, which enables them to see through the façade of some people's lives. These closer professional relationships often lend themselves to identification of issues beyond the realm of physical illness commonly encountered in general practice. This research evolved out of such interactions and would not have been possible without Fay, Win, Bette, Ken, Monica and Shirley. Heartfelt thanks to all of you for your willingness to be a part of this project and most importantly for allowing me into the most personal aspects of your lives. I have been humbled by your continuing determination and courage and hope that this research, and the two published journal articles arising from it, are worthy of your trust in me to accurately portray your experiences.

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LIST OF ABBREVIATIONS

ACAT	Aged Care Assessment Team
GP	General Practitioner
HREC	Human Research Ethics Committee
MACOP	Ministerial Advisory Council for Older Persons
NSW	New South Wales
QDA	qualitative data analysis
RBWH	Royal Brisbane and Women’s Hospital
RSL	Returned Services League
SIU	Seniors Interests Unit
USQ	University of Southern Queensland

CHAPTER ONE: RESEARCH FOCUS

> *Once you're past 65 you're invisible. Don't rock the boat, keep out of the way, don't ask for anything, just be invisible, that's all they want. Once you're needy, you're supposed to be invisible. Don't bother me, you're of no consequence* (Win, *86 years 1st Interview)*

1.1 Preface

Social isolation is a significant component of the lives of many older people living in Australia. Although descriptions vary, social isolation is generally understood to occur when a person has minimal levels of social participation and perceived inadequate social experiences (Copeland 2002; Findlay and Cartwright 2002; Fratiglioni et al. 2000; Greaves and Farbus 2006; Victor et al. 2000).

The issue of social isolation has been ongoing throughout health research for many years, with sociologists focusing on the detrimental health effects of living alone, particularly in older people. Social network research has also established health risks such as depressive illness and loneliness (Routasalo and Pitkala 2003; Segal 2000; Victor et al. 2003; Victor, Scambler and Bond 2008) along with other negative health outcomes such as cardiovascular and endocrine disorders (Hawkley and Cacioppo 2003) associated with having a small social network, infrequent contact with network members and a lack of social network diversity (Cornwell and Waite 2009). Further, Western trends of increased longevity have resulted in increased levels in utilisation of health care systems with significant additional resources required to sustain an adequate level of health and wellbeing for all older aged people (Walker 2003). The subsequent increase in expenditure occurs not only within the health budget but encompasses housing and specialised accommodation requirements. While some people may understand the problems that come with ageing, many have never considered how these are compounded by social isolation.

When associated with chronic illness or decrements in general health resulting from the normal ageing process, the lack of an adequate supportive social network can result in a detrimental negative pathway akin to a downwards spiral for older people who, consequently, may lose their capacity or opportunities for continued meaningful social interaction. Accessing the health system can become challenging for many older people, but it is even more so for those who are alone, unwell and who have to do so without the support and sharing of knowledge that is part of being in an effective social network. The quotation above, taken from one of the participants in this study, demonstrates one aspect of this phenomenon.

1.2 The Researcher

I began my ‘nursing career’ at the tender age of eight as I accompanied my mother, a District Nurse in Melbourne, on her visits to frail elderly people to provide in-home nursing care. At first a passive and silent observer, I soon became part of my mother’s routine, taking great pleasure brushing or plaiting Mrs Smith’s hair, or walking beside Mr Jones as he showed me his vegetable garden. I hold many fond memories of these early days, and of a burgeoning awareness of the *aloneness* of the people my mother cared for so lovingly. Her visits often went far beyond her paid hours and I often accompanied her on unscheduled weekend visits as she ensured all was well with those who were living in what I now know to be socially isolated circumstances.

I have always had a fondness and affinity for older people and after completing my ‘official’ Registered Nurse training, I worked for some years in an aged care unit in provincial Queensland. It was only after 20 years of practicing as a Registered Nurse that I undertook formal tertiary academic scholarship, earning not only my Bachelor’s degree in nursing but also a Master of Health. This latter was research-based and provided the impetus and foundation for this study.

Entering the PhD program was daunting and I harboured grave doubts about my academic ability and questioned not only my knowledge but also my natural writing style, as opposed to the more technical-based research I was reading. I had to experiment with writing styles, moving from the objective traditional research writing of the quantitative model to the more personal use of first person, which better conveyed the relationships between me, the participants and my adoption of the qualitative model. During this phase of self-doubt and self-discovery, my supervisor Professor Cath Rogers-Clark provided much needed encouragement and support. Through her patient mentorship, my confidence grew and consequently I have reached my highest achievable academic standard of qualitative writing.

Thus, adopting this qualitative stance, my research follows the modes of access and process of navigation of six socially isolated older people within the Australian health care system. Further investigation within this study incorporated the research questions, which focus on how socially isolated older people access the health care system, the difficulties they may experience in accessing their health care needs and how these difficulties have impacted on their health status and feelings of isolation. Information gained included participant impressions of health care initiatives specific to their age cohort.

1.3 Research Background

A significant proportion of research in gerontology has focused on health problems and care issues, but so far the issues of knowledge of, and ability to, access services remains a gap. My experience working in a general practice clinic has indicated that when people are socially isolated their ability to seek intervention from primary health care givers can be adversely affected and often results in mismanagement or non-management of specific health needs leading to poor health outcomes. Several research studies were located that identified access needs (Czaja and Lee 2007; Gray and Heinsch 2009; Gray and Scott 2003; Tanner D 2003), barriers to access, reasons for help avoidance (Howse, Ebrahim and Gooberman-Hill 2005) or that investigated service providers' perceptions of caring for socially isolated older people (Russell and Schofield 1999). A significant finding in the research literature was the omission of *how* socially isolated older people obtained knowledge of services concerning medical assistance for their health care. An extensive literature review identified many areas of research into social isolation of older people but minimal research could be located that dealt specifically with *how* this cohort accesses and navigates the health care system.

Previous research into ageing has been primarily quantitative and mainly focused on biological characteristics, longevity and illness prevention. In my opinion, there is a need for further *qualitative* research to explore and define experiential phenomena, especially the human variables that cannot be controlled in socially isolated older people, to facilitate the development of specific community-based health interventions, which allow and encourage this group to negotiate their health needs. In view of the gaps in the research and my own observations in the medical practice, I determined to establish what socially isolated older people wanted from the health system and other supportive services.

Thus, I began this research with some insight, as the plight of socially isolated older people was emphasised through my work within a suburban medical clinic in Brisbane. As a practice nurse, it is part of my role to undertake health assessments for patients aged 75 years and older. After many months of conducting these health assessments, it became apparent to me that a significant proportion of these people were not aware of community-based programs designed to assist their specific health care needs. Further, some socially isolated older people refused to utilise these services. This led to a period of puzzlement and frustration as to why this was happening. I continued to reflect on the difficulties encountered by this cohort as I continued undertaking health assessments.

1.4 Aims of the Research

This qualitative study, undertaken through a time differentiated longitudinal basis, explores six socially isolated older people’s experiences in attempting to access and navigate the health care system in metropolitan Brisbane. The potential benefit to older people living in the community of such research is significant, with the aims of this study developed to:

1. raise awareness in health care professionals of the circumstances leading to, and influencing, the development of social isolation in older people and the health care practices that affect their wellbeing.

2. enhance awareness of health professionals to the relatedness of access and navigation of the health care system by socially isolated older people.
3. bring attention to the predicament of this cohort by giving them a voice that will be heard within the literature of nursing and policy makers.
4. enhance knowledge within the spectrum of policy development of health care initiatives for socially isolated older people in the urban community, which can be marketed in such a way as to increase utilisation by this marginalised cohort.

1.5 The Research Questions

In addition to these aims, three research questions were identified and developed within the context of this study and are acknowledged as follows:

1. What actions do socially isolated older people take to meet their health needs?
2. What barriers does this group encounter in attempting to access health care and how do these difficulties affect their health status and feelings of isolation?
3. What do socially isolated older people know about health services available to them?

The trend towards community-based preventative health care has seen the appointment of an increasing number of nurses in general practice (Keleher et al. 2007). By increasing awareness of the issues surrounding accessibility and navigation of health care services by this cohort, nurses in general practice can provide opportunities for socially isolated older people to acquire health care specific to their needs.

I believe that by determining the factors that influence access to health care and acceptance or non-acceptance of community services, more appropriately focused health care initiatives could be undertaken. These initiatives would accommodate the specific needs of older people living in social isolation within the broader community.

Therefore, my research is based on the *experiences* of socially isolated older people as they attempt to access and navigate the health system, and on what ways these experiences influence their acceptance or non-acceptance of community services. This research fills a gap in the literature in two ways. Firstly, the study is qualitative and thus the human variable can be better explored. Secondly, it focuses on access to care services by the socially isolated older person.

By the provision of evidence-based findings, this study has the potential to act as a catalyst for change by informing policy makers of inadequacies or ‘gaps’ in health care services and influencing future development of community projects to more appropriately address the needs of the socially isolated older person. It is envisaged that this study will ultimately contribute to the enhancement of health care for all older people living independently within our community, regardless of their level of social isolation.

I have supported the views of Mays and Pope (1995) and Pope and Mays (2006), who posit that qualitative research should be a crucial constituent of health services research. Qualitative research facilitates more in-depth access to data not open to quantitative research. For example, both non-professional and professional health beliefs and also because qualitative portrayal is a prerequisite of good-quality quantitative research, chiefly in quarters that have been given minimal previous exploration.

1.6 Theoretical Stance

A qualitative-based research approach was best suited for this study due to the complexity of the phenomena being studied and the urgency of the study, in view of the implementation of a new policy. A grounded theory methodology, adapted from Glaser and Strauss (1967), was my first choice, but as I became more aware of my own beliefs about the nature of knowledge, I modified my theoretical stance to more closely align with the approach of Morse (1991, 1994, 1997). Morse's view incorporates key features of Glaser and Strauss's original concepts however, her broader and more flexible approach to grounded theory was more easily understandable. Further reading of works by Charmaz (2006) facilitated the decision to adopt the constructivist approach of Charmaz (2006) as best suited to the objectives of this research project.

Thus, the principal feature of grounded theory was observed namely, theoretical sensitivity, gained by investigation of the methodology as well as an extensive review of the literature. The sampling of participants was purposive and data collection and analysis were simultaneously undertaken, which was in keeping with a symbolic interactionist, constructivist paradigm. At the conceptual level, I engaged with the data in accordance with the traditional tenets of Glaser (1978, 1992), by developing categories and themes and making appropriate links without computer assistance. The following section offers a brief overview of the content of each chapter that follows this general introduction.

1.7 Overview of the Research

1.7.1 Chapter Two: Literature Review

An extensive literature review identified many areas of research into social isolation of older people. This included but was not exclusive to loneliness, depression, poor health, fear of crime, decreased mobility and disengagement related to loss of licence and lack of appropriate transport. Various theories of social isolation are discussed, as are the contributory factors, such as transport and information technology. The impact of nutrition, eating alone, hearing and visual impairment are also investigated. Broader issues of cultural influences and ageist attitudes are explored. National and international research findings are offered and these include proposed and implemented ameliorative programs and interventions. The gaps found in the literature are identified.

1.7.2 Chapter Three: Theoretical Framing—Methodology

The difference between methodology and method is highlighted and the process and reasons behind choice of constructivist grounded theory are examined. The purist canons of grounded theory are put forward and critiqued. The broader theories of qualitative data analysis and constructivism and why these better suited my philosophy, beliefs and personal style are explained.

1.7.3 Chapter Four: Method

In this chapter, I explain the selection process and criteria for participant inclusion (and exclusion) in this study as well as the processes involved in obtaining and collating data.

Development of codes and categories and the genesis of themes are provided with the assistance of diagrams to illustrate this process more easily. Ten people, identified as living in socially isolated circumstances through conducting health assessments at the medical centre at which I worked as a practice nurse, were invited to participate in this study. Six respondents accepted the invitation. Their views and experiences underpin the findings of this study. Design, setting, data collection methods and ethical considerations are also described.

1.7.4 Chapter Five: Data Analysis

The processes involved in analysing data are examined in this chapter. Extensive participant dialogue is included to emphasise and more accurately portray participant experiences. These dialogues are also utilised to examine issues that are encountered by participants as a group, as well as their individual differences.

1.7.5 Chapter Six: Discussion

This chapter provides a detailed discussion of my findings using the key themes that emerged as demonstrating lack of information: the need for coordination, difficulties with technology, escalating fear and frustration, the relationship and interconnectedness of personal perceptions, the struggle to maintain autonomy and independence, ageist attitudes and reactive behaviour patterns. I also assert that the process of modified grounded theory has enabled me to better understand the needs of this cohort and added to the body of existing knowledge.

1.7.6 Chapter Seven: Recommendations, Implications for Practice and Conclusion

The focus of this chapter is to take a short sojourn to reflect on the study aims and findings and pause to consider my own actions as the researcher, my choice of methodology and my own journey, which is inexorably intertwined with those of the participants. Were my research questions adequately answered? This is something for you, the reader, to assess. I also examine my role and influence and the evolving perceptions of my participants throughout the time-based progression of the three interviews. In this closing chapter, based on the findings of this research, I offer a number of recommendations with proposals aimed at policy makers as well as community-based health care professionals. The strengths and limitations of this study are also discussed.

1.8 Conclusion

This introductory chapter has provided a general overview of my research. The literature review that follows this introduction details the relevant previous research to date that has investigated social isolation in older people. Both Australian and overseas studies are discussed.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter establishes the background to my research, but sets out firstly to question the place of the literature review in qualitative research. It explains my stance of not rejecting an examination of previously conducted studies of the issue being researched prior to the study, despite the belief by some grounded theorists that this is inappropriate. I have included this discussion in view of my decision to use grounded theory as the methodological basis for this research. My reasons for choosing this methodology are expounded in Chapter Three.

This chapter also examines some key theories of social isolation, noting that each was developed within a particular period and epistemology. These are sometimes referred to as social or political theories and are of significance in determining and understanding inherent social processes that can affect the development of social isolation in older people. Factors identified in the literature as influencing social isolation are examined in detail and, lastly, a particular local initiative is outlined. Interestingly, nowhere in this significant body of literature could I find research that focused on *how* socially isolated older people negotiate the health care system and very few studies emphasised the voice of those concerned. Thus, with this gap in mind, I have embarked on a journey of investigation.

2.2 Timing of the Literature Review

The first issue arising in this literature review relates to timing. Despite a continuing stance from some grounded theorists (Glaser 2001, 2002a, 2002b; Glaser and Holton 2004; Locke 2001) that literature searches conducted prior to the study contaminate findings, many others advocate an approach that supports prior searches *as well* as returning to the literature as themes emerge from the data (Burns and Grove 1993, 1999; Heath 2006; Taylor-Powell and Renner 2003). Most qualitative research methodologies attempt to circumvent imposing pre-determined knowledge onto phenomena being studied, hence the view that a search of the literature should occur *after* data have been collected and analysed.

However, there is some controversy around this approach and, as Fernández (2004, p. 87) has noted, researchers attempting grounded theory are often confronted with issues of unfamiliarity regarding methodological aspects, such as the role of the extant literature. According to Fernández, adopting a grounded theory method commits the researcher to a rigorous and constant literature review process that occurs at two levels:

1) The researcher must be constantly reading in other substantive areas to increase their theoretical sensitivity.
2) Conceptual emergence forces the researcher to review convergent and diverging literature of the field related to the developing concept (p. 87).

In addition to the views held by Fernández (2004), Heath (2006) stressed that the decision of *when* to introduce or consult existing literature could be problematic, particularly for novice researchers such as me. Fernandez concluded that, after consideration of Strauss and Corbin’s (1998) seemingly opposing views to Glaser (1978), previous consultation of literature *should* take place and continue during the research.

However, Heath (2006) asserted that such readings should be diverse, to facilitate and promote sensitivity within the researcher to the possibilities in the data. Further, the readings should be in disciplines removed from the phenomena being studied to challenge preconceptions. Focused reading should only take place when the emergent theory is well-established (Heath 2006, p. 520). I have opted to follow Heath 2 and do an in-depth literature review at the beginning of the research and return to more focused reading as themes emerge. This chapter is the outcome of both these processes.

2.3 Social Isolation

This study is particularly focused on older people living independently, in social isolation within an urban community of Brisbane. Social isolation has long been identified as a significant factor in the development of negative health outcomes. Negative health outcome applies across all ages however, older people are among those who are most vulnerable and at risk (Findlay and Cartwright 2002; Victor et al. 2003).

In Australia, older people are susceptible to social isolation, particularly those who are living independently and alone (Aged and Community Services Australia 2002; Findlay and Cartwright 2002). Descriptions of ‘isolation’ often vary. Several researchers (Copeland 2002; Greaves and Farbus 2006; Mann 2000; Victor et al. 2003) have postulated that social isolation occurs in the absence of meaningful sustained relationships with significant others or when a person experiences minimal levels of social participation and *perceived* inadequate social interactions. Moreover, others (Findlay and Cartwright 2003; Russell and Schofield 1999) have argued that social isolation, particularly of older people, remains a complex phenomenon involving psychosocial, physiological, economic, demographic, cultural and religious aspects of a person's life. In this thesis, I have worked from a position that defines social isolation as the absence of meaningful social interactions, contacts and relationships with family, friends or neighbours on an individual level and with society in general.

A review of the related literature revealed a substantial body of research and scholarship; including studies by Berkman (1995), Wenger et al. (1995), Russell and Schofield (1999), Findlay (2003), Victor et al. (2003), Cattan et al. (2005) and Machielse (2006). These studies focused on social isolation and associated causative and contributory phenomena. Studies included long-term illness, age-related disabilities, chronic pain, recent bereavement, geographical isolation, relocation, living alone, decreased social and family networks and financial losses related to retirement and loss of income.

Common sense, and evidence found by, for example, Victor et al. (2003), reveals that social isolation can occur in any age group. However, Victor et al.'s work clearly revealed that significant negative health outcomes and decreased quality of life were increasingly evident in older people who experienced reduced social contact, expressed feelings of loneliness or lived alone or in isolation. These findings reflect those of an earlier study by Hall and Havens (1998), whose focus was on the effects of social isolation on the health of older women. Their findings indicated that social isolation and loneliness were co-dependent on issues such as:

- Problems in accessing or negotiating transportation
- Potential embarrassment due to physical limitations
- A general lack of awareness of available resources in their communities
- Possibility of restrictive care-giving responsibilities
- Concerns regarding personal safety issues
- Living alone
- Being primary caregivers for significant others
- Declining health

Results from the Hall and Havens 1998 study revealed that loss of family networks (19.1 per cent of females, 12.1 per cent of males) and living alone (65.7 per cent of females, 30.8 per cent of males), along with transportation costs, declining health and physical mobility problems were significant issues in the development of social isolation of older people.

Despite an extensive search of online databases and textual references, no research could be found that focused exclusively on the experiences of socially isolated older people in accessing and navigating the health care system. Several studies (Cattan et al. 2005; Dermody et al. 2003; Findlay 2003; Greaves and Farbus 2006; Hensher 2006) were found that linked social isolation and community-based intervention programs. However, access and navigation of these programs were not discussed. This review, then, will describe theories and summarise and analyse the research literature on the topic of social isolation in older people, within Australia and overseas.

2.4 The Emergence of Theories of Social Isolation

In attempting to understand and explain the ageing process, researchers have developed several different theories of ageing. These theories are significant, as they define and illustrate the interrelatedness of biological and social phenomena with the ageing process. Several key theories follow.

2.4.1 Activity Theory

Since the early 1960s, academics have been theorising social isolation. Activity theory was formalised in the 1960s by Havighurst, who believed that people who maintained participatory activity levels and social networks were less likely to withdraw from social contacts or become lonely (Havighurst 1961). However, activity theory does not differentiate between *types* of activity, assuming that any activity can substitute for significant losses of social involvement.

This loosely constructed theory had significant empirical support (Lawton 1994; Powell 2001) and it was accepted for many years (Payton Fay 2004) as explicating the achievement of successful ageing for many middle-aged and older people. Payton Fay simplified the original concept of activity theory in terms of supporting the continuation of customary activities, responsibilities and societal pursuits, with people who attain optimal age and health being those who stay active. As primary roles change, the person finds alternative activities to replace these. This theory eventually became unacceptable due to its apparent incompleteness. Powell (2001), Biggs and Powell (2001) and Tanner and Harris (2007) claimed the theory disregarded important issues of power, gender disparity, political and socio-cultural differences and norms between age groups. The validity of early social theories, including disengagement theory, were challenged in later years with researchers developing new theories or adapting existing theories to explain social processes (Havighurst 1968).

2.4.2 Disengagement Theory

In contrast to activity theory, disengagement theory, proposed in 1961 by Cumming and Henry, argues that withdrawal or ‘disengagement’ is a natural and unavoidable part of ageing. This latter view is no longer universally accepted by social gerontologists, who, according to Earle (1992) and Payton Fay (2004), believe that disengagement is precipitated by life changes that make it difficult for people to remain active within a social context, and that often lead to social isolation. That is, it is not a natural or desired process. Cavalli, Bickel and Lalive D′ Epinay (2007) also acknowledged the process of disengagement, though they viewed it as withdrawal from social participation, influenced by declining health, death of a close relative or admission into a nursing home. In their five-year study of octogenarians, the authors revisited the original concepts of Cumming and Henry’s (1961) disengagement theory, which asserted that from a particular period of human development, the decline of social participation and the psychological disconnection from customary roles were precursors to the positive ageing *desired* by many older people.

Viewed from this perspective, disengagement could be seen as *one* feasible pattern of adaptation in very old age. However, the findings by Cavalli, Bickel and Lalive D′ Epinay (2007) revealed it was more likely that purposeful withdrawal was a strategy forced on some older people in response to deteriorating health. Havighurst (1968) reviewed this theory and his earlier activity theory proposing instead, continuity theory to account for typical social behaviour patterns seen throughout the ageing process.

2.4.3 Continuity Theory

In response to the debate regarding activity and disengagement theory, Havighurst proposed continuity theory in 1968, which symbolises a more formal clarification of activity theory as it illustrates a life course perspective to describe typical ageing. According to Atchley (1971, 1989), Covey (1981), Ebersole, Hess and Schmidt Luggen (2003) and Atchley and Barusch (2004), this theory emphasises the significance of personality and highlights the relationship between past, present and future, and why continuity of ideologies and lifestyles are central to processes for coping with the inevitable changes that ageing brings.

While some withdrawal may be seen, essential aspects of personality and activities undertaken in younger years are maintained. As social isolation may still be considered part of the normal processes of ageing, it could be deduced that its negative effect may be dependent on, and influenced by, the cultural norms and personality attributes of the individual. Embedded within cultural and personality influences, lies the physical and psychological ageing process and one's *place* within their social structure. Considering these social constructs, White Riley (1974) proposed age stratification theory which was based on a person's age and socioeconomic milieu.

2.4.4 Age Stratification Theory

Indeed, one of the most influential social theories was age stratification, pioneered by White Riley (1974, 1978, 1987). This theory is primarily based on the interdependent relationship between age and social structure. Building on these views, Miller (2009) further suggests that society can be divided into various strata according to age and roles.

Thus, as society changes, so do people and their roles in each stratum. In discussing this theory, Cockerham (2007) contends that stratification, which was established on the relationship between age, personal attitudes, behaviour and social structure, developed through a person's *position* within the changing age-related environment of their particular society, inclusive of social, cultural and historical influences. Inequalities of entitlement in both social and economic processes exposed areas in which the development of social isolation could be a likely outcome, particularly in older age. Implicit in this perspective is the political economy of old age model.

2.4.5 The Political Economy of Old Age

The political economy of old age model, while not viewed in the more traditional terms of 'theory' emerged in the mid-1970s and is worthy of mention, as it developed during a time of economic constraint and rising unemployment, when a significant amount of social expenditure was allocated to older people. This had the unfortunate consequence of subjecting older people to prolonged political criticism by right-wing governments in America, Britain and other developed countries (Phillipson 1998; Powell 2001).

The political scrutiny ultimately led older people to be viewed as an economic burden on Western society. Older people were aware of this and many attempted to ameliorate their position within the social structure of the day. While some attempted to remain in the workforce in whatever capacity they could, others became involved in volunteer work within their community (Phillipson 1998).

Phillipson's early work highlights the historical and socioeconomic influences of perceptions of the ageing process and their relationship to the development of a myriad of social policies directed at the ever-growing ageing population. These underpinned concerns regarding sustainability of such funding in this sector and its effect on future care arrangements for older people.

Lying within the ideological shifts of social ageing are the reduced opportunities for ensuing generations to care for older people (Berkman 2006; Lechner and Neal 1999; Nazarko 2001) and the disquieting question, to what extent a diminishing percentage of people of working age are willing or able to support an older generation (Lowenstein and Bengtson 2003). Lechner and Neal's (1999) international study included examination of various countries' initiatives for caring for older people, the informal care given by working and non-working family members and the health impact of duality and extension of roles on caregivers. This research, which culminated in a book, *'Work and caring for the elderly: International perspectives'*, encompassed 11 countries (Japan, Uganda, Brazil, Sweden, Canada, Germany, Britain, United States, China, Israel and Mexico), with findings indicating that the impact of care giving on employment opportunities in many instances was far greater for women than for men. Further, this study revealed that for many of those with caregiver responsibilities, employment opportunities were restricted to part time or temporary work, with lower income and fewer benefits than those working full time. Despite a decade having passed since this research, its findings seem to remain relevant in society today.

A recent study by Ho, Chan, Woo, Chong and Sham (2009) examined the effects of care giving on caregivers and non-caregivers as well as on older people's health. This study obtained similar results to the 1999 study by Lechner and Neal described above. High caregiver burden, particularly in women, was positively related with poor physical and psychological health and poorer quality of life. With the increasing economic need for women to re-enter the workforce, the burden of care giving has shifted to government and local community institutions.

Women have long relinquished their traditional caregiver roles because of a need to enter or re-enter the workforce (Brody 2003; Lechner and Neal 1999; Liu and Kendig 2000) prompted by either individual choice or the increased financial burdens placed on the family unit. As the availability of home-based care diminishes, policies and programmes for appropriate care giving for older people need to be further developed with a view to sharing care administered by primary caregivers, extended family members, community service agencies and state-based institutional systems. Lying within this familial and social shift is the experience of ageing itself which can be viewed from a positive perspective such as gerotranscendence theory.

2.4.6 Gerotranscendence Theory

The experience of ageing, which may be a disquieting and alienating experience for many individuals (Carr 2004; Davey 2007; Findlay and Cartwright 2002; Phillipson 1998), can also be a positive experience. This is evidenced by gerotranscendence theory developed by Tornstam (2005). This theory views ageing from a positive perspective, describing attitudes and behavioural patterns that integrate aspects of activity and disengagement theories, rather than implying withdrawal or disengagement. It is considered the final stage in the natural course of achieving maturity and knowledge. The theory is based on the older person moving towards a redefinition of themselves and their relationships while focusing less on materialistic values.

Even though as people age they are less occupied, the older person tends to be more selective in choices of social and other activities, often choosing or cultivating friendships with another person rather than participating in larger groups. There can often be heightened feelings towards younger generations and an increased desire for solitary meditation. These *choices* are influenced by the individual’s past and present socioeconomic status, attitudes, belief systems and cultural values.

The influences of culture as well as individual life experiences can aid or hinder the development of gerotranscendence (Ahmadi 2001). Research by Tornstam (1996), Tornstam and Tornqvist (2000), Wadensten and Carlsson (2001, 2003), Wadensten and Hägglund (2006) and Wadensten (2007a, 2007b, 2007c) were based on the theory of gerotranscendence and its application to care of older people. Findings revealed that the experiences of gerotranscendence for example, solitude and fewer acceptances of social interactions, could be mistaken for pathological processes in older people by their younger counterparts, family members and professional caregivers. The authors have suggested guidelines and programs for health care staff caring for older adults that could be utilised to support the older person in their journey towards gerotranscendence.

This review has demonstrated that many social theories encompass diverse perspectives that are underpinned by a range of philosophical questions, not all of which can be examined here. However, I stress the point that the theories above reflect the particular school of thought and the social and political era in which they were conceived. Hence, these theories need to be viewed pragmatically.

Alongside the many theories of ageing are the more practical elements of the older person’s life that can lead to social isolation. These are examined next and are discussed at length in the following section, along with the impact and influences of ageism and ageist attitudes. International studies are also included to show that these issues are not experienced in cultural or demographic isolation but are encountered by older people irrespective of their cultural origins.

2.5 Factors Contributing to Social Isolation in Older People

Ageing is often accompanied by increasing limitations due to decreased mobility, visual or other health-related problems, which can influence the development of social isolation in certain individuals. Research by Gray and Scott (2003) identified that experiences of chronic illness were different for each person with the effect on daily living and social interaction dependent on the nature of the illness and the severity of the disability it produced. Among these factors were the social and psychological effects of cessation of driving and the difficulties encountered in locating and using other modes of transport. These are discussed in the following section.

2.5.1 Transport and Community Mobility to Reduce Social Exclusion

Transport concerns play a significant role in accessing health care for mobility impaired or frail older people. Research findings have indicated that the ability to maintain lifelong travel options sustains independence, quality of life and social networks for older people (Gabriel and Bowling 2004; Gilhooly et al. 2002; Hensher 2006; Whelan et al. 2006). Furthermore, Whelan et al. (2006) discovered that enforced driving cessation was linked to an increase in depression and a significant decline in social activities outside the home environment, including general public mobility.

Whelan et al. (2006) and Hensher (2006) also stressed the value of preserving older people's mobility by offering substitute transportation options other than the car, particularly after termination of driving. In their review of international literature, Whelan et al. distinguished that the availability and usage of alternative transport methods varied significantly between Australia, Britain, Germany, the Netherlands, New Zealand, Norway, Sweden and the United States of America. The importance of private transport was highlighted in view of difficulties of availability, utilisation of public transport and decreased mobility. Recommendations were made regarding the need for government infrastructure to address issues of providing appropriate community-based transport options for older people. However, adoption, instigation and evaluation of the efficacy of these recommendations requires further investigation.

Recent Australian research conducted by Harris and Tapsas (2006) involved 125 older people who had ceased driving. Findings established that the majority of these older people relied on lifts from neighbours, friends, relatives or taxis. Many respondents indicated they had trouble using public transport, though taxis were an exception. However, problems associated with using taxis were affordability and getting a taxi driver who was prepared to make short trips. Thirty-eight per cent of respondents revealed having trouble using buses and trains. The difficulties experienced with accessing transport led to a marked decrease in social mobility, which had a contributory effect in the development of social isolation.

The capability to drive has been linked with social identity, autonomy and independence (Davey 2007), especially for males, who believe that lack of car ownership or inability to drive characterises socioeconomic disadvantage, decreased social mobility and reduced quality of life. Davey’s (2007) findings also highlighted the fact that many older people without their own transport felt uncomfortable about accepting offers of transportation, especially when they could not reciprocate. This unwillingness to be a burden on, or beholden to, friends and family often resulted in fewer acceptances of lifts and, consequently, fewer social interactions, thus potentiating the development of social isolation.

A report by Hensher (2006) suggested that by improving community mobility, the vitality of older people would increase because of sustaining their activities outside the home. Findings indicated there was a universal assumption that transport for older people meant *public* transport. However, Hensher argued that older people’s use of personal transport should be viewed as a positive trend that maintained economic independence and, significantly, avoided or minimised social exclusion. Hensher believed that in reality, transportation needs for older people were just as important as were those required by the general population.

Also highlighted were transportation alternatives for older Americans. This was one of the top three issues (out of 73) deliberated on by delegates at the fifth White House Conference on Aging in Washington (2005). Significant discussion focused on the car as a crucial element in social *inclusion* and that the death of a spouse (usually the husband) posed significant problems for the remaining spouse, who in many instances did not, or could no longer drive.

From the research literature, it seems that the ability to maintain personal transport independence plays a critical role in positive ageing, physical and psychological wellbeing, public mobility and utilisation of health services. My study will focus on how this relates to accessing the health system. However, transport issues constitute only one of many factors that affect the older person’s ability to access health care services. The process of obtaining information has changed dramatically over the last several decades. Information technology has changed the way many people seek or obtain information, particularly in relation to personal health care needs. These changes are discussed in detail in the following section.

2.5.2 Information Technology—A Barrier or Blessing?

There have been numerous discussions regarding the use and effect of information technology both on the psychological health of older people and on health care delivery

(Bartlett 2003; Czaja and Lee 2007; Eastman and Lyer 2004; Gibbons, Crichton and Crawford 2002; Scott 1999; Selwyn et al. 2003; Shapira, Barak and Gal 2007; Sourbati 2009). Bartlett (2003) identified information technology as being a significant barrier to some older people and argued that government and health-oriented organisations needed to ensure that dissemination of information about services was not reliant on electronic delivery if further marginalisation of socially isolated older people was to be avoided.

Bartlett’s (2003) comments appear to contradict earlier research findings by Gibbons, Crichton and Crawford (2002),who maintained that information technology *was* an appropriate method of addressing social isolation of older people in society. Gibbons, et al. argued that appropriate information and communication technology was available that could alleviate social isolation and continue to provide mental stimulation, albeit through a different medium, thereby refuting the assumption that older people do not have the mental capacity to understand and cope with technology. A ‘pattern’ model was developed through the Public Sphere Project to bring technology and older people together in a productive and sustainable digital environment (see Appendix B). Although access and navigation of health care providers was not discussed, it is acknowledged that this model could be utilised by governments and health care institutions to develop strategies and community-based programs to assist socially isolated older people to access allied health care professionals.

Results from research studies regarding the effect of technology on socially isolated older people remain conflicting. While there is clear evidence that a proportion of older people are able and willing to utilise technology (Capel et al. 2007; Merkes 2000), there remains a significant proportion that are not (Sourbati 2009). Consistent with this notion are research findings by Scott (1999), whose earlier study explored the information needs of older people and how society reacted to these needs and the efficacy of government strategies to address these issues. Key findings included difficulty in understanding information presented electronically, technology viewed as ‘too complex’ and not applicable to the older persons’ lifestyle and lack of *accessible* training opportunities for older generations to assist them to embrace this technology.

Scott’s (1999) study revealed that information technology *could* be useful in alleviating social isolation of older people. However, significant changes were required in the delivery of such information to facilitate awareness and, importantly, encourage a willingness to learn how to use it. Nevertheless, how these proposed changes affected older people’s ability and willingness to access and navigate health care services is yet to be empirically demonstrated.

Earlier, through surveying 120 older adults and observing 60 using the Internet, Williamson, Bow and Wale (1997) provided evidence that, due to physiological changes, many older people had difficulty using a computer ‘mouse’, especially the click function (21 per cent) and remembering to place the cursor in the search box before typing (26 per cent). Fine motor coordination for placement of the cursor and scrolling were also major problems (24 per cent). Understanding and using toolbar buttons were the least problematic (65 per cent). However, light coloured text was difficult to read. It is interesting to note that a significant proportion (77 per cent) of participants in the study did not feel particularly positive towards the computer. A large proportion (42 per cent) believed that they did not need to use computers, as they were not relevant to their lives, while some (25 per cent) stated they would only use a computer only if they had to. The authors noted that those who were very positive (4 per cent) were the youngest in the study cohort and that they were likely to have been better educated and less likely to be a recipient of a government pension. Only nine out of 120 participants had ever used a computer.

Significant themes identified in Williamson, Bow and Wale’s (1997) study were later reflected in the work of Selwyn et al. (2003). These authors examined the degree and type of information and communication technology used by older adults in everyday life. Information was gathered from 352 older adults in England and Wales aged 60 years and over through a household survey of computer and Internet use. This study also confirmed that psychological and physiological changes associated with ageing make modern screen-based technologies difficult to use for older and frail aged people, further validating Scott’s (1999) research findings.

Further evidence supporting Scott’s early findings can be found in recent research by Richardson, Weaver and Zorn (2005) and Sourbati (2009), who investigated the use of computers by older people. One can speculate that attitudes surrounding the applicability and use of information technology would have changed over the past decade. However, results of these recent studies revealed similarities to above-mentioned earlier studies, with a reiteration of the difficulties older people encounter when attempting to use computer-based technology.

While the benefits of using technology by socially isolated older people were identified in Richardson, Weaver and Zorn’s (2005) New Zealand study, the authors also acknowledged the existence of both physical and psychological barriers to its use. Building on the extant literature, Sourbati’s (2009) UK-based study involved older tenants and staff from two sheltered accommodation complexes in London. The author focused on the tenants’ access to welfare service information ‘online’ and discussed issues of age, income and educational stratification related to ability and interest in using computers. Sourbati’s (2009) findings added a further dimension to previous research by providing a detailed discourse on individual experiences with use of computers.

Recent research by Tse, Choi and Leung (2008) focused on the health benefits of E-Health (electronic-based health care programs) on older people. Their China-based study examined 30 older people aged 65–80 years and their use of computers and information technology to obtain health-related knowledge. At the commencement of the study, none of the participants had access to a computer at home and 83 per cent stated a computer was unobtainable. While there was some interest in learning how to use a computer, the overall perception was minimal as to its usefulness to seek health information. Participant comments revealed common problems faced when attempting to use computer based technology. For example:

> Poor eye-hand coordination makes it difficult for us to use the mouse … I don’t know where to get help; my friends don’t know about computers, and they cannot discuss computer use with me. … I don’t know the addresses of the websites (Tse, Choi and Leung 2008, p. 478).

Despite these problems, overall mastery of computer skills increased and the experience was generally viewed as positive. However, there was no evidence of follow up of participants post completion of the program to ascertain level of skills maintained, availability or frequency of continued access to computer-based health information.

It is interesting to note that older people with severe visual impairment and functional deficits that would hinder learning and operating computers were excluded from the study.

This exclusion neglects those older people that, through significant physical and psychological deficits, would most likely be at greatest risk of social isolation and for whom computer-based health information would be ineffectual. The participant views correlate with several conclusions drawn by Williamson, Bow and Wale's (1997) study over a decade ago and highlight the continuing difficulties of older people attempting to use the computer and information technology to access their health care needs.

On a more positive note, a study undertaken by Sum et al. (2009) explored how older adults' Internet use affected their perception of online community belonging. Two hundred and twenty-two participants in Australia were recruited in an online survey. Ages ranged from 55 to 89 years. Almost half the respondents were aged between 55 and 64 years—the group most likely to be the greatest users of and the most familiar with the use and applications of computers. While social isolation and loneliness of older people were briefly mentioned in this study, its focus was on older people *already* using computers and accessing the Internet. Results confirmed the view that use of the Internet as a communication tool enhanced older people's sense of online community belonging, which had a positive effect on health and wellbeing.

The inclusion of research undertaken in the previous decade in this section of the literature review provides a deeper insight into the longitudinal perspective of continuing difficulties encountered by older people when confronted with using modern technology. Age-related health problems that affect the ability of older people to use a mouse or view a computer screen will not change despite the anticipated computer literacy of future generations. Therefore, computer programmers and software designers need to develop tools to aid use by this cohort (Capel et al. 2007) thereby increasing accessibility to health care information and cyber-social networks, which can benefit socially isolated older people. Such problems are not exclusive to Western society but span a myriad of cultures.

While technology may be a useful tool to access information for older people who are ‘computer savvy’, many others remain reliant on traditional methods of information dissemination; for example, brochures and newspaper advertisements. Evidence from several studies (Chivite-Matthews and Maggs 2002; Lupton and Tulloch 1999; Oh and Kim 2009; Pain 2000; Smith 2003) indicated some reluctance by older people to obtain home-based and other assistance (cleaning services, general maintenance or repairs) via these sources, due to perceptions of vulnerability and fear of fraud and crime.

2.5.3 Fear of Crime Increases Isolation

Research findings have consistently indicated that fear of crime often inhibits many older people from obtaining essential daily living needs (Borooah and Carcach 1997; Box, Hale and Andrews 1988; Chivite-Matthews and Maggs 2002; Clememte and Kleiman 1976; Ferraro 1995; Grabosky and Graycar 1995; Craycar and James 2000; Jackson 2004; Lupton and Tulloch 1999; Miethe 1995; Pinkerton James 1992; Sanderson 2006). These may include shopping for groceries, accessing money, paying bills or attending appointments for health care. The inability to meet socioeconomic and health care needs frequently resulted in negative effects such as feelings of loneliness and increased social isolation. These collective studies demonstrated that coping strategies to manage this fear were affected by the person’s age, life experiences and cultural background. Overall findings also indicated that considerable diversity of coping strategies existed among lonely or socially isolated older people, with disengagement and avoidance behaviours being among the most common strategies employed to reduce fear (Ferraro 1995; Lupton and Tulloch 1999; Sanderson 2006). Further, Pinkerton James' (1992) early research argued that fear of crime was a primary cause of social isolation among older people. Furthermore, Killias and Clerici (2000) claimed this was predominant in females and those living alone.

2.5.3.1 Social and Cultural Significance of Fear of Crime

Building on this evidence is research by Jackson (2004), who investigated the social and cultural significance of people's fear of crime. Jackson's research included examination of the *perceived* breakdown of social laws, the social meanings of incivilities and social disorder that directly and negatively affected feelings of insecurity and threat of victimisation. Physical, cultural, economic, environmental and societal factors associated with ageing were found to play an essential role in increasing feelings of victimisation, as did the necessity of relying on public transport or walking (often alone) to facilities for essential food requirements or health care; particularly if this had to be undertaken at night. These were often perceived as too great a risk for some older people and consequently an ever-widening pattern of social isolation occurred.

Indeed, similar conclusions were drawn from research by De Donder, Verté and Messelis (2005). This Belgium-based study analysed interview data from 4,747 men and women aged between 60 and 103 years. Results from interview-based surveys indicated that loneliness and lack of participation in both the social and cultural lives of older people demonstrated a strong affiliation with fear of crime. Demographic, neighbourhood and economic variables were also identified. Inherent in these findings were feelings of vulnerability, which increased with age.

These more recent findings correlate to James' (1993) earlier Australian-based research, which identified that fear could negatively affect the ability of older people to move freely within their neighbourhoods, to utilise public transport and shopping centres or access local health care agencies. However, these findings were dependent on suburbs surveyed. In Waverly (Victoria), fear of crime was not as high as that in Fairfield (Victoria). James (1993) concluded that the reason for this was that the social community cohesiveness was higher in Waverly than in Fairfield, which contained a high concentration of people from non-English speaking ethnic backgrounds and exhibited a very high population turnover.

In contrast, there was little or no community spirit evident in Fairfield, where results indicated a much higher overall fear of crime. This detailed scenario and the findings from James' (1993) study, though close to two decades old, have maintained relevance with latter research findings (De Donder, Verté and Messelis 2005; Jackson 2004; Franklin and Franklin 2009; Franklin, Franklin and Fearn 2008; Sanderson 2006). These recent and perhaps more applicable studies reiterate the significance of personal cohesiveness to one's community and its relationship to fear of crime. The language used to express these findings now includes terms such as 'incivilities' and 'social disorder', with greater emphasis on psychodynamics and the *perceived* threat of crime.

Despite the move into the twenty-first century, the continuances of the rationales behind fear of crime, particularly in the older population, appear to have remained largely static. Indeed, as stipulated in James' (1993) study and those that followed (De Donder, Verté and Messelis 2005; Jackson 2004; Franklin and Franklin 2009; Franklin, Franklin and Fearn 2008; Oh and Kim 2009; Sanderson 2006), those older people with close social networks and established community support experienced less fear of crime than did those who had minimal social or community interactions.

Inherent in discourses of social integration and social order is communication of crime, particularly how it is represented and disseminated by the media. This includes not only the lack of positive stories, but also the sensationalism of violent crime and the more insidious and pervasive white-collar crimes.

2.5.3.2 Fear of White Collar Crime

A number of studies have revealed that fear is further compounded by media reports and anecdotal accounts of fraud by con men preying on older people (Carcach et al. 2001; De Donder, Verté and Messelis 2005; Graycar and James 2001; Pinkerton James 1992; Sanderson 2006). These con men are reported to take unscrupulous advantage of the trust and isolation of older people, whose social situation enhances their vulnerability to personal, electronic or telephone fraud. There is also evidence (Smith 2003) that a small number of so-called ‘professional advisors’ have and continue to misappropriate funds of older persons, especially those living alone or in relatively isolated circumstances. Older people falling victim to such behaviour were often afraid to tell their families for fear of being judged incompetent to manage their own affairs or look after themselves adequately and independently. This may ultimately have resulted in the older person becoming a recluse because of fear of further victimisation and loss of autonomy (Borooah and Carcach 1997; Pain 1995; Pinkerton James 1992). It is interesting to note that findings by

Carcach et al. (2001) indicated the highest incidence of victimisation in people over 65 years was consumer fraud, with the least being sexual assault and robbery.

2.5.3.3 Perceptions of Victimisation Linked to Crime

Research findings from Pinkerton James (1992), Grabosky and Graycar (1995), Borooah and Carcach (1997), McKee and Milner (2000), Carcach et al. (2001), Franklin and Franklin (2009) and Oh and Kim (2009), suggest that concerns of victimisation and loss of or reduced community integration could negatively affect personal health. Viewed collectively, these issues may culminate in the development of social isolation, despite concerted efforts by government and community policy makers alike to ameliorate these perspectives.

The basis for the findings in the studies discussed thus far relied on quantitative survey data as well as qualitative data based on interviews and case studies with results collated from Australia and overseas. The diversity in research approaches facilitates a broader understanding and recognition of the factors influencing fear of crime. For example, Lupton and Tulloch (1999) conducted their Australian-based qualitative research on case studies of two women aged 68 who exhibited different perspectives of occurrences of crime.

The authors identified and discussed geographical, cultural, personal and social biographies that not only influenced perceptions of crime but also brought about (mal) adaptive behaviours. Findings indicated that fear of crime functions on a number of levels of meaning and consciousness, which is directly related to personal experiences and constructs, lay knowledge of other people's experiences and types of information accessed. Despite a decade passing, similar findings were revealed by Franklin and Franklin (2009), who based their research on data from the 2003 Eastern Washington Crime and Criminal Justice System Survey. Results also indicated that gender, prior victimisation, social disorder and level of social integration played a significant role in perceptions of vulnerability and fear of crime.

2.5.3.4 Fear of Crime and Neighbourhood Attachment

In contrast, research by Oh and Kim (2009) explored the reciprocal effects of neighbourhood attachment and fear of crime in older residents. The authors used survey data from the *Project on Human Development in Chicago Neighbourhoods* in 1995, which gathered information form 8,782 citizens. The survey assessed perceptions of neighbourhoods, cultural values, local crime, social order and disorder. Analyses were consistent with earlier studies (Borooah and Carcach 1997; Hollway and Jefferson 1997; Pain 1995; Pinkerton James 1992), further verifying that while age continues to play a pivotal role in increasing fear of crime, this is co-dependent on attachment or non-attachment to the individual's neighbourhood.

Similar studies, while acknowledging earlier research findings, have focused more on the psychological aspects of fear in the older population, teasing out apparently commonly held but inaccurate beliefs of the pervasiveness of crimes against older people (Adams and Serpe 2000; Carcach, Graycar and Muscat 2001; Lindseay 1991; McKee and Milner 2000; Moore and Shepherd 2007; Oh and Kim 2009; Pain 2000; Sanderson 2006). For example, Sanderson (2006) argued that the consequences of fear were genuine and potentially severe for both the individual and society, as older people often attempted to lessen their anxiety by confining their activities, such as by not going out at night or altering regular activities to decrease their *perception* of risk. While these actions were aimed at ameliorating fear, the opposite often occurred. Such increases in fear frequently lead to a further decrease in social activities and community integration for example, neighbourhood attachment resulting in social isolation (Sanderson 2006).

Investigation of the relationship of social and community integration to fear of crime, specifically social and psychological factors affecting fear of crime and subjective wellness was the focus of research by Adams and Serpe (2000). Results indicated that social integration within the local community considerably reduced perceptions of vulnerability and fear of crime.

Age, gender, marital status, cultural ethnicity, socioeconomic status and health still played pivotal roles in the development of fear of crime, with physiological detriments significantly increasing many older people’s sense of vulnerability to crime (Carcach et al. 2001; McKee and Milner 2000; Pain 2000; Sanderson 2006). According to Carcach et al. (2001), financial, social and physical vulnerability were core elements of feelings of victimisation among older age groups, which consequently heightened perceptions of fear.

In addition, Graycar and James (2000), Carcach, Graycar and Muscat (2001) and trends from the Australian Component of the 2000 Crime Victims Survey (Carcach and Makkai 2003) indicated that even though older people were in the minority for violent victimisation, their fear of crime remained disproportionate to evidenced risk. This was attributed to feelings of vulnerability related to increasing age and a decline in physical strength and fitness.

2.5.3.5 Lifestyle Modification—A Response to Fear of Crime?

Lindseay (1991) adds a further dimension to these distinctions by suggesting that reduced exposure to risk in older age groups may *also* be influenced by general lifestyle adaptations in response to the normal ageing process, co-morbid health problems or psychological dysfunction (for example, dementia) rather than fear of crime and victimisation. The author asserts that crime surveys, though reliable, do not accurately address the specific concerns of older people, which has resulted in less accurate findings. Lindseay also suggests that in addition to reduced social exposure and exclusionary behaviour patterns, sensational media reporting of violent crimes intensified the perception of risk and fear within older age groups.

Lindseay's (1991) views regarding the influence of media are supported by James (1993), Grabosky and Graycar (1995), De Donder, Verté and Messelis (2005), Sanderson (2006) and Franklin and Franklin (2009). Sanderson (2006) also contends that sensationalism in media, be it print, radio or television, can negatively affect the older person's perception of crime, therefore leading to avoidance behaviour patterns that could exacerbate social isolation. Females were predictably more influenced by such reports due to an increased perception of vulnerability (Franklin and Franklin 2009; Grabosky and Graycar 1995), although it is noted that males may have tended to under-report their feelings. Law and order campaigns also affected older residents' perceptions of fear.

2.5.3.6 Social Law and Order Campaigns and Fear of Crime

Law and order campaigns, previous victimisation and physical environment, social identity, social exclusion and physical and social incivilities also played key roles in fear of crime (Pain 2000; Sanderson 2006) as did age-related disabilities. As Jackson (2004) and Sanderson (2006) point out, physical (graffiti, litter scattered around, untidy gardens, barricaded premises) and social incivilities (groups of unruly youth, homeless people sleeping on the street, inconsiderate neighbours) influenced people's perceptions of personal risk, leading them to believe that they were unsafe and that their environment was unstable, which could lead to withdrawal behaviours and social isolation.

Adding to the various conceptual frameworks of fear of crime is the concept of rationality and irrationality. Previous research by Lupton and Tulloch (1999) observed this phenomenon through a qualitative approach involving two case studies in which the authors examined whether fear of crime was rational or irrational. Their findings revealed that fear of crime was a complex and dynamic phenomenon interrelated with numerous life experiences (including previous victimisation, death of spouse and lay knowledge).

Behavioural responses to fear appeared similar to those reported in other studies (James and Graycar 2000; Sanderson 2006), including those undertaken over a decade before (Grabosky and Graycar 1995). These results highlight the need for further studies that may facilitate examination of the conscious and subconscious dimensions of fear of crime.

2.5.3.7 The Invisibility of the Aged in Isolation—Dying Alone

It has been demonstrated that media reports, particularly of crime, significantly influence people’s perceptions of personal safety and their attachment to their community. Ameliorative behaviours, such as disengagement from personal needs activities (grocery shopping, accessing money or health care) and social interactions, has seen an increasing number of older people living and dying alone in social isolation. In 1995, during a short but intense heatwave in Chicago (US), 700 residents died, most of who were ‘elderly’. Klinenberg (2001) investigated this tragedy, basing his research on accounts from ethnographic investigations in the affected localities. His investigation highlighted the significance of restrictive behaviour patterns related to fear of crime. Through the course of Klinenberg’s fieldwork, it was revealed that many socially isolated older residents relied on television and radio for companionship and, as such, their perceptions of crime and fear increased accordingly.

Other concerns previously discussed in this section were also mitigating factors in fear of crime. While these fears were largely based on ideas, information and images of visible degradation of public spaces and perceived hostile changes within neighbourhoods also played a pivotal role in increasing fear and social isolation. An investigation of newspaper accounts of dying alone (taken from the LEXIS–NEXIS database), which included the UK, Ireland, New Zealand, US and English speaking Thai Press, by Seale (2004), also provides evidence that sensational media reporting of violent crimes plays a significant role in fear of crime. Reports from the Japanese Times relating to the increase in unnoticed deaths and older people living and dying alone (Aoki 2010; Fukue 2010) reveal a disturbing continuance of these phenomena.

References to *'mini twister clouds of flies', 'flies, maggots and pupae crawling, sticking to windows', 'a bathtub one-third full of a dark reddish liquid … This is a dead lady's body fluid and skin'* (Aoki, Japan Times 2010) and *'die unnoticed and in two months all that is left is the stench, a rotting corpse and maggots'* (Fukue, Japan Times 2010) occupy eye catching positions in the newspapers. Reports of the stress of care giving to older family members ultimately resulting in the murder of the individual requiring care by younger family members are equally disturbing, further exacerbating fears and prejudices.

Australia has not been exempt from these issues, with newspaper reports (Braithwaite *Sydney Morning Herald* 2006; Stafford *The Age Melbourne* 2008) and a segment on the ABC 7:30 Report (2008) highlighting the ongoing occurrence of deaths of older people in Sydney and Victoria. Both newspaper reports discussed how the bodies of older people continued to remain undiscovered for weeks to almost a year. In one instance, the death was of a socially isolated older woman in New South Wales (NSW), the seventh in one month. Some bodies of older people have been left undiscovered for up to eight months (Braithwaite 2006). It is concerning to read that Stafford's report in 2008 holds many similarities to Braithwaite's report two years earlier. Stafford stated that, in 2006, 263 Victorians died at least two weeks before their bodies were discovered. In 2007, 283 NSW residents' deaths were reported to have gone undiscovered for at least 7 days.

The ABC 7:30 Report discussed concerns about the disintegration of local neighbourhoods and the ongoing need for community awareness programs to alleviate social isolation in the older population. These reports serve to underscore research undertaken by Klinenberg

(2001) and Searle (2004) and the disparity in government and council initiatives to address this pervasive and increasing problem.

Seemingly in opposition to the dearth of reports and previous research are the views of Kellehear (2009), who questions the veracity of these and the general social acceptance that dying alone is tragic. The author discusses the distinctiveness of loners, reclusiveness and loneliness in the context of prominent social perspectives, ethnographic-based habits and personal life choices. While it was acknowledged that fear was a significant feature of many older people’s lives, there was doubt concerning methods and appropriateness of research models to reflect the circumstances of dying alone more accurately. Furthermore, Kellehear contends there could be understandable and practical factors that underpin the desire to die alone. It is suggested that some people may simply lose interest in a society that has little to offer them, particularly if their friends and family play no significant role in their lives.

The continuing occurrence of ‘unnoticed deaths’ of older people serves to emphasise yet again the need for social policy and community-based programs and interventions aimed at addressing and alleviating social isolation and exclusion of older people within the community. News reports, though often sensationalised, can be useful in highlighting the fear and social isolation of older people who appear to continue to slip through the health care net of medical practitioners, allied health care workers, hospital services and welfare agencies. Further, the impact of cultural diversity, along with socioeconomic, demographic and geographic factors, must be taken into account and examined within the context of social isolation and access to health care.

The substantial literature reviewed demonstrates that fear of crime, degree of community attachment, media reports and perceptions of vulnerability and loneliness can influence everyday decisions made by many socially isolated older people subsequently limiting their ability or willingness to seek or accept assistance. It is evident that a paucity of research has investigated the impact these perceptions have on access to health care. Further, the development of avoidance behaviours can act as barriers for not only accessing health care but also other activities that ensure health and wellbeing. This is evidenced in decreases in nutrition and poor eating habits.

Linking fear to eating habits, a report by Graycar and James (2000) identified concern for personal safety often resulted in older people not venturing out alone, with such restrictive behaviour often resulting in physical neglect through unwillingness to shop for food or seek health care.

2.5.4 The Impact of Nutritional Status, Health and Eating Alone

Several overseas studies (McKie 1999; Payette and Shatenstein 2005; Sidenvall, Nydahl and Fjellström 2001; Wikby and Fägerskiöld 2004; Wylie, Copeman and Kirk 1999; Donini, Savina and Cannella 2003) have identified that the nutritional requirements of older people involve a complex interaction between individual health status, co-morbid states, psychological, cultural and sociological influences. These are discussed in detail in the next section.

2.5.4.1 Reduced Mobility and Dexterity and Access to Food Supplies and Suppliers

Mobility decrements and the effects on accessibility to food supplies were investigated by Wylie, Copeman and Kirk (1999). Twelve participants were recruited from a day centre for older people in Leeds and interviewed in a qualitative study focusing on food patterns and food consumption. A 24-hour recall for type of food and drink and time each was consumed was also included. Findings indicated that while some relied on relatives, the majority used public transport to access supermarkets and other smaller food outlets. Difficulties encountered included walking on uneven pavements, lack of pedestrian crossings, bus drivers moving on before they were properly seated and getting on and off buses. Difficulties encountered in supermarkets included having to bend for items situated on lower shelves or reaching up for items located on higher shelves, carrying shopping bags and pushing trolleys. Significant physical disabilities such as arthritis or angina also negatively affected this cohort. Ten participants reported that arthritis and associated tremors also caused difficulty in preparing meals, as they could not easily open jars, cut up food, handle or move hot foods in heavy pans or on serving dishes.

In addition to the physical burdens were the feelings of loneliness encountered after bereavement. Seven participants from Wylie, Copeman and Kirk’s study (1999) indicated that their eating habits had changed since the death of their spouse and included decreased motivation to eat, not wanting to eat alone, nibbling instead of eating proper meals, not wanting to cook, decreased desire to eat food once cooked and inability to cook. Therefore, exploring dietary practices of older people is significant.

In a larger Glasgow study incorporating rural areas, McKie (1999) interviewed 152 participants with the aim of identifying and exploring dietary practices of older people living in the community. The methodology incorporated both quantitative and qualitative data. General findings were similar to those of Wylie, Copeman and Kirk (1999), with some additional difficulties experienced by those living in rural precincts, such as cost and extended distances to food amenities. In this study, geographically isolated older people who also had mobility problems were further disadvantaged by the lack of public transport and the inability to walk long distances to such transport. More difficulties were encountered on the return journey, as they were physically burdened with groceries and other essential items.

2.5.4.2 Loneliness and Meal Fellowship

In further qualitative studies, Sidenvall, Nydahl and Fjellström (2001) discussed older Swedish women’s experiences of managing food shopping, especially by those who lived alone or who had recently been bereaved, while Wikby and Fägerskiöld (2004) concentrated on investigating appetite and willingness to eat. The importance of meal fellowship and its benefits should not be discounted, as it could act as a powerful motivator for increasing nutritional intake particularly in this vulnerable age cohort (Wikby and Fägerskiöld 2004). Wikby and Fägerskiöld (2004) found that mood and meal fellowship were among the most significant factors for nutritional intake, though personal values, a sense of wholesomeness and the eating environment were important. In addition, eating alone could have a significant negative impact on nutritional status and therefore overall health and wellbeing, particularly of socially isolated older people, who were more vulnerable to inadequate or inappropriate eating practices.

