Dementia and Intersectionality: Exploring the experiences of older people with dementia and their significant others

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Thesis submitted for the degree of Doctor of Philosophy

November 2004

Declaration

I declare that none of the work contained within this thesis has been submitted for any other degree at any other university. The contents found herein have been composed by the candidate, Wendy Hulko.

Acknowledgements

This enormous piece of work is the intellectual property of one person whose mind, body, and soul shared space with this thesis for three years. Many people contributed to both the process and the outcome, however, and I would like to acknowledge the roles they played in getting me through to the end…with my smile and whimsical attitude intact.

First of all, there are my 'significant others' – the family members and close friends who have given me so much unconditional love, respect, and support throughout my life, who kept me going with their unwavering faith in my ability to do this thing, and who knew when to leave me alone and when to step in. My parents Alan and Sandy Hulko, sisters Shelley and Alanna Hulko, and uncle Lee Hulko; close friends Yvette Scrivener, Kimi Webber, Robin Irwin, Heidi Staseson, Michol Hoffman, Suzanne Scher, and Marsha Griffith; and the others who reminded me that 'that which does not kill you makes you stronger' (Nietzsche). A special thank you to my dear friends Max Todd and Nancy Gioia for sharing food, laughter, stories, and the joy of babies on so many occasions, usually at a moment's notice.

Next, I would like to thank my supervisors: Sue Tester and Jim Valentine, for the wise words, confidence in my abilities, enthusiasm about my work, intellectual stimulation, academic rigour, sound advice, and gentle manner. Thank you as well to Cherry Rowlings for input during the first year of my PhD.

Two special women who started out as social workers and became strong advocates for people with dementia and leaders in the dementia field – one in Ontario and the other internationally – influenced my decision to do a PhD and to do it at Stirling, and have inspired me tremendously; for that, I would like to acknowledge my dementia gurus: Mary Marshall and Mary Ann Chang. I also would like to thank Judy Globerman for being a wonderful mentor and an excellent reference (funding, PhD programs, academic positions); and Stephen Katz for sharing his brilliant insights and challenging me to think harder.

A special acknowledgement is owed to Shari Brotman – fellow feminist gerontologist, anti-oppression social worker, grounded theorist, mutual admiration society member, and dear friend – for collaborating, challenging, validating, encouraging, innovating, role modelling, weeping, and laughing.

I would like to thank everyone affiliated with the University of Stirling who was a supportive colleague during my time there, particularly other researchers (students and fellows) in the Department of Applied Social Science, and Alison Giles in Information Services who rescued my thesis at a critical juncture when I thought all my work had been lost. A big thank you goes out to my office mates

Abstract

The aim of this thesis is to demonstrate that new and varied views of dementia surface when the concept of intersectionality is applied to dementia research; and that these perspectives pose challenges to our assumptions about what it is like to have dementia. Grounded theory research from a feminist and anti-oppression perspective was undertaken to explore the question of the relationships between older people's experiences of dementia and the intersections of gender, class, 'race', and ethnicity. During nine months of field research in Canada, interviews, participant observation, photography, and focus groups were undertaken with eight older people with dementia and their significant others. The participants ranged from multiply marginalized to multiply privileged on the basis of their 'race', ethnicity, gender, and class. The grounded theory arising from this research explains the complex nature of the relationships between the subjective experiences of older people living with dementia and the intersections of ethnicity, 'race', class, and gender. I argue that there is a connection between social location and lived experiences of dementia; and that these relationships can be observed across and within the categories of experiencing, othering, and theorising. Experiencing captures the diversity of older people's experiences of dementia, which range from 'not a big deal' to 'a nuisance' to 'hellish': these views are associated with social location, with the multiply privileged older people holding the most negative views of dementia and the multiply marginalized older people dismissing the significance of dementia. Othering refers to the marginalisation to which people with dementia are subject: it is shown to be a marked feature of life with dementia and to be connected to social location, with the multiply privileged people being othered more often as a result of their dementia status; the more marginalised participants demonstrating resilience (as an acquired characteristic); and all being subject to both othering practices and enabling behaviours enacted by members of their social worlds, such as their significant others. The theorising category refers to people with dementia being active meaning makers who theorise about dementia: the outcome of this intellectual activity is shown to be related to social location, with the most privileged participants being the only ones to view dementia as a brain disease; and all others making strategic use of the normal aging theory to avoid marginalisation due to dementia. The result of the theorising done by older people with dementia is a dialectical theory of dementia that positions dementia as a bio-psycho-social phenomenon, disrupts the false dichotomy between normal and pathological, and integrates emic and etic perspectives on dementia.

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1.1 Context and relevance to the field

Aging in general and dementia in particular never have been particularly electrifying research topics, despite their frequent appearance in the media, around the water cooler, and at our kitchen tables. A shift towards increased support and interest in research on aging and health is occurring, however, due largely to the changing demographics of Western populations and a growing awareness of aging related issues on the part of the baby boomer cohort. Dementia is coming into its own as a legitimate field of inquiry and we are finally moving away from a lengthy preoccupation with the perspectives of caregivers and service providers, most of whom have viewed people with dementia as a homogeneous group of victims and sufferers. We are moving towards a 'new culture of dementia care' (Kitwood & Benson, 1995), one that is being created dynamically through an explosion of interest in putting the person before the disease (Kitwood, 1997a), hearing the voices of people with dementia (Goldsmith, 1996), and placing dementia in a socio-cultural context (Downs, 2000). This thesis is located within this tradition of creative, respectful, and holistic dementia research and care.

Nearly twenty years ago, and a decade before Kitwood's revolutionary ideas about 'personhood' and 'person-centred care' (Kitwood, 1997a) impacted on the dementia field and sparked the aforementioned movement, the King's Fund (1986) released a report about 'living well into old age'. Included in this report were five principles of good practice in dementia care:

1. People with dementia have the same human value as anyone else irrespective of their degree of disability or dependence.
2. People with dementia have the same varied human needs as anyone else.
3. People with dementia have the same rights as other citizens.
4. Every person with dementia is an individual.
5. People with dementia have the right to forms of support which don't exploit family and friends.

That these principles appear contemporaneous is an indication of the rather slow progress towards achieving full citizenship rights for people with dementia (Innes, 2002) and the need for continued emphasis on the socio-cultural context of dementia (Downs, 2000).

Dementia has infected the public consciousness to such an extent that it is one of the most feared conditions of modern time (Bond, 1992; Fox, 1989; Robertson, 1990). Dementia has become 'a dominant modern cultural image of becoming elderly' (Pilgrim & Rogers, 1993: 73), in spite of the fact that depression is actually more prevalent in later life than dementia (ibid). These fears have been fuelled by 'apocalyptic demography' (Robertson, 1990), in a strange twist on the social justice strategy of making personal troubles public issues (Wright Mills, 2000). Apocalyptic demography has been used to transform the personal problem of cognitive impairment into the public issue of Alzheimer's disease; substantial public resources have been allocated to fighting this epidemic (Fox, 1989; Adelman, 1995); and the costs have been attributed to the individuals with Alzheimer's disease themselves (Taylor & Sloan, 2000; Tranmer & Coyte, 2003). This has occurred in the classic victim-blaming tradition of health promotion approaches to disease, although often not explicitly stated. For example, Tranmer & Coyte (2003) found that patterns of health care use (hospitalizations, physician services, home care services, long-

term care, and prescription medications) for older people with dementia are comparable to older people in general, yet total health care costs are higher for dementia due to the increased use of services amongst this group.

This thesis contributes not only to efforts at placing the person before the disease and hearing the voices of people with dementia, but also to those that address the socio-cultural context of dementia. As noted earlier, the diversity of people with dementia has been neglected in much of the literature to date; and innovations in other fields regarding identity and difference have not been systematically applied to dementia. In an effort to draw on this parallel knowledge, this thesis focuses on dementia *and* intersectionality; and in the process, brings a sociological concept into the dementia lexicon (Hulko, 2004). This theoretical concept requires an explanation and the one I offer is drawn from earlier publications (Hulko, 2002; 2004).

Although intersectionality may be associated primarily with sociology in its current use, there is a long history of critical theorists, practitioners, and educators 'talking intersectionality' across several disciplines. Intersectionality/interlocking oppressions as a theoretical concept and level of analysis resides in a decidedly critical terrain that seems not to be marked by disciplinary boundaries and positioning, rather by a shared sense of the emancipatory potential of theory that is derived from lived experiences (Sartre, 1957) and subjugated knowledges (Foucault, 1994a), very much in the tradition of critical social theory (Agger, 1998).

The introduction of this way of thinking about identity and difference is attributed to critical legal theorists (Crenshaw Williams, 1994; 1989; Delgado, 1995; Delgado & Stefancic, 2001), although it surfaced in broader feminist and anti-racist writings of the same period (Andersen & Hill Collins, 1995; Bannerji, 1995a; Bishop, 1994; hooks, 2000a). Since then it has been adopted by social work (Carniol, 2000; Dominelli, 1997; Millar, 1998; Mullaly, 1997; 2002; Oliver, 1996; Thompson, 2001) and has made incursions into critical gerontology (Calasanti & Slevin, 2001; Dressel, Minkler & Yen, 1997; Estes, 2001; Holstein & Minkler, 2003; McMullin, 2000; Minkler, 1996; Vincent, 1995). Hill Collins (1995) made the following distinction between the micro-sociological concept of intersectionality and the macro-sociological concept of interlocking oppressions:

> First, the notion of interlocking oppressions refers to the macro level connections linking systems of oppression such as race, class, and gender. This is the model describing the social structures that create social positions. Second, the notion of intersectionality describes micro level processes - namely, how each individual and group occupies a social position with interlocking structures of oppression described by the metaphor of intersectionality[1]. Together they shape oppression (as cited in Dressel, Minkler & Yen, 1997: 583-584).

Intersectionality is used to point to the ways in which multiple and complex identity categories such as gender, 'race'[2] , ethnicity, class, age, disability, sexual orientation, and faith/religion interact to shape individual life experiences. We cannot compartmentalise people and investigate, for

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[1] The actual metaphor is that of a traffic intersection: busy with roads, cars, and people all coming together in one place. This is rarely acknowledged in the literature, however, and it seems to be taken for granted that people will make this connection immediately and easily when it is said that intersectionality is a metaphor.

[2] Placing race in quotation marks and using the term racialised people (Fanon, 1963) is meant to signal to the reader that: I view race as a socially constructed category (Haney López, 1995); I believe that people are subject to differential amounts of privilege and oppression based on their perceived racial group membership; and I agree that 'race' should not be conflated with ethnicity (Oommen, 1994), nor should it be omitted from sociological analysis altogether, as long as there exists a system of oppression called racism, one that is enacted through everyday practices (Essed, 1991).

example, how either 'race' or class contributes to individual experiences of a particular social phenomenon, as we are all 'racialised' and classed and interact with the world as holistic beings (Lorde, 2001). This thesis on dementia and intersectionality treats interlocking oppressions as the structural framework that shapes and constrains the identities and the experiences of people with dementia as they try to make meaning of their lives as intersectional beings.

The application of this analytical lens to dementia represents a progression from the preoccupation with the self/person that has characterised much dementia theorising and research since the groundbreaking work of Kitwood (1990) and Sabat and Harré (1992). It moves towards the concept of identities - as intersecting, fluid and problematised - and attempts to excavate and accord central importance to subjugated knowledges (Foucault, 1994a) regarding identities and lived experiences of dementia. Emergent interest in identity follows a decade of heavy criticism of the predominance of biomedicine in the field of dementia (Binney & Swan, 1991; Bond, 1992; Downs, 2000; Fox, 1989; Gubrium, 1986; Harding & Palfrey, 1997; Herskovits, 1995; Holstein, 2000; Lyman, 1989; Robertson, 1990). Social scientists and others have been arguing for alternative approaches to dementia that focus on the person, not only the disease/disability, and many have contested the belief that dementia is an organic condition, seeing it instead as a social construction (Gubrium, 1986; Harding & Palfrey, 1997). Although there is this aforementioned trend in dementia concerned with personhood (Kitwood, 1990; 1993; 1995; 1997a; 1997d; Kitwood & Benson; Kitwood & Bredin, 1992) and selves (Sabat, 1998;

2000; 2001; Sabat & Harré, 1992), this has not been approached with an understanding of identities as multiple and intersecting.

In this tradition that I refer to as 'the search for the self', 'identity' is used interchangeably with 'selves' and 'person' and is constructed as both universal, in that we all are presumed to have one, and particular, in that we each are seen to have a unique, personalised one. The way in which identity categories interact with one another and the broader socio-cultural context of dementia is essentially ignored in these largely psychologically oriented approaches to understanding dementia. Such approaches do, however, represent a progression from bio-medical models that saw pathology as central and excluded both psychological and socio-cultural factors. As I have argued previously (Hulko, 2002), if one ascribes to the belief that dementia is a disability (Gwilliam & Gilliard, 1996; Kitwood, 1995; Marshall, 1998), it is relatively easy to see that dementia represents an intersectional state of being, residing most often at the intersection of age and disability, as prevalence increases with age. Add gender, 'race', ethnicity, and class and the picture no longer lends itself to individualistic theories that appear to view people as homogeneous beings apart from their biology and/or psychology. To date, there has been a paucity of theorising and research in the dementia field on how older people with dementia conceptualise their experiences in general, let alone in relation to intersectionality (Hulko, 2002).

Prior to embarking on this research, I found indications in the literature that people with dementia may think of themselves as intersectional beings (Hulko, 2002); and noted growing acceptance of the need to address the socio-cultural

context of dementia (Downs, 2000). While observing that the heterogeneity of people with dementia had been overlooked by dementia researchers, Downs (2000) argued that:

> there is a clear need for comparative and intra-cultural research on dementia with implications for policy developments in dementia care…[and] a pressing need to learn about the role of socio-cultural factors in the experience and response to dementia (p 373).

This thesis is a partial answer to this call and includes clear policy and practice implications that arise from placing dementia in a socio-cultural context and hearing the voices of *diverse* people with dementia.

1.2 Starting point and theoretical perspectives

When I entered the dementia field ten years ago, research on subjective experiences of dementia was in its infancy and there was only a handful of people working in this area, most of whom were met with scepticism and incredulity. These early pioneers laid the foundation for the numerous explorations of the subjective realm of dementia underway in the UK and North America today. As my thesis is located within this body of scholarship, I owe a debt of gratitude to these intellectual ancestors whose innovative work has enabled my own.

As noted, explorations of the subjective realm of dementia are fairly recent (Braudy Harris, 2002; Downs, 1997; Proctor, 2001; Wilkinson, 2002b; Woods, 2001), despite researchers having highlighted this gap in our collective understanding of dementia well over a decade ago (Cotrell & Schulz, 1993; Froggatt, 1988; Lyman, 1989). Moreover, this body of research is incomplete,

as minimal attention has been paid to the influence of identity categories such as age, class, gender, 'race' and ethnicity on the experiential realm of dementia (Disman, 1991; Downs, 2000; Hulko, 2002;). Three actions are required to move the dementia field beyond the narrow conceptions of personhood that have been claiming space alongside biomedical views of dementia, and for which credit is due to Kitwood and his colleagues striving towards a 'new culture of dementia care' (Kitwood, 1990; 1997a; Kitwood & Benson, 1995; Kitwood & Bredin, 1992). First, we must expand the epistemological and ontological bases of dementia research; second, we should embrace lessons from parallel knowledge traditions; and third, we need to develop theory grounded in the voices of people experiencing this phenomenon (Hulko, 2004). This thesis represents one attempt to implement such an action plan and is the result of: over ten years of policy, practice, and research experience in the fields of aging and health; a gerontological interest in dementia; a sociological concentration on intersectionality; a social work concern with anti-oppression theory and practice; and a feminist orientation to understanding the social world. The development and coalescence of these theoretical perspectives is explained further in the following section, through an accounting of my own starting point and dementia history.

Immediately after completing my first degree in Sociology and Spanish, I spent the summer interviewing older people in long-term care facilities and writing their biographies for a life history project. This was my first exposure to older people as a social group and these interactions were so enriching that I went on to train as a nursing assistant. After completing a resident care attendant

Seeking a role that would allow me to move beyond 'bed-and-body work' and intervene at a structural level, I chose the social work profession. In addition to specializing in gerontology, I became more interested in anti-oppression theory and practice and 'indirect practice' (policy and research) during the course of my graduate education in social work. After accumulating more practice wisdom and experience through working as a hospital social worker, a research assistant on an Alzheimer's intervention project, and a policy advisor for a provincial government dementia strategy, I decided I was ready to channel my knowledge, skills, and values into doctoral level research. In this way, I believed I could bring together my substantive interest in aging and health, feminist and anti-oppression theoretical perspective, and that ever-present

sociological imagination. These are some of the experiences and theoretical perspectives that informed the design and implementation of this thesis on dementia and intersectionality.

1.3 Research question and aims

Having outlined the context and relevance to the field, and my starting point and theoretical perspective, I will now provide a summary of the research question and aims that guided the empirical research upon which this thesis is based. The research was designed to answer the following question:

> What are the relationships between older people's experiences of dementia and the intersections of 'race', ethnicity, class, and gender?[3]

I constructed this research question after a thorough review of the literature (see Chapters 2-4). This review confirmed the existence of a huge gap in our collective knowledge about dementia and intersectionality – both together and separately; and suggested the appropriateness of qualitative research in general and grounded theory in particular for creating new knowledge in this area. As this was exploratory research and there were no clear hypotheses to be tested, and in line with the grounded theory tradition, I wrote one open-ended research question, rather than a series of questions or hypotheses. The aims of the research were to:

> 1. Explore older people's experiences of living with a cognitive impairment, taking account of 'race', ethnicity, class, gender and their intersections and the dynamics of privilege and oppression;
> 2. Develop a theory of older people's experiences of dementia and intersectionality, grounded in the voices and (inter)actions of older people with dementia themselves;

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[3] These identity constructs are listed in no particular order and may appear in different combinations throughout the thesis. Further, I am not privileging race by placing it first in the research question, nor am I minimizing gender by placing it last.

3. Critically reflect on the research process, particularly the roles and effects on the researcher, the researched and the emerging theory, and the applicability and effectiveness of anti-oppressive/emancipatory research methods.

The first aim refers to the exploratory nature of the research and the substantive focus of the thesis, the second to the intended outcome of the research, and the final aim addresses the process by which research is/should be conducted. All of these aims were met, as will be demonstrated in the chapters that follow and argued in the conclusion to this thesis. In sum, I discovered real complexity to the relationships between older people's experiences of dementia and the intersections of class, gender, 'race', and ethnicity. I encapsulate these relationships in the three categories of my grounded theory – experiencing, othering, and theorising. The first category (Experiencing) is discussed in chapter six, the second (Othering) in chapter 8, and the third (Theorising) in chapter nine.

1.4 Structure of the thesis

Over the course of this thesis, I will present a grounded theory of dementia and intersectionality - the culmination of my efforts to explore the subjective experiences of older people with dementia from an intersectional perspective. After this introduction, the next three chapters represent a critical review of literature relating to the theoretical and substantive foci of this thesis. Chapter two details the evolution of theories on aging and the rise of the critical gerontology tradition, paying particular attention to theories about inequalities in later life and interlocking oppressions as an analytical framework, prior to reviewing dementia theorising and the limitations of this body of work. The next chapter examines identity and social location, addressing the dynamics of

privilege and oppression in general and looking at how they operate within the specific context of dementia. Chapter four offers insights into the meanings of health, illness and disability cross-culturally, plus a critical assessment of published accounts of subjective experiences of dementia from an intersectional perspective. After this appraisal of theoretical and empirical work in the areas of dementia and intersectionality, the thesis moves into a discussion of the original research from which the grounded theory was derived.

Chapter five presents the methodology and research methods, together with insights gained from this grounded theory research experience, paying special attention to the challenges of combining grounded theory with anti-oppression research strategies and of operationalising the concept of intersectionality. Chapter six serves as a bridge between the methodology and research methods and the detailed discussion of the categories and properties of the grounded theory that emerged from this investigation and introduces the reader to the research participants themselves and to the process of engagement.

Chapter seven attends to the first category of the grounded theory – experiencing dementia - and lays the foundation for the arguments that are built over the remaining chapters of the thesis. In this chapter the focus is on the ways in which older people with dementia live through this experience and the connections to their social location. Chapter eight, on othering dementia, extends the analysis to describe the impact of dementia on the social worlds of older people with dementia, and vice versa. The emphasis in this chapter is on the ways in which people with dementia are othered on the basis of their

dementia status, how and why this marginalization process occurs, and its variation by social location. The penultimate chapter concentrates on the theoretical work undertaken by older people with dementia and its relationship to 'the ageing enterprise' (Estes, 1979) and builds towards an articulation of a theory of dementia and intersectionality. In this chapter, older people with dementia are shown to be active meaning makers, drawing upon and altering established theories of dementia and employing varied strategies to mediate their experiences of dementia, based on their social locations.

The categories of the grounded theory – experiencing, othering, and theorising – and their properties, as explained over the course of the thesis, are summarized in the concluding chapter. The thesis ends with implications for policy, practice, and research that have arisen from this theory of the relationships between the experiences of older people with dementia and the intersections of 'race', ethnicity, class, and gender - a theory that challenges prevailing assumptions about life with memory problems and the nature of dementia itself.

Chapter - 2 Theories of Ageing and Dementia

2.1 Introduction

The aim of this chapter is to critically review literature on theories of ageing and dementia, with particular attention to inequalities in later life and dementia theorising. This review provides a foundation for the grounded theory to be presented in this thesis. The initial section gives an overview of theorising about ageing and older people, highlighting the most prominent of these theories, and locating this thesis within the critical gerontology tradition. The main features of critical gerontology are presented before moving on to a detailed review of theories on inequalities in later life. The next section covers theories of dementia and their limitations. Finally, the conclusion summarizes the insights into dementia and intersectionality that can be garnered from this critical review of the literature on theories of aging and dementia.

2.2 Theorising about aging and older people

Theories of ageing evolved from early individualistic theories based on order views of society, towards more structurally focused theories located within a conflict perspective (Bengston, Burgess & Parrott, 1997). The focus of theorising about aging and older people can be said to have shifted outwards from the individual to the wider society and then come to rest on the individual within society. Theorising about older people and the aging process largely has been the work of 'the aging enterprise' (Estes, 1979), and not of older people themselves (Gubrium & Wallace, 1990). Older people have not been encouraged to make meaning of their experiences of getting older and 'being

old', nor have their attempts at doing so been acknowledged by the ageing enterprise. It has been argued successfully, however, that there are remarkable parallels between the intellectual products of 'the ageing enterprise' and those of older people themselves (Auger & Tedford-Little, 2002; Gubrium & Wallace, 1990). I will return to this finding in chapter 9 when presenting data that substantiates these arguments and expands this critique to include older people with dementia.

The first and second generation theories of ageing included disengagement, activity, exchange, modernization, socio-environmentalism, age stratification, and continuity (Bengston et al, 1997). I will describe a few of these theories to show the increasing sophistication of theorising about aging and how the focus has expanded outwards from the individual to their social environment to societal structures (Katz, 1996). Disengagement theory (Cumming & Henry, 1961) argued that older people all go through a process of gradual disengagement from society in preparation for death and that older people choose to exclude themselves, and are expected to do so, as this contributes to the functioning of society. A criticism of this theory of aging is that it 'condones a policy of indifference' (Bond et al, 1993: 32) and ignores structural influences on the lives of older people. Associated with disengagement theory, as it too focused on the individual actor, is activity theory (Havighurst et al, 1963; Riley et al, 1968). This theory proposed that successful aging requires the denial of the onset of old age, and efforts to maintain relationships and networks or to replace them with new ones. Activity theory has been critiqued for being idealistic.

Moving outward from the individual, socio-environmentalism (Gubrium, 1997; 1986) saw meaning as being derived through social interaction, and behavior as learned through interactions between individuals and other members of their social worlds, very much in the tradition of symbolic interactionism (Blumer, 1962; Goffman, 1959; Mead, 1967; Schutz, 1967). Older people's responses to the aging process were thought to be shaped through the socio-cultural environment in which they found themselves and social life was said to arise from society itself, not from external structures per se. The limitations of these more traditional theories led to the development of the critical gerontology tradition - the focus of the next section.

2.2.1 Critical gerontology

Three strands of intellectual thought came together to form critical gerontology: (1) political economy perspectives; (2) the humanities with its focus on the moral economy; and (3) biographical and narrative approaches (Phillipson, 1998: 13). Critical gerontology has its roots in critical social theory which is concerned with seeking not only to understand the world, but also to transform it (Agger, 1998); and can be seen as a reaction to traditional gerontological theorising about aging and older people (Bengston et al, 1997; Estes, Biggs & Phillipson, 2003; Holstein & Minkler, 2003; Katz, 1996; Phillipson, 1998). Katz (1996: 4) summarized the work of critical gerontology as: admonishing gerontology for its narrow scientificity; advocating closer ties to the humanities; endorsing reflexive methodologies; historicising ideological attributes of old age; promoting radical political engagement; and resignifying the aging process as heterogeneous and indeterminate. Underpinning the critical gerontology

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tradition is the recognition that old age is socially constructed; and that structural inequalities differentially shape experiences of later life (Phillipson, 1998).

The political economy of ageing perspective and structured dependency theory (Minkler & Estes 1991; Phillipson, 1982; Townsend, 1981; Walker, 1981; Wilson, 1997) are examples of work that falls within the critical gerontology tradition. The political economy of aging perspective is concerned with the interrelationships between the economy, society, and polity and how this impacts on resource distribution and the lives of older people. Political economy of aging has been critiqued for its class emphasis, yet is thought to be flexible enough to incorporate gender, 'race', and ethnicity. Structured dependency refers to the dependent position in which older people, or more accurately 'pensioners', are placed in order to meet the needs of a capitalist society. Thus, retirement is an important institution for moving people out of the labor market so that others can move in and is responsible for the creation of a dependent class of people – pensioners or retirees. The next section focuses on other theories that fall within the critical gerontology tradition and that address the extent to which inequalities in later life are treated as non-existent or persistent; and additive or interactive.

2.3 Inequalities in later life

There has been much attention paid to inequalities faced by sub-groups of people in later life, for example, older women and older minority ethnic and racialised people (Blakemore & Boneham, 1994; Brotman, 1998; Calasanti &

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Slevin, 2001; Dressel et al, 1997; Havens & Chappell, 1983; Markides, 1989; Marshall & Rowlings, 1998; Norman, 1985; Vincent, 1995; Zarb & Oliver, 1993), particularly in the United States (Calasanti & Slevin, 2001; Crystal & Shea, 1990; Davis et al, 1990; Dowd & Bengston, 1978; Dressel, 1991; Dressel et al, 1997; Ferraro & Farmer, 1996; Gonyea, 1994; Hammond, 1995; Hardy & Hazelrigg, 1995; Johnson Jackson, 1997; Liska Belgrave et al, 1993; Markides, 1989; Minkler, 1996; National Urban League, 1964; O'Grady-LeShane, 1990; Stone, 1997; Wilson-Ford, 1990). Theoretical work in this area has emphasised the qualitative experiences of older people who endure oppression, while empirical research has focused on documenting quantitatively whether and to what extent older people are disadvantaged by virtue of their age, gender, 'race'/ethnicity, and/or social class. The outcome variables most frequently used are rates of poverty, physical and mental health conditions, and discrimination in health, community support and housing services.

This section of the thesis addresses inequalities in later life through an overview of the social and economic determinants of health and an analysis of several theories that have been used to explain inequalities in later life: cumulative disadvantage/advantage, selective survival, ageing as leveller, culture as resource, and the feminisation of poverty. This is followed by a critical analysis of theories and empirical research on multiple jeopardies and interlocking oppressions, and ends with implications for research on dementia and intersectionality.

2.3.1 Social and economic determinants of health

There is a substantial literature base on the role that social and economic factors play in producing health inequalities and this has been used to support calls for a radical restructuring of existing power relations (Townson, 1999). In the UK, a working group on inequalities in health released the Black report in 1980 (Whitehead, Townsend, Davidson & Davidson, 1980). This early initiative was followed by several others, the most recent being the release of *Tackling Health Inequalities: A programme for action* (Secretary of State for Heath, 2003), which includes a commitment to address the underlying determinants of health.

The Canadian government first acknowledged the influence of socio-economic factors on health in the Lalonde report (Lalonde, 1974). Although this 'green paper' was not thought to be terribly groundbreaking at the time, its legacy has been profound and lasting, largely due to its introduction of the concept of 'health field', comprised of human biology, environment, lifestyle, and health care organization (Federal, Provincial, Territorial Advisory Committee on Population Health, 1999; McKay, 2000). The report (Lalonde, 1974) signalled the beginning of the adoption of a health promotion focus on the part of Health Canada, with social factors being recognized as determinants of health and responsibility being placed upon individuals to reduce their 'self-imposed risks'; as well as the start of the alarmist discourse about the perils of an aging population (Gee, 2000; Katz, 1992; Robertson, 1990). The impact of this report may not have been anything more than theoretical, however, as 'the attempt to

raise investment in social dimensions of health equal to medical science have yet to materialize' (McKay, 2000: 24).

A more recent Canadian government report confirmed that 'health status is directly related to economic status' (Federal, Provincial, Territorial Advisory Committee on Population Health, 1999: 39) and lists the five key influences as:

1. Income (and income distribution)
2. Education and literacy
3. Employment and unemployment
4. Working conditions
5. Factors in the social environment

(Federal, Provincial, Territorial Advisory Committee on Population Health, 1999: 39)

Research on the social and economic determinants of health, located within the aforementioned ideology of population health, has not been very attentive to aging and older people. However, the literature on inequalities in later life implicitly, if not explicitly, employs this conceptual framework (Markides, 1989), and therefore, an understanding of this approach to health is key to this thesis on dementia and intersectionality.

The World Health Organization (2002) defined the determinants of health in older people as those economic, social, behavioural, personal, environmental, and systemic factors which singly or conjointly may predict the nature and quality of an individual's ageing experience; and referred to gender and culture as crosscutting determinants which influence all the other factors. Social factors in this model included social support, opportunities for education and lifelong learning, peace, and protection from violence and abuse (p 28), while economic factors included income, work and social protection (p 30). A link

between the social and economic determinants of health and the critical gerontology literature is provided by a report written for the Canadian Centre for Policy Alternatives (Chernomas, 1999) that invalidates the attribution of blame imbedded in 'apocalyptic demography' (Robertson, 1990). A review of changes in patterns of disease over the 20th century supports the argument that disease is largely a socio-economic phenomenon and not a natural-individual one (Chernomas (1999: i) and clearly makes the connection between the transformation of labour under capitalism and the rise of chronic diseases. With this knowledge, it is possible to dismantle the popular belief that chronic disease is caused by an ageing society and that blame therefore should rest with individuals who live long enough to develop disease (Minkler, 1996). Chernomas' (1999) prescription for the treatment of contemporary health concerns was to link these to concerns about the quality of our air, water, food, and work and the need for equality of income and wealth, as expressed by the environmental, nutrition, and anti-poverty movements. This need to link to parallel work or to take a holistic, interdisciplinary approach has been paramount throughout this thesis on dementia and intersectionality.

2.3.2 Theories on inequalities in later life

Several theories have been developed to explain either the continuation or the discontinuation of inequalities in later life: cumulative advantage/disadvantage, ageing as leveller, selective survival, and culture as resource. These will be reviewed in this section, along with a related theoretical concept 'the feminisation of poverty', which refers to the predominance of women among the ranks of the poor in all age cohorts. Often these theories of inequalities in later

life are juxtaposed against one another, for example, double jeopardy and ageing as leveller (Blakemore, 1989), although they do not always contradict one another (Liska Belgrave et al, 1993) and there is evidence to support both theories (Blakemore, 1989; Liska Belgrave et al, 1993). The distinction between these two theories is that double jeopardy selects race/ethnicity as the explanatory variable, while ageing as leveller focuses on age in explaining inequalities in later life.

2.3.2.1 Cumulative advantage/disadvantage

The cumulative advantage/disadvantage (CAD) theory posits that both the disadvantages and the advantages held by various social groups compound with age, as in the adage 'the rich become richer and the poor become poorer' (Crystal & Shea, 1990; Dannefer, 2003). Several studies have tested this hypothesis in various ways with differing results (Johnson & Wolinsky, 1994; Mellor & Milyo, 2001; Shea et al, 1996; Thorslund & Lundberg, 1994) and the focus often has been on health status. Although the robustness of the link between income inequality and health has been challenged (Mellor & Milyo, 2001), it is commonly accepted that there is a correlation between income and health, with health status increasing with higher income levels (Townson, 1999; Victor, 1991). Studies that demonstrate inequalities in health by social class for both men and women (Thorslund & Lundberg, 1994) refute the ageing as leveller hypothesis that posits that inequalities on the basis of 'race' or class are less pronounced among older people than they were earlier in the life course[4].

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[4] I do not support the ageing as leveler hypothesis and did not draw upon it in this research.

The popular image of the impoverished and socially isolated senior evolved out of early studies of poverty among older people. Hellebrandt's (1980) 'mini-research' project was a reaction to this stereotype; and involved asking 110 people within her circle of friends, colleagues, and fellow residents in a multi-level care facility to write to her about their 'subjective reactions to aging' (p 404). The author described her sample as:

> advantaged, old but of sound mind, well-educated, and with sufficient economic resources to live independently in a manner of their own choosing (Hellebrandt, 1980: 404).

Not surprisingly, the aforementioned stereotype was not applicable to the 101 respondents, 89% of whom were women: who did not feel old; accepted the limitations of ageing; engaged in physical and social activities; eschewed reminiscence; discussed death and dying freely; valued their independence; feared mental deterioration; and did not report any financial concerns. The conclusion that 'the negative stereotype of the aged vanishes when the old are educated, affluent, and 'healthy'' (p 404) highlights the importance of socio-economic factors in later life. The findings have implications for dementia care, as the popular therapeutic activity of reminiscence (Murphy, 2002) might not be well received by these people[5]; for understanding experiences of dementia among the affluent, as cognitive impairment is a condition that is feared and threatens cherished independence for this group (Alzheimer Society of Canada, 2003; see section 7.3.3); and for representing the disadvantaged, as the findings could reinforce the stereotype that, unlike their privileged peers, poor and uneducated older people are unreflective, inarticulate, and inactive.

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[5] Although this group of people professed to 'eschew reminiscence', some or all might actually enjoy this activity once they developed dementia.

2.3.2.2 Selective survival

An influential American treatise on aging and health (Markides, 1989) put forth the view that high early mortality rates among some ethnic/racial groups leave robust members to survive into old age - the selective survival thesis - and, therefore, group membership should not be used to predict mortality and health in later life (Markides, 1989b: 18). The shorter life expectancy for particular social groups, combined with the fact that some people apparently are able to escape their fate and live to a 'ripe old age', led the author to this ascription of robustness. This theory could just as easily apply to older people in general, however. While social class, health, and age are noted to change over time, social class is thought to be strongly related to age, gender and marital status (Longino et al, 1989). The authors found a strong association between social class and gender with the richest quartile being that in which the predominance of men is most pronounced, although they acknowledge that the data on class available to analyse was limited, thus their conclusions may not hold with more detailed data. The reasons for the association between class, aging and health are said to be: stress due to poverty, decreased coping resources, poor access to health care, and health practices and behaviours associated with poor health (Longino et al, 1989: 15). In terms of gender, aging and health, the evidence has been summarised thus:

> women's lives before the 'finish line' of death are more filled with sickness and disability, a price paid for the greater tendency to acquire non-fatal chronic problems and for longer life; men cross that line sooner, having suffered fewer years of trouble while alive (Verbrugge, 1989: 68).

Hence, policymakers are advised to:

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> pay as much attention to living as to dying - to mom's grimace [due to arthritis] a she opens a car door and Dad's empty chair [due to death] (ibid: 70).