Additionally, the significance and impact of eating habits were apparent in an Australian study by Dermody et al. (2003). The authors investigated social isolation and poor nutrition in older people within a local community in Tasmania. Findings revealed a clear link between poor nutrition, loss of appetite and social isolation. Based on the findings of this study, community initiatives were developed to target socially isolated older people utilising volunteers to provide assistance with meals and transport to venues that provided both healthy meals and an opportunity for social interaction. Although this study did not address access and navigation of health care services, the success of the community-based initiatives imply that similar strategies could be employed to assist socially isolated older people in urban areas to access vital health care.

2.5.4.3 Physiological and Sensory Deficits Associated with Eating

Physiological and psychodynamic processes were also investigated by Donini, Savina and Cannella (2003) and Iizaka, Tadaka and Sanada (2008). The authors identified specific physiological sensory decrements associated with eating that were linked with poor nutritional status. These included but were not exclusive to olfactory and visual impairment, masticatory deficiencies, ill-fitting dentures, loss of dentition and prescription medications. The medically based model discussed by Donini, Savina and Cannella highlighted the interrelatedness of physiological factors (peripheral feedback signals, central feeding drive, throat dryness, masticatory efficiency) and psychological factors (loss of motivation to eat, depression, retirement, hospitalisation, bereavement, indirect self-destructive behaviour) underpinning malnutrition in older people. Those who were socially isolated were at greatest risk for inadequate nutritional intake.

The nutritional status of older citizens in Japan was investigated by Iizaka, Tadaka and Sanada (2008). The authors surveyed 130 community-dwelling residents aged 65 and older who were enrolled at Setagaya Senior College, a public recurrent school for the healthy elderly in Tokyo. Their findings were congruent with previous research undertaken by Wikby and Fägerskiöld (2004), Dermody et al. (2003) and Payette and Shatenstein (2005), further testifying that poor nutritional status was directly linked with depression, lower self-esteem, poor health attitudes and problems associated with meal preparation.

The literature discussed thus far has demonstrated that loss of spouse, decreased mobility, inadequate transport, changes to ways in which society accesses information and fear for personal safety can often act as precursors that ultimately lead to loneliness and depression. It is accepted that social isolation, loneliness and depression can affect any age group (Hall and Havens 1998; Tanner L1999; Rokach 2001; Victor, Scambler and Bond 2008). However, the increasing number of older adults living alone, in social isolation and with significant health problems appears to be the group most affected (Findlay and Cartwright 2002; Murray et al. 2006; Palinkas, Wingard and Barrett-Connor 1990; Routasalo and Pitkala 2003).

2.5.5 Depression and Social Isolation

Although depression can occur at any age, the literature reveals that socially isolated older people are particularly at risk (Alpass and Neville 2003; Freyne et al. 2005; Segal 2000). Age-related co-morbid health problems, decrements in mobility and ability to care for oneself, decreased social networks, loss of significant companionship and living alone are among the key factors that predispose older people to depression (Akhtar and Choi 2004; Andrews et al. 2003; Bird and Parslow 2002; Rajkumar et al. 2009; Russell and Taylor 2009; Steffens et al. 2005). These key features were the basis of Russell and Taylor's (2009) research, which was based on data collected through screening surveys of 10,000 households and 1,986 interviews of four major ethnic cohorts in Miami-Dade County. The authors investigated the effects of living alone between Hispanic and non-Hispanic people 60 years and older and the influences of gender, social support and physical disability towards the development of depression. Findings revealed that living alone had causal links to increased instances of reported depression in Hispanics living alone, while the significance of primary social networks was variable between the two groups, suggesting the influence of cultural variations and family ties.

Research by Rajkumar et al. (2009) revealed similar findings to other studies (Knipscheer et al. 2000; Freyne et al. 2005; Ron 2004; Steffens et al. 2005; Weyerer et al. 1995). Rajkumar et al. utilised a case-control design framework in conjunction with door-to-door surveys, recruiting 1,000 participants over the age of 65 years. Findings revealed that physical illness, hunger and poverty were strong correlates of depression in older people and precursors for social isolation. However, in contrast to the studies mentioned, female gender, increasing age and associative cognitive dysfunction were not significant influencers on, or causally linked to, depression. In addition, depressive disorders did not signify an increase in functional disability within the cultural socio-specific milieu of this population.

An earlier Australian study by Joubert et al. (2003) found depression in older people to be interrelated with social isolation, carer stress and significant co-morbid health issues that acted as barriers to effective access of community resources and health care. This research was conducted in Melbourne and focused on appropriateness of community-based care of older people who presented to emergency departments, usually in a crisis, in major hospitals. Initial findings revealed that the majority of depressed older people were living alone (44 per cent) with 29 per cent living with a primary carer but with minimal attention paid to linkages to community services. Although access and navigation of health services was not discussed, it can be postulated that these figures infer that many older people are not accessing health care appropriately for their needs and therefore increasingly present for medical care in emergency circumstances. The study was closely involved with an innovative health care strategy developed by St. Vincent's Health, which focused on establishment and enhancement of an integrated systems approach to service delivery.

These findings echo recommendations made almost a decade ago by Dennis and Lindseay (1995) in their review of British government policy concerning depression and, particularly, suicide in older people. General trends indicated that males 75 years and over had the highest incidence of suicide, although older people of Indian ethnic origin were reportedly lower. Of significance, the authors found that older people who committed suicide had contact with a primary health care worker four weeks preceding the event. Improved educational opportunities for General Practitioner (GPs) and primary health care providers, with easily accessible linkages for appropriate and timely treatment, were among key recommendations.

Similar findings from research conducted by the Royal District Nursing Service Helen Macpherson Smith Institute of Community Health were evidenced by Nunn (2003), who surveyed 78 primary health service providers in Melbourne's south eastern suburbs. The

12-month study found that 70 per cent of older people exhibited positive indicators for depression. However, only 10 per cent were receiving professional care. Nunn concluded that the main barriers to older people getting support for their health problems were social isolation, ill health, disability and a lack of knowledge about where to find help. There was no evidence of investigation into how older people accessed necessary health care therefore, revealing a gap in the literature that this study has the potential to fill.

Additional research findings by Segal (2000) indicated that depressive illnesses precluded many older individuals from actively seeking health care intervention. These findings were closely associated with those established in a later study by Copeland (2002) who also found depressive disorders in older people to be strongly linked to social isolation. Copeland stated that 25 per cent of the older population in America are socially isolated, with figures expected to rise dramatically over the next several decades. Inadequately diagnosed depressive illness in older people could increase social isolation, as these people consequently utilise health care providers less frequently.

Copeland (2000) also estimated that less than 25 per cent of depressed older people received appropriate health care, with this cohort being the highest group to successfully complete suicide. Preventive and ameliorative measures such as patient education, addressing lifestyle issues, nutrition, physical activities, social support and appropriate environmental lighting to combat and prevent development of situational depression were advocated. However, *how* these strategies would be instigated, facilitated and evaluated was not discussed. Nor did either study explore issues associated with access and navigation of the health care system by depressed or socially isolated older people, a gap that this current study will seek to fulfil.

Social networks for older people were also found to be a significant factor in delaying the onset of dementia or Alzheimer's disease (Mann 2000). A longitudinal population-based study by Fratiglioni et al. (2000) focused on the effects of availability, contact with and perceived adequacy of social and support resources. Twelve hundred and three people aged 75 years and older and living in Stockholm (Sweden) were followed for a three-year period. No participants had dementia at the commencement of the study. At the completion of the study, 176 participants were diagnosed with dementia. Findings strongly suggest that participants who had few close social ties had a 60 per cent higher risk of developing dementia than did their socially active counterparts.

Adding to the growing body of evidence, Fratiglioni et al. (2000) suggested that for many years, most Western countries have given priority to home care health services and paid less attention to social needs, which has led to many old people living alone in socially isolated conditions for most of the time. Declining health and decreasing ability to seek health care interventions independently was purported to marginalise this group further.

Access and navigation of health care needs were not discussed in Fratiglioni et al's (2000) study. However, findings indicate that the impact of social isolation and development of dementia in some participants played a vital role in the older person's ability to instigate or access necessary personal health care interventions. Age-related hearing and visual losses also play a vital role in the development of depression and social isolation (Verstraten et al. 2005). The impact of hearing and vision loss is discussed further in the following section.

2.5.6 Hearing and Visual Impairment

In addition to the problems outlined so far, many people suffer hearing and vision loss during the ageing process, which can cause loneliness, withdrawal from social, vocational and cultural activities, reduced self-esteem and changed relationships with family and friends (Christian, Dluhy and O'Neill 1989; Dugan and Kivett 1994; Jones, Victor and Vetter 1984; Mulrow et al. 1990; Verstraten et al. 2005). In addition, undetected, ineffective or untreated hearing impairment may affect access to and delivery of health care services.

For their investigation of the effect of hearing impairment on health service utilisation, Green and Pope (2001) utilised data contained in medical health records of 1,436 randomly selected patients aged 65 years and older from the Outpatient Utilization System developed by the Kaiser Permanente Center for Health Research (Green and Pope 2001, p. 37). Findings indicated that hearing-impaired older people, though likely to make additional visits to their health care professional, did not subsequently make more contact than those who were non-hearing impaired. Possible explanations included that patients did not seek or did not receive appropriate care or that overall, hearing impairment did not require substantial increases in health care services. The authors contended that many older people appeared to accept hearing loss as an inevitable consequence of the ageing process. However, if they remained reluctant to seek advice or they were not afforded appropriate assistance, such behaviours could contribute to detrimental sequelae such as social isolation and depression. Research derived from Tay et al. (2007) reported similar findings to Green and Pope (2001). However, Tay et al. also included visual impairment in their investigatory criteria for hearing loss. Their study was based on interviews (which included a standardised questionnaire) of 284 frail older people aged 65 years and older, living in Sydney, Australia. Results indicated that moderately to severely vision-impaired older people had a significantly increased likelihood of health service utilisation. However, those with moderate to severe hearing impairment did not.

The occurrence of social isolation related to vision loss in older people with minimal social networks was not discussed in Tay et al's (2007) study. However, findings by Verstraten et al. (2005) indicated that low levels of social support most likely led to increased incidents of loneliness. Further research by Kramer et al. (2002) focused on the effect of hearing deficits in association with chronic disease states on socio-emotional characteristics of quality of life in older age. This mixed methods study recruited 3,107 people between the ages of 55 and 85 years from three culturally distinctive geographical regions in the Netherlands. Findings correlate with those mentioned in previous studies (Christian, Dluhy and O'Neill 1989; Dugan and Kivett 1994; Jones, Victor and Vetter 1984; Mulrow et al. 1990) and suggest that hearing-impaired older people demonstrated a significant increase in depressive symptoms, loneliness, anxiety and social isolation, with associated decrements in significant social networks.

Significant hearing loss coupled with chronic disease conditions could result in increased physiological effects, which negatively affect the older person's ability or willingness to participate actively in social interaction. Such exclusionary or avoidance behaviours were believed to increase the potential to develop social isolation. These results underpin the need for accurate identification and adequate and timely monitoring of people with hearing loss. Further, anecdotal stories abound regarding older people (usually a relative) who refuse to wear a hearing aid despite obvious difficulties with communication, often resulting in significantly decreased social interaction. Garstecki and Erler (1998) contended that non-use of hearing aids was related to stigmatisation, with the incidence of female non-use greater than male non-use. Other factors to consider with non-use of hearing aids were psychological control and ego strength. The authors found that males were more accepting of hearing loss and found hearing aids less stigmatising. The correlation between gender use and non-use and incidence of social isolation were not investigated by the authors.

An audio-specific study was developed by Gates et al. (2003). This study compared two screening methods used to assess hearing loss in older people. In a cross-sectional study, 546 older people were tested using both screening methods. The authors suggested that screening increased the probability of identifying disorders and, as such, that it should be used routinely in health assessment. Although this study focused specifically on hearing impairment, similar screening tools could be utilised by health practitioners to assess for psychosocial risk factors. These may include generalised beliefs in ageism and perceptions of invisibility.

The evident diversity of cultures intrinsic in societies today needs to be incorporated into all aspects of health care policy and interventions, whether investigating social isolation, fear of crime or hearing loss or other issues pertinent to the ageing population. Undeniably, research has shown that cultural beliefs and attitudes to health, social networks and the ageing process influence older people’s perception of themselves and their place in society (Lechner and Neal 1999; Lowenstein and Bengtson 2003; Messimeri-Kianidis 2007; Schröder-Butterfill and Marianti 2006). Health initiatives and policies targeting ageing populations are already in place in many countries but there are those who are unable to address these problems adequately due to lack of internal resources.

2.5.7 Cultural Diversity and its Influence on Perceptions of Loneliness, Social Isolation and Health

A significant amount of research into social isolation of older people has been conducted within a Western paradigm (Adams, Kaufman and Dressler 1989; Grundy 2006; Howse, Ebrahim and Gooberman-Hill 2005; Klinenberg 2001; Kobayashi, Cloutier-Fisher and Roth 2009; Steffens et al. 2005; Tanner D 2007). However, research involving family care giving of older people in Botswana (Shaibu and Wallhagen 2002) illustrated the significance of, and reliance on, communal societies and the role that culture and families play in the care of older people. Care of older people in Botswana is solely a family responsibility. This study investigated the role particular family members play in providing care to their elders and it is mentioned in this section for two reasons. Firstly, there is a paucity of knowledge concerning enduring care of older people in various non-Western countries. Secondly, also according to Shaibu and Wallhagen (2002), unlike in many westernised countries, in Botswana there are no government-run or funded programs to support family caregivers or provisions for care of older people within an institutional framework such as nursing homes. Care for older family members is traditionally accepted by female family members. However, this is largely dependent on time and availability, meaning that care given in many instances remains meagre.

While loneliness and chronic illness play a significant role in social isolation, their interpretation can be varied depending on cultural beliefs (Charmaz 1983; Hall and Havens

1998; Peters 2004; Rokach 2001; Routasalo and Pitkala 2003). Although applicable to all age groups, the cohort most significantly affected is older people (Ageing Research Online 2009; Peters 2004; Rokach 2001; Rokach, Orzeck and Neto 2004; Tanner L 1999; Tanner D 2003, 2007; Victor et al. 2005; Victor, Grenade and Boldy 2005). Despite cultural disparities, the debilitating effects of social isolation are clearly linked to depression, suicide, hostility, alcoholism and poor self-concept (Rokach, Orzeck and Neto 2004), which spans across cultures in later life.

In seeking to explain these phenomena, Rokach, Orzeck and Neto (2004) examined how cultural influences affected the ways in which older people coped with loneliness. Their research involved 36 participants from Canada and 105 from Portugal, with ages ranging from 60 to 83. Participants were given a questionnaire that investigated the positive strategies employed to cope with loneliness. Results revealed that the cultural milieu does influence the way in which older people deal with loneliness, particularly their use of reflection and acceptance, distancing and denial and religion and faith. Of significance perhaps, was that no gender variations were found in either Canadian or Portuguese culture. These results extend earlier findings by Hollway and Jefferson (1997), who asserted that social prejudices and fear of crime added to the older person’s reluctance to interact with others *irrespective* of cultural influence, exacerbating feelings of loneliness and increasing social isolation.

Similar comparisons were made by Yeo (1997) of white Americans and those from Eastern Europe, the Middle East, Japan and the Caribbean experiencing poor health and living in socially isolated circumstances during examination of the cross-cultural care of older adults. Emphasis was placed on individual health beliefs since perceptions of health and illness are not universal. Often older people approach the clinical encounter with culturally entrenched descriptive models of illness, many of which are not part of the Western health care system.

Findings by Yeo (1997) underscored the need for trans-cultural nursing to acknowledge the patient's perspectives on their illnesses. This is particularly appropriate when dealing with socially isolated older people, as their cultural and experiential belief systems need to be accepted with nursing and allied health interventions incorporated into what is culturally acceptable and appropriate.

Lam (2005) examined social isolation and health care utilisation in the context of cultural diversity in Melbourne, Australia. Findings revealed that many migrant older people (Vietnamese, Greek and Italian) had reverted to their native language, thereby creating barriers to communication and access of readily available health care services and increasing social isolation in the absence of significant family networks or culturally appropriate support. Interpreter services were an essential component of health care delivery. However, these were not always obtainable. These studies focused on cultural diversity in socially isolated older people and its implications for health care providers. However, access and navigation of this marginalised cohort to health care was not explored.

Several notable works by Victor et al. (2000, 2002, 2003, 2004) Victor, Grenade and Boldy (2005) and Victor, Scambler and Bond (2008) have questioned the current validity of many long-held social and academic beliefs, asserting that loneliness in older age is not necessarily as prevalent as some research indicates (Hall and Havens 1998; Hollway and

Jefferson 1997; Peters 2004; Rokach 1999). Further, questions have been raised as to the accurateness of participant responses to self-rated surveys and interview questions regarding loneliness and isolation. Although Victor, Scrambler and Bond (2008) believe that respondents may temper their answers because of the stigmatising connotations of being identified as lonely or socially isolated; earlier work by the authors (2000, 2002, 2003, 2005, 2004) omitted social constructs of embedded culture within their British-based studies. However, these limitations were identified as being a significant consideration in assessing an individual's understanding of loneliness and social isolation.

Subtle cultural differences within predominantly Caucasian Western societies should not be dismissed or viewed as a generic whole. Victor et al.'s widely based British studies incorporated responses from people with unidentified cultural backgrounds, which may have further influenced understanding or perceptions of loneliness and social isolation. The authors acknowledged that the older person's social situation and previous life experiences needed to be explored to gain a more complete understanding of the complexity of the interrelatedness of these phenomena. These studies identified that cultural beliefs and attitudes influenced adaptive behaviours towards loneliness and social isolation, which may be positive or negative in nature. Also identified were potential tensions and conflicts arising from attempting to adhere or assimilate to Western conceptualisations, which required further investigation.

We have seen that social isolation and loneliness and even fear of crime, is not exclusive to Western society but spans all cultures and geographic locations (Adams, Kaufman and Dressler 1989; Cattan et al. 2005; LaVeist et al. 1997). Socially isolated older people can be found in densely populated urban areas and living in rural and remote situations

(Klinenberg 2001; Wickramasinghe 2002), with widowhood with its own cultural constructs being a significant contributing factor affecting both males and females (Carr 2004; Lee and DeMaris 2007).

Research discussed thus far incorporates studies from Australia and overseas that encompass a variety of cultural settings. In Australia, with its multi-cultured population, these issues are particularly significant. The conferences *A Mosaic of Culturally Appropriate Responses for Australian Culturally and Linguistically Diverse Background Elderly People 2007* and *Social Inclusion for Multicultural and Faith Communities 2008* (chaired by Messimeri-Kiandis from the Federation of Ethnic Communities' Councils of Australia) emphasised the need for the social integration of ethnic minority groups, especially of older people. This call for integration must not overshadow sensitivity to the real differences that exist in how various people view illness and appropriate care.

Discussion highlighted gaps in service provider care in which specific needs of new and existing older migrants were not met. Increased government-based funding and the appointments of bi- or multilingual workers were identified as priority issues. Ethno-specific community-based organisations play a pivotal role in social integration, especially of older people, whose traditional support systems may be increasingly eroded by assimilation and diversification of younger family members, as they increasingly adopt the norms of Western society (Messimeri-Kiandis 2008). Studies discussed thus far comprise both Australian and overseas research and incorporate a diversity of cultures. In addition to culturally linked barriers, the effects of ageist attitudes both at the micro and macro level have been indicated as influencing the development and perpetuation of social isolation in older people.

2.5.8 Ageism and Ageist Attitudes

The pervasiveness of social isolation in older people has been well documented (Angus and Reeve 2006; Bytheway and Johnson 1990; Hagestad and Uhlenberg 2005; Hensher 2006; Kobayashi, Cloutier-Fisher and Roth 2009; La Veist et al.1997; Lookinland and Anson 1995; Machielse 2006; Minichiello, Browne and Kendig 2000; Russell and Schofield 1999; Thompson and Thompson 2001; Victor et al. 2003), with many researchers asserting that ageism has played a significant role in perpetuating social discrimination based on biological constructs and age segregation (Angus and Reeve 2006; Lothian and Philip 2001). Bytheway and Johnson (1990) investigated definitions and perceptions of ageism, characteristics of ageism, influences of racism and sexism and the relatedness of biological ageing. The authors identified relationships between ageism and societal mores that indicated that older people cease to be viewed in the same manner as when they were younger, or that they become somehow inferior as they become older. Further, stigmatisation of older people, social denigration and being viewed as a ‘different species’ was also revealed. In a similar study of ageist attitudes that focused on health care personnel, Lookinland and Anson (1995) surveyed 82 nurses working in a hospital setting as well as 68 high school students enrolled in a regional health career occupational program. This California-based study identified varying stereotypical views in both groups, with the student group expressing significantly more unfavourable attitudes to older people. Although access to health care was not the focus of this study, findings suggested potentially negative implications for care of older people and a need to modify curricular focus from the technologically based acute setting to include subacute home-based nursing care.

In an effort to ascertain the prevalence of ageism, Palmore (2001) developed an 'ageist survey tool'. Palmore's study, based in Durham North Carolina (US), involved 84 respondents aged over 60 years who completed a 20-question survey. Results demonstrated that ageism was prevalent in the cohort with over 77 per cent testifying to experiencing one or more incidents of ageism. Palmore (2001) designed the survey to identify specific instances of ageism within the micro-personal and wider macro-socioeconomic context. However, it is regrettable that no indicators relating to access to health care were incorporated into the survey. These may have provided valuable insight into the difficulties experienced and barriers encountered by socially isolated older people in navigating the health system and accessing community-based programs.

Experiences of ageism in terms of social integration and acceptance were a component of several key factors in Australia-based research by Minichiello, Browne and Kendig (2001). This qualitative study incorporated interviews of 18 people aged between 65 and 89 years. Perceptions of ageism or 'oldness' and the language used to describe this phenomenon were also discussed. Findings revealed that many older people accepted the concept of oldness, which did not necessarily relate to chronological age but rather to how they perceived themselves and their position in society. Once categorised as 'old', they closely aligned themselves with the negative stereotypical images of older age. Access to the broader physical environment, income and fear of becoming a burden were also investigated. Further, interactive ageism was identified as a major construct whereby informants recognised discriminatory practices such as jokes about growing old but were still able to accept the humour intended.

Conversely, ‘sageism’ was viewed as ‘positive ageism’ whereby older people felt respected when perceived to be valued by others. Instances of being asked their opinion or being listened to were recounted. Of note were informants’ negative experiences with health professionals. These were felt to be due to ageist attitudes that resulted in ameliorative behaviours by the older person to accommodate these perceptions. To what extent these behaviours affected access to health care was not examined, though there was evidence of self-segregation actions by some of the informants.

Social separation and segregation have also been identified as contributors to ageism. Hagestad and Uhlenberg’s (2005) American and Netherlands data-based study incorporated investigation of the social structuring of age, the nature of age segregation, separation by age and societal level, institutional age segregation and spatial age segregation. The authors identified the meso-level as an intermediate level which incorporates communities or neighbourhoods. This level deals with divisions within societies, how they are broken apart by income and ethnicity, social networks and meaningful interactions as an essential component of the social separation–ageism cycle. The authors further proposed development and evaluation of innovative programs designed to promote cross age interaction. Although issues of access and navigation of health care institutions and community service providers were not discussed, the potential health benefits arising from increased social interaction and social inclusion, particularly for socially isolated older people should not be overlooked.

Such constructs can be seen in Thompson and Thompson (2001) and Angus and Reeve’s (2006) research into positive ageing, which focused on the interactions and influencers of ageism across cultures and societies. Thompson and Thompson focused on empowerment of older people and the importance of shared responsibility in the planning and delivery of health care. The traditional medical care model was compared to more modernistic concepts of ‘care for the elderly’ and empowerment models. The pivotal role of social workers as facilitators and enablers within the constructs of these modern paradigms were highlighted. The main thrust of Angus and Reeve’s research was to foster awareness in both academics and health care providers of the effects of long-held traditional and stereotypical attitudes towards ageing and the ensuing barriers to ‘ageing well’. Seen as a global issue, the authors presented ageism as the ‘ultimate prejudice, the last discrimination, and the cruellest rejection’ (Angus and Reeve 2006, p. 139), asserting that such stereotypy encompasses broader cultural practices and, as such, influences policy makers and acts as a social determinant of health. New paradigms involving how society views ageing and the morbidity associated with dependency and autonomy were examined. It is hoped that armed with these insights academics and policy makers can begin to forge a better understanding and a more positive social perspective of the ageing process.

2.5.9 Social Isolation and the Impact of Trivial Events

In Scotland, approaching social isolation from a somewhat different perspective, Murray (2001) investigated the phenomena of ‘trivial events’ in the older person’s life. The study examined the relationship of a series of inconsequential events that, over time led to loss of independence and coping abilities in older people. It was acknowledged that major life events cause loss of independence in some people whereas in others, a more subtle process of minor mishaps could lead to the same results. The study discovered that older people often experience functional difficulties in coping with trivial events that become of major significance to them, resulting in increased loneliness, isolation and depression. However, the relationship between this phenomena and its effect on access to health care providers was not explored. Building on this evidence, Newal et al. (2006) investigated occurrences of trivial events in terms of ‘daily hassles’. Difficulties with everyday living such as unscrewing jars, minor home maintenance, washing curtains and changing light bulbs were identified as precursors for feelings of dependency, distress and anxiety. Although these events were not perceived as problematic on their own, the *accumulation* of these events degraded resilience to the point that the older person felt they could no longer cope.

Significant events such as death of spouse and relocation of family members and friends escalated the effect of these phenomena, leading to social isolation and depressive states. Further, Newal et al. (2006) argued that cumulative trivia need to be recognised as a multifaceted construct that encompasses psychosocial, cultural, historical and demographic aspects of the older person’s life and that qualitative research methods need to be utilised to further explore these events from within a phenomenological paradigm to more effectively influence social policy.

The inclusion of trivial events in this section is used to highlight the effect of everyday difficulties experienced by many older people and which socially isolated older people find increasingly difficult to cope with. Ability to access necessary health care needs to be explored in-depth to gain further insights into how trivial events can be better managed by this cohort. Evidence provided thus far in this review of the literature has established that social isolation of older people is a complex issue encompassing biological, physiological, social and economic factors. This phenomenon, which spans Western and non-Western countries as well as diverse cultures, is a global issue that will now be explored.

2.6 Social Isolation of the Older Person—A Global Issue

Social isolation of older people is clearly a global phenomenon, with extensive research having been undertaken in the US (Cattan et al. 2005; Ham 2002; Russell and Taylor 2009; Steffens et al. 2005; Ward 2000), Europe (Wenger 1997), the Netherlands (Knipscheer et al. 2000), Sri-Lanka (Wickramasinghe 2002), India (Rajkumar et al. 2009), Germany (Dallinger 2002), Slovenia (Domajnko and Pahor 2004), the UK (Andrews et al. 2003; Christiansen and Roberts 2005; Dennis and Lindesay 1995; Greaves and Farbus 2006; Tanner D 2001, 2003; Victor et al. 2002), Ireland (Freyne et al. 2005), Botswana (Shaibu and Wallhagen 2002) and Australia (Findlay 2003; Peters 2004; Reid 1994; Warburton and McLaughlin 2005). These studies have produced similar findings, despite the varying perspectives and focuses of individual researchers and their methodologies.

Of particular note is an evaluation article by Greaves and Farbus (2006), which discusses findings of their comprehensive UK study undertaken in 2005 incorporating the Upstream Healthy Living Centre. The authors investigated the processes and outcomes of a health care initiatives program to promote health and quality of life in a socially isolated older population. The Upstream Healthy Living Centre in Mid-Devon was established to address social isolation in the older population through the promotion of creative, social and leisure activities. Greaves and Farbus state that, as the proportion of older people increases, more are living alone. Their research findings indicated that 12 per cent of people over 65 felt socially isolated. Social isolation and feelings of loneliness are consistently associated with reduced wellbeing and quality of life in older people. Depression in particular is associated with social isolation and affects approximately 1 in 7 people aged 65 and older.

Before the introduction of the Old Age Pension in 1996, older people were the largest cohort of recipients in the 'Destitute Program' in Botswana. The pension provided a small amount of government support for those identified as being too poor to purchase food, clothes and shelter (Shaibu and Wallhagen 2002). The subsequent extension of this program reflected the disintegration of informal arrangements of shared support and increasing poverty. The abandonment of familial support was believed to be due to an increase in rural to urban migration, thus further depleting traditional extended family roles and leaving older people more vulnerable in terms of their physical and emotional needs (though these were not specifically discussed).

Findings revealed that participant caregivers were very poor, with few employed at a formal job (21 per cent). Forty-one per cent were occupied in subsistence farming or were homemakers (21 per cent). Family poverty and almost non-existent resources were of major significance in attempts to care for elders, as was appropriateness of intimate care and gender roles. Assistance from family members was considered acceptable for elder care. However, health care from outsiders or government handouts were perceived as stigmatising and therefore avoided by many families (Shaibu and Wallhagen 2002).

The concept of nursing homes was also considered an unacceptable option, so the females of the family took on the role of caregiver rather than the males. In the absence of daughters or younger female siblings, wives took on this role. There were many instances in which 'care giving' involved very short informal visits with members of the family not being in a position to spend time, supply food or assist financially towards the needs of the parent or grandparent. The significance of this study lies within broader cultural, socio-specific and political precincts. Despite the seemingly paucity of government assistance to enable access to health care needs, the stigmatising effects of utilisation of such services precluded its acceptance by those most in need.

In Germany, Dallinger (2002) investigated the effects of demographic development and political culture surrounding quality of elder care within the family. The author contended that Germany had one of the largest proportions of older people in Europe, which had significantly increased the need for care giving. Formal care and family care were discussed in conjunction with barriers erected by social policy and cultural norms. Once again, findings revealed that women assumed the majority of care-taking roles, with decisions involving withdrawal from the workforce weighted by a stronger sense of family ‘duty’.

Also discussed was the establishment of Care Insurance in 1996 by the German Welfare State. This legitimisation for financing care of those requiring social assistance resulted in formal provision of services or cash benefits for the older person to pay for a private carer. However, there were significant limitations based on level of need. Therefore, private resources were still required to guarantee adequate care of frail, older people. Summative findings suggested that financial incentives were aimed primarily at assisting caregivers by enabling them to provide additional formal care, thereby lessening personal burden and the need to disengage from the workforce. Social isolation, loneliness and depression were not the focus of this study. Rather, the focus was on factors affecting and influencing care of older people within the German population, such as government-based social policies, intergenerational relationships and cultural norms.

Contrary to findings by Shaibu and Wallhagen (2002) in their study of family care giving of older people in Botswana, German caregivers were not adversely influenced by stigmatisation of accepting government assistance, instead using this financial aid to augment their practices of care. It is suggested that further research, focusing on the experiences of older people could identify and evaluate the efficacy of such shared care arrangements.

As Rao, Warburton and Bartlett (2006) and Warburton, Bartlett and Rao (2009) assert, health and social needs of diverse cultural groups and sub-groups may be unmet due to barriers such as language differences, financial constraints and difficulties experienced through the migration process. Evidence from their 2006 study indicates that access to health care services later in life becomes more complex, requiring adaptive approaches that are culturally aligned to meet these needs effectively.

It has been demonstrated that acceptance of health care is dependent on a number of socio-cultural and socioeconomic factors (Sax 1993). As the diversity of Australia's multicultural population grows, so does the need for culturally specific health care interventions. These can facilitate and promote access to health needs, particularly from older people who are at risk of social isolation.

2.7 Attempts at a Solution

2.7.1 The International Arena

Averting further development of and alleviating current social isolation and loneliness among older people has been the topic of much research (Cattan et al. 2005; Findlay and

Cartwright 2002; Reid 1994; Wegner 1997), particularly over the last decade, with policy makers attempting to ameliorate these ongoing and pervasive phenomena by developing community-based intervention programs. However, concern continues as to the efficacy of these programs (Cattan et al. 2005; Findlay 2003; Sabir et al. 2009), as the reported incidences of social isolation and its sequelae continue to be problematic for health care providers and policy makers.

Canadian and US-based research undertaken by Cattan et al. (2005) utilised data from quantitative outcome studies between 1970 and 2002 in all languages. Findings revealed that group peer support appeared the most effective strategy for reducing social isolation. Home visits proved helpful but only if contact was continued on a regular basis. Telephone and one-to-one support services, most commonly provided at the community level, were found to be consistently ineffective for reducing social isolation or loneliness, though reasons for the failure of these interventions was not provided.

In a UK rural-based study, Greaves and Farbus (2005) investigated interventions by the Upstream Healthy Living Centre. Mentors worked closely with participants, providing exercise and cultural activities with an emphasis on social interaction. Group activities directed by mentors who also provided telephone follow-up on a regular basis proved the most successful, thus providing additional evidence along with Cattan et al. (2005) that this type of community intervention is worthwhile in combating depression, loneliness and social isolation.

Investigating care of older people in Germany, Dallinger (2002) found that the majority of care remains within the family on an intergenerational basis and continues to primarily involve women. In recent years, increased participation in the workforce by women has been offset by the establishment of ‘care insurance’, which provides some financial assistance though a legitimate institution rather than the more stigmatising social assistance schemes. However, despite these interventions, Dallinger concludes that a significant portion of care of older people remains the responsibility of the family.

Acknowledging the difficulties in categorising the more personal constructs of loneliness and social isolation, findings from British-based researchers (Victor, Grenade and Boldy 2005) suggest that innovative methods are required by project developers to incorporate the myriad of contextual influences necessary to increase the efficacy of interventions. These influences include culture, past experiences, attitudes, socioeconomic status and demographic development (Adams, Kaufman and Dressler 1989; Dallinger 2002). Implementation of such health initiatives needs to be grounded in research and followed up with appropriate evaluative processes.

An example of one such health initiative can be seen in research undertaken by Sabir et al. (2009). The authors investigated the discourse of a research-to-practice consensus workshop, evaluating both the research priorities and the practitioner-based suggestions regarding social isolation of older people. The results of this New York (US) based study highlighted the paucity of evidence of *effective* community-based interventions to reduce social isolation, particularly in homebound socially isolated older residents. It advocated further, broader development of research initiatives to address this problem more effectively. In addition, Sabir et al. (2009) discovered that research-based interventions had focused only on ambulatory older adults rather than targeting homebound older people that were already socially isolated. Further, disparity between practitioners and research priorities were highlighted, with the apparent success of group-based interventions being seen as therapeutic only for those who were ambulatory. In contrast to these working models, practitioners advocated one-on-one interventions, arguing that these would be more beneficial to those who could not access community-based venues. The authors also argued that *prevention* of social isolation was more beneficial to the greater majority of older adults in the long term and believed this could be accomplished through intentional relationship building between practitioners and researchers in the development of community and home-based interventional programs.

2.7.2 Local Brisbane Metropolitan Area

Research continues to highlight the significant impact of changing interpersonal relationships within the family, with traditional caregiver models being replaced by community-based health care packages delivered by professionals. Australian-based research by Gray and Heinsch (2009) centred on the changing caregiver role of women from a feminist perspective. Evidence demonstrated the growing trend towards community-based care regimes, which have led to the further growth of informal care, with neighbourhood services providing assistance with daily needs such as grocery shopping and domestic duties.

In a continuation of endeavours to address the ongoing issue of social isolation in the older population of Queensland, the Ministerial Advisory Council for Older Persons (MACOP) developed a model called the *Cross Government Project to Reduce Social Isolation of Older People*, which continues to be managed by The Seniors Interests Unit (SIU) of the Department of Communities. The aim of this project was to determine the foremost practice models utilised to reduce social isolation among older people. Agencies providing support in the project included:

- Australian Government's DVA
- the Home and Community Care and Mental Health units of Queensland Health
- Queensland Transport
- the Australasian Centre on Ageing
- SIU—Department of Communities
- MACOP
- Multicultural Affairs Queensland—Department of the Premier and Cabinet
- the Aged and Community Care Reform unit of Queensland Health
- the Office for Women—Department of Local Government and Planning
- Australian Government Department of Health and Ageing

The project incorporated five phases including a report by the Australasian Centre on Ageing (2002) based on an extensive literature review by Cartwright and Findlay (2002), research analysis, identification of pioneering approaches and, finally, the implementation of demonstration models in 2004 and thereafter. It was anticipated that the range of proposals would address personal, societal, district and environmental factors. In 2007, the project was in phase four, which entailed an updated literature review (Warburton and Lui 2007) detailing social isolation and loneliness in older people, with the Evaluation Report of Demonstration Projects released in 2008. Phase five, involving dissemination of information, was completed and a report detailing Best Practice Guidelines was offered in 2009 (Queensland Government, 2009b). Five organisations were granted funding to implement programs to reduce social isolation of older people: Brisbane City Council ($85,000 with an additional $30,000 for 6-month extension), Hervey Bay Council

($74,000), Fitness Queensland Association ($40,000), Greenvale State School Parents and Citizens ($46,000) and Multicultural Development Association ($55,000 plus an additional $20,000 for six-month extension). Phase four incorporated a number of demonstration projects that would build on the previous three phases.

The findings were expected to assist policy makers to improve initiatives to decrease social isolation. Phase five concerned the distribution of information about ideal practice standards that prevented or minimised social isolation in the older population. In their report on the findings from the evaluation of the demonstration projects, project phase four of the *Cross Government Project to Reduce Social Isolation of Older People,* Bartlett et al. (2008) identified that group-based activities were more effective for decreasing social isolation of this cohort. The chief objectives of the projects were to develop appropriate, sustainable community-based programs that addressed the issues identified. The authors report focused on findings from the evaluation of three demonstration projects:

1. Seniors Connecting—based in Greenvale and classified as rural/remote
2. Connecting Points/Connecting People—based in Hervey Bay and classified as regional
3. Culturally Appropriate Volunteer Services (CAVS)—based in Brisbane CBD

Overall results indicated that the three initiatives had some success in reducing social isolation and loneliness. The authors acknowledged methodological variables, such as minor changes to original wording of survey questions, lack of training and supervision of people collecting data and staff expressing personal views on survey forms rather than those of the participants, as influencing the outcomes, which raises concerns about the validity of their results. These projects were informed by an extensive literature review conducted by Findlay and Cartwright (2002) as part of the report for the *Seniors Interest Branch and Ministerial Advisory Council on Older People, Queensland Government.* The accessibility of health care and ease of navigation through the health system for this cohort was not examined in these projects.

In addition to these initiatives, the GP Link newsletter (April 2006, p. 1) highlighted visits to GPs by community-based health care organisations. These visits were an initiative by GP Partners and aimed to inform GPs and practice nurses of the various services offered to individuals in the community.

This 12-month program was funded by Queensland Health and incorporated visits to GPs by Blue Care, St. Luke’s Nursing Service (now known as Spiritus), Ozcare and Adult Community Health Services. The health care agencies informed the GPs of the wide scope of services offered and the referral procedures to access their services. Services available included home and community care, in-home respite, social support, community care packages and support programmes for those with mental health issues. While this is not an exhaustive list, the services offered were especially relevant for socially isolated older people in the community and were further enhanced by a team of volunteers who assisted in all areas of social support. Blue Care provided similar services with a focus on assisting the frail/aged within their home environment.

In addition, the Extended Aged Care Home (EACH) and Extended Aged Care at Home—Dementia (EACH-D) Packages provided assistance with all areas of clinical health care, access to allied health services, domestic assistance, home safety and palliative care. The EACH packages continue to be subsidised by the Australian Government. However, recipients are required to pay a nominal fee depending on the services required. Individuals are invited to self-refer, or may be referred by family, friends, carers, their GP or hospital. North East Community Care provides many services specific to the frail aged in the community. These include centre-based and in-home day respite, social support, community transport scheme, in-home occupational therapy, Veterans home care program and information and resource library.

The Chermside and District Senior Citizens Centre Inc. (Burnie Brae Centre) is a not for profit charitable organisation. It provides a variety of social, educational, leisure, transport and community-based services that focus on the needs of fit and frail aged people. A Coordinated Home Aid and Togetherness Scheme is specifically provided for socially isolated older people. It incorporates volunteers to assist and enhance the quality of life for those who are frail and living in their own homes (K Rouse, Secretary/Manager of the Burnie Brae Centre, personal communication, 2 June 2006).

No evidence could be found to indicate whether evaluative processes had been undertaken to assess the efficacy of these strategies, or to what extent the collaborative measures between community-based service providers and GPs alleviated social isolation and, in particular, facilitated easier access and navigation within the health system for socially isolated older people in urban precincts.

Despite the availability of extensive services within the Brisbane metropolitan area, reports continue of difficulties in accessing appropriate health care and assistance for older people. Various accounts of prolonged waiting times and lack of resources to effectively deliver services have been reported by those attempting to access them. In their study of equity in the distribution of aged care services in Australia, Gibson, Braun and Liu (2002) revealed that the supply of community aged care packages was much higher in the remote regions than in capital, rural or regional cities. Further, the authors assert that requirements for allocation of health services and funding based on age alone, underestimates the specific needs and poorer health status of Indigenous people.

Underestimating requirements may account for discrepancies in community health services' ability to provide assistance in metropolitan areas, in which service demands far outweigh supply. Gibson, Braun and Liu's study did not take into account the culturally specific health needs of older people or the effect of non-accessibility of services for those who are old and socially isolated, although further exploration of distribution and use of care services was encouraged.

In response to ameliorative strategies to address discrepancies and gaps in service provision, investigative research was carried out by Tanner (2003) and Low and Brodaty (2008) to determine access to and limitations of community services for older persons. Tanner's UK study critically evaluated social policy initiatives, with a focus on how these affected older people.

Areas and levels of need, expectations of types of assistance, shifts in focus of service providers, structuring of eligibility criteria and widening access to services were discussed. Findings indicated that further research and policy changes were required to cater for the needs of older people more *appropriately*. Tanner suggested current models of 'care' implied dependence and should be modified to promote and reflect a more positive model of 'help', thus supporting older people to maintain control of their lives. Further, services were influenced by assessment criteria, which were determined by health professionals and allowed little (if any) input by the older person on their level of need, often resulting in restriction and timing of services. How older people, who were socially isolated, gained access to health care or navigated the health system was not investigated.

Following on from Tanner's research, Low and Brodaty's (2008) Australian-based study aimed to provide a practical guide for GPs on community services, referral processes and the fostering of partnerships with allied health providers to enhance care of the older person. Findings suggested that GPs needed to refer patients in a timelier manner, rather than only when they presented in crises.

Though delays in services and lack of integration between some providers was mentioned, the infrastructure required in the GP setting to effectively facilitate and integrate these services for socially isolated older people was not examined. Further, Australian-based research by Gray and Heinsch (2009) highlighted the shortcomings of community-based health care initiatives, which included inadequate staffing, extensive delays, lack of funding for services and in some instances (EACH and EACH-D Packages), prohibitive costs to the client.

In an attempt to address difficulties encountered in the primary care setting, the Australian Primary Care Collaborative Program was instigated to assist GPs and other health providers to increase positive patient health outcomes for individuals with chronic health conditions. The program also offered strategies to improve access to GPs through shared learning, peer support and training opportunities.

The program is based on a collaborative methodology designed by the Institute for Healthcare Improvement in the US. This federally funded program from the Department of Health and Ageing began as a 3-year project funded by the *Focus on Prevention—Primary Care Providers Working Initiative*, announced in the 2003–2004 Australian Government Budget (http://www.apcc.org.au/about_the_APCC/). Phase one operated from July 2004–December 2007 and was administered by Flinders University. Approximately 500 practices within 42 Divisions of General Practice were funded to participate in the program. Phase two began in January 2008 and is currently being managed by the Improvement Foundation (Australia). The health conditions originally targeted were diabetes and chronic heart disease, along with improved access to GPs. In July 2009, further funding was granted to encompass two new topics: Chronic Obstructive Pulmonary Disease and Chronic Disease Prevention and Self-Management Anecdotal evidence to date suggests that a number of patients with chronic illnesses are receiving increased care and monitoring. However, no data is available regarding the impact of these initiatives on socially isolated older people.

Integral to programs such as this and indeed other community-focused initiatives is the appointment of suitably qualified nurses within the general practice setting. While there is industry-based evidence that an increasing number of nurses are being employed in this sector, controversy remains surrounding the scope of practice for nurses employed within the primary care domain. According to Woodroffe (2006), the extended role of practice nurses in the UK has affected the traditional concept of the GP, with much of the focus on their management of patient care, particularly in cases of chronic disease. Higher patient satisfaction was recorded when compared to GPs but it was felt that this was mainly due to longer consultation times and the rigorous application of national health guidelines.

However, concern remained regarding the ability of nurses to recognise pathological variations in disease processes due to their limited educational backgrounds (when compared to GPs).

Australian studies surrounding nurses working in primary health care (Gibson and Heartfield 2005; Hall 2007; Keleher et al. 2007) found discrepancies in role specification as well as in identifying that there was insufficient data on the practice nurse workforce. Gibson and Heartfield (2005) emphasised the difficulties encountered by practice nurses, such as role confusion, lack of GP support, lack of defined career pathways and professional isolation, advocating mentorship as a strategy to support nurses in general practice. Hall (2007) also acknowledged the paucity of support for these nurses but provided evidence that, within the framework of the Divisions of General Practice, which were generated by the provision of government funding, steps have been taken to explore and understand the role of practice nurses.

Initially based on groups of GPs, the Divisions have evolved into a network of organisations that provide support to GPs and nurses in all areas of training, information and business management. In addition, the Royal College of Nursing Australia and the Australian Practice Nurses Association are addressing the need for support for practice nurses, developing specific nurse oriented initiatives. Investigating the roles of nurses in general practice, Phillips et al. (2009) discovered six main roles that practice nurses perform: carer, organiser, quality controller, problem solver, educator and agent of connectivity to different disciplines within the practice. However, lack of GP support and task-oriented environments limited the scope of clinical care.

Added to this industry awareness is Keleher et al.'s (2007) study of Australian practice nurses, which discussed the scarcity of data collected regarding the varied roles of practice nurses. Also investigated was the income generated by these nurses according to Medicare Benefits Scheme item numbers. This study called for more research into the practice nurse workforce, development of national standards for the role of practice nurses and an evidence-based approach to policy development.

It is evident that there are numerous metropolitan community-based services available to health professionals as well as socially isolated older people. However, there continues to be a paucity of data available regarding the efficacy in providing greater understanding of and access to these services. The difficulties encountered in administering (for health professionals), accessing and navigating the health care system remain largely unresolved. This qualitative study aims to address this gap in the current knowledge, as the participants in this research were drawn from the area covered by this latest local initiative.

2.8 Summary of Literature Review

This review of available literature presented both qualitative and quantitative research studies that examined the incidence and causative phenomena of social isolation of older people in the community. Firstly, the place of the literature review was questioned. Then, social isolation was defined, determining the framework for this study. Theories of social isolation were examined and a position taken not to locate this study within any one of these, to be consistent with grounded theory, which requires that theory emerge from the data collected. Studies concerning the factors contributing to social isolation were outlined and the consequences to health care were probed, identifying gaps in the study of health care service access.

When cultural diversity was applied to the concepts discussed in this chapter, the literature revealed that *Western* shaping of perceptions of loneliness, social isolation and illness and health are not necessarily universal. However, it was confirmed that problems remain in community-based programs across cultures. Social isolation was then placed in a global context. Finally, current programs at national and local levels were examined, revealing that the effectiveness of these is still problematic and rarely subjected to examination.

The exception was a UK study undertaken by Greaves and Farbus (2006). This extensive study provided and implemented interventions strategies that were evaluated for effectiveness at the completion of the study. However, a gap in this study, and indeed in many others, (Alpass and Neville 2003; Blendon et al. 2003; Dallinger 2002; Freyne et al. 2005; Kobayashi, Cloutier-Fisher and Roth 2009; Ron 2004; Tanner D 2001, 2003; Wenger et al. 1995; Weyerer et al. 1995) was the absence of investigative procedures to assess access and navigation of *ongoing* health care for socially isolated older people. The perceptions of older people were found to be largely absent from the studies located, which did not address the subjective value and meaning of isolation, loneliness or difficulties in accessing health care needs. This study addresses these identified gaps.

2.9 Conclusion

Understanding the experience of social isolation and the factors associated with accessing and navigating health care facilities is important in theoretical, practical and policy terms. The understandings gained from this study will establish current knowledge of services available and facilitate the development of appropriate and accessible interventions that reflect the complexity of older peoples' experiences. Strategies identified to overcome physical and psychological obstacles may provide valuable information to researchers, who can subsequently disseminate this information and provide a basis for effective, achievable and sustainable future community and government interventions for positive ageing. The next chapter explores the decision-making process behind the selection of this study's theoretical framework and the resulting methodology.

CHAPTER THREE: THEORETICAL FRAMING OF METHODOLOGY

3.1 Introduction

This chapter introduces and explains the methodology chosen for this research project. The types and differences between various qualitative methodologies are explored and the process and reasons behind my choice of methodology are examined. The purist canons of grounded theory are put forward and critiqued. In addition, the choice of qualitative data analysis and a constructive approach, and why this better suited my philosophy, beliefs and personal style are explained.

Also included in this chapter is the description and validation of the research design and an explication of the links between my philosophical assumptions, theoretical perceptions and choice of methodology. Therefore, this chapter's content is closely aligned with that of Chapter 1, which introduced the study and myself as the researcher, and Chapter 2, which highlighted the research problem through an extensive literature review. Deciding on the most appropriate techniques to analyse and present collated data is crucial to any research. As the study progressed, I reviewed the data collected from the interviews with participants and my 'construction' of categories, themes, memos and summaries. It was then that I became profoundly aware that the participants and myself, in the role of researcher, conjointly constructed meaning of their experiences, bringing together our ontological and epistemological views (Charmaz 2006). After reflection and careful consideration, I decided that a constructive approach would more accurately reflect the processes underpinning this research and more accurately portray participants' views and my epistemology.

I have refined the aims of this study to focus primarily on events or interactions that occurred during the course of obtaining health care or, in some cases, community-based assistance. The following chapters demonstrate how social and personal factors influenced these interactions.

This study explores the experiences of socially isolated older people and the problems they encounter as they attempt to access and navigate the health care system in metropolitan Brisbane. This issue was of interest to me as a practice nurse working on a daily basis with frail older people who were struggling to cope with the challenges of accessing services. An extensive literature review identified many areas of research into social isolation of older people. However, minimal research has dealt specifically with the psychological or social dynamics influencing how these people obtain their health care with minimal, if any, assistance from social or family networks.

In view of the gaps in the literature, this study aims to increase awareness in all health care providers of situations that can influence and give rise to the development of social isolation in older people. This is particularly important as society moves into a phase of rapid demographic ageing. Bringing attention to the specific difficulties encountered by these people also adds to the body of health care knowledge and facilitates further development of health care initiatives, which can be tailored to meet specific needs and marketed in such a way as to increase utilisation of services offered. Use of such services is desirable for prevention, early intervention and better symptom management in older people with chronic health problems.

Social isolation can influence many aspects of an older persons' life, particularly if they have minimal social or family networks. Given the exploratory nature of this research, a qualitative approach was deemed most suitable to explore the phenomena. The principal advantage of this style of research is that it offers the opportunity to gain a deeper understanding of human experiences. This is achieved because qualitative approaches provide rich and descriptive accounts, both holistically and contextually, of the phenomena being studied (Schneider et al. 2003).

As Morse and Richards (2002) contend, the key to doing good qualitative research is the selection of an appropriate methodology that best answers the research question or aims. The terms methodology and method, although often used synonymously, are different. *Methodology* is derived from a philosophical perspective. Researchers need to be aware that they are agents of data collection and should locate themselves within the research. In addition, the research method selected must have the ability to encompass the individual predilections and philosophical assumptions of the researcher regarding the nature of reality and what counts as truth (Adkins 2002; May 2002). Readers need to understand this to understand and audit the findings. *Methodology* revolves around the question: *who is the knower* (Adkins 2002; May 2002). In this study, the 'knower' is the participant that socially constructs and gives meaning in a particular time and space. It also involves *what can be known.* This was negotiated between the participants and me (as the researcher). What counts as knowledge are the patterns that emerge after constant comparison across participants' stories, and between and within events. According to Jones, Kriflik and

Zanko (2005), one of the most important elements when considering the selection of a methodology is the assessment of each method in view of the research aims.

3.2 Methodology—Linked to Aims

I particularly identified with the views of Denzin and Lincoln (2005) who offer this definition of qualitative research:

> Qualitative research is multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials—case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visual texts—that describe routine and problematic moments and meanings in individuals' lives. Accordingly, qualitative researchers deploy a wide range of interconnected methods, hoping always to get a better fix on the subject matter at hand (Denzin and Lincoln 2005, pp. 3, 4).

This definition encompasses the broadest context of the qualitative research paradigm and is well suited to my study aims. Therefore, I decided to undertake a qualitative study.

From the literature review, it was found that previous research into ageing has mostly been quantitative and focused on biological characteristics, such as longevity, chronic disease or illness prevention. While there has been an increase in qualitative research by nurses, in view of the gaps in the literature, I felt there was a need for a qualitative-based study to explore and define experiential phenomena in socially isolated older people in the context of the social and psychological influences on accessing health care. In view of my aims, a qualitative interpretive methodology utilising a longitudinal time differentiated approach was adopted. Several qualitative approaches were considered, including phenomenology, ethnography, grounded theory, case study, narratives and action research. Research into these informed and strengthened my choice for this research. Table 1 offers a brief personal summary of the types of methodologies investigated through a diversity of readings, including the works of Morse and Field (1995), Morse and Richards (2002), Morse and Field (2003), Janesick (2003); Denzin and Lincoln (2005); Elliott and Lazenbatt 2005; and Starks and Brown Trinidad 2007.

Table 1: Types of qualitative methodologies

Methodology	Summary Description
Ethnography	Ethnography defines and explores a culture. It often requires the researcher to spend extended time in the cultural setting being studied. Ethnography requires the researcher to become immersed in the culture and to carry out fieldwork in which detailed descriptions leads to the development of concepts, hypotheses and models that ‘fit’ the reality.
Grounded theory	The emphasis of grounded theory is on the generation of theory from data. It is a general method in which the generation of theory from systematic research involves a set of rigorous procedures that lead to the emergence of conceptual categories. These concepts/categories are related to each other as a theoretical explanation of the action(s) that continually resolve the main concern of the participants in a substantive area. Its aim is to find a core category that links the various dimensions.
Phenomenology	Phenomenology explores the essence of meanings within human existence. It is formed on introspective thoughts.
Narratives	Personal views or stories—the way people make meaning of their lives.
Action research	This is the process of joint problem solving. It involves action that is aimed at presenting and demonstrating problems in a current situation and facilitating improvements at each stage.

Case studies	This is a process of collecting and presenting detailed information that portrays those elements of a specific situation that give it meaning. Case studies look intensely at an individual or small participant group, drawing conclusions about the participant or group and only in a specific context with emphasis placed on exploration and description.

Qualitative methods have often been accepted as the most appropriate way of addressing research purposes and questions. I agree with Morse and Richards (2002), who further contend that qualitative methods are ideal for investigating matters that require an in-depth understanding of a topic or phenomena about which little is known; aim to discover the experiences and meanings of the participants in a particular setting; or intend to build a theory or theoretical framework that represents others' perceptions of reality, rather than the researcher's own. This study incorporates these characteristics, as little is known about the psychosocial influences that affect the way that socially isolated older people access health care; the purpose of this study is to discover and interpret participant experiences and meanings; and the intention is to build a theoretical framework that represents the participants' perceptions of reality.

In addition to the guidelines offered by Morse and Richards (2002), Schneider et al. (2003, p. 141) contend that all qualitative research demands deliberation of three philosophical concepts. A personal summation follows:

1) *Ontology*—is a major branch of metaphysics and incorporates the study of the nature of being, reality or existence. This can be materialistic or idealistic and, as such, offers an individual 'world view' that directs the research.

2) *Epistemology*—is concerned with the nature and scope of knowledge and incorporates truth, belief and justification. This establishes the relationship between the inquirer and what is known, thus providing the focus for the research.
3) *Methodology*—incorporates existential concepts of cognition, learning and awareness. This distinguishes how we place ourselves and know the world or how we gain knowledge from it, thus providing a design for conducting a study.

Pivotal to the chosen methodology for this study is the outlining of my beliefs and the theories that may inform, implicitly or explicitly, the questions posed and the assumptions made. These theories have the potential to influence the kinds of data collected and identified as significant and inevitably the categories named and used in generating theory. I begin by posing and taking a position on a controversial belief held by Avis (2003).

Avis (2003) claims that not only is there no need to have a methodological basis for qualitative research studies but that doing so results in such studies being counterproductive, as the methodological underpinnings hinder critical reflection and empirical evidence. This thought provoking, controversial article questions the legitimacy of methodology in qualitative research and defies the strongly held views voiced by the majority of qualitative researchers. Avis bases his views on the works of Willard Quine (1980) and Donald Davidson (1984), both eminent philosophers of the late twentieth century. However, contrary to Avis's (2003) beliefs, Nachmias and Nachmias (1995) postulate that, despite science having no special subject matter of its own, it does not view every study of phenomena as science. They believe this is attributable not to the subject matter but, more precisely, to the absence of reputable scientific methodology. Further, when a branch of alleged factual knowledge is rejected by science, it is always because of its methodology. Nachmias and Nachmias (1981, 1995) believe that the goal of social sciences is to generate an accumulative body of dependable information that would assist researchers to explicate, predict and comprehend interesting empirical phenomena. Thus, we come to the question: ‘is there a need to explicate and defend clear methodological underpinnings in qualitative research?’ This is not a question that many researchers ponder because, I believe, to the majority the obvious answer would be ‘yes’.

I disagree with Avis’s (2003) perspective and support the majority view that qualitative research indeed requires a clear methodological basis. Qualitative research is based on individuals’ views of the world. It requires a sound methodological base to ensure a disciplined approach to rigour and dependability. This rigour distinguishes ‘research’ from storytelling. It is not my purpose to debate, at length, the pros and cons or scientific requirements for substantive recognised and validated methodologies for qualitative research. Rather, I would like to direct the reader to the varied and at times controversial perspectives of researchers and philosophers who, by their unique academic and scientific stances, make us *think* about what we do.

3.3 Methodological Links to Theoretical Assumptions and Nursing Research

3.3.1 Why Qualitative Research?

Traditionally nursing has focused on practices concerned with health and healing and providing support for people in times of crisis or those traversing major life events. Although much of nursing knowledge has originated within the biomedical science fields (Rice and Ezzy 1999; Schneider et al. 2003), a significant move away from these models to incorporate research that informs and facilitates a greater understanding of people's expectations, perceptions, experiences and adaptation to life events has taken place (Morse and Field 1995, 2003; Morse and Richards 2002; Fielden 2003; Speziale and Carpenter 2003; Elliott and Lazenbatt 2005). This knowledge complements and enhances the biomedical paradigm to provide a more complete or holistic framework to assist in delivery of care. It is within this context that my research is placed.

I wanted an in-depth understanding of my observed phenomena of socially isolated older people attempting, or not attempting, to access the health care services available to them. When studying *people*, qualitative research methods are often chosen, as they permit and even encourage the development of a more detailed picture of *human* experiences (Britten 1995; Knapik 2006; Morse and Field 1995; Morse and Richards 2002; Schneider et al. 2003; Speziale and Carpenter 2003). Thus, there was never any doubt that this study would be qualitative. However, choosing the most suitable method within this paradigm for this particular study required a great deal of consideration and re-examination of my beliefs.