2.3.2.3 Inequalities as persistent

The belief that inequalities observable in pre-retirement cohorts persist into later life has been substantiated by several authors (Ferraro & Farmer, 1996; Minkler, 1996; Victor, 1991). For example, an American study (Ferraro & Farmer, 1996) sought to test the double jeopardy, aging as leveller, and persistent health inequality theories among a sample of older Black and white Americans and the results refuted the ageing as leveller theory; and found the greatest support for the persistence of health inequalities over the life course. Closely related to the idea of inequalities being persistent is the feminisation of poverty theory that originated in a 1978 article by Pierce (as cited in Gonyea, 1994), who observed that an increasing number of poor people at the time were women. Later authors noted that this was not a new phenomenon and, since the coining of the term, there have been a number of studies demonstrating that women are poorer than men at all stages of the life course (Brotman, 1998; Chappell & Havens, 1980; Davis et al, 1990; Dressel, 1991; Gonyea, 1994; O'Grady-LeShane, 1990; Stone, 1997; Wilson-Ford, 1990) and that older minority ethnic and racialised women and older unattached women experience impoverishment at particularly high rates (Brotman, 1998). This has been shown to be related mainly to marital status (O'Grady-LeShane, 1990) as the transition from married to widowed drastically reduces an older woman's income (McDonald, 1997), to higher rates of widowhood, living alone, and institutionalisation among older women (Stone, 1997) and to social policies related to old age security (O'Grady-LeShane, 1990; Stone, 1997). Not all

authors invoke the double jeopardy theory when writing of older women's poverty (Brotman, 1998; O'Grady-LeShane, 1990; Wilson-Ford, 1991), with some employing the theory of cumulative disadvantage to explain findings that Black older women are the most impoverished group in society for example (Johnson Jackson, 1997; Wilson-Ford, 1990). These studies serve to counter the recently created image of the advantaged, 'active' elder that has largely replaced the earlier stereotype of the indigent, detached elder. This image resulted in a new myth that ignores class, gender and racial differences among older people; its alternative - the feminisation of poverty construct - has its own theoretical limitations for elucidating the dynamics of disadvantage in later life (Gonyea, 1994). There have been several critiques of the feminisation of poverty literature for its disregard of the race effects on poverty in later life, accompanied by calls for a more complex analysis (Dressel, 1991; Gonyea, 1994), one that recognises that older Black men are more impoverished than older white women, for example (Dressel, 1991). Stone (1997) acknowledged early on the need to look at the racial gap in poverty among older people, which was later taken up in research on triple jeopardy (Chappell & Penning, 2001). A study by Rank and Hirschl (1999) demonstrated that factors other than gender do indeed contribute to poverty in later life as the likelihood of an older American ever experiencing a year below the poverty line increases substantially when one is Black, unmarried, and/or has less than 12 years of education. In addition, 40% of all older Americans are projected to spend a year living below the poverty line at some point between the ages of 60 and 90 years.

Dressel (1991) expanded this critique of the feminisation of poverty to include the double and triple jeopardy theories that have been so popular in the gerontological literature since the 1960s. The versions of these theories that include in their analysis minority ethnic and racialised women are termed 'add and stir' approaches as 'racial-ethnic women's experiences are forced into the model rather than being utilised to refine or critique the model itself' (Dressel, 1991: 247). Indeed, it has been argued that both 'the advantaged elder' and 'the feminisation of poverty' further relegate sub-groups of older people to the margins of society. The way forward, therefore rests in taking a life span approach with an integrated analysis of race, class, gender and age (Gonyea, 1994).

2.3.2.4 Multiple jeopardies

The term double jeopardy originates in legal theory and has been adopted by social scientists seeking to highlight differential experiences of inequality and discrimination in later life. This started with the National Urban League in 1964 (as cited in Dressel et al, 1997) that drew attention to the double disadvantage of older African Americans due to their age and 'race'. One definition of double jeopardy is 'falling into two or more social categories, which increase the risk of having some poor outcome' (Hammond, 1995:5-6). This conceptualisation has been expanded to triple jeopardy to refer to older minority ethnic and racialised women (Chappell & Penning, 2001) and quadruple or multiple jeopardy to encompass the additional burden facing disabled or lesbian/gay/bisexual older people (Ward, 2000; Zarb & Oliver, 1993). A number of authors have applied this language to dementia, hypothesising that dementia results in an additional

jeopardy (Allan, 2000; Anderson & Brownlie, 1997; Bowes & Wilkinson, 2002b; Innes, 2003; Marshall & Rowlings, 1998; Wilkinson, 2002b). This additive model has been critiqued for the way in which theorists refer to layers of oppression or jeopardies being built one on top of another and resulting in quantitatively different (more negative) experiences for the older person in question (Dressel, 1991). In addition to questioning its robustness as a theory (Simic, 1993), critics have accused the multiple jeopardies approach of creating a 'deficit thinking mentality' that is highly disempowering to minority ethnic and racialised communities and overlooks their strengths in favour of showcasing disadvantage (Minkler, 1996).

In a twist on the triple jeopardy concept that conflates social location with service outcomes, Norman (1985) claimed, in an oft-cited quote, that older immigrants who are long time settlers in the UK are:

> not merely in double jeopardy by reason of age and discrimination...but in *triple* jeopardy, at risk because they are old, because of the physical conditions and hostility under which they have to live, *and* because services are not accessible to them (p 1, emphasis in original).

Although Norman (1985) did not refer to the North American literature on double/triple/multiple jeopardy that had been accumulating (Chappell & Havens, 1980; Dowd & Bengston, 1978; Havens & Chappell, 1983; National Urban League, 1964; Penning, 1983; Posner, 1980) and conceptualised triple jeopardy differently than these earlier authors, her work has been treated in the UK as being representative of this theoretical tradition. It is frequently cited as the author did demonstrate that older Jewish, Irish, Afro-Caribbean, Asian, European, Cypriot and Chinese long-time immigrants to the UK are subject to

service shortcomings in several areas, including housing, health care and community services. Much later, immigration status in itself was noted as meriting inclusion in multiple jeopardy theories (Berdes & Zych, 2000). While UK survey research (Silveira & Ebrahim, 1998) found support for the multiple jeopardy theory among Bengalis and Somalis in London, studies of double/triple/multiple jeopardies have had inconsistent results (Liska Belgrave et al, 1993). For example, an early finding on double jeopardy is that older Blacks are doubly disadvantaged in terms of income and physical health, but not in mental health (Jackson et al, 1982, as cited in Blakemore & Boneham, 1994). Yet, in an article specifically on double jeopardy and mental health, Rodeheaver and Datan (1988) claimed that:

> those who are already vulnerable in the social system and in the mental health system - the poor, minorities, and women - remain so in old age, where they face double and triple jeopardy (648).

This point was reiterated by Rodin and Ickovics (1990) who noted that ageing women will experience a double jeopardy and that the greatest attention should be paid to particular sub-groups of women: 'minorities, the handicapped, and poor women' (p 1029).

Alzheimer Disease is said to create two particular problems for older women (Rodeheaver & Datan, 1988; Rodin & Ickovics, 1990): (1) more of them have the disease than do older men; and (2) women who do not have the disease, yet have other treatable problems with symptoms that mirror those of Alzheimer's disease, are often overlooked by health practitioners who believe that senility is part of normal ageing. The conclusion reached by Rodeheaver and Datan (1988) is that:

growing old and needing mental health services may indeed be risky business for women (p 652);

and clinicians need to be more sensitive to social and economic factors, such as role changes and poverty, and to view older persons as resources and as resilient (Minkler, 1996).

2.3.2.5 Culture as resource

Another author sought to demonstrate that culture is a resource (Simic, 1993), claiming that the double jeopardy theory neglects the benefits provided to older people through ethnic group membership, such as adaptive strategies, positive self-image, and insurance, and citing the involvement of older people in activities, roles and rituals as evidence of the strength of this argument. This is an important point - ethnic and 'racial' group membership may result in benefits as well as disadvantages. However, it discounts the fact that structural disadvantage differentially affects minority ethnic and racialised older people and that communities provide their members with resources in the face of inequitable, oppressive and systemically patterned social conditions (see resilience discussion in chapter 8).

Liska Belgrave et al (1993) in their study of double jeopardy, ageing as leveller and cultural resource theories of aging argued that double jeopardy and culture as resource are both important factors and called for a two-pronged research strategy that (1) undertakes longitudinal prospective research to determine subgroups experiencing the greatest inequities and why this is occurring and (2) in-depth qualitative research on how people actually experience being in double jeopardy and what role their culture plays in this. Further support for

linking objective and subjective data on disadvantage is provided by Johnson (1994) who concludes that 'economic well-being is as much a subjective phenomenon as an objective reality' (p 26). The following description of an interviewee indicates how discontent may be attributed to physical or mental health conditions, rather than located in the socio-economic circumstances of an individual's life:

> tearful and distraught during the interview, complaining repetitiously about her poverty, emotions her niece traced to her being in an early stage of Alzheimer's Disease (Johnson, 1994: 24).

Exploring the subjective dimension of disadvantage and privilege through problematising 'race', ethnicity, class, gender, and their intersections is the focus of this research on dementia and intersectionality and links to these proposed future research directions (Liska Belgrave et al, 1993). Hardy and Hazelrigg (1995) found support for the additive theory of oppression in terms of gender and race/ethnicity[6], and not for the interaction of race/ethnicity and gender in terms of producing supplemental disadvantage to that of the two forms added together. The results of their analysis may provide a basis for solidarity among older women (Hardy & Hazelrigg, 1995), which has been threatened in an era of identity politics and post-modern sensibilities.

2.3.2.6 Interlocking oppressions

Several critical gerontologists note the importance of looking at forms of oppression as interacting with one another in complex ways and rooted in processes of domination and subordination; and viewing marginalised peoples

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[6] Race and ethnicity are often conflated in the literature, despite thoughtful critiques of this practice (Oommen, 1994). When the terms race and ethnicity appear as race/ethnicity in this thesis, it should be read as an indication that the cited authors have conflated these terms, not of support for this practice.

as having strengths, and as actively resisting oppression (Browne, 1995; Blakemore, 1989; Dressel, 1991; Ginn & Arber, 1995; Gonyea, 1994; Holstein & Minkler, 2003; Levy, 1988; McMullin, 2000; Minkler, 1996; Victor, 1991; Vincent, 1995). In order to move towards an integrated theory of class, age, gender, and ethnicity/race, McMullin (2000) argues that class, age, gender, and ethnicity/race need to be seen as categories of social relations and as interlocking sets of power relations. Calasanti (1996) and Calasanti and Slevin (2001) expand the critique of additive approaches to oppression by engaging with privilege, as well as oppression, noting that privilege on one axis does not cancel out oppression on another (1996: 149) and that social life is relational. In calling for research that problematises power, Calasanti (1996) states that:

> because privileged groups have long served as the 'norm',
> researchers often forget that their experiences are shaped by the
> same power dynamics as those who have been oppressed (p 155).

Although dementia is not addressed in their book on inequality and aging, when Calasanti and Slevin (2001) argue for reclaiming the word 'old' and imbuing it with positive connotations so that old people can 'be old, in all its diversity' (p 203), one wonders if this means that old people should accept dementia or other physical and mental health conditions.

In reference to the health needs of poor and racial/ethnic minority women, Zambrana (1988) also calls for an integrative model that takes into consideration the interaction of race, gender and class, the influence of historical, cultural and socio-economic factors, and the heterogeneity within racial/ethnic groups. The author refers to poor women and women of colour as the most disadvantaged sectors of the population (p 137) and proposes a

research agenda for minority health needs that includes a focus on 'poor and racial/ethnic minority women and aging', noting in particular the subjective meaning and quality of aging among different cohorts of poor and racial/ethnic women and the relevance of their educational and work backgrounds. Further support for an integrated analysis is found in the work of Blakemore and Boneham (Blakemore 1989; 1997; Blakemore & Boneham, 1994) who endorsed the concept of ethclass, first used by Gordon (1964, as cited in Blakemore & Boneham, 1994) to denote the intertwined nature of ethnicity and class. Blakemore and Boneham (1994: 15) argued that focusing on 'racism' alone may lead to a 'passive victim' picture and that social class, employment, age, period of immigration, locality and neighbourhood are important factors in an integrated analysis. In an earlier work, Blakemore (1989) argued that 'it is misleading to think of variables operating as discrete influences' (p 173), as the picture is more complex; and cautioned against automatically assuming that older minority ethnic and racialised people are worse off than their white majority ethnic peers.

Interlocking oppressions was a theme in Vincent's (1995) book in which he attempted to introduce a holistic life course theory of inequality, referring to processes of exploitation and hegemony as underpinning various forms of inequality. Additive and reductionist approaches were rejected in favour of an integrative analysis that sees inequalities as intersecting and as structuring life course opportunities and people as cohesive units, not divided into strands of identity (p 189). This perspective was articulated by Levy (1988), albeit in a less complex fashion:

> both age and sex emerge as powerful systems of ranking and discourse, but neither can be understood fully without reference to each other...thus it makes little sense to view the properties of gender and aging as separate domains (p 485).

Zarb and Oliver (1993), in their report on aging with a disability referred to the additive approach as 'serving to atomise, distort and marginalize' (p 16) experiences and called for connections between aging with a disability and other forms of oppression, such as sexism, racism, ageism, and classism. Sayce (2000), in putting forth the view that the disability inclusion model is the way forward for people with mental health problems to be treated as citizens, noted the model's 'acknowledgement of difference or complex triple or quadruple-barrelled identities' (p 131) and its focus on simultaneous discrimination, rather than multiple jeopardies. This approach was seen to be particularly appropriate as:

> most disabled people are working class men, women, gays and lesbians, older people and people of Irish, Jewish and many other ethnic origins (Sayce, 2000: 131).

It is these very groups of people that by and large have been left out of research on subjective experiences of dementia and thus are of concern to this thesis on dementia and intersectionality. With an understanding of theories about inequalities in later life and the need for an intersectional analysis, we now move on to an analysis of theories on dementia and their limitations.

2.4 Dementia theorising

Several ontological theories regarding dementia have been put forward, yet phenomenological perspectives remain a major, acknowledged gap in the literature. Given this lack of experiential theories, the focus here will be on

theories that address the nature of dementia. It is argued, however, that in order to begin to understand dementia, we need to ask the people who are labelled as such about their experiences and then generate theory from these answers, rather than imposing a meta-theory on observed /described phenomena. Current theories on dementia may be loosely classified as: (1) dementia as a brain disease, (2) dementia as a normal part of the ageing process, (3) dementia as a psycho-neurological condition, (4) dementia as a disability, and (6) dementia as a social construction.

Table 1- Various Approaches to Understanding Dementia[7]

Approach	Beliefs	Practice	Selected authors
Bio-medical (brain disease)	Dementia is a pathological brain disease that results in particular symptoms and behavioural problems that follow a certain course over a defined period of time	Treatment focuses on early diagnosis, drug trials and therapies, symptom management, and individual adaptation, including preparation for the inevitable decline	Dilmann, 2000; Jacques & Jackson, 2000; Khachaturian, 2000; Leibing, 2002; Shenk, 2001
Normal aging	The brain loses strength and function over time, therefore dementia, or rather senility, is not a disease, but part of the natural aging process	Acceptance & care in community until institutionalization necessary (warehousing, 'bed-and-body work')	Holstein, 2000; Huppert, Brayne & O'Connor, 1994; Shenk, 2001 Gubrium, 1997
Psycho-neurological condition	Dementia represents the interaction of the brain (pathology, development, and activity) and the social-psychology of the individual	Person-centred care that focuses on the person living with the disease and strives to limit ill-being and maximize well-being in dementia care	Cheston & Bender, 1999; Kitwood, 1990; 1993; 1997a; Kitwood & Bredin, 1992; Sabat 2002; Sabat & Harré, 1992
Social model of	Cognitive impairment is	Focus on social and	Bartlett, 2000;

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[7] Chart developed for guest lecture at McMaster Summer Institute on Gerontology, June 2003.

disability	made a disabling condition by a society that is not inclusive and doesn't design dementia-friendly policies, services, and buildings	environmental context and changing disabling environments; advocacy; alliances with other groups	Crow, 1996; Gwilliam & Gilliard, 1996; Kitwood, 1995; Marshall, 1998; Oliver, 1996; Pool 2000
Social constructionism	Dementia is a socially constructed phenomenon whereby certain people and their actions are labelled as deviant and they are thereby subject to social exclusion	Efforts at reducing the stigma associated with dementia and promoting citizenship rights of those affected	Bond, 1992; Fox, 1989; Gubrium 1986; Harding & Palfrey, 1997; Lyman, 1989; Robertson, 1990; Vittoria, 1999

This proliferation in the number of theories, or alternative conceptualisations of this phenomenon we call dementia, is closely related to dissatisfaction with the ability of the medical model to adequately account for the variability and diversity of symptoms and behaviours found in people with dementia. The arbitrary manner in which dementia was classified as a brain disease assists us in understanding the dissatisfaction with this model as an explanatory theory and will be briefly reviewed below.

2.4.1 Dementia as a brain disease

The medical model sees dementia as a brain disease and has been the dominant paradigm in this field since Kraepelin named an amalgam of symptoms and associated behaviours Alzheimer Disease (AD) in 1910 and classified it as a distinct subset of senile dementia (Cheston & Bender, 1999; Dillmann, 2000; Fox, 1989; Gubrium, 1986; Herskovits, 1995; Holstein, 2000; 1998; Leibing 2001; Robertson, 1990). This naming served to differentiate AD from senile dementia, a decision which Alois Alzheimer himself disputed at the time as he believed that what he had witnessed clinically was not the result of a distinct disease process, but rather a variant of senile dementia. A related

debate, which predated this declaration of AD, was whether any distinction could be made between senile dementia and normal ageing. These scientific deliberations fell largely dormant until the early 1970s when AD was 'rediscovered' by medicine and psychiatry and agreement was reached to treat AD as an organic condition that is both related to and distinct from senile dementia (Fox, 1989). This led to the reintroduction of the general category of dementia in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) in 1994. As Cheston and Bender (1999) stated, this:

> re-creation of Alzheimer's disease...has served to place people with Alzheimer's disease within a constricting explanatory framework in which they tend to be perceived as diseased brains rather than as social beings with active mental lives (p 44).

There is undeniably an association between dementia and ageing in that incidence and prevalence increase with age. However, this does not support the belief that dementia is a normal part of the ageing process. Contemporary theorists view dementia as a pathological condition that primarily strikes individuals at random. In this sense, the brain disease theory is akin to the personal tragedy theory heavily criticised in disability studies (Bond & Corner, 2001; Crow, 1996; Hughes & Patterson, 1997; Morris, 1991; 1996; Oliver, 1990; 1996; Shakespeare, 1996; Tragaskis, 2002) which sees disability (dementia) as a tragic quirk of fate that leaves the affected individual subject to the pity of others. The resulting societal responses focus on assisting the individual to adapt, rather than fundamentally altering social structures to accord disabled people full citizenship rights. The discovery of a pathological brain represents just such a personal tragedy in the world of biomedicine, a tragedy that medicine is driven to avert through the discovery of a cure.

2.4.2 Questions of normalcy and critiques of the biomedicalisation of dementia

Ageing is not a condition, but rather a process. Although various conditions may attach themselves to older people as they age, it is questionable whether the process of ageing itself can be said to cause a condition such as dementia. There are compelling arguments that ageing has been turned into a condition through a process of medicalisation (Estes & Binney, 1991; Robertson, 1990), and the same process has been said to have solidified the location of dementia 'under the gaze' (Foucault, 1994b) where it is then subject to regulation by the medical profession (Bond, 1992; Lyman, 1989; Robertson, 1990). As Dillmann (2000) concludes, dementia can be thought of as:

> a subset of the changes identified by the usage of the concept of aging [and] this subset is the result of a normative decision to evaluate a particular area of the range as 'abnormal' (p 151).

This process of ascribing phenomena with a designation of normal or abnormal certainly applies to dementia, just as it has operated in the past for 'madness' and 'senility' (Foucault, 1965). Indeed, the determination of whether dementia and other conditions that connect brain and behaviour exist as facts or whether we have created them relies on an understanding of the creation of 'the Other' and the designation of behaviour as normal or abnormal.

Early treatises on the creation of the Other in relation to ideas of normalcy may have been concerned with ostensibly different subject matter, for example 'madness' (Foucault, 1965), 'stigma' (Goffman, 1963) and 'deviance' (Becker, 1963), yet the common thread is the identification of a condition or situation that has been problematised by society and that subsequently results in

discrimination of those who are classified as Others, in this case people with dementia. The term 'senility' has been reclaimed as a rejection of the medical classification of dementia, which is thought to be concerned only with the pathological (Cohen, 1998). The use of the word 'senility' is a political act meant to signal a concentration on the physiology, political economy and social relations that structure loss and decay of the body and its voice (Cohen, 1998; Traphagan, 2000). The term, however, cannot escape its contested past in which it was equated with the ageing process and as a result senility was seen to be an expected part of the ageing experience. The degree to which dementia and senility are believed to be qualitatively different conditions is still under debate and although we may think now that the former term represents an advance in medical thinking and social awareness, it may just be a surface appeasement. That is to say, the response to dementia has not improved in terms of removing the stigma and engaging with the other in a meaningful way. The political economy of social relations of domination and difference has not been structurally altered by adoption of the clinical term dementia. Poverty, marginalisation, and social exclusion are seen as 'non-medical issues' and through their omission from under the gaze, the ageing process is effectively depoliticised (Robertson, 1990). Once we deconstruct the use of the words and the conditions they describe, we may come to the conclusion as stated above that it is all about the social construction of the other and if that is the case, then society is necessarily implicated. And as Sayce (2000) states in referring to mental illness in general:

purely genetic explanations let society off the hook (p 92).

2.4.3 Dementia as a psycho-neurological condition: the inclusion of the mind

Given the concerns with the reductionist, and quite possibly unscientific brain disease theory, it is no surprise that a move to a theory that took into account individuality and personality characteristics was embraced by those concerned more with the care than the cure of people with dementia. Kitwood's concept of personhood (Kitwood, 1990; 1993; 1995; 1997a; 1997d; Kitwood and Bredin, 1992;) and Sabat and Harré's corresponding focus on selfhood (Sabat, 1998; 2000; 2001; Sabat & Harré, 1992) was readily embraced and people eagerly adopted what they saw as a social-psychological approach, not the integrative theory that Kitwood proposed (Pool, 2000) that sees dementia as the interaction of both neurological and social-psychological domains. Factoring in the mind, Kitwood and Bredin (1992) argued, allows for the possibility of observing 're-mentia', an idea that was soon supported by empirical research (Sixsmith et al, 1993). Kitwood did not disavow the influence of pathology, rather he added another component - the social-psychological - and asked that we view dementia first as a disability and then as an illness (Kitwood, 1995; 1997a). This call has been taken up by others in the dementia field (Bartlett, 2000; Gwilliam & Gilliard, 1996; Marshall, 1998; Pool, 2000). Kitwood expanded the notion of what constitutes dementia and developed a method of assessing both well- and ill-being in dementia and an approach to care based on this synthesis of social-psychology and neurology (Kitwood, 1997a; Kitwood & Bredin, 1992; Pool, 2000). At the same time, Sabat and Harré (1992) and Sabat (1998; 2000; 2001) were busy accumulating proof of the existence of selves in people with dementia, selves that seemed to persist well into the

disease process and whose maintenance was shown to be dependent on the actions of others in their environment.

Personhood as defined by Kitwood (1993; 1997a; 1997d) refers to a standing or status that is conferred on an individual by others in the context of a relationship. The uniqueness of persons can be appreciated through acquiring personal knowledge and demonstrating empathy, two qualities that when combined are thought to be able to produce miracles in dementia care (Kitwood, 1997c: 39). Dementia is said to 'emerge in a social context' (Kitwood & Bredin, 1992: 275) and Sabat and Harré acknowledged that social constructionist theory (Sabat 2000; 2001; Sabat & Harré, 1992) forms the backdrop for their research on selfhood. However, neither Kitwood's nor Sabat and Harré's work truly enters into the social realm. It stays not only at the level of the individual, but at the basic psychology of the individual, leaving little room for an articulation of the role and influence of intersecting identities based on class, gender, 'race' and ethnicity. Another limitation of this theory is that it is not grounded in experiences of people with dementia; people with dementia were not asked how they would explain dementia (Harding & Palfrey, 1997). Although he did not apply this critique to his own theory of dementia, Kitwood did call attention to the fact that research subjects have not been asked 'what it is like to experience dementia?' (1997b: 11) and certainly endorsed this as a direction for future research (Kitwood 1997a; 1997b).

The personhood/selfhood concept and the accompanying theory of the interaction of brain (pathology, development, activity) and psychology is important to this research on dementia and intersectionality as it expands on

the bio-medical notion of dementia as solely a brain disease, it champions the importance of understanding the person behind the disease and in doing so, lays the groundwork for further explorations of the nature of identity and the socio-cultural context of dementia. Dementia can be seen to challenge our notions of normalcy (Kitwood, 1997b) and encourage us to better understand what it means to be a person (Kitwood, 1997a; 1997c). I argue that our next step should be to explore what it means to be a person with multiple and intersecting identities, a person of a certain 'race', ethnicity, class and gender, an exploration that would take us into the sociological realm of understanding dementia. Kitwood (1997a) intimated this direction in his conclusion that the paradigm he espoused:

> brings into focus the uniqueness of each person, respect for what they have accomplished and compassionate to what they have endured (p 135).

The question of endurance in the face of discrimination is central to the following theory which views dementia as a disability and which is in essence a sociological theory.

2.4.4 Dementia as a disability and the connection to mental health and illness

Disability theorists and activists have not addressed dementia or mental ill health specifically, however it is becoming increasingly common in dementia and in mental health and illness to turn to the social model of disability championed by Oliver (1990; 1996) as a more adequate paradigm for understanding cognitive impairment (Bartlett, 2000; Gwilliam & Gilliard, 1996; Kitwood, 1995; Marshall, 1998; Pool, 2000; Sayce, 2000). The attractiveness

of the social model of disability is that it does not see impairments as problematic; rather it postulates that society has problematised impairment. Society is seen to disable people in the way that people with impairments are unnecessarily isolated and excluded from full participation in society (Oliver, 1996); society has not shifted attitudes and adapted environments to accommodate those who differ from the norm (Phair & Good, 1995). This is a move completely away from brain disease theory into the realm of the social, towards a political economy of disabilities. However, Oliver sees a clear distinction between theories and models and does not refer to the product of his thinking as a theory. He calls it a model since he believes models aid in understanding (Oliver, 1996) and do not seek to explain as theories do. There are differing opinions as to what distinguishes a theory (McMullin, 2000). This semantic distinction has not been as critical in dementia, and so this model has been adopted as an explanatory theory - a theory of how dementia should be viewed, not how it is caused. Naming dementia as a disability moved dementia theorising to a focus on society, away from the brain, or the brain and behaviour combined. The realm of the social leads us to questions as to how society shapes and constrains the experiences of people with dementia through our conceptualisation of this disease/illness/disability and the interaction of relations of domination. It is this question that Oliver (1990) poses in his suggestion that the way forward on a theoretical level for disabilities is the creation of social oppression theory, developed by disabled people, and in this way grounding the theory in the experiences of people living with impairments, who are consequently disabled by society. Oliver (1996) further highlights the need for an analysis that sees oppressions as intersecting and acknowledges that the

social model of disability does not address this issue. The imperative for the future is that theory be derived from the experiences of the people under study, a need that was identified earlier in relation to future dementia research. Initial indications are that it is natural for people to talk in the language of intersectionality, as the following quote demonstrates:

> As a black disabled woman, I cannot compartmentalize or separate aspects of my identity in this way. The collective experience of my race, disability and gender shape and inform my life (Hill, 1994, as quoted in Oliver, 1996).

The concern expressed in the quote of the dangers in and futility of sectioning off parts of oneself is at the heart of an intersectional analysis. Aligning dementia with disability places cognitive impairment in a socio-political context and moves towards an understanding of the status of being disabled as an outcome of relations of subordination and privilege.

An analysis of intersecting oppressions is central to Sayce's (2000) investigation into the discrimination and social exclusion of people with mental health problems and how to overcome this state of affairs. Her finding that people with mental health problems, referred to as users/survivors, are socially excluded, and that this intersects with other forms of discrimination, is based on extensive research with users/survivors, mental health professionals, policy makers, disability activists, advocates and lawyers in the US and the UK. She concludes that the disability inclusion model (based on the social model of disability) is the most likely model to lead to social inclusion and full citizenship rights as it places users/survivors as a minority group in society, it is inclusive of differences within the group in terms of decisions about whether to receive treatment or not, it acknowledges intersecting identities and it builds alliances

with other groups to address simultaneous discrimination. Her rationale for focusing on oppression/ discrimination, rather than 'stigma' for example is that the latter stays at the level of the individual and the former points to patterned or systemic exclusion from social and economic life (Sayce 2000). The adoption of the disability model by users/survivors, being people who are socially excluded due to mental health problems, lends further credence to its applicability to dementia.

2.4.5 The influence of sociology: dementia as a social construction

Sociologists have been criticised for not engaging with the needs and concerns of older people with mental health problems (Pilgrim and Rogers, 1999). Indeed Sayce (2000) identifies older people with mental health problems as those among the unheard voices that we need to actively seek out and suggests that mental health groups should build alliances with older people's groups in order to increase their strength as social movements. Although there is little evidence of sociological theorising on dementia specifically, sociological theories have been applied to the study of dementia (Bond, 2001; Bond & Corner, 2001; Bond, Corner & Graham, 2004; MacRae, 1999) and this link has not always been recognised. The impact of work that has applied a sociological perspective to dementia has been profound in terms of our understanding of the social construction of Alzheimer's disease (Gubrium, 1986; Harding & Palfrey, 1997) and the purpose it has served for the 'Alzheimer's Enterprise' (Binney & Swan, 1991), the biomedicalisation of dementia (Bond, 1992; Lyman, 1989; Robertson, 1990) and the emphasis on lived experiences of dementia (Bond 1992; Bond & Corner, 2001; Braudy Harris, 2002; Froggatt, 1988; Keady, 1996;

Lyman, 1989;1998; Robertson, 1990; Vittoria, 1998; Wilkinson, 2002b).

Dementia as a subject matter seems to have:

> fallen through the cracks between social gerontology and medical gerontology, with neither specialty paying much attention to the social forces that affect the conceptualization and experience of the disease (Lyman, 1989: 599).

This in turn has led to a lack of social theories of dementia.

In line with the question of normalcy addressed earlier in relation to the brain disease theory and the biomedicalisation of dementia, social constructionists view normalcy as a socially negotiated designation (Harding & Palfrey, 1997; Pilgrim & Rogers, 1999) based on social constructions of unwanted or deviant behaviour. This theorising is derivative of Szasz's 1961 thesis *The Myth of Mental Illness* (Szasz, 1994) and Berger and Luckmann's (1966) seminal work *The Social Construction of Reality* in which they stated that:

> questions of psychological status cannot be decided without recognizing the reality-definitions that are taken for granted in the social situation of the individual...psychological status is relative to the social definitions of reality in general and is itself socially defined (p 196).

Rather than biology or physiology, it is society that is seen to create mental illness through its definition of normative behaviour. The resulting label of abnormal is applied differentially and it has a variable effect on those to whom it is applied based on factors such as their 'race', ethnicity, class, gender and age (Cohen, 1995). Harding and Palfrey (1997) question to what extent dementia is a label applied to people who resist oppression through an assertion of their individuality and their independence. Pilgrim and Rogers (1999) claimed that:

> it is the roles and context of people's situations that influence the type and rate of mental distress (p 40).

Referring to the social construction of senility in particular, Traphagan (2000) states that it is a:

> matter of human identities as they change and are negotiated
> between and among people over their lives (p 186)

and stresses that this social construction is not universal, it is culturally mediated. For this reason, anthropologists, such as Traphagan (2000) and Cohen (1998), refer to senility as culturally, rather than socially, constructed. Viewing dementia as a social construction is helpful in that it speaks to the political economy of dementia - the interaction of the political, the economic and the social structures (section 2.2.1), and their impact on human experience. It runs the risk, however, of negating the very real experience of disorientation, memory loss, diminished judgement, and other symptoms endured by people with dementia. Further, it does not adequately explain the role of intersecting identities, nor does it place people in a socio-cultural context that differentially supports or disables them based on where they lie on the multiple axes of privilege and oppression. For older people with dementia who are experiencing the intersectionality of age and disability, without even factoring in other dimensions of their identities, there is a need for theory that is grounded in their lived experiences and that further develops our understanding of the intersecting nature of oppression.

2.5 Implications for future theoretical developments

Three themes ran through the above review of dementia theories: (1) prior theorising on dementia has not been based on the lived experiences and viewpoints of people with dementia themselves; (2) dementia theories have

failed to account for the socio-cultural context of people with dementia, the intersectional nature of identities, and the interaction between these realms; and (3) future sociological theorising on dementia and intersectionality needs to be grounded in an analysis of the structure and function of privilege and oppression in order to adequately account for the experiences of people who are simultaneously oppressed on the basis of multiple and intersecting identity categories (Hulko, 2002).

The first section of this chapter, on theorising about aging and older people, argued that the critical gerontology tradition represents a more holistic and politically engaged approach to aging studies and emphasised the importance of seeing older people as theorisers and determining their views about aging and 'being old'. With respect to inequalities in later life, there are several implications for this thesis arising from this critical engagement with the literature.

As noted, the concept of multiple jeopardies was suggested to be applicable to dementia by several authors (Allan, 2000; Anderson & Brownlie, 1997; Innes, 2003; Marshall & Rowlings, 1998; Rodeheaver & Datan, 1988; Wilkinson, 2002b) who claimed that people with dementia are subject to an additional layer of jeopardy. This hypothesis has not been systematically tested, to my knowledge, to see whether it holds up either quantitatively or qualitatively. Moreover, the approach that treats oppressions as interlocking has not been operationalised to date in dementia research apart from an analysis of dementia theorising and the subjective experiences of people with dementia that I undertook and which had some promising results (Appendix A). The

concept of interlocking oppressions is attractive on a personal level, as it seems to fit with our subjective experiences of what is it to be a person inhabiting complex social locations or multiply situated in terms of identity categories. On a theoretical and political level, it leads us away from fruitless attempts to find the ultimate oppression to which all others can be reduced.

A key concern arising from the literature on intersectionality/interlocking oppressions is that it is a difficult concept to operationalise (see chapter 5) and thus, there is a lack of empirical research to substantiate all the theorising and personal reflections. It poses a challenge to both quantitative and qualitative researchers - a challenge that has been answered by the former group (Hardy & Hazelrigg, 1995), but apparently not by the latter. I would argue that it may be easier to try to prove statistically whether interaction effects exist in data on inequalities in later life than to figure out how to ask questions or observe behaviour in a way that teases out the nature and extent of oppression and privilege and their interplay in the daily lives of older people. We have a formula and prescribed techniques to apply to the first concern, while the second one defies formulaic solutions. Possible questions like 'tell me about your self?', 'how do you identify as a person?', 'what role do gender, 'race', ethnicity and class play in your life?' seem vague, tiresome or difficult. There are no easy questions though with a complex subject matter such as this. First, it calls for creativity and the willingness to take chances with the design of interview guides and the use of research methods, as well as reflexivity in the field to be able to follow leads and weave together threads of meaning.

Second, it requires us to ask about privilege as well as oppression and to look for acts of resistance, rather than assuming capitulation (see chapter 5).

From this critical review of literature on theories of aging and dementia, we move on to another set of theories that relate more to the substantive focus of this thesis. The next chapter examines the dynamics of privilege and oppression in general and specifically in the context of health, illness and disability, with the implications for dementia being evident throughout and summarized at the end.

Chapter - 3   The Dynamics of Privilege and Oppression

3.1 Locating (my)self

Researching and writing this chapter required a blurring of any remaining lines of distinction between the personal and the professional.   Identity and oppression are not simply words in an academic text, they are concepts that hold real, complex, and often disputed meanings in our daily lives. It is difficult to comprehend what these meanings may be and the dialectical relationship between the personal and the political from solely a structural level analysis. Consequently, it has been recognised by feminist and anti-racist scholars that researchers and practitioners should engage in explorations of the subjective realm of oppression in order to better understand the personal impact of structural relations of domination (Alway, 1995; Mama, 1995a; Millar, 1998; Moraga, 2001; Smiley, 1993; Smith, 1987), to get at the lived experiences of relations of ruling (Smith, 1987). A lack of attention to personal experiences was an early criticism levelled at the social model of disability by feminist disabled women (Crow, 1996; Morris, 1991; 1996) and attention to this subjective arena has been promoted as a way forward in understanding disability oppression (Marks, 1999; Shakespeare, 1996). Towards this end of linking the personal and the political and situating this paper in the context of everyday dialectics of oppression and power (Charlton, 1998), I wrote a story of the collision of my professional and personal lives, following the example set by June Jordan in Report from the Bahamas (2001) in which she highlights the intersections of race, class, and gender as they operate on her vacation.