Much has been written, and will continue to be written, on the various qualitative research methodologies (Ploeg 1999; Rice and Ezzy 1999; Speziale and Carpenter 2003; Elliott and Lazenbatt 2005) and the richness and diversity of information that can be gathered and potentially play a major role in health-focused applications. The various methodologies are often closely aligned to the chosen topic or phenomena being researched. Therefore, I re-examined my beliefs, my questions and aims to ensure the methodology chosen was a correct 'fit'.

It is understandable that qualitative research methods have been involved in nursing research for decades, as they present the researcher with a multitude of alternatives and avenues to investigate the intensity, richness and intricacy innate in the occurrences being examined (Carr 1994; Gramling and Carr 2004; Ploeg 1999; Rice and Ezzy 1999). Morse (1999, p. 393) stressed this viewpoint, writing:

> They offer alternatives in analytic approaches; cater to different disciplinary perspectives, assumptions, and agendas; provide a means to explore various levels of analysis, from micro-analytic to complex behaviors; and permit the development of the necessary level of conceptualization of results.

In accordance with these views, Burns and Grove (1999) believed that qualitative research is valuable within the nursing profession, as it focuses primarily on understanding the complete experience, a belief that is fundamental to the philosophy of nursing. My topic involves complex human issues and a need to understand a complete experience. Consequently, I endorse the view that the in-depth view offered by the qualitative approach may reveal a new understanding of the phenomenon of health care for the socially isolated older person, which, if applied more generally, may offer new avenues for nursing practice, while facilitating and promoting theory development.

3.3.2 Qualitative Research in Nursing

Researchers primarily associated with nursing (Schneider et al. 2003; Roberts and Taylor 2002), including those associated with allied health (Grbich 1999; Elliott and Lazenbatt 2005; Charmaz 2006), assert that qualitative research methods have evolved to provide a theoretical framework for investigating problems or issues in social and clinical settings. This framework allows for investigation of issues that are often inadequately answered by traditional quantitative means: when numbers are not enough and in which variables cannot be controlled. I agree with these views and believe that many clinical (particularly nursing) research studies are qualitatively focused in an effort to gain an understanding of human experiences that cannot be achieved by quantitative measures alone.

Additionally, I support Rice and Ezzy (1999) and Roberts and Taylor (2002) view, that possible answers to problematic social issues lie embedded in textual rather than numerical data, which can be probed in depth within specific philosophical and ethical paradigms using the methods found in qualitative research. The voices of my participants provide the text for analysis. It has been my observation that this type of research often reveals the subtle 'just beneath the surface' layers of phenomena being studied, thereby facilitating, enhancing and promoting more precise and intricate explanations and theories that are often the basis for future research.

Other researchers such as Morse and Richards (2002), Thomas (2006) and Charmaz (2006) also testify to this phenomenon. These authors, along with many others in the nursing field—for example, Leininger (1988), Munhall (1989), Polit and Hungler (1997), Burns and Grove (1999), Thorne (2000), Schneider et al. (2003), Morse and Field (2003), Elliott and Lazenbatt (2005), have demonstrated how qualitative methods assist researchers who attempt to make sense of events and experiences as they occur in an individual's natural environment. These authors discuss the selection processes of particular methodologies and methods, which detail explicit or implicit theoretical frameworks that carry specific assumptions about social 'reality' (ontology) and how that reality can be understood (epistemology). This is of particular significance in my research of socially isolated older people in which individual experiences are influenced by personal attributes, perceptions and values, along with the nature and lived history of the person conducting the research.

3.4 Variations within Qualitative Research

It has been demonstrated that various qualitative approaches offer different perspectives on reality or what can be known (Charmaz 2006; Denzin and Lincoln 1998; Grbich 1999; Janesick 2003; Law et al. 1998; Lincoln and Guba 1985; Morse and Richards 2002; Roberts and Taylor 1998). Thus, qualitative enquiry can be undertaken through grounded theory (Glaser and Strauss 1967; Strauss and Corbin 1998), hermeneutic theory (Gadamer 1976; Heidegger 1978), be based on descriptive phenomenology (Husserl 1859–1938), ethnography (Denzin and Lincoln 2005) or narrative analysis (Kohler and Riessman 1993–2002). The feminist approach and action research are also acknowledged as valid qualitative research methodologies that are essentially inductive. Each methodology has its own subtle differences on what constitutes reality and what can be known, and has a unique place in the realm of qualitative research.

What constitutes reality can clearly be seen in the work of Lincoln and Guba (1985, p. 77) as they discuss constructed realities as being ‘events or situations [that] are theoretically open to as many constructions by a single individual as imagination allows’, while supporting the view that:

> individual realities often overlap one another, simply because many of them are an effort to deal with the same putative phenomenon and in the sense making in which each actor engages in order to keep his or her world whole and seamless (Lincoln and Guba 1985, p. 82).

This view is essentially how I envisaged my research questions: that there would be multiple realities overlapping within and between the participants.

Qualitative research reaches out over many disciplines, fields and subject matter. It involves a complex interconnected unit of terminologies, concepts and assumptions, while transcending the traditional approaches associated with positivism, post-structuralism and various qualitative research perceptions or processes linked to cultural and interpretive studies (Denzin and Lincoln 1998). After careful consideration of the various methodologies investigated, I chose grounded theory for this research, as it is an approach that can be used to identify and relate characteristics that can be employed to define and explain relatively unknown situations. It has been widely utilised in areas of human interest and works in an inductive fashion to make sense of what people say about their experiences. I believe this was the best ‘fit’ for my research questions and aims. Little did I know at the outset how this decision would be challenged by the multitude of ‘experts’ claiming different approaches as ‘grounded theory’.

3.5 Grounded Theory: Classic or Broader Interpretation?

Grounded theory, which grew out of the symbolic interactionist tradition (Glaser and Strauss 1967), is an approach to collecting and analysing data with the intention of building theories ‘grounded’ within actual observations (Roberts and Taylor 2002). However, despite an overall consensus on the fundamental principles of grounded theory, there are continuing debates in the literature about what constitutes grounded theory (Backman and Kyngäs 1999; Elliott and Lazenbatt 2005; Glaser and Holton 2004; Glaser and Strauss 1967; Grbich 1999; Leininger 1985; Morse and Field 2003; Morse and Richards 2002; Polit and Hungler 1995; Roberts and Taylor 2002; Schatzman 1991; Schneider et al. 2003; Strauss and Corbin 1998; Thorne 2000; Wells 1995), with the theory having been analysed and modified (Charmaz 2006; Cutcliffe 2005; Miller and Fredericks 1999; Morse 1994, Thomas 2003; Strauss and Corbin 1990) for over four decades.

Baker, Wuest and Stern (1992), Bourke, Cikoratic and Mack (1999) and Nathanial (2003) contended that the original concept of grounded theory by Glaser and Strauss in 1967 challenged the prevailing view of the era that the only scientifically rigorous form of systematic social inquiry consisted of quantitative methods. The development of classic grounded theory gave much needed structure to qualitative research and, over the following years, garnered increasing respect as it took advantage of reputable mathematical ideologies and combined them with qualitative concepts. This was an important breakthrough in research methodology. Over the ensuing years, Glaser has meticulously detailed the purist form of this methodology, while Strauss formed what was to become a long standing association with Juliet Corbin (a former student), together conceptualising a considerably different approach (Strauss and Corbin 1990, 1994, 1998).

Strauss and Corbin described an exacting, linear approach. However, according to Glaser (1992), the resulting theory can be a forced result, rather than a natural emergence of the application rules and procedures for conducting his form of grounded theory. Thus, I have chosen not to follow Strauss's discipline, as its repeated emphasis on retaining the principles of good science, such as replicability, generalisability, precision, significance and verification, may place him closer to traditional quantitative doctrines that are not appropriate, given the goals for this research. Although all three have published many articles relating to their stance on grounded theory, Glaser remains critical of Strauss and Corbin's perspective. Glaser appears to justify his point of view in his article (with Holton 2004), as he describes classic grounded theory as 'simply a set of integrated conceptual hypotheses, systematically generated to produce an inductive theory about a substantive area'. It was from this position that I began my research.

I support the view that grounded theory is created solely from the data, revealing the participants' perceptions, which is evidenced in the results (Glaser and Strauss 1967; Roberts and Taylor 2002). Present theory is not enforced on the data, but is employed to support the evolving theory. I also felt comfortable with his notion of, 'a highly structured but eminently flexible methodology'. In the same article, Glaser appeared to defend his original classic position against the subjectivity and constructivism involved in what he labelled 'qualitative data analysis (QDA)', particularly as seen in Morse's (1994) work. This puzzled me as I accept that people's worldviews are constructed in multiple contexts. Glaser himself acknowledges that the QDA method is legitimate, even 'worthy, respectable, and acceptable' (Glaser with Holton 2004), but repeats it is *not* grounded theory. On reflection, Glaser's arguments appear to be boundary marking, but along with other qualitative researches (Morse 1994, Thomas 2003), I concur that QDA can be utilised in conjunction with grounded theory methodology.

I am particularly drawn to QDA's focus on description and acceptance of constructivism. QDA methods incorporate processes in which qualitative data are meaningfully examined and interpretations developed to understand people and their situations, thus facilitating exploration of personal experiences, belief systems and meanings. Clearly, Davidson (2002), Morse and Richards (2002) and Charmaz (2006) consider Glaser and Strauss (1967) and Strauss and Corbin (1990) to be the model's greatest advocates, due to their formulation of grounded theory as a qualitative research method that uses a methodical set of protocols to foster an inductively acquired grounded theory about experiences. However, they advocate going beyond this, to embrace constructivism. The objective is to work from the general to the specific, without losing sight of the uniqueness of the research study.

In my research, a linear process could not be utilised, as there was need to move back and forth within the data as the interviews progressed. I thus followed the canons of Denzin and Lincoln (1998), Morse and Richards (2002), Davidson (2002), McCallin (2005) and Charmaz (2006), who concur that data collection, analysis and theory formulation are indisputably associated in a reciprocal relationship, and that grounded theory includes precise procedures to guide this. Although I had decided on a methodology, I still felt I needed to know more about the complexities of grounded theory and how this had been incorporated into broader interpretations of QDA.

3.6 Grounded Theory—A General Inductive Approach?

A researcher who initially influenced my move to a broader view was Thomas (2003), whose general inductive approach provides an efficient way of analysing qualitative data without the rigid framework of traditional theories. Thomas (2003) argued that key themes are often obscured, reframed or remain undetected due to bias in data collection and analysis procedures imposed by deductive data analysis, such as those used in experimental and hypothesis testing research. Thomas (2003) believed that novice researchers would find using the general inductive approach less complex compared to some of the conventional or long-established approaches to QDA. However, researchers such as Morse et al. (2002) and Charmaz (2006) may well disagree with Thomas's (2006) seemingly overly simplistic claims that those who follow his guidelines can expect results from their analyses to be similar to those derived from grounded theory without the burden of learning and utilising complex technical terminology.

While keeping Thomas's (2003) flexible guidelines in mind, I elected to perform a detailed analysis involving line-by-line coding of transcribed text, to ensure that many analytical cuts into the data, possibly at different stages of the research, would be possible. By following this methodical process for analysing qualitative data, I hoped to achieve a detailed analysis, guided by the explicit aims of this research. To achieve this, repeated comprehensive readings of raw data were undertaken to facilitate development of categories, sub-categories and themes. This process was more closely aligned with Glaser and Strauss's originally developed tenets of theory building.

Roberts and Taylor (2002) state that grounded theory, initially developed by Glaser and Strauss (1967), begins from the ground and works up in an inductive fashion to make sense of what people say about their experiences and to translate these assertions into theoretical proposals. My analysis follows this more disciplined approach of line-by-line analysis from fully transcribed interviews and is closely aligned with the general principles of classic grounded theory, differing only in accepting the constructivist philosophy used by Charmaz (2006).

Careful consideration has been given to the expanse of articles and books on qualitative research methods. Therefore, the theoretical framework for this study incorporates and follows the constructivist guidelines of Charmaz (2006). Charmaz has discussed her move away from Glaser's didactic stance on grounded theory (Puddephatt 2006), with divergence apparent in her views on co-construction of reality. During an interview with Tony Puddephatt (2006, p. 10) discussing this point in relation to Glaser's views on forcing or legitimising constructions influenced by researcher perceptions, Charmaz stated:

> what you try to do is to understand as best you can, knowing that it always comes out of your own perspective, but you try to understand how the people that you

> are talking with or studying, construct the situation. I think grounded theory can be an enormous help with the checks to catch the kinds of constructions, and to have a sense of them. But it always comes from our perspective.

In further clarifying her stance, Charmaz (2006, p. 9) posits that grounded theory methods are, ‘a set of principles and practices’ and emphasises flexible guidelines, not methodological rules, recipes and requirements. In contrast to Glaser’s position, Charmaz (2006, p. 10) assumes that:

> neither data nor theories are discovered. Rather we are part of the world we study and the data we collect. We construct our grounded theories through our past and present involvements and interactions with people, perspectives and research practices.

Charmaz contends that basic grounded theory guidelines, incorporating contemporary methodological assumptions and approaches, can be used within the qualitative research paradigm. It was this construction of grounded theory that I adopted.

Relating Charmaz’s explanation to my research epistemology, it was important to me to understand the social constructions and personal views of socially isolated older people and how their past and present experiences influenced and affected their access to health care and navigation of the health system. It was also important to me that I took into consideration how my own experiences of the world had affected their constructions and the way I read these. I believe that constructing theory grounded in participant experiences in this way may provide a unique insight into these people’s lives that may enhance the understandings of health professionals and policy makers, thus providing pathways for easier and timelier access to health care.

Other researchers appear to concur (Denzin and Lincoln 1998; Morse and Richards 2002; Janesick 2003; Thomas 2006) that the main purpose of the inductive approach is to permit research findings to emerge from the recurrent, prevailing or major themes innate in raw data, *without* the restraints required by structured methodologies. Denzin and Lincoln (1998) and Morse and Richards (2002) concur that qualitative researchers utilise inductive analysis to categorise themes and patterns that emerge from the data with Janesick (2003, p. 63), suggesting:

> There is no one best system for analysis. The researcher may follow rigorous guidelines described in the literature … but the ultimate decisions about the narrative reside with the researcher.

I believe that Charmaz (2006) supports these views within her flexible guidelines and adaptation of Glaser's original grounded theory. Further, she adds dimension to the views of Mays and Pope (1995), who, in their exploration of research in health care, affirm that qualitative methods are ideally suited to research aimed at identifying real behaviours and intended meanings in people's portrays of their experiences, feelings and conduct. In his theoretical stance, Thomas (2006) reiterates that key fundamental elements present in grounded theory (description, conceptual ordering, explanatory schema) are also present in the general inductive approach (brief summary formats, establishment of links, develop theory of experiences). Although the descriptive process is different, the outcomes are often similar in these closely aligned methodologies. The basis for Thomas' arguments for data analysis is similar to that of Morse (1997) in which coding and themes from transcripts are categorised into specific stages.

This move away from Glaser and Strauss's traditional models highlights the differences in constructivist grounded theory in which significance is placed on how the process of data collection, its analysis and methodological approaches acknowledge and incorporate both participant and researcher perspectives and interactions. These more recent views of Charmaz reflect those in her earlier work in which she claimed, 'Data do not provide a window on reality. Rather, the “discovered” reality arises from the interactive process and its temporal, cultural, and structural contexts’ (Charmaz 2000, p. 524). Thus, social reality and self are constructed and dynamic, with recognition of multiple realities and research as joint constructions of knowledge.

Given the objectives and framework of my research, theoretical constructs that reflected a social constructivist position seemed most appropriate. I acknowledge that this position takes me beyond the classic grounded theory as defined by Glaser (1992, 2001). From this position, the knowledge and experiences of individuals could be constructed and more clearly defined.

3.6.1 Choice of Method

Charmaz (2006), who would be considered by Glaser as one of the QDA researchers, asserts that grounded theory methods facilitate viewing data in new ways by allowing for the investigation of ideas throughout early analytic writing. Further, she believes these methods consist of orderly, yet malleable procedures for assembling and examining qualitative data to develop theories ‘grounded’ in the data themselves. Grounded theory offers a group of universal values and heuristic processes rather than prescribed policy. The following quotation by Jones, Kriflik and Zanko (2005) epitomises the accepted canons of grounded theory as I now believe it to be:

> Meaning is conveyed through dialogue and action and within dialogue and action is embedded understanding, experience and emotion, and only through interaction and discourse can meaning be unlocked and conveyed to the observer. From this perspective, Grounded Theory [as interpreted in QDA] provides a method which enables a researcher to adduce true meaning and understanding. Most of all Grounded Theory allows researchers to get into the field, and quickly acquire an empirically grounded understanding of social phenomena, and to evaluate the phenomena without reliance on extant theory. The research allows theory to

> emerge through the inductive process of Grounded Theory (Jones, Kriflik and Zanko 2005, p.10).

3.6.2 Methodological Links to Personal Predilections

Other researchers support the views held by Glaser and Strauss (1967) but add that more general guidelines and procedures allow for and encourage freedom for ingenuity and creativity when generating theory (Denzin and Lincoln 1998; Eaves 2001; Janesick 2003). This perspective suited my predisposition. According to Denzin and Lincoln (1998), grounded theory studies share a number of resemblances with other approaches undertaking qualitative research. Sources of data are the same and include interviews, field observations, diaries, videotapes and letters. Grounded theorists who apply the broader interpretation redefine the common scientific principles for the explicit purpose of studying and understanding human behaviour, believing that interpretations must include the perspectives and voices of the people who are being studied. This proposal was of particular significance in my research, as each participant's unique perspective regarding their sense of self, their place in society and their ability to access health care demonstrated and highlighted the personal attitudes that influenced and affected their interactions with health care personnel. I also acknowledge my interpretive role and responsibility for accurately interpreting what is observed, heard or read.

During my 30 years of nursing experience, I have learned to recognise and accept the existence of multiple interpretations of reality from an inter- and intra-individual perspective. Through a myriad of social interactions within the health care system, I believe that there can be no absolute truth, only general patterns of human phenomena, which can be probed, described and theorised. Thus, as Glaser claimed in his original work with Strauss, everything *is* data. However, diverging from classic grounded theory, both the researcher and the participants' world views influence what can be constructed. A more specific explanation of this follows under the heading of *constructivism.* Meanwhile, attention must be drawn to the fact that many of the researchers who claim 'grounded theory', along with qualitative method writers who describe broader applications of it, including constructivism, do not acknowledge that Glaser deems this *not* to be grounded theory. I deliberately highlight this.

From this point on it should be noted that my preference and acceptance is of the broader application of grounded theory, while being mindful that Glaser rejected this being named grounded theory. Grounded theorists redefine the common scientific principles for the explicit purpose of studying and understanding human behaviour. There is a belief that interpretations must include the perspectives and voices of the people who are being studied. I have followed these principles by ensuring that the voices of my participants are heard throughout this research. Adopting this approach has been achieved by the use of direct quotations to portray significant events as accurately as possible.

The essential question guiding all qualitative research is 'what is happening here?' This is an integral part of theory that is commonly situated in experiences in which change is expected or inevitable. This question is apt for my study, as it is not known how elderly people negotiate the health care system and to what extent psychosocial influences affect their interactions. It was my intent to listen, to learn about the participants' experiences negotiating the health care system. In this situation, much of the innovatory potential of knowledge and research derives from the cross-fertilisation of ideas from different frameworks. Thus, I believe that it is important to have a base method, in this case grounded theory. Upon this base, a layer that accepts a constructivist view can be added, creating a theoretical framework that remains open across boundaries.

Another difficulty I experienced was taking a position on ‘bracketing’. I accepted that the researcher’s personal perceptions, attitudes, ethnicity and belief systems play a key role in the creation of data collection and the development and construction of theory. This perspective is supported by Roberts and Taylor (2002), who claim that the preconceptions and bias of the researcher should be acknowledged at the beginning and then cast aside to permit the data to ‘speak for itself’. However, I do not think it is easy to cast personal bias aside. Although bias is acknowledged, it is unrealistic to suggest that one’s personal thoughts, perceptions and values can be completely removed from any situation being studied. Much lies at a subconscious level. Bias can be minimised, but inevitably influences how data are treated by the researcher. Hence, the following section sets out my own thoughts, perceptions and values in relation to this research.

I have been working as a practice nurse (GP rooms) for over 11 years. The scope of nursing in this role is wide and encompasses providing health care to people of all ages. The inspiration for this study stems from conducting health assessments for people 75 years and older. It became increasingly apparent to me that some older people were not only living in substandard conditions, but were also unaware of many community-based, government-funded programs to assist older people to maintain their physical, emotional and socioeconomic health. Surprisingly, once informed of the myriad of community services available to them, some of my patients were disinclined or declined outright to access these services. I felt the need to know more about why these people did not want to become involved in activities that would reorientate them socially or, perhaps more importantly, allow them to access broader health initiatives aimed and designed to meet their specific needs.

The choices that I, as a clinical nurse in a busy suburban medical practice, made about what might count as relevant or important data in answering the research questions were an integral part of the tenets of theory building of a constructivist approach. The viewpoint that reality is continually shifting and being negotiated led me to actively inquire into these events over time. I believe that all researchers consciously (or unconsciously) focus on particular aspects of their data. Therefore, I acknowledge and value my interpretations and choices made and invite readers to share and debate my constructions. One must be aware that researchers and research participants construct suppositions about what is factual, have accumulated knowledge, are involved with social status and pursue objectives that shape their individual outlook and behaviour when in the company of each other.

As a practicing Registered Nurse, I have a strong preference for face-to-face interaction. Thus, the interview technique appealed to me. I also deal on a daily basis with the problems that older people, especially those that are socially isolated, experience in negotiating the health care system and was motivated by a desire to make a difference in this regard. Thus, the research questions grew out of personal experience of an apparently frequently occurring problem in which the variables could not be readily identified or controlled. I could lay my worldview out for readers to interpret, but I could not claim to have set bias aside or bracket it. It is an essential part of the data and theory building.

I acknowledge that I bring personal and professional values and belief systems to the research study due to my continued employment as a nurse and ongoing professional development spanning 30 years. My aim is to make awareness of self and possible bias evident in my inclusions of questions asked together with quotations from interviews, constructing the data analysis with a view to aiding transparency and reflexivity, which encourages the reader to make their own value judgements on the concepts presented.

3.7 Grounded Theory as a Constructivist Research Paradigm

During my examination of the various qualitative methodologies, I recognised that my study was best located in the constructivist paradigm. According to Charmaz (2006), a constructivist approach fosters precedence on the phenomena being studied and views data and their analysis as shaped from mutual experiences and interaction with participants and other contributories of information. Constructivists examine how and why participants create meaning in explicit circumstances.

A constructivist approach means more than looking at how individuals view their situations. It theoretically conceives the revelations of research participants and acknowledges that the subsequent theory is an interpretation. I believe that the emergent theory is contingent on the researcher’s worldview and cannot be removed from this relationship.

In other words, what *are* important are the subtle differences in context that shape what the observer and participant is able to construct. Having acknowledged my constructivist position, I endeavour to be insightful about my assumptions and how they influence the research. However, I cannot be certain how my beliefs and questions might shape the dialogue. Nevertheless, by providing a background for the reader, their auditing of my work is facilitated.

Qualitative research acknowledges the subjectivity of a person's feelings. Knowledge that emerges from such subjectivity intends no universal claim to be truth for everyone in all circumstances, but rather it encompasses personal experiences and truths that may be similar or in contrast to others' experiences (Janesick 2003). Consistent with this idea, and thus defending the views of Glaser and Strauss (1967), Roberts and Taylor (2002) posit that the qualitative researcher attempts to understand these complex relationships, thereby taking into account inherent inter-subjectivity between individuals. However, Denzin and Lincoln (1998), Morse and Richards (2002) and Charmaz (2006) appear to have taken a somewhat different stance, claiming that this technique discovers and links specific features that may be utilised to define and explain the 'unexpected'.

Adding to these concepts, Charmaz (2006) and Morse and Richards (2002) further contend that the constructivist approach entails discovering in what way and to what extent experiences are entrenched in larger, sometimes unseen situations and associations. As variations, contrasts and similarities between people become discernible, the researcher must remain observant of circumstances in which such variations occur and are retained. Generally, constructivist grounded theorists adopt a reflexive position in relation to the research process and contemplate in what way or to what extent their theories may develop (Charmaz 2006; Schneider et al. 2003). They presuppose that data and their examination are societal interpretations that mirror what their construction involved. Therefore, any analysis, according to Charmaz (2006, p. 131), is 'contextually positioned in time, place, culture and situation'.

This study follows the suppositions by Morse (2003), Charmaz (2006), Schneider et al. (2003) and other like-minded qualitative researchers. Self-awareness of personal constructs and ideologies as well as time, place and situation are interwoven with those of the participants, and attention has been given to making this conscious and presenting it for readers to compare with their own experiences.

Since constructivists perceive truths and ideologies as linked, they acceptwhat they observe—or do not observe—depending on an individual's ideals and worldview. The constructivist approach is diametrically opposed to the objectivist approach, which removes the societal milieu from which data appear. In addition, it negates the power of the researcher, and frequently the exchanges between them and their research participants. This is strength in qualitative research, that these are not only recognised and acknowledged but that they are openly displayed. Intra-interview respondent validation was a frequently utilised stratagem to ensure that my interpretations of each participant's worldviews were an accurate, reasonable and trustworthy reflection of their experience. An objective constructivist research project presupposes that data characterise impartial truths about a predictable world. In grounded theory, it is believed that the researcher discovers from within the data, theory that already exists.

Continued examination of these opinions again led me to Charmaz (2006, pp. 125, 126), who views positivism as an epistemology that follows a unitary scientific method, consisting of objective systematic observation and experimentation in an external world. Further, Charmaz (2006) claims that proponents of this view see their theoretical concepts as variables and that they therefore construct functional meanings of their concepts for hypothesis testing through accurate, replicable empirical measurement (pp. 125, 126).

The positivist view of deterministic explanation, generalisability and universality was not adopted for my study, as it was deemed an unsuitable stance in view of the phenomena being studied and the intended methodological base of grounded theory. Perhaps even more importantly, no commitment to objectivist grounded theory has been made either. Rather than predict solutions or claim objectivity, I was interested in understanding *why* difficulties occurred and *what* influenced these difficulties when socially isolated older people attempted to access and navigate the health care system. My focus was *'what is happening here?*'

Consistent with the supposition of neutrality, classic grounded theorists regard how they depict research participants in their writings as unproblematic. Such researchers view themselves as authoritative experts who convey an objective view to the research. Interestingly Glaser (2002b) insists that *constructivist* grounded theory is incorrect terminology, but conversely states that grounded theory is a perspective centred methodology and one where people's perceptions often vary, including that of the researcher.

Further, Glaser (2002a, 2002b) disagrees with Charmaz's (2006) focus on necessary 'data accuracy' within the qualitative data process. Glaser explicitly rejects the concept of grounded theory being constructivist but appears to accept constructivism implicitly as a joint construction of interactive, interpreted and produced data in which an epistemological bias exists to achieve credible descriptive accuracy of data collection. In addition, Glaser alleges constructivism is an effort to privilege data and avoid issues of confronting researcher bias, yet contends that if data are acquired through structured or forced interviewee responses, then interviewer constructivism not only exists but is nothing more than another social variable.

I have adopted a broader approach and, while acknowledging the centrality of a core theme, I further suggest that the constructivist view recognises numerous individual realities and concentrates on how people’s behaviour and attitudes influence their personal situations and milieus. Therefore, I have taken a constructivist approach in an endeavour to demonstrate the intricacies of particular worlds, beliefs and actions. Glaser however, does not support these views, classifying them as ‘story telling’. I believe that story is crucial in presenting the participant’s experience and to generating theory that is convincing and seen to be trustworthy.

3.8 Conclusion

This qualitative study has adopted a general inductive approach more in line with QDA than classic grounded theory, although it does accept the additional rigour of line-by-line analysis of grounded theory, situating this within the constructivist paradigm, which is in keeping with my ontology and epistemology. Elements of grounded theory have informed the design of the study and particularly the first phase of data analysis. The following chapter will describe my method, based on acceptance of these assumptions.

CHAPTER FOUR: METHOD AND RESEARCH DESIGN

4.1 Introduction

The previous chapter examined questions of methodology and the choices I made prior to undertaking this research. It identified the more general approach to grounded theory, following the models of Charmaz (2006) and Morse (2003), as being suited to both the research questions and my personal strengths and predispositions. It has been a journey of discovery from tentative beginnings, through to the development, implementation and evaluation of this research project.

This chapter introduces the research design and describes in detail the methods undertaken to conduct this research. Based on the research questions, a constructivist qualitative approach incorporating the foundational work of grounded theory was deemed most appropriate, as it works in an inductive manner to generate and explain meanings of people’s experiences based on social values, personal perceptions and human behaviour (Charmaz 2006). Subsequent theory generated solely from the data gave ‘voice’ to participant perspectives that are reflected in the findings (Roberts and Taylor 2002).

This methodological approach, which originated within the symbolic interactionist tradition (Glaser 1967, 1978), has evolved to encompass explanation of human action and interaction in social, psychological and spiritual aspects of life. This model has been adapted throughout the progress of this project, ultimately embracing the original foundations of grounded theory (Glaser and Strauss 1967; Glaser 1978, 1999, 2001, 2002a, 2002b), but also incorporating a broader constructivist approach (Charmaz 2006; Morse 1991, 2003; Roberts and Taylor 2002; Thomas 2003, 2006). From a constructivist perspective, my research findings are based on interaction with and interpretation of data. Thus, reality is presented as a socially constructed concept in which multiple truths reside and in which truth is provisional (Charmaz 2006; Denzin and Lincoln 2005). Design, selection criteria, sampling methods, setting, data collection, ethical considerations and the process of data analysis are outlined and justified in this chapter.

4.2 Design of the Study

This qualitative research seeks to comprehend and communicate the meanings of people's experiences. As Burns and Grove (1993), Polgar and Thomas (1998) and Hadjistavropoulos and Smythe (2001) all note, methodology based on humanistic values is often highly successful in achieving insight into and illustrating personal experiences. With these views in mind, a longitudinal time differentiated qualitative interpretive approach allowed me to interview each participant on three separate occasions over a two-year period.

Roberts and Taylor (2002, pp. 15–16) describe the interpretive form of qualitative research as being concerned with creating meaning from an individual's experiences and valuing the subjectivity of such experiences. Schneider et al. (2003) also contends that longitudinal studies allow the investigator to follow each subject separately, which facilitates an increased depth of responses whereby early trends can be investigated. This longitudinal perspective was gained by collecting data from each participant at timed intervals of approximately 6 months to establish the types of experiences socially isolated older people encountered as they accessed and navigated the health care system.

4.2.1 Nurse versus Researcher

My tenure at the medical centre spanned over six years, extending beyond the duration of the research study. My familiarity with the participants as patients was well established, with my role as 'researcher' adding a new dimension. To deal with this situation, I took steps to clearly delineate the duality of my roles. During the interviews, I explained that I was there as part of my research, rather than in my clinical role. I took care not to be drawn into my clinical role to offer specific medical or nursing advice while interviewing, instead focusing on drawing out the experiences of the participants in attempting to manage their health needs. This does not imply that information was withheld at any point. At the completion of each interview, issues that could appropriately be addressed within my scope of practice at the medical centre were discussed and resolved in a setting separate to that of my role as researcher.

4.3 Selection and Recruitment Processes

Initial contact with potential participants was made via my position as a practice nurse in a busy suburban medical centre, where part of my role involved conducting health assessments for those aged 75 years and over. I sought and gained ethics clearance from my university as well as approval to use the patient database from the Medical Director of the Centre. The basis for participation in the study relied on the inclusion criteria (see Section 4.4), accessed via doctors' notes and information obtained from the annual health assessments I conducted in the course of nursing duties at the medical centre. Six participants from the medical centre were invited and agreed to participate. The medical centre is located in a northern Brisbane suburb and is the same medical centre in which I worked as a practice nurse.

4.4 Sampling Method

Grounded theory, which in the early stages underpinned this study, uses sampling strategies to inform research questions and/or to reflect a population experiencing similar phenomena (Charmaz 2006; Morse 1991, 2007). In this study, the process of initial sampling relates to the selection of a particular population according to age and degree of social isolation, which was informed by the conduction of health assessments.

The types of sampling methods chosen for qualitative research are dependent on the phenomena being studied and the methodology chosen by the researcher (Polit and Beck 2004). Although there are many methods that may be utilised, the following were chosen for this study:

1. *Critical case sampling:* These cases are selected to provide rich stories that can provide further information on the phenomenon being studied.
2. *Purposeful sampling:* This method incorporated diverse strategies that may be employed by researchers to meet the theoretical requirements of their research and may involve maximum variation sampling, homogenous sampling and extreme case sampling, as this provides rich and intense descriptions.

Morse (2007) further identifies *shadowed data* as a process whereby participants speak for others, either identifying themselves with a similar class or as being apart from it. Here the researcher looks to other participants who may have similar experiences or who identify with similar classes or groupings that would prompt more in-depth or further sampling. Morse goes on to reject the common belief that purposeful sampling is qualitative research's major weakness, stating that often qualitative inquiry is rather like problem solving and 'detective work' in which the researcher looks for clues and sifts and sorts through all manner of data to 'build a case' (Morse 2007, p. 238). In accordance with Morse's views of shadowed data, I recognised patients who were in similar situations and sought out others who appeared to identify with a similar class or groups. Therefore, this research study utilised purposeful sampling according to the criteria developed below.

Inclusion criteria:

- 75 years and over
- Living in social isolation as defined as active social networks comprising two or less individuals with limited (less than two) meaningful social contacts per week
- Difficulties experienced accessing or navigating primary or allied health services appropriate to their health needs (self-reported or determined through health assessments)
- Able to give informed consent

Exclusion criteria:

- People less than 75 years of age
- Active social contact greater than twice per week

- Active social network/actively sought social contact comprising more than two individuals
- Demonstrated ability to adequately access and navigate primary or allied health care services
- Unable to give informed consent (related to health conditions)

A number of participants (10) were invited to participate, as I felt a larger number of participants would provide too great a volume of data to be reasonably managed within the scope of this project. This is especially the case given the longitudinal nature of the work, in which each participant was interviewed on three separate occasions. The research study was discussed verbally, with potential participants who met the inclusion criteria. At this initial discussion, potential participants were very clearly informed that they were under no obligation to participate in the research, and that their decision would have no bearing on the ongoing care they received from myself and other staff at the medical centre.

These people were then formally invited to join the study via a letter that again clearly indicated that participation was voluntary and that their personal care would not be compromised or affected by their choice to participate or not participate in the study (see Appendix A). Written permission was sought from each client and withdrawal from the project was available at any stage of the study. Couples and single persons of either gender were invited to participate to augment diversity within the small group and invitees included members of disparate cultures and people with a range of health issues, social issues and personal biases. Participants resided in the inner northern suburbs of Brisbane, comprising Brighton, Aspley, Chermside, Kedron, Windsor, Taigum and Bracken Ridge areas.

4.4.1 The Participants

As noted earlier, 10 invitations were posted to prospective participants. Six accepted the invitation. Participants who were willing to participate in the research were posted a plain language statement outlining the research and they were asked to complete a consent form, which was returned to me via a reply paid envelope (see Appendix A). Once received, I contacted each participant to arrange a suitable time and place, at the participant's discretion, to conduct the interview. Of the six participants who accepted the invitation to be involved in this study, five were female and one was male. One participant was widowed and another was divorced. Of the three remaining participants, two attended the interviews with their husbands, while one attended alone. The male participant was single and had never been married. Table 2 illustrates participant demographics at the commencement of the project.

Table 2: Participant demographics

Age	Number of participants	Male	Female	Married	Single	Widowed	Divorced
76	1	0	1	1	0	0	0
77	1	1	0	0	1	0	0
80	2	0	2	1	0	1	0
85	1	0	1	0	0	0	1
87	1	0	1	1	0	0	0

The three single, widowed or divorced participants were not involved in any form of ‘couple relationship’ and lived alone. The three married participants were in heterosexual relationships. Those participants who were married lived independently in their own homes. Two female participants lived independently and alone in their own homes. The male participant lived in his own caravan in a local caravan park. However, at times, he lived in his caravan on his brother’s property. Previous professional occupations of the participants included beauty and hairdressing, nurse education, secretarial services, building trades and public speaking. The one male participant stated he had worked at odd jobs and labouring, while another stated her ‘career’ involved domestic duties and mothering her children. During these years, she was involved in community volunteering and sold craft work to augment household finances. These undertakings were dependent on personal health and ability to maintain such activities.

At the commencement of this study, the overall health of the participants was relatively poor due to the effects of long-term chronic medical conditions that included congestive heart failure, osteoporosis with multiple fractures, diabetes, severe osteoarthritis, hemicolectomy and decreased lung function associated with gastro-oesophageal reflux disease. In view of the considerable deleterious co-morbid health conditions of the participants, extensive ethical considerations were applied to this study.

4.5 Ethical Considerations

In health research in which the welfare and lives of individuals participating in the study may be at risk, ethical considerations play a crucial role in research development and implementation. Polgar and Thomas (1998, pp. 33–35) contend that even when a given research proposal is deemed to be ethical, it may not be seen as moral by specific groups or individuals within the community. Thus, the ethical principles of beneficence, non-maleficence, respect for human dignity, privacy and justice were considered and strictly observed at all times in this study.

As a framework, ethical considerations for this study followed the protocols of the University of Southern Queensland’s (USQ) Human Research Ethics Committee (HREC). In addition, the guidelines developed by the Australian Government National Health and Medical Research Council and laid down in the National Statement on Ethical Conduct in Human Research (2007) were adhered to; specifically, section 2 (Themes in Research Ethics: Risk and Benefit, Consent, pp. 15–24) and section 3 (Ethical Considerations Specific to Research Methods or Fields pp. 25–28). The application for ethics approval was submitted to USQ’s HREC via a detailed information sheet, which included a plain language statement, outlining all aspects of the research proposed. This study did not proceed until ethical approval was obtained from USQ’s HREC(see Appendix F). Once ethical approval was received, a formal letter was drafted introducing me as the researcher, which was subsequently given to each prospective participant. The letter briefly outlined the purpose and aims of the study, the extent of participant involvement and the expected outcomes of the study. Participants were informed of their rights and researcher obligations within the context of the study. Participants were informed that withdrawal from the study was available at any time.

4.5.1 Informed Consent

Informed consent is the canon that governs and regulates participation in research (Schneider et al. 2003), and is crucial to all research involving humans, whether it is for their own or other people's benefit. Rumbold (1993) endorsed the view that any research should be carried out with consent freely given and fully informed. Johnstone (1999) further contended that disclosure, comprehension, voluntariness, competence and consent form the components of informed consent, citing that each individual must be able to comprehend the information given and the implications of giving consent. These well-established guidelines were adopted and adhered to for this research. However, in contrast to these traditionally held beliefs, Eysenbach and Till (2001) argue that, as society embraces the technological age, Internet-based research brings its own unique difficulties when it comes to ethics and informed consent.

Eysenbach and Till investigated methods of conducting qualitative research utilising online chat rooms, discussion boards or mailing lists to obtain data for qualitative research. Issues of privacy, confidentiality and the perceived intrusiveness of researchers to these forums illuminated gaps in traditional ethical protocols, with subsequent suggestions for further investigation and ameliorative action by ethics committees. While this style of informed consent may be applicable to some research methods, it was not appropriate for my study, even though two participants had access to computers. Their rudimentary knowledge, limited dexterity and lack of ability to navigate the software programs made this type of communication unsuitable. However, this researcher recognises that the relevance and significance of this method of conducting research requires further consideration and investigation, as future generations may be primarily accessible by these methods.

Therefore, maintaining awareness of the significance of computer technology and the changing manner in which many people communicate remains a crucial consideration of ethics and informed consent in contemporary society.

Flick (2009) adds another dimension to this issue, claiming that although informed consent is considered mandatory, certain types of research may limit the ability to obtain such consent. Examples given included case studies in which participants interacted with other people (who were not part of the study, and had therefore not consented) on a casual or opportunistic basis. Such limitations were considered particularly relevant in the field of ethnographic and action research. The validity of these points is acknowledged and substantiated in this study, as several participants involved their spouses during the interviews. These spouses were offered the opportunity to consider information about the study and provide informed consent. The need to sign consent forms were waived at the direction of the spouses, who felt that their involvement was incidental, as they were not actually part of the participant group but provided support only when asked by their partner. Some limited comments made by spouses during the interviews were included in the transcripts with their consent.

In accordance with views held by Rumbold (1993), Johnstone (1999) and Flick (2009), participants were informed of the aims, goals, methods and potential risks and benefits of the research verbally, and via a plain language statement and consent form (see Appendix A). A consent form was signed and the right to withdraw from the study at any time was reiterated. There was no cost incurred or remuneration for the participants involved in the study.

4.5.2 Maintaining Confidentiality and Anonymity

The principles of participant confidentiality and anonymity have been entrenched in research ethics for decades (Grbich 1999, Morse and Field 1995, Roberts and Taylor 2002, Schneider et al. 2003) and have been adhered to in this research. All data collected for this research are currently maintained on my password secure home computer network, while the taped interviews are stored in a locked filing cabinet in my home office.

Both Grinyer (2002) and Fluehr-Lobban (2003) discussed issues of anonymity and confidentiality in relation to research participants, noting that orthodox assumptions and ethical codes of conduct are based on the premise that research participants not only deserve the protection of anonymity and confidentiality, but also actively desire it. I acknowledge the ethical concerns associated with legal requirements and accepted ethical standards for anonymity and the traditional boundaries that are crossed when real names are used. However, using participant names is not a ‘new’ ideology, as is evidenced by Fluehr-Lobban (2003), who delineates anthropological challenges to the dictum of confidentiality as far back as the early 1990s.

During the initial development of this research participants were offered textual anonymity, in accordance with accepted ethical practice, utilising numeric coding to de-identify names. However, one participant felt strongly about ‘her story’ and requested that her real name be used:

> *Once you’re past 65 you’re invisible. Don’t rock the boat, keep out of the way, don’t ask for anything, just be invisible, that’s all they want, that’s all they want. Well I don’t want to be invisible. You can use my name, it’s my life, it’s happening*

> *to me and I'm still here. If you use someone else's name or no name at all then—who am I? (Win 86 years 1st Interview).*

This prompted further discussions with other participants regarding issues of anonymity and confidentiality within the *written* context of this study and any publications that may arise. Four felt that they would like to retain 'ownership' of their experiences, while two participants did not mind if their real name or a pseudonym was used. It was collaboratively decided that real first names only would be used in this research. Before the final submission of this thesis, participants were contacted to verify the use of real first names. All supported their decision not to use pseudonyms.

This collaborative decision to use real first names supports earlier work by Grinyer (2002) and Fluehr-Lobban (2003). In her investigation of the effects on families with young adults diagnosed with cancer, Grinyer found that many did not want to use pseudonyms, instead preferring to maintain 'ownership' of their stories. While this may prove an ethical dilemma for many researchers, particularly in view of potential risks of personal revelation, the issue of anonymity should be discussed throughout all stages of the study with the researcher(s) ensuring as far as possible that the participants remain fully informed and that their decisions regarding confidentiality and anonymity are respected (Hadjistavropoulos and Smythe 2001). As noted above, this has been addressed in my work.

4.5.3 Risks and Benefits of Qualitative Research

Qualitative research frequently raises concerns regarding the protection of confidentiality, not only of participants but also of third parties mentioned in transcribed narratives. Attempting to understand people’s experiences from personal perspectives often involves greater interaction and a closer developing relationship with the researcher. This can lead to unanticipated disclosures, which can implicate others not associated with the research. In their study of the elements of potential risks in qualitative research, Hadjistavropoulos and Smythe (2001) highlighted the moral and legal implications of third party disclosure, for not only the participant but also researchers and institutions that sanction research. In addition to third party disclosure, the negative emotional effects of spontaneous self-disclosure were also discussed. Latent depressive feelings could be brought to the foreground, leaving the participants vulnerable and at risk. Hadjistavropoulos and Smythe recommended that ethics committees pay close attention to potential risks involved in qualitative research and instigate procedures and protocols to maximise protection of participants and third parties unintentionally involved in the research process. These beliefs further explicate those of Polit and Hungler (1997), who contend that the risk/benefit ratio is measured in terms of whether the risks to participants are proportional to the benefits to society and health professionals regarding knowledge acquired through the study.

In accordance with the views posited by Polit and Hungler (1997) and those discussed by Hadjistavropoulos and Smythe (2001), careful appraisal of the risks and benefits of this study were undertaken prior to and during the interviewing process. It is acknowledged that the participants have potential emotional vulnerability, which may be increased by the effects of social isolation. In view of this, the interview process was loosely structured, with every attempt made to create a relaxed atmosphere, thus encouraging the participants to reveal sensitivities and opinions at their own pace. The focus of the research was on describing experiences and meanings and participants who desired the presence and support of their spouses were accommodated. Further strategies were implemented to facilitate timely referral of participants to appropriate health professionals if required.

A GP counsellor and clinical psychologist working through the medical centre agreed to assist with participants who experienced any degree of emotional distress due to the personal nature of issues discussed in the course of the interviews. This service was offered free of charge to the participants. An additional safety measure of debriefing after the completion of each interview was also utilised to minimise the potential risks of emotional distress related to unanticipated or spontaneous self-disclosure. Further, to ensure participants' emotional safety, a review with their regular doctor (GP) was offered after each interview. Each doctor agreed to review, assess and address any concerns that emerged because of the interview. This was offered as a Medicare rebated consultation to ensure the participant incurred no financial burden. Each participant was informed of these supportive measures. Formal consent was not required.

While these strategies were offered at timely intervals, no participant chose to have counselling or GP follow-up during the course of this research. All participants indicated they felt no ill effects from discussing personal issues during the interviews and expressed satisfaction with the informal discussion and debriefing at the completion of each interview. Positive feedback was received by several participants, who stated they felt a measure of comfort and relief from being able to talk about their personal issues, experiences and feelings with someone who was prepared to take the time to listen.

4.5.4 Setting for the Interviews

I offered to conduct interviews in the participant’s home, as I felt a more familiar, personal environment would offer the participant both physical and emotional comfort while at the same time allowing me to *experience* first-hand the milieu unique to the individual. It also served as a tangible basis in which to construct questions, while observing nuances within verbal responses and the participant’s non-verbal cues. Permission was also obtained from the Practice Principal for the interviews to take place in the medical centre if the participant preferred.

While the medical centre provided a more structured environment for the participant, it was nevertheless a familiar setting and it was anticipated that this would not detract from the focus of the interview. Local parks were discussed as potential alternative venues for interviews if the participant felt uncomfortable about accepting me into their home or did not wish to be interviewed within the boundaries of the medical centre. However, no participants elected to be interviewed in this setting.

4.5.5 Conducting the Interviews

All interviews were taped. The initial interview was followed by a second interview six months later and a third 10 months after that. Several informal follow up telephone discussions were conducted to clarify meanings of sections of transcribed interviews for several participants. The length of interviews ranged from one, to one and a half hours. All participants chose to have the first round of interviews at the medical centre. For the second round of interviews six months later, one participant requested that the interview be undertaken in her home. This was done with her husband present throughout the interview.

During the ensuing six months, one participant and her husband moved to NSW at the request of their daughter, who resides there. As this participant had significant hearing loss, a telephone interview was not suitable. Thus, for the third interview, questions were posted to the participant, whose written responses were returned in a reply paid envelope. Four of the third interviews were conducted in the medical centre at a time convenient to the participants. One interview was conducted in the participant's home. Additional informal discussions occurred with participants during the following six to nine months, which was documented and added as an amendment to the final transcripts.

4.5.6 Interviewing Style

Initially, I engaged the participants in informal discussions to ascertain the most effective methods for gathering data. Following Glaser's orthodoxy that 'all is data' I decided to utilise open-ended, loosely guided questions in the first interviews. However, during these interviews it became apparent that a more structured approach was needed to elicit specific information relating to experiences with access to health care. Further, as the interviews progressed, I noticed that conversation became stilted and less spontaneous once the tape recorder was turned on. Based on these early observations, I included questions that more easily guided the flow of conversation (see Appendix D) and placed the microphone in a more unobtrusive location to alleviate participant discomfort and create a more congenial atmosphere. Only one participant, a retired nurse educator, was comfortable with having the microphone placed in clear view. As these changes were met with positive feedback, this format was maintained for the remaining interviews.

The general guidelines for interviewing were followed according to the principles of Ivey and Ivey (2003). Strategies and skills such as verbal underlining, verbal tracking, use of silence, paraphrasing, non-attention techniques and attentiveness to body language were among those utilised throughout the interviews. All interviews were taped using a standard recording device once permission was given by participants for this to occur. Data were gathered regarding each participant’s current knowledge base regarding primary and community health care initiatives specific to their age cohort.

I was mindful of Ivey and Ivey’s (2003) view that the purpose of interviewing was to uncover what people think. Therefore, I endeavoured not to influence the thoughts or opinions of others by voicing my own, or by manipulating the framing of my questions to elicit a favourably biased response. This was difficult, as initially I felt that extended silences were uncomfortable for the participant. I attempted to bridge these silences by asking more prompting questions and as a consequence, I constantly reviewed the transcripts for unwarranted leading. In some instances, I needed to ask specific closed questions to elicit particular information that was otherwise not forthcoming. However, this was kept to a minimum. Wherever possible, I avoided questions starting with ‘why’ as they not only presuppose that reasons should be knowable, but in my opinion, they position the interviewer as an interrogator who demands that a position freely stated be defended.

In all interviews, the principle of active listening (Ivey and Ivey 2003), combined with conscious reflection on the circumstances and content of the immediate interview and data gathered previously, provided a mechanism by which new themes could be explored, while continuing to extend and modify those already generated (Francis 2002). Where the participant was married, they were offered the option of having their spouse present during the interview. All participants who were married preferred that their spouse was present, with the exception of one whose husband was suffering from a long-term illness. Some difficulties arose during the interviews with spouses present, as they promoted discord of opinions as to the accuracy of statements made by the participant. In addition, their involvement and additional responses lengthened the interviews considerably. I also question whether the participant's true feelings were fully expressed under these circumstances.

After the initial interviews, the participants' journeys were discussed in the second and third interviews. A combination of open-ended and semi-structured guided questions were utilised accordingly at each interview in an effort to elicit information regarding experiences of access as they navigated their way through the health system in the preceding months.

4.6 Stakeholder Checks

Intra-interview checks were conducted to verify the meaning of participant responses and the accuracy of my interpretations. Limited paraphrasing occurred in the initial interviews, but as I gained experience, this occurred more frequently and appropriately throughout the ensuing interviews. At the completion of each interview, I held a short debriefing to encourage the participant to discuss their feelings on personal issues that had been raised. Participant feedback and reviewing of transcripts were actively encouraged. However, only one participant provided written feedback of her initial interview transcript. All participants preferred to provide verbal face-to-face informal feedback throughout the duration of the study and interview process. Summaries were made of each transcript and these, along with previous transcripts, were discussed and checked for accuracy prior to subsequent interviews.

The following section discusses the development and structure of data collection, coding, diagrams and commencement of analysis as performed in grounded theory. Detailed explanations are provided to facilitate a more complete understanding of the processes involved in a constructivist grounded theory approach.

4.7 Process of Data Collection, Coding and Commencement of Analysis

Data analysis within the paradigm of grounded theory began as a ‘thinking’ process during the interviews. As each interview progressed, stories were read that were compared and contrasted between participants and extant literature. The initial interviews were transcribed and examination of the data commenced (see Figure 1).

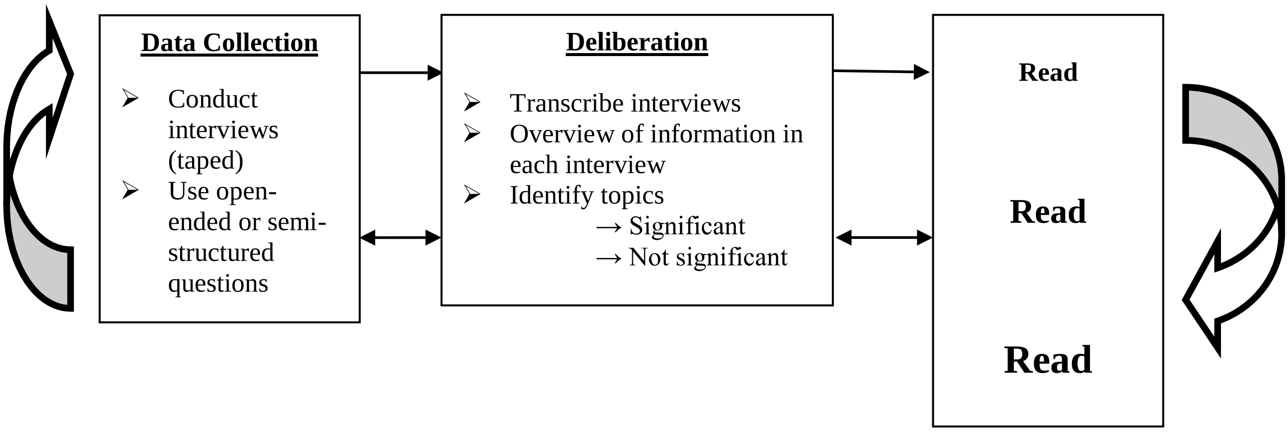


Figure 1: Initial processes of data collection

The taped interviews were co-jointly transcribed by a professional transcribing service and me. To begin with, I read over each one to get a ‘feel’ of what had been said. Firstly, I focused on words alone, then paragraphs, trying to glean inherent meanings. What I wanted at this stage was an overall picture. These feelings or impressions were noted within the transcript. The open-ended questions encouraged participants to voice opinions and were utilised as a guide to elicit increasingly specific responses. For example, the opening questions used for the first interviews included: a) Could you describe your use of health care services? b) How has this been for you? c) Based on your own experience, what are the main things that you have had difficulty with when accessing or finding your way through the health system? Participant responses to these questions were closely scrutinised for similarities in descriptive words. The audiotaped interviews were re-listened to multiple times to ensure accuracy of transcribing. Contradictory statements were noted for later probing. Emphasis, nuances and body language were also noted.

It is acknowledged that the phrasing of the third question, and perhaps others intuitively asked during the interview, assumed that difficulties *were* being experienced by the participant. This was indeed the case, as the participants were selected through the undertaking of health assessments and therefore some prior knowledge of their personal circumstances inevitably existed. It was also part of the inclusion requirement. While this type of questioning may be criticised, I felt its use was reasonable considering my reciprocal familiarity with the participants and the aims of the research.

Participants' views of their experiences with the health care system provided the 'raw' data, and I utilised inductive reasoning to interpret and organise meanings. Although closely aligned with the precepts of grounded theory according to Glaser and Strauss (1967), my analysis incorporated and adopted the views of Charmaz (2006). The theoretical lens from which I approached the phenomena, the strategies I used to assemble or construct data and the understandings that I had about what might count as relevant or important data were all analytical processes that, in part, influenced the data collected and the analysis, which I willingly acknowledge.

Coding occurred simultaneously as an explicit step in theoretically interpreting the data set as a whole. Using specific analytic strategies such as line-by-line coding, raw data were transformed into a new and coherent depiction of the phenomena being studied. Coding involved identification of words and segments of data, which were simultaneously categorised. These categories remained open to allow for additions, with any repetitions noted within codes and categories. This process continued until the third interviews were completed and transcribed. While brief mention has previously been made of these processes, these steps are discussed in detail in the next section in an effort to facilitate transparency of the methods used to generate theory.

4.7.1 Sampling: Selective/Purposeful/Theoretical

There has been longstanding debate regarding the terminology of selective, purposeful and theoretical sampling (Coyne 1997; Glaser 1978, 1992; Glaser and Strauss 1967; Morse 1991; Morse and Richards 2002; Sandelowski 1995). The consensus is that the terms, although having specific literary meanings, encompass the *purposeful selection* of participants, whose information guides the establishment of categories in the coding process, which in turn guides more *theoretical* sampling, as this sampling is now based on and within the codes and categories generated.

At its inception and early developmental stages, this research followed sampling techniques congruent with qualitative methods. Initial purposeful (selective) sampling was undertaken, which extended into theoretical sampling as interviews progressed and data collected were simultaneously coded and analysed. According to Morse (1991) and Coyne (1997), theoretical *and* purposeful sampling occurs when selecting an initial group of participants who have knowledge of the topic being researched. Morse explains that, as the study progresses, more specific information is gained and those participants with explicit knowledge are sought. Glaser (1978) also contends that in grounded theory, theoretical sampling refers to pertinent data that are utilised to expand and clarify categories that will generate theory. Both Coyne (1997) and Charmaz (2006) assert that sampling can be an intricate procedure within the qualitative research setting. Like Morse, Coyne and Charmaz believe these terms are often viewed as one and can be used interchangeably. However, the numerous misconstructions correlating to the different representations of the terminology can sometimes lead to confusion, particularly for novice researchers.

4.7.2 Coding

Coding may take many forms, but all have the overall aim of providing essential links between data and the development of emergent theories. Embedded in the analytical structure of QDA, data were scrutinised by a multilevel analysis achieved via consecutive coding processes, which included initial, focused and theoretical phases (Charmaz 2006). My initial coding consisted of concentrated scrutiny of the data, while I concomitantly maintained an awareness of all potential theoretical directions indicated by multiple readings of the data. I considered sentences and individual words and wrote potential themes in the margins. This focused coding identified recurring ideas and developed prominent categories, and this is where theoretical integration began. My general principles and practices of coding reflected the views expressed by Mills, Bonner and Mills, Bonner and Francis (2006a) and Charmaz (2006), who contend that coding from data is the elemental analytic tool of traditional grounded theorists (and other inductive approaches), which uncovers emergent grounded theory from the domain under investigation. Several coding processes were utilised throughout this study; namely, open coding, axial coding and constant comparative methods, which led to the emergence of themes and theory making. These, together with other analytical processes are discussed in the next section.

4.7.2.1 Open/Line-by-line Coding

I uphold the view of Charmaz (2006), who acknowledges that language plays a pivotal role in how and what researchers code. My codes were constructed as I defined what was revealed in the data. The words chosen to interpret the data reflect my observations. This process was clearly collaborative, as I constructed and phrased my questions according to participant responses elicited from their personal worldviews. Line-by-line coding was adopted for analysing transcripts from interviews in this study. This type of coding was chosen as it allowed me to remain open to the data, increased the perceptibility of the nuances within the data and facilitated a closer view of what participants said and where they had trouble in their narratives. It also minimised my initial premature selection of themes that were possibly less relevant. I followed Charmaz's (2006, pp. 50–53) description of this process by:

a) Breaking data into components
b) Defining the actions on which data rest
c) Explicating implicit meanings and actions
d) Looking for tacit assumptions
e) Crystallising significant points
f) Comparing and contrasting data
g) Identifying gaps

Open coding circumvented the potential to become excessively involved in each participant's construct of reality. As each line of data was coded, I gained insights and ideas and discovered patterns on which I built theory. The preliminary codes assisted me to separate the data into categories and develop major themes. In the initial phases of coding, I identified six main themes, further developing 22 categories and 130 sub-categories. These categories are illustrated in Appendix C.