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I am a holder of multiple privileges by virtue of my 'race', ethnicity, class, and able-bodied ness and feel that it is my responsibility to remain cognisant of that fact in interactions with others and to seek to transform oppressive practices. Using my privilege in what I hoped to be an instructive manner, if not emancipatory, I turned my subjective gaze to the multi-racial and multi-ethnic household that was my home for eight months during the first year of my doctoral studies. In this externally constituted flat, the dynamics of gender, 'race', ethnicity, and class shaped the everyday interactions between the seven occupants. The most blatant example arose four months into our cohabitation when one flatmate disclosed to me that another flatmate had made prejudicial comments about Blacks and Indians. He proceeded to describe his feelings about an Asian woman from Hong Kong placing herself higher (closer to whiteness) in the racial hierarchy than himself, a British Pakistani man. He recalled a lifetime of being viewed as a foreigner, although he is native born, and was angered that a 'real foreigner' to this land, who shares his visible minority status, could evoke those not so dormant feelings of being the other. This was followed by the retelling of an incident in which another Asian woman flatmate who was from Taiwan had expressed that 'yellow is better than brown because it is closer to white'. He did not, however, reject this racialised ranking of status, rather he questioned their relative positioning in this hierarchy, indicating that he should be placed higher by virtue of being born in Britain.

In describing her reaction to hearing the term 'rainbow women' being used by a group of non-white women to identify themselves, a feminist author wrote:

> This colour hierarchy...falls back, even if unconsciously, on the
> hegemonic common sense of social culture and politics of slavery

and apartheid. What colour are you, it asks: are you black, white, yellow or brown? (Bannerji, 2001: 544).

Upon hearing the above story from my flatmate, I thought 'where am I - on a plantation?' as this type of thinking was, in my mind, text-bound and historically situated. Upon relating this story to my mother, she exclaimed 'but they're educated people' and her comment reminded me of the prevalent belief that education erases prejudice, or at least makes one more discrete about it. However, this belief does not stand up to empirical testing, as noted by a cursory look at several atrocities perpetrated over the last century alone, the Holocaust being the most extreme and horrific example of well-educated people enacting their prejudices (Essed, 1991).

In terms of distinctions between prejudice, discrimination and racism, the dynamics of ethnicity and 'race' in my flat evidenced prejudice, defined as:

> A negative attitude toward a person or a group based upon a social comparison process in which the individual's own group is taken as the positive point of reference (Jones, 1972).

Instances of 'racial' and ethnic prejudice seem to stand in sharper relief than gender and class which operate in ways that are more difficult to pinpoint, as they are more amorphous, yet no less prevalent. Further, it is difficult to untangle these dynamics, as 'race', ethnicity, class and gender are necessarily entangled (Andersen & Hill Collins, 2001b; Anthias, 1992; Bannerji, 1995b; Bhavnani, 2001; Brah, 2001; Brah & Phoenix, 2004; Crenshaw Williams, 1994; hooks, 2000). At the start of our co-habitation, the Asian women aligned themselves with the males in the flat and were careful not to counter them if there was another person in the room, and stayed silent if another female was being disparaged. Although in the earlier example one of these women saw

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herself as superior to one of the men based on her belief in the racialised hierarchy, in most instances she and her compatriot placed themselves in a subordinate position and acceded to the gender power held by the men.

Class may be evident in lifestyle discussions, yet when all are inhabiting the ambiguous status of students, it is easier to 'pass' (Goffman, 1963) as one of the group and avoid unmasking one's inferior, or perhaps superior, status. As is the norm in capitalist societies, there seemed to be a relentless compulsion to spend and the ease with which one can do so was taken as evidence of class privilege. In my flat, there appeared to be a process of positioning at work based on ownership of goods such as televisions, laptops, and stereos and plans to travel to places such as London, Paris, and Amsterdam.   Once acquired, possessions were seldom shared.   This jockeying carried over to academic matters, such as number of books read or words written, with seemingly no awareness of structural constraints that could affect scholarly output. Similarly, the type of food purchased (frozen versus fresh, name brand versus generic) was more an indicator of economic security than one of taste. Such was the nature of class relations in my flat. Although the most shocking in its blatancy, 'racial' and ethnic prejudice was not the only relation of domination operating in my flat: class and gender were implicated as well and could not be easily teased apart. A more detailed analysis of this household could reveal some clues as to the nature of intersecting oppressions, as the actors seemed to be conscious of the dynamics of oppression though not that of privilege.

3.2 The everyday articulations of identity and oppression

My intention with this story was to situate this review of the literature on identity and oppression; having done so, I now move on to an analysis of this largely theoretical body of literature. After addressing definitions of these two concepts as they appear in the literature, I take a brief look at terms that have arisen from cultural studies in attempts to make sense of identity and difference, then review the notion of subjectivity, along with articulations of identity as fluid, multiple and contingent and oppression as a matrix of domination, and end with an indication of the applicability to dementia studies and potential ways forward. This section on identity and oppression draws on a largely theoretical body of literature, with attention paid to how these concepts have been conceptualised in the literature, the notion of subjectivities, articulations of identity as fluid, multiple and contingent, and oppression as a matrix of domination.

Intersectionality and its corollary interlocking oppressions were discussed in Chapter 1, therefore I will only highlight a few points here before proceeding to definitions of identity and oppression. These concepts are rooted in Freire's (2001) depiction of oppression as a structure of domination in which all humans participate, both as oppressors and as the oppressed. In the 30 years since the first publication of Freire's seminal text on oppression, terms like multiple, simultaneous, interdependent and interlocking have been affixed to the root word 'oppressions' in an attempt to broaden the theory to include systems of inequality other than class and to do so in a way that consciously avoids the 'add and stir approach' (Dressel, 1991). This is more fully articulated in later feminist and anti-racist writings that use, for example, a matrix of

domination/social oppression (Adams, Bell & Griffin, 1997; Hill Collins, 2000 as cited in Andersen & Hill Collins, 2001b), a polyhedron (Williams, 1992), a flower of power (Lee, 1985 as cited in Bishop, 1994), an intersectional model (Wineman, 1984, as cited in Mullaly, 2002), or a birdcage (Frye, 2001) to represent multiple and intersecting axes of oppression and privilege. Freire himself was engaged in this linking work, as noted in the introduction to the 30th anniversary edition of Pedagogy of the Oppressed:

> Freire's later works make it clear that what is important is to approach the analysis of oppression through a convergent theoretical framework where the object of oppression is cut across by such factors as race, class, gender, culture, language and ethnicity (Macedo, 2001:15).

3.2.1 Definitions of identity and oppression and their interconnections

Identity is sometimes understood to refer to one's outer self as opposed to one's inner self or subjectivity. Deaux (2001: 1) suggested that 'identity is sometimes used to refer to a sense of integration of the self, in which different aspects come together in a unified whole' which points to the multifaceted nature of identity or identities. The author elaborates in this definition by introducing the concept of intersectionality, which she refers to as:

> the condition in which a person simultaneously belongs to two or more social categories or social statuses and the unique consequences that result from that combination (Deaux, 2001:1).

This definition of intersectionality is problematic in that it implies that this simultaneous belonging is not universally experienced. The function of identity is said to be 'to give us a location in the world and present the link between us and the society in which we live' (Woodward, 1997a: 1). Our identities are formed from a 'multiplicity of sources - from nationality, ethnicity, social class,

community, gender, sexuality' (ibid) and these may conflict with one another and cause fragmented identities.

One taxonomy of social identities included these characteristics: relationships, vocation/avocation, political affiliation, stigma, and ethnicity/religion (Deaux, 2001; 2000). The present study of dementia and intersectionality does not fit this typology very well, as I am concerned with two of the categories (ethnicity and stigma), as well as 'race', class, and gender, which do not appear in the list. This is the first indication of the notable difference in the literature between social psychological and sociological approaches to identity. Strauss (1997) set out in 1959 to overcome the 'crippling dichotomy of social structure versus social interaction' (p 2) by showing how 'personal identity is meshed with group identity, which itself rests upon an historical past' (pp 175), and in doing so, introduced a sociological view of identity. In fact, he hints at the importance of an intersectional analysis in commenting that the changing significance of others over the course of one's life is related to age, race, nationality, social class, social status, and sex; and notes that in order to take these factors into account, a sociological model is needed (Strauss, 1997). It should be noted, however, that Marx pointed out the futility of separating the individual from the social some time ago (Bannerji, 1995b).

A sociological approach to identity is taken by Jenkins, who notes that 'power and politics are central to questions of identity' (1996: 24) and refers to the study of identity as 'the best device...for bringing together 'public issues' and 'private troubles' and encouraging us to use one to make sense of the other' (p 3). This sentiment is (consciously) evocative of C. Wright Mills' (2000) and is

shared by feminist and anti-racist approaches to the study of identity (Bannerji, 2001; 1995b; Bhavnani, 2001; Brah, 2001; Woodward, 1997b). Jenkins stresses the importance of seeing identity as a process, one of being or becoming, and rejects efforts to distinguish between selfhood and personhood - a preoccupation of prominent dementia scholars (Kitwood, 1990; 1995; 1997a;b;c; Kitwood & Bredin, 1992; Sabat, 1998; 2000; 2001; Sabat & Harré, 1992) - as he sees 'the 'internal' and the 'external'...[as] inextricably entangled' (pp 31) for each of us and thereby implicating one another. The typology of social identities developed by Barth (1983, as cited in Jenkins, 1996) - ethnicity, religion, history/descent, occupation and class, settlement and lifestyle, gender - shares features with the model presented above, while giving prominence to gender and class. It is thought to be flexible enough to accommodate further 'universes of discourse such as kinship and age' (Jenkins, 1996: 101). One salient feature of the Deaux model is that it includes stigma, an important identity category for an investigation of older people with dementia (MacRae, 1999; McColgan, Valentine & Downs, 2000). Although these authors have developed models of social identities, little attention has been paid in this field to intersectionality or multiple identification (Woodward, 1997a). In studies that look at the impact of 'crossed group membership' on inter-group relations (Crisp & Hewstone, 2000), the power and politics thought to be so central to identity inquiries (Bannerji, 1995b; Jenkins, 1996; Shakespeare, 1996) do not make much of an appearance and the results do not indicate what life is like for people who tick more than one box.

Although his treatise on identity is oft-cited, Giddens (1991) does not really tell us much about identity construction and maintenance in high-modernity except that 'self-identity becomes a reflexively organised endeavour... [that] takes place in the context of multiple choice as filtered through abstract systems' (pp 5). Capacity for self-reflexivity is not universal, however, as was demonstrated by the inability of the men in Whitehead's (2001) study to articulate the meaning and impact of their gender on their careers. Moreover, the diversity of lifestyle options said to exist for people engaged in these identity projects (Giddens, 1991) does not appear to match the reality of life for many people, especially poor people, many of whom are older people as well. Marx highlighted the way in which structural constraints impinge on individual choice some time ago in claiming that people create their own histories but not under conditions of their own choosing (1979, as cited in Bannerji, 1995a), an idea that has such currency today that its originator is often unacknowledged (Gilroy, 1997). Kaufman (1981) describes a similar approach to Giddens (1991) of identity construction and reconstruction arising from her life history study of older people. The participants constructed themes to give meaning and coherence to their life experiences and integrated these themes into the ongoing formation of their identities. These themes were thought to assist in adaptation to changing surroundings, ordering experiences, and communicating with others. While important to understanding processes of identity formation, neither of the aforementioned works seek to link the personal and the political. Giddens takes a structural and historically contingent approach to identity - the macro view - and Kaufman takes a phenomenological approach - the micro view - and

in doing so, neither achieve Strauss' (1997) goal of overcoming the great divide.

Phenomenology has been critiqued for neglecting the social-structural and economic factors that lie behind prejudices (Barber, 2001) and which need to be considered in order to understand manifestations of oppression, and indeed resistance to oppression, at the individual level. Williams (1996) notes that disability researchers who focus solely on interaction and the negotiation of identity run the risk of being:

> sucked into a bottomless pit of phenomenological analysis where the structures which underpin or destroy identity are lost from sight (pp 195).

A similar myopia in the form of class reductionism can be the outcome of studies of oppression that look at social structures alone or together with groups of people as the unit of analysis (Abberley, 1987; Charlton, 1998; Ferguson, 2000). Analyses of oppression which treat class as foundational are rejected by those who see identity categories such as gender and 'race' as cutting across class divisions (Andersen & Hill Collins, 2001a; Bannerji, 2001; 1995a; Brah, 2001; Brittan & Maynard, 1984; hooks, 2000b; Woodward, 1997b).

3.2.2 Cultural Studies: hybridities and diasporas

Empirical data is lacking to substantiate theories of identity and difference developed by Cultural Studies (Williams, 1992) and can be taken as further support for the need to talk to real people about their experiences and to generate grounded theory. Through the archaeology of knowledge (Foucault,

1994b) in Cultural Studies, the word Diaspora has been discovered and imbued with renewed theoretical significance (Gilroy, 1997; Hall, 1997). Gilroy (1997) refers to Diasporas as relational networks developed as a result of the 'scatterings' of people through war, genocide, famine, poverty, enslavement, political repression, 'with the inevitable opening of their culture to new influences and pressures' (pp 304) and a shared need to remember the reasons for their dispersal and the process by which it occurred. 'Diaspora' first surfaced in relation to Jewish people who were forced to 'scatter' as a result of the pogroms in Eastern Europe. The historical connotation and the specificity of this term are in danger of being erased or neglected with the promotion of this concept as applicable to any and all scatterings of people. Diasporas are said to give rise to hybridized identities and as such point to new understandings of self, sameness and solidarity, and situate questions of identity in the realm of indeterminacy, contingency and conflict (Gilroy, 1997). Hybridity is a controversial concept as well in that it implies acceptance of the ideology of racism, which purports that there are 'pure races' or pre-hybrid peoples.

Both the concept of Diaspora and that of hybridity could conceivably be applied to people with dementia who are cast out of the land of the living into an indeterminate 'third space' (Rutherford & Bhabha, 1990). Given the aforementioned concerns with both of these concepts, I would not advocate for the adoption of either of these terms in dementia studies. This could be the theoretical argument behind the application of the concept of liminality to people

with dementia (Cohen, 2000; Davis, 1989; McColgan, 2001), however, pointing

as it does to that space in-between or to 'the border-land' (Anzaldua, 2001).

3.2.3 The articulation of subjectivities and oppression as a matrix of domination

There are two approaches to the study of identity/subjectivity, with one

approach seeing identity as 'fixed and transhistorical' (essentialism), and the

other treating identity as 'fluid and contingent' (Woodward, 1997b); it is the

latter approach to identity that this study employs. Subjectivity has replaced

identity as the focus of investigation for several feminist and anti-racist scholars

(Mama, 1995a; Sudbury, 2001) as it denotes status as a subject, signifies the

'coming to voice' of oppressed peoples (hooks, 1990 as cited in Smiley, 1993)

and indicates the relational nature of a sense of self experienced in a social

context (Woodward, 1997b).   At the same time, subjectivity is used

interchangeably with identity, with the latter being seen to have a political

meaning (Bannerji, 1995b), viz:

> identity, in the sense of historical and social subjectivity and agency,
> is produced from and susceptible to divergent political-cultural
> notions of difference (ibid: 26).

Subjectivity implies a rejection of the artificial separation of psychological and

social worlds (Mama, 1995a) and is seen to be fluid, dynamic and contingent.

Thus defined, subjectivity allows for the possibility of actors having and using

agency and opens the door to analysing resistance to oppression.   The

concepts of positionality and movement are drawn on to assist with the bridging

of the socio-historical and the intra-psychic required by Mama's (1995a) theory

of Black women's subjectivity. Burman (1994) also advocates the use of the
concept of positionality, which she sees as:

> attending to the process of constructing identifications, with identities
> thereby rendered as textual productions rather than as some
> personal attributes or references to events (pp 156).

These meanings and uses of positionality were picked up on and the term was
imbued with its own theoretical significance in Anthias' (2001) work on
'translocational positionality'. This can be seen as the latest concept to be
offered up in the ongoing efforts to distance critical theorising from identity
politics and its essentialism, as was evident behind the adoption of the term
subjectivity (Mama, 1995a). In Anthias' (2001) use of the term, positionality
relates to 'the space at the intersection of structure and agency' (Anthias, 2001:
635) and translocational:

> references the complex nature of positionality faced by those who
> are at the interplay of a range of locations and dislocations in relation
> to gender, ethnicity, national belonging, class and racialization (pp
> 634).

Although the origin of the current use of the term oppression has been noted
already, some more notes on its meaning and use are in order. The term
oppression has been used by several authors who have infused it with their
own interpretations (Adams et al, 1997; Andersen & Hill Collins, 2001a; Bishop,
1994; Brittan & Maynard, 1984; Carniol, 2000; Essed, 1991; Freire, 2001; Frye,
2001; hooks, 2000a; Mullaly, 2002; Young, 1990) and whose work has
influenced my own understanding and use of this 'dynamic and relational
concept' (Mullaly, 2002: 27). Essentially, oppression is a condition in which a
particular social group is exploited or constrained for the benefit of another
social group, whose members may not be conscious of the privilege and

culpability they own.   Frye (2001) called attention to the root of the word oppression – 'press' - and describes this action using words such as mould, immobilise, reduce (p 49) and the metaphor of a birdcage.   Oppression is enacted through everyday practices (Essed, 1991; Smith, 1987), and supported by institutional and ideological regimes. Oppression, whether based on 'race', class, gender, ethnicity, age, disability, sexual orientation, religion, language, can be seen to be operating at the individual, cultural and institutional levels (Jones, 1972).   Young (1990) referred to the five 'faces' of oppression - exploitation, marginalisation, powerlessness, cultural imperialism, and violence – as the forms that oppression takes or the ways that is enacted in the social world. hooks (2000a) summed up the effect of these practices of domination in her succinct statement that 'being oppressed means the absence of choices' (p 5), while Lorde (2001) noted that 'systematized oppression creates surplus groups of people: Black and Third World people, working class people, older people and women' (p 177).

Oppressions interact with one another and are supported by the same practices of domination, which calls for 'macroscopic vision' (Frye, 2001: 52) in this counter hegemonic work of uprooting oppression.   Indeed Jones (1972) suggested a telescope metaphor for looking at the individual, cultural and institutional levels at which oppression operates.   At the individual level we cannot 'pluck out some aspect of oneself' as this 'eclipses and denies other parts of self' (Lorde, 2001: 182).   Indeed, oppression involves a dialectical relationship between 'the oppressor' and 'the oppressed' (Bishop, 1994; Freire, 2001), positions which are often held simultaneously, as we are all differentially

located, and locate ourselves in different ways, along multiple axes of oppression and privilege. In our common struggle against oppression, hooks (2000) argued that we need to 'understand, address and incorporate experiences of people on the margins who suffer sexist oppression and other forms of oppression' (p 163). These articulations of the dynamics of oppression that arise from feminist and anti-racist activists and scholars underpin my theoretical and methodological approach to this research.

Despite the proliferation in writing about subjectivity and oppression, there have been few empirical studies to date that look at the construction and maintenance of subjectivities in the context of relations of domination and subordination (Jenkins, 2002). Few notable exceptions exist and include Mama's (1995a) grounded theory study of Black women's subjectivity, in which the latter was found to be 'dynamic, multiple and historically and socially produced' (p 163) and 'transcend[ing] dualism because it conceptualises the individual and the social as being produced simultaneously' (p 133). The psychological and the social-historical form a dialectic and their interaction creates subjectivities, a view akin to that put forth by Jenkins (2002) in a talk on the importance of both the concept of difference and that of similarity in the study of identity, during which discussion ensued as to the difficulties of translating these theoretical concepts into questions to ask respondents for empirical research. Another example of empirical research on subjectivity and intersectionality is that of Petersen (2000) who found support for the hypothesis that African American women's identity development is marked by continuity of

self-definition, while Caucasian women relinquish their identities under pressure from the constraints of their culture.

Another promising direction is embodied in research that looks beyond oppressive structures and their manifestations in everyday life towards indications of resilience and oppositional strategising. In reviewing the impact on Aboriginal communities in Canada of ongoing processes of colonisation, sedentarisation, bureaucratic surveillance, and technocratic control, Kirmayer et al (2000) pointed to a connection between cultural discontinuity and oppression and high rates of indicators of mental distress. Similarly, Blandford and Chappell (1990) found that lower levels of well being among native elders than among non-native older people are caused by the effects of their worse health and disadvantaged social circumstances, not by virtue of being native. Kirmayer et al (2000) stressed the importance of looking beyond individuals, towards the degree of local control and cultural continuity of the community, to gain a sense of the impact of mediating mechanisms on mental health and find ways to eliminate oppression. Sonn and Fisher (1998) sought to apply the concepts of resilience and community competence to oppressed groups in their study of coloured [sic] South Africans in activity settings in Australia. Their study reinforces the importance of looking at the cultural level in Jones' (1972) schema in order to connect lived experiences of oppression and the political, economic and social structures underpinning it (Sonn & Fisher, 1998). Sudbury (2001) looked to mediating structures as well to understand oppression and identity construction and found that identifying with the signifier Black was an oppositional strategy used by multi-'racial' women in Britain, with the author

concluding that 'an intersectional approach is critical if collective identity analyses are to avoid unidimensional analyses of identity formation' (pp 45).

In addition to finding resilience and oppositional strategising at the cultural level, there is evidence that individuals employ techniques to resist oppression, for example passing (Goffman, 1963) among lesbians and gay men (Kanuha, (1999). Further, 'the process of passing is not based on a rejection of stigmatized identity, but situationally employed to resist social oppression' (Kanuha, 1999: 1). These acts should be seen as resistance strategies, rather than indications of internalised oppression or false consciousness (Freire, 2001), which occurs when the oppressed begin to take on board the oppressor's negative valuation of the social group to which they belong. A study (Watson, 2002) found that disabled people do not identify themselves as disabled, yet this should not be interpreted as internalised oppression or false consciousness, but rather as efforts to 'challenge the idea of normality and refuse to be categorised on the basis of bodily difference' (Watson, 2002: 525).

It has been argued as well that the oppressed possess double consciousness (Du Bois, 1953) or epistemic privilege (Whitehead, 2001) owing to their lived experience (Sartre, 1957) of oppression. This theory posits that the oppressed are acutely conscious of the dynamics of oppression and privilege, and of their own relative positioning, and that this affords them double vision - an awareness of the privilege of their oppressors and the way that efforts to sustain that privilege result in their own oppression.

3.3 Meanings of health, illness, and disability

Mental ill health is thought to be a universal phenomenon, yet definitions of mental ill and well being appear to be culturally relative. What may be considered abnormal behaviour in one social context may not be in another (Castillo, 1998; Yeo & Gallagher-Thompson, 1996). Further, some forms of mental disorder that are common in one society may not exist in others at all, as in the case of anorexia nervosa which is rarely seen outside western nations (Dawkins, 1996; Kleinman, 1988b). Finally, various people within one society or cultural group may define abnormalcy differently than the dominant biomedical paradigm, and indeed from one another. The defining of behaviour as either abnormal or normal and differing conceptions of health, illness and disability are applicable to the study of dementia and intersectionality for several reasons. As noted previously, the theme of striving for normalcy is notable in the accounts of the experiences of people with dementia which indicates its predominance as a theme in their lives. The status of 'normal' is not readily accorded to people who are marginalised due to their ethnicity, 'race', class, age and/or gender, however, and is even less likely to be applied to a person with dementia, regardless of their 'pre-morbid' identity. Once labelled 'demented', people with dementia embark on a defined moral career (Goffman, 1961); this label represents a culturally sanctioned stamp of disapproval that sets in motion a new or renewed attempt to achieve normalcy.

This section addresses the issue of meaning making while living with illness, either mental or physical, and the influence of socio-cultural factors. The concept of illness narratives (Kleinman, 1988b) is important to this field, as

evidenced by its popularity in this largely anthropological literature, as are definitions of health. Illness is commonly seen to be the subjective experience of symptoms and disability and is contrasted with disease, a biomedical classification that may or may not accord with the patient's feelings and experiences (Emami et al, 2000; Kleinman, 1988a). Conceptualising illness as a subjective experience shifts our focus, away from the disease-ridden patient to the person who is sick (Conrad & Kern, 1981). Kleinman's (1980) early work on explanatory models of illness led to a widespread understanding that individuals and communities have differing belief systems that they draw on in order to make sense of their illness experiences. The notion of explanatory models has been contested in research with people newly experiencing mental health problems in a rural community in northern Wales (Williams & Healy, 2001), with the authors suggesting that 'exploratory maps' is a more accurate term for the meaning making process their participants engaged in. Exploratory maps capture the fluidity of this process of adopting flexible, multiple, and sometimes conflicting definitions (Williams & Healy, 2001).

Kleinman expanded upon his initial conceptualisation of explanatory models of illness in his 1988 oft-cited study of illness narratives (Kleinman, 1988b), in which he stressed the importance of eliciting subjective accounts of illness experiences and suggested how clinicians can do this in their encounters with patients. Illness narratives are essentially the stories that people tell of being ill. Research has demonstrated how these narratives are embedded in their socio-historical contexts and involve the active creation and recreation of meaning (Bury 2001; Frank, 2000; Hyden, 1997). The act of telling, and the intended

3.3.1 The relationship between meanings of illness and coping

Several studies on meanings of illness have sought to test the hypothesis that patients view illness as having one of the following eight meanings: challenge; enemy; punishment; weakness; relief; strategy; loss; and value; and that these meanings have associated coping strategies that are either positive or negative (Lupowski, 1970, as cited in Luker, Beaver, Leinster & Owens, 1996; Schüssler, 1992).   Results have indicated that 'illness concepts are interrelated and interconnected with each other' (Schüssler, 1992: 428); that both type and severity of disease are related to illness concepts, and that coping strategies

can be correlated with illness meanings (Luker et al, 1996; Schüssler, 1992). While challenge has been the most popular concept (Luker et al, 1996; Schüssler, 1992), the validity and usefulness of these illness concepts has been questioned (Luker et al, 1996). These studies do not give us a fulsome picture of the subjective illness experience, and for this reason more in-depth qualitative research, primarily ethnographic and phenomenological, has been undertaken in this area (Abrums, 2000; Aidoo & Harpham, 2001; Emami et al, 2000; Ezzy, 2000; Fox, Levkoff & Hinton, 1999; Hedelin & Strandmark, 2001; Hinton & Levkoff, 1999; Mathews, Lannin & Mitchell, 1994; Migliore, 2001; Nygård & Borell, 1998; Saris, 1995).

3.3.2 Culture and illness - mental and physical

There is an extensive literature supporting the belief that definitions of and responses to illness, whether physical or mental, are influenced by culture (Aderbigbe & Pandurangi, 1995; Dassori, Miller & Saldana, 1995; Desjarlais, 1992; Emami et al, 2000; Fox et al, 1999; Kirmayer & Young, 1998; Kleinman, 1980; 1988a; 1988b; Mechanic, 1968; Migliore, 2001; Patel, 1995; Patel et al, 1995a; 1995b; Pollack & Aponte, 2001; Pollitt, 1996; Weiss et al, 1995; White, 1992; Zborowski, 1981). In the case of dementia, it has been observed in older people in almost all populations and nearly all studies have found the most important causes to be Alzheimer's disease and cerebrovascular dementia (White, 1992). Despite the purported universality of this phenomenon, some researchers feel that dementia is 'basically a Western diagnostic category' (Pollitt, 1996: 2) and highlight the difficulties in determining its existence and meanings cross-culturally with the use of western tools and techniques. The

distinction between emic and etic approaches to cross–cultural psychiatric research (Patel, 1995a) corroborates this problematic in dementia research. The etic approach assumes that mental illness is universally similar and thus classification and measurement systems will apply globally, despite their western origin, while the emic approach:

> evaluates phenomena from within a culture and its context, aiming to understand its significance and relationship with other intra-cultural elements (Patel et al, 1995a: 486).

The process by which the dementia label is assigned to an individual and the creation of meaning in living with this particular illness is certainly influenced by socio-cultural and other factors, such as the diagnostic process and tools.

Little cross–cultural research on the meaning of dementia has been undertaken to date (Forbat, 2003; Smith, 1996), however knowledge gained from research into cultural definitions of mental health and chronic disease more generally may be transferable to dementia. For example, themes of coming to terms with the diagnosis, the importance of personal metaphors, and dealing with the medical model (Pollack & Aponte, 2001) that arose in research with younger ethnically diverse in-patients with bi-polar disorder in the United States may be applicable to dementia. Several authors have noted that people with dementia make extensive use of metaphors in their communications (Crisp, 1995; Killick & Allan, 2001) and the predominance of the medical model in dementia is well established (Binney & Swan, 1991; Bond, 1992; 2004; Fox, 1989; Harding & Palfrey, 1997; Herskovits, 1995; Holstein, 2000; Lyman, 1989; Robertson, 1990). The fact that the authors (Pollack & Aponte, 2001) discovered more similarities than differences when they analysed the responses by ethnic group

membership supports the importance of looking at other identity factors that affect one's social location. Finally, the finding of support for Kleinman's (1988a) belief that telling one's story has therapeutic value (Pollack & Aponte, 2001) links to favourable reactions by people with dementia to reminiscence programs (Murphy, 2002).

3.3.3 Spiritual/religious explanations of illness

The use of spiritual/religious explanations in illness narratives as observed above has been noted in several studies (Abrums, 2000; Fox et al, 1999; Goodman, 2001; Mathews et al, 1994; Patel, Musura, Butau, Maramba, & Fuyane, 1995). In an ethnographic study of the meanings of illness for poor and working class African American women (Abrums, 2000), the researcher found a connection between church members' belief systems and their meanings of health. The power these women felt over their own health and the health care system was driven by their belief that since doctors are only the instruments of God's will, they could remain in control and usurp the power of doctors through placing their faith in God (Abrums, 2000). Participant observation in a small Baptist missionary church solved anticipated access problems and meeting with these women in a site where they held more power than in a clinic or hospital enabled the collection of their life histories and observation of their socio-cultural context. In another study involving the illness narratives of Haredi male patients and their rabbis in Israel (Goodman, 2001), a connection between religious explanations and power is seen, however it did not favour the patients. Patients seeking to avoid a stigmatising label of mental illness by attributing their experiences to supernatural forces had their voices

silenced by their rabbis as they were seen to challenge established social orders and threaten the power of the rabbis to define experience (Goodman, 2001).

In a study of the illness narratives of ten caregivers of older African Americans with dementia (Fox et al, 1999), the authors sought to problematise the common depiction of African American caregivers as more religious than white caregivers and as drawing on prayer and the church for assistance. The findings showed that faith and the role of the church were rarely mentioned in the illness narratives of this sample of caregivers and that, when asked, the participants reported that the church was not an important source of support to them as caregivers (Fox et al, 1999). It appears that the influence and role of religious/spiritual beliefs and their interplay with power is not yet clear and thus warrants further investigation (see section 7.3.4). Although this was not addressed specifically through this research, I thought it could arise in the data, owing to Dreidger and Chappell's (1987: 46) claim that religion is a significant factor in any research on older people in Canada.

3.3.4 Folk narratives, power and discrimination

The application of the label 'folk narrative' appears to be related to the degree to which the account diverges from biomedical conceptions of disease and integrates religious/spiritual explanations of illness. Several studies have problematised folk or lay narratives and endeavoured to situate them within structures of power and domination (Abrums, 2000; Goodman, 2001; Saris, 1995) to contextualise meaning making in illness. Both the study by Abrums

(2000) and the one by Goodman (2001) highlight the role and influence of power in not only the creation of meaning but in the legitimisation of meaning. In his analysis of the illness narrative of an Irish man with schizophrenia, Saris (1995) proposes that:

> a narrative of a chronic condition is not simply a story of personal experience [but] rather, deeply embedded within various institutional structures that influence its production as a story (1995: 39).

Hinton and Levkoff (1999) conducted a qualitative study into illness narratives and ethnic identity with African-American, Chinese-American, Irish-American and Latino caregivers in the United States and found that caregivers drew on both biomedical and cultural understandings of dementia in their creation of stories and that while these stories did differ across and within ethnic groups, all evidenced moral concerns. In the same study (Fox et al, 1999), it was found that African-American narratives offered a view into the individual impact of large-scale social forces like racism and class oppression and demonstrated a connection between these forces and meaning making regarding family members' dementia.

Phenomenological studies demonstrate an intensive interest in interpreting individual experiences of illness within particular social contexts, yet tend to ignore social structures and relations of domination and subordination and rarely problematise identity concepts such as gender, age, class, ethnicity and/or 'race'. The studies mentioned above are notable exceptions and demonstrate the importance of an approach that explicitly looks at power and discrimination and seeks to make evident oppressive practices so as to facilitate their dismantling. The role and influence of one's standpoint in

shaping all or parts of the research process such as question formulation, data collection, analysis and presentation of findings is highlighted by Saris (1995) as he comments on how the study that he undertook could have provided support for bio-medical understandings of mental disorders had it been approached from a different perspective.

3.4 Applicability to dementia and future directions

From the few empirical studies of identity and oppression reviewed in the first section of this chapter, there appears to be support for the concept of intersectionality, a view of subjectivity as fluid, multiple and contingent and oppressed people as active agents, resisting oppression. Although the results of these studies are grounded in the voices and experiences of oppressed persons, the participants were mostly politically engaged and well educated people (Mama, 1995a; Sudbury, 2001). This was not the case in this study of dementia and intersectionality, as not only is self-organising and advocacy a recent phenomenon among people with dementia (Friedell & Bryden, 2002; McKillop, 2002; Robinson, 2002) but there also is a higher incidence of dementia in people with lower education levels (Lindsay, Laurin, Verreault, Hébert, Helliwell, Hill et al, 2001) and I worked with people with varying levels of education and political fluency.

Cohen (2000) in the United States and McGolgan (2001) in Scotland both used the term liminality to describe the curious positionality of people with dementia, whom Cohen (2000: 1) claimed are 'standing at an increasingly critical margin between two kinds of life'. His articulation of a 'life-on-the-border' (ibid)

existence for people with dementia is reminiscent of feminist theorising (Anzaldua, 2001; hooks, 2000) and evokes the sentiment of the concept of Diasporas that was (re)discovered and imbued with additional theoretical significance by Cultural Studies scholars (Gilroy, 1997; Hall, 1997). As noted, this concept of liminality was used in dementia prior to Cohen (2000) and McGolgan (2001) by Davis (1989) in his personal account of Alzheimer's Disease, in which he refers to himself as 'being partly there'.

Perhaps the way forward is indicated by a Scottish study that found evidence of the dialectical nature of power and oppression, while providing an account of life on the margins (Smith, 1993), in this case people living in the Borders community of rural Scotland. Smith concluded her analysis of a marginalised community's annual week-long festival with the observation that:

> oppressors can also be oppressed and the marginal also marginalise, to the extent that it is no longer possible or appropriate to think of 'the' dominant group or culture, or to oppose 'the' core to 'the' periphery (1993: 304).

This is the approach that Jenkins (2002) advocated for the study of identity, although he termed it 'the simultaneity of difference and sameness'. This review of the literature on identity and oppression, while it may not have enriched dementia scholarship specifically, points to the importance of social location, and the need for awareness of our relative positions on the multiple axes of oppression and privilege. Observations of the everyday dialectics of power and oppression (Charlton, 1998; Essed, 1991; Smith, 1987), such as I non-purposively undertook in my student flat, can breathe life into these dynamic and relational concepts.

Through a review of the literature on health, illness and disability cross-culturally, it has been shown that conceptions of illness show similarities and differences across and within cultures. Explanatory models of Illness as conceived by Kleinman (1980) and later reconceptualised as exploratory maps by Williams and Healy (2001), the concept of illness narratives in its original form (Kleinman, 1988a), and definitions of health that are holistic and incorporate the concepts of balance, continuity, agency, and confirmation have been shown to be important to the study of meanings of health, illness and disability for older people. An explicit gender analysis is lacking in much of the literature reviewed, despite the fact that several of the studies looked either at women (Abrums, 2000; Hedelin & Strandmark, 2001; Luker et al, 1996) or at men (Goodman, 2001; Saris, 1995) in isolation. The idea that meanings of health, illness and disability vary by gender group membership, in spite of shared cultural affiliations, is clearly missing in these studies which essentially treat gender as a variable and nothing more (Calasanti & Slevin, 2001). Several themes that are evident in the literature have been reviewed: the relationship between meanings of illness and coping; culture and illness (mental and physical); spiritual/religious explanations of illness; folk narratives, power and discrimination; and the limitations of phenomenology.

It appears that illness narratives should be critically analysed with an eye to both the temporal and the socio-cultural context in which the teller lives and in which the tale is told. Further, in order to elucidate the impact of interlocking oppressions on individual experiences of illness, it is important to begin from a critical social science perspective and to employ a methodology that seeks to

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link individual (micro) and community (meso) experiences to social structures (macro). Through doing so, the connection may be made between subjective meaning making in illness and social forces that may support or impede the lives of people with dementia.

Chapter - 4   Subjective Experiences of Dementia

4.1 Experiences of dementia

The movement to hear the voices of people with dementia started with a few pioneers who called attention to the overemphasis in dementia research on caregiver coping, stress, and burden and the need to examine what people with dementia experience themselves (Cotrell & Schulz, 1993; Cotrell & Lein, 1993; Froggatt, 1988; Lyman, 1989; Robertson, 1990).   This probably was not a revelation for a number of people working directly with individuals with dementia who had come to realise experientially that:

> perhaps the PDWADs [persons diagnosed with Alzheimer's disease] themselves...have something to tell us about what it means to be human in the face of such dissolution, if we but ask and listen (Robertson, 1990: 436).

Nevertheless, a movement was born that sought to understand the subjective experiences of people with dementia, through eliciting their perspectives and observing their social interactions. Resulting research has covered biomedical concerns of diagnosis, symptoms and treatment; the psychological arena of cognitive change and its impact on performance, affective states, loss and coping mechanisms; anthropological investigations into cross-cultural definitions of and attitudes towards dementia; and sociological questions about the nature of being in the world and the influence of structural factors and institutions such as work, the family, the state and 'the ageing enterprise' (Estes, 1979). These sociological questions are perhaps the least researched, as addressing the psycho-social needs of people with dementia and their

caregivers has taken precedence for social workers and others who might have been inclined to explore these larger issues.

These pioneering researchers acknowledged that their proposed line of inquiry would be fraught with difficulties, primarily in terms of methodology (see Chapter 5). In addition, the assumption that people with dementia are not 'reliable historians' or 'credible witnesses', even about/to their own lives, was omnipresent (Wilkinson, 2002b). This was part of the culture of dementia care at the time and thus was accepted as the norm, until Kitwood and Benson (1995) enumerated the limitations of this approach and described an alternative vision. This focus on the impossibility of research with people with dementia rather than on or about them flowed from the judgement that we cannot learn anything from people with dementia because they are unable to phrase their answers in a way that we can understand and/or that would be considered legitimate by the research community. This dismissal was inconsistent with growing evidence to support the refutation of similar arguments that had been applied to 'almost every oppressed and disempowered group in society' (Proctor, 2001), examples being people with disabilities and children. A direct link seems to be made between cognition and validity in a demonstration of what has been aptly termed 'cognitive superiority' (Shepphard, 1991, as cited in Harding & Palfrey, 1997: 42). Although used by Shepphard (1991) to refer to the exclusive control of experts over the diagnosing (defining) of dementia, cognitive superiority translates to the belief that if someone's cognitive capacities are impaired, anything they tell us should be viewed as suspect. Moreover, emotional responses are not seen to carry as much weight as

cognitive responses, if any at all, which greatly impacts upon people who communicate primarily through non-verbal means, such as those with advanced dementia. This attitude of cognitive superiority effectively means that a person with dementia does not have the power or authority to define his/her own experience. Maybe the unspoken problem is that asking people with dementia about their experiences might lead us to question and potentially re-evaluate our definitions of normalcy and abnormality and leave us with an uncomfortable doubt in our own cognitive superiority. It is within this context that we can understand this move to hear the voices of people with dementia and the composition of the group of individuals we have heard from to date.

4.1.1 Knowledge sources

The literature I reviewed took the form of personal accounts (Boden, 1998; Davis, 1989; Friel McGowin, 1993; Henderson, 1998; Rose, 1996), narratives produced with the involvement of a supportive other (Killick & Cordonnier, 2000; Living Archive Project, 2001; McKinlay, 1998; Snyder, 1999; Zabbia Howes, 1996), qualitative research studies (Chatterji, 1998; Cheston, 1996; Cohen, 1998; Cotrell and Lein, 1993; Froggatt, 1988; Gillies, 2001; Keady et al, 1995; Labarge, VonDras & Wingbermuehle, 1998; Leibing, 1997; Lyman, 1998; Mills, 1997; Phinney, 1998; Proctor, 2001; Sabat, 2001; Sinason, 1992; Snyder, 2001; Sutton, 1994; Vittoria, 1998) and stories posted on Web sites or available in hard copy for the purpose of raising public awareness (Alzheimer Society of Toronto, 2000; Ashley, 2001; Booth, 2001; Pauline & Mica, 1996; Shelia, 2000). Past research into subjective experiences of dementia has employed various methodological approaches, such as ethnographies, case studies, clinical

observations, participant observations, focus groups, and semi-structured and structured interviews; has taken the person with dementia and/or their caregivers/family members as the primary subject(s); and has occurred in a number of different field settings, for example, care facilities, homes of people with dementia, neighbourhoods, hospitals, and adult day programs.

At the start of doctoral studies, I conducted a critical review of this body of literature (personal accounts, narratives produced with the involvement of a supportive other, qualitative research studies, and stories posted on internet sites), the results of which are to be found in Appendix A. I looked at who was telling these stories of dementia, what these stories told us, whose voices were still silent/silenced, and how untold experiences might differ.

4.1.2 Who is telling these stories of dementia

Although there has been exponential growth in work of this nature and thus many sources now exist, some troubling generalisations can be made regarding the voices that we are hearing: younger people in their forties to sixties who are well-educated, white, married, professionals, with strong religious or ideological beliefs and supportive families, who would be classified as early stage[8] in terms of their disease progression. These are generalisations and as such will not be applicable to all sources cited nor to all narratives produced by or with the involvement of individuals with dementia. The explanatory purpose of grouping this set of characteristics is to evoke a

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[8] Downs (1997), in a cogent review of the emerging trend in dementia research of looking at the person with the disease, notes that the emphasis has been on people in the early stages of dementia.

sense of the dominant voices that have captured the public consciousness and thus have come to speak for a marginalised group of people with varied experiences as a whole and intersecting identities as individuals. A promising exception is the book by Snyder called *Speaking Our Minds: Personal Reflections from Individuals with Alzheimer's* (1999). For her exploration of the subjective experience of Alzheimer's disease, Snyder had 'deliberately chosen people of different ages, ethnicities, and educational and professional backgrounds' (1999: viii) and these biographical details came through in the narratives.

It is apparent, however, that the seven people whose lives were showcased in the book were not asked in the taped, in-home interviews, whether and in what way these controlled-for identity constructs shaped their experiences of dementia. The influence of strong religious and/or ideological beliefs was evident in all but one of the narratives and may be a consequence of the author's decision to pursue this specific line of questioning (Snyder, 1999: viii). The role of religious beliefs will be returned to in a later section of this paper, as this is a recurrent theme in many of the personal accounts published to date.

4.1.3 What these stories tell us about identities - problematised and intersecting

I looked at Snyder's (1999) collection of experiences of dementia in depth for two reasons: (1) it was groundbreaking in that the author set out to hear voices of people with dementia, diversified her sample in terms of age, ethnicity, educational and professional background, and published the results in a format that was accessible to the public; and (2) the narratives indicated the influence

of gender, age, and class on the interviewees' experiences of dementia *despite* the author's inattention to this - she did not ask about this according to her notes (Snyder, 1999: viii) and did not analyse its appearance in the narratives either in this journalistic tale or in an academic piece based on the same research (Snyder, 2001). Given Snyder's noted attention to identity constructs in the selection of her sample, it is logical to presume that these accounts have the most likelihood of furthering our understanding of dementia and intersectionality. As the excerpts indicate, gender, age and class may be important to these individuals in terms of how they make meaning out of their experiences of dementia. Moreover, ethnicity may factor in as well, although its role and influence were invisible in the narratives presented in the book. The information given does not give us a complete picture, but it does raise the possibility that identity categories do shape individual experiences of dementia in an intersecting fashion. There are indications in the words of Snyder's (1999) interviewees that they may conceptualise their experiences in terms of identity categories, age being the most pronounced, with gender and class evident as well, and in an intertwined fashion. Specific examples arising from this detailed analysis can be found in Appendix A.

4.1.3.1 Religion

The first published personal account of living with dementia was written by an American evangelical priest named Robert Davis (1989) and could be said to have shaped the way that subsequent true stories of dementia have been framed and interpreted. For example, Davis' use of the word journey to describe his experience of dementia was repeated in several accounts that

followed (Crisp, 1995; Friel McGowin, 1993; MacKinlay, 1998;); it figured prominently in the title - *Each Person's Journey is Unique* - of an article in which a number of these insiders' tales of dementia were reviewed (Laurenhue, 2001); and Keady et al (1995) found from their in-home interviews with six people in the early stages of dementia that this was an apt description of the experience, adding that it was a journey largely into the unknown. A related theme of spiritual redemption and acceptance of God's will is echoed in many of the stories of dementia that followed Davis' account (Bailey & Darling, 2001; Brennan, 1995; Cheston, 1996; Friel McGowin, 1993; Living Archive Project, 2001; MacKinlay, 1998; Phinney, 1998; Snyder, 1999; Zabbia Howes, 1996) although none of these views of people with dementia demonstrated quite the same degree of fervency as Davis (1989). Examples from this analysis can be found in Appendix A.

4.1.3.1 Whose voices are still silent/silenced?

I found through this review that we have not heard from traditionally marginalised groups of people such as minority ethnic and racialised people, lesbians/gays/ bisexuals, poor people, and uneducated people (Hulko, 2002). The influence of 'race' and ethnicity on subjective experiences of dementia is a relatively unexplored domain (Bowes & Wilkinson, 2002b) although interest in 'race' and ethnicity has been growing in the areas of risk and prevalence, assessment, service provision and care giving (Anderson & Brownlie, 1997; Innes, 2003; Patel et al, 1998; Yeo & Gallagher-Thompson, 1996). Snyder (1999) identified ethnicity as one of the bases upon which she diversified her

sample; however, it seems that she used ethnicity as a polite word for 'race'[9]. We were given hints through the author's narrative about the 'racial' background of two of the respondents in a way that asked the reader to integrate their assumptions into the text and no clues were given as to the 'ethnicity' of the five other people with dementia that were profiled, leaving us to assume that they were all white and not members of any ethnic minority groups (see Appendix A). The other research studies covered in this review reported on factors such as gender, age, diagnosis, marital and family status, past occupation, and sometimes faith in terms of the composition of the samples. The lack of information on 'race', ethnicity, sexual orientation, and abilities leads one to assume firstly, that the participants were all white able-bodied heterosexuals from the majority ethnic community and secondly, that this information was not relevant for understanding subjective experiences. Further, if the information was given at all, it was reported in a descriptive fashion; these identity constructs were not seen as worthy of investigation either holistically or separately. We will not know whether and in what way an individual's unique and intersecting identity shapes their experience of dementia until we include these sorts of questions in our research design and ask them directly of the people whose lives we are studying.

4.1.4 How experiences might differ – 'striving for normalcy'

Another theme that ran through the literature and that was relevant to this research on dementia and intersectionality was that of striving to be normal, normal usually taken to mean 'pre-morbid' or 'without dementia'. Comparing

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[9] See Oommen (1994) for an insightful critique of the practice of conflating race and ethnicity.

oneself to others in terms of normalcy and striving for normal status was prevalent in personal accounts of living with dementia and could reflect motivations for publicising one's private troubles - yes to make it a public issue (Wright Mills, 2001), but also to normalise the experience, to hold onto the status of oneself as a normal human being.   Normal, but different - this sentiment echoes the voices of disability and mental health activists (Morris, 1991; 1996; Oliver, 1990; 1996; Sayce, 2000).   This theme of striving for normalcy is important to dementia and intersectionality for the simple reason that for marginalised peoples - older people, women, ethnic and 'racial' minorities, poor people, lesbians/gays/bisexuals, disabled people, people with mental health problems - striving for normalcy is the stuff of daily life.   It is *extra*ordinary for most oppressed people to be seen and treated as normal, to have a powerful voice, to be part of the dominant discourse, to be seen to have legitimate knowledge claims. Further, some marginalised people reject societal definitions of normalcy or embrace their so-called abnormality as something of which they are proud, disabled activists being the prime example of this. With this understanding of the variability of definitions of normal and the connection to experiences of marginalization, the importance of locating this type of research within an analytical framework of intersectionality/interlocking oppressions and of making links across experiences of oppression should be clear.

4.2   Identity factors and dementia

I identified class, gender, 'race', and ethnicity as the specific identity constructs to focus on in this thesis and as I was interested in the interactions, I did not

intend to separate these for analysis. However, I found two things in reviewing the literature on subjective experiences of dementia that prevented me from presenting the findings in an intersecting way. First, it was difficult to locate relevant work on 'race' and ethnicity and second, gender and class seemed to be intertwined with one another especially. This section will present definitions of these terms (see Appendix B) and the findings of this review.

4.2.1 'Race' and ethnicity

There is a recognised gap in our knowledge of the relationship between 'race' and/or ethnicity and dementia, yet little research has been undertaken to close this gap, and that which has does not add to our understanding of the lived experiences of people with dementia. Research in this area has been primarily concerned with: risk, incidence and prevalence of dementia by 'racial' groups; challenges in diagnosis and assessment in a multi-cultural context; provision of services to minority ethnic and 'racial' people with dementia and their caregivers; care giving amongst minority ethnic and 'racial' groups; and the meanings of dementia for different 'racial'/ethnic groups. Several reviews have been written (Anderson & Brownlie, 1997; Daker-White, Beattie, Gilliard & Means, 2002; Herbert, 2001; Smith, 1996; Yeo & Gallagher-Thompson, 1996.) detailing the state of knowledge in this area and pointing to the need for further research. In addition, there have been calls to address the ethnic/'racial' dimensions of dementia within reviews of the socio-cultural context and subjective meanings of dementia (Downs, 2000; Disman, 1991; UBC Dementia Research Collaborative Working Group, 2000). For example, the UBC Dementia Research Collaborative Working Group (2000) highlighted the

neglect in research of the 'wider socio-environmental and cultural matrix' (p 11) and exclusion of people who do not speak one of the official languages in large scale epidemiological studies such as the Canadian Study of Health and Aging.

Another issue that has been addressed in this body of literature is terminology and the difficulty in using Western concepts such as dementia, which do not exist in many languages (Bowes & Wilkinson, 2002; 2004; Forbat, 2003; Innes, 2003; Yeo & Gallagher-Thompson, 1996). The term 'memory problems' is thought to be a workable alternative (Bowes & Wilkinson, 2002; Forbat, 2003; Gillies, 2000), as it might carry more significance for minority ethnic and non-native English speakers than the term dementia and might avoid some of the stigma associated with madness, which it the closest translation of dementia in several South Asian languages (Bowes & Wilkinson, 2002). The issue of terminology is addressed in depth in chapters 5 and 6.

4.2.2 Class and gender

The aim of this section of the thesis is to critically review literature that pertains to dementia, gender, and class. I had expected to find a large volume of work pertaining to this topic, yet found this to be a relatively under-researched area, with insights being offered by the parallel literature. Further, I had anticipated finding more sources on gender and dementia than on class and dementia and was wrong about this, as the large number of studies on education and cognitive impairment fall within the area of class and dementia. What follows is a short review of dementia, class, and gender; education and cognitive (dys)function; mental health, class, and gender; gendered identities and roles;

and dementia and related issues of sexual orientation, rurality and literacy. I will start with a few definitions, prior to delving into the aforementioned review.

Class is understood and operationalised in several different ways, more often than not as occupation, education, income, wealth/assets, or a combination of these variables. Less common is the approach proposed by E.P. Thompson (1968) in his classic treatise on the English working class of basing class on a subjective evaluation of one's location in the social world. Bourdieu's concept of social capital is important to understanding social class as well as it points to the networks and cultural resources that members of the middle and upper classes benefit from whether they retain their status or slip down a few notches. This research drew on both Thompson's notion of class and Bourdieu's concept of social capital (Bourdieu, 1986) in that the social class of participants was determined by taking into consideration each of the participant's self-positioning as well as my knowledge of their educational and employment backgrounds, current income and assets, and social networks. This assessment was complicated by factors such as 'presentation of self' (Goffman, 1959), disorientation to time and place, as well as the fact that 'nowadays it is fashionable to talk about race or gender; the uncool subject is class' (hooks, 2000b: vii).

Perhaps it is because class is an 'aggregative collectivity' and thought to be a fluid concept (Oommen, 1994), particularly for all those who fervently believe in the American dream, that it appears to defy discussion and elucidation. While class is said to intersect with race, ethnicity and gender and the (class) divisions between the rich and the poor can be seen to be racialised and

gendered, rarely are these socio-cultural factors interrogated conjointly in a way that illuminates the social structures that underpin privilege and oppression and that does not fall prey to class reductionism (Bannerji, 1995b). Undeniably, 'class is still often kept separate from race' (hooks, 2000b: 8) and is not interrogated as holistically as gender or ethnicity or race (Ahmad, 1993). Although most epidemiological studies of dementia have not looked explicitly at social class, there is a UK exception in a survey that grouped respondents by British social class categories (based on occupation). The authors (Lindesay et al, 1989 as cited in Cheston & Bender, 1999) found a correlation between prevalence of dementia and social class membership with upper classes (I/II) at 0%, the middle classes (III non-manual and III manual) at 1.3% and 4% respectively and the lower classes (IV/V) at 7.3%. This apparent correlation between dementia and social class will be addressed in more detail in the following section and in relation to the findings presented in chapter 7.

As has been noted, the socio-cultural context of dementia has been largely neglected in dementia research to date (Downs, 2000), with the exception of epidemiological studies that document risk, incidence and prevalence by variables such as 'race'/ethnicity, education, gender and age. The tendency to view older people as a homogeneous group results in a lack of attention to factors such as age, gender, class and ethnicity that are widely acknowledged to differentiate people below the age of 65 years (Victor, 1991). This trend is even more pronounced in the field of dementia where the need to acknowledge that people living with dementia are indeed *people* was, and is still, paramount (Kitwood, 1990; 1997; Kitwood & Bredin, 1990). The belief in the passivity of

people with dementia unfortunately is still apparent in dementia care and research today (Wilkinson, 2002b).

In a qualitative exploratory study, Proctor (2001) looked at gender and power in relation to the service experiences of four older women with dementia in a day hospital. As mentioned previously, this study was unique in its focus on gender and dementia, specifically power dynamics, and in the application of this emphasis to the research process itself: the method of data analysis employed was developed specifically to uncover the voices and experiences of disempowered individuals (Brown & Gilligan, 1992, as cited in Proctor, 2001). The main themes arising from the interviews related to relationships and power - power in the research relationship and power in 'othering' relationships, mainly with health care professionals. The author followed the tradition in feminist research of focusing on women, although many researchers now believe that a gender analysis necessitates looking at both parties in the binary: women and men (Calasanti & Slevin, 2001).

Although it is the role of gender that is under investigation in Proctor's (2001) study, the influence of class can be found in the words of the older women as well. This intertwining of gender and class is evident in Leibing's (1997) study of the illness narratives (Kleinman, 1988a) of 52 caregivers of Alzheimer patients. Respondents believed that, in addition to genetic factors, the ill person's biography and personality played a role in their current status as Alzheimer patients: stress, loss and a hard life were thought to bring on the disease. The findings indicate that the social context is important to subjective explanations of dementia and that the caregivers' responses could be

perceived as 'a wider societal way of coping in a world which does not seem to have space for everybody' (Leibing, 1997: 236). It is possible that gender played a role with adherence to strict gender roles being observed in the sample - the women were mostly housewives and the men were primarily in the military - and the women with dementia more likely to be described as 'happy personality types'. The role and influence of gender is not clear however, as the explanations as to cause of the disease did not vary by gender.

Cohen (1995) found differences in perceptions and explanations of behavioural and personality changes in old age by the gender and class of the older person in question, but not by the respondent, although this was not the case for all conceptualisations of aberrant behaviour. This ethnographic research was undertaken in Banaras, a city in India with a high concentration of older people and pronounced stratification by social class. Cohen (1995) found that 'old voices in Banaras are heard primarily as extremes of power or abjection' and:

> to be listened to effectively, one must ensure that one's voice is
> heard as powerful and not abject; yet for women, powerful voices
> risk becoming curses (p 323).

The disease label functioned to 'isolate the body of the old person and deny her subjectivity' (Cohen, 1995: 331), rather than to improve familial relations and maintain the older person's role in the family (ibid).

Several studies have documented the higher prevalence of dementia among women than among men (White, 1992) and have pointed out that women and men are disproportionately represented within sub-types of dementia (CSHA Working Group, 1994). An analysis of prospective data from the second phase

of the Canadian Study of Health and Aging (Lindsay et al, 2001) revealed, however, that gender was not a risk factor for dementia as had been previously discovered through the analysis of retrospective data gathered in the first phase of the study (CSHA Working Group, 1994). An Irish study (Swanwick, Coen, Maguire, Kirby, Walsh, O'Neill et al, 1999) found an association between the gender of patients and the duration of symptoms, with women having a longer duration of symptoms at presentation. Although the authors did not come to this conclusion, it may be that adherence to stereotyped gender roles resulted in the earlier recognition of men's cognitive impairment (Cottrell & Lein, 1993). For example, dementia may interfere with performance of work roles for men while women who perform traditionally female roles such as homemaking may find their cognitive impairments are less noticeable or easier to mask. Women may also normalise the experience more than men as something to be expected of 'dotty old women' and for which nothing can be done, so there's no sense complaining about it. Referring to the tendency of older women to endure more problems and disabilities at home on their own than men, Hughes and Mtezuka (1992) suggested that:

> after a lifetime of socially-constructed dependency of all forms, older women themselves have low expectations and easily accept the consequences of disability...They may have also learned that they have to simply get on and make the best of things (p 226).

This concept of resilience and its relationship to experiences of dementia will be addressed in detail in chapters 7 and 8.

Regardless of who is at more risk for dementia, there are still more women than men living with dementia owing to the longer life expectancy of women which has resulted in 'the feminisation of the elderly' (Ginn & Arber, 1995). Allan

(2000) suggested that the stigma of dementia, combined with the 'double jeopardy suffered by older women' (p 448) and the marginalisation of their experiences are all reasons for the lack of focus on women living with dementia.

Several theories have been put forth to explain the connection between education and cognitive function: (1) brain reserve capacity, built through a rich environment in one's early years; (2) mental stimulation throughout the life course, with education leading to more mentally stimulating occupations that preserve cognitive function; and (3) a false association due to differential test-taking abilities or cultural biases in the assessment procedures (Cagney & Lauderdale, 2002). All three theories have been supported in dementia research to date (Cagney & Lauderdale, 2002; Gatz, Svedberg, Pedersen, Mortimer, Berg & Johansson, 2001; Turrell, Lynch, Kaplan, Everson, Helkala, Kauhanen et al, 2002). The third theory is associated with the heavy criticisms of the Mini Mental State Examination (Folstein, Folstein & McHugh, 1975) and its use as a screening tool (Yeo & Gallagher, 1996), as it has been shown to result in false positives for people with advanced age, limited education, illiteracy and lower socio-economic status (Jagger, Clarke, Anderson & Battcock, 1992; Keefover, Rankin, Keyl, Wells, Martin & Shaw, 1996). Efforts are underway to develop assessment tools that take factors such as literacy, education, language and ethnicity into consideration (Yeo & Gallagher-Thompson, 1996).

A great deal of literature has accumulated on gender, class and mental health since Chesler's (1989) groundbreaking work on women and madness was

published in 1972 and since Browne and Harris (1978) identified the social origins of depression in 1978. Browne and Harris (1978) developed a causal model of vulnerability factors and provoking agents and found working class women with children to be those women most at risk for depression. The authors dispelled the notion that origin is destiny and showed that social factors are important in influencing the onset and course of depression. Social causation and social construction are the main arguments put forth by feminist researchers (Busfield, 1996) for the differential rates of mental disorder in men and women. There is now an emphasis on men's and women's 'madness' and 'badness' and a recognition that while the mental health system is harmful/oppressive to both men and women, there are important distinctions in terms of labelling and treatment of mental disorder by class, 'race', ethnicity, sexual orientation, and age as well (Busfield, 1996; Prior, 1999). Evidence shows that not only are men overtaking women in terms of rates of mental disorder, but they also number higher in terms of those in mental health institutions in the UK (Prior & Hayes, 2001). The change in rates of mental disorder can be linked to the social construction argument as substance abuse and personality disorders, which men are more likely to experience than women, are now included in classifications of mental disorder and thus more mentally disordered men are captured in the official statistics. There are now two main sub-populations in mental health facilities in the UK: women over retirement age and men of working age (Prior & Hayes, 2001) and this has important implications for the design and delivery of services.

Gender tends to be thought of as a fixed socio-demographic variable that does not change throughout time and/or space for any one individual. In actual fact, gender may be more fluid than class - the supposedly dynamic construct - as it has been stated that gender relations can not be assumed to be static over the life course (Ginn & Arber, 1995). Gender has been said to vary spatially, temporally and longitudinally, yet somehow older men seem to lose their gender and there is little research on older men's lives (Thompson, 1994). The fluidity of masculinities is acknowledged, with authors noting that 'they change over time, over space, and, not least, during the lives of men themselves' (Whitehead & Barrett, 2001: 8).

Indeed, researchers have begun to look at gender relations and gender roles in chronic illness/disability and in later life to ascertain the extent to which gender is fixed or transmutable (Charmaz, 1997; Girdham, 2002; Wilson, 1995). Girdham (2002) and Wilson (1995) both found that gender roles 'had become less distinct and had mellowed' (Girdham, 2002: 8) with disability and old age with the result that 'stereotypical gender roles are altered and reduced' (Wilson, 1995: 113). Women were seen to have more choices as to how to express their identities as women and greater role flexibility in advanced old age than men (Girdham, 2002; Wilson, 1995). Both men and women did however experience constraints on changes in their gender roles, owing to ill health and family interference, as well as the persistence of societal constraints on gender roles (Wilson, 1995). Ginn and Arber (1995) put forth the idea that ageing is potentially liberating for women and men with regards to gender roles and the studies cited above appear to provide some support for this view.

One of the findings of Charmaz's (1997) research on the identity dilemmas of chronically ill men was that the men devoted much effort to the preservation of self in order to maintain continuity, and women generally 'showed more resilience and resourcefulness than men in preserving aspects of self' (p 51), *except* for those women with cognitive impairments [emphasis mine]. Men benefited from the identity maintenance work that their wives did on their behalf, yet women were not similarly aided, as they were less likely to have a spouse than the men (Charmaz, 1997). This has implications for older people with dementia who are more likely to be women, and by virtue of their age, more likely to be unmarried (Brotman, 1998). Who will shore up the identities of older women with dementia if this is what is wanted and will those who want to change their identities be allowed to? Research by Perry and O'Connor (2002) indicated preliminary support for the idea of gendered strategies for preserving the personhood of a spouse with dementia, which the authors noted warrants further research. As well, Barer (1994) stressed that:

> male roles throughout life place a premium on competency, activity, productivity, independence, and self-reliance, all characteristics that are difficult to sustain with the increased disability that occurs in late-late life (p 30-31).

As it is thought that men and women are likely to differ in their adaptation to continuities and discontinuities (Charmaz, 1997), it is likely that gender differences may exist in responses to dementia by the person who has it and the person charged with their identity maintenance or 'structuring and destructuring the course of illness' (Gubrium, 1987).

Calasanti and Slevin (2001) suggested that a gender lens is needed in gerontology to uncover the process by which men and women are gendered

and the manner in which gender functions as a societal organising principle. This gender lens would focus on the intersections of old age with gender and other factors such as race, ethnicity, class, and sexual orientation and the resulting disadvantages and advantages experienced by older people, their strengths, and their acts of resistance. The themes of resistance and conformity has arisen in life history interviews with older women (Ingrisch, 1995) and make clear the links between the micro level of older women's experiences and the macro level of the social structures that shape and constrain those experiences (Bernard & Meade, 1993). Older women's agency is highlighted in Mathews' (1979) study of the social worlds of old women in which the women were clearly shown to employ strategies to avoid the label of 'old woman' in order to preserve their self-identities. We have a lot to learn from older people about their self-identities, as indicated by Mathew's (1979) commentary:

> ...death and the dying process are not seen as the end of the self,
> but as situations requiring careful planning to maintain the person
> that the old woman *sees herself to be (*p 149, emphasis added).

A sociology of masculinity (Whitehead & Barrett, 2001) emerged to critically address the other half of the gender binary that was overlooked by feminist researchers more interested in uncovering the voices and experiences of women. This conscious neglect may have bolstered the reified status of man who grew to become 'the invisible gendered subject' (Whitehead, 2001). Sociologists of masculinity believe that it is important for men to recognise that, like women, they too have a gender and to see it as shaping their experiences, as it does for women. While Whitehead (2001) highlights the importance of interrogating dominance as well as subordination - asking what is it like to be a

man - the male education managers in his study were unable to answer a seemingly simple question about how their subjective perception of their own gendered identity. They had never reflected on themselves as men and thus 'any critical understanding of themselves as 'men' was beyond them' (p 362). This was in marked contrast to the women interviewed, therefore, Whitehead (2001) concluded that the findings support the belief that 'women's marginalisation does provide 'epistemic privilege' informed by strong reflexivity' (p 363), an argument made by Calasanti (1996), with respect to the vantage-point of the oppressed (Du Bois, 1953).

4.2.3 Other identity factors - sexual orientation, rurality, literacy

There are several other aspects of a person's identity or social location that have not been investigated in any depth in dementia research. A few are related to gender and class: sexual orientation, rurality, and literacy. The first of these neglected dimensions upon which older people also differ is overlooked in dementia care where 'the views and experiences of lesbians and gay men are largely unrecognised' (Ward, 2000: 24).

An exploratory study (Ward, 2000) found that many of the older lesbian and gay respondents 'felt isolated and vulnerable' (p 25) and were fearful of accessing mainstream services where they might encounter homophobia and/or have to hide an important component of their self-identity. Making explicit the connection between sexual orientation and self-identity, one man described his fears thus 'it's just the thought of losing me really' (Ward, 2000: 24), a quote

reminiscent of the words of people with dementia thinking ahead to the future (Keady, Nolan & Gilliard, 1995).

Another issue that does not seem to have been adequately addressed is geography, in terms of rural and urban differences. This is a particularly salient issue for Canada (Havens, 2002) with its numerous rural and remote/isolated communities. Further, Keefover et al (1996) found that certain types of dementia may be more common in rural areas; care giving may be more demanding for rural families; and current screening tools may misclassify rural people as having dementia. The authors explained the latter point by virtue of the greater number of people with limited education, illiteracy, and lower socio-economic status in rural communities - all factors that have been shown to affect performance on widely used screening tools (Keefover et al, 1996). Literacy, as distinct from educational attainment, is another important domain for investigation, as Baker et al (2000) found that functional health literacy was negatively associated with age and cognitive function, as measured by the MMSE (Folstein et al, 1995).

4.3 Conclusions

As has been argued, most of the literature that address 'race', ethnicity, and dementia is not relevant to this thesis as there has been very little attention paid to the subjective experiences of minority ethnic and racialised people with dementia. There has been ample attention paid to socio-economic status in research on dementia and there are indications that class might be the unspoken, yet most salient, variable in dementia research. In addition, the work

of the broader field of social and economic determinants of health may eventually cross over to directly impact on dementia research.

Gender relations may be an extremely important variable as well, in terms of how people experience dementia in relation to their life long gendered patterns of behaviour, and the support that is available to either maintain or alter their gender roles in later life, and in the context of dementia. In the absence of knowledge of the individual and his/her unique background and identity, dementia care has tended to reproduce gendered patterns of behaviour through stereotypically gendered activities (Hulko, 1997). Person-centred care, with its call for maintenance of personhood and continuity of identity (Kitwood, 1997a) may lock older people, especially older women, into rigid gender roles, which may be contrary to their wishes at that stage in life. Approaching age 65 years at the time, Sarton (1997) wrote that 'in old age we have greater freedom than ever before to be our true selves' (p 231) and observed that her friends 'seem to become more and more themselves, rather than less so' (p 230) as they grow older. She herself looked forward to this 'growing into another dimension' (Sarton, 1997). The challenge is to ascertain how people with dementia feel about their gendered and classed identities and their gendered and classed relations with others, without structuring their experiences based on the expectations, assumptions or wishes of others with more agency and power.

Through a review of the literature on subjective experiences of dementia, and dementia and 'race', ethnicity, class, and gender, it has been shown that identity as a concept has not been addressed to any great extent. Moreover, an understanding of how people are simultaneously situated and describe their

experiences in terms of their intersecting identities has not been evident in the work to date. This gap in the literature exists for three reasons: (1) the dominant voices telling their stories of dementia have not included, by and large, marginalised people - ethnic and 'racial' minorities, older people, lesbians/gays/ bisexuals, disabled people, poor people, uneducated or minimally educated people – who may conceptualise their experiences differently than mainstream voices; (2) when identity constructs i.e. gender, age and class have been referenced, they usually have not been problematised or seen as salient concepts in furthering our understanding of experiences of dementia; and (3) the striving for normalcy theme in the dominant discourse does not leave space for those who were likely concerned about their full human rights before/apart from their diagnosis of dementia, those who were striving already, as well as those who reject societal definitions of normalcy. As a starting point, future dementia theorising and research needs to move beyond a limited focus on the self/person, towards an awareness and investigation of identity. The next step would be to build in an understanding of intersectionality/interlocking oppressions – meaning an analysis of how we are all differentially located on axes of both oppression and privilege and how this is determined by where we are situated and situate ourselves in terms of our own intersecting identities. Only then will we have the possibility of unearthing the subjugated knowledges that lie buried under the dominant dementia discourse - le savoir des gens (Foucault, 1994a: 41) - that should serve as our guide to and through this realm of human experience.

Chapter - 5   Exploring Dementia: Methodology and research methods

5.1 Purpose and aims of the research

As has been intimated, the purpose of this research was to further gerontological and sociological understandings of lived experiences of dementia in later life, particularly the influence of social location on this life process. As a feminist, critical gerontologist, and anti-oppression social worker, I had an expressly political purpose in undertaking this research and have attempted to account for this by writing myself into the story as much as possible. Such reflexivity is a key component of feminist research (DeVault, 1990;1999; Kirby & McKenna, 1989; Lather, 1991; Letherby, 2002; 2003; Opie, 1992; Ramazanoglu, 1992; Smith, 1987; Wasserfall, 1997), arising from an awareness that researchers influence the research process whether or not they openly acknowledge it; and to believe otherwise is both naïve and inconsistent with feminist theory. Indeed, 'we who do empirical research in the name of emancipatory politics must discover ways to connect our research methodology to our theoretical concerns and political commitments' (Lather, 1991: 172). The argument that 'methodology is a political issue' (Young & Ackerman, 2001: 187) is an oft-heard refrain from disability researchers (Swain et al, 2004) and as such, efforts to make disability research more inclusive or participatory have informed this project as well (Hubbard, Downs & Tester, 2003; Stalker, Gilliard & Downs, 1999).