According to Charmaz (2006), line-by-line coding moves the researcher towards fulfilling the two criteria (fit and relevance) for completing a grounded theory analysis. This study set out to use line-by-line coding to establish categories that reflect and clarify the participant experiences. Relevance is evidenced by the inclusion of a perceptive analytical framework that deciphers what is happening, and allows associations between procedures and constructs to be visible.

Glaser (1978, p. 57) believes that analysing the data line by line, though painstaking and time consuming, ‘is necessary for achieving full theoretical coverage which is strongly grounded’, asserting that:

> The line-by-line approach forces the analyst to verify and saturate categories, minimizes missing an important category, produces a dense rich theory and gives a feeling that nothing has been left out (p. 58).

He appears to have modified his stance in his later years, preferring to focus on constant comparative analyses in which incident is compared to incident, concepts are compared to incidents and concepts are compared to concepts in the generation of theory (Glaser and Holton 2004).

Thus, following Glaser and Holton’s (2004) premise, I undertook open coding as the beginning of my theoretical analysis, which was, in essence, the development of codes from the data, which ended when a core category was identified and defined. In accordance with Mills, Bonner and Francis (2006b), my theoretical codes acted as conceptual connectors that constructed associations that linked categories to their characteristics. I also incorporated Glaser’s more recent perspective, using both line-by-line coding and constant comparisons in this study. Participant interviews were transcribed and each line of text numbered. Multiple readings of each line detected significant and commonly used descriptive words, which were circled, underlined or highlighted.

4.7.2.2 In Vivo Coding

In vivo codes are representative of the participant's spoken words and are often used as quotations, safeguarding the meanings of the participants' personal views (Charmaz 2006; Floersch et al. 2010; Harry, Sturges and Klingner 2005; Thomas 2006). Particular attention was paid in all interviews to documenting the exact phraseology of participant responses. Line-by-line coding assisted here by ensuring that I did not overlook any of the frequently occurring ideas. In vivo codes were used extensively throughout this study because it gave me the opportunity to scrutinise implicit or extant meanings within participant responses. I found that some words or common phrases held different meanings for some participants. This supports the views of Charmaz (2006, p. 55), who states that 'in vivo codes serve as symbolic markers of participant's speech and meanings'. For example, the term 'social isolation' held a different personal meaning for most participants. Specific meanings were clarified and included along with each participant's quotation. I have adhered to the principles of scrutinising implicit meanings and comparing them with explicit statements when building categories and themes.

4.7.2.3 Axial/Theoretical Coding

The main purpose of axial coding is to arrange, manufacture and coordinate significant quantities of data and reconstruct them in innovative ways subsequent to open coding. Grbich (1999) and Charmaz (2006) refer to this process as extracting detailed elements of categories, which subsequently follow the development of a major category. Therefore, my axial coding attempts to connect categories with sub-categories was by determining *how* they are interrelated. I maintained rigorous examination of each category that was created and acknowledge that oscillation between open and axial coding occurred throughout this process. Strauss and Glaser (1967), Strauss (1987) and Strauss and Corbin (1990) provide meticulous procedures for axial coding, which I chose not to implement. Although Charmaz (2006) acknowledges these steps, Glaser (1992) seemed to have reconsidered them since his earlier works and, along with Grbich (1999), now views these as unnecessarily didactic. I followed the later premise of Glaser's constant comparisons of incident-to-incident and incident-to-emerging categories, as they were deemed sufficient to focus and strengthen substantive codes.

In attempting to demystify the process of axial coding, Punch (2005, p. 209), while supporting the views held by Charmaz and Grbich, describes axial coding as the second stage of coding and further explains that it is essentially the idea of placing an axis through the data that links the categories determined throughout the process of initial open coding. While this may be a valid process, I have demonstrated that Glaser's (1978) more general *theoretical coding* amply describes and can be applied to this stage. Links to themes, categories and sub-categories and their associated interrelatedness can easily be identified, as one remembers that one category or theme does not produce an effect in isolation, but is influenced by the presence of those surrounding it. Thus, the purpose of axial coding is to identify the characteristics and size of a category, while providing links to categories and sub-categories and contributing answers to why these relationships exist. Consequently, axial coding pursues the growth of a main category from its embryonic stage of development. Charmaz (2006) also provides evidence within her own research for *omitting* axial coding, instead developing categories and sub-categories and providing links between them (pp. 60–61). While no specific mention is made to the core category, the links made between categories and themes relate to the central empirical focus. I believe that this is a form of axial coding and wonder if this is a case of the manipulative use of language to describe an already established process.

Although I acknowledge the veracity of the views held by Charmaz, I firmly believe that the processes of axial coding strengthens the associations and interrelatedness of emergent themes and genesis of categories, facilitating a more detailed and complete representation of the data. My general methods of theoretical coding revealed similar words and phrases used by participants to describe comparable circumstances and experiences when attempting to access specific health care requirements. Initially these words and phrases were coded separately. These were subsequently re-grouped and further coded as new links or extensions of the same were identified. This process was repeated until saturation of the data was obtained and no new categories could be found. Memo writing began alongside the identification of categories. My memos were not extensive. However, they facilitated exploration of categories and informed the process of further data collection.

4.7.2.4 Memos

I undertook writing brief memos simultaneously during open coding. This involved writing brief notes that were prompted by my thoughts and ideas. There is no fixed method on how to accomplish early memo writing. Each researcher has his or her own unique way of capturing and conceptualising initiatives. I focused on particular descriptive words or phrases and wrote corresponding comments in an adjacent column next to the transcribed text. Glaser (1978, p. 61), Strauss and Corbin (1998, p. 218), Fernández (2004, p. 86) and Charmaz (2006) depict memos as early theoretical writings that elevate theoretical levels through the constant process of comparing and conceptualising. These memos were the basis of the summaries for each interview, informing and directing further questions in data collection.

4.7.2.5 Flexible Focus

As stated above, memos were written throughout examination of the transcripts, which allowed a flexible focus to be maintained. These memos were incorporated into the process of coding, which consequently enhanced the richness of the data collected. Coding involved a sustained systematic process throughout the initial readings of the data, with identification of new categories more easily linked by the concomitant use of memos alongside significant words or phrases (Charmaz 2006; Glaser 1978; Grbich 1999; Hoepfl 1997; Layder 1993). A combination of code memos (relating to open coding) and theoretical memos (those relating to axial coding) were utilised to assist formulation and modification in theory generation throughout the research process (Strauss and Corbin 1990).

I believe that by its very nature, qualitative research must retain a flexible focus and employ equally flexible techniques of data collection and analysis (Layder 1993). As new categories arose, I used my intuition to construct probes to further explore issues. In doing so, I acknowledge that I am an integral part of the data. Thomas's (2003) claim that researchers unfamiliar with traditional processes involved in qualitative analysis often find existing literature 'too technical to understand and use' (p.2) implies that following rigid steps impedes full, creative exploration of the problem. It also could be interpreted as meaning that researchers using the general inductive approach take shortcuts to simplify reading, data collection and analysis. However, I reject this. If one's research findings are to be taken seriously, there can be no shortcuts in the rigour applied. Good qualitative research is necessarily time consuming, mentally challenging and thorough.

4.7.2.6 Constant Comparisons

Maintaining a flexible focus facilitates recognition of new issues, thus ensuring data collected are of sufficient depth and diversity to inform the research questions. To achieve this, constant comparing of data sets helps to clarify categories and themes, delineate patterns and frame discourses. In this study, constant comparative methods were used to ascertain analytic differences and similarities and were conducted at every level of analytic work. In her constructivist approach, Charmaz (2006, pp. 187) defines constant comparative method as:

> a method of analysis that generates successively more abstract concepts and theories through inductive processes of comparing data with data, data with category, category with category, and category with concept. Comparison then constitutes each stage of analytic development.

Comparisons within data are important to identify variations in the patterns found. In some instances, the similarities and differences are easily identifiable. Although readily identifiable as a classic grounded theory process, general qualitative approaches may also adopt and adapt these strategies as I did, comparing incidents to incidents, concepts to incidents and concepts to concepts. Throughout the process of coding, I utilised the technique of constant comparisons (Charmaz 2006; Strauss and Glaser 1967) to establish differences and similarities at each level of analytic work. Sequential comparisons were also made between the first, second and third interviews. These methods were adapted from Strauss and Corbin (1998) and Charmaz (2006) to scrutinise the boundaries connecting construction and method to illustrate the interaction involving social groups and their epistemological and ontological worldviews.

In this study, the interview responses of each participant were compared to responses from other participants for each interview. In addition, data were sequentially compared and cross-referenced over a longitudinal timeline to locate and identify similarities and differences. I also searched for contradictions inter and intra-participant interviews. Similar to other researchers in nursing and other social sciences using qualitative methods, I applied the techniques of more traditional approaches, increasingly selecting, over the period of the study, those that had the potential to generate meaning within the social experiences and constructs of participant realities.

4.7.2.7 Saturation

In this study, these emergent categories and themes were initially grouped together sequentially. When no more categories could be extracted from the text, saturation was achieved. The categories were again scrutinised to identify patterns and ascertain links and relationships between categories, with the subsequent development of substantive codes, and with a core theme finally identified. Raw data in the form of quotations were also utilised to preserve accuracy and the intent of participant responses. Implicit and condensed meanings were also integrated into the memos.

4.7.2.8 Diagrams

Diagrams, which are often an essential element of the coding process for qualitative researchers, were utilised in initial coding processes and within higher-level analyses. The use of diagrams illustrates the intricate connections between the different levels of conditions (Hoepfl 1997; Huberman and Miles 2002; Miles and Huberman 1994; Schooley 1995; Strauss 1987; Strauss and Corbin 1990, 1998). Schooley (1995) discussed the application and practicability of Venn diagrams and Chenail's Research Diamond in qualitative studies, indicating that both conceptual tools assist in evaluating the feasibility and coherence of project designs. In accordance with these views, I constructed and altered diagrams as the study evolved. Although not all of these found their way into this thesis, they helped clarify my thinking and many will be revisited in future writing.

Charmaz (2006) supports the use of diagrams as they offer concrete images of ideas while providing visual representations of categories and their relationships. I consider diagrams an integral part of method, as they allow me to illustrate relationships between categories by offering a visual platform for readers of the thesis. Strauss and Corbin (1998, p. 238) discuss memos and diagrams as a simultaneously evolving process throughout the empirical analysis, stating that:

> Diagrams in selective coding show the density and complexity of the theory. Because of this, it is often difficult to translate the theory from words into a concise and precise graphic form. Yet, the very act of doing the final integrative diagram will help the analyst finalize relationships and discover breaks in logic. In the end, it is important to have a clear and graphic version of the theory that synthesizes the major concepts and their connections.

I developed categories and sub-categories that were then grouped sequentially. The schematic representation below (see Figure 2) follows on from the initial data collection and illustrates the concurrent stages of coding, process of analysis and the generation of categories and themes.

By constantly comparing text and codes to identify similarities and discrepancies, sub-categories were identified that led to the construction of expansive themes. During the initial interviews, 22 categories were identified that incorporated 130 sub-categories, which are depicted in Appendix C. These categories were generated according to participant accounts of their feelings regarding the ageing process and included, but were not confined to, personal wellbeing, illnesses described, difficulties with transport, self-perception and experiences in accessing health care.

Theories were developed and the accuracy of findings was evaluated by intra-interview respondent validation. Primary themes were further developed and theories were constructed and defined. Participant quotations, or ‘in vivo’ codes, were written verbatim from the transcripts to maintain auditability of original meanings.

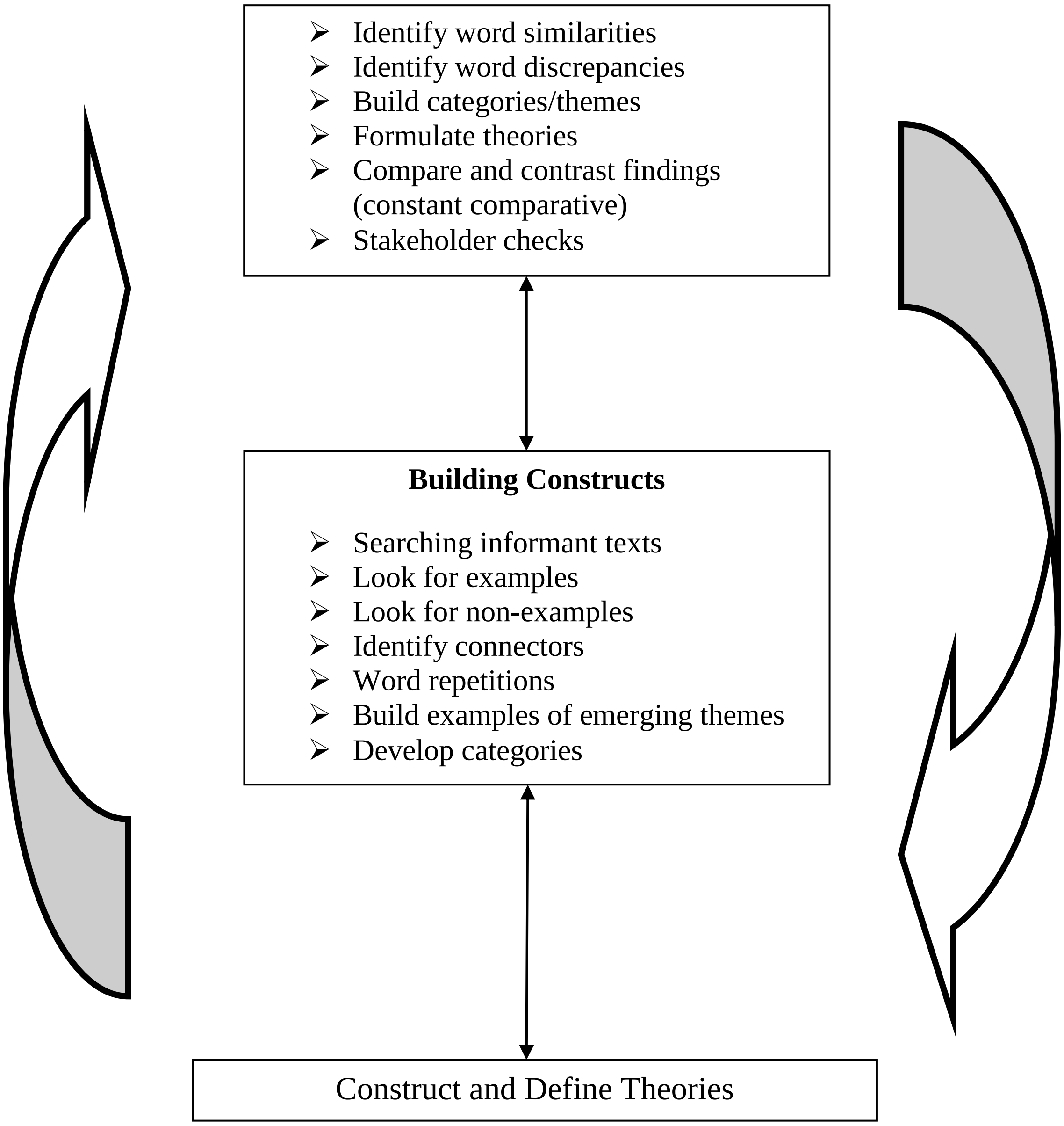


Figure 2: Process of simultaneous coding and generation of categories and themes

Grammatical errors and omissions within participant quotations are followed by [sic]. This bracketing format is also used for explanatory supplementary text. Parentheses have been used to identify the participant and the number of interview. An ellipsis is used to indicate omitted text within quotations.

4.8 Theoretical Sensitivity within this Study

There are many dimensions to theoretical sensitivity, with authors such as Strauss and Corbin (1990), Charmaz (2006) and Mills, Bonner and Francis (2006a) asserting the importance of researcher insight into the area being studied. In keeping with the views of these authors, the prime focus of theoretical sensitivity in this study centred on my attentiveness and insightfulness to nuances and complexities within the data. Further, significant attention was paid to identifying what was important, and isolating what was not. I identified potentials, established connections within the data and built on information given in previous interviews, tailoring my enquiries and interviewing techniques to gain more pertinent and specific information. Further, I recognised and developed concepts based on patterns and conscientiously responded to nuances, clues and meanings within the data, thereby overcoming boundaries interconnected with personal experiences. I concur with the views held by Morse and Field (2003, p. 133) regarding theoretical sensitivity, which hold that:

> Theoretical sensitivity is the ability of the researcher to recognise what is important in the data and to give it meaning. Theoretical sensitivity comes from continual interaction with the data through collection and analysis and by being well grounded in the technical literature. If the researcher is sceptical and uses constant comparison, data contamination will be avoided and theoretical sensitivity will be achieved.

These concepts were closely adhered to within the framework of my study, with particular attention focusing on potential theory and development of models and relationships that may generate theoretical insightfulness. Two essential characteristics are necessary for the growth of theoretical sensitivity (Glaser and Holton 2004). The first is the ability to sustain investigative detachment and tolerate disorder and regressions. Secondly, one must maintain awareness of preconscious processing methods and be perceptive towards theoretical emergence. While the first of these proved difficult and frustrating at times, I maintained constant awareness of these characteristics throughout the interview process, and checked for transgressions after each interview. I remained mindful throughout the process of collecting, collating and analysing the data.

4.9 The Process of Data Analysis

I chose a linear descriptive method to assist the reader in understanding the processes involved, which led to the initial emergent findings building upon information and interpretations of participant experiences. This journey takes the reader from the amorphous beginnings of deciphering patterns, through the construction of categories and themes, to the eventual identification and discussion of the core theme. The process followed was in accordance with Charmaz (2006), whereby:

- Raw textual data were condensed into a brief summary format.
- Clear links were established between research objectives and summary findings derived from the raw data to demonstrate transparency and defensibility.
- Theory was constructed about the fundamental framework of experiences evident in the textual raw data.

Explicit themes (those that provide direct answers to specific research questions) and implicit themes (themes that fit into the overall context of the dialogue and connect with other aspects of the text) were identified and manually colour coded throughout transcription of the interviews. The text indicates a more orderly and sequential building of what was essentially a messy and very complicated process.

These themes were reviewed against the research aims and objectives. Precise transcribing of the interviews ensured accuracy and lessened the potential for personal interpretations of the participants' responses. Categories and sub-categories were generated using line-by-line coding. In addition, words and phrases with similar meanings were grouped together and re-coded to reduce the number of sub-categories and categories that were placed into major themes. This led to the 'core theme'.

4.10 The Significance of the Core Theme

Initially, I had difficulty with the different terms used here—for example, core category, central category and central theme but I resolved this by focusing on how the categories related. The fundamental position of the core category incorporates all of the theory's diverse features. According to Strauss and Corbin (1998, p. 146):

> The central category (sometimes called the core category) represents the main theme of the research. Although the central category evolves from the research, it too is an abstraction. In an exaggerated sense, it consists of all the products of analysis condensed into a few words that seem to explain what 'this research is all about'.

In addition, the 'central category has analytic power because of its ability to pull the other categories together to form an explanatory whole' (Strauss and Corbin 1998, p. 146). Fernández (2004) describes the core category as being the pivotal point of theory, as other categories relate to it and it accounts for most of the variation in pattern and behaviour (p. 89). Fernández (2004) and Glaser (1978) postulate that the prime function of the core category is to integrate theory and cause it to become thick and saturated as emergent relationships increase.

Glaser and Holton (2004) and Jeon (2004) reiterate the purpose and significance of the core category, which, in broad context, accounts for variations concerning the issue that is the focus of the empirical research. In their elucidation, Glaser and Holton (2004) also consider that the core variable can constitute any kind of theoretical code or process with its primary function being integration of densely saturated theory . Thus, before the core category can emerge, constant comparisons across the data must be undertaken.

In this study, main themes were tangibly recognised during the initial coding process. Subsequently, the main categories identified with sub-categories were linked to developing themes. Six main categories encompassing experiences of loss, dependence on others, the influence of doctors, personal feelings on ageing, powerlessness and utilisation of services were developed. This resulted in 58 sub-categories. Through multiple re-readings of the transcripts, these themes and sub-categories were re-structured to define links and relationships more clearly. The resultant reduction of themes and sub-categories now comprised: 1) dependence and sense of loss, 2) illnesses described, 3) transport issues, 4) a sense of powerlessness, 5) waiting times for services and 6) becoming invisible, with sub-categories remaining extensive. Fear was initially established as the core *link* towards the end of the second interviews, after significant coding had been completed. Fear, an emotion or feeling stated in a myriad of ways, remained a recurring link in the data, thus representing the main themes and initially providing an explanation of the phenomena being studied. Further analysis of the data set which included the third set of interviews, revealed an ongoing process that altered the core theme, revealing less emphasis on fear, but other increasingly strongly held emotions and concepts. These findings are discussed in detail in Chapter Five.

4.11 Verification (Rigour)

The applicability of the term ‘rigour’ has long been debated in the qualitative arena, with some researchers (Guba and Lincoln 1981, 1982, 1989; Sandelowski 1986, 1993) suggesting renaming its analytical process to more accurately portray its different epistemological assumptions. However, Morse, Barrett, Mayan, Olson and Spiers (2002) strongly oppose these views, categorically stating that the use of parallel terminology delimits qualitative investigation from mainstream science and scientific legitimacy. Morse (1997) further argues that rather than explicating the term, the pursuance of alternative criteria undermines the issue of rigour. I do not intend to debate this ongoing issue within this thesis. However, I believe there are valid arguments for maintaining traditional terminology along with re-defining and re-contextualising criteria to further establish scientific legitimacy. These five well-known dimensions were considered when evaluating rigour in this research.

4.11.1 Credibility

In qualitative research, credibility is a term that relates to accuracy or authenticity of data obtained from participants (Beck 1993; Chiovitti and Piran 2003). This is often achieved using participants’ own words and ensuring statements and meanings are represented precisely. Credibility in this research was maintained by member validation. Feedback from participants was sought to ensure that findings accurately reflected their experiences. Each participant was offered a copy of his or her transcript for comment. As several participants declined to read their transcripts, a detailed process of intra-interview respondent validation was utilised to confirm or refute my interpretation of responses. In addition, summaries were constructed from the transcripts and discussed with each participant to establish accuracy of findings and truthfulness of contextual representation.

4.11.2 Auditability

In addition to credibility, auditability is used by researchers to ensure rigour. This can be achieved by the construction of a decision trail that can be scrutinised by researchers to determine the consistency of the procedures and techniques of a research project (Chiovitti and Piran 2003). To address this, I have specified recruitment criteria, sampling techniques and why participants were selected for this study. I have also provided details of the processes used to analyse data. The coding of both explicit and implicit themes is included so the reader can understand how interpretations of meaning were achieved. My techniques follow the guidelines suggested by Grbich (1999, p. 62), who believes that auditability enables the tracing of the conceptual development of the research from raw data, coding, analysis and findings.

4.11.3 Fittingness

Fittingness is transferability with further discussion centred on the naturalistic paradigm (Hoepfl 1997). In this study, the transferability of generated theories to other situations depends on the degree of similarity between the original situation and the situation to which it is transferred. Lincoln and Guba (1985) argue that the researcher cannot specify the transferability of findings. However, they can provide adequate information for readers to determine whether the findings are applicable to other situations. Schneider et al. (2003, p. 150) and Roberts and Taylor (2002, p. 380) add that fittingness relates to the use of literature to maintain or disprove the concepts that emerge from data. However, Trochim (2002) suggests that there are unpredictable elements in qualitative research, arguing that researchers are likely to begin formulating their own ideas about causative phenomena. In this study, particular attention has been paid to maintaining accuracy of interpretations within the data.

It is envisaged that the concepts and conclusions of this study will reflect the worldview of the participants as shaped in the particular context of our interactions. In addition, I have integrated strategies to achieve credibility and fittingness, as conveyed by Davis (1997). These include:

1. Checking that descriptions and explanations are accurate by obtaining validation from the participants
2. Checking for the representativeness of the information as a whole, giving consideration to the coding of categories, reduction of data and presentation of data
3. Consciously attempting to disprove a conclusion drawn from the data

It is acknowledged that independent analysis of data by another researcher can serve to establish credibility. This was achieved through regular reviews by my supervisor at USQ and other postgraduates. It is anticipated that this study’s findings will be relevant to other applications and other age groups within the health care framework.

4.11.4 Confirmability

Confirmability is attained when credibility, auditability and fittingness can be established (Roberts and Taylor 2002, pp. 380–381). Davis (1997) agrees with this view, but argues that confirmability is also based on engagement between researcher and participants with emphasis placed on the subjective reality of the participant's life experiences. In this study, participant discourse was valued and active involvement in various stages of the study was sought through voluntary feedback and transcript validation.

4.11.5 Trustworthiness

Trustworthiness of findings was determined by feedback from the participants in the study. This was achieved by verbally summarising the data at the completion of each interview. Participants were encouraged to correct errors, clarify my interpretations and add further views. Therefore, my process of coding entailed:

a) Initial readings of transcripts of interviews, followed by multiple re-readings
b) Identification of specific segments of information through line-by-line coding and the grouping together of similar of words and phrases
c) Construction of categories and sub-categories, remembering that segments may be in more than one category. Where possible, segments were combined to reduce overlap and redundancy
d) Development of a model that incorporated the most significant categories and major themes

However, another perspective, *strength,* can be related to rigour. Greenhalgh and Taylor (1997) argue that the strength of qualitative research lies in validity (closeness to the truth), thus contradicting several theorists (Glaser 1992; Strauss and Corbin 1997) who contend validity is a quantitative concept. Further testimony from Giacomini and Cook (2000) reveals the apparent acceptance of the implicit meaning of validity, though the term ‘valid’ is avoided in favour of ‘credibility’ to more accurately express this concept when viewed in the context of qualitative research. In this research, I did not attempt to control variables but rather invited the rich array of possibilities and investigated them directly (Holliday 2001). I view the non-controlled element of human experience as critical to the qualitative paradigm. Therefore, my aim was to gain an in depth understanding of the experience of particular individuals within their specific milieu. My view was informed by Thomas (2006), who, in his article *a general inductive approach,* discusses the four aspects of trustworthiness as outlined by Lincoln and Guba (1985). Credibility, transferability, dependability and confirmability are terms deemed more suited to qualitative analysis. These terms were adopted within this study in their broader context in accordance with Thomas’s views and are inclusive of my choice to avoid the term ‘credibility’ within this study.

4.12 Conclusion

This chapter was presented in two sections. First, the reader was introduced to the methods undertaken to produce this research. Second, the more intricate details of the processes involved in data collection and the genesis of theory within this project were presented.

To accomplish the aims of this study of socially isolated older people in their accessing of health care services, it was important not to enforce previously conceived categories and perceptions, stemming from my own professional knowledge base, onto the method of data collection. To achieve this, I tried not to separate the stages of planning, data collection and analysis, but to go back and forth between the raw data and the method of conceptualisation, as shown in Figure 2. In this way, I could make logical deductions from the data during the phase of data collection. Mays and Pope (1995) and Pope and Mays (2006) support the value of this type of ‘standalone’ qualitative research, as it is progressively more widely acknowledged in investigations relating to health service institutions and health policies. I have supported these authors’ views that this type of research may be particularly valuable in analysing health services in times of restructuring or policy change from the point of view of the patients and health professionals. The next chapter formalises the process of analysis and the evolution of the core theme.

CHAPTER FIVE: ANALYSIS AND INTERPRETATION OF FINDINGS

5.1 Introduction

Ageing is a natural process and, for many people, it can be a positive and rewarding journey. However, as the following analysis reveals, some older people’s journeys are difficult and protracted due to the influence of social isolation. The participants in this research give voice to the specific problems, barriers and pitfalls they have encountered while navigating the health care system to meet their health needs. Simultaneously, the participants’ changing perceptions of self, and how they view society’s perceptions of their presence, is discussed.

This study provides evidence that ageing and declining health bring unique difficulties to those living in social isolation. As the literature review demonstrated, a multiplicity of influences, including psychosocial, cultural and economic factors, can negatively affect an older person’s ability and, at times, willingness to accept assistance or professional care. For this reason, discussion of the participants’ relevant personal circumstances is included in this chapter, to facilitate a more complete understanding of their journeys.

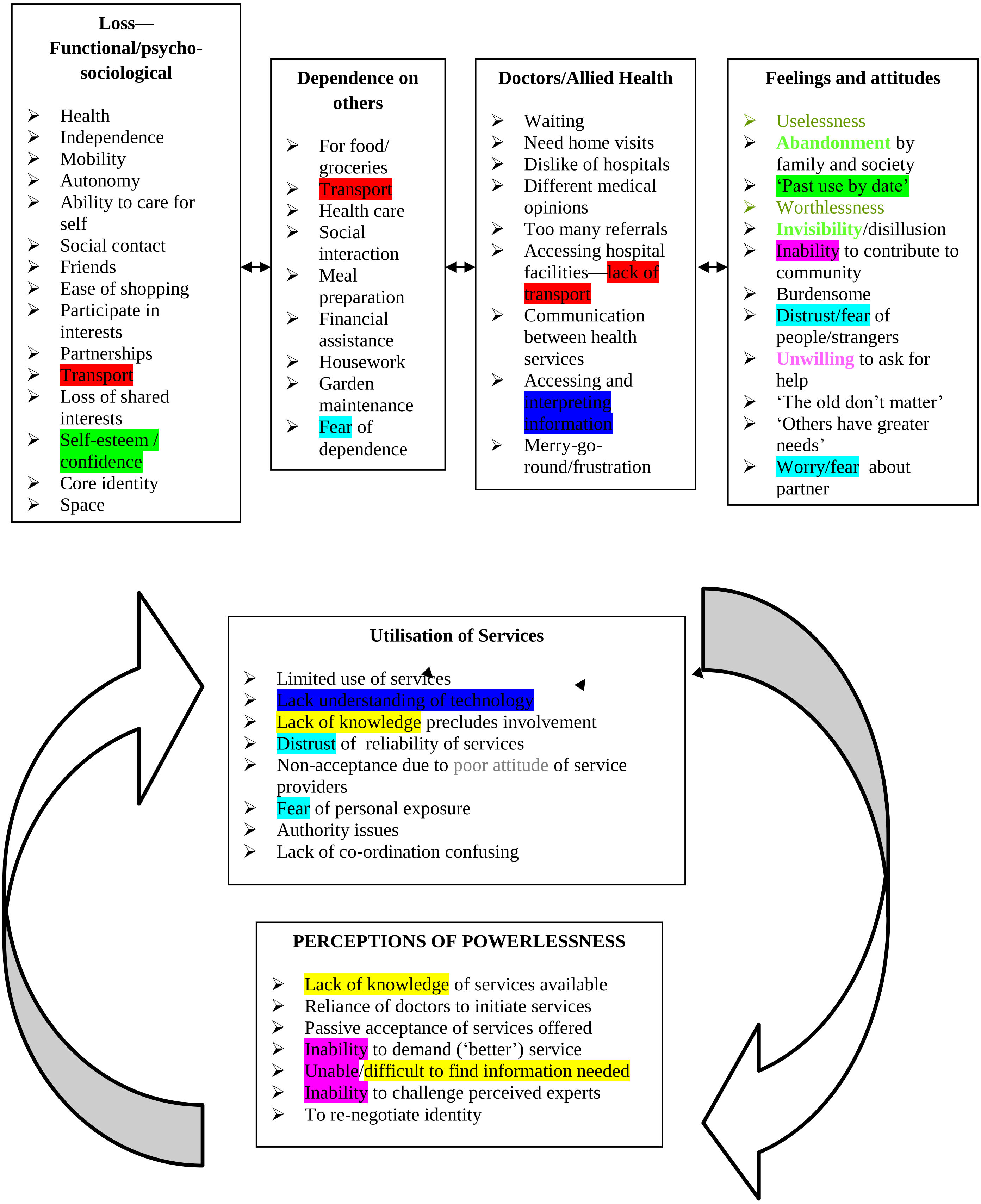
The previous chapter described the method for this research, which included an outline and description of the choices made and steps taken for participant recruitment and selection, mode of data collection and the beginning of analysis, according to the tenets of classic grounded theory. The move to a constructivist approach was informed by Charmaz (2006), who contends that reality and meaning making is an interactive process between participants and researcher, resting within cultural and structural contexts. Thus, the shift from classic grounded theory to a constructivist approach more closely aligned with Charmaz (2006) and Morse and Field (1995, 2003), though still maintaining its rigorous methods, was explicated throughout Chapter Three, before being further demonstrated in Chapter Four. Ethical considerations embedded within these processes, which nest alongside issues of anonymity and confidentiality, have been comprehensively discussed in Chapter Four. Rigorous processes of identifying and constructing categories, sub-categories and themes grounded in the data have been provided in these previous chapters, along with the use of diagrammatical representations to illustrate these processes.

The focal point of this research is to gain an understanding of the experiences of socially isolated older people as they access and navigate the health care system. By adopting a constructivist approach, social processes, personal beliefs and attitudes that may influence these interactions were explored to ascertain the ways in which these factors affected accessing health care needs. This chapter analyses and discusses the findings of this research, following its longitudinal progression.

In writing this analysis, constant referral is made to the data to reveal how they have been shaped to reflect participant circumstances and perspectives. Adhering to the views and guidelines of Morse and Field (1995) and Charmaz (2006), I remained aware that my interaction with the participants *produced* data that were subsequently co-constructed. Therefore, I revisited the data (including memos and summaries) and my constructions of themes, categories and sub-categories in an attempt to more clearly *see* the processes involved and how they shaped or influenced the ontologies and epistemologies of the participants. Accepting the centrality of my role as co-author of ‘meaning making’, I further reviewed the categories and their positioning, which resulted in adaptations, renaming and enhancements of each category within the diagrammatic models.

I have opted for the somewhat unusual format of firstly introducing some diagrams to give the reader a better sense of the complexity and thoroughness of the process. The participant stories follow later in the chapter, beginning in Section 5.1. The overlaps visible within categories are consistent with the process of a constructivist approach to grounded theory as some sub-categories fitted into more than one category or theme. Figure 3 depicts the overlaps of sub-categories, which are highlighted in different colours to assist recognition of patterns and significance. Softer colours of the same colour palette were utilised for text in which different words were used to convey similar meanings. Further discussion revealed an underlying ‘uneasiness’ or ‘worry’ regarding many aspects of health care and ageing in social isolation.

Analysis continued throughout the first interviews, with preliminary codes, categories and themes gaining density as similarities across participant experiences were identified. As the line-by-line coding progressed and the significance of these incidents increased, categories were re-assembled and renamed according to experiences across the participant group. This resulted in the generation of Figure 4, which represents the issues confronted and feelings generated within the participant group during the first interviews relating to health, personal circumstances and interactions with the health system.



Loss—Functional/psycho-sociological

- Health
- Independence
- Mobility
- Autonomy
- Ability to care for self
- Social contact
- Friends
- Ease of shopping
- Participate in interests
- Partnerships
- Transport
- Loss of shared interests
- Self-esteem / confidence
- Core identity
- Space

Dependence on others

- For food/ groceries
- Transport
- Health care
- Social interaction
- Meal preparation
- Financial assistance
- Housework
- Garden maintenance
- Fear of dependence

Doctors/Allied Health

- Waiting
- Need home visits
- Dislike of hospitals
- Different medical opinions
- Too many referrals
- Accessing hospital facilities—lack of transport
- Communication between health services
- Accessing and interpreting information
- Merry-go-round/frustration

Feelings and attitudes

- Uselessness
- Abandonment by family and society
- 'Past use by date'
- Worthlessness
- Invisibility/disillusion
- Inability to contribute to community
- Burdensome
- Distrust/fear of people/strangers
- Unwilling to ask for help
- 'The old don't matter'
- 'Others have greater needs'
- Worry/fear about partner

Utilisation of Services

- Limited use of services
- Lack understanding of technology
- Lack of knowledge precludes involvement
- Distrust of reliability of services
- Non-acceptance due to poor attitude of service providers
- Fear of personal exposure
- Authority issues
- Lack of co-ordination confusing

PERCEPTIONS OF POWERLESSNESS

- Lack of knowledge of services available
- Reliance of doctors to initiate services
- Passive acceptance of services offered
- Inability to demand ('better') service
- Unable/difficult to find information needed
- Inability to challenge perceived experts
- To re-negotiate identity

Figure 3: Integrative development of codes and categories and emergence of themes

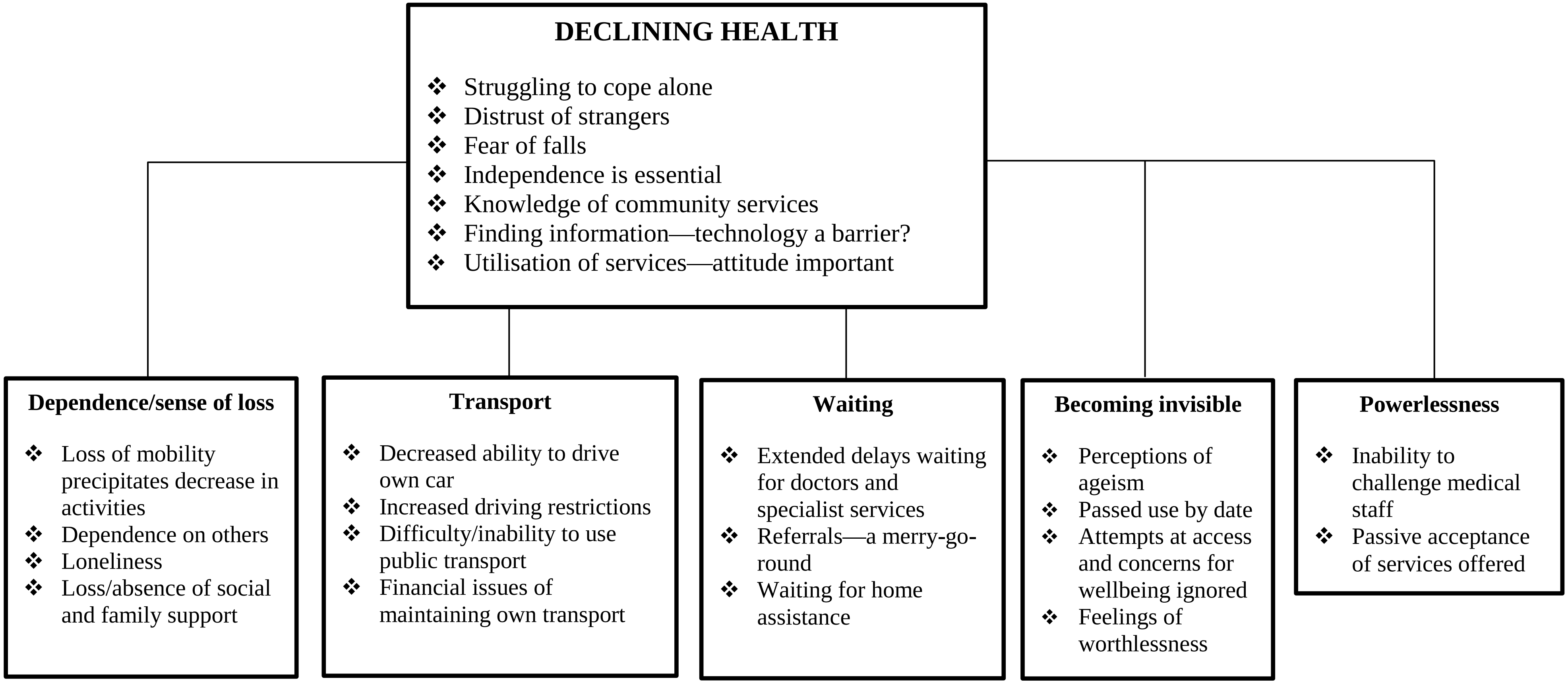


Figure 4: Theoretical coding after initial interviews

Information elicited from the participants revealed that difficulties were experienced in a variety of settings. These were voiced in a multiplicity of terms. My decision to use ‘topic’ headings in conjunction with participant dialogue was influenced by this divergent use of language by the participants to illustrate or explain events, feelings or personal situations that held significant meaning. Further, as the interviews progressed, new themes and categories emerged, while others were integrated into existing categories broadening their scope and meaning. Several sub-categories remained somewhat amorphous, fitting equally within two or more main themes. For example, a sub-category of the first main theme, ‘independence is important’, was generated when discussing issues of dependence and loss. This encompassed not asking for assistance and maintaining the participant’s current lifestyle. However, independence regarding maintenance of private transport and driver’s licences was also important.

Despite the significance of this category, I decided not to make it a main theme. This is because over-riding the need to maintain independence was a profound reluctance across all participants to be dependent on others. For these participants, the maintenance of independence in the face of the social, economic and personal losses that permeated many aspects of their lives was of the upmost importance. In view of these findings, categories and themes were renamed or modified throughout the constant comparison of data within and across interviews. It is within this framework that I have introduced and represented the participants’ voices through extensive use of quotations to more accurately demonstrate their personal perspectives. Consequently, the final theme headings were modified to the following:

- Declining Health—'I can't do the things I used to'
- Dependence/Sense of Loss—'You lose yourself—everything'
- Transport—'I want to travel like everyone else'
- Waiting—'A merry-go-round'
- Becoming invisible—'Only the young matter'
- Powerlessness—'People just don't listen'

These six main themes, generated from the data, invoked the most prolific responses from the participants overall, spanning perceptions of the effect of declining health and illness along the health/wellness continuum, increasing dependency and loss of functionality, problems with transport options, extended waiting times for medical consultations and feelings of invisibility and powerlessness. The central theme, which is discussed in detail later in this chapter, incorporated strongly felt interconnected feelings of anger, frustration, disillusionment and fear. I found that the intense feelings portrayed by most participants did not occur as one entity alone, but rather existed as an interrelated closely knit 'family' of feelings with one (or more) taking precedence over another, depending on the situation confronting the individual at any given time.

The major themes and sub-categories are discussed, incorporating a longitudinal period that maps the progression and interrelatedness of factors influencing social isolation and the subsequent effects on the participants and their experiences in accessing their health care needs. The poems that precede discussion of each theme have been inspired by participant comments in the interviews and have been taken directly from the transcripts. Each line represents an experience or thoughts of each participant and has a specific relevance to each of the categories within the theme.

Progressively, meanings were uncovered, and theory gradually took shape as the data revealed rich descriptions of the problems experienced by the participants as they attempted to access the health system. Stories told in the initial interviews appeared to remain static with little or no differentiation in progression of ability to access health care needs over a twelve-month period, revealing that the same or similar difficulties were continually being encountered. However, there was a marked change in the level of emotion as health declined and services failed to meet expectations. Gradually declining health, increasing difficulties in coping and not knowing where to look for service providers was a problem encountered by all of the participants. The poems that begin the sections that follow are mine, but encapsulate words and phrases spoken by the participants throughout the interviews.

5.2 Declining Health

Sore feet, gnarled hands

Eyes that cannot see

The now withered face

My slower pace

Just so I can breathe

I used to run and jump

Without thought for falls and broken limbs

But while I was preoccupied

Old age caught up with me

As we age our bodies change in numerous ways, which ultimately affects the way we function. These changes occur incrementally and progress over time. However, the rate of this progression varies from person to person. Both genetic and environmental factors play a pivotal role in how people age. Recognising that every individual has their own unique genetic make-up, personality and environment, which interrelate with each other in a dynamic changing relationship, helps health professionals understand the divergent needs of older people. These are often difficult to ascertain particularly in socially isolated older people. This section discusses the effects of declining health and ageing in isolation from the perspective of the participants and encompasses their coping strategies, feelings about strangers, fears of falling and personal safety, the importance of maintaining independence, knowledge of community services, the role of technology in accessing information and finally, utilisation of services.

5.2.1 'I can't do the things I used to' (Bette)

For the majority of participants, decreased ability to continue activities and maintain social connections signalled significant life changes. Interestingly, there was an overall impreciseness regarding awareness of onset of these changes. Some recalled noticing small difficulties in routine activities such as gardening or home maintenance in their early fifties. Others only became aware of the impact of their restricted abilities much later in life, though no definite age-delineated time frame was identified. As the poem at the beginning of this section, which is constructed from participant comments illustrates, over an indefinable period, activities that were once taken for granted began to require the assistance of others; for example, one's spouse, family member, neighbour or friend.

Where these networks were minimal or absent, each participant coped to the best of their ability in isolation.

For some, issues of acceptance of assistance were linked to a pervasive sense of mistrust of strangers, which was identified as a significant barrier to accessing supportive community services. Further, maintaining personal and financial independence remained vital to all participants, who often improvised home repairs and maintenance or just ‘put up’ with the deterioration of their surroundings, rather than burden infrequently seen family or friends with their needs. Throughout the three interviews, which spanned a two-year period, a consistent lack of awareness of community services persisted, despite information being provided or reiterated at each interview.

Although illness is not exclusively associated with the ageing process, recovery from or development of chronicity states appear to be more difficult to cope with, especially for those living in social isolation. Declining health was experienced in both similar and divergent ways by the participants, who believed that their illnesses, along with their increasing physical limitations, were an inevitable result of their advancing age and something that had to be endured. The following section discusses how issues of coping, the challenges of accepting strangers into one’s home and the significance of maintaining independence affects the accessing of health services to address health care needs.

5.2.2 Struggling to Cope Alone

Maintaining the ability to cope with everyday life and the challenges it brought was paramount to all participants. However, the first interviews seemed to indicate that none of the participants had reflected on their ageing, health problems or personal circumstances, or perhaps that they were not yet comfortable enough with me to share their thoughts on these issues. Responses were hesitant rather than spontaneous when discussing difficulties encountered, with long pauses apparent as participant ‘thought’ about their circumstances, as Ken’s comment indicates:

> *It’s just sort of natural you know. I don’t know how to comment on it really (Ken 1st Interview).*

Ken’s comments reflected an unquestioning acceptance of his declining health and the subsequent limitations this brought to his lifestyle. He was the only participant who seemed to accept his progressive deterioration in health as part of the normal sequence of events along life’s journey. Despite experiencing a myriad of health problems, at the time of the first interview Ken’s only voiced concerns were his problems with painful feet and poor balance. This had resulted in decreased ability to walk and ride his bicycle, which was his primary mode of transport:

> *I’ve never sort of worried about my breathing you know, but I do worry about aches and pains. My feet were giving me trouble. This balance thing—but it’s a pretty common thing with old people as far as I know (Ken 1st Interview).*

Other participants’ opinions and feelings were influenced by personal expectations, experiences and perceptions of societal norms. These factors became a significant consideration as the interviews progressed and data revealed an increasingly comprehensive picture of how declining health affected various aspects of the participants’ lives. During her first interview, Bette verbalised her annoyance with the effects of advancing age:

> *I'm old and weak and I don't like it. I hate being old and wrinkled (Bette 1st Interview).*

While Bette's worldview encompassed a self-perceived image of 'oldness, weakness and altered body image', she also reflected on how her physical condition affected her increasing social isolation:

> *As we've got older our lifestyle has changed. Well, I don't even read now. I used to read a lot but my eyesight is not good now (Bette 1st Interview).*

Bette's multiple health problems caused her (and her husband) much concern:

> *I have frequent pain in my back, in my groin, in my leg, in my neck. That just goes on, it's consistent. I never know when the pain will hit me. I can't do very much when that happens. I just go to bed and stay there until I feel better. Sometimes that could be days (Bette 1st Interview).*

Bette reiterated that, despite her significant health problems, she disliked the hospital environment and was always reluctant to accept admittance. Further exploration of this topic revealed Bette's worry over leaving her husband at home alone:

> *He's very slow and a bit deaf. I worry—he's not at all well. I think if anything happened to me, he'd go into a home. I'm sure because he's like—he wouldn't manage here on his own (Bette 1st Interview).*

Further evidence of Bette's profound concern over her husband's welfare became apparent when she recounted experiencing an episode of acute back pain over a long weekend.

> *I was writing something and the phone rang and I tried to get off the chair and I couldn't. The pain was excruciating and I couldn't get to the phone. I couldn't get off the chair. We couldn't get medical attention unless I went to hospital. It was the May Day long weekend (Bette 1st Interview).*

Bette endured excruciating pain for several days waiting for an appointment with her GP rather than permitting her husband to call the ambulance for assistance (thereby leaving him alone). Later investigations revealed a crush fracture of two joints (L4 and L5) in her lower spine, which was a direct result of advanced osteoporosis.

This acute episode highlights the factors that can influence decision-making processes involved when considering asking for medical assistance. While access to immediate assistance *was* available, Bette chose to remain at home, ostensibly because she disliked the hospital environment. In reality, Bette's concern over her husband's ability to care for himself was the deciding factor in her choice to remain at home. Bette's decision was clearly influenced by their socially isolated living circumstances, thus highlighting the significance of personal values in determining willingness to access available services. This micro-management in the face of adversity and the imperative of maintaining control over one's environment is reflected in the accounts of other participants, indicating this is not a 'one off' response but rather one that is evidenced by others.

In contrast to Bette's situation, Win's experiences in attempting to access health care were of *not* being able to obtain treatment for a painful shoulder, which she had sustained after a traumatic fall many months previously. During the first interview, Win revealed that chronic severe pain permeated every aspect of her life. Due to injuries sustained in a separate fall, Win found it very difficult to attend to many activities of daily living:

> *I can't make a bed and I can't sweep the floor. You try sweeping with one hand—you've got no hope. I vacuum with one hand and then I take painkillers (Win 1st Interview).*

During an unrelenting and intense episode of pain, Win travelled by bus, walking a considerable distance uphill from the bus stop to the emergency department of a major hospital in Brisbane, where she was on a waiting list for surgery to her injured shoulder. Win recounted the difficulty she had in walking uphill:

> *Once I get off [the bus] there, by the time I get into the hospital I'm gasping for breath. ... my heart is going bang, bang, bang and I can't get my breath and it's all uphill and there's nothing, nothing at all. You know when it's hot, in the hot weather, I am just absolutely buggered (Win 1st Interview).*

The inability to walk uphill, ascend stairs or walk longer distances was a problem common among the participants. This significantly affected, and at times, restricted their daily activities. Further evidence of this was provided by Monica, who lived alone and had no close social or family networks. Difficulty shopping for groceries and an inability to walk far due to breathlessness necessitated parking in close proximity to all service providers. As Monica explained:

> *Because of my breathlessness, I can't walk any great distances. I'm slower these days. I've got a walking stick now but it's hard to manage a walking stick sometimes. It's difficult getting groceries into my house, carrying the groceries up the stairs—I have to make several trips. I can't carry too many [groceries] at a time now. But I haven't really got anybody that I could ring up and ask them to come. That's where I—perhaps I feel isolated (Monica 1st Interview).*

Like Monica, Fay had problems with mobility due to arthritis in her right hip and right foot, which had been exacerbated by the continual heavy lifting she had done in the course of caring for her invalid husband at home. Her general exhaustion had negatively affected her overall health and ability to cope, not only with the care of her husband, but also with the general upkeep of the home. Fay disregarded her own health problems, instead focusing on the daily challenges of looking after her invalid husband and attending to household duties and general home maintenance.

> *I don't rest; I find that I've just got too much to do. Yeah, everything inside, outside; I do everything still. Got to keep going; well you just struggle on, you struggle on alone and you go downhill (Fay 1st Interview).*

During the initial interviews, it became apparent that the participants were confronted by, and struggled with, a variety of health challenges that incorporated not only personal issues but also those of loved ones, which at times, took precedence over their own wellbeing. Issues of access or non-access to medical services were determined by availability of services, physical accessibility and personal decisions as to whether to use them. While Bette and Fay's stories revealed an overwhelming concern for their spouses, Shirley's account reveals this was not always the case.

In contrast to Bette and Fay, Shirley's concerns centred on her deteriorating health, despite her husband's co-morbid health conditions, with much time spent attempting to source further medical and dental treatment to alleviate the long-term side effects of radium treatment for facial cancer. Although the cancer had been successfully removed, the treatments had left Shirley physically disfigured. The internal structures of her mouth were permanently impaired, leaving Shirley unable to chew food properly or communicate effectively. These ongoing difficulties inexorably led Shirley to be increasingly excluded from most forms of social interaction. Shirley's husband, who was present during the first two interviews and who was also experiencing significant health issues, explained their situation:

> *The major difficulty is getting the message through to people to understand how she has reached the point where she is at and that is a major difficulty. Besides Shirley's speech, she has trouble eating and drinking (Harold on behalf of Shirley 1st Interview).*

Shirley's story of difficulties coping with communication and its interrelatedness with social aspects of eating and drinking highlighted the impact of declining health on social activities and personal dignity. While the social aspects of declining health are discussed in detail later in this chapter, mention is made here of Shirley's unique circumstances, as her situation foregrounds the social imperative of effective communication as well as the interrelatedness of social acceptance.

> *I'm supposed to have no saliva ... because of the radiotherapy, but whatever this is ... It just flows all the time anyway and it's so uncomfortable and I'm very conscious of it and I'm very embarrassed. And as far as going out, and apart from people staring at me, but to engage their attention, they usually walk away ... It gets to me and it's hurtful, and then the ones that can't understand what I'm saying, well, they just let me know they don't want to know me (Shirley 1st Interview).*

Shirley's strong emotions relating to socially acceptable behaviours and her interpretations of the attitudes of those she has attempted to interact with have resulted in avoidance behaviours and subsequent increased social isolation.

Being able to communicate effectively was an essential element common among all participants. However, Ken's lack of willingness to *initiate* communication was apparent when relating difficulties in accessing his health care needs. Ken revealed that he relied on notification from the medical centre for the majority of his appointments believing that it was up to the doctor to decide if he should be reviewed:

> *They usually send me a letter (Ken 1st Interview).*

This resulted in Ken going without medications for weeks or months before the next reminder letter was sent out. It was only during times of acute and severe illness that Ken would seek medical assistance, often presenting himself at the emergency department of a major hospital rather than going to his GP. Ken's story highlights the significance of social constructions and personal perceptions when identifying roles of the individual and those in the health care team, and further demonstrates the importance of effective communication between doctors and their patients. Although this research was not interventional, once aware of Ken's situation, I encouraged him to make timely appointments with reception staff at the medical centre. I also amended the automatic recall and reminder system to include monthly reminders to Ken to ensure continuity of treatment and regular reviews by his GP. During Ken's second interview, he revealed that he had been regularly attending the medical centre. As this form of communication appeared satisfactory to Ken, and evidence of regular attendances at the medical practice had been documented, I ensured that routine reminder letters continued to be sent.

As the interviews progressed and data coding continued, categories, sub-categories and themes took further shape, thus providing a comprehensive background that informed and guided the second round of interviews. These took place approximately six months after the first round of interviews. At the commencement of each subsequent interview, a short time was spent reviewing what had been discussed in the previous interview. This process had two purposes. Firstly, it re-familiarised the participant with what had previously been discussed and, secondly, it helped to focus the participants on the events that had taken place in the preceding months. Monica's second interview revealed that her attention remained on physical ailments as she reiterated concerns regarding her decreasing mobility, painful arthritis and continuing breathlessness:

> *They [people] don't understand that you have to be slower, you can't run down stairs to do something or you can't rush to answer the phone because—your pain, your immobility, you can't do as much as you could. I have to take things a lot slower because I get very breathless. That, the breathlessness, has sort of increased say over the last six months and it takes me a longer time to get things out of the car. And I'm extremely breathless by the time I get to the top of the stairs (Monica 2nd Interview).*

The ongoing physical effects of declining health were also expressed by Bette, whose health had deteriorated, causing her to remain within her home for extended periods:

> *I feel too ill to go anywhere, I'm just lying here. I've got so much pain I can't even stand. As far as I'm concerned—because that [pain] isolates me from even what I am. I've never been like this, I now have to think I'm going to do so and so and I try to do it and I can't (Bette 2nd Interview).*

Fay also spoke of the physical and psychological symptoms she was experiencing as she battled to cope with the ongoing demands of caring for her husband.

> *Well, I'm having difficulty eating, I'm having difficulty sleeping. I'm not in a regular pattern of things. I'm not enthusiastic about anything. Nothing appeals to me anymore or I feel just a bit out on a limb, you know. I feel nauseous a lot ...*

> *it's just that nothing appeals to me about food. There's [sic] a lot of things I can't eat. I've had tummy problems and bowel problems. That's getting worse actually (Fay 2nd Interview).*

Locating and accessing assistance was a problem encountered by all participants. For Ken, the problem was in understanding the need to initiate contact with medical staff. In Shirley's case, it was dental procedures. Obtaining relief from pain was difficult for Bette and Win. Getting assistance with caring for a loved was the problem faced by Fay. Further accounts in which access to services was problematic related to home services and tradespeople and personal safety when travelling on public transport. Difficulties were encountered by Monica, whose fear of strangers precluded her from contacting service providers. Other participants also voiced such sentiments, though the language used to convey their feelings encompassed *worry, concern* and *dislike* of unfamiliar people in their homes.

5.2.3 Distrust of Strangers—A Barrier to Access?

Several participants voiced concerns about allowing people into their home who were not known to them, or were not well known or trusted. These concerns stemmed from past personal experiences, or stories they had heard or read in the media. As Win testifies:

> *You have no idea how many liars and thieves I've come across and even the chap that was starting my mower for me and all that, he stole off me … he robbed me. I've got no proof he did it but I know he did it. So that was it (Win 1st* Interview).

Fear and distrust, not only of strangers but also an awareness of their ‘aloneness’, affected many aspects of the participants’ daily lives. Monica voiced concern regarding her inability to attend to home repairs. She required assistance with all general home maintenance. However, her distrust of strangers became a significant barrier to accepting services:

> *I think the elderly person like myself; I wouldn’t be keen to have people coming into my home that I could not trust. I wouldn’t have anyone coming to my home any more, particularly after dark and I wouldn’t have a stranger knocking on my door either because you just can’t trust people any more. I’d be very wary. If anyone comes to my home ... I’d say ‘Well, look I want to see some identification’ and I’d ask for that identification (Monica 1st Interview).*

While this was also a concern for Bette, she and her husband reluctantly agreed to home help organised by Bette’s GP in conjunction with Veteran Affairs. Bette recounted their experiences:

> *They got somebody to come in and do the cleaning. She was cleaning the mirrors in the bedroom and she said, ‘I have to go now’. The mirrors were half cleaned. I don’t like that. She should have finished the job she was getting paid for. I wasn’t satisfied because she was more trouble than she was worth. I didn’t want anyone, so I‘ve never tried them again (Bette 1st Interview).*

This perceived poor work ethic resulted in Bette refusing these and subsequent services offered, preferring to manage on her own with whatever assistance her husband could give her.