Reflexivity can be seen to be a response to traditional (positivist) research that promotes the denial of one's subjectivity; aims for neutrality and objectivity; and sees research as an a-political endeavour (De Vault, 1999; Kirby & McKenna, 1989; Letherby, 2003). The rationale for a reflexive approach to knowledge creation in feminist research is summarised thus:

> All researchers should be explicit about the politics of their research, as it is more logical to accept our subjectivity, our emotions and our socially grounded positions than to assume that some of us can rise above them (Ramazanoglu, 1992: 211).

Sociologists have long called attention to the politics of research, the situated-ness of knowledge, and the need for reflexivity on the part of researchers (Becker, 1966; Manning, 1967; Schutz, 1967). Becker (1966) argued that '…the question is not whether we should take sides, since we inevitably will, but rather whose side we are on' (p 239); and offered this advice:

> We take sides as our personal and political commitments dictate, use our theoretical and technical resources to avoid the distortions that might introduce into our work, limit our conclusions carefully, recognize the hierarchy of credibility for what it is, and field as best we can the accusations and doubts that will surely be our fate (Becker, 1966: 247).

Having an awareness of the politics of research and the situated-ness of knowledge, and wanting to be honest with myself and my research participants, I adopted a reflexive approach to knowledge creation and determined to take the side of my research participants as much as possible.

5.2 Research design

As this was an exploratory study in an area in which there had been little prior research (Hulko, 2002), I decided that the research question would be best

answered through the use of grounded theory methodology. This approach allows the researcher to go beyond a description of the phenomenon under study, towards an explanation of the phenomenon (Hulko, 1998). Grounded theory was 'discovered' by two sociologists – Barney Glaser and Anselm Strauss – conducting research on dying and death and reflects their training in quantitative methods at Columbia (Glaser) and symbolic interactionism at the Chicago school (Strauss). In the 35 years since the publication of their seminal text (Glaser & Strauss, 1967), the authors' opinions on the approach have diverged in a way that underscores the difference in their sociological origins and in their training in research methods.

Two researchers have become nearly as synonymous with grounded theory as its originators: Juliet Corbin and Kathy Charmaz. Corbin, a nurse researcher, collaborated with Strauss on several methodology texts in the 1990s (Strauss & Corbin, 1990; 1994; 1998) and Charmaz, a sociologist, has carved out her own niche as a constructivist grounded theorist (Charmaz, 1983; 1990; 2000; 2002), while also publishing in her substantive area of chronic illness (Charmaz, 1991;1997). Grounded theory has been widely used in health research, particularly in nursing (Baker, Wuest & Stern, 1992; Chenitz & Swanson, 1986; Johnson, Long & White, 2001; Keady, 1999; Melia, 1997; Wimpenny & Gass, 2000) and appears to accord well with the principles of social work practice (Gilgun, 1994).

I explored alternate methodologies and considered combining cross-national comparative social research (CSR) – Scotland or the UK and Canada - with grounded theory, yet ultimately rejected this approach for theoretical and

methodological reasons [10].   Once I made this decision, carrying out the field

research in Ontario, Canada, rather than in Scotland or the UK, made more

sense, as I was more familiar with the health care system in Canada than in the

UK, there is greater ethnic and 'racial' diversity in Toronto than in Glasgow or

London, and I had an established network of contacts in Ontario to assist with

access.   For all these reasons, I returned to Canada and spent 11 months

undertaking field research in Toronto and Peterborough, Ontario.

5.2.1 Grounded theory – from conception to completion

My understanding of grounded theory arises from research training for a

Masters of Social Work degree and the application of grounded theory methods

to the design of my MSW thesis (Hulko, 1998). Since that time, I have read a

great deal of the literature on grounded theory and have engaged in

discussions and debates with other researchers and postgraduate students

about what grounded theory is and what it is not. Rarely have we entertained

the question of what it *should be* and this is something that I wanted to explore

through this research. While reflecting upon the 'tensions and congruencies'

(Wuest, 1995) between grounded theory and other forms of meaning making

such as feminist/emancipatory research, I found Charmaz's (2000) reframing of

the grounded theory debate and efforts at (re)visioning grounded theory to be

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[10] In assessing the goodness of fit between these two methodologies, I focused on the extent to
which CSR would add strength to the grounded theory and whether it would complement or
detract from the primary methodology. Trying to make the study cross-national resulted in the
need to simplify or somehow make it more manageable, however, and led to the decision to
limit the sample to older women, leaving out older men. After much reflection, I decided not to
do a cross-national study for theoretical and methodological reasons, including a weak rationale
for CSR; the time intensive and complex nature of grounded theory on its own; CSR as a
secondary methodology affecting the primary focus of the study; doubling of access issues,
which were expected to be problematic; lengthening of time to completion due to the need to
learn two systems, develop two sets of contacts, and compare two separate grounded theory
studies; and the realisation that removing one country, rather than one gender, would achieve
reduced complexity *and* better congruency with the research topic.

helpful. Through clearly distinguishing between objectivist and constructivist approaches to grounded theory and asserting the importance of the latter for sociological inquiry, Charmaz (2000) skilfully raised these deliberations to the level of future possibilities, while remaining committed to the basic strategies of grounded theory. The distinction between objectivism and constructivism rests largely on the answers to questions of ontology - what is the nature of reality; epistemology – what is the relationship between those involved in the knowledge creation process; and methodology – how should knowledge be created (Guba & Lincoln, 1994). Constructivists view reality as socially constructed and research as a subjective enterprise in which the researcher's role in knowledge creation needs to be written into the text, through a process of 'working the hyphens' (Fine, 1994). At the time of designing this research, I felt most closely aligned with Charmaz (2002; 2000) who espoused constructivist grounded theory and Wuest (1995) who advocated for feminist grounded theory, both of whom do not diverge from the basic strategies of grounded theory. After completing the research, my allegiance still resides with feminist and constructivist grounded theory.

Regardless of where on the continuum from Glaser to Strauss and Corbin one locates oneself as a grounded theorist, a number of basic strategies should be followed by all claiming to do grounded theory research. These are listed by Charmaz (2000: 510-511) as:

- simultaneous collection and analysis of data
- two step data coding process
- comparative methods
- memo writing to construct conceptual analyses
- sampling to refine emerging theoretical ideas
- integration of the theoretical framework

Most grounded theory methodologists seem to agree on these core constituents and on the outcomes of grounded theory - core variables, basic social processes, and integrated theory (Lowe, 1996). The sequencing of the steps or strategies appears to be up for debate, however, which could be due in part to different interpretations of the function of theoretical sampling - whether it is to develop or to verify theory (Charmaz, 2000; Glaser & Strauss, 1967). Strauss made the critical point that many people have mistakenly thought of grounded theory as simply a form of inductive inquiry, although 'all three aspects of inquiry (induction, deduction and verification) are absolutely essential' (1987: 12). Strauss further noted that not everyone will be skilled at all three, or even two, of these modes of inquiry and that all of these analytic skills can be developed (p 13) through doing grounded theory research.

Through undertaking grounded theory research and critically reflecting on my experiences throughout, I hope to add to debates about the future form(s) this methodology may take and to avoid 'one of the main causes of impoverishment of sociological monographs [which is] that their authors have not written 'simply as a human being' (Bell & Newby, 1977:14). The approach that I took to grounded theory, as detailed in this thesis, can be used as an exemplar for other researchers hoping to steer their way clear of ongoing debates, and willing to take on the more interesting challenge of defining what grounded theory can and should be.

5.2.2 A note on literature reviews in grounded theory

The original text (Glaser & Strauss, 1967) did suggest that knowledge of the literature does not need to be attained in advance of data collection. The admonitions against doing this, and the warnings about its deleterious effects, came later, however, and are to be found primarily in Glaser's work (Glaser, 1978; 1992; 2001; Lowe, 1996), although Charmaz did concur with this view in her early writings (1983; 1990). Glaser contended that grounded theory researchers should not review the literature in their substantive area prior to embarking on data collection as he believed that this leads to the adoption of concepts that force theory development, rather than allowing theory to emerge from the data (Glaser, 1978; 1992; 2001; Lowe, 1996). At the same time, grounded theorists were advised to treat their prior knowledge and experiences as data, to be drawn on in theory development as appropriate (Baker et al, 1992; Glaser, 1978; Glaser & Strauss, 1967; Strauss, 1987; Strauss & Corbin, 1998). As Charmaz (2000: 510) asserted, this suggestion did not mean that Glaser, Strauss, and Corbin aligned themselves with constructivism, which

> assumes the relativism of multiple social realities, recognizes mutual
> creation of knowledge by the viewer and the viewed, and aims
> toward interpretive understanding of subjects' meanings.

Constructivism is consistent with 'research from the margins', a form of anti-oppressive/emancipatory research that also requires 'intersubjectivity' and 'critical reflection on the social context' (Kirby & McKenna, 1989: 129).

Several authors have argued convincingly that we all carry certain concepts in our heads and that these concepts influence our interpretations of the events that we observe and the stories that we hear (Kirby & McKenna, 1989;

McCracken, 1988; Potts & Brown, 2002).   In light of this awareness, the researcher is advised to explore and set down on paper his/her 'conceptual baggage' (Kirby & McKenna, 1989) and to remain continuously aware of its potential to influence the research process. This may be facilitated by doing a thorough cultural review (McCracken, 1988) at the outset and by keeping a reflexive journal (Kirby & McKenna, 1989) in which thoughts about and reactions to the research process are recorded on a continual basis. These suggestions are congruent with the grounded theory strategy of memoing, which was defined by Glaser (Lowe, 1996) as 'any ideational production that comes to mind while coding, collecting and analyzing'.

Orona (1997: 178) remarked about her experience doing grounded theory that the only mandate was to write whatever was emerging from the data without concern for linear or orderly thinking. The aforementioned strategies do, however, go beyond memoing. A cultural review and the recording of conceptual baggage should be done much earlier than memoing, i.e., during the questioning or problem formulation stage, and then be reflected upon throughout the research process (Kirby & McKenna, 1989; McCracken, 1988).

Contrary to the dire predictions of some grounded theorists (Glaser, 1978; 1992; 2001; Lowe, 1996), I did not believe that the literature review that I completed prior to designing this research was going to lead me to force a set of concepts onto the data that I was to gather on older people's experiences of dementia and the intersections of 'race', ethnicity, class and gender. Rather, I felt that it had confirmed the appropriateness of grounded theory for researching this question, in that I was no closer to arriving at a theory that

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adequately captured this phenomenon, despite having read broadly in my substantive field and in parallel fields. This suggested to me that if a researcher is able to locate enough relevant information from the extant literature to be able to formulate a working hypothesis *prior* to data collection, then grounded theory is not the best method to use in seeking to answer the question. That said, I did acquire more concepts than I started out with and acknowledged that any number of these might prove significant in developing theory on older people's experiences of dementia and the intersections of 'race', ethnicity, class and gender.

5.2.3 Operationalising Intersectionality

Undertaking a PhD on dementia and intersectionality and choosing to do grounded theory research from a feminist/anti-oppression perspective required me to grapple with the operationalisation of intersectionality, which meant figuring out what this theoretical concept could look like in research practice. My concerted efforts to apply an intersectional perspective led me to question everything about the research, from the overall design, to the composition of the sample, to tools such as conversation aids, to dissemination strategies. I documented all of this in my reflexive journal and had the opportunity to share these challenges and my attempts to address them with other researchers through conference presentations in the UK and Canada. I have detailed some of these challenges and my attempts to overcome them elsewhere (Hulko, 2004a; Appendix C). The methodological challenges associated with operationalising intersectionality that I highlighted were: configuring the sample, translating sociological concepts, describing the project, designing interview

questions, and being reflective and reflexive (Hulko, 2004). In chapter 9, I will discuss some of my conclusions with respect to the utility of the concept of intersectionality. At this juncture, I would like to state that it is possible to operationalise intersectionality, it takes a great deal of creativity and vigilance, and, if done in earnest, the process and the outcomes of research are radically different.

5.2.4 Sensitising concepts

Between October 2001 and August 2002, as I worked on a thorough review of the literature for this research, I consciously wrote myself into the story, thereby acknowledging my subjectivity as the researcher (Fine, Weis, Weseen & Wong, 2000) as well as introducing the theoretical framework and conceptual baggage that I brought to this research. In supervision sessions, it was agreed that my efforts at critical self-reflection and locating myself in the research process were important to this research and that I should continue to do this. My awareness of the mass of concepts that I had stored in my head grew as I thought about my research methods and how to distil all that reading and writing into a short summary of the literature. In addition, I had started to reflect on the perhaps contradictory positions espoused by representatives of the epistemological and methodological traditions guiding my work – feminism and grounded theory - and on how this accorded with my own process to date which had included a thorough literature review and the aforementioned efforts at critical self-reflection and locating myself in the research process. I decided that it was time to make a record of this and sat down to write up a list of my own conceptual baggage - those concepts in my head that might be significant to

this research. After 15-20 minutes of brain storming and then an equivalent period of reflection and more writing, I generated a list of 76 concepts (individual words or pairs/groups of concepts), which is attached as Appendix D.

I included this list of concepts in the research proposal and attached it to this thesis as documentation of the conceptual baggage that, from my vantage point at the time, I thought might prove relevant to the process in which I was engaging. This process can be seen as one of: questioning; designing and re-designing; seeking, listening, learning; making meaning; posing conclusions/questions; and taking more action (Potts & Brown, 2002). This inventory was partial, and I intended to add to it as the research progressed; however, I stopped documenting concepts per se and chose to use my reflexive journal to record ideas generated by the research, in the form of theoretical memos.

To engage in this reflexive process is to acknowledge one's subjectivity as the researcher (Burgess, 1984; DeVault, 1999; Fine, 1994) and to refute the idea that the objectivity that reputedly comes from not reading the literature in one's subject area is possible and desirable. I do not believe that disobeying this injunction made me any more likely to impose a theory on my data rather than facilitating its emergence. Unlike a trend noted in the literature in which researchers claim to have used a grounded theory approach when it seems to be little more than inductive analysis (Glaser, 2001; Strauss & Corbin, 1994), I used all of the strategies of grounded theory, and infused them with feminist and anti-oppression sensibilities. As Wuest (1995) notes, grounded theory as a

methodology is well suited to feminist research in that it recognises multiple realities and the influence of structural conditions and views theory as a process. Wuest (1995: 129) lists three principles underlying feminist research:

1. knowledge produced by the research should be useful for the participants
2. the research method should not be oppressive
3. the research method should be reflexive

As has been expressed in earlier sections of this chapter, these three principles underpin this thesis and were captured in the third aim of the research: to critically reflect on the research process, particularly the applicability and effectiveness of anti-oppressive research methods. Grounded theory is said to require a cast of multiple, diverse characters in order to enrich the theory under development (Charmaz, 2000; Strauss & Corbin, 1994; Wuest, 1995) and, as such, aligned well with the aims of this research as well.

After the thorough literature review and accounting of relevant sensitising concepts described above, I felt ready to jump from the literature into the empirical world of research; thus, I had reached the transitional phase referred to by Glaser (2001) in the following way:

Thus Wendy takes on the literature as something to discount as conjecture with a desire to change it, redirect it, modify it, and correct it. In essence it is time to ground it by a Grounded Theory (p 37).

5.3 Research methods

Grounded theory researchers frequently use a range of data collection methods (Charmaz, 2000; Dick, 2002; Glaser, 2001; Strauss & Corbin, 1994) in order to explore the research question from different angles and to triangulate the data that arises (Erlandson, Harris, Skipper & Allen, 1993; Lincoln & Guba, 1985;

Lather, 1991). Employing various data collection methods also helps to ameliorate problems that may arise with people who have diminished cognitive or communicative abilities (Rowles & Reinharz, 1988), particularly on a topic that might be difficult to discuss, regardless of one's cognitive capacity. Also, it addresses the researcher's desire to afford participants different means and opportunities to express themselves (Ikels, Keith & Fry, 1988). This latter goal accords well with politically engaged research for which multiple methods and a commitment to engaging with differences, especially between the researcher and the researched, are essential (Fine et al, 2000). The methods that I selected for this research were interviews, participant observation, and photography with persons with dementia, together with focus groups with their significant others[11].

Being committed to the social work principle of 'starting where the client is at', which Gilgun (1994) suggests is reflected in grounded theory methods, the primary focus of this research was people with dementia and their unique and varied experiences. I began data collection with the interviews and observations, therefore, and planned to move on to the focus groups with significant others once a theory had emerged from the data and been verified through theoretical sampling. Having gathered more data than anticipated from talking with older people with dementia themselves, and observing them interacting with their significant others, and feeling the pressure of time, I decided to forego focus groups and to give feedback jointly rather than

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[11] Based on the work of Mead (1967) and other symbolic interactionists, I used significant others to refer to members of their community whom my interviewees identified as playing a significant role in their lives, i.e. spouses, adult children, friends, neighbours; and did not use this designation for service providers.

individually. More details of the specific methods will be offered below, following a brief review of key methodological issues in past dementia research.

5.3.1 Methodological issues in dementia research

Methodological issues raised in research that treats people with dementia as subjects, not objects, have centred on: informed consent and the role of proxy decision makers (Allan, 2001; Bartlett & Martin, 2002; Bowes & Wilkinson, 2002b; Cheston, Bender & Byatt, 2000; Clarke & Keady, 2002; Dewing, 2002; Downs, 1997; Feinberg & Whitlach, 2001; Froggatt, 1988; Hubbard, Cook, Tester & Downs, 2002; Innes, 2001; Reid, Ryan & Enderby, 2001; Wilkinson, 2002b); the morality/ethics of research that may adversely affect mood and functioning (Cotrell & Schulz, 1993; Froggatt, 1988; Keady et al, 1995); the need to corroborate information and/or triangulate data (Barnett, 2000; Cotrell & Schulz, 1993; Froggatt, 1988; Innes, 2001; Phinney, 1998;); the degree to which emancipatory or participatory research is possible (Hubbard et al, 2003; Goldsmith, 1996; Living Archive Project, 2001; Nolan, Ryan, Enderby & Reid, 2002; Proctor, 2001; Ray, 2000; Reid, 2003; Stalker et al, 1999; Wilkinson, 2002b); the involvement of the caregiver or spouse (Cheston et al, 2000; Cotrell & Schulz, 1993; Forbat, 2003; Froggatt, 1988; Phinney,1998; Snyder, 2001); the need for a pre-interview meeting, multiple interviews, and post-interview follow-up (Clarke & Keady, 2002; Hubbard et al, 2003; Living Archive Project, 2001; Phinney, 1998; Proctor, 2001; Snyder, 2001); the extent to which understanding of and respect for 'culture' is taken into consideration (Bowes & Wilkinson, 2002; Chater, 1996; Forbat, 2003; Ray, 2001; UBC Dementia Research Collaborative Working Group, 2000); effects of the disease itself such

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as distractibility, difficulty recollecting facts, problems in communication and fears or suspicions of strangers (Barnett, 2000; Bowes & Wilkinson, 2002; Cheston et al, 2000; Clarke & Keady, 2002; Cotrell & Schulz, 1993; Froggatt, 1988; Goldsmith, 1996; Innes, 2001; Keady et al, 1995; Proctor, 2001; Snyder, 2001; Wilkinson, 2002a); gaining access and getting past the gatekeepers (Bartlett & Martin, 2002; Bowes & Wilkinson, 2002; Cotrell & Schulz, 1993; Froggatt, 1988); the importance of having researchers who are trained in dementia care (Froggatt, 1988; Hubbard et al, 2003; Keady et al, 1995); and difficulties in obtaining funding for research of this nature (Bowes & Wilkinson, 2002b; Froggatt, 1988).

Several of the above mentioned authors, and others, have suggested ways in which we may learn about the experiences of people with dementia. First of all, a 'repertoire of strategies' is advised (Hubbard et al, 2003) and then specific techniques are suggested such as: (1) personal accounts; (2) interviews and group work; (3) listening in everyday life; (4) observing behaviour; (5) consulting people who have had dementia-like illnesses, i.e. depression and meningitis; (6) poetry; and (7) role play (Kitwood, 1997a: 73-79). Although Kitwood undertook very little empirical research himself, his list of strategies is frequently cited in the dementia literature. I made use of several of these techniques, including the first one for my analysis of published accounts of dementia (Hulko, 2002) and the next three in the empirical research. Cheston et al (2000) created a list for service related research questions: (1) questionnaires and structured interviews; (2) semi-structured interviews; (3) observation; (4)

These lists of research methods have a history of extensive use in the social sciences, which may be one reason for Bond and Corner's (2001) claim that there are not unique methodological issues in dementia research. Several of these forms of knowledge creation have been used in dementia research and the results that have been made available to the public form a solid basis for further explorations of the subjective realm of dementia. Themes identified in a 1997 review of 'the emergence of the person in dementia research' - (1) the individual's sense of self; (2) the person's rights; and (3) attention to the perspectives of people with dementia (Downs, 1997) - are evident still in literature published in the intervening years, though citizenship rights have not been accorded sufficient attention to date (Innes, 2002). The aforementioned strategies and themes are all pieces of work that I consciously built upon in this research on dementia and intersectionality. My own experience in dementia research and care and the growing literature on how to do research *with* people with dementia, informed the research design, described in detail in the sections that follow.

5.3.2 Interviews and participant observation with people with dementia

Through reviewing the recommendations arising from past research using an interview format with people with dementia, it appeared to me that interviews should:

- Be short, flexible, conversational in nature and occur more than once;
- Include time for (re)introduction to the researcher and the research, (re)negotiating consent, and orientation to the topic;
- Take place in a setting that is comfortable for the participant, preferably their home or a setting that is connected to the questions being asked;
- Happen during the best part of the day for the participant and at a time of their choosing;
- Be conducted by someone with training in dementia care/knowledge of dementia;
- Occur in the native language/language most commonly spoken by the participant, through the use of an interpreter if needed; and
- Be audio-taped, if agreed, and supplemented by notes on nonverbal communication, mood, and the interview process.

Taking these suggestions into consideration, I planned a series of three short (20-30 minutes) interviews with each of the people with dementia involved in the research, interspersed with two participant observation sessions per person, lasting roughly two hours per session. The sequencing of the schedule was such:
Interview 1 ⟶ Observation 1 ⟶ Interview 2 ⟶ Observation 2 ⟶ Interview 3

While I did complete the entire sequence with each of the eight participants, I had to alter the timeframes, as the interviews all lasted between 40 and 90 minutes, more in line with interviews with older people generally (Wenger, 2002). The interviews were structured around the individual's self-identity and social location and his/her experiences of living with cognitive impairment; and I created a new interview guide each time I met with a participant (see initial interview guide in Appendix E). At the second or third interview, I asked participants to show me a photo or object that might assist in answering the research question (the more accessible version) - how does who you are as a person shape living with memory problems, and to describe the meaning that it

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held for them. My thinking was informed by Wenger (2002: 271), who noted that: the homes of older people tend to give clues as to their earlier lives; questions about photographs or objects can provide a good starting point for discussion; and taking photographs of artefacts may provide useful data. My design was further influenced by visual sociologists and their recognition that 'the power of the photo lies in its ability to unlock the subjectivity of those who see the image differently from the researcher' (Harper, 2000: 729).

I was aware that a therapeutic benefit could result from this activity as well, as it is thought that older people derive pleasure from sharing photographs or objects (Rowles & Reinharz, 1988). Photographs and objects have the potential to trigger painful memories and to increase awareness of losses due to dementia, however, and this was something that I encountered in the course of the research. For example, some of the participants did not recognise themselves or were unable to recall the names of the people or events depicted in the photos. Pleasure was far more commonly expressed than pain, however, especially when the participants were discussing people and events from the past.

The observation sessions took place in a setting or at an event that held significance for the person with dementia; and this was negotiated with the participants and their significant others in some cases, at the end of the first and second interviews. During these sessions, as a participant-observer, I interacted with those present as appropriate: engaging in informal interviewing (Chenitz, 1986), taking photographs as permitted, and making brief notations on my observations and reflections. After leaving the scene, I expanded upon

my notes and wrote them up in full for coding as soon as possible after the event. I hoped that these observation sessions might provide additional, and possibly conflicting, information to that garnered through the interviews (Hubbard et al, 2003; Lambert & McKevitt, 2002) and that they would allow me the opportunity to record non-verbal communication and interactions with others which have been shown to be meaningful and purposive for people with dementia (Hubbard et al, 2002; Seman, 2002). Participant observation helps to balance 'what people say with what they actually do' (Ikels et al, 1988: 283) and to 'situate an interviewee's statements and the circumstances of the interview as far as possible in the broader contexts of that person's life' (McKevitt & Lambert, 2002: 211). The former comment relates to the fact that much of what social researchers are interested in studying is not of interest to our participants or is something of which they are not conscious themselves (Ikels et al, 1988: 283). Thus, using participant observation in this study, provided another means to assess the influence and interaction of gender, class, 'race' and ethnicity on the participant's experiences of dementia, which was not easily articulated in an interview.

It was only through combining methods in this way that the second category of the grounded theory emerged – othering dementia. Had I relied on interviews alone, I would not have witnessed the othering to which people with dementia are subject and been able to explore the impact of this with the participants in follow up interviews. As well, the interspersing of the interviews and the observation sessions allowed me to think through my observations and then ask more focused questions in the subsequent interviews, consistent with

grounded theory strategies (Charmaz, 2002). Indeed grounded theorists are advised to use 'multiple sequential interviews [as they] form a stronger basis for creating a nuanced understanding of social processes' (Charmaz, 2002: 682).

5.3.2.1 A note on tools

The primary tool in interview and observation research is the researcher her/himself (Charmaz, 2002; Wenger, 2002) and all that s/he brings to the research – knowledge, skills, experience, values, and biases. I did not make use of any psychometric tools, as the degree of cognitive impairment, as measured by these instruments, was not an important factor in this study. An official diagnosis of dementia was not important either, although most participants, if not all, had been given a diagnosis due to the nature of the recruiting sites. In lieu of a demographic face sheet, I constructed diagrams for each participant depicting where I thought they resided on multiple axes of oppression and privilege, based on information from the gatekeepers and significant others and my sociological imagination (Wright Mills, 2000). In doing this, I was drawing on a tool from anti-oppression workshops that is used to graphically illustrate an individual's social location: multiple axes of oppression and privilege are drawn in a form reminiscent of the spokes of a wheel and each is labelled with a different identity construct such as age, gender, class, sexual orientation, 'race', ethnicity, religion, (dis)ability, language, and health status (Appendix F). The centre of the circle represents privilege and the outside represents oppression/marginalisation (hooks, 2000a). The task is to situate oneself on each of these axes in relation to the margin and the centre and, through doing so, to become (more) conscious of the degree of privilege

and oppression that one owns and which makes the everyday world problematic (Smith, 1987). As I felt that this exercise might be too cognitively and emotionally challenging for people with dementia to engage in, I used their words and actions to inform my own constructions (Appendix F).

The interview questions were designed to evoke subjective reflections on living with cognitive impairment as a person of a particular 'race', ethnicity, gender, and class and made use of conversation aids, such as varied images of older people (see Figure 1) and third person questioning (Dewing, 2002). Although I began with an initial interview guide (Appendix E), these questions were altered, discarded, and replaced on an ongoing basis to meet the analytical requirements of the grounded theory research, such as refining and verifying the evolving conceptual categories (Appendix G). Ascertaining the meaning behind the words and actions of people with dementia can be challenging and requires active listening and creative, non-linear thinking skills (Goldsmith, 1996; Hubbard et al, 2003; Killick & Allan, 2001). Participants may speak in metaphors and string together words in a form that has been termed 'word salad', as the words appear to be jumbled together and it is difficult to discern the thread of meaning. As Woods (1997: 12) stressed:

> it is all too easy to discount the words and behaviour of the person
> with dementia as being random and unpurposeful, but a difficult
> endeavour to identify reliably the fragments of meaning and affect
> that undoubtedly remain.

To do this properly, an interviewer needs to be flexible enough to piece the words together, to pick out the thread, and to probe for the meaning contained within. In this regard, De Vault's (1990) suggestions for capturing the unique features of women's talk are highly applicable to dementia research, i.e.

listening more carefully and recording more than words. This style of interviewing necessitates a dialogue, rather than a rigid question and answer format, and is consistent with a relationship-centred approach to dementia care (Nolan et al, 2002; Zgola, 1999), a reflexive approach to research (Charmaz, 2000; Fine et al, 2000), and active interviewing strategies (Holstein & Gubrium, 1995).

This research is also located within a newer research tradition known as visual sociology (Prosser & Schwartz, 1998), which dates back to Becker's (1974) innovative article linking photography and sociology. Although Prosser and Schwartz (1998) note that 'little has been written regarding the role photographs can play in the research process' (p 115), it is felt that there is a goodness of fit between grounded theory and visual methods, particularly with respect to enabling the comparison of emic and etic perspectives and the iterative process of data collection and analysis used by both research methods (Prosser & Schwartz, 1998). In addition to generating photographs throughout the research, I used a form of visual sociology known as photo elicitation (Alexander, 2001; Becker, 1974; Harper, 2000). Visual materials such as photographs taken at the observation sessions, the images of older people that I brought to the initial interviews, and artefacts in the participants' homes, were used as tools for the elicitation of information about the topic at hand. The visual data created was of people with dementia interacting in their social worlds, and of any significant objects that were shared with me. Being new to visual sociology, I followed the advice of my intellectual ancestors and aimed to photograph with sociological consciousness (Becker, 1974). Although the

photographs of the research participants and their social worlds were not systematically coded, they were used to help build theory (Harper, 2000), as exemplified by the emergence of the second category of othering dementia.

The two primary purposes of the photographs were: to facilitate data collection; and to represent the research in publications and presentations, according to the wishes of the participants. Such use illustrates and brings life to the text (Wenger, 2002) and helps to make visible an invisible population (Fine et al, 2000), consistent with moves to make dementia research more inclusive (Dewing, 2002; Nolan et al, 2002; Stalker et al, 1999; Wilkinson, 2002a). Wenger (2002: 272) encouraged such efforts, as 'most of the older people that [she] and [her] colleagues have photographed have been happy, even delighted, to have their likenesses used to illustrate [their] work.' A caution was issued as well for researchers 'to employ sensitivity in using photographs of recognizable people to illustrate dependency, impairment, and other less positive aspects of old age' (Wenger, 2002: 272).

Most of the photographs that I took counter the familiar images of people with dementia that depict them as frail and incompetent (Hulko, 2004b; see Appendix H). I acknowledge that this is a controversial area and for that reason, approached this with caution, treating as primary the wishes of the participants, and assessing carefully their comprehension of the implications of consenting to public exposure of their images. In addition, my aim was to counterbalance the negative images of people with dementia that currently exist with images of active older people with dementia who are integrated into the social fabric of their communities. The words of people with dementia who are

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involved in research and who are speaking out about their experiences are instructive in weighing the risks and benefits of publicising the words and/or images of people with dementia (McKillop, 2002; Robinson, 2002; Young, 2001). For example, one research participant by the name of Sue Sweeney, replied, to a request to use her quote, that she wanted her full name attached to her words, so that the audience would know that 'a real person is saying these things and feeling these things' (as quoted in Seman, 2002: 139). This implies to me that the option of being made visible needs to be offered to people with dementia, with sensitivity, rather than protecting them from what we perceive to be a danger by not asking the question. The older people with dementia with whom I worked were very interested in the photographs and did not object to my taking or using them, with the exception of a few photographs of two of the women which they felt portrayed them as haggard or would not make sense to others (see chapter 7).

The images of older people that I used for photo elicitation did not work in the manner I envisaged them, however, and I stopped using my 'deck of image cards' after the fourth initial interview. First of all, the participants were less cognitively impaired than people with dementia with whom I had worked in the past and were able to engage with the photos on a deeper level, asking questions about who the people were, were the photos had been taken, what was going on, etc. Second, the responses to the images were very interesting and provided me with insights into processes of identification and differentiation, however, it was really tangential to the main focus of the research. To illustrate these points, I have included four different reactions to

the same photo of an older white woman grocery shopping; the first is from a multiply privileged participant, the second from an in-between participant, the third from a multiply marginalised participant, and the last one from an in-between participant.

Figure 1 Health Canada photo of older white women grocery shopping

Jim Heather: Uh…hard life I would think… She's looks weary, tired, she's well enough, good coat. Um [pause] probably doesn't have anyone to love her or look after her or… The basket's sort of got fair bit in it for uh person of her age…

Joe Brown: …and here's old mama, I like, I like that picture. Oh, I like this picture, she looks happy man. She one of those happy-go-lucky ladies boy, oh yeah, oh yeah. Oh happy about life, with what she's doing, she's shopping.

Ester Hernandez: [in Tagalog] I don't know…I don't know, maybe somebody, sometimes a person who is poor [gesturing with hands someone walking]…with like newspaper for example, and they stealing, and take it.

Bosse Knudsen: Ohh, she's an old one…Yeah… Well, the wes-, the way she dresses and…that looks like an old that, a young person would not dress like that.

These very different responses to the same picture demonstrate how our social location and our values and beliefs can influence what we see in a photo and the value we place on the person so depicted. Used in this way, photo elicitation can be a very useful tool for soliciting views of people that are both

different than and similar to the respondent. This was not the main focus of this project, however, and seeing as dialogue was not as much as a challenge as anticipated, I felt it prudent to abandon the use of the deck of image cards.

5.3.3 Feedback sessions and focus groups with significant others

As mentioned previously, the focus groups were intended to happen at the end of the process, so as not to bias the data collected from older people with dementia and the emergent theory, and to elicit feedback on research findings obtained through the interviews and observations conducted earlier in the research (Cronin, 2001; Morgan, 1988). Focus groups can allow the researcher to draw out contradictory opinions from members of the same profession or field (Smith, 1996) and this was an important factor, as I suspected that the significant others might have differing opinions about dementia and the importance of social location based on their own experiences and personal identities. Although I carefully planned the focus groups, I did not use this method of data collection, as I felt that (1) it would not add to the overall research question; (2) there was insufficient time; and (3) not enough participants could attend with the more marginalised ones being less able to be present. I did hold two feedback sessions with the participants and their significant others, one in Toronto and one in Peterborough, and paired these with focus groups conducted by the Alzheimer Society of Ontario (ASO) on how best to involve people with dementia and their caregivers in decision-making processes. As several of the significant others were disappointed that I would not be holding focus groups as part of my research, and I was keen to address the 'so what?' factor, this opportunity for people with dementia and their

5.3.4 Data analysis procedures

Data collection and analysis occurred simultaneously, as prescribed by grounded theory methodology (Charmaz, 1983; 1990; 2000; 2002; Chenitz & Swanson, 1986; Dick, 2002; Glaser, 1978; 1992; 2001; Glaser & Strauss, 1967; Lowe, 1996; Strauss, 1987; Strauss & Corbin, 1990; 1994; 1998). My intention was to transcribe the data immediately after collecting it and to perform both open/initial and selective/focused coding on the data prior to the next interview or observation session. I did not do the second stage of coding, however, for reasons to be addressed in section 5.6. Charmaz (2002: 684) details components of the coding process as:

- Studying the data prior to checking with the literature
- Doing line by line coding
- Using active terms to describe what is happening in the data
- Following leads from the open coding in further data gathering

Focused coding involves sorting through the initial codes and distilling them down into categories that represent recurrent themes across the data, taking account of cause, conditions, context, actions, and consequences of the phenomenon under study (Glaser, 2001; Lonkila, 1995). This is supplemented by memo writing which 'prompts [the grounded theorist] to raise their codes to conceptual categories' (Charmaz, 2002: 687) and which can occur at any point. Theoretical sampling is then undertaken to fill out the conceptual categories

and discover variation, as the grounded theorist works towards theoretical saturation and an integrated theory.

All of the data was stored and organised in a project file in QSR NUD*IST Vivo (N*Vivo), as I had been told this software would facilitate the analytic process, particularly coding and memoing (Richards, 2000). N*Vivo enabled linking to the non-text based data that I collected such as photographs and other visual images.   It is also more suited to grounded theory than other software packages, as it supports a bottom up approach and has functions such as modelling, linking concepts and data, and embedding notes and memos (Richards, 2000).   Computer-assisted data analysis has proven popular for researchers using grounded theory (Lonkila, 1995). Whilst computers are not recommended by Glaser (2001)[12], the utility of software such as NUD.IST (the precursor to N*Vivo), for grounded theory has been demonstrated (Lonkila, 1995). My concerns about software packages such as N*Vivo and the way that they support the conflation of coding with analysis will be addressed in section 5.6.