Distrust of strangers encompassed interactions with unfamiliar persons both inside and outside the home environment. While acknowledging an inherent wariness of strangers, Ken's greatest concern was his personal safety, as several serious assaults and two murders had taken place in the caravan park in which he lived. He acknowledged that he was very reluctant to have anyone enter his caravan that he did not know well:

> *Everyone's running around putting locks on their doors. I think everyone is sort of worried about people breaking in (Ken 1st Interview).*

Personal safety was also a significant concern for Win. Although she maintained a driver's licence, she relied on public transport for attendance at hospital appointments, as she could not cope with driving in the heavy city traffic, nor could she afford the expense of inner city parking fees. During the previous two interviews, Win indicated that there were no bus stops near her home. However, during the third interview she revealed that fear of assault influenced her unwillingness to board buses in suburban streets. Win's fears were based on television and newspaper reports of increasing daytime violence. Win expressed feeling vulnerable, as she was no longer as strong as she used to be. Consequently, she resorted to driving to the local shopping centre, from which she felt safer catching the bus. On the occasions that Win felt too unwell to drive, she stayed at home and cancelled any appointments she had pending:

> *Now I wouldn't be game to walk down to the bus stop because you never know what's going to happen ... and you know you're defenceless. You are just so in fear of your life when you go out and that's why I can't do without a car (Win 3rd Interview).*

Fear was expressed in a myriad of terms and experienced in a variety of situations, many of which led to non- or limited utilisation of service providers:

> *I haven't got anyone. I'm the only one in my family left now. All my brothers and sisters have died, our parents [sic]. Most of my peer group are in nursing homes and these days you don't know your neighbours in the streets (Monica 1st Interview).*

Fear of strangers and unfamiliar situations existed alongside fear of being perceived as incompetent, as a pervasive mistrust of strangers applied not only to transport issues, (for example, volunteer drivers from the local Community Centre and strangers at bus stops), but also to in-home services, as evidenced by Monica and Shirley's experiences. Ken feared for his safety to the extent that he avoided social interactions with fellow residents in the caravan park and he would not consider in-home community assistance. Train stations were not considered a viable option for access to medical services by the participants due to unfamiliarity with automated ticketing machines, fear of falls and, perhaps more importantly, the lack of human staffing, perceived as essential for communication, guidance for access and maintenance of their sense of security.

5.2.4 Fear of Falls

Accessing and travelling on public transport was an important consideration when planning medical visits, with fear of falling and reduced ability or inability to embark or disembark independently resulting in non- or minimal use of public transport options. In addition, all participants revealed that fear of falling, whether at home or when out, was a constant concern, with access within and around the home often impeded. Declining health appeared to heighten awareness of the potential consequences of falls, such as fractures, which in turn prompted the development of ameliorative behaviours to limit risks. All participants had experienced falls and sustained injuries during the duration of this research. Likewise, each one continued to strive to maintain their personal independence:

> *M y balance is very bad. I have to hold onto things. I think there is a lot of fear attached to it but you are always frightened you're going to fall so you're very, very cautious. I can lose my balance very easily. I'm very frightened of falling as I would probably break something and then have to go into hospital and I don't want to do that (Bette 1st Interview).*

Despite the increasing risks and occurrence of falls, Fay strived to maintain her (and her husband's) independence within their home:

> *My main fear was that if I was to have a fall or he [husband] was to have a fall or we both fell, where would we finish up? That worried me. There were a few anxious moments, a few falls as you know, and they were the biggest fears (Fay 2nd Interview).*

Monica had been struggling to cope with both internal and external stairs, but had delayed contacting tradespeople for the necessary renovations, as she did not want strangers in her home. However, after several significant falls within her home, Monica took the initiative to contact a tradesperson who she and her husband (now deceased) had known previously:

> *Falls is [sic] a big thing that I was afraid of falling. My sight has deteriorated, my mobility has decreased and my joints are not as active as they used to be. I suffer quite a lot of pain. I fell down and broke my nose; I fell down the stairs and fractured my nose (Monica 3rd Interview).*

The physical and emotional obstacles that the participants encountered played a pivotal role in their struggles to maintain personal independence. This remained an integral feature of their experiences of the ageing process and access to medical services.

5.2.5 Independence is Essential

> *I'm still independent but I'm not the person I used to be* (Bette 1st *Interview)*

Efforts to maintain independence highlighted an awareness of varying degrees of increasing dependency, which co-existed with an amorphous sense of loss for the former self. This was difficult to define as most participants were not accustomed to personal reflection and often did not question why they chose to act or react in certain ways to situations they found challenging.

All participants recalled work activities and social networks of former years with several explicitly mentioning previous personal achievements such as public speaking (Bette), prize-winning craftwork (Shirley) and academic achievements (Monica) with obvious pride. There appeared to be a superficial philosophical acceptance of restrictions with advancing age. However, underlying this was a sense of frustration that, for some participants, developed into anger and bitterness as their lives progressed and further difficulties were encountered.

This spiral of deterioration was a phenomenon common to all participants, who went to extraordinary lengths to maintain a familiar lifestyle that afforded them continued autonomy and dignity. Consequently, much needed supportive services or offers of assistance from family, friends and neighbours were declined in an effort to preserve the façade of former abilities. Among the most significant tenets was the ability to live independently at home. Win's fierce independence became increasingly apparent throughout the interviews as she reiterated choosing to attend to all aspects of self-care and home maintenance wherever possible, despite offers of assistance from a neighbour:

> *Rosemary would do everything for me if I'd let her but I won't let her. I think that if you let people do so much for you; you get lazy (Win 1st Interview).*

> *I brought up my kids on my own. I've always done for myself. If I've been sick I've still done it … Well, it's just that you've been your own boss, nobody has told you what to do or when to do it. I'd like her* [neighbour] *to do a few things but I can't ask her, I won't ask her because I'm not going to let her think I'm dependent on her (Win 2nd Interview).*

Ken’s quietly spoken words indicated some small awareness of community-based health agencies. However, he maintained an attitude of independence towards his self-management of his health needs. This independent nature was increasingly evident over the three interviews, as he reiterated that he could ‘look after himself’ and did not need any assistance from anyone. Despite several significant falls from his bicycle, Ken’s personal independence remained an integral aspect of maintaining his confidence to cope with life’s challenges:

> *Like, I would struggle on as much as I could. I don’t need any help really. I can handle this job all by myself (Ken 2nd Interview).*

Without exception, all participants spoke about concerns of being a burden to others. Several indicated that acceptance of, or asking for, assistance from their peers or family members somehow diminished their equality, while others were more concerned with being a burden, which would eventually result in further decreases in already minimal contact. This was particularly evident if assistance was offered by those who were perceived as ‘worse off’ than the person that was being offered help:

> *but the thing—my brother is not good. You know you’ve got to think, you don’t ask someone that’s worse off than you to help you, do you? (Ken 2nd Interview).*

The importance of maintaining personal independence overrode the need to locate information regarding the availability of community support services. It was only in times of crisis that such services were considered and sought. However, as the following section outlines, this proved to be complex with participants unable to locate appropriate assistance or aborting attempts at accessing community health services.

5.2.6 Knowledge of Community Services

During the first interviews, knowledge and utilisation of community-based health services was discussed. Overall findings revealed a general lack of knowledge regarding community services on the part of the participants, although several services were known by name. The most commonly known services were Veteran Affairs, Meals on Wheels and Blue Nursing Service. Lesser-known services included St. Luke's Nursing Service, Oz Care, Home Assist and Returned Services League (RSL) Home Services. Community and Senior Citizen Centres such as Burnie Brae (Chermside), Aspley Respite Centre and North East Community Care (Northgate) were unknown to all but two participants. Fay had heard of but not accessed Burnie Brae and Aspley Respite Centre. Monica (a retired health professional), had been a volunteer at Burnie Brae several years previous, but had not accessed the service for her own needs. Significantly, no participants had heard of the 'Linking Seniors' Program, a Brisbane City Council Social Inclusion Project. Linking Seniors is part of the larger *Cross-Government Project to Reduce Social Isolation of Older People,* managed by the Queensland Government, Department of Communities (Lisa Edgerton, Community Development Officer Social Inclusion Access and Equity Team Brisbane City Council, personal communication, 31 October 2006, <lisa.edgerton@brisbane.qld.gov.au>). A free call number provides information on social activities, healthy ageing, transport options, concessions, legal issues and much more. The program also provides a TTY Hearing Impaired Service. Leaflets detailing the services provided by this program were given to all participants at the time of interview. Table 3 illustrates participant knowledge during the research period.

Table 3: Participant knowledge of community services at the time of the first interview

Participant Knowledge of Community Services				
Service	Known	Unknown	Heard of/unsure how to access	Accessed service
St. Luke’s Nursing Service	4	2	4	0
Chermside Community Health	2	4	1	1
Meals on Wheels	4	0	2	1
Oz Care	1	5	1	0
Commonwealth Care Link	1	5	0	0
Veteran Affairs	6	0	5	1
RSL Home Services	2	4	1	1
Silver Cord Service	1	5	0	0
Burnie Brae Community Respite Centre	2	4	1	0
Aspley Respite Centre	2	4	2	0
Blue Care Nursing Service	6	0	5	1
North East Community Care	0	6	0	0
Linking Seniors Program BCC	0	6	0	0
Home Assist	5	1	3	1
Council Cab Services	3	3	3	0
Gordon Park Respite Centre	1	5	0	1

During the second and third interviews participant knowledge of community-based health services was again discussed in relation to services accessed in the preceding months. I focused on this aspect of access to health care due to decrements in health and difficulties in coping identified in the first interviews. During this time of reflective discussion, I felt that transfer of these data to a pie chart would enhance readability and provide more depth of participant use and knowledge of community services. Figure 5a and 5b provide a percentage based diagrammatical representation of participant knowledge of community services. The percentages shown are the proportion of the total known services attributable to each service.

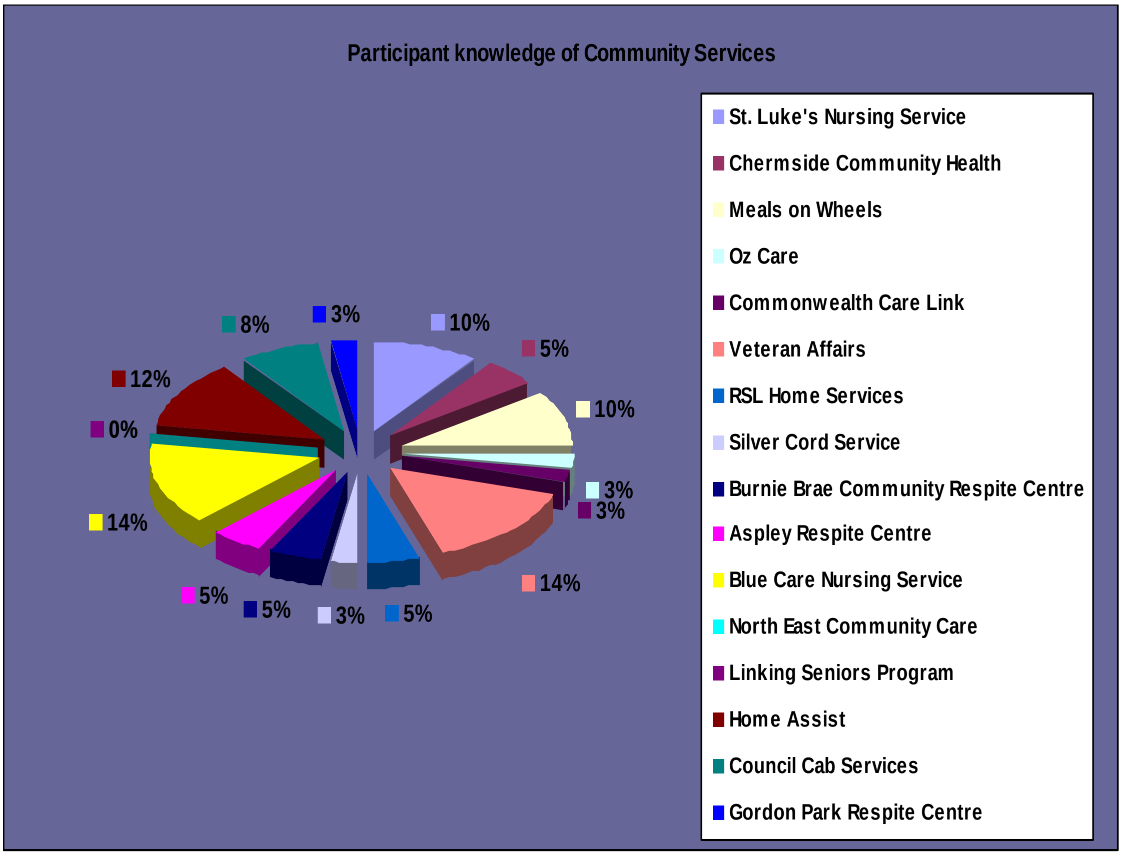


Figure 5a: Participant knowledge of community services as reported during the first interviews

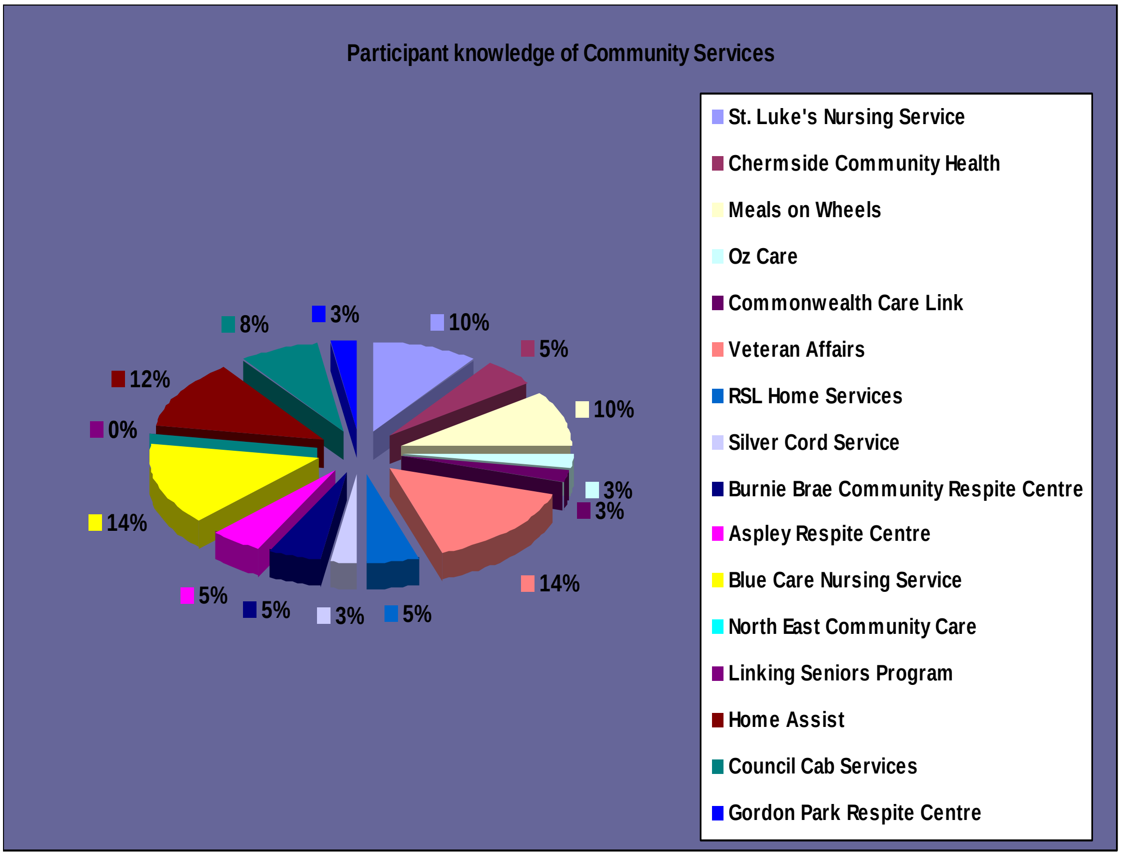


Figure 5b: Participant knowledge of community services as reported during the second and third interviews

The comparison of the two pie charts from the first and later interviews demonstrates that the level of participant knowledge regarding community services remained largely unchanged throughout the research period. Several participants admitted that they had not read the information I had supplied in the first interviews. Reasons given ranged from not requiring services to being content to manage independently. The only exception was Fay, whose inability to continue caring for her invalid husband had prompted her to seek assistance from another medical practice:

> *I knew nothing, absolutely nothing to start with. It's only going from one thing to another and from getting a bit of information here and a bit of information there*

> *and then coming somewhere [new GP] where you get a lot of help. That's the only way you get anywhere and if you haven't got that help coming, GP or a family member that's maybe involved in aged care or in any other sort of care … I mean it all gets back to, get back to your GP who should know all these things or have access to all these things and just by what I hear, there's not a lot out there that do. I don't think there's enough information comes out to the GPs or where we outside can read about it or television, people watch television, whatever. I mean, we just don't get, we don't have any access to what's out there, just can't get the information (Fay 2nd Interview).*

Like Fay, Win had the support of her GP, but continued with personal efforts to hasten her appointment for surgery. She did not review information supplied at the initial interview, preferring instead to utilise the telephone directory to locate contact numbers for government departments. She maintained regular contact with her GP and continued to lobby local politicians. Win's actions highlighted her predilection to utilise pathways of communication that were familiar to her. She believed that local government agencies were the people to contact, which often resulted in numerous telephone calls with no positive outcomes.

> *You don't know some of the excuses I've had when I've rung. 'We don't do that kind of thing here. Oh, you would have to ring so and so'. And I get sent round and round and round the mulberry bush. It's like being on a treadmill you never get anywhere. I think I made 17 phone calls one day … Seventeen phone calls and I got the run around from every single one (Win 1st Interview).*

Fay and Win's accounts demonstrate the expectations and reliance placed on the GP's knowledge of community services, the pivotal role doctors and staff play in disseminating accurate information and the ameliorative actions taken when this was not available. Ensuing discussion with remaining participants revealed they also assumed their GP or staff at the medical practice would organise any extra assistance they required. Often the expectation was that they would get a referral to the appropriate specialist or agency and appointments would be made on their behalf. While several participants recounted negative experiences with their GP regarding instigation of interventional treatment or lack of referrals for specialist services, Monica revealed experiencing more positive interactions with her GP:

> *I find Dr Gerard looks after my total patient care. She does everything. She will refer me on for tests which I will have if I need them (Monica 1st Interview).*

Monica's account confirms traditionally held expectations that one's GP would provide *total* health care. However, in circumstances in which this was not evident, participants relied on other techniques to gather information required or desired. The following section highlights the experiences of some participants as they attempted to locate appropriate resources to meet their individual needs.

5.2.7 Knowledge and Information: Finding Information—Technology a Barrier?

Not knowing where to look for information regarding community services was problematic for all participants who sought assistance from community-based service providers. Experiences revealed that support or literature provided by GPs, nurses and ancillary staff in medical practices was often lacking in up to date information relating to community referral systems and eligibility criteria. This resulted in delays in accessing appropriate assistance. Fay's account highlights the difficulties she encountered:

> *I didn't know where to look (Fay 1st Interview)*

As Fay's coping abilities diminished, she enlisted the aid of her daughter, who located the contact details for Commonwealth Carer's Link by searching the Brisbane telephone directory:

> *I really was desperate and I didn't know where else to call. My daughter found it in the phone book. She said, 'There's a 24 hour number that you can ring'. And she said, 'Ring it', and I did. And I think by the way I sounded, I mean I was pretty awful, just desperate. Anyway, they sent someone out straight away (Fay 1st Interview).*

It was during this time that Fay moved to another medical practice. In reiterating the events that led to this move, Fay explained that her husband was initially admitted to hospital for investigations. However, his stay lasted several weeks. During this time, his health deteriorated further, with staff advising that nursing homes should be considered. Fay did not want to consider this alternative and requested that her husband be discharged home in her care. Fay's account highlights the emotional and physical consequences of long-term illness when there are minimal supportive networks. She explained the difficulties experienced in attempting to access assistance with the care of her husband:

> *You make some calls, you get all sorts of information but you don't always come up with anything that's really helpful. You ring certain departments and they say yes, they'll get back to you and they don't. Yeah gaps in communication is a thing, you know there's just a breakdown in communication. You get bogged down as to what you can have and what you can't have and what you can do and what you can't do. What's the cut-off here and what it's going to cost you. It is very confusing. And you can't get the right information you just [sic] it just doesn't come (Fay 2nd Interview).*

The sequence of events that led Fay to contact the Commonwealth Care Link service demonstrates the difficulties she had in finding information:

> *I only found that out by accident through my daughter. But had I not known about that or had that connection, heaven knows and there'd be a lot of people out there who wouldn't know. I wouldn't have known where to look (Fay 2nd Interview).*

In contrast to Fay's experiences, Bette believed that assistance would be found through contacting social workers, as Veteran Affairs had provided these services to assist with organising allied health services in previous years. Although help was not sought through this avenue during this study, Bette was adamant that she would 'contact a social worker' if she needed to. In discussing accessing health services, Bette explained:

> *If they've ever been to hospital, there would be social workers (Bette 2nd Interview).*

However, if a person had not been in hospital previously, Bette admitted that accessing services or knowing where to go for help would be problematic:

> *I don't think they could. I mean, if they're very ill. I don't think they could. They would just give up and lie down I think—probably (Bette 2nd Interview).*

These diverse accounts exemplify personal perceptions of gaining access to assistance, while demonstrating that information regarding *how* to access medical or allied health services within the community setting is not readily available to those living in socially isolated circumstances. This lack of awareness was also apparent in Shirley's attempts to obtain an appropriate oral prosthesis that would not only fit the altered contours of her mouth but also allow her to consume food and drink in a socially acceptable manner. Through the course of this study, I became aware of Shirley's inability to locate a dental technician who was suitably qualified and skilled to manufacture a new modified denture. Although not intended to be interventional, it was only through Shirley's involvement in this research that I became aware of her predicament and was able to provide some assistance. This was accomplished during the course of my duties as a practice nurse at the medical centre and remained separate to the study.

I located the Australian Dental Prosthetics Association via an Internet search and contacted their staff who provided me with contact details of technicians in the Brisbane metropolitan area. Appointments were made and a new modified set of dentures was obtained. However, Shirley's experiences were less than satisfactory:

> *As it turned out it is so much worse than it was, it's just unbelievable, it's untenable, it's almost making an insane person of me. If it's fitting my mouth, it gives my jaw stability, it gives the whole mouth stability which it badly needs, but if I put it in, I can't swallow with it. I can't drink even the tiniest drop of water with it. I can't swallow even the tiniest bit of food with it (Shirley 2nd Interview).*

Shirley's story is further evidence of the lack of readily available and accessible health literature. She attempted to locate a suitable technician via the telephone directory. However, due to her significant difficulties with her speech, it was difficult for Shirley to make herself understood. While her husband made a concerted effort to assist her, he too failed in finding an appropriately skilled dental technician.

Not all participants encountered difficulties in accessing health services during the duration of this study. Ken remained concerned about losing his independence and consequently believed that he would also lose his autonomy. This influenced his decisions not to seek community care services, despite his deteriorating health. He was given a number of brochures and pamphlets regarding community and home care services after the first and second interviews but did not attempt to make contact with any agency, preferring to manage on his own for as long as he could.

> *I haven't used any community services. Oh, I just haven't got around to it really. Like, I don't know really. What services? I don't know, I really don't know. I don't like asking for help but I will if I have to. You know a lot of these things aren't as simple as they look. You've got to—you know there's conditions [sic].*

> *You've got to be in such a condition that—yeah for a lot of help (Ken 1st Interview).*

Ken's avoidant approach to health care interventions was a stark contrast to Win's feisty attitude, which had withstood many disappointments in attempting to access several community services. However, in their own unique ways, both understood that often access to health care was restricted by eligibility criteria and therefore not as simple as it seemed.

Overall, participants sought information in a variety of ways. Primary sources were from leaflets and brochures on display at the medical centre, the local telephone directory and newspapers. At the time of the first interviews, only one participant owned or had access to a computer. The application and appropriateness of information disseminated through computer technology is discussed next.

5.2.7.1 Technology—A Wider Generation Gap

> *Computers—they're of little use to me (Bette 1st Interview).*

Advances in technology have seen the transition from paper-based information dissemination to computer-based resources (Merkes 2000; Richardson, Weaver and Zorn Jr. 2005; Scott 1999; Selwyn et al. 2003). Of note is the influence that technology has had over the past two decades on the dissemination of health resources, with the majority of health resources accessible 'online' (Tse, Choi and Leung 2008). While computers are a familiar mode of communication for present generations, this is not the case for many older people, particularly those who have physical limitations and who are socially isolated.

At the beginning of this study, only Monica had regular access to a computer. By the second interview, Win had enrolled in a free community-based computer workshop delivered through the local library. While both Monica and Win achieved basic computer skills, during the duration of this study, neither of the women used this technology to access health-related or community services information. Reasons given for the limited use of these newly learned skills included difficulties with seeing the information on the computer screen and limited dexterity with using the mouse. Deeper examination revealed a lack of comprehension regarding how to navigate to separate pages within a website, thus limiting access to further information.

Feelings of embarrassment and a sense of ‘not being smart enough’ to understand such technological methods of accessing information resulted in a withdrawal from computer use and a resumption of more familiar methods of finding information. The remaining participants remained dubious as to the usefulness or practicality of computers at their age with comments ranging from *‘I wouldn’t know what to do’, ‘I just can’t use it’* to *‘I’m just not interested—I’m too old’.* Fay relied on her family to find information regarding community services, as they were familiar with computers. However, she further indicated that because she had such limited contact with her children she often did not know what to do. Thus, despite the obvious benefits of computer technology and its ability to provide access to much needed resource information, the consensus between the participants remained unchanged. As Shirley reiterated in her final interview:

> *No, I would not [use a computer] it is too hard for me to learn in my state. I can't do things quickly enough, you know pressing the button. I was shown once but really couldn't see anything properly (Shirley 3rd Interview).*

Bette and Ken also felt little need or interest to learn this method of communication. As far as Ken was concerned:

> *Well, I think they'd be pretty useless, I mean—I read the newspaper (Ken 3rd Interview).*

Ken's dialogue inferred that he believed he could obtain the same information from 'known' sources, thus negating the need to learn new skills to access information in new ways. Other participants, while acknowledging the benefits of computer technology, felt that computers were best suited to younger people, as Fay's comments indicate:

> *Well, I suppose I hadn't really—seriously considered it—computers I mean. The young ones use them. It's not something I'd do. I haven't got one. I could ask my daughter but, well no, I just wouldn't. It's easier for me to get on the phone, though it's often hard to find people who can help you (Fay 3rd Interview).*

Throughout the interviews, the participants placed minimal emphasis on the use of computers and dismissed the relevance of them in their daily lives. Reflecting on this aspect of omitted communication and following the principle of constant comparison, I revisited the literature review in conjunction with re-reading consecutive interviews for each participant. Interestingly, attempts to engage in discussion regarding the applicability of computers in follow-ups after the completion of the third interviews was met with little interest.

Although Monica and Win developed rudimentary computer skills during the course of this study, their use of computers remained minimal. In a post-interview discussion regarding finding information by using computers, Monica repeated her earlier comments:

> *Well, I don't really use it in that way—no. My skills are quite limited still I'm afraid. If I wanted to know about a service, I would ask my GP (Monica post 3rd Interview follow up).*

When asked how she would find health and community services using a computer, Win's reply was:

> *I wouldn't—I haven't mastered that as yet. Anyway, most people my age don't use computers so why bother? It's really just a bit of a hobby (Win post-3rd* Interview *follow-up).*

Despite the obvious potential benefits of computers to enhance communication and alleviate social isolation, the findings of my study provide an additional and perhaps contradictory dimension to key markers for non-use of technology. These are shown in Figure 6. Note the linear connection to 'what is known' and the absence of links to what is unknown or *perceived* as problematic, keeping in mind that only two participants had a limited knowledge of how to use a computer. This is not to say that physical difficulties with dexterity or decrements in eyesight were absent, but certainly, the willingness to *'try'* or *'persevere'* was.

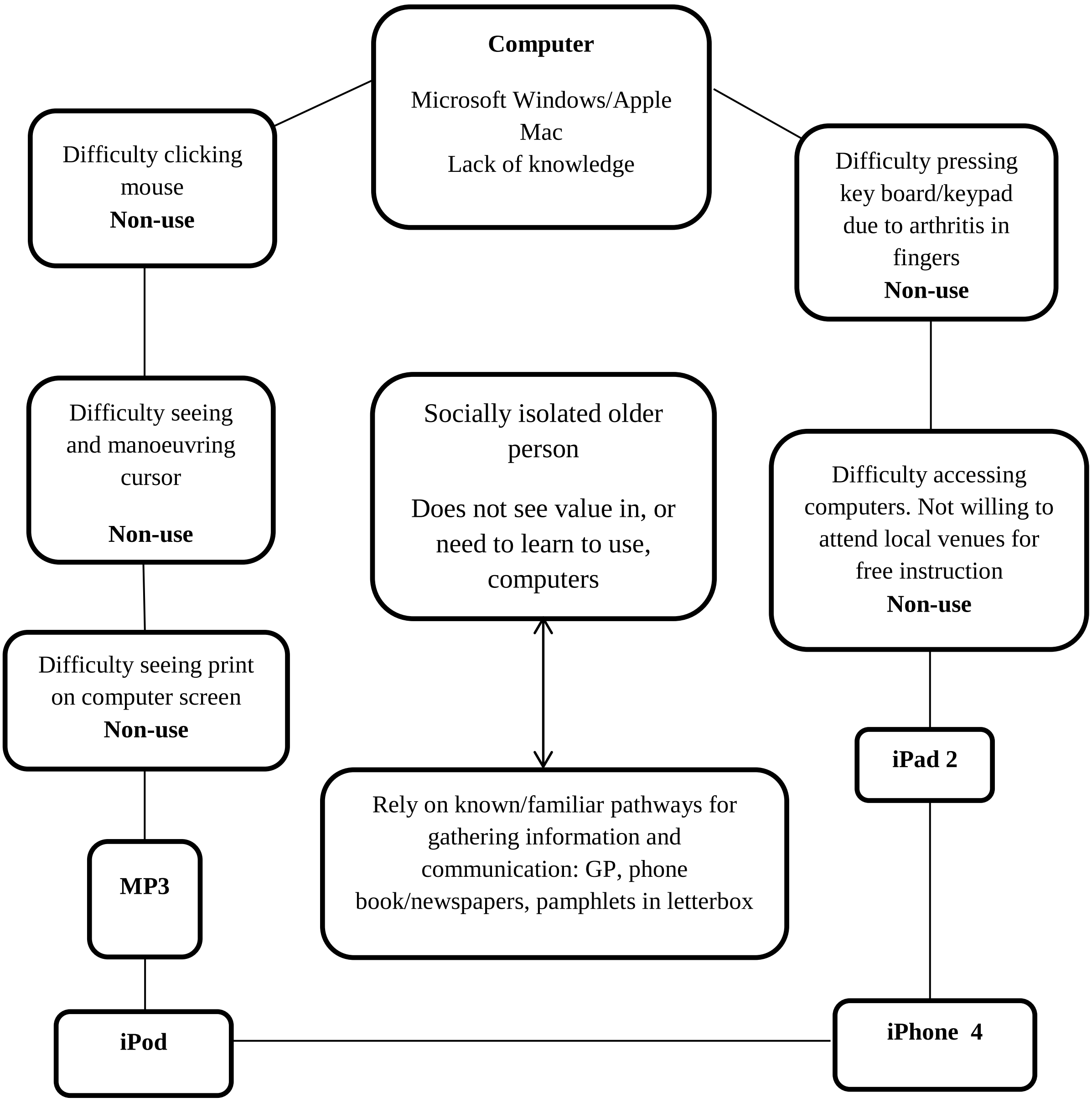


Figure 6: Participant experiences of computers to access information

Figure 6, constructed from dialogue from the set of three interviews and follow-up discussions, depicts participants maintaining a strong preference for accessing information by familiar means such as telephone directories, newspapers and pamphlets. Once located, utilisation of services was found to be influenced by first impressions made by individual service providers. The following section outlines the factors influencing acceptance or non-acceptance of assistance.

5.2.8 Utilisation of Services—Attitude and First Impressions are Important

The attitudes of community service providers when first meeting socially isolated older people were paramount in the decision-making process of whether their services were to be accepted or rejected. All participants indicated incidences of interactions with health professionals in which they felt they had been treated as lesser citizens than their younger counterparts. Both Monica and Shirley felt that health care professionals who visited them were intrusive, rude and lacking in sensitivity regarding the feelings of the older person and perceived this to be a lack of respect. Consequently, they refused the service being offered. Shirley discussed the attitude of one community service worker, who was part of the Aged Care Assessment Team (ACAT) sent to assess Shirley's home environment (post-facial surgery), and how this affected all future attempts at providing much needed home support:

> *She would have been the most obnoxious woman I've ever had come into any home I've ever lived in. 'That has to be removed. You've got to remove all those fittings. You've got to do it; you've got to do it'. And then she started assessing, like I was a prize cow (Shirley 1st Interview).*

This visit took place during Shirley's early convalescence, after extensive surgery for cancer. The health worker was aware of the extended time Shirley would spend at home resting. However, her comments regarding activities were reported and perceived by Shirley as very unhelpful and demeaning:

> *'You're going to need something to do because you're just going to be sitting around. Now you're going to need some crafts or something like that ... Looking at you, I don't think you would have ever indulged in any crafts' (Shirley 1st Interview).*

Contrary to the health worker's assumptions, Shirley is an accomplished artist with many of her paintings and craftworks displayed throughout her home. Shirley's husband was present during this visit and, at Shirley's request, asked the woman to leave their home. Subsequently another health care worker from the same ACAT service visited Shirley:

> *A few weeks later they sent a lovely lady, an older lady to ask us would we re-consider. I said to her, 'I really appreciate that they have sent you and that I'm sorry I cannot' (Shirley 1st Interview).*

Throughout the remainder of this study, Shirley did not accept any community worker into her home, stating:

> *Because of my terrible experience, what little faith I had left is now gone forever. I can't trust anybody (Shirley 1st Interview).*

Having faith in people, especially those who provide health care and assistance was a common term used by several participants. Fay's feelings of gratitude and relief towards respite workers organised through Commonwealth Care Link soon turned to disbelief and dismay.

> *Somebody would come into my home and the first lass I got was lovely. Then I got someone else the next time who wasn't. They did the night shift for me. But there was another one came and she just went to bed and slept. A couple of times, they didn't show up (Fay 1st* Interview*).*

Fay found that despite paying for the service, the carers were not necessarily experienced in their role:

> *They got someone, RSL, and it was a young man. I was astounded because I thought I would get someone experienced, but he's not experienced* at night work. *He used to look after children ... So he's there sleeping and getting paid and I'm getting up (Fay 1st Interview).*

Although very unhappy with this situation and with the constant procession of strangers in her home, Fay did not complain to the health service provider; accepting the different carers provided by Commonwealth Care Link and RSL, as she feared the loss of the service and realised she could not cope alone.

Fay and Shirley's stories highlight the importance placed on attitudes of health industry workers, providing insight into personal circumstances that govern acceptance or rejection of community-based services. Older people who are socially isolated are at increased risk of poorer health outcomes when distrust of strangers, coupled with inappropriate behaviour and inadequate service provision by community-based health workers, influences them to reject assistance. Further, as declining health and difficulties in accessing timely and appropriate health care affected already depleted personal reserves, a palpable sense of loss permeated the interviews, encompassing all aspects of participant lives. Loss of former self, physical abilities, body image and social and family networks led to intensely felt fears of dependency on others. The following section discusses participant perceptions of dependency and loss and its influence on seeking medical assistance and accessing the health system.

5.3 Dependence/Sense of Loss

Who will notice me as I sit wrinkled and forlorn?
Who will notice that the light still shines in my eyes?
For I am old but not yet dead
My thoughts are young
Songs and laughter play in my head
Look beyond what you can see
There is so much more to me
The gnarled hands and the laboured step
A life well lived
I do agree
Please sit a while and talk to me
Peel away the layers
Discover the wisdom and beauty hidden in me

Losses associated with the ageing process were ill defined at the commencement of the first interviews. However, as the study progressed, the participants actively reflected on how declining health affected their daily lives. While each story was unique, many similarities were evident in self-perceptions and expectations of treatment by others. Losses intermingled with fears or concerns about current or potential situations, as Monica's first interview revealed.

> *I feel I could go down very quickly if I felt I was dependent on people all the time and I was being a nuisance to people. I think that's an underlying fear that I have, that I will have to be too dependent on people (Monica 1st Interview).*

Individual perspectives on illness underpin feelings of loss and the growing dependency that commonly occurs in older aged people. In the following dialogue, Bette revealed her desire to continue with long-pursued activities (such as public speaking) in older age, but because of a multitude of health problems, she reported having found herself confronted by her own resentments as she struggled to cope:

> *I feel helpless and I don't like feeling that way. I have always been so independent. It's humiliating to have to come to this. I hate being dependent on other people (Bette 1st Interview)*

Concerns regarding becoming dependent on others co-existed with losses of former self. The next two excerpts reveal that despite the twelve-month interval between the first and third interview, Bette's perceptions had not changed. She seemed to remain at an impasse in trying to cope with her co-morbid health conditions and in coming to terms with the limitations and restrictions that pervaded her life as ageing progressed and her health worsened:

> *Well, I suppose because you're not able to cope with what you were once. You [pause], there's a big difference in the way you move and a big difference in the way you cope with things and it's a very, very disappointing difference. Well, you're disappointed because you're not able to do what you want to do. Well, I don't adjust very well to it. I resent it terribly. I don't resent getting old; I resent what it's doing to me. It's not allowing me to be what I want to be. I'm not able to do what I want to do. Well, mentally you find you want to do things and you're not capable of doing them physically. So it is a physical thing as well. Oh, the loss of not being able to cope with what I [pause], my life. I'm not able to cope with it, I feel disappointed in myself, terribly disappointed in myself. I'm old and weak and I don't like it. I hate being old and wrinkled (Bette 3rd interview).*

While Bette continued to struggle to come to terms with her physical losses, by the third interview, Monica appeared to have accepted many of the physical changes that older age brought. This was a stark contrast to her earlier views, which were expressed during a time when she was particularly unwell. Although Monica discussed fears of falling and dependence on others, profound significance was placed on the loss of family and social networks, which ultimately left her feeling alone and vulnerable:

> *Well, I lost a lot of my peer group. They were dying off. All my family had died and I thought 'Well it's my turn. What's going to happen to me?' (Monica 3rd Interview).*

As constructions of participants' realities progressed, it became apparent that loss and dependence co-existed in participants' lives, with personal perceptions, expectations and experiences playing a pivotal role in determining what services (if any) were accessed. Fay disclosed her profound sense of loss for the life she expected to have with her husband in their retirement. By the time of the third interview, he had been placed in a nursing home where Fay visited him every day:

> *Loss, it's a great loss. Going back I would say two years it happened. That's where the loss was, that's where you lost all—you basically lost one another. He lost me, I lost him. And your life is totally turned upside down. You—you know, you have no social life. He's got no life, he's just existing from day to day; you're doing the things you do every day. It's just—and as for going out, I don't go out. I talk to my family, I call the family once or twice a week, talk to them on the phone and you just get withdrawn in yourself. You just don't want to go out. You can't be bothered. ... Yeah, it's a [sic] lonely, very lonely and very—you do get depressed. ... The loss is just awful. You lose yourself, everything (Fay 3rd Interview).*

Fay also spoke of enjoying craft work and socialising with family and friends, but had lost the desire to continue these activities. The emotional toll on her sense of wellbeing precipitated withdrawal behaviours, and this ultimately led to a largely reclusive lifestyle. Other participants found that physical disabilities had a profoundly negative impact, not only on their ability to continue daily activities, but also on their willingness to participate in social interactions, even within their own home.

5.3.1 Loss of Mobility and Decrements in Health Precipitate Decrease in Activities

The ability to maintain one's independence incorporated basic canons of daily living. Several participants revealed that their difficulty with mobility, or simply sitting for long periods, caused them to decline invitations. These sentiments were embedded throughout Bette's story and remained static across the three interviews. Once an avid theatre patron, she could no longer enjoy this activity with her friends:

> *I love watching plays and old movies. I couldn't go out now; I wouldn't be able to sit through anything now. I used to go out a lot but not anymore and I never go out at night. I can't sit through a movie because of my back (Bette 1st interview).*

Not being able to do activities that were once enjoyed was a common occurrence among participants. Activities ranged from the simple enjoyment of afternoon teas, attending the theatre or opera with friends or just chatting to neighbours. Win's recounting of her social networks held many similarities to Shirley's experiences in that her decreased mobility precluded access to social events. She was involved in two craft clubs that had closed down and she had been unable to maintain friendships fostered with people that were in the club. Win's lack of mobility and increasing difficulty driving her car resulted in disengagement from social networks. Fay too talked about social interactions that had all but ceased as her caring role for her husband consumed the entirety of her time:

> *I wasn't able to go out when I felt like it, or go out to see family like I used to and I just miss that interaction with my family mostly and the odd friend that I have. I*

> *used to have a bit of family life, go shopping and do family things and so forth and which I, you know, haven't done for so long—not even now. No, I don't have any [social interaction] at this stage. I used to do patchwork quilting and things like that but I gave that up because I just couldn't concentrate (Fay 2nd interview).*

Thus, though personal health issues were unique to each participant, the resulting demise of social networks and interactions were a shared experience. The death of loved ones and friends and the relocation of others to other suburbs or nursing homes also affected several participants' social and community connections. Ill health, lack of mobility and lack of social confidence hindered the desire to make new friends.

5.3.1.1 Diminishing Circle of Social Contacts—A Precursor for Loneliness

Death of friends or their transition to nursing homes along with relocation to be closer to relatives was significant in diminishing the circle of social networks for most participants. Monica had only brief and sporadic contact with her few remaining friends who had moved into nursing homes:

> *I miss going to the opera and to concerts and things like that. That's the big thing about getting old is that I can't go to those sort of things, to shows. My husband [deceased] and I had season tickets there but you know I haven't been out. I don't go out at night anymore to those sorts of things. I would like to go with somebody, but see, there's no-one around my age group (Monica 1st Interview).*

Shirley also testified that many long-term friends had passed away in recent years or had moved into nursing homes. Other friends had moved away to be closer to family support. Shirley was disinclined to continue with friendships and socialising, as she felt embarrassed about her appearance and the problems she had when attempting to communicate or consume food and beverages. Consequently, there were fewer invitations extended to her and her husband. Both had long episodes of ill health that contributed to further social isolation:

> *Well, we are absolutely isolated ... because of my disability—and so there are no afternoon teas, there are no lunches. All that has stopped because I am too much trouble (Shirley 2nd interview).*

Social acceptance was also very important to Bette, who, since her stroke several years ago, no longer attends functions or socialises with friends. Her disengagement continued to be influenced by unexpected speech inconsistencies, which caused embarrassment. Many friends had drifted away and Bette no longer received social invitations. This ever-decreasing network of friendships has had a negative impact on most participants, as their withdrawal or loss of networks has provided the impetus for them to become or remain uninformed about their community and the health and support services that are increasingly available.

Dissimilar in many ways to the other participants, Ken held a unique position within the group, as he appeared to have had no close friendships or social networks for some years. Over the course of the three interviews, Ken became increasingly open about his concerns regarding the content of his conversations, which revealed deeply held feelings of social inadequacy. Ken’s following comments, given within his first and third interviews belied an underlying lack of self-confidence, which may have resulted in avoidance behaviour patterns, thus influencing his passive stance towards accessing health care within the community setting:

> *Maybe for two or three weeks you mightn’t talk to anyone. Lots of times I don’t like talking to a lot of people because, sometimes you go back and—’What have I said that I shouldn’t have said?’ (Ken 1s interview).*

> *You lose your confidence you’ve lost everything (Ken 3rd Interview).*

Limited mobility played a pivotal role in the loss of social contacts and increased social isolation. Although much research has linked social isolation with depression and loneliness (Victor et al. 2003), these feelings were not apparent in my participant group. One participant made a brief reference regarding her feelings of ‘aloneness’ after the death of her husband some years previously. However, no other mention was made to this in her interviews. Fay also made a brief reference to having felt lonely after the institutionalisation of her husband. However, she did not dwell on this aspect of her life. The overall absence of meaningful dialogue in relation to loneliness could be attributable to lack of in-depth exploration in this area, as this study was not focused on aspects of loneliness in relation to social isolation but rather its affect (if any) on access to health care.

Decreasing mobility and its relatedness to the development of loneliness or depression were not limited to personal decrements in health but also incorporated limitations imposed on the ability to drive and maintaining unrestricted driving licences. By the time of the final interviews, several participants were no longer able or legally permitted to drive at night or outside their immediate suburbs. This further limited independent accessibility to the wider community and friends who had moved suburbs. The following section discusses the importance of maintaining personal transport and the impact on those whose use was decreased or removed.

5.4 Transport: Travel—Just Like Everyone Else

My car is my wings
Taking me to wherever I want to go
No hassles with timetables
Or not being on time
No other strangers
To occupy my mind
Without it I am lost
Beholden to others
A nuisance
A burden
I won't ask for help
That's not for me
My freedom
Is very important to me

At the forefront of participant concerns was the pivotal need to maintain independence and autonomy. Avoidance of or inability to utilise public transport or shop for groceries independently and the loss of, or restrictions on, using own transport had a significant effect on access to and obtainment of health care for all the participants to varying degrees. Further, imbued within these viewpoints were concerns about financial capacity to maintain a car or the affordability of taxis as an alternative private mode of independent transport. These are discussed in detail in the following sections.

5.4.1 Decreased Ability to Drive Own Car

A major issue for all participants was transport to and from medical (GP) and hospital appointments. The minimalist social networks evidenced were unable to provide assistance with appointments outside the local suburban areas and, at best, only limited assistance with the more regular appointments required to attend the GP. Monica along with other participants relied on private transport for the majority, if not all, of their transport needs.

> *I don't know what I'd do without my car (Monica 1st* Interview).

With the exception of Fay's husband and Bette, who had access to Department of Veteran Affairs (DVA) transport facilities, all other participants relied on personal transport, public transport or taxis to convey them to and from specialist appointments in the city or at major hospitals. However, as deteriorating health and problems with mobility increased, so did the ability to drive longer distances or cope with peak hour traffic. As a consequence, ameliorative behaviours were adopted to enable continuation of driving practices. Shirley's husband spoke of timing medical appointments to enable him to drive and the impact on both of them when they had to travel by taxi:

> *With you know, the old vehicle that I've got, I can travel short distances. Well, depending upon time of appointment makes a difference. If we have an afternoon appointment somewhere and we have to get a taxi, it's all usually fairly stressful in getting home in the evening (Harold on behalf of Shirley 1st Interview).*

Although Bette had the support of Veteran Affairs for many of her personal transport needs to specialist appointments, difficulties with personal transport for routine medical appointments remained a concern:

> *I have a taxi, A Veteran Affairs taxi. I use that if I have appointments to go to and Walter can't drive because it's too far or the traffic is heavy. Walter doesn't drive when the traffic is bad. It's too stressful (Bette 1st Interview).*

Already adapting their lifestyles and behaviours to accommodate personal restrictions, several participants were confronted with an added encumbrance of the instigation of driving restrictions when renewing licences. Age-defined barriers were suggested by the participants as predictors rather than the capabilities of continuing safe driving practices.

5.4.2 Increased Driving Restrictions

Despite the need to maintain personal transport, several participants' licences were further restricted by their GP during the course of this study. Monica voluntarily ceased night driving. However, this had little effect on her lifestyle, as she no longer ventured out at night. In contrast, for Bette and her husband, Shirley's husband and Win, increased driving restrictions significantly affected their daily lives.

Even though Bette's poor health precluded her from driving, the sense of autonomy and freedom to choose whether she drove was significant in maintaining her self-esteem and dignity. However, the restrictions placed on her husband's driving distances caused difficulty accessing routine medical appointments, as their GP was located in a neighbouring suburb that was outside the permitted driving distances. In view of this, Bette stressed the increasing need for home visits by their GP, which were not always available. Further, travelling by public transport to medical appointments was not considered an option, particularly by Bette:

> *Oh, I would love to have a home visit, but that's what I miss (Bette 1st Interview).*

> *I wouldn't attempt to get on the bus. Because my balance is so bad, I couldn't get on. If I fell getting on a bus you know, it would be awful and I don't want to fall and I would have trouble getting off. I would be a nuisance getting off. I would be so slow (Bette 3rd Interview).*

Shirley's comments echoed these sentiments, as travel by public transport was never considered a viable option and, as such, maintaining personal transport, or travelling by car, was considered imperative to accessing health care:

> *If I wasn't available and we didn't have the old vehicle, I don't know how we'd survive (Harold on behalf of Shirley 1st Interview).*

By the time of the third interviews, Shirley and her husband were in the process of moving interstate. This was at the direction of their daughter who felt better able to assist them in accessing health care if they lived in closer proximity. This proved problematic as, once relocated to a retirement village, only minimal contact was possible, as their daughter was continually busy with work commitments. Shirley's husband was unable to renew his licence so they relied on taxis for all their transport requirements:

> *Transport in the taxis is the pits. The taxi situation is uncomprehendable [sic]. We live a kilometre from a lovely little new shopping centre, but unless being driven by family, is useless to us as … there is not a taxi will pick you up at the centre, not even if you get someone to call them. They will just ignore that anyone called and leave you stranded (Shirley written response 3rd Interview).*

Difficulties with mobility and transport were closely linked to ability to access health care resources. All participants had different experiences when attempting to access medical assistance, with several revealing occasions on which they were too unwell or incapacitated to drive themselves or travel on public transport to see their GP. In these instances, they remained at home until well enough to travel, despite the availability of an after-hours medical service. Interestingly, the availability of subsidised private transport provided by volunteers of the Burnie Bray Chermside Community Centre was not considered by the participants, despite information being supplied on this service. The following section details the difficulties experienced when forms of transport other than personal transport were utilised.

5.4.3 Difficulty/Inability to Use Public Transport

Difficulty with travelling on public transport was an integral factor in the accessing of health care for most participants, with timing of medical appointments reliant on driving capabilities or affordability of taxis. However, it soon became apparent that difficulties were experienced in meeting other medical needs as well. For example, accessing hospital services was problematic for Win, who relied on public bus services to travel to appointments in major hospitals within the city. However, these bus services did not provide stops in close proximity to the hospital.

> *That walk up to the hospital, it's a stinker, it really is. You go up, up, up, right up to the hospital and it's all up hill. By the time I get there, my heart is going bang, bang, bang and I'm out of breath. By the time I get into the hospital, I'm gasping for breath. In the hot weather, I am just absolutely buggered (Win 1st interview).*

Win was able to utilise public transport to the Royal Brisbane and Women's Hospital (RBWH), but found the long walk uphill from the bus stop very difficult to manage. The steep and uneven surface of the path resulted in two falls on hospital grounds, further injuring her damaged shoulder, which consequently required ongoing treatment by a physiotherapist. Ironically, Win had to contend with the steep path once a week for 6 weeks until she completed her course of treatment. She was apprehensive about falling again each time she made the trip but felt she had no choice, as the only way she could attend the much needed physiotherapy appointments was by council bus.

> *Sometimes they don't ... put the bus down. You know they can lower it and sometimes they don't and I've got to hang on like grim death. And of course you've got hold of the post, you've got your bag in your hand or shopping and it's bloody difficult when they don't lower the bus and they don't always do it and you come thump and it is painful (Win 3rd Interview).*

Fear of falls associated with using public transport was a concern for several other participants, who required assistance to ascend into the bus and also the lowering of the platform or steps to facilitate safe disembarking. Further, difficulties boarding and disembarking public transport were not the only deterrents for limited or non-use of these services. Several participants stated that their mobility had slowed and they were aware of and embarrassed by their lack of dexterity. Feelings of being perceived as incompetent, heightened by disparaging comments by fellow commuters and a lack of assistance from bus drivers, resulted in avoidance of these services.

Though he still maintained his driving licence, Ken did not drive or own a car, instead preferring to utilise his bicycle for the majority of his transport needs. Despite his compromised health status, Ken would endeavour to ride his bicycle 15–20 kilometres to the RBWH, but was sometimes too tired to complete the return journey.

Although he did not like to use public transport, on these occasions, Ken would utilise the train service, never once attempting to catch the more frequent bus service. Ken was hesitant in explaining his reasons for this but alluded to a fear of being refused entry onto the bus as he had his bicycle with him. This reticence may have been due to some council buses not having the facility to harness bicycles in transit. These difficulties sometimes resulted in Ken declining appointments later in the day, instead waiting for extended periods for an appointment at a time of day at which he could manage to ride his bicycle.

Several participants in this study had considered obtaining taxi vouchers through their GPs in an effort to facilitate easier access to medical appointments. Harold made several attempts to discuss his difficulty with driving Shirley to medical appointments in the city. However, his concerns were not addressed by his GP. He then broached the issue with Shirley's GP. However, his endeavours to access taxi vouchers were initially met with rejection. As Harold relates:

> *I have on occasions spoken to a doctor about taxi vouchers, but the response has always been negative. I don't know why. No, I think they think the application for it is a bit hard for them to handle (Harold with Shirley 1st Interview).*

After several failed attempts to acquire taxi vouchers, Harold gave up and paid full taxi fares to medical appointments in the city. As Shirley's health deteriorated, they again repeatedly approached the GP requesting a disabled parking permit. Eventually the appropriate forms were completed and submitted to the Department of Main Roads Queensland. However, once again they received a negative response, as Shirley explains:

> *And we also applied for disability parking and were completely and soundly knocked back for that. They don't give reasons, just 'no' (Shirley with Harold 2nd Interview).*

Shirley's extensive medical and dental appointments placed a significant burden on their finances, as taxi fares were often approximately $50 to and from each appointment, with these often scheduled twice weekly.

Harold's tenacity in attempting to access assistance with this cost reflected his deeply held concerns regarding the effect on their personal finances. Shirley and Harold believed they were ineligible for taxi vouchers because Harold held a current driver's licence and continued to drive locally. These incorrect perceptions indicated their lack of access to accurate information. They did not meet eligibility criteria as stipulated on the Taxi Subsidy Scheme Application Form F2330 from the Department of Transport Queensland, though they were never informed of this by their GP.

Organisation of transport by medical centre staff may have added benefit by assisting in preserving the older person's sense of dignity and autonomy due to the collaborative processes involved. As my findings revealed, participants' concerns of reciprocity, being a burden or loss of equality resulted in their declining offers of assistance from friends, neighbours or family members, who occasionally offered to drive several participants to their appointments.

Fay felt that as she was still able to drive she did not require assistance from family members to attend appointments. However, by the third interview, she indicated that she was struggling with negotiating the heavy traffic when visiting her husband, who had been placed in an inner city nursing home.

This was particularly difficult for Fay, as she had to ‘fit in’ with doctor’s rounds at the nursing home to discuss her husband’s care, which necessitated her driving at peak periods. Despite repeated requests, telephone access to the GP remained unavailable. Again, the timing of travel possible for older people is an issue not often considered by medical and nursing staff.

Despite its potential accessibility, none of the participants utilised the volunteer transport service provided by Burnie Brae Respite Centre. This service offered older people transport to medical and dental appointments for a nominal fee. The availability of this service was discussed during the initial interviews and reiterated during the second and third interviews. However, only Win and Monica indicated they would consider using it. Interestingly, even though this transport was provided in private cars, comments indicated an overall preference to call a taxi ‘just like everyone else’, thus further demonstrating an innate need to be viewed as a ‘normal’ member of the community rather than one who required special consideration. This perception suggested an ageist attitude that could be considered a response to, or awareness of, modernistic societal stereotypical views of older people.

It has been demonstrated that declining health, maintaining independence and concerns regarding dependence on others were pivotal in the desire to maintain personal transport or the ability to travel alongside other commuters on public transport. Further analysis of transport issues revealed a financial aspect previously unidentified.

5.4.3.1 Financial Issues—Maintaining Own Transport

Maintaining a vehicle was a significant financial expense for participants who owned a car. The third interviews revealed that Monica and Win had purchased automatic cars in an attempt to alleviate difficulties experienced when driving with a manual transmission. Monica had organised a reverse home loan to purchase her car, while Win maintained that she could barely manage her budget on the government pension. She eventually purchased a cheaper car outright as she was unwilling to take out a loan. Win was superficially aware of several community service providers, but she would not consider accessing them or accepting assistance, as she assumed (correctly) that a co-payment was required for such services. She viewed the purchase of a car as an extravagance *and* a necessity due to her fears for personal safety:

> *I can probably get a lot of help from different sources, but they need paying for it and I haven't got the money. Some of them will do two hours housework for you for so much but then what do you take it from, your food bill? This is where people won't say anything because they think, 'Oh, she's mean'. But I mean you've just got to look at it and say, 'Well, I haven't got the money' (Win 1st Interview).*

> *But you are just so in fear of your life when you go out and that's why I can't do without a car (Win 3rd Interview).*

Win's dialogue throughout the three interviews indicated her desire and willingness to accept assistance. However, she believed that she could not afford any additional expenses on her income. Unlike Win, Shirley and her husband viewed the maintenance of personal transport as essential both from a financial perspective and also in view of Shirley's perceived inability to travel on any form of public transport.

As they did not receive taxi vouchers, the ongoing cost of transportation to medical and dental appointments throughout the city placed a greater burden on their personal finances:

> *With the old vehicle I've got I can travel short distances. If we have to go into Wickham Terrace [city], we would get a taxi to wherever the appointment is. It's reasonably frequent that we have to do it because as we're getting older we're wearing out. We would do this [taxi] at least once a fortnight or more. If we go to Wickham Terrace, it's around $40 to go and come. If we go to Milton for the dentist, it would be about $50. I'm not complaining, but it certainly affects the finances (Harold with Shirley 2nd Interview).*

Taxis were utilised by some participants on a regular basis. However, they reported that the impact of this ongoing financial burden was not seriously considered by health professionals. Necessary walking aides rendered other community transport options inaccessible due to company regulations. Therefore, participants were left with only the option of attempting to use public transport. On several occasions, medical appointments were cancelled for this reason.

The increasing difficulties in using public transport continued to force some participants to struggle to maintain private transport despite declining health. Ken held a unique position in the group, as he was the only participant not affected by the issue of transport costs. Through further analysis, a commonality was found across all participants irrespective of type of transport used. Timing of appointments continued to remain dependent on non-peak hour traffic, road conditions, ability to drive and affordability of taxi services. These ameliorative behaviour responses resulted in extended waiting times for appointments with GPs as well as specialist appointments. The following section outlines the varied experiences of the participants as they waited for health services.

5.5 Waiting Times

Waiting for appointments

Waiting for operations

Waiting for transport

Waiting for family to visit

Waiting to be heard

I open a door

Death waits for me

It has been revealed that declining health, concerns of dependence on others, sense of loss and the significance of personal transport or independence in travelling has influenced the accessing of health care by these participants. In addition to these factors, extended waiting periods for medical intervention or assistance in times of health crisis was a significant issue, and it will now be discussed. Waiting is an accepted part of medical care. However, excessive waiting times can have negative health consequences, particularly for older people who are socially isolated. In co-constructing participant stories, I have attempted to represent their personal realities accurately. Thus, this section discusses participant experiences of waiting times for doctors, hospital appointments, allied health services, specialist services, surgical interventions and interactions with medical, nursing and non-nursing staff.

5.5.1 Extended Delays in Waiting for Doctors and Specialist Services

All participants experienced varying wait times to see their GP. This was often attributed to extensive patient workloads. However, other contributory causes were the self-imposed restrictions on driving times, acceptableness of appointments offered by staff and participant willingness to be reviewed by other doctors within the practice. Four participants preferred to wait for their regular GP, while two were prepared to see another doctor within the same practice. Monica was philosophical about waiting to see her GP, as she was reluctant to discuss her health care with other doctors:

> *I can't see her [GP] because she's very, very busy; then I see one of the others but I don't like to discuss too many things with the other doctors in the clinic, although they're very, very nice. Sometimes I run out of medications and that's a problem. I just need a script done and you've got to wait, you've got to wait quite a while but I understand that (Monica 1st Interview).*

Monica's view reflected those of other participants who also accepted delays in obtaining appointments with their GP as the norm. However, this was dependent on the urgency of need, as was evident in Win and Fay's situation in which urgent or immediate medical review was actively pursued. While Monica was prepared to see other GPs within the medical practice thus addressing her need for continuation of medication and reducing waiting times, Ken's dialogue revealed he continued to rely on communication from the GP to instigate ongoing health care. When this did not occur, extended wait times resulted in medication not being taken, which had the potential for negative health outcomes:

> *I've only come in here once without being told to come here and that was when I woke up in the morning with a hernia. Like I always thought the procedure was for a letter to turn up. I stopped taking the tablets 'cause I didn't think I needed them. I read somewhere they could be bad for you. I just go on my own judgement. ... To tell you the truth, I thought you's [sic] could be away. To tell you the truth I was disappointed, and I don't know; I don't know why I just stopped taking the tablets—that was the reaction (Ken 2nd Interview).*

Ken's repeated reference to not hearing from his GP highlighted his continued dependence on written communication and the guidance this provided in the management of his health. His words *'that was the reaction'* indicated that as a consequence of Ken's disappointment in not being contacted, he chose to cease taking his medication, preferring to rely on his own judgement rather than discussing his concerns with his doctor.

A reluctance to discuss concerns regarding non-urgent matters was a common occurrence, with consensus among the participants that their GP would not be particularly interested in their personal or social issues and, perhaps more significantly, that they should not 'waste the doctor's time' talking about these matters, as they perceived their doctor as always busy attending to ‘more important’ problems. Consequently, these non-disclosed concerns were often hidden within the spectrum of their personal and social situation. As Monica states:

> *Because you can’t spend a lot of time, the GP hasn’t got the time to talk to you for too long, it’s either ten minutes or maybe twenty minutes but you’ve got to let that go, there’s not a lot you can do in that particular time* (Monica 2nd Interview).

Such ideologies attest to the significance of time constraints on GPs and the need for practice nurses with adequate time and infrastructure to meet the demands of identifying, planning and coordinating community services effectively and in a timely manner, thereby reducing unnecessary delays in accessing health care.

The absence of practice nurses, the need to wait for appointments with GPs and specialists and time restrictions in appointments resulted in increased health risks for participants. Further, such delays negatively affected participants’ ability to cope with pain, with deteriorating health often resulting in increased pain and emotional turmoil. The lack of supportive networks further exacerbated the feeling of inability to cope effectively until medical assistance was available, which resulted in both physical and psychological exhaustion. This was evidenced by Fay’s initial revelations of ongoing struggles with her husband’s nocturnal wandering:

> *He was up and down all night, we had anything from 10–16 times a night and walking around the house basically all night, just get back to bed and he was*

> *back up again. No, there was absolutely no rest and I was totally exhausted (Fay 1st Interview).*

Bette’s frequently voiced sentiments of staying in bed until she felt well enough to make the journey to see the doctor also highlighted the obstacles several participants had to contend with and the undeniable importance of home-based medical care. While deputised after hours services were available, this medical care was not administered by doctors that were associated with the medical practice or known to the participants and therefore was not utilised. Monica was the only participant who contacted this service during this study. However, this was for an acute episode of gastroenteritis.

5.5.1.1 Waiting Times for Appointments: Hospital and Specialist Services

Waiting times for hospital specialist appointments were protracted in most cases, with participants recounting numerous occasions on which they waited months to be given an appointment, which, in the case of Win, was often re-scheduled to a later date. Ken recounted waiting eight months for a specialist appointment at a major hospital in Brisbane. However, longer wait times were experienced by Win, who waited almost two years for a shoulder reconstruction operation, changing doctors in the interim in an attempt to gain access to medical assistance. She recalls:

> *I changed doctors and I’ve been waiting now for two years, I’m still waiting! I haven’t had anything—I haven’t had a call, I haven’t had a letter, I’ve had nothing and I mean it’s just not good enough (Win 1st* Interview).

Win’s sustained efforts to gain access to hospital-based medical services culminated in a protracted journey to and from a major hospital where she was on the waiting list for surgery, as she could no longer tolerate the excruciating pain of her injured shoulder. She presented herself to the staff at the emergency centre but she was denied any form of supportive treatment. Win’s story continues:

> *‘I can’t help you, we’re only doing life threatening operations’*, and I said *‘Oh, pain doesn’t matter’*, and she said *‘No’*. The doctor at the Emergency told me that. *There’s a waiting list—you get to the top and they bring you to the bottom again and so it goes, ring-a-rosy. You get nowhere, absolutely nowhere. I had to get two buses home; I was in agony, agony! I don’t know how I did it, I had no one to help me and I couldn’t afford a taxi* (Win 1st Interview).

Win’s stark account reveals a lack of compassion by medical staff towards her. There was an obvious lack of supportive interventions, either offered or available until a surgical review could be arranged. Win’s priority status for surgery had been reassessed on several occasions, which resulted in further extensions of waiting times. Win was never notified of her change in status and no explanations were provided by the hospital. Similarities were evident across participant experiences, irrespective of personal health circumstances, with delays in surgical interventions and specialist reviews the most commonly experienced. Stories of extended wait times and lack of treatment were also common among the participants who maintained private health insurance:

> *We have private health cover but we still have to wait a long time sometimes for things to get done. You don't want to wait around when you are feeling unwell (Bette 1st Interview).*

These encounters persisted throughout the three interviews, with participants seeming to remain static in their endeavours to gain access to medical and specialist services, particularly those provided through the hospital. These same issues were reiterated throughout the second and third interviews. Additional wait times resulted from delays in processing referrals, whether interdepartmental or via GPs in the community. Participants continued to be confronted by these barriers to access, irrespective of which specialist they needed to see.

5.5.1.2 Referrals a Merry-go-round

Extended waiting times also involved the referral process to specialists and community health service providers. Waiting lists were the norm for non- or semi-urgent reviews. All participants experienced extended wait times for specialist reviews, although there were several instances in which this was reduced by the participant being seen as a private patient, thus indicating that timing of access was at least partially dependent on availability and current workload of specialists in a particular field. Win and Fay experienced the most difficulty in attempting to gain access to specialist medical interventions and extended delays significantly affected their personal health and ability to cope with routine daily activities. Fay recounted receiving a referral for a neurologist to review her husband. However, as this specialist did not attend patients at the hospital where Alfred was admitted, another referral had to be organised. Three weeks passed with no specialist review and, as Fay saw further deterioration in her husband's health, she discharged him home in her care against the advice of hospital staff:

> *He was there three weeks and just getting worse and worse and worse. And they just left him in bed and they didn't even get him out of bed. He couldn't feed himself, he didn't know what day of the week it was, he knew nothing, they just left him there. They were quite happy to send him to a nursing home … eventually got him out after three weeks. They couldn't get rid of me quick enough. And they said you know, 'You won't manage him'. I said, 'Well I'll try anyway and give it my best shot. If I can't, I can't; but I've got to try (Fay 1st* Interview).

Waiting times were compounded by less than adequate care from medical and nursing staff. This perceived lack of care prompted Fay to remove her husband from the hospital environment, returning home with the assistance of several community services. In the ensuing weeks, additional services were required. However, waiting lists for these were extensive. Waiting times for community services or home assistance is discussed in detail in the following section.

5.5.1.3 Waiting for Home Assistance

Waiting times for community assistance were also prolonged, with similar issues recounted over the three rounds of interviews. Several participants were referred to community-based providers for assistance with domestic duties and home maintenance. Others sought these services independently from their GP. Lack of communication seemed to be the common link between GPs and community service providers. Despite a Central

Referral Unit set up by State and local community services, participants still floundered through the maze of referrals required, geographical boundaries, eligibility, financial contributions and waiting periods. In all cases there were extended waiting times and, in several instances, the service was inadequate or no longer provided, as the following excerpt demonstrates:

> *I was getting a reasonable amount of help but it wasn't reliable. It was on again, off again. People would turn up some days and then wouldn't turn up. No, as I say, you'd have an appointment at the hospital and you'd ask them to come early for a shower or anything like that and they wouldn't show and you'd end up showering and then getting ready by a certain time … And then they'd come one day and say, 'Well you know I won't be here tomorrow but somebody else would be here' and then somebody else wouldn't turn up and this sort of thing. And that's where it got—it really fell apart because as I said it's not worth it, it's not worth the worry, it's not working. Like I said there was [sic] night times that they were sending someone to do nights and they'd just go to bed and go to sleep and things like that (Fay 2nd Interview).*

Fay's story highlights the difficulties caused by the attitudes and work ethic of community health personnel, with non-deliverance of 'paid for' services. However, influenced by a critical need for assistance, formal complaints were withheld. Other participants have recounted similar circumstances of dissatisfaction with service provider personnel. This resulted in a continued effort to manage as best they could or, as Bette and Shirley disclosed, the sourcing and paying for services privately. However, in view of concerns over personal safety and wariness of strangers, this alternative was not often considered.

Win's enquiries for assistance with garden maintenance did not receive a satisfactory response, with community-based service providers only able to offer very limited assistance:

> *Home Assist have [sic] been very good to me. They told me—when I went about the mowing they said, 'Oh yes, they would do it three times a year'. How nice—I'd be lucky to find my bloody house if I had it three times a year. Can you imagine getting to your house, your grass mowed three times a year? (Win 3rd Interview).*

Excessively long wait times sometimes resulted in non-acceptance of both medical and community services. Win, like other participants, continued to attempt to attend to all essential activities. While acknowledging that under certain circumstances, such as acute illness or injury, assistance would be acceptable, when inadequate assistance was offered or available at these times, all participants endeavoured to continue with lifelong routines, which proved difficult or impossible to sustain. The practicality and affordability of accepting community services was also considered, along with past negative experiences of individual allied health personnel. Previous experiences that had had negative outcomes impacted upon participants in several ways. Some refused the service outright, or they were subsequently disinclined to persevere with the accepted service. Others declined further or future services based on prior unsatisfactory experiences.

Fay's home situation and personal health deteriorated during the time between the second and third interviews and she reluctantly accepted the inevitability of placing her husband in a nursing home. However, this too proved problematic.

> *There are long waiting lists everywhere. I had his name down in seven places and nothing, nothing has come up. I would ring each week and find out what—I was told it was the only thing to do so I did that (Fay 3rd Interview).*

In an attempt to assist Fay, her GP arranged for emergency respite care for her husband. During this time, Fay was contacted by a social worker who provided much needed support and guidance through the maze of health care options and packages within the community while her husband was waiting for permanent placement in a nursing home. The social worker's ability to inform, coordinate and facilitate implementation of services supports Bette's earlier statements of contacting social workers to access home-based care:

> *The social worker there would be the best person I ever had to deal with and found them exceptionally good. Yes, I found the social worker good. I originally went to Commonwealth Care Link who were marvellous, absolutely marvellous because I was so desperate. I found them absolutely great, but there again; they had some that didn't want to work (Fay 3rd Interview).*

The combination of deteriorating health, sense of loss and increasing dependence on others, transport difficulties, extended waiting times for medical care and the lack of compassion on the part of health service personnel resulted in many participants feeling they were worthless in society now that they were older. The many obstacles and undesirable attitudes and responses that they constantly faced when attempting to access not only medical services but also general community services engendered ageist feelings that were often recognised and internalised, eventually becoming incorporated into personal belief systems and attitudes. These attitudes directly affected interactions with others, ultimately leading to further disengagement of fundamental social interaction. As the interviews progressed and constructions of participant realities continued to be built, a comprehensive picture of personal perceptions emerged of younger people being given priority to access health care resources. This was a common belief across all participants, further supporting findings of an awareness of ageism within the community. These perceptions and experiences are discussed in detail in the following section.

5.6 Becoming Invisible

I stand here my questions unanswered
People brush past me
Not looking my way
Am I invisible?
Why do you speak to me so rudely?
Telling me things that just aren't true
You don't know who I am
Don't judge me by what you see
Medical textbooks don't know about me
Take the time to listen to this 'non-entity'
Come down from your lofty heights
Take my hand
Learn about my reality

The problems encountered by the participants and uncovered through the interview process seemed to be layered one on top of the other. To begin with, at the outermost layer, was the balance of experiences of illness versus wellness and the imperceptible decline of health. Changes in behaviour patterns and the increased need for assistance became apparent as the participants moved towards the second layer. This layer incorporated issues of dependency and the loss of social or family networks and physical prowess. The third layer included transport issues, maintaining a car and drivers licence and the ability to travel on public transport. The effect of extended waiting times for medical assistance or specialist appointments were found in the fourth layer, along with problems negotiating the referral process. These combined difficulties resulted in a fifth layer, which held feelings of invisibility and a focus on ageist attitudes, both personal and from within the broader community. This fifth layer, here termed ‘becoming invisible’, allows us to more completely understand the complexities involved with ageing in isolation and the influence that difficulty in accessing health care needs has on the participants.

5.6.1 Surpassing the ‘Use-by’ Date

The participants acknowledged that being treated as equal members of society was essential for their sense of belonging to the community and to their self-esteem. However, as the interviews progressed, participant stories revealed a disquieting array of similar negative experiences that related to poor attitudes of health professionals. Several participants’ attempts to access health and community-based services were disrupted by the attitudes and actions of hospital and community services personnel, which ultimately led, in some instances, to non-use of services available. Shirley’s reaction to a visit by a community service provider who, while assessing their home environment, ignored explanations by Shirley and her husband, further highlighted this phenomenon:

> *Apart from angry it made me—it made us both feel very put down, very, very put down at the greatest level because as far as we knew throughout our life we weren't some kind of low life, you know, people who hadn't lived a decent life. I think in many areas, in many different directions, I do not think they listen to the patient. To me that seems to have been the catalyst of the whole thing. They have not listened to the patient. You know, they know what they want to do and they know what is the usual procedure and too bad if you want to deviate from that or have a say about it (Shirley 2nd Interview).*

Similar claims were made by three other participants who experienced an exacerbation of health problems as a direct consequence of non-availability of health services influenced by, they believed, their advanced age. One of those affected was Win, who increasingly believed that, once aware of her 'pensioner' status, both health professionals and politicians dismissed her repeated requests for assistance:

> *Yeah, you might as well talk to a brick wall—politicians do not listen. The minute you mention you are a pensioner, you're invisible, you're nothing. You don't count. You are just a big nothing because you are aged and you know, you just don't know anything and people will argue with you. You will say one thing and you know it's true and they will argue with you because you're a pensioner or you're 86 or you're old (Win 3rd Interview).*

5.6.2 'Brick walls—only the young matter'

The term 'brick wall' was used by other participants as they traversed various health care pathways, including repeated requests made to GPs, gaining access to specialist or allied health services and implementation of referrals for home assistance. Ongoing disputative interactions within the health system revealed a subtle decline in perceptions of self-worth and a burgeoning sense of futility. Three participants made particular reference to young people being more important than were older people, stating that they had 'had their time' and being old meant that they were 'not important'. This further indicated a personal ageist attitude and a strongly held perception that they were no longer valued. Bette's sentiments, often echoed by other participants, appeared throughout the interviews:

> *I feel we're past our use-by date—no one really cares. We've had our time here, only the young matter today. Yes, lots of money is spent on the young. No one really cares that I'm in pain all the time (Bette 1st Interview).*

Perceptions of ageism and of their no longer being valued members of society were significantly influenced by a lack of willingness to communicate on the part of health care personnel. These interactions were interwoven in participants' constructions of reality, which ultimately led to withdrawal or disengagement from health care programmes. Bette's excerpt provides a deeper insight and emphasises several participants' experiences in which concerns, questions and opinions continued to be ignored or disregarded:

> *Very often in hospital you experience it between the staff. Sometimes you get terrific staff but they go off. And they go off duty, somebody else comes on and*

> *they don't know how to … I think they listen to you. I think very often they listen to you but they don't always hear. A lot of them don't hear what you're saying. Their mind is somewhere else. A lot of people shouldn't be in the medical profession (Bette 3rd Interview).*

5.6.3 Perceptions of Ageism

Participants felt their concerns had not been taken seriously, which resulted, for some, in further withdrawal from society and social interaction. One participant adopted a defeatist attitude, indicating that he did not expect anything more than what he received because he was 'old and that was how old people were treated'. By the third interview, Shirley was no longer interested in pursuing specialist dental prosthetics. Shirley's ongoing conflictive interactions with the dentists and prosthetic technicians within the practice resulted in a retreat from her minimal family network. Shirley felt devalued and insignificant as her concerns and escalating difficulties eating and speaking were continually ignored. As she said:

> *I have tried to seek a good deal of help in many, many directions, persistently trying always to disregard costs, with the hope of some benefit. Sadly the disappointments have been many, sometimes degrading and upsetting, but with few benefits along the way (Shirley 3rd Interview).*

Although they did not retreat further from society, Win and Fay felt they were also adversely affected by the ageist attitudes of various personnel within the health system. Win's well-documented clashes and antagonistic interactions belied a deep-seated fear that she was viewed as ‘of no significance’, which further lowered her self-esteem. While she received documentary recognition for her extensive volunteer contributions to the Queensland Cancer Foundation, Win felt she received little courtesy or respect from many people involved directly and indirectly with her health care:

> *There is no respect for older people. Well, I’m entitled to my pension and I’m entitled to be—somebody (Win 3rd Interview).*

Although Win was the exception to the rule at the outset insofar as she was willing to speak up and question health personnel, she was discerning about whom she approached. Win seemed better able to articulate her dissatisfaction with reception staff or nursing staff associated with or employed by health and community service providers. However, she was noticeably less confrontational with medical practitioners and specialists, indicating an awareness of ‘doctor status’ and the interplay of power and authority associated with this hierarchy. Win made a personal connection with ‘old age and pensioner’ interpreting its meaning to be socially derogatory and exclusionary. These feelings were strengthened by her continual combative interactions with health care professionals and local politicians alike:

> *Well, it’s just that nobody thinks about you. You talk to them and you’re forgotten in the next breath. People don’t treat me like a female, like a human being. They treat me like a something that hasn’t got a brain because of my age. You are invisible the minute you mention you are a pensioner, you’re invisible, you’re nothing. You don’t count on this earth. You’re not a person; you’ve lost your identity. You don’t get answers, you get fobbed off. Old age pension, you know*

> *you kind of go down like a pricked balloon. Can't they find something else like, 'I'm a citizen, something citizen'. Not 'old age', not 'pensioner' but a 'superior citizen'—because I am (Win 3rd Interview).*

Monica echoed Win's sentiments, though she spoke not of herself but in terms of 'other' aged people, signifying that she did not feel part of this stigmatised and marginalised group:

> *open communication yes, and to treat them with dignity. Even though they're aged, their mind may not have deteriorated to any great extent. Don't patronise them. People don't like being called 'Mrs' if they are a 'Miss'. They don't like being called 'petal' or 'sweetie pie' or things and I think you've got to respect the aged person and that can help them with their problem a lot more than just this offhand, air fairy sort of approach. Yes, respect of the person as a human being (Monica 3rd Interview).*

5.6.4 Attempts at Access and Concerns Ignored

While the other participants did not appear as strongly focused on their 'pensioner' status, all acknowledged that they felt they were treated differently due to their advanced age. This was particularly evident in the case of Fay, who, like Win, experienced feelings of being 'fobbed off'. Although tentative at first, Fay challenged both nursing and medical personnel in their care of her husband.

Her assertiveness stemmed from the pain and discomfort she often found her husband suffering; first when he was in hospital (during the first interviews) and later when he was placed in a nursing home (during the interim between the second and third interviews). Similar to Win, Fay experienced many abortive attempts to communicate with doctors in their treatment of her husband. Further, Fay's concerns regarding inadequate nursing care were met with indifference by several key staff members in both nursing homes in which her husband was placed, which heightened her feelings of ageist attitudes among some health professionals and the health system as a whole. In her words:

> *Thinking you are going to a nursing home to be well looked after is just wishful thinking because it just doesn't happen. They don't have the staff, nobody takes responsibility, you can't get things done. You just cannot get any answers, you can't get anything fixed or changed. I mean I can't go home and rest. I stay there for hours, go home for a little while and go back because he [husband] needs the fluids. Why can't I want the best for my husband? Why can't you get what you want for them in their old age? Why isn't he entitled to get what I want for him? Unfortunately, the system, once again, lets us down (Fay 3rd Interview).*

These examples augment the findings of Australian-based research by Minichiello, Browne and Kendig (2000), whose investigation into ageism and older people's perceptions reported findings of negative adaptive behavioural responses by older people who recognised discriminatory behaviours by health professionals. These findings provide additional insight and increase evidenced-based academic knowledge in the area of health care. This is further evidenced by participant comments in this study relating to being old and 'past the use by date' or that 'only the young matter'. Such comments encompass a holistic ageist perception of their ‘place’ in society and a somewhat tenuous hold on personal value.

5.6.5 Feelings of Worthlessness

Other perceptions of ‘oldness’ related to being a pensioner and subsequently being of less value in society. Win was adamant that this stigma prevented her from accessing many health and community services. *‘Once you’re a pensioner, you’re a nobody’* was often repeated by Win, whose pensioner status underpinned her low self-esteem and bitterness at not being able to afford appropriate health services that her self-funded peers could access.

While Minichiello, Browne and Kendig (2000) and Hagestad and Uhlenberg (2005) focused on perceptions of ageism and segregation of older people, the effects on those living in social isolation and their ability, willingness or difficulties in accessing health care were not discussed. My study goes further to expose the effects of ageism on the socially isolated older person and the reciprocity of its effects. The impact of such encounters when attempting to access health needs was significant, with the incidence of increasing barriers to access defined by perceived poor attitude of health care providers, which in turn determined the responsive behaviours of participants. Prolonged wait times for medical appointments and health interventions, along with ‘not being listened to’, were experienced by all participants, with several perceiving that their age determined when they would be seen instead of their urgency of need.

The participants often reiterated that they felt ‘invisible’, as many of their concerns and difficulties went unheeded by medical and allied health professionals, though they themselves at times perpetuated this phenomena by their largely unconscious acceptance of the reciprocal nature of old age, ill health and frailty. Figure 7 represents the layering effect caused by the interplay between participants' experiences and expectations. Although these were not necessarily unidirectional in a linear context, they nonetheless illustrate the longitudinal progression of events as the participants continued to age in social isolation.

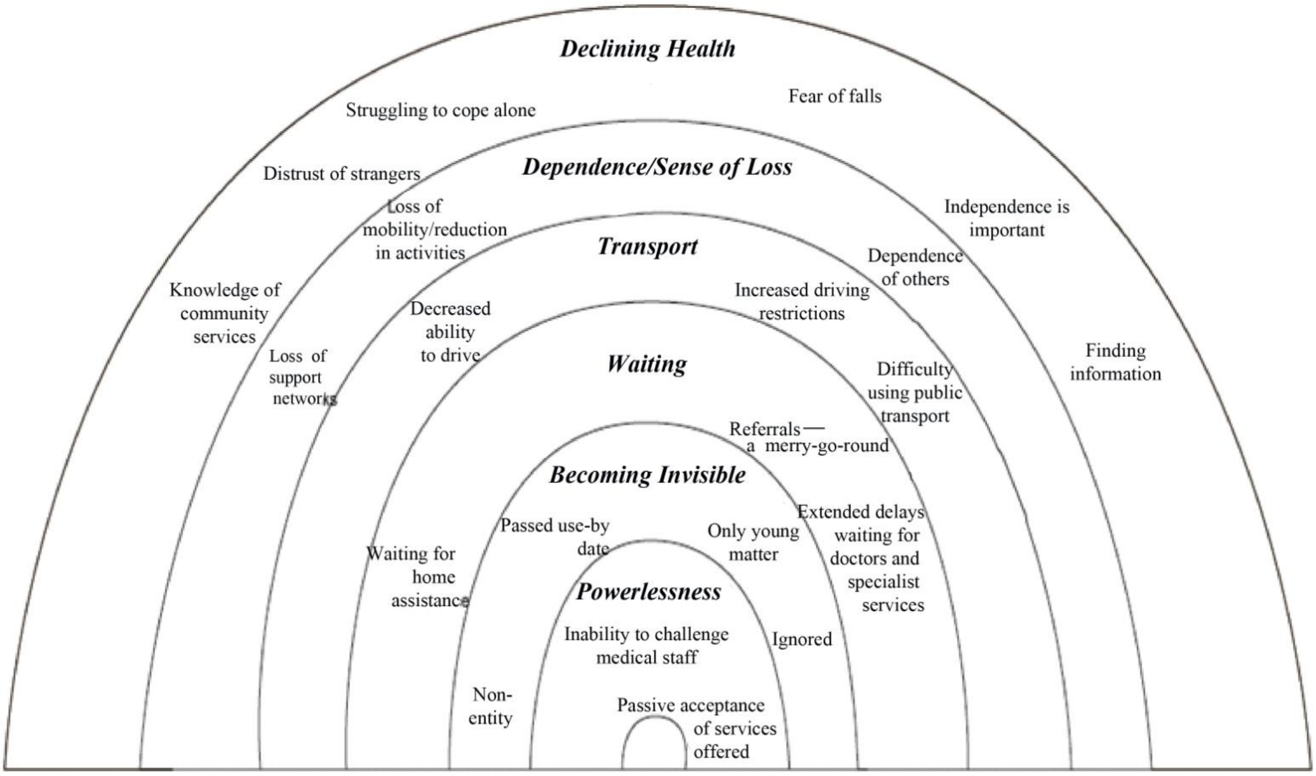


Figure 7: Layering effect of themes and categories linked with experiences

As discussions and interviews progressed, a pattern of increasing self-awareness became evident. During multiple re-readings of initial, second and third interviews, the participants' dialogue became more detailed and representative of thoughtful insight and reflection regarding personal circumstances and reactive or responsive behaviours to challenging situations when requesting or considering acceptance of assistance. Feelings of invisibility, of being ‘past one’s use-by date’ or a ‘non-entity’ and of having a sense of ‘worthlessness’ appeared to culminate in a powerlessness common to all participants. This sixth theme (powerlessness) applied not only to physical changes associated with ageing but, significantly, resulted in the participants’ inability to collaborate actively with health care professionals. This is discussed in detail next.

5.7 Powerlessness

I am spoken about as if I am not here
They may listen but don’t really hear
Is it only the young that matter today?
I have my dignity
I am not cutie, petal or dear
Address me by my name
It is something everyone wants to hear
My pain is real
My life I bear
No one will listen
No one truly cares
To be fobbed off and forgotten
By those I hold dear
I sit abandoned
Is it because I am old?

The term powerlessness brings with it not only a plethora of descriptive terms but also physical and spiritual connotations that are far from pleasant. To be powerless may mean, for some, to be defenceless, vulnerable, weak, dependent or helpless. For others like Ken, it can mean a total loss of autonomy:

> *Powerless means to me if you get sick and have to get government health care, they take over and you are powerless to do anything about it (Ken 3rd Interview).*

Ken's unique circumventious style of responding to questions made it difficult at times to determine his feelings about interaction with medical professionals. He pondered extensively over his verbal responses within the third interview, eventually resorting to written responses that he posted to me after the interview.

All participants expressed their feelings in a variety of terms but, significantly, they combined and interpreted them as a process relating to advancing age and increasing social isolation. Simply put, they felt vulnerable *and* weak, *and* dependent *and* helpless, and added a few descriptive terms of their own, such as wrinkled, old, pensioner, invisible, past use-by date and non-entity, to describe how they felt in *their* world. It is to these perspectives that we now turn. In doing so, we are permitted glimpses into the reality of entering life's twilight in social isolation.

The social constructions of each participant's reality are viewed both collectively and individually, thus offering a detailed representation of experiences in accessing and navigating the health system and the impact on the lives of this small group of socially isolated older people. As the participants' stories evolved over the three interviews, a sense of powerlessness, not recognised as such at first, gradually took shape, as repeated stories of experiences with medical, hospital and ancillary staff revealed a disquieting number of incidences in which concerns raised or questions asked were repeatedly ignored, discounted or overtly rebuffed. All participants experienced this phenomenon to varying degrees in a multitude of settings demonstrating an eclectic mix of actions, reactions, assumptions and emotions, which were evident in all interactions.

5.7.1 Inability to Challenge Medical Staff

Shirley's many accounts of her inability to challenge medical and nursing staff during her radium treatment highlighted the difficulties older people can encounter, particularly when dealing with professionals. Shirley's understanding of her treatment regime was different from what was administered. However, her concerns were never addressed:

> *It was sometimes openly mal-administered ... I was never supposed to have radiation on the left side. But I was the one who was the sufferer of that, never to be able to be mended. They make this mask and they put it over your face and it clips down on to the radiotherapy table. Ok, and they tell you once they've got you right, 'Raise your hand if something is wrong'. So mine unclipped a few times didn't it? And I put my hand up, but no, nobody came. It was administered. I was by myself ... and there was [sic] all these people around me. So they did one full week ... I ended up with skin like molten toffee (Shirley 1st Interview).*

Shirley's story reveals not only her expectations, perceptions and emotions regarding the radium treatment and the subsequent effects but, significantly, her inability to challenge the medical professionals who were with her during its administration. Also apparent was Shirley’s sense of aloneness and powerlessness to challenge what she believed was incorrect treatment.

Other participants spoke of similar instances in which they felt powerless or intimidated by health professionals, thus passively accepting treatment they felt was inappropriate. Fay’s sense of powerlessness was heightened when she attempted to access long-term care for her husband in a nursing home. Her statements echoed those made by several other participants who encountered similar situations with health care professionals in the course of attempting to access medical treatment or community-based care:

> *I think you’re powerless most of the time because you don’t get anywhere. You—you know, you speak to the managements and the people that are running the nursing homes and things like that but they really look at you as much to say, ‘Well, there’s not much I can do about it.’ So how do you get to them, the people that run these facilities? They’re in their ivory towers and they have no idea what goes on and what people have to cope with, not only residents and [sic] resident’s families (Fay 2nd Interview).*

Bette’s unpleasant experiences with dental, medical and nursing professionals resulted in avoidance of dental care and hospitalisations, which eventually led to detrimental health outcomes, as she insisted on remaining at home during times of acute illness, relenting only when doctors (or ambulance officers) were alerted to her predicament by her husband. In these exceptional circumstances, Bette did not argue with health professionals:

> *Because I just feel I can't argue. I just feel—I just feel intimidated by him [dentist]. I must be feeling intimidated because I don't question what he's doing. They're doing what they want to you and it's very, very hard to question (Bette 3rd Interview).*

Bette spoke further about an incident with a male nurse while she was hospitalised that caused her to refuse further admissions. Her feelings of powerlessness in the situation demonstrate how attitudes of health personnel can negatively affect an older person's perception and future acceptance of health services:

> *He had the jurisdiction over me. But he was a real cruel little bastard and he was cruel and he was mean. He went out one day and I heard him say, 'God I'm sick and tired of these silly old women'. I could hear him talking to the other nurse outside ... and I thought, 'Yes, he's referring to me'* (Bette 3rd Interview).

Not feeling able to, or having the opportunity to, express concerns, be listened to, or be fully informed by health professionals of what to expect regarding medical procedures increased participants' feelings of powerlessness. However, despite this, one participant demonstrated admirable loyalty to her GP despite her dissatisfaction with her health care, remaining a patient until the GP's retirement before moving to another medical centre at which she found a GP who was attentive and willing to listen to her concerns. She recalls:

> *Well, I wasn't really happy with the doctor who was caring for me at the time. He wouldn't allow me to express how I felt. He wouldn't allow me more or less to ask questions and there were a lot of questions that I wanted to ask. I knew him*

> *professionally and he was a very, very nice man—but he wasn't helping me as a patient. Powerless—I think there's always been a little apprehension between the lay person and the medical profession and a lay person is perhaps afraid of saying the wrong thing, 'the doctor will laugh at me or think I'm silly' (Monica 3rd Interview).*

Monica's comments were representative of several participants' reluctance to engage medical professionals openly in collaborative discourse regarding their health management. It is interesting to note that Monica also used descriptive words such as 'apprehension' and 'afraid' to further explicate influencers of perceptions of powerlessness. Such interactions with medical professionals act as barriers in that they discourage discourse from older people, thus disallowing them opportunities for collaborative involvement in health goals.

Decrements in health, previous disagreeable experiences with health personnel and increasing dependency associated with feelings of worthlessness and invisibility within the health system led several participants to passively accept whatever services were available. However, the remainder rejected assistance outright. The only exception was in instances of critical need in which the decision-making process was temporarily overruled by doctors or specialists. However, even in these circumstances, feelings of powerlessness co-existed with those of passivity.

5.7.2 Passive Acceptance of Services Offered

Entwined in perceptions and feelings of powerlessness was a sense of futility and passive acceptance. This was evident even in those participants who actively attempted to achieve their health goals. Although initial attempts were often impassioned, these were gradually blunted, eventually becoming overshadowed by resignation and acceptance of the boundaries and obstacles embedded within the health system. Additionally, two participants diligently maintained their efforts to access health care throughout the research period, others accepted their perceived inability to alter the course and timing of referrals and waiting times for services. Inadequate and poorly coordinated community-based services did little to meet individual needs resulting in decreasing health, increased difficulty in coping and dependency, which in turn further increased social isolation and disengagement from society.

By the third interview, it appeared that little had changed for Win. She was still attempting to gain access to health care but she was continually met with the same responses encountered two years earlier:

> *You go as far as you can and then you think, 'Oh hell, what's the use?' Well you just don't get anywhere ... Then I was told it was a ten year wait. I mean anther ten years and I will be 96, would it be worthwhile? So what the hell do you do then? There's powerlessness. You can't do anything. You can't go to them and say, 'I can't wait that long'. They just wipe you. So I have a ten year wait (Win 3rd Interview).*

The shifting boundaries between waiting times, invisibility and powerlessness seemed to merge, with several participants indicating that they felt they did not receive priority for services due to their advanced age. A perception common to all was that the needs of younger people had more significance than those of older people, despite community-based programs dedicated to meeting the needs of this cohort. The problems reported by the participants painted a poor picture of these interventions, which were viewed as inaccessible, under-staffed and under-funded. Several participants refused to speak up or take further action when confronted by perceived ageist attitudes from health care professionals, further revealing that such attitudes played a pivotal role in the acceptance or rejection of assistance offered.

As the participants' journeys unfolded, I was again struck by the interconnectedness of their experiences, which seemed at times to be a cyclical process, with each interaction linked in some way to affect another. Revisiting the transcripts, I began to think beyond the linear model in an attempt to conceptualise the phenomena. After further reflection, an adaptation of earlier diagrammatic models was undertaken. Figure 8 represents the reduction of sub-categories, categories and refining of themes and illustrates the different language participants used to describe similar feelings. These have been colour coded in addition to separate coding for words and phrases. The different colour codes indicate links between language, meaning making and the core theme. This was an interpretive concept that I, as the researcher, gave meaning to by taking into account individual non-verbal body language, facial nuances and other cues, such as inflection and tone of speech.

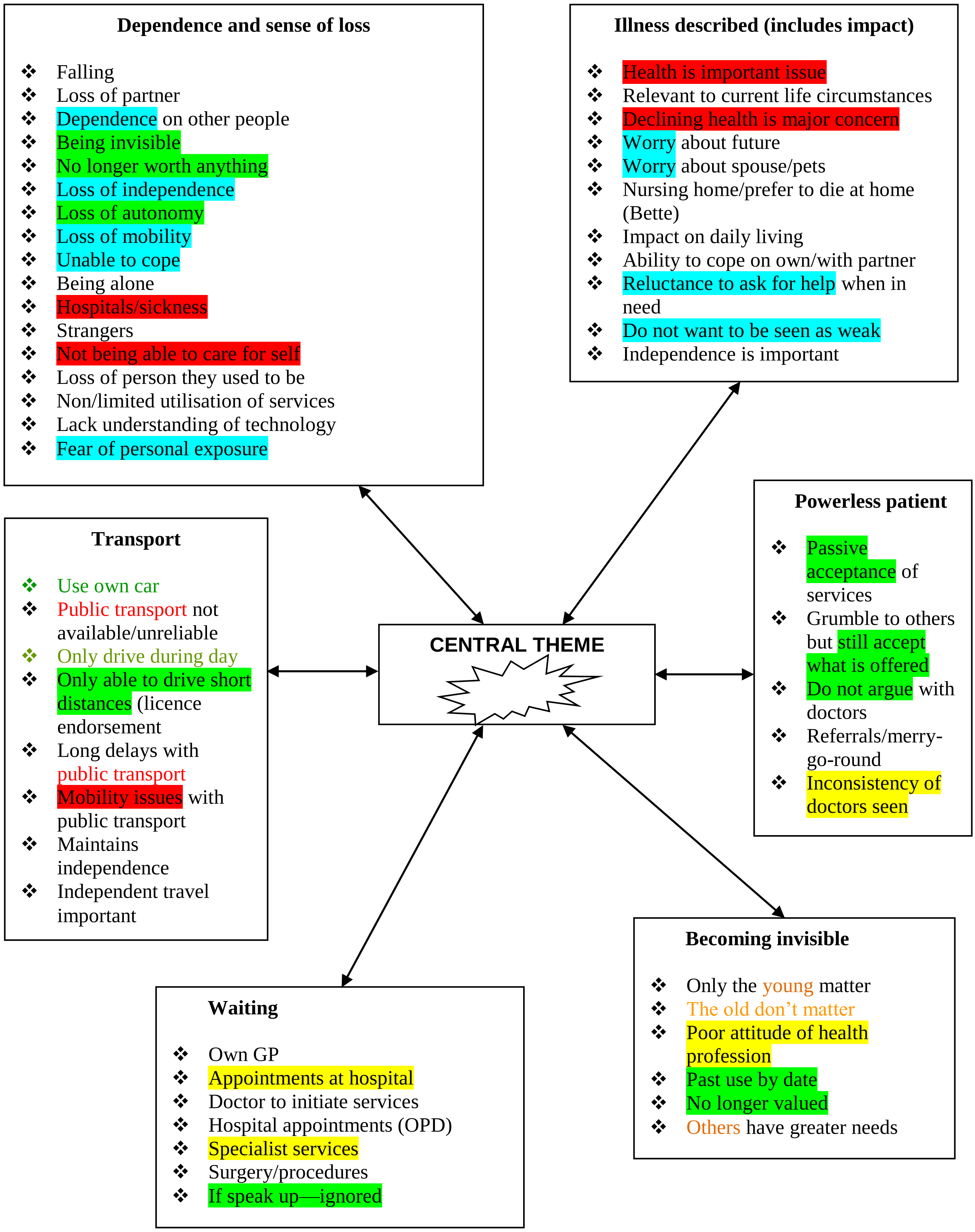


Figure 8: Reduction of sub-categories and categories and refining of major categories and themes

These stories detailed the experiences of the participants over the course of the research, revealing the depth of emotion that underpinned all interactions with health care professionals and community-based personnel. More than just a collection of poignant stories, they added depth and dimension to our understanding of older people's experiences in attempting to access and negotiate the health care system, resulting in the uncovering of core issues essential to the phenomenon. This study revealed that social connectedness is affected by declining health, issues of dependency and loss, access to personal transport and extended waiting times. Further, the participants' feelings of invisibility and powerlessness were compounded by internal and external perceptions of ageism, heightening existing emotional undercurrents, until their full revelation in the third and final interviews.

As the participants' experiences were more deeply probed, several negative emotions were identified as key components of these experiences. A fifth common element also became apparent—the re-negotiation of identity, which has become the seventh and final layer and the central theme. The re-negotiation of identity was found to be a culmination of experiences, as participants became resigned to their situation, or began to see themselves as they perceived others to see them. This theme will be explored next, beginning with the final poem—an anthology of previous participant comments as encapsulated within the six major themes.

5.8 Anger, Frustration, Disillusionment and Fear

I'm angry and hurt

I feel betrayed

My disillusion for all to see

Bitterness swells inside of me

No one told me life could be like this

So many brick walls I cannot climb

I struggle to cope

My friends are all gone

No one will listen or stop to lend a hand

I am frightened of losing those things I hold dear

My health and independence are slipping away

For I am invisible—a powerless being

I have a voice but cannot be heard

Brushed aside because I am old

Youth has long passed as life's journey nears its end

Who am I now?
A non-entity

This final theme comprises strongly held emotions of anger, frustration, disillusionment and fear, which are discussed below in relation to participant experiences, as well as on an individual basis due to their omnipresent nature. Each participant exhibited these emotions to varying degrees depending on personal circumstances, such as how urgently access to medical or community services was required or how often it was denied. The ageing process, in conjunction with increasing social isolation, played a significant role in the construction of participant perceptions, attitudes and values, which have in turn influenced the journey through the health care system and the extent to which difficulties have been perceived and experienced. During the third round of interviews, several participants became vocal about their continuing efforts to combat barriers to health goals.

An example of this was the continual barriers Win encountered that served to increase and justify her feelings of frustration and anger towards a health system and society that she perceived as having no tolerance for the needs of older people. Once again her focus on ‘pensioner status’ is clearly evident:

> *My feeling now is frustration, just frustration. It is really frustrating and they don’t realise how angry you get at them. Oh, people who are like Social Services, like Social Security, Centre-link, whatever, and um politicians, they don’t give a continental about a pensioner. See, money again, money, money, money. It counts; it’s the one thing that you have to have in Australia to be a person. You’ve got to have money; you’ve got to be rich to be a person, to be a human being in this society. You’ve got to have money and when you’re a pensioner and you’re aged you haven’t got money, you haven’t got respect, you’re not a human being (Win 3rd Interview).*

Although personal circumstances and health goals were different, Fay’s experiences fostered similar feelings of discontent. She expressed her anger at the continued barriers she encountered throughout the course of attempting to access appropriate assistance with the care of her husband, which continued after his placement in a nursing home, as the following excerpt indicates:

> *Well, anger is what I've got at the moment. I'm very, very angry. I'm angry at the system. I'm angry at how hard it is to get your loved one looked after, everywhere you go. I've found that I think it's probably the worst period in my life. I feel desperate, absolutely desperate and angry. I am so angry at the moment because it's so hard to get through to anyone. You don't get anywhere. That really does make me feel angry because no matter who you talk to in the system, you can't get anywhere and I mean you know; where do you go? How do you get some of your questions answered? They talk about advocacy and that sort of stuff. I just want to get to the right department and let them know what is going on out there (Fay 3rd Interview).*

Other stories revealed different perceptions and experiences, with Monica and Bette acknowledging that though at times services had been less than satisfactory, there had been instances in which care given had been timely and appreciated. As Bette reveals:

> *I've had a couple of rotten experiences in hospital and other times, I mean you couldn't say anything but how wonderful they were, but anything bad that happens to you you're more likely to remember than good things (Bette 3rd Interview).*

Monica’s sentiments concur with these comments, adding that:

> *I’m not sort of always happy with the way they treat me. They treat me as I’m a sort of old aged person and I resent that. I know they’re coming with good intentions but I don’t like the way they speak to you. It’s sort of rather humiliating for me anyway that, [sic] but I will accept (Monica 3rd Interview).*

This account by Monica suggests that, although resentful of the perceived condescending manner in which she was spoken to, Monica was still willing under specific circumstances to accept the assistance of service providers. This finding was in contrast to other participants, who, having experienced similar situations declined or refused to continue with the service offered. Throughout the three interviews, several participants showed a degree of reticence in their discussions on access and navigation of the health system. Therefore not necessarily implying ambivalence but perhaps rather a conscious decision to avoid expressing feelings with words they found personally confronting. To explicate further, in the following excerpt Bette at first denies but then acknowledges feelings of anger, demonstrating the interplay of word associations and the juxtaposition with other strongly felt emotions. Bette’s emphasis of dialogue from a more personal perspective is evident:

> *Mentally I’m not the same as I was before. I know because I’m slow ... because I’m not able to do things, I’m very frustrated. See, I don’t accept any of this. I don’t like it and I don’t accept it. I’m not angry, I’m very frustrated. I’m very, very frustrated. Frustration is a terrible thing; it really is anger. I feel half the time I want to do that and I am powerless. I’m just a shell; I’m not me at all.*

> *You're just a burden and you're not yourself at all. You don't even look the same, you don't feel the same. I can't get from A to B without struggling (Bette 3rd Interview).*

Difficulty maintaining daily activities was a common experience among the participants, with expressions of fear reiterated throughout the interviews. Feelings of frustration vied with a sense of fear, with predominance often seesawing between the two, as shown in the following quotation:

> *I think my heart has affected me a lot. It's a very frightening feeling—you're just frightened how it's going to go (Bette 3rd* Interview*).*

Fear was frequently expressed, at times carefully; for example: *'I'm really quite concerned', 'I'm a bit apprehensive about that', 'when I think about the future I suppose I get anxious sometimes'* and '*I just don't want to think about that'.*

The phenomenon of fear was experienced by all participants in a multitude of situations, which precipitated further discussion, often revealing an innate sense of vulnerability not only of a personal nature but also fear of other people not well known. Fear of unrelenting pain and, significantly, what the future held, was prominent among most of the participants. For example:

> *There's no light at the end of the tunnel. I suppose you just go on doing what you're doing every day. I worry the whole time. You can't think about the future. You just go from day to day, week to week. And I will do that until one of us*

> *finishes up you know, and are no longer here and that's my future (Fay 3rd Interview).*

Overall perceptions of the future were viewed bleakly, devoid of any evidence of optimism. Over the course of the interviews, intense feelings of anger and frustration gave way to feelings of disillusionment, generated by a sense of powerlessness and concern about the future. Expressions such as: *'Well, there's nothing I can do about it', 'I have no say in it', 'Well, I just do as I'm told, I'm not the one in control', 'What can I do, if I say anything it doesn't do any good, nobody listens'* and *'I lie awake sometimes and think a lot',* reveal the participants' sense of disillusionment and unease. In addition, offensive or ageist attitudes during interactions with health professionals culminated for some in rejection of assistance and further disassociation from society. A lack of respect for older people and their specific needs was pivotal to these perceptions. As Win reiterated:

> *[The future] Pretty bloody bleak; you can write, you can ring, you can talk to them, you can do anything but you cannot get anywhere with them and you're wasting your time (Win 3rd Interview).*

Win's cynical and at times disparaging comments belied her disillusion with the health system. Many of these were echoed by other participants, particularly those whose need to access health services was urgent. At other times, feelings of disillusionment stemmed from within and were therefore not always attributable wholly to external factors, as Monica's story indicates:

> *I was a little bit disillusioned and I was fearful the last time I spoke to you, but since then I've accepted my ageing—you know the change that has taken place in ageing which I didn't accept before. I had a fear that I wasn't going to get any better. Even though my health has improved but then the disabilities of ageing have increased; but I'm accepting of those and I limit myself to what I can do. I think I was rather aggressive that I had to give up all the things that I wanted to, but now I've reached a stage where I can accept my limitations and live with them. I was very angry when the diagnosis of osteoporosis was made because I didn't think that should happen to me. Even though I knew that these things were going to happen, I think I, like a lot of people, 'It's not going to happen to me.' But it has happened and I'm accepting of it (Monica 3rd Interview).*

Deeply held feelings and perceptions influenced responses and interactions with health professionals, which in turn mitigated willingness to accept assistance across all participants. Personal losses encompassing body image, loved ones and expectations of later life achievements and conviviality with family or friends increased disengagement from long-established daily routines and activities, further increasing social isolation.

Furthermore, the move interstate for Shirley heralded a new series of obstacles, resulting in a marked deterioration in health. This further highlighted the importance of maintaining networks in association with familiar surroundings. Previously discussed issues of powerlessness continued to play a vital role in the co-constructions of realities, which were modified to accommodate the unique challenges precipitated by new surroundings and living conditions. As Shirley wrote:

> *Oh, how we miss our closeness to everything at home—home being the operative word. At the moment I am not seeing any positives. There are only negatives even in this place; rather sickening ones, some infuriating ones and especially now they feel they have the right to stand over you, like you are perhaps a prison inmate, more like, instead of a decent living fine human being (Shirley 3rd Interview).*

Declining health, personal losses and loss of familiar surroundings, difficulties with transport, striving to maintain independence and autonomy, extended waiting times, feelings of invisibility, perceptions of powerlessness and the poor attitudes of health care professionals and ancillary staff culminated in a profound sense of frustration on the part of the participants, intermingled with anger. Feelings of frustration were generated and fostered by the seemingly endless barriers encountered when attempting to access appropriate and timely health care and assistance with domestic duties and home maintenance.

Difficulties were often encountered at the outset, with unexpected variances between service providers, along with extended wait times for commencement of services. Confusion regarding eligibility and a merry-go-round effect fuelled feelings of anger and resentment at a health system that was perceived to not understand or appreciate the ongoing difficulties experienced by older people. Perceptions of invisibility, worthlessness and being ‘past the use-by date’ added to the burden, promoting negative feelings that were, for the most part, representative of a profound sense of futility, forced acceptance and entrapment within the confines of ‘old age’.

Considering the ongoing and increasing difficulties being experienced by most participants, during the final stages of this research opinions on future health needs were explored. Without exception, all participants viewed retirement settlements and nursing homes negatively. The strong emotions conveyed were reminiscent of past and present experiences with loved ones. Without exception, all participants viewed supervised communal accommodation as a last resort, preferring to remain in their homes for as long as possible. An underlying sense of fear for the future was a pervasive phenomenon common to all participants, whose very avoidance of the word 'fear' brought this feeling into focus. Non-acknowledgement or avoidance of the effects of increased needs was a subject that the participants were reluctant to discuss in any depth. Interestingly, personal views were more willingly expressed when discussing other people. The experiences of friends were readily acknowledged, with several participants advocating accommodation and lifestyle adjustments they themselves were not willing or able to accept.

These views prompted me to re-visit the transcripts of the interviews. I felt that I had missed something significant, though not necessarily apparent. Was my picture complete? Here, following the tenets of constructivism and the foundation of grounded theory, I read each line of dialogue again, focusing on the meanings resting 'between the lines'.

Others may question this strategy, deeming it researcher biased. However, I believe I discovered significant 'links' in the 'micro-dialogue' that indicated more happening in each participant's life than just an overall non-acceptance of the ageing process and the inevitable and inescapable changes this brought to their lives. My own construction of participant realities based on in-depth analysis of each transcript indicated a constant ebb and flow of *re-negotiation.* Despite this never being openly acknowledged, or perhaps consciously recognised, the shifts and modifications to behaviour patterns offer testament to its presence. This phenomenon is explored more fully in the next section.

5.8.1 Re-Negotiation of Identity—‘I don’t want to get old’!

Throughout our lives, we are met with normal physical and emotional challenges, with each stage being crucial to our growth and development. However, the transition to older age continues to be met with abhorrence and fear by many who are already experiencing other health problems, social isolation or are gerontophobic. Historically, social isolation of older people and issues on ageing such as loneliness and depression have been well documented (Cattan et al. 2005; Cavelli 2007; Findlay and Cartwright 2002; Greaves and Farbus 2006; Hensher 2006; Rokach 2001; Rokach, Orzeck and Neto 2004; Vangelisti and Perlman 2006; Victor et al. 2003; Wenger et al. 1995). How we perceive older age is largely influenced by gender, cultural and spiritual values and socioeconomic status. For some people, ageing is a positive experience, with closely maintained family and social networks. For others, these essential networks are significantly diminished or they no longer exist, leaving the person to ‘negotiate’ this significant stage of life’s journey alone.

Re-negotiation of identity is an inherent part of life as we move through childhood, adolescence, young adulthood, middle and older age. Youth appears to have a resilience that, for many, appears to diminish with age. The psychological and physical effects of chronic illness, coupled with the normal decrements in health associated with ageing, can have a significant negative effect, particularly on socially isolated older people. Charmaz (1983) discussed issues of ‘loss of self’ and suffering in people who were chronically ill, identifying key issues of loss of self-worth, dependency, disruptions to the core-concept of self and incompatibilities with choices and freedom. Charmaz' findings revealed that many people with chronic illnesses analysed interactions for evidence of dis-accreditation and negative reflections of self, often becoming sensitised to perceived meanings of others toward themselves. This resulted in personalisation of dis-accreditation. My study has identified that these same issues are of paramount importance with ageing. Further, in the context of socially isolated older people, my study reveals the impact of such perceptions on self-esteem and in accepting or accessing health care.

The analysis of the time-differentiated interviews illustrates that daily activities that would once have been handled with little effort may now be perceived as insurmountable 'obstacles'. Such activities include travelling by public transport, negotiating medical appointments and other health needs and attending to home maintenance. There are also shifts in roles, with a 'parent', 'teacher' or other competent person used to being in a position of authority and autonomy suddenly finding him or herself being advised or having their decisions challenged by adult children, neighbours or younger professional people with less life experience. Participant comments regarding issues of invisibility and powerlessness validate this shift in power, which results in an undermining of confidence in one's own ability to make appropriate decisions and extends to other aspects of life and interactions with others. While these closely held beliefs may appear unsubstantiated considering the scope of interventional health care services aimed at the ageing population, it must be remembered that the participants in this study forged their constructions of reality and opinions of events based on personal experiences and difficulties with accessing health care needs.

These significant life events did not always transpire in a strictly linear progression but re-occurred at various stages of later life, often simultaneously with each other. The role and significance of re-negotiating identities is a significant finding, as concepts of sustaining the ‘self’ influenced how the participants perceived themselves and others’ attitudes towards them. This consequently shaped discourses with health professionals and those in the larger community. It is here that the *reasoning* underpinning issues of self-worth, denial of need and non-acceptance of assistance or community services were exposed.

5.9 Conclusion

This chapter presented the results of a constructive thematic analysis, which was underpinned by the basic tenets of constructivist grounded theory. This generated six major themes: declining health, dependence/sense of loss, transport, waiting, becoming invisible and powerlessness. The central or core theme houses several smaller categories incorporating anger, frustration, disillusionment and fear—which represented the culmination of the analysis.

Also embedded and integrated within this core theme was re-negotiation of identity, which surpassed all boundaries, linking each of the six major themes and their sub-categories. The findings are representative of three time-differentiated interviews detailing the experiences of six socially isolated older people living in the northern suburbs of Brisbane. The analysis of participant stories reveals not only their struggles to cope alone with little or no social networks but also the importance of maintaining independence. The influence of prolonged waiting times, along with ageist attitudes by health professionals and the greater community, reflected decisions of acceptance or rejection of community services, playing a pivotal role in revealing how realities were constructed and the impact of perceptions in interactions with health professionals and community service providers. The following chapter offers a detailed description of the findings from this study in conjunction with extant literature. This assists to identify where my research ‘fits’ with present evidence-based research and also serves to demonstrate new knowledge that has previously not been discussed in the literature.

CHAPTER SIX: DISCUSSION

> The great secret that all old people share is that you really haven't changed in seventy or eighty years. Your body changes, but you don't change at all. And that, of course, causes great confusion.
>
> Doris Lessing (1919–) British Writer (Bowden 2011 pp.305)

6.1 Introduction

Emerging academics may view research as a disarranged, multilayered puzzle, with the researcher holding the centrepiece, or focus, which identifies a problem or issue of interest. This essential focal point then becomes the basis of the research, often incorporated in the first or introductory chapter. However, qualitative research, particularly within a constructivist worldview, is not that simple. The journey begins with a literature review, (see Chapter Two), whereby the researcher searchers for and gathers information that will reveal what has been done in a particular area to identify gaps in current knowledge. As a result, a 'bigger picture' is built and more questions are clarified.

Pursuing this style of research has not been easy especially considering that possibilities grew as my knowledge of the subject increased. The previous chapters incorporate methodology (see Chapter Three) and method (see Chapter Four), which described the personal philosophy of the researcher, the type of research selected and the steps taken to identify and locate the missing pieces—a kind of 'mapping out of strategies'. Chapter Five, the analysis, constructed the story. Gradually, layers were identified and further constructed and although some are extended, others are discarded as not essential to understanding the questions posed. Throughout Chapter Five, emphasis was placed on diagrammatical models that were constructed, adapted, deconstructed and then reconstructed in an attempt to provide a picture of the *processes* involved in the construction of knowledge. Participant journeys along the time continuum seemed to be channelled in a downward spiral of increasing health problems and situational difficulties that eventually culminated in a repository of strongly held negative emotions, which exacerbated their situation and further depleted personal internal and external resources.

This sixth chapter offers a review and discussion of the saturated data and collaboratively constructed narrative. I acknowledge that constructivist qualitative research can never be a complete picture, as lives and experiences do not remain static. However, it can provide a rich snapshot of a particular time that will lead to greater depth of understanding of the issues from the perspective of the participants as constructed by the researcher.

The focus of this dissertation was to explore the experiences of socially isolated older people in their attempts to access and navigate the health care system in metropolitan Brisbane. In the process of sifting through the layers and fitting the pieces together, the aims and contribution this research project brings to extant methodological knowledge are examined. The limitations of this study and issues identified within this work that merit further investigation are addressed in the following chapter. Throughout the preceding chapters, additional pieces of the narrative have been provided by the participants, combining to construct a picture of the phenomenon of '*the experiences of socially isolated older people and how they access and navigate the health care system'* collaboratively.

Embedded in this picture are the three sets of time-differentiated interviews that incorporate participant responses pertaining to the research aims proposed for this study. These included: *What actions do socially isolated older people take to meet their health needs?* W*hat barriers are encountered by socially isolated older people in attempting to access health care and how do these difficulties affect their health status and feelings of isolation?* While some of this research's findings corroborate those from extant literature, the experiences outlined in the participants' stories go beyond what is currently known, providing new depth to current knowledge. Inconsistencies with previous findings are also identified and discussed in this chapter.

The ensuing discussion follows the framework of the six major themes identified in the analysis, beginning with declining health and culminating in the central theme. Throughout this chapter, the findings of this research are compared and contrasted with extant knowledge identified in the literature review. The reflections of participants on their journeys and experiences in accessing the health system have been incorporated into this chapter, which begins with the effects of declining health and its relationship with social isolation.

6.2 Declining Health and its Reciprocal Relationship with Social Isolation

The interrelatedness of social isolation and chronic health conditions, particularly in older people, has been well documented (Cattan et al. 2005; Machielse 2006; Victor et al. 2003) and the key arguments have been discussed in Chapter Two. Embedded within this milieu is UK-based research by Murray (2001) and Newall et al. (2006), who investigated the negative effect of accumulated trivial events on the lives of older people. The authors explored functional difficulties in coping with trivial events in the older person’s life that often resulted in increased loneliness and social isolation and influenced the development of depression. Additional research by Newal et al. (2006) revealed the effect of difficulties with everyday living, such as inability to open jars, change light bulbs, mow lawns and attend to everyday household maintenance. This research corroborates and extends these findings by identifying that unalleviated decrements in health, over time, can accumulate to compromise coping mechanisms. Further, it was found that negative personal perceptions, a strong desire to maintain independence and lack of willingness to accept assistance play pivotal roles in this complex and often overlooked scenario.