5.3.5 Sampling decisions

Theoretical sampling is the type of purposive sampling that is associated with grounded theory research (Charmaz, 2000; 1997; 1990; Dick, 2002; Glaser & Strauss, 1967; Glaser, 1978; Lowe, 1996; Strauss, 1987; Strauss & Corbin, 1998), yet it is not undertaken at the outset of the data collection process. Initial data collection is driven largely by theoretical sensitivity (Glaser, 1978),

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[12] This injunction against computers is consistent with Glaser's rather rigid approach to the interpretation and use of grounded theory (see Glaser, 1993; 2001; 2002).

by an awareness of different sites in which one might reasonably expect the phenomenon under investigation to be encountered. Only when the researcher has constructed a conceptual basis, derived from the data, that can guide sampling decisions, does s/he engage in theoretical sampling. At this stage of data collection, the researcher's aim becomes the selection of sites and participants that will lead to further development and eventual refinement of the emergent theory. My thinking about sampling at the beginning stage was guided by theoretical sensitivity (Glaser, 1978), and an awareness of the most fruitful places for locating older people with dementia – in hospitals, memory clinics, care facilities or doctors' offices, through the local Alzheimer Society or another community agency, at adult day programs or community centres[13].

In choosing sites from which to recruit research participants, I took into consideration the reality that a diverse group of older people with dementia may be difficult to locate, along with my preference for a social setting, so as to limit the influence of bio-medical conceptions of dementia and maximise opportunities for the expression of various world views. In addition, I was

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13 I initially thought that locating a sample of older people with dementia that would be diverse in terms of ethnicity, 'race', gender and class would be extremely challenging in the Peterborough area and only slightly problematic in Toronto. This was based on my assumption that the contrasting ethnic and racial composition and rural–urban distribution of the populations of the two areas provided an indicator of the client base of the Alzheimer Society and other community services for older people. I was surprised, therefore, to discover from my early conversations that the Alzheimer Society of Peterborough (ASP) was very optimistic and enthusiastic about my research, especially about locating participants through their office and their community contacts, while the Alzheimer Society of Toronto (AST) was less forthcoming with support. Granted, there are higher percentages of older people in Peterborough County (18%) and the adjacent area of Kawartha Lakes (19%) than in Toronto (13.6%) according to demographic profiles (Statistics Canada, 2002a; 2002b; 2002c), which means that a larger potential client base, as a percentage of the overall population, exists in Peterborough than in Toronto. However, as AST is situated in one of the most ethnically and 'racially' diverse cities in the world (James, 2002) and has its own ethno-racial access committee, one might reasonably expect this society to be able to facilitate access to an ethnically and racially diverse group of older people with dementia more readily than could their counterparts in a smaller city.

conscious of the need to have a large pool of potential participants as my question required a sample that is diverse in terms of 'race', ethnicity, class and gender. In order to meet these objectives, I felt that I would have to draw people from a health or social service, and then ensure that the interviews and observations took place in social settings removed from the service/health context, yet meaningful to the person with dementia in question. The recruiting sites for the Peterborough area were the Alzheimer Society and a local geriatrician; and for Toronto, a community health service for older people based in an acute care hospital. The site in Toronto required the approval of its research and ethics board, which I received after four months of negotiation.

The actual participants themselves, as a group, represented various social locations, rather than different mathematical configurations of the variables of 'race', ethnicity, class, and gender. I had played with different algebraic formulas in an effort to devise a 'diverse sample' and considered using Ragin's (1994) truth table method of quantifying data when researching diversity. I was able to reject this process of essentialising people with its ostensible goal of simplifying complexity/diversity once I came upon an alternate method that was more in line with my research aims and still resulted in a sufficiently diverse sample. My approach called for the selection of people who lie at different points on the axes of oppression and privilege, based on their 'race', ethnicity, class, and gender. In this way, similar/shared social locations, ranging from multiply privileged to multiply oppressed, rather than individual characteristics, form the basis upon which the sample is stratified. Although I was aware that gatekeepers –

those individuals in an organisation who have the power to grant or withhold access to people or situations for the purposes of research (Burgess, 1984: 48) –

might interpret this research as being solely about minority ethnic and racialised people (the other), I felt that the inclusion of privileged people was equally important in seeking to understand the dynamics of privilege and oppression (Calasanti & Slevin, 2001; Lee, 1993). Regarding my status as a white, Anglo-Saxon, middle class, able-bodied, younger woman, I did not attempt to hide my difference in relation to the participants. I demonstrated my legitimacy/credentials in order to gain access to research participants and to build rapport, through my initial flyer for gatekeepers (see Appendix I). In each interaction, however, I tried to make use of my alienness to the socio-cultural context and the phenomenon of dementia, rather than attempting to minimise any social distance between the participants, and myself, which would be to deny my privilege. There were exceptions, however, as I found myself referencing indicators of upper middle class status and drawing on my social capital (Bourdieu, 1986) with the multiply privileged participants, perhaps in an effort to minimise social distance. This was unexpected to me and led to some critical self-reflection, during which I was able to situate my behaviour in the context of challenges of interviewing elites, which are particularly salient when transformation is a goal (Kezar, 2003). More often, I tried to make use of my alien-ness to the participant's socio-cultural context, rather than attempting to fit in, which led to problems of a different nature (see chapter 7). This latter approach accords with that of the stranger in naturalistic inquiry (Gutmann, 1988) and calls for making use of difference and 'turning it into the fulcrum of the interview itself' (ibid, p 307).

As my sampling requirements were determined on an ongoing basis by the simultaneous process of collecting and analysing data, it was impossible to delineate at the outset the characteristics and size of the sample. However, in order to anticipate the logistical requirements of research, such as time and cost, I planned for a certain sample size, with the understanding that this number might be higher or lower than the final figure. The estimated characteristics of my sample of older people with dementia were:

o 12 people in total belonging to varied 'racial', ethnic, class, and gender groups
o 4 multiply privileged, 4 multiply oppressed, 4 in between on the axes of oppression and privilege
o 6 in Toronto and 6 in the Peterborough area.

Although I was aware that locating people that met the above criteria might be difficult, I believe it is important to attempt to do so and then to reflect on and document both the process and the outcomes. As Lee (1993) cautioned, researchers may use access issues to mask their reluctance to get out there and face the problems in the field. Giving in to the anxieties caused by complex research and opting for an easy to locate sample would be inconsistent with a reflexive and anti-oppressive approach to research.

I recruited participants on an ongoing basis, which meant the gatekeepers delivered information leaflets (Appendix J) to potential participants after we had determined which of their clients met my theoretical sampling criteria at that point in time. The final sample had the following characteristics[14]:

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[14] The difficulties encountered and the sample limitations are addressed in section 5.5.

- 8 people in total belonging to varied 'racial', ethnic, and class groups
- 5 women and 3 men
- 3 multiply privileged, 2 multiply oppressed, and 3 in between on the axes of oppression and privilege
- 5 in Toronto and 3 in the Peterborough area

After gatekeepers made contact with potential participants and gave them the information leaflets, I met with the older person with dementia and their significant other in most cases, and we went over both the information leaflet and the consent form (Appendix K). The next section addresses in more detail some of the ethical aspects of the research that have been hinted at thus far.

5.4 Ethical considerations

There has been much concern expressed about the ethical aspects of research with people with dementia (Allan, 2001; Bartlett & Martin, 2002; Bowes & Wilkinson, 2002; Cheston et al, 2000; Dewing, 2002; Downs, 1997; Feinberg et al, 2001; Froggatt, 1988; Hubbard et al, 2002a; Innes, 2001; Reid et al, 2001; Wilkinson, 2002a), yet most of this work focuses solely on the consent process. Certain ethical and methodological lessons can be drawn from research with other vulnerable groups, such as disabled people (Davis, 2000; Kitchin, 2000; Stone & Priestly, 1996), people with learning disabilities (Booth, 1998; Stalker, 1998), older people (Rowles & Reinharz, 1988; Sankar & Gubrium, 1994; Wenger, 2002), and women (DeVault, 1999; Mama, 1995b; Smith, 1987). For example, warnings about research with lonely people, articulated with respect to people with learning disabilities, are certainly applicable to people with dementia, as they too may 'choose the researcher as a way out of their loneliness' (Booth, 1998: 133).

In the case of dementia, loneliness may be brought on or exacerbated by the 'malignant social psychology' evident in dementia care (Kitwood, 1997). As the researcher, it was my responsibility to anticipate potential reactions to my presence and think about how I would respond to the 'terms of engagement' that might be proposed by the researched (Stalker, 1998). I needed to pay particular attention to the impact of the research on my participants, particularly any strong emotions or painful memories that might be stirred up by the questioning, or merely by my presence in their lives. Planning for withdrawal from the lives of research participants, regardless of the extent of my involvement or my view of its (in)significance was another important consideration (Booth, 1998), as was thinking about how the findings, in this case the grounded theory, might be interpreted and used by different parties (Brannen, 1988).

This research was guided by the ethical guidelines of the Alzheimer Society of Canada (1995), the British Sociological Association (2002), the Canadian Sociology and Anthropology Association (1994), and those expressed in the Tri-Council policy statement (Medical Research Council of Canada et al, 1998). These guidelines refer to participation and respect for wishes; informed consent and proxy consent; ongoing communication and negotiation and balancing of risks and benefits. The acknowledgement of the right of people with dementia to participate in research, regardless of the stage of their disease (Alzheimer Society of Canada, 1995; Medical Research Council et al, 1998) is likely a response to the criticism of past dementia research for its neglect of people with dementia and their subjective experiences (Braudy Harris, 2002; Cotrell &

Schulz, 1993; Downs, 1997; Froggatt, 1988; Gillies, 2000; Goldsmith, 1996; Kitwood, 1997; Lyman, 1989; Proctor, 2001; Wilkinson, 2002a; Woods, 1997; 2001). This is distinct from research with other vulnerable groups for whom ethical guidelines assure the right not to be studied (Canadian Sociology and Anthropology Association, 1994); of course, this right does apply to people with dementia as well.

Other ethical issues that are standard and that I guaranteed for all participants were the right to privacy, confidentiality and anonymity. These protections do not, however, absolve the researcher from the responsibility of reporting abuse or neglect if s/he becomes aware of its occurrence (Canadian Sociology and Anthropology Association, 1994), which is not inconceivable in research with older people with dementia. When discussing their rights with the research participants, I addressed the limits of confidentiality, noting that should I be made aware of abuse, neglect or threats to safety, I would discuss my intentions with the person being harmed prior to acting. In terms of anonymity, this was guaranteed for any publications or presentations arising from the research, with the understanding that this could be compromised with the publication of photographs. At the initial meeting, I asked participants for permission to use their images, as captured in the photographs that I took, for inclusion in publications and presentations on the research. At the end of the research, I went over each photo and encouraged participants to identify any photographs that they would not like me to use, as well as their favourite image of themselves. I asked the participants to select their own pseudonyms at the introductory meeting and used these names in all records, in lieu of codes, at

times failing to remember the participant's real name. With the exceptions noted, the views that people expressed, the stories that they told and the actions that I observed, have been kept confidential, including from those who are also involved in the research, for example from the significant others and gatekeepers in the case of the people with dementia and from the people with dementia and gatekeepers in the case of the significant others. Finally, all of the audio-tapes are to be destroyed following award of the PhD and all other data to be stored in a secure location for at least seven years.

The importance of attention to power differentials in the relationship between the researcher and the researched is a prominent theme in other fields (British Sociological Association, 2002; DeVault, 1999; Oakley, 1999), yet has not been well conceptualised in the dementia literature to date and thus, empirical data is scarce (Hubbard et al, 2002a; Living Archive Project, 2001; Proctor, 2001; Wilkinson, 2002a). There is, however, some notable work happening in the United Kingdom (Stalker et al, 1999; Wilkinson, 2002a) to make dementia research more inclusive and participatory. For example, Proctor (2001) attempted to shift the power imbalance in her research on older women with dementia through the use of a reflexive analytic strategy and returning to the women for their comments on her analyses and permission to use their stories. The Living Archive Project (2001) is also exceptional in that the three women and one man living with dementia who were individually interviewed were shown how to switch off the tape-recorder; the transcripts were brought back to them for their approval and content editing if desired; no other editing of the

words was undertaken; and the only copy of each tape was given to each participant at the end.

I applied some of these methods of reducing power differentials between the researcher and the researched to this research, such as participant validation/member checking, sharing control of the equipment, and refraining from cleaning up the quotes of people with dementia. As involvement in and commitment to the research are said to be requirements for respondent validation to be a meaningful process for the participants (Bloor, 1978), I was interested in how this technique could be adapted for research with people with dementia in a way that served a purpose beyond easing the anti-oppressive researcher's conscience. Fine et al (2000) suggested that we can facilitate voice though the use of long narratives, underplaying hegemonic voices, and creating room for counter hegemonic narratives. For this research, this meant using quotes from people with dementia, although it might have seemed to be no more than 'word salad' at times; giving more narrative space to the multiply oppressed people with dementia than to the multiply privileged; and stressing the voices of the people with dementia over those of their significant others and the literature. I did not do as well with the second injunction as with the other two as it was necessary to present data from the more privileged people in sufficient quantity to demonstrate the contrasts with the perspectives of the more marginalized people.

The complexities of eliciting informed consent from people with dementia have been dealt with extensively in the literature (Allan, 2001; Bartlett & Martin, 2002; Bowes & Wilkinson, 2002; Cheston et al, 2000; Clarke & Keady, 2002; Dewing,

2002; Downs, 1997; Feinberg et al, 2001; Froggatt, 1988; Hubbard et al, 2002a; Innes, 2001; Reid et al, 2001; Wilkinson, 2002b). The traditional consent process in dementia research has been disempowering for people with dementia in that they are usually left out of what has been seen to be a one-off event (Dewing, 2002; Hubbard et al, 2002a). The equation of a dementia diagnosis with incapacity has meant that family members or next of kin, who are not necessarily legal 'substitute decision makers', are routinely asked to sign proxy consent forms, without anyone assessing the person's capacity to consent or ascertaining their views on the research. To make this process more meaningful for people with dementia and perhaps more ethically sound, I engaged in ongoing negotiated or process consent (Allan, 2001; Dewing, 2002; Hubbard et al, 2002a; Reid et al, 2001). In doing so, I was following a burgeoning tradition in dementia research that appeared to be consistent with both anti-oppressive research and the relevant legislation on informed consent and substitute decisions (Province of Ontario, 1992; 1996). This approach is supported by the ethical guidelines of the Canadian Sociology and Anthropology Association (1994), the Alzheimer Society of Canada (1995) and the British Sociological Association (2002), although not explicitly stated.

Standard protocol on informed consent was followed, including the requirements that consent be given voluntarily, without coercion or influence; participants be informed of their right to withdraw from the study at any time, without any adverse consequences, especially in terms of services from the host agency; capacity to consent be determined by the ability to understand the nature of the research, the consequences of participating, and any alternative

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options; the consent process be documented and signed consent forms only used if they are not culturally inappropriate and do not pose social risks to the participants; and information be provided in accessible language on what the research is about, why it is being done, who is doing it, who is funding it and how it is to be disseminated and used (see Appendix K) .

The additional elements of negotiated consent included the following:

- the person with dementia was approached first about participating in the research, when possible, and prior to the significant other when not
- a substitute decision maker was approached, and their consent sought, only if the person with dementia was incapable of providing informed consent at the time
- proxy consent from a substitute decision maker did not preclude me from also seeking assent from the person with dementia
- securing consent/assent was not a one-off event, as consent/assent was (re)negotiated on a continual basis with the person with dementia
- determination of willingness to participate took into consideration both verbal and nonverbal communication, regardless of the person with dementia's consent to participate in the research
- props were used in seeking consent/assent, including the tape recorder, microphone, and both cameras, as well as a photo of an older person being interviewed

As this research drew on parallel knowledge traditions and crossed disciplinary boundaries, I realized that the findings were likely to have implications for several fields of study - dementia, ageing, disability, gender, ethnicity/race - and disciplines as varied as sociology, gerontology, anthropology, social work, cultural studies, and community health. When designing the study, I thought that the implications could be for any level of scholarly activity (theory, research, policy, practice), but felt the emphasis could be on theory, given the nature of the study. As the potential audience is wide and the research-policy-

practice interface important to me, both as a knowledge producer and consumer of research, I thought carefully about ways to disseminating the findings that balance ethical concerns and action research goals (Bryden-Miller et al, 2003). The latter requires publishing in multiple genres (DeVault, 1999; Fine et al, 2000), so as to reach the broad audience of people who may benefit from having the information (Kirby & McKenna, 1989). Towards this end, thus far I have presented my findings at local, national, and international conferences in the areas of dementia, social work, sociology and gerontology; published two book chapters and one photo-essay; shared the findings with research participants at feedback sessions in Toronto and Peterborough and with service providers at an in-service at the Toronto recruiting site; and developed an accessible hand-out on the key findings (Appendix O). Some dementia researchers might question the purpose and utility of sharing results with participants as the nature of their cognitive impairment may preclude any understanding of what is presented to them. Yet, as Elaine Robinson (2002: 106) wrote of her experience taking part in research:

> it would be very disheartening for us to spend our time taking part in interviews or providing written material only to find that we never hear from those conducting the research.

5.5 Rigour, trustworthiness and limitations

To ensure rigour in qualitative research, there are two goals that Mays and Pope (1995: 110) suggest researchers should strive towards:

> 1. an account of method and data that can stand independently so that another trained researcher could analyse the same data in the same way and come to basically the same conclusions
> 2. a plausible and coherent explanation of the phenomenon under scrutiny.

While I was aware of the possible incongruency of the first goal with a reflexive approach to research and a view of knowledge as situated (Mama, 1995b), I believed these goals were broad enough to adopt them for this research. To assess the rigour and trustworthiness of my research, I employed the criteria established by Glaser and Strauss (Glaser & Strauss, 1967; Glaser, 1978; 2001; Lowe, 1996; Strauss, 1987) to evaluate grounded theory: fit, workability, relevance, and modifiability.

In addition, I used several of the techniques that Lincoln and Guba (1985) proposed qualitative researchers use to establish the trustworthiness - the credibility, transferability, dependability, and confirmability – of their research. Of their suggestions, the methods I used were: persistent observation in the form of 'purposeful, assertive investigation' (Erlandson et al, 1993: 161); triangulation though interviews, participant observation, and photography with people with dementia, feedback sessions and focus groups with people with dementia and their significant others, and making use of the literature; referential adequacy with current and historical photographs of people, settings/events, and significant objects; peer debriefing through discussion of the research process and emergent categories with supervisors and fellow researchers in dementia/ageing; member checking in sharing working hypotheses and observations with the participants during the subsequent interviews and inviting their responses and giving written and oral summaries of the findings at the feedback session at the end of the research; reflexive journal in which I recorded my thoughts throughout the research process; purposive sampling for selection of all participants, consistent with theoretical sampling in

grounded theory; and an audit trail through entry of all documents created since start of research in N*VIVO project file.

As noted earlier, I initially estimated that the final sample would be comprised of 12 older people with dementia, four of whom would be multiply marginalized, four in-between multiply marginalized and multiply privileged, and four multiply privileged, on the basis of their relative positioning along axes of privilege and oppression labelled 'race', ethnicity, class, and gender. I realized within a few months of being in the field, that my sample would be smaller for two reasons: (1) I would not need 12 people to reach theoretical saturation, as long as the sample was diversified along the lines previously mentioned; and (2) I would not have enough time to complete the entire interview and observation cycle with 12 participants, as every step was taking two to three times longer than estimated, primarily because the interviews were running between 40 and 90 minutes in length, rather than the 20 to 30 minutes recommended in the dementia literature. As a result of these two factors, I decreased the estimated sample to 9 or 10 people, and would have reached this number had I been able to find another man willing to participate who was *not* multiply privileged[15]. I

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[15] As the recruiting sites in Toronto and in Peterborough were having difficulty coming up with potential participants who met my inclusion criteria in this last phase of data collection, I tried to draw on other community contacts, including a social worker for the Tamil community and a nurse practitioner with a senior's wellness clinic at another acute care hospital, both of whom were members of the Alzheimer Society of Toronto's Ethno-Racial Access Committee. Unfortunately, they did not send me any referrals, despite repeated requests; this lack of response may have been a result of the SARS outbreak that was overwhelming all health care workers in Toronto that summer. SARS had increased the workloads of the gatekeepers at my Toronto recruiting site, which prevented them from being able to help me, as much as they would have liked. For these reasons, I agreed to a friend's suggestion that I meet with his uncle, who appeared to meet the criteria for the in-between category - former chief petty officer in the Canadian military (middle class), White, Francophone from Quebec (minority ethnic), and a gay man (in the closet at the facility he was living in and with most members of his family). My hesitation related to the fact that this man was living in a long term care facility; he was not affiliated with either of the recruiting sites, his nephew was not sure whether he would be willing or able to talk to me, due to his cognitive impairment and his guarded nature; and I knew that I would have to do a lot of boundary maintenance work with his nephew. After weighing all these

was not able to secure the participation of a ninth older person with dementia who was a man and was either multiply marginalized or in-between multiply marginalized and multiply privileged. For this reason, I can not say for sure whether the findings with respect to gender differences, detailed in section 6.5, relate to 'being a man' or 'being a multiply privileged man', for example.

I have detailed the methodology and research methods used for this grounded theory study in the preceding sections of this chapter and will review their efficacy and suitability for this research and implications for future research in chapter 10. At this point in the thesis, I will provide more information about the actual process by which the categories[16] were derived from the data, before proceeding to discuss their properties[17] in the analysis chapters that follow. The three categories that emerged from the data are experiencing, othering, and theorising and the process by which these categories were extracted is detailed below.

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factors, I went to see this older man with dementia on my own and spent some time talking with him in his room at the facility. Although he had greeted me in a pleasant manner and showed a degree of interest in the study, his receptivity quickly waned and he lay down to sleep; I decided it was time to leave and told him that I would come back another time, to which he nodded assent. After a few more weeks of fruitless attempts to find another appropriate candidate, I tried to meet with this gentleman again, this time in the presence of his nephew. Due to the SARS outbreak and infection control procedures, we both could not enter the facility, so were forced to hold our discussion sitting in a row on a bench in front of the building. The potential participant declined to join the study, citing his hearing impairment as the reason for his discomfort; I suspected, however, that his concerns were more related to the possibility of probing personal questions and potential exposure of his sexual orientation, together with a lack of identification with and trust of a 'non-gay male' researcher (see Lee, 2003).

[16] I have decided to use 'categories', in line with grounded theory terminology. While I recognize the bounded nature of this term and that this is an example of the more technocratic elements of grounded theory, I wanted to acknowledge that this was a grounded theory study from conception through completion, not one that drew on grounded theory strategies. While 'themes' may be more preferable for its fluidity and recognisability, it pertains to qualitative data analysis more generally, rather than grounded theory specifically.

[17] 'Properties' is a grounded theory term that refers to the descriptive features of the categories.

As discussed in section 5.1.2, the data collection and analysis process in grounded theory is marked by its simultaneity; it is a back and forth process, with the analysis driving data collection, once the initial data has been gathered. The recommended data analysis procedure for grounded theory involves preparing the data[18]; reading segments of the data closely and repeatedly and asking questions of the data; forming two levels of codes – first concepts and later categories - through this close engagement with the data; making comparisons between and within cases; writing memos and diagramming relationships throughout the analytical process; and sorting the memos to form a theoretical framework. While my own analytical process did make use of all of these techniques, I did not follow a rigid, linear pattern. I struggled with the two step coding process, in particular line by line coding, as it seemed to result in a loss of vision; the basic social process in question was apt to slip out of sight while I was diligently breaking the data into tiny segments, applying a label to each of these parts of the whole, putting it all back together in a different shape, and calling the end product a category. Despite these reservations, I persevered and, as a result of analyzing all the interview and observation data for the first four participants plus data from the first interview with the fifth participant, developed the following working hypotheses on April 10, 2003:

> Social location does make a difference in terms of perspectives on memory problems (whether one problematises it or not) and thus how one adapts to it.
> How much privilege and/or disadvantage one has had affects how others respond to them with the more privileged folks being othered more often and more marginalized folks being treated 'normally' more often.

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[18] This may include listening to and/or transcribing some or all interview tapes, if one chooses to audiotape interviews rather than simply taking notes or memorizing significant details, writing up field notes from observations and interviews, and scanning or uploading photographs and other visual data, after they have been developed or photocopied.

> Self-identity is either the same or different in later life (as when younger) and it seems to be gendered (women=same; men=different) but not related to class or race/ethnicity so far. This is expressed as either/or, not both/and.

After further analysis and completion of the first interview with the 6th participant, I refined these hypotheses on April 15, 2003, discarding the third one in the process as it was not central to the study. On May 1, after interviewing the seventh participant for the first time and doing an observation session with the sixth participant, I made further revisions to my working hypotheses and added a definition of dementia as a bio-psycho-social phenomenon; these changes can be seen in the theoretical memo attached as Appendix L.

5.6 Emergent categories

The three categories I developed – experiencing, othering, and theorising - are all verbs and, as such, unintentionally conform to Charmaz's (2000) recommendation that grounded theorists use action words in their coding schemes. I had difficulty with this prescription at the outset of my analysis as I was struggling with knowing what was and was not relevant in the data and how to organize it, as with any grounded theory research, let alone which word forms would be most appropriate. It was only at the start of the writing-up phase of the research (Autumn 2003) that I came to understand the reasoning behind action words for codes in grounded theory: they indicate movement as opposed to rigidity; and help to illuminate the basic social processes underlying the phenomenon in question - a goal of grounded theory research (Glaser & Strauss, 1967; Charmaz, 2000). This knowledge came after a lengthy and difficult process of reconciling my research methods with grounded theory

dogma, particularly the more technocratic elements (Strauss & Corbin, 1998) that I felt constrained my thinking. Wuest (1995) indicated the potential for this intra-psychic conflict in her discussion of the 'tensions and congruencies' between grounded theory and other forms of meaning making, such as feminist research; and some feminist researchers feel that this can not be overcome (Letherby, 2003). This reconciliation process required that I first embrace the accompanying anxiety, and next locate an inhabitable space between conforming to the basic principles of grounded theory and diverging from it for justifiable reasons – in this case, to make the research process a more empowering and less oppressive experience for the participants. Despite my critical approach to grounded theory and hence rejection of some of its tenets, other researchers perceived me to be a 'purist' when I questioned their use of the label 'grounded theory' to describe research that did not appear to me to conform to the basic principles of this methodology. The most common example of the latter point is the adoption of the constant comparative method of data analysis in the absence of any other GT strategies, such as theoretical sampling and memo-writing.

5.7 Conclusions

This chapter has outlined the methodology and research methods employed in this research. I have shown how feminist theoretical perspectives and anti-oppressive methods can be applied to grounded theory research in order to make the research experience more meaningful for participants and researchers alike. I demonstrated the applicability and effectiveness of particular techniques such as process consent, photo elicitation, sampling by

social location, member checking, and dialogical interviews. In the next chapter, I will begin to explain some of the outcomes of this more inclusive method of research.

Chapter - 6   Engaging with the Dementia Subject

6.1 Introduction

This short chapter serves as a bridge between the previous chapter in which the methodology and research methods were detailed and the following three analysis chapters that explicate the properties of the categories of the grounded theory. In the sections that follow, I will discuss the concept of social location as it has been used in this research, introduce the research participants, and present data that relates to the process of engaging with older people with dementia and with the topic of dementia itself.

To introduce each of the research participants, I had intended to include short biographies accompanied by an emblematic photo and their self-selected pseudonym. I decided against the biographies as I felt I could not make this an inclusive process that allowed for self-representation and control over the outcome, which would be a written portrayal of a life story. I could not figure out how to write something other than a social work case profile without returning to the participants for more information and confirmation of the results and had not built this into the research design. In retrospect, I should have asked the participants to write a one page biography with the assistance of their significant others, which I could have included in the thesis. This is something that I will do in future research projects.

In lieu of the biographies, I have attached the attributes table that I created in N*VIVO (Appendix M); this serves as a reference for the analysis chapters in

which the participants are referred to only by their pseudonyms. Appendix F

contains the social location diagrams that I created for each participant and

Appendix N includes the emblematic photos for each participant. The

photographs I have included either were selected by the person in question as

their favourite or chosen by me, if the participant did not express a strong

feeling about any of the photos; in the latter case, the images are ones that I felt

were particularly emblematic and that I have used in past presentations on the

research. In the next section, I will explain my approach to social location and

its determination for each of the research participants, taking into consideration

the variability of social location, based on context, phase of the life course, and

other factors.

6.2 Social location

As detailed in chapter 3, social location refers to the relative amount of privilege

and oppression that people possess on the basis of their 'race, ethnicity, class,

gender, as well as other identity constructs that were not the focus of this

investigation, such as sexual orientation, age, and (dis)ability. I am using social

location interchangeably with intersectionality in the analysis chapters of this

thesis, as the former was an easier term to use during the course of the

research; and I now believe that intersectionality is a metaphorical state of

being that exists only in the consciousness of theorists and therefore can be no

more than an analytical lens through which a researcher views the social world.

The determination of the social location of each of the potential and actual

research participants[19] is unapologetically subjective, as this was a sociological

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[19] In trying to construct my theoretical sample from the sampling frame (gatekeeper referrals of
patients meeting the inclusion criteria), I used the socio-demographic information given to me to
draw diagrams for each potential participant; plotted them each along a continuum; and then

designation based on the participants' membership in particular social groups, such as lower income people, men, Anglo Canadians, and Black people. In this way, social location is similar to oppression in that it describes an externally imposed situation arising from the patterned attribution of positive and negative qualities to perceived social identities, with an understanding of power, and particularly the power to define others as 'invalid' (Hughes, 2002; Zola, 1982), being integral to this theoretical concept. The word oppression is often misused as referring to an individual perception of having been personally disadvantaged or wronged in some way, irrespective of social group membership (Tester, 2003); such usage indicates a disregard for the sophistication of theories about the dynamics of oppression and privilege.

While this thesis demonstrates that social location is connected to older people's experiences of dementia, it is important to note at the outset that social location itself is context dependent - this is not a static or fixed category. Two concepts developed by sociologists to indicate the fluidity of identity – 'translocational positionality' (Anthias, 2001; see section 3.2.3) and 'denationalized citizenship' (Sassen, 2003) – may be of relevance to this discussion of the context contingent nature of social location.

Though Sassen (2003), like Anthias (2001), is concerned with bridging structure and agency, her work relates more to the political economy of citizenship and rights than to 'those who are at the interplay' (Anthias, 2001: 634) or the intersectional being referred to in this thesis; her work asks us to consider

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based my decisions about which people to approach on this graphical information. These diagrams are attached as Appendix 6.

> to what extent citizenship, even though highly formalized, might actually be less finished as an institution than its formal representation indicates (pp 5-6).

Signs of such a termination of rights and responsibilities based on nation-state membership – 'denationalized citizenship' - can be found

> by tracing what are at this time micro-transformations in the institution of citizenship on the inside of the national state…tracing where we see continuities and changes in the formal bundle of rights at the heart of the institution and when the changes represent a movement towards post-national and/or denationalized features of citizenship (pp 21).

Both of these concepts point to the variability of social location, whether based on notions of citizenship and national belonging (Sassen, 2003), or on more transcendent identity constructs such as gender, ethnicity, class and racialisation (Anthias, 2001). This context contingency applies more generally to the Other and those who inhabit this category in various temporal-spatial localities. Reimer Kirkham (2003: 775) found in her study of inter-group health care relations that 'the construction of who is the other and who belongs is thus not stable but shifts across place and time'. To further support this argument about the context dependent nature of social location, I will give three examples: the first deals with ascriptions of 'racial' group membership and the connection to class; the second is about the variability of privilege due to ethnicity; and the last focuses on class and its interrelationship with age.

Processes of racialisation vary in different locales, so that a person may hold privileges due to their perceived whiteness in one setting and experience discrimination as a 'black person' in another. Angela Huggins explained how different 'racial' statuses were ascribed to her, depending upon whether she

happened to be in the West Indies, where she was born and lived until the age

of 14 years, or in Canada, her home for 'over 50 years'[20]:

Angela Huggins:	Well, I, I accept the fact that, that Canadians do look at me as a Black person.
Wendy:	Yeah?
Angela Huggins:	Yeah. So I, I…
Wendy:	But you don't see yourself like that?
Angela Huggins:	I, I don't classify myself as Black. I, I have four different races in my blood, I mean, how can it be…
Wendy:	How can you single out one? [laughs]
Angela Huggins:	Exactly! And in, in the islands, we don't discriminate like that. We have a class thing…

Later in the same interview, I returned to this point for further clarification:

Wendy:	So in Canada you're considered Black as you're saying.
Angela Huggins:	Yeah.
Wendy:	What would you be considered in, in Trinidad-?
Angela Huggins:	White.
Wendy:	[speaking at the same time]-in the West Indies? Yeah.
Angela Huggins:	[laughs] It's, it's funny isn't it?
Wendy:	Yeah, it's interesting. Hmm.
Angela Huggins:	And I could not go out with a Black man in Trinidad. I, I would be disowned.

As we can see from Angela Huggins' experiences in Trinidad and in Canada,

'race' is indeed context dependent and interrelated with class, as well as

ethnicity. However, ethnicity should not be conflated with race (Desflor Edles,

2004; Oommen, 1994), as the next example demonstrates.

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[20] It had actually been 60 years, which was clarified later on in the research when Angela Huggins confided that she has underestimated her age for years, and confirmed that the age her daughter had told me was correct.

Growing up in Canada as a white, upper middle-class, Anglo-Canadian, I took for granted my membership in the majority group culture and undoubtedly enjoyed the privileges associated with this status, although I was not conscious of having white privilege (McIntosh, 1989) until much later in life. My own 'moments of questioning' (Frankenberg, 1993; Tyler, 2004), which were no doubt prompted by a developing 'sociological imagination' (Wright Mills, 2000), took on greater significance when, at the age of 20 years, I lived in Spain for eight months to complete the third year of my undergraduate degree in Sociology and Spanish. Although I retained my white and class privileges, I was firmly located as an outsider throughout my residency in Andalucia (Southern Spain), being a non-native Spanish speaker; having no Spanish/Latino ancestors; wearing clothing, accessories, and a hairstyle that marked me as North American; essentially, being an ethnic minority. My outsider status was reinforced daily by shouts of 'guiri' (derogatory term for a foreigner) as I walked along the street, being ignored in the line-up to buy produce at the local supermarket, having groups of young Spanish students point and laugh at me, among other instances. After I had been in Spain for about four months, the Gulf War started and, as a precautionary measure, Canadian students were advised to follow guidance issued by the American embassy – not to speak English in the streets, not to wear clothing with American insignia, and not to gather in groups, particularly near train and bus stations. Although Canadians spend a lot of time emphasizing the differences between ourselves and our neighbours to the South, every time I spend an extended period of time outside North America, I am forced to acknowledge that our similarities are much greater than our differences, in an international

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context. To further demonstrate the complexities of ethnicity and privilege, although my North American accent marked me as an outsider in Spain, while I was working on a community development project in Costa Rica five years later, I was treated with deference more often than inferiority. This was due to the fact that Costa Ricans saw me as having a Spanish accent and speaking correct Castellano, as opposed to having a Latino accent and speaking the more colloquial Spanish of Latin America; and my Anglo-Canadian ethnicity and fluency in both Spanish and English were markers of status in that context.

I have related a few stories of my own experiences in an effort to be critically self-reflective; to demonstrate that ethnicity can be context dependent; and to highlight the importance of separating 'race' and ethnicity, if we wish to achieve an understanding of the complexities of marginalization and domination. I will now proceed to offer a third example that speaks to the variability of social class and the relationship with age or phase of the life course, in particular (Longino et al, 1989).