Thus, findings from this study remain congruent with various aspects of previous research (Cattan et al. 2005; Machielse 2006; Murray 2001; Newall et al. 2006; Victor et al. 2003), confirming that both individual and societal factors influence the extent to which older people become isolated. The factors investigated included living arrangements that is, living alone or in a carer relationship personal level of health, socioeconomic status, degree of mobility and personal attitudes and expectations. The frequency of social support from family and friends and emphasis on individual self-sufficiency and maintenance of independence irrespective of personal hardship were identified as key factors in the development of social isolation within this research. The following sections discuss *how* these factors affected the participant’s ability and willingness to access health care, thereby adding a further dimension to extant literature.

6.2.1 Interpretations of Social Isolation

Despite knowledge of the focus of this research, and acceptance to participate in the study, during the initial interviews, all participants either denied they were socially isolated or described social isolation in terms of ‘others’, avoiding reference to themselves. None of them had thought much about the notion of social isolation, and when they did, it was rebuffed. However, as the interviews and discussions continued, all participants gradually came to acknowledge their isolated circumstances, though often with constructed reasoning. This acknowledgement revealed a perception that being socially isolated was somehow a ‘stigma’ and that they were no longer considered equal to others in their age cohort. To avoid this ‘label’ and its prejudicial social connotations, several explanations relating to solitary lifestyles were offered such as lifelong habits of ‘being a loner’, or ‘not being particularly sociable’. In this way, the participants created a picture of ongoing normal behaviour patterns. Embedded within these constructions of reality are the tenets of several theories of ageing, which will be explored next.

6.2.2 Declining Health and Social Isolation—A Relationship with Theories of Ageing

In trying to find how all the pieces fit together, it became apparent that I needed to understand the life experiences of the participants, and how these experiences influenced the way they accessed health care. Stories of youth, family and friends, work environments, academic accomplishments and travel all provided insight into individual perceptions and attitudes that informed and influenced present opinions.

Many aspects of the stories are congruent with the theories of ageing discussed in Chapter Two. Purposeful withdrawal from previous activities and social interactions as defined by disengagement theorists (Cavalli, Bickel and Lalive D′ Epinay 2007; Earle 1992; Payton Fay 2004) were apparent in several accounts, along with ideologies and lifestyle relationships between past and present as posited by Covey (1981), Ebersole, Hess and Schmidt Luggen (2003) and Atchley and Barusch (2004). However, perhaps the most significant feature of the stories was the interaction with age stratification theory as pioneered by White Riley (1974, 1978, 1987) and Cockerham (2007). The most prolific responses from the participants involved perceived reduced social standing and lack of respect, often felt due to the ageist attitudes of health professionals and society in general and captured in the phrase ‘only the young matter’. Interestingly, my research revealed that these ageist attitudes became personally ingrained over time and were increasingly reflected in actions and interactions with others. The result was a re-shaping of personal attitudes and future behaviour patterns.

The ‘political economy of old age’ (Phillipson 1998; Powell 2001), while not viewed as a theory in traditional terms, was also evident in the participant group as they perceived or encountered inequalities of entitlement both in social and economic terms. These feelings generated a sense of being a ‘burden’ both in time and financially to others and to society as a whole. Two participants adopted ameliorative behaviours, becoming involved with voluntary work and demonstrating an attempt to adapt to their new social position and maintain a worthwhile place within the modern social structure.

My findings reveal that these theories do not exist as separate entities as previously portrayed but rather are experienced as an eclectic ‘blended’ mix throughout the ageing continuum, forming and shaping behavioural patterns and attitudes. Further, the experiences of the participants contradict the assumptions of gerotranscendence theory (Tornstam 1997a, 1997b, 1999, 2005; Wadensten 2005), with none of the participants achieving any explicit or implicit tenets purported by these authors. This finding may indicate that the theory has foremost relevance for those older people who have maintained close family relationships and supportive social networks.

The importance of maintaining supportive networks was the basis of research by Lechner and Neal (1999), Nazako (2001), Lowenstein and Bengtson (2003) and Berkman (2006), who identified a trend for women, the traditional caregivers in the family, to return to the workforce due to familial economic constraints. The resultant lack of assistance available within the family to care for older members has necessitated the implementation of government strategies and programmes, both in Australia and overseas, to address the increasing need for health-related care of the ageing population. My study acknowledges and supports this trend, but raises questions by revealing the continuing problems with accessing timely health care by those who no longer have family support networks and live in socially isolated circumstances. Participant stories of struggling to cope alone at home with minimal information regarding the availability of community resources have been discussed in the previous chapter. These stories highlight important real gaps in effective dissemination of information regarding service provision within the local community. It is this knowledge, or rather its lack, that we turn to next.

6.2.3 Knowledge of Community Services: What People Do I Contact and How Do I Contact these People?

A lack of knowledge of community services, identified in Chapter Five, revealed problems associated with being able to access appropriate government departments and personnel. Contact details supplied by GPs or medical practice staff were sometimes out of date and in some case the designated agency was no longer the service provider for the care package or program required. Often a merry-go-round of telephone calls resulted in the participant being referred back to the person to whom they made the initial call.

Difficulties encountered by participants related to not knowing where to find information, particularly when they were unsure of which service provider to contact. The manner in which information was sought was largely traditional that is, via telephone directories and newspapers. Three participants indicated they relied on pamphlets provided by medical centres, though these were not always accurate. Although much research on the use of computer technology by older people has indicated that it can have both social and health benefits, this study revealed that anticipated benefits, such as social integration via virtual communities and access to information, was not achieved by the two participants who had access to a computer and had achieved a basic knowledge of how to use it (Czaja and Lee 2007; Gibbons, Crichton and Crawford 2002; Richardson, Weaver and Zorn 2005; Selwyn et al. 2003; Shapira, Barak and Gal 2007; Sourbati 2009; Tse, Choi and Leung 2008). Furthermore, despite recommendations by Gibbons, Crichton and Crawfod (2002) and Tse, Choi and Leung (2008) for collaboration of community partners and government agencies to develop and instigate e-health programs aimed at older people’s needs, there is little evidence that older people living in social isolation would embrace the technology, even if it were offered through known community venues such as public libraries.

For over a decade, research has been undertaken in Australia and overseas to investigate the older person’s use of modern technology with findings generally positive for its use in reducing social isolation, particularly for those older people who are house-bound due to chronic health conditions (Capel et al. 2007; Czaja and Lee 2007; Gibbons, Crichton and Crawford 2002; Eastman and Lyer 2004; Richardson, Shapira, Barak and Gal 2007; Scott 1999; Selwyn et al. 2003; Sourbati 2009; Tse, Choi and Leung 2008, Weaver and Zorn Jr. 2005; Williamson, Bow and Wale 1997). Australian-based research by Gibbons, Crichton and Crawford (2002) and a UK study by Selwyn et al. (2003) indicated that the perceived relevance of computer use on the part of the older person determined engagement with this technology, with reliance placed on family members to assist with familiarisation and assimilation of processes involved with learning how to use computers.

Drawing on research by Gibbons, Chricton and Crawford (2002), Shapira, Barak and Gal (2007), Czaja and Lee (2007) and Capel et al. (2007), a diagram was constructed (see Figure 9) to illustrate the predicted advantages of computer use in socially isolated older populations. Although acknowledging both physical and psychological disabilities in older people, these researchers focused on identified benefits of computer technology, mainly decreasing social isolation through increasing modes of access to information relating to health and community services. It was felt that increasing the older person’s awareness of what services were available would make them more likely to access these services. Enrolment in free computer courses available through community libraries and participation in programs especially developed for older people was anticipated, with participation in 'virtual communities' predicted to overcome social isolation issues.

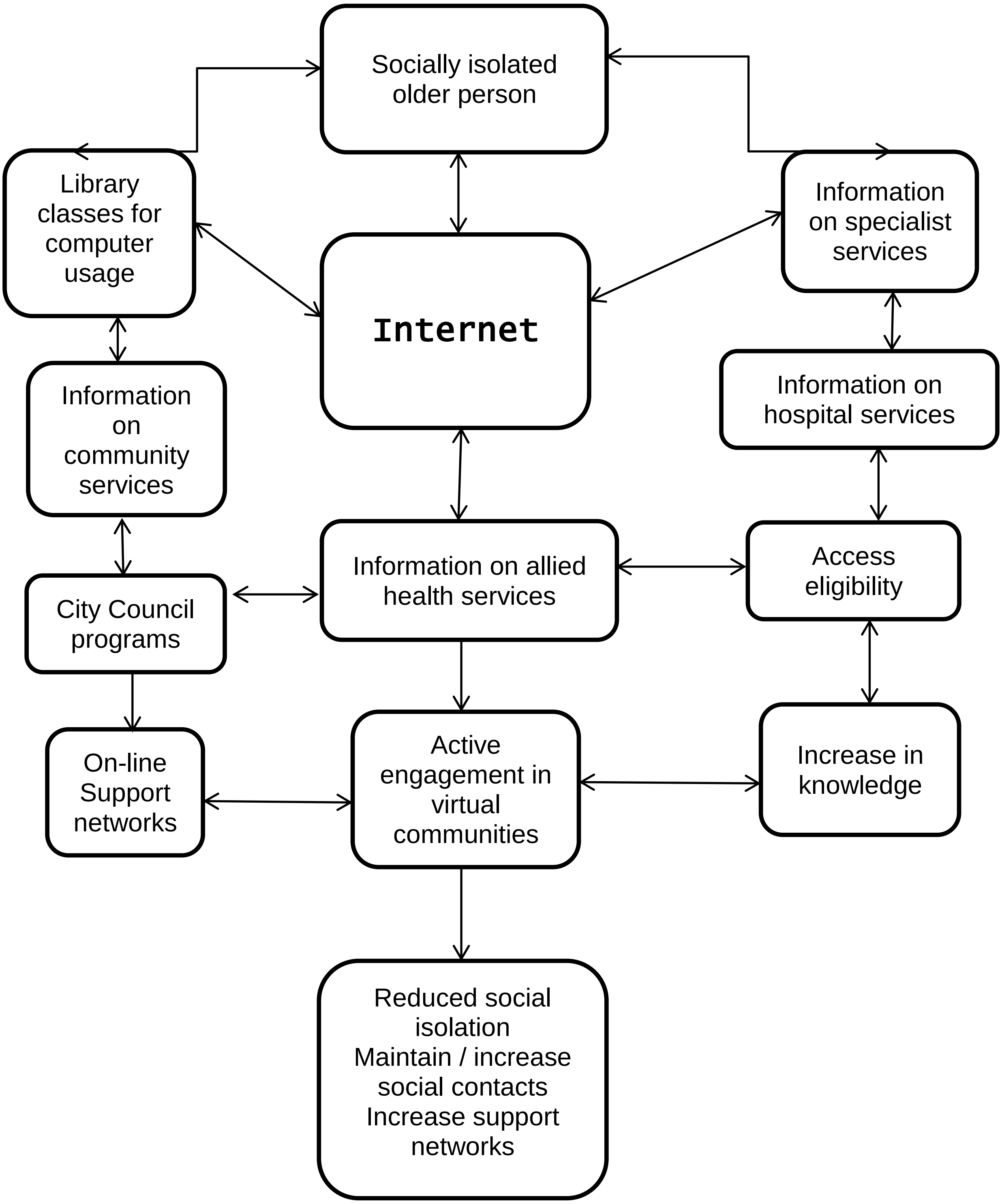


Figure 9: Predicted advantages of computer use in socially isolated older people

Although Gibbons, Crichton and Crawford (2002) focused on integration of socially isolated older people through development of community-based computer programs, there seems to be a continuing gap in service uptake, possibly due to the dearth of appropriate programs easily accessible to this cohort. Similar findings by Tse, Choi and Leung (2008) and Sourbati (2009) corroborated these earlier conclusions, with authors reiterating the importance of family and social networks in the adoption and use of computer technology. No consideration was given here to those that are socially isolated.

While social benefits of use and difficulties most commonly experienced were identified in all studies, gaps remain as to *how* socially isolated older people, if they cannot or choose not to use this method of communication, access health and community resources information. It is at this point that this study identified and elaborated on factors that contribute to non-use of computer technology.

Firstly, those participants who did not own a computer felt no desire or need to purchase one. Reasons included that they were too old, did not need it or that they were 'just not interested'. However, closer examination revealed that several participants avoided using such technology because they felt embarrassed at their perceived inability to understand its basic concepts. Such feelings acted as a strong deterrent, with negative opinions remaining static for the duration of the research. Secondly, accessing training to use a computer was problematic for all participants. Although local libraries occasionally offered free computer courses, travelling to the venue was often felt to be too much trouble for too little benefit. Thirdly, assimilating and consolidating information learned was also seen as a barrier, due to the limited time spent with the teacher (one hour per week for the duration of the course) with no opportunity to practice at home without purchasing a computer, which was in itself deemed an unnecessary and unaffordable expense. The two participants who were able to access computers used them minimally, often reverting to older ‘traditional’ methods of communication, such as the telephone, hard-copy directories and letter writing, as their primary mode of communication.

Physical restrictions such as diminished eyesight and reduced fine motor dexterity were identified as barriers to use of computer-based technology in previous research, and this was corroborated in this study. However, two participants also identified feelings of inadequacy and lowered self-esteem generated by such difficulties, which led to a more determined avoidance of this type of communication.

Although participants resorted to ‘old fashioned’ methods of locating service providers, this in itself proved problematic because, once telephone contact was made, they were often referred to Internet sites for additional information regarding scope of services provided. Further, telephone automated response prompts were found to be difficult to hear, understand and negotiate, particularly when options offered did not equate with the request or inquiry. If the options did not match what was required exactly, the participant believed the service was not provided. These combined factors often resulted in the participant terminating the call. While losses in ability to ‘keep up’ were not reported directly by the participants, their continued difficulties in accessing information indicated this was a problem they faced.

Integral to the availability and provision of services was the appropriate dissemination of information, with research indicating that computer-based forums present unique difficulties in accessing information, particularly for older people who experience psychological and physiological decrements in health associated with ageing. Both earlier studies (Scott 1999; Williamson, Bow and Wale 1997), which are now viewed as dated, and recent studies (Selwyn et al. 2003; Tse, Choi and Leung 2008) have presented similar findings on this issue.

In addition to corroborating that older people have ongoing physical difficulties when attempting to use computers—particularly in terms of their fine motor dexterity in mouse clicking—my findings revealed that socially isolated older people do not necessarily lack interest in learning to use such technology to access information. However, difficulties with use, perceived lack of applicability and relevance to daily life and inconsistency in being taught the relevant skills, particularly in the absence of supportive networks, acted as strong deterrents to their use. Further, embarrassment due to lack of knowledge or understanding, the expense of purchasing a computer and the ongoing costs of Internet access also played a significant role in avoidance of use.

Therefore, although Sum et al. (2009) identified 'older' people aged 55 to 64 years as being significant users of computer technology, their findings were based on those people who were *already* familiar with this mode of communication. Despite participants in this study being aware of computer technology as the 'modern' method of accessing information, they nonetheless preferred more traditional and familiar information formats. Where these were not available, the participants remained uninformed.

In addition, as the participants in this study demonstrated, without ongoing support and encouragement within the home environment, there was little incentive to continue attempting to learn the skills needed to obtain computerised information. Further, difficulties in travelling to community venues and interacting with other members of the community were viewed as obstacles by three participants, who felt ill at ease in the presence of people they did not know. Four participants believed that computers were of no benefit to them, yet acknowledged that they were a source of information regarding community health services. All participants demonstrated a strong preference to continue using traditional methods of locating and obtaining information, despite the time-consuming nature of this approach.

The responses of the participants pose further questions and warrant additional exploration of the place of newer technology, and the ability to use devices such as MP3 players, the iPad, iPhone and iPod, in the daily lives of this current older socially isolated cohort. Essentially speaking, *where* do these technologies ‘fit in’, if at all in the current aged population, particularly those living in social isolation?

The unwillingness or inability to learn new methods of communication and information gathering by this cohort has resulted in more emphasis being placed on the accuracy of information provided in medical centres and the timeliness of referrals by GPs. Brodaty’s (2008) claim that GPs need to refer older patients in a timelier manner to avoid clients presenting at the medical centre or hospital in crisis situations holds true, but no proposals on how to do this have been put forward. Perhaps going some way to assist in the development of such a proposal, the stories and experiences of the participants in my study demonstrated *why* timely identification of older clients that would benefit from additional interventions such as those available from community-based agencies was so important for comprehensive care, particularly for those living in social isolation.

Referrals consisted of arranging in-home visits by an ACAT or Veterans' Home Care service provider where eligible. My study highlighted the importance of GPs and their staff having the skills to navigate these systems and knowing about the health care packages being offered. For example, Community Aged Care packages, Extended Aged Care at Home Package (EACH) and Extended Aged Care at Home—Dementia (EACH-D) and Home and Community Care services. While these services can be accessed through domiciliary services, allied health professionals, carers or relatives and friends of the individual experiencing difficulty, in the absence of these supportive networks, the expectation from the participants was that their GP would organise the health care package or service provider to meet their specific needs.

My study further revealed that GPs often did not have the time or up to date knowledge to assist individuals with accessing health services. Low and Brodaty (2008) demonstrated ideal pathways for facilitating access of community health services. However, the time involved and resources required in organising such services was not investigated or discussed. Further, the authors acknowledged anomalies in the coordination of community service providers for case conferences and as such, the ongoing lack of coordinated informative processes, the impact of time constraints and consideration of the financial viability of hiring more staff in the GP setting were not investigated.

The extensive participant dialogue provided in Chapter Five, accentuated the limitations of community services. The delays in provision of services often resulted in extended waiting times for those in need of urgent home care, highlighting a lack of integration of some services and the existence of service gaps. These issues, along with the GP time constraints experienced by the participants within general practice, often prolonged the ongoing difficulties encountered.

My research highlighted that the socially isolated participants were at significant risk and that they often did not know where to turn for help. The problems that the participants experienced during times of personal crisis were often the result of factors that were already present, such as physical frailty, exacerbations of chronic illness and lack of supportive social networks. Over the course of the research, several participants appeared to live in perpetual or ‘slowly moving crises’ on a daily basis, but because of its insidious progression, time constrained health care providers often neglected to identify and instigate either medical or socially focused interventions.

Adding to these problems and compounding the daily struggle to cope was a strong desire to maintain independence at all costs, which saw some participants *declining* offers of assistance or refusing to access available health care. Such attempts to avoid dependency on others resulted in behaviours that increased the negative impact on deteriorating health. Despite provision of current literature detailing community service providers and eligibility criteria at the completion of the first interview, no participants acted on the information received.

During discussions within the second interview, three admitted that they had not read the information they had received. Reasons given were vague and alluded to the lack of need for any *outside* intervention. This was incongruent with their demonstrable decline in health and highlighted their overwhelming desire to remain independent and autonomous. This interrelatedness of dependence and loss is explored further in the following section.

6.2.4 Concerns of Dependency and Losses Relating to Declining Health

The importance of maintaining independence in older age has been identified in numerous research (Greaves and Farbous 2006; Cockerham 2007, Kellehear 2009; Minichello, Brown and Kendig 2000; Tanner D 2007, Victor, et al. 2003; Victor, Scambler and Bond 2008). However, the majority of these studies have focused on depression and loneliness in later life. While the need to maintain independence and autonomy was acknowledged, the long-term impact on those older people who are socially isolated was not investigated. This study adds depth to previous research by identifying the consequences of maintaining independence 'at all costs'.

Throughout the research period, all participants continued to strive to maintain their independence despite the increased risks of injury and for some, deleterious health outcomes due to deliberate non-access of available health care. According to Howse, Ebrahim and Gooberman-Hill (2005), deliberate non-access to health services was directly influenced by the potentiality and preference of older people to be 'looked after' by family members. However, the effect on decisions to decline services in cases in which these networks were not available was not investigated. In contrast to findings by Howse, Ebrahim and Gooberman-Hill (2005), the participants in my study demonstrated a collective aversion to accepting assistance from family members due to feelings of being a burden *and* a desire to maintain their independence.

Lack of regular contact with family generated a sense of social and reciprocal inequality, thus providing the impetus for the disinclination to 'ask for help'. Although Howse, Ebrahim and Gooberman-Hill (2005) noted that assumptions of non-availability of particular services acted as a barrier, my study revealed that reasons for non-access often went beyond what was believed available. Rather, non-access often related to a combination of an overall lack of knowledge of available services, assumptions of non-eligibility, fear of loss of independence and, significantly, loss of or inability to communicate effectively through modern media.

Further, results from discussions regarding accessing services indicated that, for several participants, both male and female, a perception of 'lost ability' was strongly felt if services were accepted. This perception was challenging to the participant, as they were forced to acknowledge they were no longer able to cope independently. Moreover, affordability and appropriateness of services was also identified by Howse, Ebrahim and Gooberman-Hill (2005) and corroborated in my study as barriers to access, my findings also indicated that *timing* of services and *attitude* of personnel delivering the service were significant determinants of acceptance or non-acceptance. Throughout discussions of access and acceptance of assistance from health care and community service providers, all participants, even when they were accepting services, indicated that they preferred, wherever possible, to maintain control over all aspects of their lives and that they adapted their behaviours to accommodate or compensate for difficulties encountered.

Loss of mobility and fine motor dexterity, fear of falling, loss of visual acuity, deterioration of hearing and continuing or increasing decrements in health resulted in restrictive behaviours that included remaining within the home environment, not shopping for essential grocery items and further withdrawal from social contact. Several participants cancelled or refused to make medical appointments when they were ill, stating they would do so ‘when they felt better’. These actions indicated that they felt too ill to drive to their GP and, in the absence of support networks, they waited until they were able to access health care independently. Access of after-hours medical services (where available) was also avoided by most participants, often because the doctor was unknown to them, or if they had a vehicle, they did not drive at night.

6.2.4.1 Distrust of Strangers—A Barrier to Access

A reluctance to interact with people not known encompassed not only medical practitioners but also those providing community-based services. As evidenced by participants’ stories in the previous chapter, mistrust of strangers also acted as a barrier to accessing supportive health services. While much research (Graycar and James 2000; Franklin and Franklin 2009; Franklin, Franklin and Fearn 2008; Moore and Shepherd 2007; Pain 2000; Pinkerton James 1992) has focused on older people’s fear of crime and its effect on quality of life and its influence on social segregation, little is known about how this fear impacts on the lives of older people who are *already* living in socially isolated circumstances.

Analysing patterns of conventional crimes against older people in Australia and overseas, Pinkerton James (1997) suggested that older people’s fear of street crime was largely unfounded, with fear of theft among those crimes that were least likely to be committed against them. However, there were mixed feelings across the participant group regarding perceptions of fear of crime within the neighbourhood. One participant felt fearful of street crime, as she believed that due to her age she would be an ‘easy target’. Her concerns were influenced by media reports of increasing daytime violence. Another participant harboured feelings of unease due to the communal living arrangements of the caravan park in which he lived, and yet others displayed no overt insecurities when talking about their neighbourhood.

Most participants felt secure within their own homes. However, two reported instances in which they believed they had been the victims of theft from community services personnel who they had either been referred to or sourced independently. Occurrences such as these led to increased wariness and further distrust of admitting people who were unknown into their homes, including referred allied health service providers. These concerns were more apparent with participants who were living alone. However, a degree of wariness was also evident in those that lived with their spouse.

Perceived intrusive attitudes from service delivery personnel were also associated with dislike or wariness, which often led to refusal or discontinuation of the service (although decisions were often dependent on the urgency of need). In Fay's situation, despite being dissatisfied with the poor conduct of several personnel providing care for her husband at night, she did not refuse the service. At times a sense of age-related vulnerability co-existed with imprecise and unspoken fears of 'being taken advantage of'. These perceptions undermined interactions with health professionals and community service providers and in this instance contradict the findings of Moore and Shepherd (2009), who investigated the relationship between fear and age based on British crime statistical data from 2001, with findings suggesting that people aged over 60 years were the *least* fearful of personal crime. One suggestion for this apparent anomaly is that socially isolated older people may not have taken part or been identified in the statistical data. While similar comparisons to this and extant research (Franklin and Franklin 2009; Franklin, Franklin and Fearn 2008; Graycar and James 2000; McKee and Milner 2000; Pain 2000; Pinkerton James 1992, 1997) can be drawn, insights from this study add a deeper dimension to these findings.

Social disorder and incivilities both of others and within the physical environment raised more significant fear reactions in females than in males (Franklin, Franklin and Fearn 2008). Social integration relied on traditional concepts of gender roles and the continuance of social activities within the community with findings remaining congruent with previous research. While specific perceptions of fear of crime and behaviours were explored, the effect of these on socially isolated older people was not investigated. My study addresses this gap by providing insight into how concerns for personal safety either within or outside the home environment are managed, furthering the notion that such concerns cannot be considered within a single dimension but rather should be considered within a paradigm of integrated belief systems and personal perceptions. While the inherent need to maintain personal independence and minimise dependence on others influenced most interactions, fear and mistrust of strangers often resulted in non-acceptance, limited use or termination of services.

Several participants revealed feelings of disquiet when strangers entered their homes. Perceived strangers included community health care and other service workers, who may have been referred by their GP. Much of this underlying concern related to issues of insecurity and vulnerability, especially when personal details were requested. As one participant revealed:

> *I was a little distressed at the intrusiveness of the person who interviewed me. I thought it was only for cleaning. I didn't see why they needed to have my full medical care and all that [sic] sort of personal things (Monica 3rd Interview).*

Further, the participants' preference to manage independently led to behaviours that, at times, resulted in further decreases in health and compromised ability to cope. Although distrust of strangers played a significant role in non-acceptance of assistance, inherent in these adaptive behaviours was the perception that one *should* be able to cope despite the infirmity of older age. Monica and Bette's stories highlighted this belief. After sustaining significant injuries from falls at home requiring hospitalisation, both of these participants endured a protracted recovery only to return home to confront the same difficulties that had preceded their injuries. Further, they had the additional burden of trying to cope with the challenges of further decrements in mobility due to the residual effects of injuries sustained.

To several participants, their *place* in society, along with their identity, depended not only on being able to remain self-sufficient, but to be *seen* capable of doing so by their peers. These perceptions permeated all interactions with health care providers and others who offered assistance in times of need, such as neighbours, friends or relatives. Issues of reciprocity for help offered often determined whether it was accepted, with those who were not in a position to 'repay' the kindness declining all offers. Concerns of being a burden to others were used to substantiate non-acceptance, thus forcing participants to continue struggling on as best they could. Research by Tanner D (2007) investigated older people's coping strategies, with findings suggesting that continuation of lifelong activities, while achievable for some could be problematic for others with concomitant health problems.

My study further revealed that attempts to stem losses in physical ability and mental acuity resulted in the development of anti-social, often alienating behaviours, which resulted in a decline in or cessation of social invitations and increasing social isolation. While several of Tanner's (2003) findings are represented in my study, including maintenance of daily routines and continuity of independence, further revelations by participants highlighted the erosion of coping capabilities as a result of physical exhaustion, as evidenced by Fay's experiences in attempting to care for her husband, which culminated in her own hospitalisation. Fay's situation exemplifies the extremes of duress that can be experienced by those living in socially isolated circumstances, whose role has adapted from partner to a more defined carer relationship with their spouse.

Losses demonstrated by several participants also included expectations of planned futures with their spouse or themselves; for example, travelling and social activities that were no longer achievable. As a consequence of these loses and increased physical isolation, feelings of loneliness emerged in several participants. However, in contrast to findings by Victor et al. (2000), whose research suggested that perceived stigmatisation of loneliness made older people unwilling to identify themselves as lonely, the participants in my study did not appear to place such significance on feelings of loneliness, instead placing the stigma on social isolation itself. This is a significant finding. While feelings of loneliness were acknowledged by Fay, Bette and Monica, the participants' focus remained largely on escalating health issues, decreasing mobility and transport concerns.

The ability to operate and maintain private transport was of significant concern to participants throughout the research period. While Ken was an exception as he did not own or drive a car, his almost total reliance on maintaining the lifelong skills necessary to ride his bicycle paralleled other participant concerns. The following section explores the effects of driving restrictions and the ability to maintain private transport.

6.3 Decreasing Ability to Drive and Maintain Own Transport

All participants utilised private transport, with only two relying on public transport to gain access to medical appointments at the major hospitals in Brisbane. Even in these instances, private transport was used to gain easier access to major bus interchanges, as suburban bus services were felt to be inadequate and poorly timed. As previously stated, Ken was the only participant who did not own a car, preferring to ride his bicycle, often over many kilometres to appointments in all weather conditions.

The importance of sustaining access to private transport has long been established. Hensher (2006) suggested that this mode of transport was crucial to maintaining social networks for some older people. Access to transport was certainly the case for the participants in this study, who equated private transport with independence, their enduring place in society and thus their personal identities. However, decreasing health heralded increased driving restrictions, which negatively affected driving for pleasure and gradually resulted in cessation of acceptance of invitations to social gatherings. Two participants had their licences renewed during the research period with restrictions imposed for driving distances. These restrictions had several consequences, one of which was the undermining of the perceived capability to drive, which resulted in some participants waiting longer for medical care because they no longer felt secure driving, particularly in peak hour traffic conditions. Additionally, restrictions further impacted on their ability to obtain medical appointments, with participants compelled to find alternative transport arrangements if the location of their GP was beyond the permitted driving zone. Where possible, all participants attempted to arrange their medical appointments at non-peak times, thus supporting Harris and Tapsas' (2005) concerns regarding traffic conditions. My study goes further to highlight the effect on the socially isolated person's ability to obtain timely health care from their GP and specialists.

Despite Hensher's (2006) recommendations for more user-friendly public transport for older people, a disparity in these services appears to continue, with several participants indicating that they were unable to utilise buses and train services. As interviews progressed, participants revealed that finding suitable alternatives to private transport was problematic.

6.3.1 'I don't like using public transport'

No participant wanted to or felt comfortable travelling on public transport. Several reasons were given, including concerns for personal safety and security while waiting at suburban bus stops, long wait times between scheduled stops, re-routing of regular bus routes, difficulty embarking and disembarking, unruly behaviour of others and the general inconvenience of using this type of transport. These stories corroborate findings of previous research by Gilhooly et al. (2002) and Hensher (2006), who identified similar barriers to older people using public transport. However, my findings also revealed that underlying these often self-imposed restrictions was a profound sense of personal vulnerability.

Unfamiliarity with using public transport compounded fears of falling or being jostled by other commuters and caused embarrassment due to lack of knowledge of bus timetables, routes, how to gain entry and payment options. In addition, self-consciousness regarding slowness of movement and the necessary use of walking aides resulted in a determined avoidance of public transport wherever possible, with several participants going to extremes to avoid its use, resulting in non-access to urgently needed medical care. Therefore, recommendations for changes in public policy by Hensher (2006), which included a call for additional infrastructure—such as larger and more easily understood signage, along with increased staffing both on public transport and at interchanges—may be more suited to ‘healthy’ older people who have maintained a working knowledge of public transport procedures or those whose supportive social networks are able to provide assistance with the transition from private to public transport. These changes are less likely to benefit the socially isolated.

The difficulties experienced by the participants in this study demonstrated that measures such as those outlined above will not necessarily alleviate the barriers faced, as the determinants for use and non-use are more deeply ingrained than simple physical restrictions, also encompassing the psychological embodiment of ‘old age’ as a holistic process. As Davey’s (2007) New Zealand study suggested, many older people were reluctant to accept lifts from others due to their inability to reciprocate or because of their fear of being a burden to family members. Consequently, opportunities for spontaneous outings for pleasure or recreational shopping declined and eventually ceased.

Davey’s study focused on how older people coped without having a car and investigated the determinants of quality of life and strategies for community integration. From the survey based study—which involved 28 couples and 43 single people—the author described a high percentage of older men (81 per cent) and women (55 per cent) being negatively affected by no longer having private transport. However, the ability to cope was ameliorated to a varying extent by the assistance of family, friends and neighbours.

Significant difficulties were identified in my study when minimal or no support networks existed. Three participants reported remaining at home for extended periods during times of ill health, not seeking medical assistance due to not wanting to be seen as incapable of coping. Therefore, difficulties encountered were often ‘played down’, with several participants indicating that they would utilise taxis if circumstances and need required they do so. Statements such as these were indicative of a perception that they maintained choices to ‘travel just like everyone else’ within the community. Maintaining choices was also related to the maintenance of personal self-esteem. That they did not do this suggested that these claims were more to do with maintaining image and identity. However, on deeper investigation, this mode of transport was equally problematic due to the cost involved and the effect regular use had on personal finances.

6.3.2 Financial Concerns using Alternative Transport

The importance of maintaining private transport in older age has been well documented, (Davey 2007; Hensher 2006), with benefits such as increased quality of life, psychological wellbeing, ability to sustain social networks and preservation of identity and independence being the most common indicators. When private transport is no longer a viable option, an alternative means of transport needs to be found, although this can also bring unique challenges to those living in social isolation.

In the absence of private transport, or where use of that transport is restricted, participants needed to locate alternative means of travel. Despite two of the participants in this study having a neighbour who would have been able to assist, neither was inclined to ask for help. Personal pride played a significant role in acceptance or rejection of assistance offered. In addition, the type of relationship and ability to reciprocate were also key factors when considering accepting help.

Ken, the only participant who did not own a car, remained adamant about travelling to medical appointments on his bicycle, despite the distances involved, utilising train services only as a last resort. Ken indicated that he would not use a taxi due to the prohibitive expense. Two participants made numerous attempts to access taxi travel vouchers, available through the government taxi subsidy scheme. However, this was always met with a negative response by the GP. Comments indicated a belief that the GP found the application process too difficult, was too busy or could not be bothered. Repeated requests for a disability parking permit by another participant also resulted in a negative response from the Department of Transport and Main Roads Queensland. No explanation was provided by the GP for the reasoning behind the denial of the permit. This illustrates the ongoing barriers in communication, not only with medical professionals but also with government personnel, which further reduced access to community services.

It is here that my study revealed a gap in the provision of community services. Despite research findings by Gilhooly et al. (2002), Harris and Tapsas (2006) and Davey (2007) and recommendations by Hensher (2006), there is a continued inflexibility of government policy associated with the personal transport requirements of older people. This inflexibility indicates an urgent need to develop guidelines that allow flexibility in eligibility criteria to enable access to health care and community services for older people that would otherwise be forced to continue to be marginalised.

Participants' mobility and health conditions were assessed and compared to the prerequisite requirements for taxi vouchers. My study illustrated the need for a more flexible policy on taxi vouchers. Table 4 has been adapted to illustrate the inequity of eligibility criteria for a taxi subsidy and the difficulties that participants in this study experienced with accessing transport. Its inclusion within the text of this thesis serves to highlight the ongoing gaps in government policy. Although Criterion 2 was met by one participant, she remained ineligible for taxi vouchers. One suggestion for this may be that documentation from the GP was not completed adequately or the significance of the participant's restricted mobility was not conveyed to their GP.

Table 4: Requirements of the Queensland taxi subsidy scheme (Adapted from the State of Queensland Department of Transport and Main Roads, 2009a)

Queensland Taxi Subsidy Scheme	
• Be a permanent resident of Queensland	• Fully meet at least one of the eligibility criteria listed below
1. Physical disability requiring dependence on a wheelchair for all mobility outside the home.	No participants met this criterion.
2. Severe ambulatory problem that cannot functionally be improved and restricts walking to an extremely limited	Several participants were significantly mobility restricted and could not walk without the aid of a walking stick or

distance.	‘wheelie walker’. One participant could only walk a matter of meters before having to stop due to shortness of breath.
3. Total loss of vision or severe visual impairment (both eyes).	No participants met this criterion, although two had significant visual disturbances due to cataracts and glaucoma. However, these were not binocular.
4. Severe and uncontrollable epilepsy with seizures involving loss of consciousness.	No participants met this criterion.
5. Intellectual impairment or dementia resulting in the need to be accompanied by another person at all times for travel on public transport.	No participant met this criterion. However, two required supervision and assistance by their spouse when travelling due to significantly restricted mobility. Due to this, the participant was unable to travel on public transport even when accompanied.
6. Severe emotional and/or behaviour disorders with a level of disorganisation resulting in the need to be accompanied by another person at all times for travel on public transport.	No participants met this criterion.

Source: http://www.transport.qld.gov.au/Home/Assistance_and_services/Concessions/Taxi_subsidy_scheme/, viewed 21 July 2010.

The right to access transport should not be pre-determined by rigid polices but rather assessed on an individual basis. Obviously, some structure and mandatory criteria as assessed by medical practitioners are required—this is not questioned. However, where access to health services is (increasingly) restricted, a consultative process should be available whereby individuals can gain assistance or temporary assistance as their needs dictate.

Once made aware of the difficulties being experiences by two participants that were unable to use public transport or obtain a taxi subsidy, I contacted the Burnie Brae community respite centre at Chermside regarding transportation services. I was informed that there were only certain suburbs neighbouring Chermside that could be serviced and Shirley and Harold's was not one of them (Burnie Brae Transport Coordinator, personal communication, 8 October 2008 and 13 August 2010). Further inquiries identified an additional transport service, Medi-link, which was accessible through Burnie Brae. However, there was an increased cost for this transport to major hospitals in the Brisbane area ($6.00 each way instead of $3.00 if only travelling to local clinics) with set times during the day for drop off and pick up. Further, walking aides such as wheelie walkers were not transportable. Therefore, only individuals who were mobility independent and lived within the designated suburban area were eligible to access this service (Burnie Brae Transport Coordinator, personal communication, 13 August 2010). These are important findings, as my study has revealed not only gaps in transport services provided but also that community services are not uniform across geographical areas, thus demonstrating inequity of access.

These issues further highlight the important roles practice nurses have in coordinating services for older people. They are well placed to identify such ameliorative practices and may be able to reduce waiting times for appointments with specialists and GPs alike, or, where necessary and available, they could coordinate alternative transport. Awareness of restrictions with transport availability allows practice nurses to investigate and initiate alternatives.

The significance of difficulties with or inability to access public transport was an issue raised by Harris and Tapsas (2006) and Hensher (2006). These findings were affirmed, particularly by Shirley's accounts, and though Bette indicated she would 'catch the bus' or 'travel by train' if her husband stopped driving, this was not the reality when this situation did arise. Both Shirley and Bette always travelled by taxis if private transport was not available. Though different reasons prompted their decision not to use public transport, one common denominator was a desire to maintain a sense of independence by *choosing* their mode of transport. Having a choice supports Davey (2007), whose research identified the importance for older people of reciprocity and choices in determining timing and types of transport used. Being able to continue making choices regarding transport, whether it was which shopping centre to travel to or when to make medical appointments, was important to all participants in this study.

Once again, these are issues that could be addressed by practice nurses who are ideally placed within the medical practice setting. With the relevant system support, practice nurses could seek out viable alternatives and encourage in-depth discourse by which patients can gain a clearer understanding of the scope and indeed limitations of subsidiary community services. The ability to make choices can foster a 'willingness to try' attitude by older clients caught in these situations. Practice nurses could also ensure that correct, fully informed and meticulously completed documentation is provided to government departments when applying for services such as the taxi subsidy scheme. For those who, like Fay, felt they could continue independently, this additional knowledge could facilitate a more complete understanding of community services, and most importantly, the pathways for future access that maintain a feeling that they have some control in their choices and subsequent health care.

Recent State Government initiatives to make communities more ‘seniors’ friendly’ are set out in the *Positively Ageless QLD Seniors Strategy 2010–2020* and incorporate initiatives to improve access to public transport. These proposals are heartening, with future transportation goals addressing such issues as larger signage, additional bus service stops in residential areas and education for bus drivers to increase their awareness of the needs of older passengers. These include lower steps for buses, waiting until elderly passengers are safely seated before re-commencing driving and providing physical assistance to older people embarking and disembarking the vehicle. The appointment of train station personnel to provide support and guidance to correct platforms and offer assistance to older passengers on to and off trains has also been advocated by policy makers (Positively Ageless QLD Seniors Strategy 2010–2020). However, I see no evidence of these being implemented and my participants had no knowledge of them.

Interestingly, several of these objectives closely resemble those discussed and recommended by Hensher (2006), whose Australian-based study highlighted similar issues including inadequate public transport signage, the importance of increased staffing on public transport and at interchanges, the difficulties of traversing steep hills to get to services, the need for flexible transport systems more suited to the needs of older travellers and more appropriate and strategically placed rest areas within the transport system for older commuters.

My findings support both Hensher's (2006) recommendations and also the goals of the *Positively Ageless QLD Seniors Strategy 2010–2020*. Further, they facilitate deeper insight into these socially isolated people's lives, by illustrating the negative impact of difficulties accessing appropriate transport, with the continuing difficulties reported affecting their health, personal finances and difficulty maintaining a positive identity. This situation fosters feelings of frustration and even despair in older people who do not have the 'luxury' of door-to-door transport that so many others who have close family and social networks take for granted.

Decreasing mobility can act as a barrier to accessing much-needed health care—despite the 'availability' of public transport. The inability to walk from the bus stop to the desired location posed as insurmountable a barrier as not being able to utilise the transport service in the first place. Long waiting times for limited bus services was also a factor in decisions not to use this method of transport, with unexpected changes in routes and drop off and pick up points also barriers to continued use of services. In addition, train stations were felt to be perplexing, with often no staff available to ask for directions to the correct platform. Participants were forced to rely on fellow passengers, who often could not or would not assist them with the necessary information. The inability to access information often resulted in undue stress and anxiety and was a significant factor in why this mode of transport was rarely utilised.

How far the ‘Positively Ageless’ strategies and programs, developed over the next several years, positively affect the health and successful ageing of socially isolated older people; and what improvements lead to increased utilisation of community-based transport services, will depend on timely and accurate evaluation processes. While we wait for these government initiatives to be implemented and evaluated, other barriers to access of health services should be explored.

A significant finding of this study revealed that extended waiting times surpassed those experienced by those travelling on public transport to include waiting for appointments with GPs, specialists, medical and surgical treatment and community services. The following section discusses participants’ experiences of waiting times for medical and community support services, and the interrelationship with maintaining independence.

6.4 Waiting Times

Participants encountered extended wait times for a variety of health-related services. These included appointments with doctors and specialists, with one participant likening her experiences of obtaining referrals and subsequent services to a ‘merry-go-round’ as she was passed back and forth from various community agencies who no longer provided the service required or who did not have the resources to take on new clients. Identifying and investigating limited government resources was one aspect of the research by Tanner (2003), whose findings revealed that health expenditure was directed to those who met pre-determined eligibility criteria, resulting in those with high demand needs gaining access to resources at the expense of those who were not necessarily in crisis situations.

While prioritising individuals most in need is necessary, those who ‘miss out’ and subsequently have to wait extended times in turn become those in crisis, resulting in higher demands on health care resources. This cycle was also acknowledged by Gray and Heinsch (2009), who investigated Australian labour shortages in the care industry and the increasing high demands for care that exceed supply. Extended waiting times for various community-based services were identified and mention was made of older people’s need to maintain independence. However, *how* factors of extended waiting times affected their ability to cope on a daily basis where access was declined or unavailable was not explored.

The daily difficulties experienced by the participants in this study have further identified both new and continuing shortfalls in current services. The need to maintain independence continues to compete with the increasing need for assistance with many aspects of daily life, including attending medical or specialist appointments, personal care, domestic chores, maintenance outside the home, grocery shopping or transport. The impact of extended wait times for services often resulted in the depletion of financial, physical and emotional resources, which ultimately led to poorer health outcomes and presentation to primary health care providers in crisis situations, as in the case of Fay. The prolonged waiting times to access appropriate community resources led to inadequate assistance in the care of her husband with Fay ‘picking up the slack’ where needs remained unmet despite accessing service providers. Continuing high costs that could not be sustained by Fay resulted in the service being terminated and only resumed when additional funding was available. At other times, Fay paid for services while waiting for community services.

During these times, Fay was forced to manage her husband’s care on her own or with the limited assistance of other services. Other participants grappled with similar financial constraints, often ‘opting out’ or not even bothering to acquire the service once it was known that a financial contribution was required. Win’s abortive attempts to gain access to pain relief or an earlier appointment for surgery further highlights this problematic aspect of health care services, along with the detrimental effects of prolonged waiting times for medical intervention.

Tanner’s (2003) UK-based study, which investigated older people and access to care, described health and social policy initiatives in terms of eligibility criteria. However, as the participants in this study have revealed, closer scrutiny of home support and personal finances, or lack thereof, should also be an equal-based determining factor alongside core physical and mental health criteria in prioritisation of access to services. One participant spoke of a ‘back up plan’ if she could not find relief of her physical symptoms. The plan consisted of prescription medication that was to be used if intense pain could no longer be tolerated. This ‘back up plan’ was never conveyed to the GP or hospital staff and clearly demonstrates how extended waiting times can affect the lives of older socially isolated people who, particularly in the absence of support networks, believe they have no other recourse.

Certainly personal perceptions and attitudes of others influence pathways of communication where either party constructs opinions regarding the other’s willingness to listen to concerns or complaints and act on what is conveyed. This is especially important in the GP setting, which is often the first and perhaps only level of interaction socially isolated older people maintain. Several participants commented that they would not discuss ‘social issues’ with their GP, as they were aware of time constraints within the general practice setting but there was also an underlying belief that the GP would not be interested.

These comments add a deeper dimension to Murray et al.’s (2006) opinions that GPs have difficulties identifying depression and other psychosocial conditions in their older patients. While the authors posit that older people are disinclined to discuss psychosocial issues (predominantly related to depression) with their GP, the comments by participants analysed in the previous chapter provide evidence that this phenomenon extends beyond the willingness to talk about depression to other psychosocial issues.

Personal perceptions, gender, socioeconomic status, cultural influences and past experiences play a pivotal role in what is deemed acceptable to reveal to others including GPs. Other contributing factors include perceptions of ageism, both personal and societal, loss of feelings of self-worth and embarrassment at being identified as living in social isolation and experiencing additional problems with coping associated with extended waiting times for health services. These perceptions discourage communication, particularly when personal experiences are compared to the anecdotal accounts of peers who maintain social supportive networks. In addition, the limited time afforded them by GPs was also mentioned by the participants, who felt they should not take ‘too much time’. Therefore, the role of the practice nurse is vital in identifying issues that would not necessarily be revealed within the medical consultation.

Medical practice nurses who were interviewed in Murray et al.’s (2006) study believed that older people were not able to articulate their feelings of psychosocial distress easily. However, my findings have revealed that this is not necessarily the case. Several participants in this study made numerous abortive attempts to communicate with health professionals and community health personnel with resultant negative outcomes and were very willing to tell me of their difficulties and worries. The following section discusses the interrelatedness of personal perceptions of ageing, the impact of attitudes of personnel directly involved with the delivery of health care and the largely negative feelings these interactions generated in the participants.

6.5 Perceptions of Invisibility—'why won't anyone listen?'

As previously discussed, ageing is a natural process on life's continuum. However, *how* people age differs greatly and, as research has shown, it is significantly dependent on personal wellbeing and the maintenance of core supportive social networks. In the absence of either or both of these conditions, difficulties can be encountered that cause distress and contribute to a further deterioration in both physical and emotional health, particularly in socially isolated older people. The skill of 'active listening' is fundamental for good communication. Although health outcomes may not necessarily be affected by such measures, the fact that older people are listened to and their concerns acknowledged and, wherever possible, acted upon is an essential component in maintaining their sense of self-worth and self-esteem.

6.5.1 Perceptions of Ageism

All participants exhibited an acceptance that ageing inevitably brought decreases in physical and psychological wellbeing. However, this was often tempered by a perception that once a 'certain age' (not necessarily defined in chronological terms) was reached, they were no longer seen as valued members of society. Comments made by Win relating to her 'pensioner' status and Bette's references to 'only the young matter' and being 'past the use-by date' highlighted feelings of loss of self-worth as well as a sense of loss of 'place' in society. This internalisation was particularly evident in Ken’s attitude towards medical care. His belief that one could not expect much at his age gave a clear indication that minimal assistance was expected simply because he was ‘old’. No one was exempt from this phenomenon of personalised ageism with all participants expressing a variety of views that essentially accepted (albeit unwillingly for some) ‘old age’ and all its encumbrances.

Embedded in these constructs were the reciprocal ageist attitudes of health professionals, who were seen to disregard traditional tenets of respect or courtesy towards older people. Previous research (Angus and Reeve 2006; Hagestad and Uhlenberg 2005; Lookinland and Anson 1995) has identified negative attitudes and ageist perceptions from health care workers towards older people and the effect of age segregation and social separation. However, none of the aforementioned studies investigated the impact of such factors on older people already living in social isolation.

Several participants in this study spoke extensively of feelings of invisibility and encountering ‘brick walls’ as their health concerns and questions were brushed aside by doctors and nurses alike. Further, two participants declined home services due to the intrusive and offensive comments by allied health personnel that alluded to age-related competencies. Fay’s accounts of her concerns for her husband ‘falling on deaf ears’ and abortive interactions with GPs in attempting to obtain medical assessments for her husband led to feelings of invisibility as she felt her concerns were continually ignored, eventually forcing her to seek help elsewhere. Other accounts of requests being ignored directly influenced participants’ decisions to disengage from further interactions with health professionals, with them instead preferring to rely on their own abilities to manage as best they could.

Research focusing on delivery of care by social workers (Thompson and Thompson 2001) advocated a shift from the medicalised traditional ‘caregiving’ model focusing on welfareism to an empowered model of care towards older people, thus widening the restricted ageist view of older people’s needs. The empowerment model fosters a facilitative and enabling role of social workers working in partnership *with* all parties to identify needs and how best to meet them. This study has provided meaningful insights into the effects of personalised ageist attitudes, feelings of invisibility and the impact this has had on declining or acceptance of care initiatives. My findings indicate that the need for policy development or adaptation of current initiatives is urgent, particularly in the area of ageist attitudes.

Much has been documented about ageism (Angus and Reeve 2006; Hagestad and Uhlenberg 2005; Lookinland and Anson 1995; Thompson and Thompson 2001) with suggestions having been made for changes in various aspects of policy making for almost 20 years. However, despite this knowledge, ageism remains a significant component of modern society and the lives of older people living within it. As this study has demonstrated, not only do ageist attitudes foster a sense of invisibility, they also reveal were intense feelings of powerlessness, which in the case of these participants, resulted in further marginalisation and disengagement from health professionals, community services and the broader society, placing this group at much higher risk of poorer health outcomes.

6.6 Feelings of Powerlessness

Co-existing with feelings of invisibility was a deeply held sense of powerlessness. This phenomenon was common to all participants and stemmed primarily from their health concerns not being listened to by medical and nursing staff. Stories of requests for assistance were varied across participants and they included requests for explanations of decisions regarding specific treatments, reasons for withholding medical interventions, information regarding waiting times for medical reviews and compliance with care regimes. Several participants were particularly determined in their attempts to obtain services and answers to their questions. However, none was successful. Of particular note were Fay's difficulties dealing with staff in the nursing home in which her husband was eventually placed. These remained ongoing and despite submitting a complaint against staff in writing to the management of the facility, no changes were instigated.

Research exploring key issues in the quality of health care for older people in the UK (Thompson and Thompson 2001) found that older people in health institutions were being treated unacceptably and ageist, stereotypical, negative attitudes of staff towards nursing home residents were identified. While the findings of my study corroborate these views, Fay's in-depth accounts of futile discussions with staff provides insight into the difficulties experienced and 'brick walls' encountered by carers of older people, highlighting their sense of powerlessness to change the attitudes and care regimes of medical and nursing professionals. Fay believed that the ability to care for older people with compassion and gentleness while maintaining their dignity should not be considered outside the scope of practice for any health care provider. She campaigned in earnest for changes to the manner in which her husband was treated, eventually becoming discouraged at her apparent ‘invisibility’. Requests to talk to doctors were heard but not acted upon. This was a common occurrence in her interactions with many nursing home staff.

Other accounts of feelings of helplessness were voiced across the participant group. Although Ken never openly questioned his medical treatment or complained about extended waiting times for appointments, after the third interview he nonetheless withdrew from medical services and did not return to the practice. His concerns that the ‘government would take over and he would be powerless to do anything about it’ if he accessed services are disquieting as such perceptions can obviously deter willingness to accept assistance.

Howse, Ebrahim and Gooberman-Hill (2005) suggested several reasons for help avoidance in older people, including assumptions of non-availability, lack of affordability, appropriateness of services offered and denial of need. However, as my study has revealed, feelings of helplessness, powerlessness and fear that those in authority may assume a dominant or commandeering role in their lives also acted as precursors to rejection of services. As indicated previously, accounts of powerlessness varied between participants, with several accepting treatment or lack of treatment passively, despite being less than satisfied with what was being offered. For example, throughout the course of the research, Bette fought against admissions to hospital. However, once there, she succumbed to the ministrations of medical and nursing staff without voicing objections. Bette felt she could not argue, indicating she felt intimidated because she was in the ‘jurisdiction’ of the health professionals. These comments during the final interview once again highlighted her ongoing feelings of powerlessness and vulnerability.

Somewhat in contrast to the other participants, Monica, who had worked within the health profession for a number of years, demonstrated a more understanding and tolerant attitude towards the problems she encountered. Monica tempered her feelings with academically based explanations, thus constructing a reality in which she was not an 'outsider' trying to gain access but rather remaining part of the system and a much-needed advocate. Monica held on to and reiterated these views in spite of experiencing similar feelings of powerlessness and vulnerability when dealing with specialists and community service providers who she felt were intrusive and used demeaning terms such as 'dearie' and 'sweetie' that devalued her sense of dignity.

Being shown respect by others, be it community care workers, nurses or doctors, was important to all participants. However, as their stories revealed, being shown respect was not evident in the majority of interactions with health professionals. Feelings of lack of respect corroborates Lothian and Philip's (2001) opinion that issues of insensitivity and disrespect were apparent in health care workers. Furthermore, Lothian and Philip suggested that improved training and increased contact with older people would have a positive effect on attitudes of health care professionals and those they cared for. However, as my study has demonstrated, these difficulties have remained within the realm of care providers. A sense on the part of service providers that older people should be treated with the kindness one shows to a child, or the other extreme of being in control of the individual, persists. Both deny the wisdom of the individual or their ability to make their own decisions.

Win, who was the most vocal of the group, recounted many instances in which she was 'fobbed off' or treated differently because of her age and in particular her 'pensioner status'. She felt that being on the government pension somehow made her less of a person in the eyes of the community and, as a consequence, viewed all interactions through this lens. Her combative discourses both written and verbal with hospital staff, nurses, community service personnel and even local politicians revealed an inherent sense of powerlessness and low self-esteem that remained masked by a 'tough as nails' attitude. Win felt stigmatised by her 'pensioner status' and believed that it was because of this that she was treated with a less than courteous manner by people in general. Her futile attempts to obtain free community services such as lawn mowing resulted in several letters of appeal to local politicians. However, here too she was unsuccessful in obtaining a reply let alone a satisfactory outcome. These factors played a pivotal role in Win's increasing sense of powerlessness as she traversed a system that could not adequately meet her needs.

For most participants unmet needs underpinned actions and non-action as they negotiated the health system because the need to maintain independence vied with the need for assistance. It is here that practice nurses engaged in conducting health assessments need to take a greater role in health management planning, as they have the opportunity to identify problems being confronted by socially isolated older people and the ability to work collaboratively with individuals to overcome these issues. Education of doctors, nurses and other community-based workers in the area of aged care or gerontology should be given priority as inappropriate responses offered with good intent can lead to poor, even harmful, outcomes for this marginalised cohort. Findings from extant research (Angus and Reeve 2006; Lookinland and Anson 1995; Lothian and Philip 2001; Hagestad and Uhlenberg 2005) along with new insights gained in this study illustrate ongoing problems with the delivery of health care to older people, particularly those living in socially isolated circumstances. Further, personalised constructions and internalisation of ageist attitudes fostered strong negative feelings towards the health profession as a whole. Negativity directly influenced interactions with health and community service providers. Further, these negative feelings, each seemingly interlinked within a downward spiral of health and coping capability, played a pivotal role in many interactions with health care providers and community-based agencies. These often resulted in unsatisfactory outcomes, which ultimately led to non-acceptance of services.

6.7 Central Theme: Fear, Anger, Frustration, Disillusionment: The Culmination of Decreasing Health and Ageing in Social Isolation

The culmination of feelings that were engendered by experiences of ongoing difficulties with access to and availability of health services are depicted in Figure 10. This diagrammatical representation of participants' journeys illustrates not only the centrality of emotions but the interconnectedness and co-dependency of the categories situated within each theme.

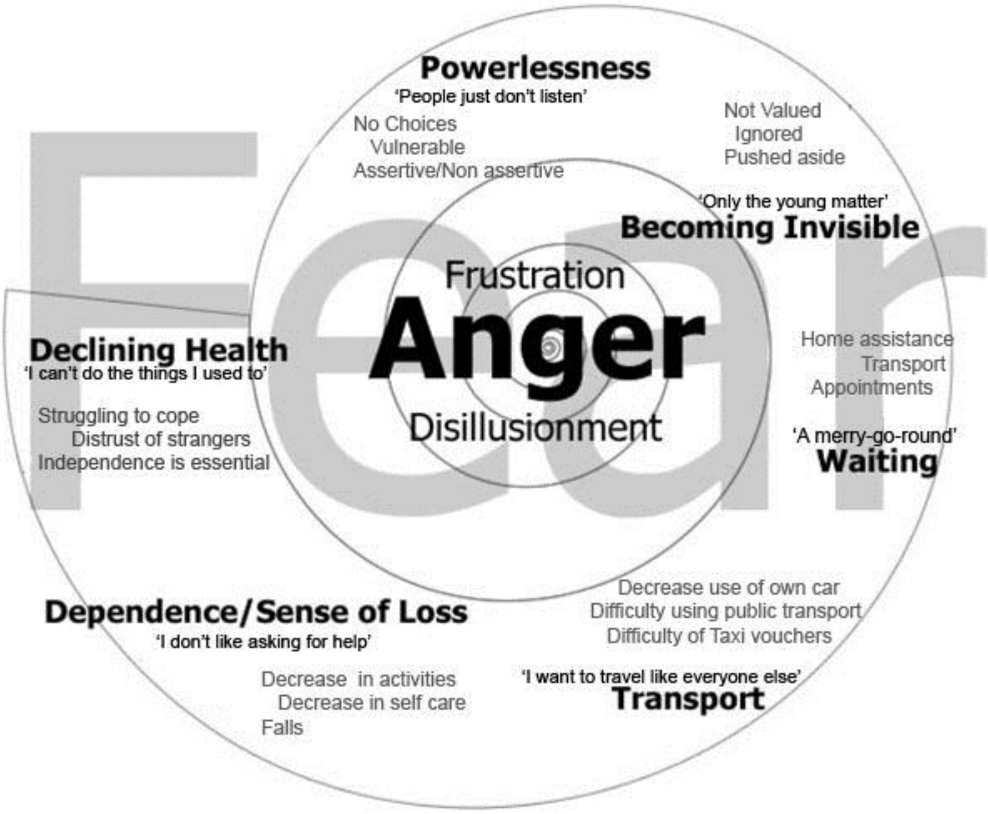


Figure 10: Spiral representation of main themes

Throughout this thesis, participant stories have combined to build a sombre picture that has illustrated the progression of declining health, the origin of which has remained indeterminable in chronological terms. Its eventual impact on daily living and the emergence of subsequent adaptive behaviours to maintain all aspects of independence and position within accepted societal norms have been identified throughout the analysis and interpretation chapter and further examined within the discourse of this chapter. Like building a puzzle, each participant's story has provided 'pieces' of information that have facilitated the construction of a picture of *what goes on* during interactions with medical and allied health professionals and significantly *what happens* to individuals living in socially isolated circumstances when needs remain unmet.

During the course of the three interviews, many layers of the participant's 'self' were uncovered. These layers included but were not limited to perceptions, emotions and personal attributes that, during the coding process, became the major themes and sub-categories of this thesis. Over time with participant and researcher reflection, more insight was gained into the interrelatedness of various influencers. These included, for example, past experiences, expectations and personal attributes that dominated and often determined interactions with, and reactions towards health professionals and community-based personnel. This final, central theme is the culmination of combined participant experiences and incorporates not one but several inseparable facets comprising anger, frustration, disillusionment and fear. These interrelated, strongly felt and deeply ingrained emotions underpinned many participant interactions with health care providers, each becoming more evident as the interviews progressed, particularly in those participants who were experiencing ongoing difficulties with accessing personal health care and community-based assistance. The following section discusses these emotions and the events and experiences that influenced their development.

6.7.1 Emotional Merry-go-rounds

The genesis of negatively grounded emotions originated in several key areas of the participants' lives. Once again, personal perceptions and sense of 'self' and societal position played a pivotal role in interactions with health service providers. In particular, those with chronic, severe debilitating health conditions demonstrated a deeper negative impact on their lives that inevitably led to increased social isolation. According to Charmaz (1983), chronic illness in any age group often leads to loss of choices and freedom to act independently. Lack of independence ultimately results in devaluation of individuals’ sense of ‘self’ and in turn leads to lower self-esteem and increased voluntary restrictive lifestyles. Charmaz (1983) also identified stress and frustration as end products of such restrictions, which were a maladaptive attempt to ameliorate the impact of physical debility.

The participants in this study demonstrated these behaviours and emotions. However, their frustration was overshadowed at times by anger that appeared to be reactive and that was outwardly directed towards those who were relied upon for assistance such as GPs, hospital or nursing home staff and community health personnel. For instance, Win’s comments about the way she was treated by people once they knew her age and that she was a pensioner revealed several processes at work—her own perception, others’ attitudes and Win’s reciprocal dialogue and behaviour based on personalised stigma. Her feelings of frustration and anger were often directed towards people who she felt treated her in a condescending manner.

Instances of anger directed toward the self in response to the physical effects of the ageing process and limitations of decreasing health and all that it encompassed was evident in participant stories. Much of the discourses surrounding these emotions were generated from these interactions, rather than internalisation of the impact of decreasing health. These reactions were primarily based on failed attempts to access specific and timely assistance from health care providers. Tanner’s (2003, 2007) view that the limitations of health services based on eligibility criteria should be broadened have merit, as this study has identified ongoing problems associated with limited access for those who are deemed to have ‘low level’ needs.

Fay's summation of her feelings and experiences in the final interview highlighted the impact of continuing unmet needs and the lack of choices for someone in her circumstances. Much of her anger was directed at a health system she believed failed to provide adequately trained staff and facilities to meet the needs of older people requiring long-term care. Fay also indicated similar feelings towards health professionals who ignored or appeared disinterested in facilitating ameliorative changes to address inadequacies identified, even following written complaints and suggestions. *'You don't get anywhere'* was a familiar comment by the final interviews, with three participants having repeatedly recounted similar experiences over the course of the interviews.

The culmination of extended waiting times, not being listened to by GPs and the attitudes of nursing home staff and community service providers resulted, at times, in a reciprocal antagonistic response or otherwise total rejection of services offered. Drawing on Russell and Schofield's (1999) detailed descriptions of service providers' perceptions of social isolation in older Australians and the opinions of Lothian and Philip (2001) regarding insensitivity and disrespect shown by care givers towards older people, it is concerning that many of these elements can still be found in the accounts of the participants in this study. There is a clear indication that 'nothing much has changed' over the past 10 years despite extensive adjustments to National Health Policy and in particular the Cross Government Project to Reduce Social Isolation of Older People (2004). Many participants felt disillusioned with a system that claims to offer much, but delivers very little in reality. Moreover, Win's comments testify to the inadequacies of a health system that promises services, yet could provide little or no appropriate support. It appeared that continued inability by community service providers to address requests for assistance fostered escalating hostile emotions in participants who were in crisis situations but could not breach bureaucratic protocols. *'Sorry we can't help you'* was yet another commonly identified response, which ultimately resulted in participants 'giving up' and managing the best they could on their own as they realised they could not change anything.

6.7.2 Nothing Changes—Why Bother?

When reviewing previous findings from Charmaz (1983) and other researchers perhaps it is not surprising to find instances of reactive contentious interchanges with primary health care providers, as it appears that, over time, the same hurdles are continuously being confronted by socially isolated older people (Cornwell and Waite 2009; Lothian and Philip 2001; Tanner D 2003; Thompson and Thompson 2001). Feelings of anger at not being listened to, feelings of frustration at being made to feel invisible and a sense of disillusionment were common among the participants and increasingly expressed throughout the course of the interviews. Further, the detailed accounts from the participants acknowledging that 'nothing ever changes' provided a unique 'insider view' of *why* some older individuals disengage from or refuse further offers of community assistance, eventually disengaging further from society. Disengagement was evidenced in this study by Ken's withdrawal from the medical practice and also Shirley's eventual refusal of all community assistance and engagement with GPs, unless contact was unavoidable in times of crisis.

Across these largely negative views, one participant demonstrated a moderate level of tolerance for inconsistencies in her health care. Having worked for many years in the health industry, Monica appeared to possess an insight that remained elusive to other participants. Despite incorrect diagnoses and treatments, she nonetheless remained resolute in her support of her GP and although re-affirming her disappointment, anger and frustration to ageist and demeaning attitudes of community service providers, she remained affiliated with the medical profession as a whole. This affiliation stemmed from a longstanding association with the health profession, which she felt set her aside from ‘others’ who she believed may not fully understand the necessary restrictions to resources for health care and its deliverance to those in greatest need. However, despite these assurances of understanding regarding health service provision, Monica, like the other participants, harboured deeply held concerns regarding the future and the ability to maintain the independence and autonomy that were crucial to her wellbeing.

6.7.3 ‘I’m not frightened—well not really’

The difficulties encountered in accessing care packages as evidenced by Fay’s stories and the lack of appropriate services available as described in detail by Win and Shirley provide a background from which landscapes of socially isolated older people’s lives can be built. These illustrate how seemingly small obstacles can develop into major hurdles (Newal et al. 2006; Murray 2001). It is interesting to note that the word ‘fear’ was avoided by the majority of participants and at times was dismissed out of hand. However, as discussions progressed a familiar pattern of *choice* of words became apparent. For instance, participants selected words like worry, concern, distress and anxiety to convey their apprehension or *fear* towards many aspects of their lives. For Win, fear of crime against her person was an effective deterrent to waiting at suburban public transport stops. Other participants spoke of unwillingness to permit people unknown to them into their homes, thus revealing a sense of vulnerability and subsequent lack of trust.

Although Carcach et al. (2001) contended that the lowest incidence of victimisation against older people was robbery or sexual assault, Win's fears and the concerns of other participants serve as a stark reminder that even if these perceptions *are* unfounded, they nevertheless play a significant role in perpetuating and exacerbating social isolation, particularly in this cohort. Participants revealed that reading and listening to news reports of escalating neighbourhood violence increased their sense of vulnerability and heightened their fears of victimisation thus providing a deeper insight into the multifaceted long-term effects of social media. Participant's perceptions of crime and victimisation support and extend findings of early works by Pinkerton James (1992) and others (Graycar and James 2001; Lupton and Tulloch 1999; McKee and Milner 2000; Pain 2000; Sanderson 2006; Smith 2003). Although acknowledging the role of social media in perceptions of crime, much of this early research focused on the 'end product' of fear such as social isolation. However, as my research has revealed, fear was an insidious and pervasive phenomenon that, for some, went largely unnoticed or unacknowledged in everyday life.

Fear encompassed many aspects of participant lives with significant focus on loss of physical functionality. Fear for what the future held was also demonstrated by several participants who indicated no desire to move into community dwelling or a nursing home despite increasingly poorer health and advice to do so from their GP. Often opinions were based on anecdotal evidence. However, several participants had first-hand knowledge of the discrepancies in care given to their loved ones, which served to bolster their negative opinions and decisions to remain at home, despite the risks involved.

6.7.4 Who am I? Who Have I Become? Issues of Re-Negotiation of Identity

Throughout the interviews nuances and omissions in discourses left curious gaps and silences, leaving the construction of meaning making incomplete. While the pieces of the puzzle seemed to 'fit', there was something missing. On further reflection and after extensive re-reading of the stories, I found that there was a core phenomenon underpinning and shaping participant belief systems and their interactions with the larger community, which went far beyond the accepted norms that could be located in extant literature.

Early work by Charmaz (1983) identified a process of 'loss of self' in chronically ill people in which discrediting statements by others sometimes validated hidden fears, resulting in a re-casting of the person's self-image in an unfavourable light. While several participant stories corroborate these views, I believe a new finding has emerged—the re-negotiation of personal identity in a 'whole person' context. This feature underscores all the findings across themes and sub-categories, with each one building on the one previous, to culminate in the final 'core' theme, which incorporates co-dependent elements of anger, frustration, disillusionment and fear. Embedded and cocooned in these feelings rests re-negotiation of the 'self' in terms of physical, psychological, socioeconomic and spiritual needs. The difficulties participants experienced stemmed from a mixture of social and personal determinants as they progressed through life. The absence of supportive family and social networks led to ameliorative, though often maladaptive, behaviour patterns, which were exhibited to varying extents by each participant and, which, over time, influenced their actions and interactions negatively when attempting to access health care.

Throughout all stages of growth and development, from infancy through childhood and onto teenage and adult years, we have societal norms and parental influences guiding and shaping the person we will eventually become. We learn to live within these boundaries, identifying ourselves within groups of peers and socioeconomic and professional strata (White Riley 1987). As the participants in this study revealed, these boundaries appear to break apart as older age is reached in social isolation, leaving gaps in the social continuum. According to Angus and Reeve (2006), society informs this cohort of its obsolescence through ageist attitudes, which becomes internalised and lead to further disengagement from normal activities and society. My study supports and extends these findings, with participant's comments regarding being relegated to nursing homes and retirement villages indicating an awareness of social exclusion and segregation from general society.

Hagestad and Uhlenberg (2005) discussed the effects of age segregation on both young and older people. The authors found that for older people, ageist behaviour patterns were congruent with enforced separation from society in the form of managed environments such as retirement villages and nursing homes. Such restructuring in living arrangements encouraged and facilitated movement away from normal social interaction with other age groups. The desperate need to 'maintain independence' so often evident in older people can also be viewed as maintaining an 'identity' that is perceived of being of value, not only by the individual but also within the broader precincts of society. The importance of professionals and young people within this valuing is crucial.

Thus, the spiral of deteriorating health and physical ability marked first by small decrements in health, inexorably progressed to issues of dependency and need, which converged on issues of autonomy and independent transport options, further extending to waiting times for medical and community services. The culmination of these factors led to feelings of invisibility and worthlessness, resulting in frustration, anger and fear. Figure 11 demonstrates the chronological progression of the events experienced by the participants and the genesis of the model of re-negotiation of identity.

Figure 11: Re-negotiation of identity

This study has shown that such re-negotiation takes place on a ‘hit and miss’ basis, at times not occurring at all, with participants struggling to come to terms with the downward spiral of deteriorating health, particularly the loss of physical ability. Seemingly ill prepared for the next stage of life, most participants portrayed an attitude of ‘living through a looking glass' as they attempted to continue living within the more familiar boundaries of their youthful adult years. As Tanner (2003) pointed out, *care* models of health intervention diminish the worth of this cohort as they become identified as *needing* to be cared for rather than being collaborative partners in their health interventions. Such losses of dignity, self-esteem and social standing serve to marginalise these people. Win's comments that 'once you are a pensioner you are a nobody' echoed the complexity of the negative emotions felt by other participants in the group, who held an acute awareness that their age pre-determined their treatment by others. Other comments by participants of being ignored or not listened to also highlight the ongoing plight of socially isolated older people, who appear to have less right to be heard that their younger counterparts.

Despite ongoing government interventions to reduce social isolation of older people, little appears to have changed in terms of timely access to health and community resources. Bette's dialogue throughout her interviews, reiterating that *'only the young matter'*, revealed a deep sense of loss for the person she *used* to be. Bette often focused on accomplishments in her youth, revealing her continuing identification with the past and inability to accept her declining health and the difficulties she faced when attempting to access medical or community service providers. For Bette, re-negotiation of identity had not occurred, which left her angry and frustrated with herself.

In contrast to others in the group, Ken appeared to accept the increasing limitations that the ageing process brought. However, rather than seeking assistance, he often refused to accept medical diagnoses and treatment. His comments *'what health problems?'*, demonstrated not only denial of significant chronic health conditions but also rejection of those he saw as authority figures who could *'take over'* and dictate terms of how and where he lived. These perceptions permeated Ken’s attitude towards his lifestyle with comments pertaining to his past reminiscent of Bette’s preoccupation with her ‘self’ during a time of independence and personal achievements. Avoidance behaviours in older people, when offered access to community services, stem from the associated stigma of no longer being capable of independently attending to their own needs. While this remains true, the inadequacies in services and its providers were also a significant reason that some services were rejected. Past experiences with rude, lazy or dishonest health workers provided further impetus for participants to try to hold onto those activities that they experienced difficulty with or could no longer do. As Oscar Wilde aptly put it:

> The tragedy of old age is not that one is old, but that one is young.
>
> Oscar Wilde (1854–1900) Irish poet and dramatist (2011, p. 235)

Wilde’s quotation epitomises the participants in this study who remained young in mind and spirit, but whose age and associated physical infirmity prevented them from being the people they wished to be.

6.8 Conclusion

The purpose of this research was to explore and understand the experiences of socially isolated older people as they attempted to access and navigate the Australian health system. This chapter has provided a detailed discussion of six people’s experiences of accessing medical care and health-related community services while keeping within the constructs of the broader themes identified in the previous chapter. The complexities of participant experiences and the relationship and impact of continuing decrements in health, loss of physical ability and independence and ageist attitudes highlight continuing difficulties when attempting to access government health initiatives and programs within general practice and other community-based settings.

Several key issues have been identified in relation to the delivery of services by medical, nursing and community providers (see Figure 11), including indications that the attitudes of personnel discourage access and uptake of health resources. Research into the social isolation of older people and its effect on physical, psychosocial and socioeconomic status has been extensive. However, the interrelatedness of diversity in perspectives, *emotional* responses and resultant behaviours and *long-term effects* has been largely underexplored in the extant literature that investigates these phenomena in older age groups. This study has provided in-depth insights into these ongoing difficulties, contributing knowledge and providing a foundation for future research. In the following chapter, further implications, detailed recommendations for practice and discussion of the limitations of this research are presented.

CHAPTER SEVEN: REFLECTION, STRENGTHS AND LIMITATIONS: RECOMMENDATIONS FOR PRACTICE

7.1 Introduction

We often ask what relevance or influence a particular study has to the efficacy of delivery of nursing care and interventions by other health professionals. In the academic arena, the ‘worthiness’ of a thesis is examined in terms of what new knowledge has been discovered and how this knowledge can be utilised or adapted to enhance the effectiveness of health care strategies or assist in the development and delivery of programs for the target cohort. Generalisability was not the intention of this study, but findings revealed many similarities in participant experiences, suggesting that results could be generalised to other socially isolated older people within the wider community. This chapter encompasses the culmination of my dissertation and begins with a personal reflection of my journey. The strengths and limitations of the research follow, before the chapter concludes with my recommendations for practice.

7.2 Researcher Influence—A Personal Reflection

Researcher bias has long been acknowledged and scrutinised, particularly in qualitative research. However, adhering to the established norm of influencing the behaviour and values of participants as little as possible imposes on the researcher a form of restrictive one-way communication incompatible with a view of knowledge as socially constructed.

Dialogue demands that the judgements and values of all participants be made apparent and tested critically within the course of inquiry. Thus, I pondered my own beliefs and constructs of social isolation of older people in an attempt to gauge to what extent I may have influenced participant dialogue or perceptions of ‘isolation’, particularly in view of my established nursing experience. All participants had not previously thought of themselves as living in social isolation. However, as interviews progressed, the participants became increasingly introspective, with all eventually admitting that this was indeed the case, though personal circumstances varied. It is interesting to note that participants used less stigmatising words in acknowledging their isolated circumstances. There remained an awareness of the negative connotations of ‘social isolation’. This in itself was significant, as it appeared that a certain amount of ‘aloneness’ was anticipated and accepted as normal as people age. I have come to believe that the spirit of scholarship lies in the degree to which language facilitates and encourages analytical discourse both in the academic world and in the world of the people whose lives are touched by the ideas raised.

Reflecting on what *new* knowledge had been discovered in this study, I revisited my initial aims to see whether I had achieved my set goals. To begin with, I wanted to raise awareness of the factors that influence the development of social isolation in older people by examining the health care strategies that affect their wellbeing. In doing so, I hoped to enhance the understanding of health professionals on the significance of difficulties encountered in accessing and navigating the health care system by this cohort. I also sought to establish what socially isolated older people wanted from the health system.

By bringing attention to the predicament of this cohort, these people were given a voice that will be heard within the literature of nursing and policy makers. In addition, I wanted to identify the various strategies socially isolated older people employed to access and navigate the health system. Finally, I sought to add to the body of health care knowledge by facilitating reflective practice. It is hoped that the findings from this study promote further development of health care initiatives for socially isolated older people. It is also hoped that these community programmes can be tailored to meet specific needs and marketed in such a way as to increase utilisation by this marginalised cohort. Here, I have taken a few moments to reflect upon the beginnings of this study and the processes that have brought me to the final chapter of this thesis.

Reflection at various stages of any study accomplishes several things. Firstly, it refreshes the memory, illuminating subtle references to important issues that may previously have been overlooked. Secondly, reflection often allows the researcher to re-visit the initial aims and objectives and determine to what extent they have been addressed and what influence participant information has had on these objectives. Thirdly, reflection allows focus on what remains unspoken and leads to further probes. Finally, reflection facilitates clarifying the central story and helps to render a disarrayed and complex collection of data into a readable sequence that affords a focused or structured guide for the final stages of writing. Below I summarise my methodology and its influence on the data obtained.

This qualitative dissertation is methodologically positioned within a constructivist paradigm, with its foundation strongly established within a classic grounded theory approach as originally developed by Glaser and Strauss (1967). Other important contributors to the methodology employed include Charmaz (2006), whose constructive approach informed the methodology, and qualitative research advocates such as Morse and Richards (2002), Morse and Field (2003), Thomas (2003) and Morse (2007). It has been a complex journey, encompassing in-depth exploration and consideration of a number of qualitative methodological approaches and research methods. I initially struggled with the perceived static 'truth' that is implied in grounded theory and became more at ease with a constructivist view of the world in which there is no one truth that applies to all human cases. I believe a constructivist approach is congruent both with my own view of what constitutes reality and with the aims of the study. The methods utilised generated large volumes of participant experiential 'talk', which is the norm, particularly in qualitative research (Charmaz 2006; Morse 2007; Morse and Field 2003; Morse and Richards 2002).

At times it was difficult for the participants to remain focused on their issues of concern, with conversation often digressing to other experiences not related to accessing health needs. However, these digressions revealed a more comprehensive picture of the intricacies in the lives of the participants, their attitudes and beliefs on a wide variety of topics, thus permitting a deeper insight into why they approached their health care needs in the manner they chose. Stories told during the three sets of face-to-face interviews both complemented and contrasted each participant's experiences. This dual outcome allowed the participants stories to be sorted and for connections to be made, revealing their many layers and facilitating deeper examination both by the participants and myself (as researcher).

7.2.1 Service Integration: To What Extent Can This Be Achieved?

The initial interviews revealed a paucity of knowledge of community-based programs and health service providers with participants unable to describe *how* they would access their health care needs. *'I wouldn't know who to contact'* was a common comment, with an overall expectation that the GP or practice staff would provide them with the necessary information or would make arrangements on their behalf. This lack of knowledge spanned the three interviews, despite each participant being given current literature and contact numbers of community health service providers at the completion of the first interview. Services such as Meals on Wheels and Veteran Affairs were known to participants but many other services that focused on the specific needs of older people remained unknown.

Subsequent interviews revealed that several participants had not read the literature supplied, perhaps indicating a desire to be informed only when the need arose. However, even when informed, this group did not necessarily take up services despite an obvious need for assistance. There were several reasons for this, with the first being the continuing lack of coordinated health services. Health systems that are fragmented can cause bewilderment and confusion in those requiring coordinated care. Three participants who accessed these services eventually withdrew feeling disillusioned and angered by long wait times for appointments, complex referral procedures, lack of appropriate care, poor work ethics and ageist attitudes. As one participant discovered, connections between primary care and social services (such as respite care) are limited, especially for older people. Although there is unanimous agreement regarding the value of communication and the streamlining of intake procedures, some agencies continue to function independently from each other. As a result, some service organisations are unable or limited in their ability to provide *coordinated* care.

7.3 Strengths and Limitations

Several strengths can be identified in this research. I made constant choices about what questions to ask, what responses to probe and what non-verbal communication to note. Close attention to a small number of participants allowed for repeated review of the whole corpus of data and led to knowing the participants well, resulting in an in-depth understanding of the problem areas as perceived by the participant group. This insight is a major strength of good qualitative research. To guard against over generalisation, I gave special attention to non-examples of patterns identified.

The qualitative constructivist approach of this study has also provided a unique insight into the physical and emotional effects of ongoing difficulties experienced by socially isolated older people as they attempt to access and traverse the Australian health care system. Cross-participant comparisons of in-depth interviews have provided rich detail and understanding of the phenomenon of social isolation. Despite Federal funding and initiatives by both State Government (Bartlett et al. 2008; Warburton and Lui 2007) and local councils to address the issue of social isolation in the older population, there remain significant gaps in service provision, which this study has identified.

The phase four report from the *Cross Government Project to Reduce Social Isolation of Older People* (2008, p. 27) provided some evidence that programmes such as *The Linking Seniors Project* had met its objectives. However, the participant stories in my research contradicted these conclusions, revealing instead that continuing lack of awareness of such initiatives in addition to lack of knowledge of key health professionals and community workers played a pivotal role in largely negative decision-making processes. It is here that

I have been privileged to bear witness to the ‘silent battlers’ who, against formidable odds, strive to continue to maintain their dignity, independence and social place in society. The insights gained by this research will serve to increase the awareness of those involved in the deliverance of health initiatives and to improve *understanding* of the processes involved in ageing in isolation.

Also of significance is the rigour with which this research was carried out, with strict adherence to all processes of sampling, data collection, coding and theory building. I continually returned to the literature as new information was uncovered in the data, further subjecting my interpretations to critical scrutiny by colleagues in key fields and my supervisor. In addition, I have strived for transparency at all stages of this dissertation, from the inception of the topic, through participant selection and method of data collection, to processes of analysis and discussion of findings. While I do not claim this provides a complete picture, I believe the repeated and methodical negotiation of interpretations augments the credibility of my findings and the likelihood that they will be an appropriate and satisfactory foundation for action in the given context. Although it is accepted that findings from qualitative research are not generalisable, due to the diversity within the participant group, it is possible that the results of this research may be applicable to other socially isolated older people.

The transferability of the information and conclusions presented in this research will ultimately be determined by its readers. Therefore, a significant challenge for me, as the researcher, has been to provide adequate descriptive contextualisation of the study to enable readers to determine the degree to which their circumstances match the research context. Great attention has been given to the voices of the participants to ensure the accuracy of their stories. These have been detailed in the analysis (see Chapter Five), in which I have used participant quotations extensively to demonstrate the many layers of experiences and interactions that determined how the participants interacted with health care providers. Gradually a picture was co-constructed, following the tenets of Morse and Field (2003) and Charmaz (2006), by painstakingly putting the pieces together as a collaborative project with the aim of informing the both the professional and lay community on the phenomenon being studied.

When reflecting on the weaknesses of this research, selection of participants unknown to the practice may have provided greater cultural and socioeconomic diversity. My findings have been inevitably skewed by my focus on a city context and on an Anglo-Saxon population. Therefore, there remains a need to extend this research to rural areas and more varied cultural groups. However, given that social isolation in older people is not limited to geographical boundaries, nor is it culturally exclusive, I believe that the cohort willing to participate in this research provided a typical cross section of older people living in the northern suburbs of Brisbane.

The imbalance of gender in the participant group may also be considered a weakness of this study. I acknowledge that an equal proportion of males and females would offer increased generalisability in data and their analysis however, I believe the depth and richness of data obtained throughout this study is truly representative of qualitative methods.

Although I have contended that my knowledge of participants is a strength within the context of this research, a pre-existing relationship with the researcher may also be viewed as a limitation. Perceptions of friendship may have influenced participants to focus on the negative aspects of interactions with health care providers, thereby minimising their reports of positive encounters in which access was achieved without difficulty. In answer to this, I defend my prior knowledge and professional relationship with the participants and argue that due to this relationship, the participants were more ‘at ease’, as they were talking to a person known to them, who they felt they could trust with personal revelations. As mentioned above, I also consider the geographical boundaries that were selected for this research to be a limitation insofar as selection of participants from different suburbs in Brisbane may have yielded greater diversity within the data and added depth and dimension to this study. However, in support of my choices for keeping the geographical boundaries restricted, I believe I have been able to gain information and insight relating to a specific cohort that is not dependent on the physical environment.

Reference has been made earlier in this chapter to researcher bias and, while this is considered a limitation of all qualitative research, I defend my interpretations and findings, as care has been taken to minimise this influence. In addition, prior acknowledgement of researcher involvement has been taken into consideration within the context of mutual construction of knowledge with the participants and in accordance with their perceptions of reality.

It is pertinent to acknowledge at this point that a lone external researcher such as myself may be faced not only with physical distance from the supervisor but also with extensive family and work commitments that can limit the researcher’s ability to critically discuss interpretations of transcripts, non-verbal cues, constructs, focus, insights and recommendations. Therefore, frequent and open communication must be established to minimise the effect on the quality of the research. Professor Cath Rogers-Clark, the principal supervisor for this study, understood the importance of regular contact and facilitated face-to-face meetings and other forms of regular communication to alleviate these issues.

All research has its strengths and limitations. It is envisioned that the findings of this research will facilitate and promote awareness in health professionals, particularly nurses based in GP practices, of the specific needs of this marginalised cohort, to assist in providing comprehensive and timely health interventions. The following section outlines this study's contribution to methodological knowledge and incorporates several recommendations for future practice.

7.4 Recommendations for Practice

Discussion thus far has focused on the journeys of six socially isolated older people as they traversed the health care system in Brisbane, Australia. Included is my own journey as researcher and facilitator of this dissertation. Seven key themes have been identified and recommendations for ensuing practice will follow the guidelines that were adopted in previous chapters.

As declining health, chronic conditions and ageing progressed, participants became increasingly reliant on their GPs (and staff) to provide information on community-based services (Gibson and Heartfield 2005; Phillips et al. 2009). However, as previously discussed in Chapter Five, a lack of relevant and timely information resulted in non-access or, at best, the provision of care that was administered by people who were perceived as not appropriately trained. Despite evidence in the final report of the *Cross Government Project to Reduce Social Isolation of Older People* (2004) and subsequent *Positively Ageless Queensland Seniors Strategy 2010–20* of integration and uptake of community services by older people, there remain significant gaps in the dissemination of services to those who remain socially isolated. In view of these findings:

> ***I recommend the urgent development of national and local strategies that are easily locatable and accessed by those living in social isolation. I suggest that information packs be prepared and sent via mail to each eligible household or person on the electoral roll. Information packs would include up to date contact numbers for all service providers. Eligibility criteria also need to be included and clear; simple language must be used to assist individuals to locate the required services. Links to individual service providers, plus all costs applicable, should also be included. In addition, such information packs should be made available to key stakeholders in the community, such as medical and community centres, and all allied health providers.***
>
> ***Further, I recommend the appointment of specialist practice nurses within or across GP practices that are allocated appropriate time and an increased capacity to keep up to date with local and national services available, so that they can provide follow-ups and act as facilitators, to allow GPs to focus on medical treatments. In addition, these practice nurses can check that referral forms are correctly filled in and lodged to appropriate agencies for coordination and personalisation of timely services.***

Thus, my research highlights not only the difficulties encountered by participants in attempting to access health services but also the need for appropriate time to be allocated to practice staff to verify that the patient fulfils eligibility criteria for specific care packages and to coordinate and initiate commencement of the service. My study highlights the urgent need for more practice nurses with the role of attending to these tasks, whether in individual practices or in a centre shared by a number of practices.

My study also raised the issue of the interrelationship between an increased incidence of depression in the socially isolated participants, and their difficulties accessing appropriate care. Many older people resist treatment for depression and other disorders, as their association with illness is based on negative images and stereotypes frequently propagated by the mass media and popular culture. In no other age group is the combination and interrelationship of physical, social and economic problems as significant as with the older person. The participants in my study assumed that complaints such as sleep disturbances, changes in appetite, chronic pain and diminished coping ability were related to physical problems associated with the ageing process. This tendency is reinforced by physicians, who also often attribute these symptoms to the ageing process. Medical practice today does not usually allocate time for taking the detailed medical and social history that would encourage a more accurate diagnosis. Therefore:

> ***I recommend that practice nurses be given the opportunity for ongoing education, financially supported by GPs, within the medical practice setting, in recognising depression and disengagement, so they may more readily recognise social cues that are indicative of reduced coping skills and declining emotional reserves.***

My data also raise the issue of busy GPs not having time to deal with emotional issues if not raised directly with them. Most of the people in my study would not have thought of themselves as depressed but spoke more of frustration and anger.

Lack of trust was often the forerunner for these emotions, as all participants had experienced unsatisfactory encounters with service providers. Five participants had unsatisfactory dealings with personnel that resulted in disengagement from the service. First impressions were important, particularly when service providers were admitted into people's homes. There was no evidence of pre-employment training for those working in community-based health services (for example, regarding communication techniques, or the characteristics and traits of the socially isolated older person or their specific needs in terms of establishing confidence and trust). This lack of training was evidenced by the many accounts of inappropriate, offensive remarks made by those working in the community health services industry.

> ***It is my recommendation that more training is made available for carers on the needs of the older person, including ways of valuing their choices and supporting personal decision making to maintain identity and dignity. Additionally, such training is made mandatory for service provider personnel.***
>
> ***In addition, there needs to be more variety in social activities provided by services and community groups (beyond bingo), incorporating trips to the theatre, musical afternoons with some classical artists and book clubs that***

> ***provide a discussion forum. These should be included within services coordination records and be made accessible to practice nurses.***

For others, particularly those working in institutional settings, simply caring about the older person is not enough without specific training in interpersonal communication and a knowledge and empathy for specific emotional needs. GPs are often primarily concerned with a medical model for health care provision. However, in an ideal world, social, emotional and psychological needs would be given equal weight with physical health needs. Realistically, in the current context, busy GPs have no time to build an intimate knowledge of individuals, let along take the time to meet their unique needs or keep up with the rapidly changing services available.

> ***Therefore, I foresee opportunities for practice nurses to gain in-depth insight into the older person's needs by further developing and enhancing the scope of health management plans. By providing truly 'holistic' care encompassing social, spiritual, psychological and physical needs, practice nurses can act as facilitators and gatekeepers for the GP as well as being advocates and collaborative partners for the needs of socially isolated older people.***

The findings from this research have clearly identified the need for an expanded role for practice nurses, who have previously established trust and rapport with the socially isolated client.

> ***The opportunity to foster a 'buddy system' similar to the 'adopt a granny' initiative advocated by Cartwright and Findlay (2002)—but replacing the***

> ***'granny' as this word reinforces a one way ageist concept is worth considering, Furthermore the practice nurse can act as facilitator, introducing the individual to social groups once common interests are established.***

The expansion of the role of practice nurses as facilitators is what is currently missing. As the participants in this study have revealed, socially isolated older people will not go to group activities because of their isolation, poor self-concepts and inappropriate activities, but if a successful 'buddy match' were made, over time this could lead to acceptance of others and a willingness to participate in social activities.

> ***I envisage a need for specially appointed practice nurses in the primary care setting whose role it is to keep up to date with changes in service providers while establishing and maintaining databases of services within their own area and practices. Once rapport is established with socially isolated clients, practice nurses could more easily facilitate referrals according to individual needs. Nurses are ideally positioned to establish initial contact with services relevant to that particular individual and, importantly, they can carefully monitor the effects of different services in different physical and social contexts.***

One major concern within the participant group was the need to maintain personal transport. For all but one participant, this meant holding on to a driver's licence and owning a car, which was not without its difficulties. Restrictions on driving times and distances resulted in three participants being forced to utilise taxis to get to medical appointments, particularly when these appointments took place within the inner city precinct. Expounded within the literature review and later discussed in Chapter Five, ample evidence (Gabriel and Bowling 2004; Hensher 2006; Gilhooly et al. 2002; Whelan et al. 2006) has been provided supporting the argument that maintaining personal transport or the ability to *choose* transport options was integral to self-esteem and independence. In view of the difficulties encountered by the participants in accessing taxi vouchers and parking permits:

> ***I recommend an urgent review of taxi voucher eligibility criteria, with consideration given to increased autonomy for GPs to endorse taxi vouchers or parking permits for specific periods of time.***

For those who are unable or have difficulty utilising public transport:

> ***I further recommend the appointment of staff or volunteers in uniform with identity cards by city councils for the purpose of directing and physically assisting older people safely onto trains and buses. This would alleviate embarrassment for those who are disabled or unable to mobilise quickly enough to keep up with other commuters. This could be accomplished by the installation of a 'call for assistance' button on automatic ticketing machines.***

Bus driver willingness to lower steps to facilitate easier access by older people appears to be inconsistent. Participant stories revealed many bus drivers would not use these devices even when asked, thus discouraging further use of this type of transport.

> ***In view of these accounts, I suggest the development of clear guidelines and rules of conduct for bus drivers in dealing with older people, with mandatory***

> ***reporting of those that disregard established procedures. Bus drivers also need to be educated on the needs of the older person, including those with additional physical disabilities. This educational process could incorporate an awareness program whereby bus drivers are informed of the results of this research such as older people's fear of catching a bus and the need to lower the steps at all times. The provision for bus stops in closer proximity to major hospitals and medical clinics would also encourage older people to utilise this form of transport.***

Participants met many barriers on their journeys within the health system, one of which was ageism. Myths and misperceptions about older people, perpetuated by the media and public and professional health service providers, have negatively affected service delivery to this cohort. This held true for several participants, who experienced extended wait times for appointments and medical interventions. One participant revealed that she had been notified of a 10-year wait for the eye clinic at a major Brisbane Hospital. At the time of notification, she was 86 years old. Obviously, it is essential to prioritise the needs of the public who require access to and use of finite medical resources. However:

> ***A common sense approach should prevail when constructing and administering waiting lists and the health needs of older people should be given equal priority to those of younger people, considering their lifespan and critical health issues. Practice nurses need to act as advocates and gatekeepers to ensure timely health interventions are established, thereby minimising the risks of older patients being overlooked. Further, increased government funding should be allocated to community-based transition care packages, so that socially isolated***

> ***older people who are discharged early from hospitals can return to their homes with full care until they feel capable of keeping up normal daily activities.***

The many ‘brick walls’ that the participants encountered served to foster increased feelings of frustration and disillusionment. For the majority of participants, the result was disengagement with health service providers and the community. Ultimately, this situation resulted in participants not presenting to their GPs until they were in crisis. To alleviate these often reactive and maladaptive behaviours:

> ***I recommend the development and administration of ‘positive ageing’ programs by practice nurses within the GP setting who are already known to ‘at risk clients’. The purpose would be to counter negative attitudes adopted and adapted by those most influenced by stigmatising societal propaganda, the socially isolated older person. Similar programs should be developed by policy makers and offered within the broader community with the target audience reached during their ‘middle-aged’ years to intercept and deter adoptive perceptions of ageism, instead fostering a positive re-negotiation of identity that is fundamental to successful ageing. The development of these life skills at a time when health and social integration are still strongly retained is crucial to maintaining a positive perception of one’s sense of ‘self’ and place within the broader community later in life.***

One method that has been suggested for maintaining social integration and empowerment is the use of computer-based technology. Despite mostly positive evidence on information technology’s ability to facilitate social networks in older people (Bartlett 2003; Czaja and

Lee 2007; Eastman and Lyer 2004; Gibbons, Crichton and Crawford 2002; Scott 1999; Selwyn et al. 2003; Shapira, Barak and Gal 2006), the participants in my study were largely disinterested in using computers as a method of communication, instead preferring to use more familiar tools, such as telephone directories, newspapers and leaflets. Television and radio were also viewed as primary sources of information. It is interesting to note that, despite Scott's (1999) study over a decade ago, highlighting the need for changes to the way technology is presented to older generations, there is little evidence that such recommendations have been adopted by computer and software manufacturers to accommodate the special needs of older users. Therefore:

> ***I reiterate the need for urgent changes to software and computer manufacturing to accommodate the needs of older people. This may include larger key pads, computer tools that do not involve rapid 'mouse clicking' but rather push button features for ease of use for those with diminished dexterity in hands and fingers. In addition, software programs that are similar to those in mobile phones for the visually impaired may encourage a 'willingness to try', especially if mentored by practice nurses as part of their holistic care.***

Computer courses conducted through local libraries have met with mixed success for older people. Once again, the participants in my study chose not to pursue these courses, stating difficulties with transport and a disinclination to 'mix with strangers'. Therefore:

> ***Here too, is a need that practice nurses can initially fill. Their role within the primary care setting could expand to encompass the mentoring of socially isolated older clients. With the aid of government funding, in-house nurse-led***

> ***programs could bridge the gap for those living in social isolation. I believe that clients of the practice would be more willing to attend learning sessions in a familiar environment with people they know. In time, small social groups may develop under the guardianship of the primary care team, thus reducing isolation and fostering new communication skills. For those with transport difficulties, a free transport system could be developed to encourage participation in the program. This could be run with the assistance of the local council or through established volunteer groups, such as Rotary.***

To address the issue of accessing health services within a technological framework for future generations, I believe:

> ***Software manufacturers need to prepare and develop programs that allow for the continual updating of aged care services for national and local areas, particularly those in remote geographical areas. Provision of a central point for service providers to input current data and for the older person (or practice nurses) to access is essential. Over time, manufacturers should develop software that can be personalised to individual needs.***

Finally, from analysing similar and repetitive comments made by participants regarding their negative experiences traversing the health system, discussed in detail in the analysis (see Chapter Five), I offer one final recommendation.

> ***Although there is evidence of the inclusion of older people on steering committees in government policy making, a significant omission exists whereby***

> ***project developers do not seek opinions from those older individuals living in socially isolated circumstances (Findlay 2003; Findlay and Cartwright 2002; Positively Ageless Queensland Seniors Strategy 2010–20). A registry of 'skills of older people' could be established to acknowledge older people's contribution to the community. These could be set up as mentoring programmes staffed by older aged volunteers.***

Through involvement in steering committees and mentoring programs true and meaningful knowledge can be gained for future policymaking. Taking the time to talk to people and ascertaining what *they* want or need from health services must be a priority if positive changes are to be brought about in the living circumstances of those already living in social isolation. These people's experiences of life stand in stark comparison to those who, although old, live with the care and support of close social and family networks.

7.5 Conclusion

This dissertation has investigated the experiences of six socially isolated older people as they attempted to access and navigate the health care system in the northern suburbs of Brisbane, Australia. Their thought provoking stories have highlighted not only the continued difficulties they encounter in their dealings with health service providers, but also the extent to which ageist attitudes abound in the health industry. For these participants, these attitudes led to internalised negative feelings and a perception that society had abandoned them in favour of those more youthful and 'deserving' of resources.

This final chapter has provided a reflective journey into the development and carrying out of this research, which has been argued to offer a unique insight into the lives of a small group of socially isolated older people. It is expected that the findings from this small but in-depth study and resulting recommendations will assist practice nurses and other health professionals to provide appropriate collaborative support and health care to older people living in socially isolated circumstances. It is also anticipated that this research will promote further discussion across and within professional groups on ways of promoting and supporting a positive identity for older people.

Following is a brief addendum of the current circumstances of the six participants, with a view to providing closure for the readers of this dissertation.

ADDENDUM

Where are they now?

During the course of this research, I continued working at the medical centre at which the participants were patients. After the completion of the final interviews and my departure to new employment, I remained in informal contact with all participants as there had developed a certain reciprocal ‘bond’ between us. This friendship remains today. For the benefit of the readers, I have provided a brief summation of ‘where they are now’.

Win

Win still lives independently in her own home and she has received a measure of surgical intervention for her shoulder and knee. She has remained unsuccessful in obtaining assistance to mow her lawns and, at age 91, attends to this herself. She is still driving.

Bette

Bette and her husband remain living independently in their own home. They have refused community services and ‘manage as best as they can’ with each other for support. Attempts by her GP to encourage a move into a retirement village with on-site support services continues to be declined. Bette’s health has deteriorated significantly as has that of her husband.

Shirley

Shirley lives alone in a retirement village on the outskirts of Perth. She is now completely deaf. Her ability to eat has decreased considerably, which has led to significant weight loss. Her husband passed away in January 2009. She avoids social contact due to her increased inability to communicate and may not see other people for extended periods. There is minimal contact with her family, who insisted on and facilitated her move. Her primary method of communication is the written word, which is hindered by deteriorating eyesight and arthritis in her fingers. Telephone access by TTY (services for the hearing impaired) has not been particularly successful and is utilised infrequently.

Fay

Fay continues to live independently in the family home. Her husband passed away in April 2011. She has more contact with her family now. However, she has minimal social contact with people outside her immediate family.

Monica

Monica continues to live independently in her own home. She has had an increase in social contact since the commencement of this research, due to some improvement in her chronic health conditions. She continues to decline assistance of community services. Due to a motor vehicle accident while driving, she no longer drives or owns a car.

Ken

Ken’s whereabouts is unknown. He no longer attends any known medical practice near his previous address. Communication by brief letter is sporadic with no return address.

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APPENDICES

Appendix A

The experiences of the socially isolated older person in accessing and navigating the health care system.

You are cordially invited to participate in a research project conducted by Moira Greaves (PhD student, University of Southern Queensland, Toowoomba). The principal supervisor is Dr Cath Rogers-Clark. This study explores the experiences of socially isolated older people as they find their way through the health care system in metropolitan Brisbane. Personal stories will be sought from participants regarding any issues related to obtaining health care. There are many aspects of social isolation, but limited research has dealt specifically with how this group obtains appropriate health care specific to their needs.

The aims of this study are to explore the experiences of the socially isolated older person by determining their level of knowledge in relation to the supportive community services available to them and establishing what they require from the health system. Identification of effective coping skills employed by this group of people will also be examined.

If you agree to join this study, you will be asked to participate in a total of three interviews with the researcher, which will be conducted either in your own home, at the medical centre or at an appropriate venue chosen by you and acceptable to the researcher. The duration of each interview will be approximately 45 minutes to one hour. With your permission, the interviews will be recorded on audiotape and then transcribed. A copy of your interview transcript will be sent to you. Please read this to verify its accuracy.

All information you provide us will be strictly confidential. Your participation is voluntary and you can withdraw from the study at any time without prejudice by contacting Moira

Greaves (Principal Researcher) Ph: (07) 3263 4047 or The Principal/Medical Director at the Medical Centre Ph: (07) 3861 4455.

Upon completion of the study, a summarised report will be offered to each participant. If you have any questions or concerns in relation to this study, you are able to contact the Secretary of the USQ Human Research Ethics Committee by phone: (07) 4632 2956.

If you wish to participate in the study, please indicate that you have read and understood the information in this letter by signing the following declaration and returning it via the pre-paid envelope. Upon receipt of this consent form, the researcher (Moira Greaves) will contact you to arrange a mutually convenient time to arrange an interview.

The experiences of the socially isolated older person in accessing and navigating the health care system.

Consent Form

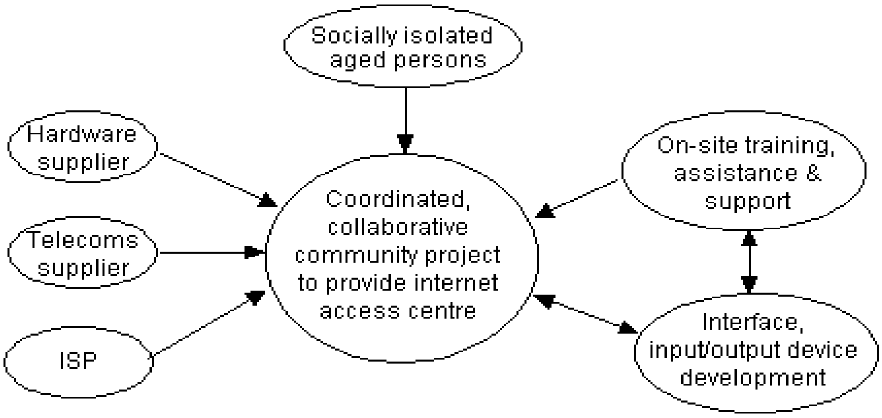
I, (print name) ____,

have read the letter titled: *'The experiences of the socially isolated older person in accessing and navigating the health care system'* and agree to participate in the study by Moira Greaves. I understand that my participation is voluntary and that I may withdraw at any time by contacting Moira Greaves or The Principal/Medical Director at the Medical Centre. I understand that any information I give will be kept confidential.

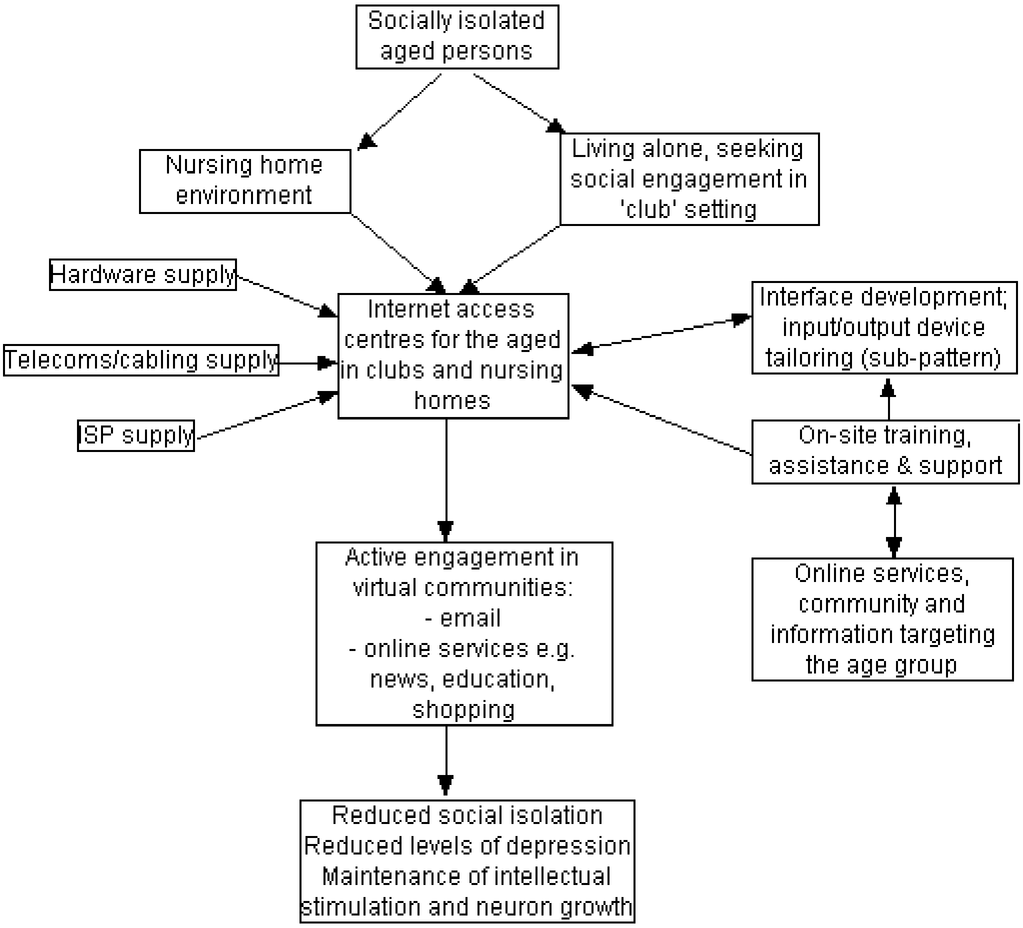
Signed: ________________________

Date: ____________________________

Appendix B



Source: Gibbons et al. (with permission) <http://diac.cpsr.org/cgi-bin/diac02/pattern.cgi/public?pattern_id=39>.



Source: Gibbons et al. (with permission, viewed 18 May 2006) <http://diac.cpsr.org/cgi-bin/diac02/pattern.cgi/ public?pattern_id=39>.

Appendix C

Emergent Categories and Sub-Categories

Category	Sub-categories
1. Illness impact—ageing, health/wellness continuum	Health conditions Time frame Predictability of health problems Knowledge of what to do Aids used or not used Medication use/non-use
2. Impact of illness—fear emerging as major issue	Mobility Difficulty with steps/hills Lies down a lot Poor/deteriorating balance Fear of falling Having to depend on others Feeling of having ‘passed use-by date’ Decrease in social contact Difficulty with shopping
3. Transport difficulties—private v. public transport	Dependence on partner to drive Ambulance transfers Use of taxis Issues of licence endorsement Problems with parking Need for disabled sticker Time taken to obtain transport Use of public transport
4. Differing medical opinions—confusing	Specialists focus on different parts of the body, therefore, need for additional medical reviews

	Different verbal opinions—confusing
	Number of referrals required Mistakes made in diagnosis
5. Timing of medical visits—personal perspectives	When feels in better health Preference for home visits Wait times to see doctor
6. Helpers/services needed—acceptance v. non-acceptance	Doctors Partner Meals on wheels Friends/neighbours Immediate family members Help with housework Obligation to pets DVA (seems generally known and trusted) Knowledge of community services
7. Dependence/sense of loss—emerging major issue	Driving—restricted Being able to care for self Comparison with younger self
8. Assertiveness—willingness/non-willingness to speak up for self	Signs for disabled parking/availability Medical opinions Health services provided
9. Medical insurance—may impact on service provided	Yes/No
10. Personal characteristics—self reflective	Sociability (or lack of) Compliance/assertion Willingness to ask for help
	Confidence in self Trust in people Distrust of people/strangers Personal pride Range of interests

11. Changes with ageing—physical v. psychological	Decreased social contact Decreased mobility Decreased attendance at clubs and sporting participation Decreased sight and hearing Empty house Decreased confidence Decreased appearance Decreased influence/becoming invisible Pain (does not matter—see Win) Becoming dependent (associated with fear) Forgetfulness Worry about present circumstances/future
12. Importance of attitude of health professionals—influences acceptance/non-acceptance of services	On first contact Fits in with personal routine Perceived competence Personality outweighs job well done Ethics of health care workers/politicians Doctor arrogance Perceived role of politicians
13. How helpers are located	Medical referral Recommended by friends/family Written information Ask around
14. What determines acceptance/non-acceptance of services?	Timing Perceived usefulness Personal attitude How initial assessment is made Perceived reliability Ease of contact Others perceptions of helplessness/dependence

15. Knowledge of services available (check-list for all participants/graph result)	Not known Known Know but not specifics Misconceptions—have specific conditions or high cost
16. Nursing home/the future	Interference Loss of privacy Loss of space Loss of choices Loss of 1:1 care Loss of car/independent mobility Pets limit options
17. Problems experienced with services	Coordination Attitude Relevant experience (night work—see Fay) Waiting times
18. Cost of service/financial issues	Home renovations to cater for changed needs Service costs Transport costs—car maintenance/taxi Balancing budget—choices: Do pets or I eat?
19. Care for carer partner	Medical checks Availability/use of respite services Emotional support
	Physical support (physiotherapy/hydrotherapy) Awareness of care for self Social contact—maintenance/loss
20. Powerless patient (major issue)	No control over services offered (take it or leave it) Reliance on doctor to initiate services Inability to demand better service

	Passive acceptance of (inadequate) services
21. Waiting times (major issue)	For hospital appointments For surgery/procedures For community services For action on communication For specialist appointments For reimbursement
22. Needs	Social visits v. routine service Better information on costs of community transport options Better information on ‘conditions’ of community transport Less referrals/better coordination to stop ‘merry-go-round’ (see body as a whole) Limit costs (perhaps % of pension) Communication of services Lifts installed to private homes at low/subsidised cost Consistency of doctor/home visits by GP Stimulating intellectual activities missing from senior activities Low cost/subsidised fee for podiatry and/or physiotherapy care for both carer and client

Appendix D

Sample open-ended questions for interviews:

1. Based on your own experience, what are the main things you have difficulty with when accessing or finding your way through the health system?
2. How would you describe social isolation?
3. In what way would social isolation affect your ability to access and obtain ongoing medical health care?
4. What types of community services are you aware of that are specifically structured for older people living in the metropolitan area of Brisbane?
5. What is your opinion of these services?
6. What types of community programmes or services would you like to see in your area that would assist you in accessing health care?
7. How would you access these services?
8. If you are aware of community services for the aged, could you please explain why you are not utilising them?
9. In what way does paying for medical services affect your lifestyle (for example, managing your budget?
10. How often do you receive regular general medical care?
11. How far do you have to travel for these services?
12. How do you think health care services (for older people living in social isolation) could be improved?

These are only examples and some, all or other questions may be asked during the interview process, depending on the information given by the participant. The purpose of these questions is to elicit as much information as possible regarding accessibility and navigation of health care services. It is envisaged that each participant will provide personal information regarding similar issues of access.

Appendix E

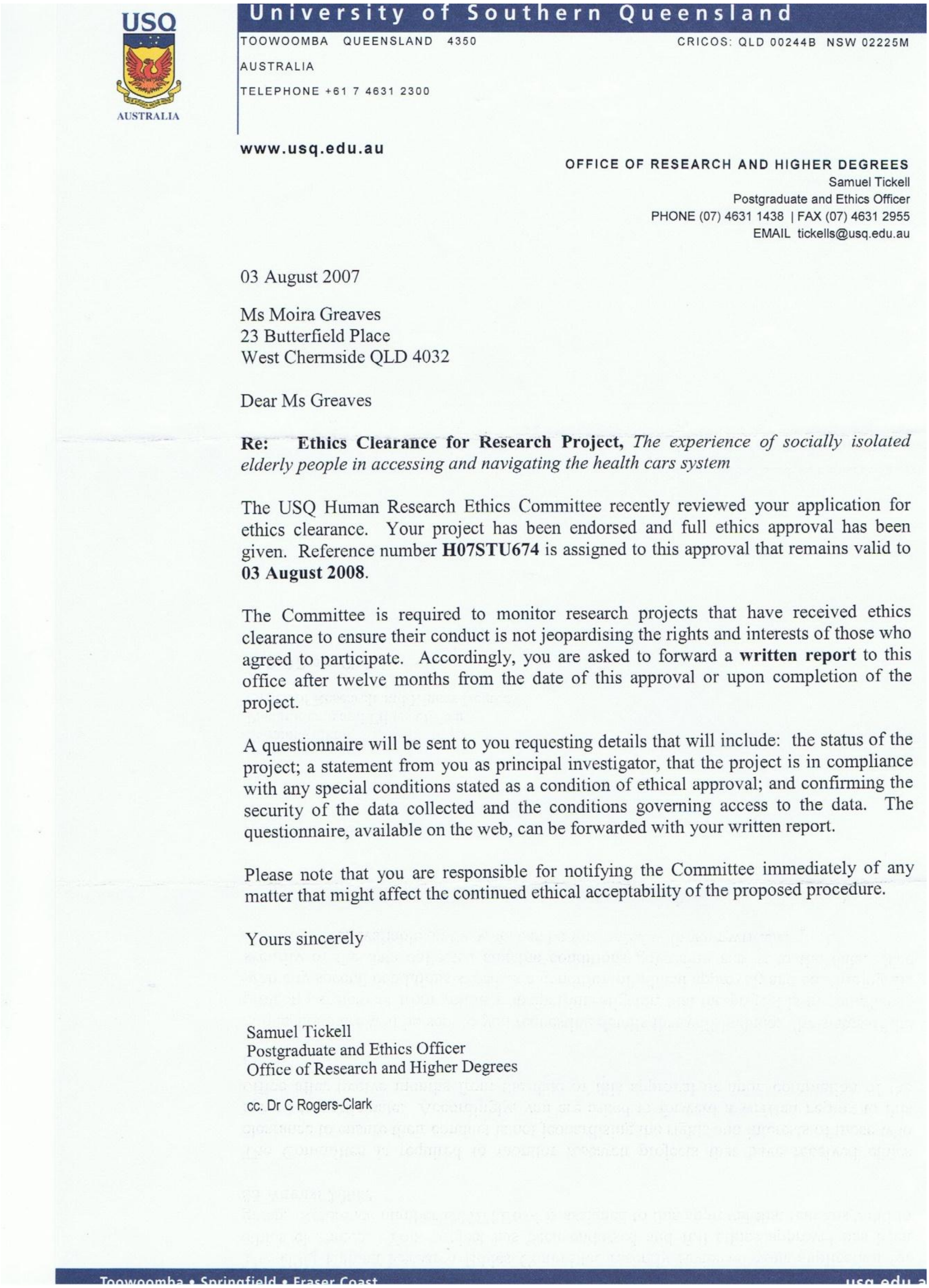
Publications Arising from this Research

Greaves M and Rogers-Clark C, 2009 ‘The experience of socially isolated older people in accessing and navigating the health care system’, *Australian Journal of Advanced Nursing*, vol. 27, no. 2, pp. 5–11.

Greaves M and Rogers-Clark C, 2011 ‘Once I became a pensioner I became a nobody—a non-entity’: The story of one woman’s experience of the health care system’, *Contemporary Nurse*, vol. 37. no. 2, pp. 204–12.

This dissertation has been proofread by Elite Editing Services Australia

Appendix F



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03 August 2007

Ms Moira Greaves
23 Butterfield Place
West Chermside QLD 4032

Dear Ms Greaves

Re: Ethics Clearance for Research Project, *The experience of socially isolated elderly people in accessing and navigating the health cars system*

The USQ Human Research Ethics Committee recently reviewed your application for ethics clearance. Your project has been endorsed and full ethics approval has been given. Reference number **H07STU674** is assigned to this approval that remains valid to **03 August 2008**.

The Committee is required to monitor research projects that have received ethics clearance to ensure their conduct is not jeopardising the rights and interests of those who agreed to participate. Accordingly, you are asked to forward a **written report** to this office after twelve months from the date of this approval or upon completion of the project.

A questionnaire will be sent to you requesting details that will include: the status of the project; a statement from you as principal investigator, that the project is in compliance with any special conditions stated as a condition of ethical approval; and confirming the security of the data collected and the conditions governing access to the data. The questionnaire, available on the web, can be forwarded with your written report.

Please note that you are responsible for notifying the Committee immediately of any matter that might affect the continued ethical acceptability of the proposed procedure.

Yours sincerely

Samuel Tickell
Postgraduate and Ethics Officer
Office of Research and Higher Degrees

cc. Dr C Rogers-Clark

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