That social class can vary in time and place, taking on more significance in one country than another, can be seen in Angela Huggins' statement that her social class was more significant in Trinidad where they 'have a class thing' than in Canada where there is more discrimination on the basis of 'race'. The contingency of social class is particularly evident amongst older people after they retire and become wholly or partially dependent on the government for income support (see the discussion of structured dependency theory in chapter 2). Julianna Molnar was a physician and her husband Gyorgy an engineer during their working lives in their native country of Hungary. After they retired

from their respective careers and, a few years later, immigrated to Canada, their financial and social status changed dramatically. They became 'pensioners', with all the constraints and stigma associated with that label (Bytheway, 1995). In highlighting significant components of her life history, Julianna Molnar – the only survivor of the Holocaust from her family of origin - noted that anti-Semitism was the overriding problem during her youth in Hungary and that being dependent on the Canadian government and her family for financial support was the challenge of her later years:

Julianna Molnar: My youth was, it was very, it was very… There was a lot of anti-Semitism in Romania; there was a lot of anti-Semitism in Hungary. When we lived in Hungary, there was the big problem with anti-Semitism. Since we live here, we [inaudible], we are living on the government's money. But we are okay. For ten years, my son was providing for us. Then after that we got, how do you say…?

Wendy: Pension?

Julianna Molnar: It's a pension. I'm going to go ask my husband…

At this point, Julianna Molnar called her husband Gyorgy into the room and he proceeded to explain that their income support as a couple includes quarterly restitution payments from the German government to low-income Holocaust survivors, in addition to old age pension and rent-geared-to-income housing provided by the Canadian government. Although this amount is meagre, they can 'meet debts with it' and it allows them to be independent from the two adult children who supported them for their first ten years in Canada.

The first section of this chapter on engaging with the dementia subject draws on my own experiences and those of two of the research participants to

demonstrate the context contingent nature of social location, and to explain the way that I have approached social location in this thesis. I will now proceed to discuss the findings related to engaging with the dementia subject.

6.3 Reluctance to discuss dementia

In the previous section, I explained my understanding of social location and its application to this thesis and referred the reader to Appendices F, M and N that contain socio-demographic information and visual representations of Jim Heather, Joe Brown, Ester Hernandez, Bosse Knudsen, Angela Huggins, Julianna Molnar, Gus Holden and Nancy Matheson. The voices and actions presented in the following pages bring to life these people with whom I worked. Now, I will discuss the process of engaging with the dementia subject, focusing on the widespread reluctance to discuss dementia and the insight question in particular. The presentation of this initial data is meant to situate the reader and to prepare him/her for the detailed discussion of findings that is undertaken in the subsequent analysis chapters.

Most of the eight older people with dementia in this study were initially uncomfortable talking with me about what it was like to have dementia, although they had agreed to do so at an information and consent meeting held in their own homes less than two weeks prior to the first interview, and their consent was confirmed at each subsequent meeting. The participants did not refuse to answer questions on this topic, rather it was an area about which they were not as forthcoming, and to which I had to return repeatedly during the course of a single interview. This resistance to discussing memory problems is

exemplified by an extract from the third interview with Nancy Matheson, during which I tried anew to ascertain her views on having memory problems, which she again deflected:

Nancy Matheson: I don't understand why it's important to anybody what I remember or what I don't remember. I mean, it's nobody else's business.

Wendy: Okay, well I'm not interested so much in what you remember and what you don't remember, what I'm interested in [is] what you just said, that 'it's nobody's business what I remember', right?

Nancy Matheson: Yeah, that's right.

Wendy: Okay, can you tell me more about that?

Nancy Matheson: Well no, it's just a simple-I think the statement says itself; it really explains itself.

Wendy: It's nobody else's business?

Nancy Matheson: It's no one else's business. Uh-huh. I mean, I can remember something that happened 10 years ago or something but that wouldn't matter to anybody. That's not going to matter to anyone. Mm-hmm.

This feeling that one's personal thoughts and feelings surely would not be important to other people was expressed by other respondents as well, as shown in the following excerpt from an interview with Bosse Knudsen:

Bosse Knudsen: Yeah. Hey, come in here too [to her husband in the other room who tells her that it's okay and to go ahead and talk with Wendy]. No, I can't take it [to husband].

Wendy: It's just, it's just you and I talking…

Bosse Knudsen: Oh.

Wendy: Bosse. Yeah.

Bosse Knudsen: How come?

Wendy: How come?

Bosse Knudsen: Yeah.

Wendy: 'Cause it's you I'm interested in.

Bosse Knudsen:	Well how can you be int-, int-, interested in just me?
Wendy:	In just you?
Bosse Knudsen:	Yeah.
Wendy:	'Cause I'm interested in talking to you about what it's like to forget things.

In this case, Bosse Knudsen wished to defer to her husband, as indicated by her comment 'I can't take it', which does not mean 'I can't stand it', rather 'take' is used in the sense of 'conduct', as in conduct an interview. While Bosse Knudsen's appraisal of her own (in)ability to perform and of her husband's authority on the matter was likely a direct reference to her cognitive impairment, this can be seen also as an example of 'embedding one's subjectivity in another' (Gubrium & Wallace, 1990).

A slightly different explanation for her own reluctance was given by Nancy Matheson who felt that what she was going through could not possibly be of interest to anyone else as we are such unique individuals; therefore, the experiences of others are bound to be different than hers and of no significance to anyone but themselves. In her mind:

Eventually you'll have problems with something that you don't remember. And it's not going to be important to anybody but you at the time.

This insistence on the incomparability of experiences was part of Nancy Matheson's overall strategy to avoid the label of dementia, as discussed further in Chapter 8; this meant that she rarely responded to a direct question with a direct answer and presented excuses to explain her behaviour. For example, at the end of one particularly frustrating exchange, I asked her about the post-it

notes that were affixed to items all over her apartment and that appeared to carry little reminders.

Nancy Matheson:	What little sticky notes are you…?
Wendy:	Well, there's the one on the microwave, one on the tape player, up on the thermostat, there's a note by the entry phone…
Nancy Matheson:	Uh-huh…Mo-, most of them I think were maybe put up by Sandy [her daughter].
Wendy:	Oh, okay. And why did she do that?
Nancy Matheson:	In case, if I wanted a telephone number or anything like that, I would have it available. Uh-huh….
Wendy:	Maybe some of them are actually for the workers who come in-your support workers?
Nancy Matheson:	Could be.
Wendy:	Like the one on the microwave says, 'Please plug radio back in when through with microwave.'
Nancy Matheson:	Yeah, mm-hmm…mm-hmm.

At the end of this conversation I colluded with her in suggesting that the person the notes were meant to assist was not her, although I could have asked her to explain how the note next to the entry phone could be for anyone but her, as she lived alone and it contained instructions about which buttons to press to open the door for visitors.

The examples given thus far indicate the reluctance to discuss dementia encountered with nearly all the participants. I will return to this issue after addressing the insight question, a question that inevitably arises in research of this nature.

6.4 The insight question

What I have described as a reluctance to discuss dementia should not be seen as a lack of insight on the part of the person with dementia, as this was not the case. The concept of insight in dementia refers to 'the awareness of a patient that she has changed and that the changes are due to an illness' (Jacques & Jackson, 2000: 210). Determining the extent (or lack) of a person's insight is a standard part of any assessment, as 'insight and the lack of insight is a crucial ingredient in the progressive disorder that is dementia'   (Fairbairn, 1997: 17). Insight is believed to 'begin to fail very early on in the illness' (Jacques & Jackson, 2000: 211) and denial of insight is thought to be a coping mechanism, in that awareness of one's deficits has been found to be associated with depressive symptoms (Cotrell & Lein, 1993). The conclusion of a study of assessment procedures used to determine insight in people with dementia (Howorth & Saper, 2003: 113) was that 'insight in dementia is a complex, multi-dimensional, and value-laden concept'; and there is a need to develop an appropriate protocol for the determination of insight that features objective and subjective measures.   The term 'awareness' seems to be preferred by researchers concerned with the psychosocial context of dementia, although it too is acknowledged to be a complex concept (Clare, 2003). As intimated at the outset of this section, the insight question was raised repeatedly by gatekeepers in conversations about the research methods and potential participants; and I had to reiterate continually that I was interested in subjective experiences of dementia, not the relative truth value of statements about life with dementia.

My conclusion that the reluctance to discuss dementia that I encountered was not due to lack of insight is based on a subjective evaluation of each of these older people with whom I interacted on multiple occasions, for prolonged periods, in varied settings; this was informed by prior experience working with people with dementia in nursing, research, and social work and the unsolicited opinions of gatekeepers and significant others. The process by which an astute observer can distinguish between lack of insight and purposive action is not easily supported by a single data bite, as it represents an assessment of an individual built up over several interactions. Although she refused to acknowledge her memory problems, Nancy Matheson did show awareness that her memory was a concern to others and indicated that she felt she was being tested to see how well she could perform – both signs of insight. This can been seen in my notes from her 87th birthday party, the site of the second participant observation session, detailing our first greeting and the second time I approached her that day:

> After the others had said hello, I came over and said hello and she
> greeted me warmly by name and then exclaimed 'you're the memory
> girl.' I reminded her of why I was there - to observe and take
> pictures and at mention of the pictures, she said with a grin 'and I'll
> say I don't remember.'
> …
> When I wandered over towards Nancy again, who was sitting beside
> Louise [her best friend] and joking and laughing with Ann [a friend of
> her daughter], she said with a smile 'here's Wendy trying to test my
> memory'. I responded that I was 'not testing her, just watching.'

The question of what it is like to live with memory problems was the primary focus of my research and therefore, I had to repeat and rephrase this question several times in order to gradually piece together a picture of each respondent's attitude about dementia, which I then used in future interactions with them.

There was a Tagalog interpreter present for the interviews with Ester Hernandez, who alternated between English and Tagalog, and we tried several different forms of this question, partly because Ester was easily distracted due to her moderate-severe cognitive impairment. During one interview Ester Hernandez answered the question 'can you tell me what it's like to have problems with your memory?' with:

> I can remember, I have no problems with my memory, I can remember everything. Yeah, I can remember everything, every worker for example.

She then proceeded to talk about the workers in the Philippines and what they had called her, as well as the cleanliness of the apartment she shared with her daughter – the site of all of the interviews. A while later I pointed to a picture of an older Indian woman with dementia.

Figure 2 Alzheimer International Mary from India
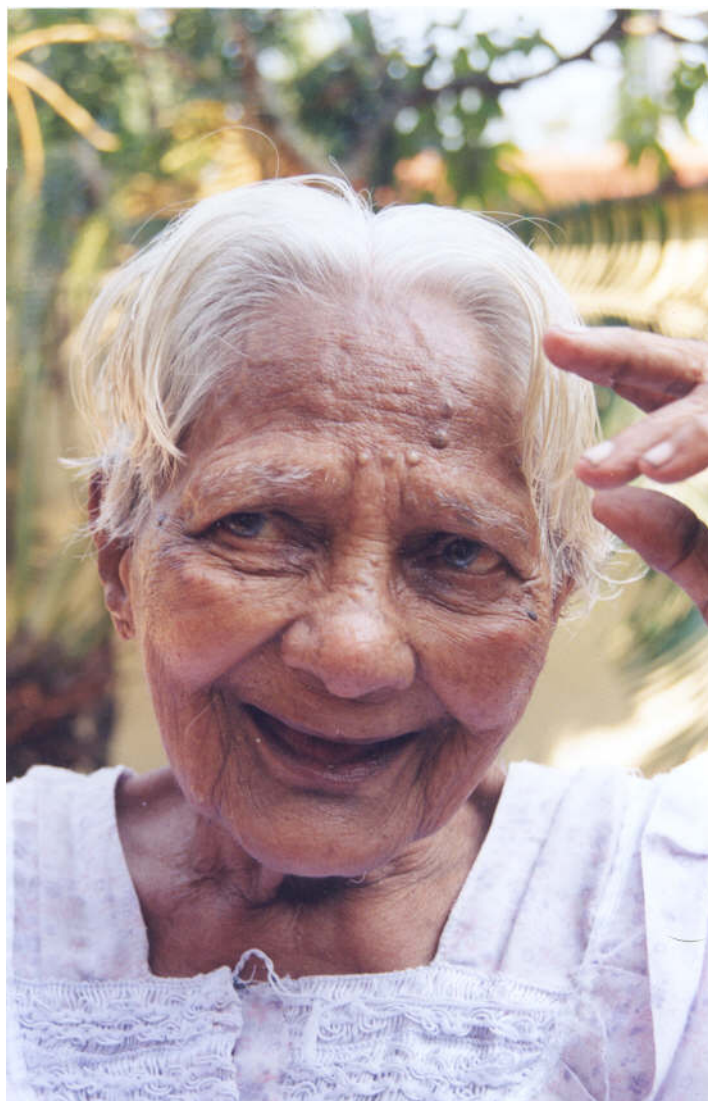
I told Ester that this woman had trouble remembering things and asked her what she thought that would be like. The ensuing conversation went like this:

Ester Hernandez: I don't know, somebody will…

Wendy: What do you think that'd be like?

Ester Hernandez: I don't know, I don't know.

Wendy: Well, what would it be like for you if you couldn't remember things?

Ester Hernandez: I do not, I do not interfere with any, any of them anyway. I don't understand what they are talking about like that.

Wendy: You don't understand what who is talking about?

Ester Hernandez: Yeah.

Wendy: Who?

Ester Hernandez: For example, somebody is talking, they are with it and they are not like others asking what are you guys talking about, I don't ask.

Wendy: So you keep to yourself, you don't interrupt?

Ester Hernandez: I don't ask what is the problem with you, I do not cross like that.

Wendy: So, if you see somebody else has a problem, you don't ask?

Ester Hernandez: No.

Wendy: No, okay. What about if you had a problem?

Ester Hernandez: I am not talking today.

Wendy: No, you don't wanna talk about that?

Ester Hernandez: I don't, I, I, I did not know, I do not know, I do not talk, I do not interfere, I do not ask.

Wendy: Okay. Do you have any problems at all?

Ester Hernandez: No.

Wendy: No?

Ester Hernandez: No.

Wendy: Okay, no problems.

Perhaps Ester Hernandez was resisting being categorized as a 'person with a problem', which is something even I seemed to be doing. Maybe she simply does not ask other people their business, and, therefore neither should I. Whatever her motivation, this interview segment indicates that Ester Hernandez was conscious of being considered 'with problems' by other people.

Participants often changed the subject when we were engaged in discussion of what it is like to have dementia. A poignant example of this is shown in the following passage taken from the second interview with Julianna Molnar, conducted in Hungarian and English, with the aid of a Hungarian interpreter:

Julianna Molnar:	Right now it doesn't affect it very much. But my husband, we go out almost every day, go for a walk, wherever we go, the ones that we keep in touch with, we speak either Hungarian or Romanian. Even if I speak to them, situations arise where I forget what I want to say. Other than that, it doesn't really interfere. Not in particular, there are certain things that I may forget, but if somebody reminds me, then…
Wendy:	Yeah. How do you feel when you forget things?
Julianna Molnar:	[laughs] Not good.
Wendy:	Not good?
Julianna Molnar:	[in English] Not good.
Wendy:	Can you tell me more about that?
Julianna Molnar:	To say more? I know very well, I was a doctor, I know well that at a certain age, there are certain things that are forgotten and your brain not working as it used to. For, at a certain level, at a certain level, I think it's normal but I don't feel good about it. I'd like to ask if you [the interpreter] could ask her [the interviewer] would you like to try some kind of sweet?
Wendy:	[laughs] Well, it's, we…
Julianna Molnar:	Because last time you were here, you didn't want it.
Wendy:	I had one, I had one last time.

> Julianna Molnar: One. I'm going to bring it [starts to get up].
>
> Wendy: Wait, wait just a few minutes. We're almost out of tape so [laughs].

After she admitted how it made her feel to forget things, Julianna Molnar deftly steered the conversation away from this uncomfortable topic by offering her guests some baked goods from the kitchen. The distraction was successful; and when I tried to resume the interview, she was saved from further interrogation of her feelings by the end of the tape.

With one notable exception (Nancy Matheson), none of the people in my sample outright denied having memory problems; they all admitted to cognitive difficulties to some degree, although Ester Hernandez was particularly cagey about this, denying having any memory problems during the interview and then joking afterwards that the interpreter had caught her forgetfulness (see section 9.5). This willingness to expose one's failing memory is reflective of the widely held view that forgetfulness is simply part of getting older, and therefore it is not particularly risky to admit to this deficit. The extent to which these older people - who had all been diagnosed with some form of dementia - were willing to ascribe to themselves medical labels such as Alzheimer's disease, dementia, or cognitive impairment varied, however, and a few did claim not to have dementia or to be familiar with this concept, notably Joe Brown and Ester Hernandez, although the former used the phrase 'old-timers' after I asked about 'Alzheimer's'. Owning up to memory problems did not require one to admit to having dementia, as these were taken to be two different things – one normal and one pathological. Katz (1996) explains in his seminal work on the formation of gerontological knowledge how the biomedicalisation of aging

process (Estes & Binney, 1991) resulted in 'a discourse of senescence' in which 'the aged body was neither diseased nor healthy but both normal and pathological' (Katz, 1996: 44). This dialectical view of the aged body will be addressed in Chapter 9 in relation to the theories that older people with dementia drew upon to explain what was happening to them.

In discussing what it had been like to be part of the research, Joe Brown admitted that he told people who had seen us together during the participant observation sessions that I was his nurse, rather than a researcher, so that they didn't think he was crazy.

Joe Brown:	People ask me and I just tell them, I say that's my nurse.
Wendy:	That's my nurse [laughs]. Why do you tell them that?
Joe Brown:	Well they ask me, I say that's my nurse.
Wendy:	But I'm not your nurse, why do you tell them that?
Joe Brown:	What should I say to them?
Wendy:	….well, I'm a researcher but I don't know if that would mean anything to them.
Joe Brown:	Well, then they say, oh man, you must be going crazy or somethin' [laughs].

Joe Brown told the bank tellers that I was 'a lady doctor' when we stopped by to say hello on our walk about the neighbourhood; his friends at the pub were informed that I was a police officer after they questioned him about me on his next visit there. All of these alternate identities for 'the researcher' helped Joe Brown to shift the focus of others to his physical health status, away from any suggestion of mental health problems. When I tried to ascertain whether Ester

Hernandez had ever heard of Alzheimer's disease, she interpreted my description of:

> …a disease that people get when they're older…when they, they forget things…no, it's not contagious…it's in your head…it's when changes happen in your brain

to mean 'mentally crazy'. After I had described Alzheimer's disease in these terms, she said:

> Me, I don't know…walking a lot…an old person walking around…

The interpreter explained that Ester Hernandez thought that Alzheimer's disease means that a person is 'sick in the head' or 'crazy'.

Several authors have noted that the word dementia does not exist in many languages other than English and that the concept itself does not translate well (Bowes & Wilkinson, 2002; Forbat, 2003). It is for this reason that I chose to use the term 'memory problems' at the outset of this research, though I had knowledge of the actual diagnoses from the gatekeepers. In addition, there appears to be much confusion amongst laypeople about the relationship between dementia, Alzheimer's disease, and memory problems, and the words are often used interchangeably; this can be seen in notes from the second observation session with Gus Holden:

> Sue introduced me [to Westie, a cottager] as a new friend doing research on dementia in Scotland and told Westie that since Gus has memory problems, he is working with me on this project. Westie registered recognition and told of his 93 year old mother-in-law who has Alzheimer's and is living in a care facility now and how he suspects his wife is 'going that way as well'. He prefaced his comments by noting that he doesn't know the difference between Alzheimer's and dementia, yet did not pause long enough for me to give him the explanation.

It was primarily due to the cultural relativity of the term dementia and the seemingly less threatening and more understandable nature of the phrase memory problems that I used the latter expression in the written materials and introduced the study with these words. After engaging with each participant, I adjusted the language used, selecting from a repertoire that included Alzheimer's, Alzheimer's disease, dementia, memory problems, little memory, memory loss, forgetting. The terms that I used in the interviews did not appear to correlate with the participants' views of dementia, and this was confirmed when I ran searches in N*VIVO for these terms. Through checking on this, I uncovered a significant finding: the participants did not draw upon the dementia lexicon at all for the most part; rather, I used these words and the participants talked about 'it', treating dementia as 'the white elephant' (Albee, 1965) in our interactions. I noted this studious avoidance of the topic of dementia on the part of significant others when having lunch with Jim Heather, his spouse and his eldest son during the first observation session:

> Despite discussion of my research, at no time was dementia
> mentioned by the family members or other people encountered
> (generally or specifically), nor was it acknowledged that Jim Heather
> has AD.

It was much later that I became conscious of this having occurred with the older people with dementia themselves; the N*VIVO search was instigated by a discussion about my theorising chapter with a fellow dementia researcher who asked me what words people had used to talk about dementia and whether or not this was related to their theories of dementia. The few exceptions were Gus Holden who referred to Alzheimer's constantly in all of our interactions, Angela Huggins who increased her use of the word Alzheimer's from our first interview

on March 27, 2003 to our last on July 28, 2003 and Jim Heather who talked around dementia, mentioning Alzheimer's related problems and Alzheimer's medications. This avoidance of the word dementia and associated terms on the part of the research participants is further evidence of the general reluctance to discuss this topic, and efforts to resist a problem focus and being reduced to a disease label. This resistance was not universally expressed, however, as will be discussed in section 8.5 on internalized shame.

6.5 Participants' evaluations of the research

Although discussion of their current lives in the context of dementia was not always welcome (see section 6.2.1), there was considerable interest in doing life review on the part of the participants. Invitations to share some background information with the interviewer were met with lengthy, detailed stories that took up to 45 minutes to recount; thankfully, the study design allowed for this flexibility. At the end of the research process, all of the participants reported that they had enjoyed the experience. Bosse Knudsen, who was one of the more cognitively impaired people in the sample, said about the experience:

> Now that, I have enjoyed it.

When I pressed her for reasons, she added:

> …just that you, you seem to think me for what I am… Not that, don't, you don't try to change me.

Angela Huggins, who had told me in the first interview that she was a private person, highlighted at the end of the process the extent to which she had opened up in the interviews:

> Angela Huggins: Yeah, because I don't even talk this much to um my homemaker, 'cause that's not what she's here for, and I-I'd be keeping her back from her work. But uh, with you I have voiced my innermost feelings, so. I mean I have been more honest with you than with her.
>
> Wendy: Mm-hmm. And how do you feel about that? What was that like for you?
>
> Angela Huggins: Fine. I felt more at home with you than the doctor. Poor soul [reference to second observation session].

Several authors have noted the importance of multiple interviews for building trust, as described in chapter 5, and this research has reinforced the value of doing so, even with people who may not recall a previous encounter with the researcher[21]. Angela Huggins suggested that the people who expressed negativity about their experiences with dementia might benefit the most from being part of research such as this, as it would allow them the opportunity 'to vent'. Some of the other participants highlighted in particular the opportunity to discuss dementia and how it had positively affected their lives and their sense of self in the time since they first had became engaged in the research. Gus Holden, in a long and thoughtful passage, told me:

> …I, I think it's been a good thing f for me because if I hadn't had it I would have sort of been crumbling like this, people who really don't know how to handle it would be saying things and I'd be trying to wrestle with them and see how they plug in and I think well I don't really know. But uh, this way you've made me think and you haven't told me how to think but you've just uh brought up a subject and then how do I feel about it and uh, you haven't uh for the most part said, 'no that's wrong.' Uh, you've just then asked another question which makes me think, 'hey, I hadn't thought about that so instead of going that direction, I'll be able to go that direction and around because of A B or C. Uh, I think, no question these have been a big help to bringing me back to my more or less an even keel in my life.

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[21] I took a Polaroid photo of myself with the participant at our first meeting and left it with them as a memory aid for our next meeting.

It was particularly gratifying when people spoke of the positive impact that participating in the research had had on their lives, especially in light of the long-standing, and hopefully now historical, tradition of avoiding talking to people with dementia about their experiences (Cottrell & Schulz, 1993; Downs, 1997; Froggatt, 1988; Lyman, 1989), a tradition that this study was designed to overcome.

6.6 Conclusions

This short chapter described the process of engaging with people with dementia as research participants and with the subject of dementia itself. The attributes table (Appendix M) emblematic photos (Appendix N) are meant to give a flavour of the diversity of the people with whom I worked and a sense of their individual lives. The data given in this chapter pertains to the participants' reluctance to discuss dementia, the strategies employed to avoid this topic, and the researcher's need to continually return to this area of inquiry and rephrase questions, in order to ascertain participants' views about the overall research question. This chapter has also attended to the insight issue, by arguing that this reluctance to discuss dementia was not simply lack of insight, rather it was a purposeful act. In addition, an unexpected finding was presented - that interactions were marked more by a lack of reference by the participants to any words from the dementia lexicon than by the predominance of any one term. I will now proceed in the first analysis chapter to introduce the experiencing category of the grounded theory, highlighting the continuum of views about life with memory problems expressed by this diverse group of older people with dementia and the spheres of activities in which they were engaged.

Chapter - 7   Experiencing Dementia

7.1 Introduction

The purpose of this study was to explore the relationships between older people's experiences of dementia and the intersections of 'race', ethnicity, class, and gender; in doing so, I discovered that there is indeed a connection between social location and subjective experiences of dementia.   These relationships between social location and the experiences of older people with dementia are complex and can be observed across the categories of experiencing, othering, and theorising, the focus of the three analysis chapters of this thesis.   This first analysis chapter focuses on the category of experiencing and sets the stage for the two subsequent chapters on othering and theorising. The aims of this chapter are twofold: (1) to examine the ways in which older people with dementia conceptualize their experiences of living with memory problems; and (2) to analyze the effects of their social location on their subjective experiences of dementia.

There has been an explosion of interest in ascertaining the views of people with Alzheimer's disease and other forms of dementia about their illness experiences (Braudy Harris, 2002; Wilkinson, 2002a). Although these efforts have been rather limited in scope, in that the focus has been on a narrow range of people, it is this particular 'partial view' (Henderson, 1998) that has shaped service delivery for all people with dementia. As became apparent through the course of this study, however, if a diverse group of people is sought out and asked for its opinions about dementia, a very different image of 'the experience

of dementia' emerges. Indeed, we can not say there is one experience; rather there are a multitude of experiences that reflect the gender, 'racial', ethnic, and class backgrounds of the participants of any research. As this thesis demonstrates, with a diverse sample, only a minority of the views expressed will conform to our present understandings of life with dementia – which are overwhelmingly negative. The first section of this chapter details the findings about life with memory problems for older people with dementia, and the continuum of perspectives represented, ranging from 'not a big deal' to 'hell'. The next section explains the connection between older people's experiences of dementia and their social location in more detail, using Maslow's hierarchy of needs as a heuristic device, and putting forth a reconstruction of self-actualization. After this, the narrowing and expanding of social worlds that occurs with dementia is described and the observed gender differences are presented. Lastly, some conclusions are offered about experiencing dementia, which lead to the next chapter on othering dementia.

7.2 Life with memory problems - from 'not a big deal' to 'hell'

This first section of the experiencing chapter offers a portrait of life with memory problems for the eight research participants, and introduces the main arguments that build over the course of the thesis and result in conclusions about dementia and intersectionality. I will describe the continuum of views about life with memory problems, from 'not a big deal' to 'hell' before moving on to look more closely at the preoccupations and spheres of activity of the research participants.

When I asked older people with dementia what it is it like to have this form of cognitive impairment, their responses ranged along a continuum from 'not a big deal' to 'a nuisance' to 'hell'. That is, very few actually described dementia in the negative terms employed by prominent books such as *The Loss of Self* (Cohen & Eisdorfer, 1986); *Who Will I Be When I Die?* (Boden, 1998); and *Losing My Mind: An intimate look at life with Alzheimer's* (DeBaggio, 2002). There was more of a diversity of opinion than has been seen in the literature to date and these varying views correlated with the social locations of the respondents. The more marginalized people dismissed the significance of dementia in their lives and the more privileged ones confirmed the commonly held belief that dementia is a living hell, as illustrated by the following extract from the second interview with Jim Heather:

Wendy:	Now how, what is it like to have Alzheimer's?
Jim Heather:	Hellish.
Wendy:	Hellish?
Jim Heather:	Hmm.

For Jim Heather, the world 'hell' summed up his views on living with dementia. When I asked him to elaborate on this, he went on to talk about the symptoms or limitations that it posed:

> Well, having um a difficulty coming out with the right words for example or phrases or um having difficulty with uh numbers and um dates, times, um having difficulty coming up with um, difficulty um, coming up with just a common expression uh, or um even words that are very frequently used by anyone without the disease and um having difficulty coming up with just ordinary expressions…

In contrast, for Joe Brown, forgetting things was not such a big deal, as his memory didn't play a big role in his life.

Joe Brown:	I forget things that I don't wanna remember.
Wendy:	Mm-hmm. But what's that like?
Joe Brown:	Don't bother me.
Wendy:	Don't bother you? How come it doesn't bother you?
Joe Brown:	I pay my bills, what else I gotta do. What, what else have I got to do, what other memory do I got to have?

Perhaps Joe Brown's communicative competence was not as bound to his self-identity as it seemed to be for the two other men in my sample (see section 6.5.2) - Jim Heather and Gus Holden, both of whom held more privileges than Joe Brown, on the basis of their 'race' (white) and social class (professional/upper).

Until now we have been exposed mainly to views that reflect the negative conceptualization of the dementia experience referred to earlier. As I have noted previously (Hulko, 2002), the voices of people with dementia that have been elicited to date have been limited in the degree to which they represent older people in general. The typical person with dementia encountered in published accounts of living with Alzheimer's disease or another form of dementia is a middle-aged (40 to 60 years old), well-educated, white, married professional in the early stages of dementia, with strong religious or ideological beliefs, and a supportive family (Hulko, 2002). This description almost perfectly matches the multiply privileged participants in my study. The exception is their age, as the average age of my sample was 77 years, with a range of 73-87 years.

As noted, several of the participants dismissed the significance of having dementia, some writing it off as age related and others focusing on the lack of impact it had on their lives. As Joe Brown stated several times:

> I'll tell you one thing about life, you remember what you wanna remember and you forget what you wanna forget…

Joe Brown did not see dementia as being significant or problematic in his life because, as he said:

> 'long as I can take care of Joe, that's all I'm worried about.

When I tried to ascertain whether or not Angela Huggins felt that dementia mattered in her life, she pointed out that 'old age' posed more challenges for her than dementia:

Angela Huggins:	Well I guess I'm lucky because I have a family around me. It's not something I'm ashamed of or anything like that. I, I don't really think it matters.
Wendy:	Okay, so you're more with the people that say it's not a big deal…
Angela Huggins:	Yeah, yeah…It's more the old age that is bothering me because I can't keep up, I can't run, like I say I can't go dancing, you know, this type of thing.

Several of the participants tolerated dementia, noting the inconvenience it caused and downplaying the negativity associated with it. Bosse Knudsen dismissed the significance of her memory problems and referred to her use of humour as an important 'coping' technique. A typical statement of hers evokes the acceptance shown by many of the older people with dementia:

> Yeah. My memory is not all that good. But here I am and here I stay [laughs].

Bosse Knudsen stressed repeatedly throughout our final interview that she was not treated any differently by those around her, whether they were aware of her dementia or not, and that people had always accepted her for who she is. The following exchange happened in the latter half of the interview and is an example of her efforts to convince me that people do not treat her any differently because of her memory problems:

Bosse Knudsen: Nobody, everybody has accepted me as I am.

Wendy: Mm-hmm. So you don't think there's anything wrong?

Bosse Knudsen: It might be that I have it [Alzheimer's] but what I am trying to say is they, they accept me the way that I am.

Wendy: Okay, well, how about how you feel about yourself though?

Bosse Knudsen: I feel good about myself.

Wendy: Do you feel any different?

Bosse Knudsen: No.

Wendy: No.

Bosse Knudsen: I am just a person that has something wrong with me and everybody accept me the way I am and I think that's wonderful.

Wendy: Yeah, I agree.

Bosse Knudsen: Yeah.

For those people who accorded dementia slightly more significance than Joe Brown, for example, several claimed that their memory problems were not a big deal, as the things that they tended to forget really were not that important.

I don't forget things I'm really interested in. - Angela Huggins
I always feel that if something's important, I'll remember it. I usually do. - Nancy Matheson

or they felt that it was a tolerable inconvenience:

Yeah, I'm forgetful…and it's a nuisance. – Bosse Knudsen

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While Julianna Molnar did eventually acknowledge that forgetting things caused her some emotional upset, by and large, she felt that her memory problems were quite manageable and pointed out how the actions of other people negatively influenced her ability to remember things.

Julianna Molnar:	It's a normal thing that at this age, certain things a person forgets, but they are, there are others who are able to keep their memory. My husband is six years older but has a fantastic memory.
Wendy:	Right, okay, so what…?
Julianna Molnar:	I forgot a lot of things.
Wendy:	Can you give me…?
Julianna Molnar:	So when somebody reminds me of it, then I remember. But when I have to think about it myself, about certain things, there are lots of things that I, I can't recall.
Wendy:	Can you give me an example?
Julianna Molnar:	For example, we are talking to each other, and I wanna explain something, to say something, somebody interrupts me…
Wendy:	Like me.
Julianna Molnar:	…and then I forget what I was going to say.
Wendy:	Like I've been doing.
Julianna Molnar:	[in English] Yes [laughs].

This awareness of the disabling actions of other people was evident in Angela Huggins' accounts of living with dementia as well. While acknowledging that dementia limits her activities, Angela pointed out that this is connected to the views of others and their assessment of her ability to function. Her words suggest that the impact of not being allowed to participate in a personally significant event due to another person's fears that she would fail could actually be worse than any negative outcome that might result from letting her try to do all that she can, and possibly failing in the attempt.

Well, it limits, it limits my activities. Like, the [Caribana[22]] parade is going to be on Saturday. Ashley [daughter] is in the parade, you know. [struggles with words] Uhh… [pauses and sighs] I don't even think I'm going 'cause she's against it. She says it's too crowded and I'm going to lose my sense of direction, which I do. Even driving, when I was, have my own car, when I was married and uh, I never know which is North or South. So she says you're going to get confused although I know the Lakeshore perfectly. But she says with so many people there I might even stumble and fall and [pause] but uh, I can't see staying home and not going, you know. Honest to god it's going to be-I'll probably cry.

As mentioned, there were a few people who saw dementia in a very negative light; they felt that it was extremely problematic in their lives. More pessimistic views of dementia were expressed by those in the sample with the most privilege on the basis of their gender, 'race', ethnicity, and class. The following quote from Jim Heather is representative of this view:

…awkward knowing that in front of you lies the territory we've never experienced before and that it's getting worse uh, a slippery slope which is um, uh, either you don't know whether it's steep or going to be…gradual.

Gus Holden did not have quite as negative a view of dementia as Jim Heather, yet he did clearly identify it as a problem in his life, as the following exchange demonstrates:

Gus Holden: Oh, it makes a difference, no, no.

Wendy: Makes a difference?

Gus Holden: Yeah, yeah. You can fight it or try to overcome it or step around it, but it's there and it's not as if you can say that 'what a nuisance, I'll push it aside and carry on uh, my regular, no, you can't, it's just a. It is a different way of life. And you can roll with it or I suppose you could go and hibernate, uh, tuck yourself away, but yes, it does make a difference.

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[22] Caribana is an annual festival of Caribbean culture that takes place during the August long weekend in downtown Toronto and is the largest festival of its kind outside the Caribbean; the highlight is a parade along the Lakeshore of dancers in traditional dress accompanied by musicians playing steel drums.

Gus Holden claimed that you cannot refer to Alzheimer's as a 'nuisance', as it is much more significant than that, yet 'a nuisance' is the exact term that Bosse Knudsen used to describe her life with memory problems, as seen earlier in this section.

While for the most part Nancy Matheson denied having any memory problems herself, she did describe what it might be like for 'other people' to have dementia, using familiar imagery and demonstrating some awareness of popular conceptions of life with dementia.

> I think they'd be sort of, it's like living in a fog, that you wouldn't know, you [hits table with open hand] wouldn't have any things [hits table again] you could grab hold of, you know as a, as a fact, that uh, yeah. I think that would be very difficult.

At the following interview, I returned to her description of what it might be like to have dementia (as above plus later comments) and, as can be seen in the excerpt below, in rejecting the application of these words to her own situation, she admitted to having dementia herself, and indicated that it is not as problematic an experience for her as it is for others.

> Wendy: One of the things that you talked about last time, you talked about how you thought having Alzheimer's would be like being in a fog or feeling lost and that you thought it would be very sad. So I'm wondering if you can tell me some more about that.
>
> Nancy Matheson: I don't really give it a thought. I don't really think about that. I don't feel like that. Uh-uh. I don't think so. I don't agree that I feel as though I'm in a fog. If I ever said that…

Some of the participants changed their opinions or had them validated over the course of the research through being exposed to the views of other older

people with dementia or having the opportunity to talk about what they were going through (see catalytic validity in section 5.5). Angela Huggins pointed specifically to the opportunity to compare herself with others as an element that she liked about being part of the research and noted how this had affirmed her own approach to dementia, which was to dismiss the significance, not to worry about it, and to focus on her remaining abilities.

Wendy: …Okay, well what did you like about the experience, about being a part of this research?

Angela Huggins: Well because I learned that there are other people who are worse off than me and some, you know, their- their trials, what is- what is bothering them, how they adapt. And then, then I think how lucky I am that I'm not as - My God, if I had- I think I would go crazy, if everyday I was saying, 'Oh god, I can't do this and I can't do that.' Oh no.

Gus Holden referred more to his own developmental growth that occurred over the course of the research, as opposed to himself in relation to others. At the start of each interview, he shared with me a self-assessment, focusing mainly on his mood and ability to perform tasks. Below is one of these reviews, taken from the final interview, and indicating progress towards the state of equilibrium that Gus Holden refers to having attained at the end of the research process.

It's interesting this uh, this week- and the previous week- have been very good ones: I get up and I feel as though it's going to be a good day, and sure enough it is. And that goes, I would say for the, four of the seven two weeks ago- the others weren't really bad. This week has been good up 'til today. And today I felt- nothing to do with you coming at all [laughs] - but uh, it was still reasonably better than it used to be. Because there are times when I thought 'No, this day is just hopeless; I just haven't been able to do anything.' I keep on trying mind you. But uh, others I feel I've really done something and yes, I understand that, and I remember what I did yesterday kind of thing. So, it's been up and down, but I would say, oh [sighs], since the beginning, this has been a good week. Not a great week but uh, compared to my…not a great week compared to what it used to be, but better than it had been for quite some time.

As has been shown in this section, there was real variability in the experiences of older people with dementia and their reactions ranged from seeing it as 'not a big deal' to 'a nuisance' to 'hellish'. These views were not static, however, as some people moderated their opinions over time, others divulged more feelings as trust increased, some learned to adapt to the limitations posed by dementia, and others had their views reinforced by hearing of the experiences of other older people with dementia. Further, perspectives on dementia were shown to be related to the reactions of other people and the extent to which their 'impairments' were made 'disabling' by their significant others, as will be discussed in more detail in Chapters 7 and 8. The connection between social location and experiences of dementia will be explained in the next two sections of this chapter.

7.3 Preoccupations or spheres of activity

The next section explores the preoccupations of the older people with dementia and how this relates to their social locations. I start with an explanation of how I came to use Maslow's hierarchy of needs (Maslow, 1970) as a heuristic device. After laying out this conceptual framework, I proceed to look at experiencing dementia in relation to the different areas of Maslow's hierarchy, treating them as spheres of activities or preoccupations, rather than basic needs, and demonstrating the relationship to social location.

7.3.1 Maslow's hierarchy of needs as an heuristic device

Not long after I started collecting and analysing data, I discovered that Maslow's hierarchy of needs (Maslow, 1970), originally published in 1954, was a useful

tool for explaining the associations I had begun to see in the data, particularly to people with some post-secondary education and no knowledge of sociological concepts (see Appendix L). Maslow's hierarchy is so ubiquitous (Rowan, 1998) that most of the people I spoke with were familiar with his theory and nodded in recognition as I reviewed the five levels in the hierarchy – physiological, safety, love and belonging, self-esteem, self-actualization (Maslow, 1970). By referring to this conceptual model and linking my findings to it, I was able to turn complex research into dinner party and barbeque conversation. As I collected and analyzed more data, I realized that there might be more significance to the Maslow connection and that I needed to find out what this social psychologist actually wrote about human behaviour, rather than relying on secondary sources. After critically reviewing the source document (Maslow, 1970), I turned to empirical testing of the hierarchy of needs and discovered that relatively little research of this nature had been published in the past 30 years (Rowan, 1998); moreover, despite the scorn that sociologists heap on Maslow's work, I found only two distinctly sociological applications/critiques of the theory (Bay, 1980; Sirgy, 1986). The sources I reviewed did not address one of my main criticisms of the hierarchy of needs, namely that Maslow attributes a person's inability to progress up the hierarchy to their individual neuroses, rather than seeing social location as an impediment to need fulfilment, as a sociologist and social worker such as myself might be inclined to do. Indeed, Maslow's (1970) conceptualization of a hierarchy of needs was rooted in Marx's materialist conception of history, as noted by Bay (1980); the latter is explained by Engels (Feuer, 1969: 11) as the:

> fact that men must first of all eat, drink, have shelter and clothing, therefore must *work,* before they can fight for domination, pursue politics, religion, philosophy, etc.

Several reviews have determined that there is a lack of empirical support for Maslow's hierarchy (Soper, Milford & Rosenthal, 1995) yet its popularity persists. Most of those who refer to the hierarchy, however, neglect the amendments and clarifications that Maslow made in his later publications (Rowan, 1998; an example of this can be found in Hanley and Abell (2002). Interestingly, if the changes proposed by Maslow had been adopted in later interpretations, the hierarchy would be well-supported by empirical evidence (Rowan, 1998). For example, Maslow distinguished between two types of self-esteem (self and other), yet this has not been adopted by his followers, some of whom critique him for presenting self-esteem as only derived from within (Rowan, 1998). Even more astoundingly, Maslow did not diagram his hierarchy (ibid); nevertheless, it is commonly presented as a pyramid (Trevithick, 2000), to the extent that this image has become synonymous with Maslow's hierarchy of needs. As I discovered, there are substantial grounds upon which a sociologist could theoretically engage with Maslow; for this thesis, however, I am treating his hierarchy primarily as a heuristic device. That said, I am putting forth a reconceptualisation of self-actualisation that I believe should be explored in more detail in future research.

7.3.2 Marginalization and physiological and safety needs

As noted previously, the more marginalized people in my sample did not see dementia as particularly problematic. They appeared to be preoccupied with their physiological and safety needs, and as long as the memory problems they

were experiencing did not interfere with their ability to attend to these needs, then dementia was not something to worry about. Joe Brown expressed this sentiment in the first interview and repeated it at the observation session that followed.

> I remember what I want to remember. I don't forget to pay my rent,
> to pay the hydro, etc. I eat, I sleep. Listen, dear, I'm 75 years old.
> Life's not the same when you're older.

He also talked of the importance of being able to take care of oneself and stressed that this was something he had been doing successfully his whole life. It was clear, however, that other people in his social world helped Joe Brown to maintain his independence and that sometimes this was appreciated, yet at other times, it was not; Joe Brown's receptivity to assistance depended upon whose involvement was required. Both of these instances are illustrated by an excerpt from my field notes written after our first meeting.

> While I was on the phone [talking to his niece about the research],
> someone banged on the door and gave Joe a pack of fish; he said
> people looked out for him and wondered if I told the woman
> downstairs why I was here. I said no as I wasn't sure if it was her
> business and he agreed that it wasn't her business and told me not
> to talk to her about why I was there.

Joe Brown lived in a social housing building for older people and 'the woman downstairs' was the manager of the building; he was worried that if I reported to her that he was having difficulties living on his own, she would force him to move out of his apartment. After Joe Brown and I completed all of our interview and observation sessions together and prior to the end of the research, Joe Brown was hospitalized due to a fall and did have to move into a care facility and relinquish his apartment. Fortunately, it was only a block away from his former home, which made it easier for him to maintain his community

connections and to continue with some of the patterns of his daily life. A few pictures from the observation sessions, which both occurred prior to his relocation, illustrate Joe Brown taking care of himself, through focusing on his physiology and safety needs. The rhythm of his daily life is best explained through his own words and related images:

> Whatever I do today, ain't, ain't gonna be no different than tomorrow.
> I get up, eat my breakfast, watch television, go out on the street,
> walk around, come home, watch TV and relax, bullshit, know.

Figure 3 'Joe Brown' walking with his neighbour

Figure 4 'Joe Brown' talking with the tellers in the bank

Figure 5 'Joe Brown' eating a Jamaican patty at 'the donut shop'

Joe Brown's constant 'sex talk' during our interviews can be taken as further evidence of a participant's preoccupation with physiological needs, as sex was identified by Maslow (1970) as one of the elements of this first level of his hierarchy of basic needs.   Sex is usually left out of enumerations of physiological needs in the literature on Maslow (Groves, Kahalas & Erickson, 1975; Hanley & Abell, 2002; Soper at al, 1995; Rowan, 1998; Trevithick, 2000). This trend is quite pronounced when the hierarchy is applied to older people (Umoren, 1992; Nydén et al, 2003), likely because older people are generally seen as asexual (MacDonald & Rich, 1983; Thompson, 2001). One exception to this omission of sex in relation to older people and Maslow's hierarchy is found in Nicklowitz and Choi's (1994) application of Maslow's hierarchy and the concept of aging in place, to the design of a university-linked retirement community. References to sex and money were very frequent in some of the initial interviews with older people with dementia, which could be an indication of a preoccupation with physiological needs. At that stage of the research, I was unsure what might prove relevant to the research question and, therefore, was diligently line-by-line coding all the data I had collected up to that point. Through this process, I had created 'sex talk' and 'money talk' codes, under which I filed away all the references to sex and money I encountered, thinking they were tangential and not at all important to the research. This could be an indication of the influence of secondary sources on Maslow - that omit sex, along with popular conceptions of sex and money as not important to older people, and certainly not basic needs.

Angela Huggins spoke of her ability to meet her physiological needs in order to counteract her daughter's concern about the effect of her memory problems; she dismissed as unimportant her inability to remember what she ate for lunch, focusing instead on the fact that she knew whether or not her nutritional needs had been met:

> …Like if you say 'what did you have for lunch today' and I sit here and I'm thinking, I, it's not important, why are you asking me this nonsense for god's sake. I mean I ate, I did eat, I'm not starving. But she [daughter], she wants to know every little thing you know what did I do, blah, blah. She, she's practicing her social work on me [laughs].

My own line of questioning was influenced by the fact that I had been a social work practitioner myself, as I detected a problem focus running through some of the interviews, in spite of adopting a theoretical position that older people with dementia remain active and capable social actors. Further evidence of this preoccupation with physiological and safety needs on the part of the more marginalized participants is provided by a conversation between myself and Ester Hernandez about cooking, during which we can see that the prospect of not being able to meet her physiological needs through cooking caused Ester Hernandez great distress:

Wendy:	Now you used to do a lot of cooking, didn't you?
Ester Hernandez:	I am cooking by myself.
Wendy:	By yourself?
Ester Hernandez:	Yeah, eating.
Wendy:	And how does that go for you? Do you have…?
Ester Hernandez:	Noth-, nothing, it goes for me for eating my, myself and my granddaughter.
Wendy:	Do you, do you manage okay cooking for yourself?
Interpreter:	[repeats in Tagalog]

Ester Hernandez:	[in Tagalog] Yes, [in English] I can do it by myself.
Wendy:	Okay, okay. Can you, what do you think it would be like if you couldn't do it for yourself?
Ester Hernandez:	What?
Interpreter:	[repeats in Tagalog]
Ester Hernandez:	[in Tagalog] Why, why can't I, why can't I cook? [In English] I can cook it by myself.
Wendy:	Ester [start of attempt to diffuse situation].
Ester Hernandez:	There is nothing wrong.

Julianna Molnar's preoccupation with physiological needs was indicated by her attention to ensuring that her guests were adequately fed and watered at each interview (see section 6.4). Her concern with both physiological and safety needs is shown by her story of the difficulties she had walking and going to the grocery store, which she told me about in the third interview in response to a question about whether forgetting has changed her sense of self in any way.

> It wasn't that I'm forgetting that changed me. It's more so that I'm having more difficulty moving, having more difficulty doing things. For example, I'm…um…I'm scared to go out alone for a walk. Now that my husband is not home…I have my walker there. If I really have to go to IGA [grocery store]…if the sun's shining, I might go a little further and then I come back. But I'm always holding on to that [indicates walker].

A preoccupation with physiological and safety needs amongst the more marginalized participants has been demonstrated through their talk about sex, money, groceries, cooking, eating, sleeping, walking, and paying bills, for example. Not only are these all features of the hierarchy of needs, they are also 'activities of daily living' (ADLs) or 'instrumental activities of daily living' (IADLs) – both major preoccupations of those working in the dementia field (Beck, Zgola & Shue, 2000). The link does not seem to get made between Maslow's hierarchy of needs and the dementia discourse on ADLs and IADLs

(Beck et al, 2000), however, though this clearly was the foundation for this taxonomy.

7.3.3 Privilege and love and belonging and self-esteem needs

The most privileged people in the sample had the luxury of being preoccupied with their love and belonging and self-esteem needs, as their physiological and safety needs were never an issue. Yet, because they were focused on these 'higher order' needs whose fulfilment required the involvement of others and which were more threatened by dementia, being cognitively impaired was a very big deal for them. Jim Heather spoke often of 'the slippery slope' and was preoccupied with the impact of his having dementia on his family members, particularly his becoming a burden to his wife and the reactions of his grandchildren, as well as the quality and duration of the disease trajectory. His words evoked a sense of the existential concerns he was contemplating:

> …and um I'm concerned about [wife's name] um having the same feeling, you know is this going to be steep or shallow or what is it going to be and how is it going to affect both of us and what, what's, what um can we do or you know, you really feel that you've got no attack, from our point of view to prevent what's going to happen.

Gus Holden similarly focused on his family and the role that they played, particularly his spouse Sue:

> If a man doesn't have a wife that's patient, they're in trouble.

As he was talking about the significance of his wife's support, Sue Holden entered the room and, surprised by her husband's words of thanks, chose to respond in a joking manner:

> Gus Holden: It's wonderful to have, uh, to see, uh. Without her, I'd probably be tucked away in some in-, institution.

Sue Holden:	Yeah, well other times you probably wish I was tucked away somewhere.
Gus Holden:	[laughs]

Gus Holden also talked of the impact his dementia had on his ability to perform tasks that were associated with his prior career as an administrator and the gender roles in his household, which were being challenged by his memory problems. In the first interview Gus Holden described some of the difficulties he had been experiencing in managing the family accounts. When he returned to this topic in the second interview, he connected his task performance with gendered role expectations in the household, and it became clear from the content and delivery of his words that dementia was impacting on his self-esteem needs.

> It's when I am trying to do something that I've always done, well, finances is a good example. Uh, I've always looked after the family finances… That doesn't, Sue [spouse] not, she hasn't looked after the books so to speak, I have. And uh more and more I am finding it difficult to just sort simple things. There's a whole lot of cancelled, cancelled cheques and how do I sort them and how do I enter that in the computer.

In the final interview, Gus Holden spoke about the emotional impact of his memory problems and indicated once again that his self-esteem needs, as well as his love and belonging needs, were concerning him.

> Uh, I must admit there've been times when I've felt that Sue [spouse] has sort of abandoned me because she's so busy, she has so much going on and uh, she's inclined to say, 'Well, you did such and such,' uh, yes, of course I don't remember that…so I'm not, I'm not reacting properly. I should take it a that it's a problem for her and the girls [their daughters] and for anybody else to not understand uh, I guess I've said to myself several times, 'Oh, if only so and so could have a day feeling the way I do; that would make them understand what it's like.' Because you can't explain it as far as I'm concerned. I don't feel, uh, there are words to explain it, but I don't feel the words, the vocabulary I have will get that feeling across. Uh, but uh, I'm feeling, yeah, I think I'm feeling better. That it was a long slide down, leveled

off and I sort of [clears throat] almost gave up, I mean I chat with you, sort of, what's going to happen, how long can I possibly go on like this, and then, I would say that the last two weeks, maybe three, have improved. Now that doesn't mean that everyday I get up and say, 'By golly, I got this,' nothing like that. But I come down and I say to Sue [spouse], 'I think this is going to be a good day.' And there's nothing specific…it's not long before I think, oh yes, here's something that oughta be done and I'm going to tackle that first so uh, I…

This approach, that involved struggling against dementia and 'tackling' things that 'oughta be done', was employed by the men more often than the women, as will be reviewed in section 7.5.2.

The one multiply privileged woman – Nancy Matheson – focused on 'higher order' needs (Maslow, 1970), such as love and belonging and self-esteem more often than either physiological or safety needs. She did employ a personal support worker to ensure that all of these basic needs were being met, however, which mediated her experience of dementia (see section 7.4). In the first interview, after confirming that her independence was important to her, Nancy Matheson told me of the pleasure she derived from living on the 21st floor and entertaining 'lots of people':

Wendy: I, I get the sense that your independence is quite important to you.

Nancy Matheson: Well, yes. I think it is to most people.

Wendy: Yeah, I think you're right. I think it is to most people as well.

Nancy Matheson: Yeah, mm-hmm.

Wendy: Yeah.

Nancy Matheson: Yeah. I enjoy living on this floor, I have lots of people that come to see me and uh, uh, you know we have great discussions and everything and uh, I love it like that.

In looking at the photos from the first observation session, which took place primarily in the kitchen of her spacious condominium, Nancy Matheson once again drew my attention to her surroundings and the view from the 21st floor, overlooking a large urban park[23:]

> Nancy Matheson: This is my friend Barbara [personal support worker] in the kitchen…Barbara and… [chuckles quietly] a picture of Barbara and me at the table [laughs again wistfully]. This has been a great kitchen. I've enjoyed this.
>
> Wendy: Mm-hmm? What do you like about the kitchen?
>
> Nancy Matheson: I like the light, I like all the panes where I can see, you know, so far around the building. Mm-hmm, mm-hmm….oh yeah…

In section 7.4, further examples will be given to support the connection between Nancy Matheson's social location and her experiences of dementia, in relation to the narrowing and expanding of the social worlds of the research participants. In this section, I have demonstrated that love and belonging and self-esteem needs were more of a preoccupation than physiological and safety needs for the multiply privileged older people with dementia and that this affected the extent which they saw dementia as problematic.

7.3.4 Self-actualization through dementia

The most problematic aspect of Maslow's hierarchy (Maslow, 1970) is its presumed endpoint - self-actualization, which is often visually presented as the top of a pyramid (Trevithick, 2000). As noted earlier, Maslow did not diagram his hierarchy of needs and I was quite surprised to discover that the ubiquitous

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[23] Nancy Matheson did not grant me permission to use either of the photos that she was looking at while talking in this excerpt, as she felt 'they wouldn't mean anything to anybody'; I suspected the real reason was that the pictures contrasted with the image of herself as independent that Nancy Matheson was anxious to preserve and to present to others.

pyramid was not his product, as are other people when I share this little-known fact with them. If he had diagrammed the hierarchy, he probably would have included a parallel pyramid with cognitive and aesthetic needs (Maslow, 1970). This kind of visual representation of the hierarchy of needs - the pyramid - has proven problematic in that it implies (a) that there is an end point to individual growth and development and (b) that this is not far away (Rowan, 1998). This part of the hierarchy was not readily observable in the views that older people with dementia expressed about their experiences; for this reason, I have referred to the four other needs in discussing the findings of this research. There are indications in the data, however, that older people with dementia may have peak experiences and be able to achieve a degree of self-actualization, not in spite of having dementia, rather as a result of living with this impairment. McKinlay (1998: 1) hints at this notion in her description of dementia, which she included as a preface to her moving collection of telephone conversations with her mother prior to her mother's death due to multi-infarct dementia:

> A devastating disease of the brain. Unrelenting unstoppable losses.
> A way of dying. It could also be a state of mind. An experience of
> being stripped to essences. A journey of the soul.

This tentative theory that dementia facilitates self-actualization in a spiritual sense is consistent with the characteristics of peak experiences described in a little book Maslow wrote after formulating the hierarchy of needs: *Religions, Values and Peak Experiences* (1964). Disorientation in time and space, being more loving and accepting, and a move to uniqueness and 'to become more a real person' (p 67) are a few of the many features that Maslow highlights. As in the pyramid and the definition of self-esteem, this might be another example of Maslow having been misunderstood, as the spiritual element of the hierarchy of

needs is missing in much of his followers' work based on the hierarchy. Maslow himself might not have agreed with this tentative theory of mine, however, having written that:

> the aging body and the nervous system is less capable of tolerating a really shaking peak-experience (Maslow, 1964: xv).

Further, Maslow's opinion as to the rewards of achieving self-actualization does not exactly accord with accepted knowledge about dementia:

> living at the high level means greater biological efficiency, greater longevity, less disease, better sleep, appetite (Maslow, 1970: 57).

Summerlin and Bundrick's (2000) research testing the generalisability of Maslow's hierarchy that found that self-actualization is indeed possible under conditions of strain, is another possible source of support for a theory of self-actualization through dementia. Through interviews with homeless men, most of whom were African-American and middle-aged, they discovered that these multiply marginalized men had a very clear perception of who they were and their place in the universe and in this way could be seen to have achieved self-actualization. This awareness of one's place in the universe is evident in the words of Ester Hernandez, the most cognitively impaired of the participants, who told me that white people hold the power in the Philippines, as sugar plantation owners, and that they are hated by the rest of the population, including herself:

> No, no, but the ones who have lots of money is the white, they have lots of money, but every does hated them as long as we can. They can lead a big sugar making that all.

At the second observation session, Ester Hernandez again demonstrated her ability to distinguish class privilege, as shown in this excerpt from my observation notes:

> Ester said to me 'I think you are rich' and I asked her why she thinks that, what it is about me. She would or could not say why she thinks that.

Indeed, I was struggling with this very issue myself – the visibility of class privilege and the reactions of others – as can be seen in notes about a visit to the neighbourhood where both Ester Hernandez and Joe Brown lived, for a participant observation session with Joe Brown:

> I felt too white and posh for the surroundings in my clothing and with my gear (cameras). As I was walking along Bloor Street near University Avenue [wealthy retail area] earlier that day, a panhandler had asked me to 'spare some change for poor white trash.' Upon reflection I felt that this was not the way to dress in [Joe Brown's] community, for either place we visited [bank and 'donut shop'], my apparent (white and class) privilege in relation to them seemed to make people feel that they needed to impress me and perhaps to obey me or grant me whatever I requested. However, if I had dressed more casually I would not have been given the same respect and my outsider status would not be as noticeable, which I think it should be.

Maslow's theory (1970) contained the caveats that (a) one does not need to fully satisfy one need before progressing on to a higher order need and (b) certain conditions need to be in place in order for people to satisfy their basic needs, such as the absence of war or famine. Thus, his theory did not preclude that under conditions of strain, when presumably people are not having their physiological needs completely met, it is possible to meet higher order needs such as self-actualization. If dementia does indeed open one up to episodic peak experiences, this may mean that the hierarchy, as it is commonly used, is turned upside down. That is, people with dementia are self-actualizing through

their illness experiences, yet need assistance with their physiological needs – their 'activities of daily living'. As I mentioned earlier, Maslow believed that people are psychologically unhealthy if their needs are not met (Keegan, 2002), but what does this mean for people with dementia who are presumed to be psychologically unhealthy by virtue of their diagnosis?

Maslow (1970) sees life as being more complex at the level of higher order needs; higher need gratification leads to more individualism, which is thought to be positive; and 'the search for love and respect necessarily involves other people' (1970:58). Is self-actualization inherently spiritual or does it neglect spirituality as claimed by Hanley and Abell (2002)? Groves, Kahalas and Erickson (1975) suggested modifications to the upper end of the hierarchy, as they found self-actualization hard to operationalise; they added power, competition, accomplishment, and other-directedness (self, service, spiritual). Umoren (1992) uncritically applied the hierarchy to older people in nursing homes and called for more efforts to help residents move towards self-actualization, with the underlying assumption being that residents of nursing homes are capable of achieving this state. The extent to which self-actualization should and indeed can be assessed by others is an unexplored point in the debate over the validity of Maslow's hierarchy; as is the reality that this 'need' seems to be interpreted as being about having a competitive nature (Groves et al, 1975), as opposed to a spiritual one. If self-actualization is a spiritual goal, its achievement may not be outwardly visible, particularly to those who equate it with power, status and wealth; it may be an inwardly derived achievement.

Spirituality and dementia is a relatively unexplored area (Bell & Troxel, 2001; Froggatt & Moffitt, 1997; Snyder, 2003), despite the fact that religiosity is a theme in the majority of published accounts of living with dementia (Hulko, 2002), and that religion or spirituality have been found to affect meaning making in dementia and coping with the disease (Snyder, 2003). Work to date on spirituality and dementia has been primarily focused on recognizing that people with dementia are (still) spiritual beings and suggesting ways to support their spiritual needs (Bell & Troxel, 2001; Froggatt & Moffitt, 1997), as well as highlighting the role that religion and spirituality play in the lives of people with dementia (Snyder, 2003). The primary emphasis has been on the maintenance of spirituality, which exposes an underlying assumption that continued spiritual growth is not possible once a person develops dementia. Snyder (2003: 309) suggests that since there is a link between faith and cognition - 'to have a specific faith requires a degree of cognitive capacity to formulate a set of beliefs' - people with dementia might need the assistance of others to continue to practice their beliefs. If we view self-actualization as a spiritual and a subjective state, and acknowledge that it is possible to achieve under 'conditions of strain', perhaps a disabling condition such as dementia can facilitate spiritual growth and allow for self-actualization through dementia. There are indications of this possibility in a conversation between Anthea McKinlay and her mother that occurred less than a month before the older woman's death, which I am using to conclude this section. These poetic words of an older woman with dementia support my call for further consideration of the possibility of self-actualization through dementia:

> A: We're hoping that you're coming home very soon to live near us.
> C: Am I? We'll see.

A: Don't you believe it?
C: No, no, you see I have to go to a meeting upstairs to find out which way I'm going.
A: How do you mean?
C: You just go away and think about it.
(McKinlay, 1998: January 1997 entry)

7.4 Narrowing and expanding social worlds

The social dimension of the experiences of people with dementia is clearly an important area of research and is addressed in detail in the next two chapters; this section provides a bridge into the social realm. Some of the people in the study described how their social worlds had narrowed after receiving a diagnosis of dementia or once they started to have troubles with their memories, a theme in Snyder's (1999; 2001) compilations of the reflections of people with dementia. Keady (1997: 26) termed the basic social process undergone by people with dementia, following the appearance of symptoms, as 'maintaining involvement', which he saw as requiring transitions through 'taking the initiative', 'responding to events', and 'withdrawing from situations'. Although withdrawal from social contact is an expected phase of the dementia experience and clearly was part of some of the participants' experiences, it was not a widespread phenomenon in this study. Rather, the accounts reflected both a narrowing and an expansion of social worlds.

In this research, those with narrowing worlds were the more privileged people who tended to have wider social circles, serving on boards of voluntary organizations, being prominent local businesspeople, attending church or participating in ethno-cultural activities, for example. After a period of disengagement, they had reconnected with some of the groups with which they had been involved, though their engagement with civic affairs was very limited

compared to their lives before dementia. Jim Heather and Gus Holden were the best examples of this, as they had been community leaders, active with various groups including the board of the local hospital, Scouting, The Canoe Museum, and The United Church. Both men had withdrawn from responsibilities with these organizations following their diagnoses of dementia, and had started to gradually reacquaint themselves with some aspects of their former lives after this initial period of disengagement.

An example of ethno-cultural activities is provided by Bosse Knudsen and shows how her social world had decreased, and how she felt about this. For the second interview with Bosse Knudsen, her husband Sven produced a photo album with pictures of the two of them folk dancing with other members of the Scandinavian Society, as well as attending events at the Scandinavian Club in Oshawa (a larger city mid-way between Peterborough and Toronto). As she flipped through the photos and struggled to remember the people and the events captured on film in order to share this with me, Bosse Knudsen indicated her feelings of affection towards the Scandinavian community, of which she had been an active member. She expressed a sense of loss as well, believing that this was all in the past, and that such a gathering only happened in Denmark.

> Bosse Knudsen: Oh yeah, I know him and I know this one. This lady I don't seem to know and that man, these here I don't know. They don't look familiar to me at all. I don't know, do you think there are; are groups like that over here now?

Figure 6 'Bosse Knudsen' looking at photos of Scandinavian folk dancing

Wendy:	This one is here from what Sven was saying, this is the Scandinavian club that you go to here…the Scandinavian club I think is in Oshawa.
Bosse Knudsen:	Oh.
Wendy:	And the Danish church is in Toronto.
Bosse Knudsen:	[said with incredulity] Does, does it really still exist?
Wendy:	Yeah and Sven said you go only about twice a year, around Christmas time and then in the summer for some kind of barbeque.
Bosse Knudsen:	Yeah…yeah.

Gus Holden described how the difficulties he is now having with memory and language had forced him to withdraw from public roles and how his wife had taken over some of this voluntary work:

> The idea I can still, I still know how it should be done, how I'd like to do it but um, I, I know that if I got up in front of a group of friends and wanted to tell them something, um, I wouldn't be able to pull all these bits back and mesh them together into, not only a, an interesting comment or a, uh, exciting or a humorous one. But uh, I just couldn't do that now. But as far as, well, right now, [my spouse] Sue's got this whole thing clear in her mind and [intake of breath] she's going back and she's talked to so and so about such and such and she's gathered all this together and then she goes to a meeting and um, I wouldn't say she takes over, but she's completely at, at home, at meetings than what she used to be.

Gus Holden went on to explain how his wife was the one in control now, having taken on many of the functions he used to perform both publicly and privately; and when I asked him what that felt like for him, he spoke of the mixed emotions evoked by this simultaneous withdrawal (for him) and engagement (for her), which represented a transfer of roles in a sense:

> Uh, well on a good day, it's fine, uh, it doesn't bother me at all. I accept the fact that I can not do these things so don't hold it against Sue [spouse], it's uh. There have been days, bad days when I think 'uh, she's just taken everything that I used to do, I used to do that and I didn't have any trouble, why are you doing that, are you just

trying to put me down'. But uh, for the most part, I can keep that
from happening.

The final statement in this passage evokes the sense of mastery demonstrated by the men in the sample when describing efforts to control their responses to the disease and to overcome its limitations (see section 6.5.2). Gus Holden described how he felt he had achieved more of a balance in his life now than in the months following his diagnosis and how he had started to reconnect with activities and people from his 'pre-morbid' life:

Um, I do know that I've had a, a lot of peaks and hollows. Um, in the
last, since the last year probably more um, fewer bad spells and
more of equilibrium. I don't think I'm [intake of breath]; I don't worry
about it as much. Um, I've felt better for I don't know why, just life
seems to, well this is the way it used to be, I can continue it.

There was one group of people with whom Gus Holden felt more comfortable now than he had before he developed Alzheimer's. This was a group of men who had cottages on the same lake as he and his wife Sue. This community of cottagers – part of Sue's social world since birth – had always seemed insular and exclusionary to Gus Holden; yet with his disclosure of having Alzheimer's, he was made to feel an insider. The first quote, taken from the third interview during which we discussed the participant observation session at the cottage, illustrates Gus Holden's perspective on the cottagers as a closed community:

They know each other, they know the histories of the other families
up there, they know when these people had their cottage built, what
happened to them, when the first boat came etc. etc.

When he discovered that they shared something in common, namely their status as people with Alzheimer's disease, Gus Holden felt more comfortable around this group of men, a fact that he mentioned in two separate interviews:

Turned out that there must have been, we, there was a group
particularly going to a certain uh, uh, person's place and there must

have been ei-, ten, twelve of us and turned out that three of us, three of us had Alzheimer's and we compared notes.

…

And one of the things that made me feel better was a meeting which I think I may have mentioned, with a group at Stoney Lake, uh, who were my first contact with anybody who had Alzheimer's.

The narrowing of Jim Heather's social world was evident in the recounting of his withdrawal from the board of the hospital fundraising committee, a decision he had made so that his diminished cognitive functioning would not negatively impact on the work of the board.

Wendy:	So they wanted you to continue…
Jim Heather:	Yes.
Wendy:	…and you decided not to.
Jim Heather:	Um-hmm.
Wendy:	How, how did that go?
Jim Heather:	That, from their point of view, they were perfectly happy to go with anything that I suggested. Um and um that uh when they, I was surprised that they suggested that they would like to have me around still.
Wendy:	Why?
Jim Heather:	Um, particularly when, when uh, when I'd found out what, what my problem was which had come on very rapidly, um I expected, I assumed that, that um it, it wasn't the thing to do, to stay on, on the board. I think it, it would be um awk-, an awkward situation to be a member of the board and um be in a position where I had to come up with some important information and so on and to be involved in the amount that I was involved earlier would be, would not be in the best, the best interest of the, of the, the board or myself. [pause] And it's worked out quite well.

This expectation of shunning, and withdrawal in order to avoid it, will be discussed further with respect to internalized shame in section 7.5. As shown earlier with Gus Holden, although Jim Heather withdrew from a number of his social engagements, there was a group of people with whom he felt

comfortable in his new incarnation as a person with dementia and which provided him with opportunities for meaningful social interaction. This group – called the Turtles - was composed of retired male professionals associated with the United Church and may have been people amongst whom Jim Heather had much higher status pre-dementia. Since he had relinquished his driver's license, a member would pick him up and drive him to group activities, such as the monthly pub lunch. Unfortunately I was not allowed to attend the meeting that occurred during the data collection period, as women are not invited to attend, which was the precise reason I wanted to observe this part of Jim Heather's social world. The number and range of social engagements open to both Jim Heather and Gus Holden is evidenced by the possibilities that existed for observation sessions. For example, I did three participant observation sessions with Jim Heather and could have gone to at least three other events over the six weeks, yet with Ester Hernandez, it was a challenge to come up with two different possibilities during the same time period.

Angela Huggins was quite an independent person and accustomed to spending time on her own; the annual festival of Caribbean culture and music – Caribana (footnote 16) – was a very important part of her life, as was the neighbourhood in Toronto in which she lived. With respect to these two examples, her social world definitely had narrowed, yet this was not seen to be due to dementia; she attributed her withdrawal from Caribana more to her arthritis and her lack of social interaction to her recent (reluctant) move to a new city. This is shown in an excerpt from my field notes from the first observation session:

> Angela told me that she would love to go to Caribana but is not sure how she would get home afterwards as Ashley [her daughter] will be

performing in it again this year, exclaiming 'I'll be so frustrated if I can't be there.' Ashley asked what we were talking about and I filled her in. She said she's not confident about leaving her mother on her own with what's going on, so Angela asked 'what's going on?' Ashley gave a vague response about how Angela is forgetting things and this was not pursued at all.

During the second interview, Angela Huggins pointed out one of the factors that negatively affected her life at present – being alone in the daytime. She knew this could not be changed, as Ashley [her daughter] had to work, and so she felt that she had 'to grin and bear it'. Later in the same interview, she clearly identified factors other than her dementia as causing the narrowing of her social world:

> The only thing I'm feeling now is being up here [a mid-size city 100 kilometres North of Toronto]. So, you know, that's the only thing. I'm not, I'm not conscious of having Alzheimer's or anything like that.

Julianna Molnar's situation was different than the other participants, in that her social world had been drastically reduced following the Holocaust in which her entire family was killed; and had narrowed again after her immigration to Canada in later life. In Toronto, Julianna Molnar's opportunities for social interaction were quite limited as neither she nor her husband were in paid or volunteer employment and she did not feel confident communicating in English. Nevertheless, she did mention a few people with whom she socialized and noted a few of the factors affecting her ability to spend time with other people, such as her age and the availability of other Hungarian or Romanian speakers.

> Julianna Molnar: The situation is that the people who are our age, we can't really get together. There is a couple who live at the other end of Scarborough [community in East Toronto]; we get along the best, who are going for a month tonight to Budapest. We get along with them best because they are the ones closest to us in, in their…

> Wendy: Physically close?

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Julianna Molnar:	…years.
Wendy:	Oh, age wise, meaning their age.
Julianna Molnar:	In their years, age. We also deal a lot with younger ones, especially the ones that my son gets along. Uh, we were there just, they are from Romania specifically. It's a young couple. The woman's aunt, we went to university together.
Wendy:	Do, do you…?
Julianna Molnar:	She is nine years younger than I am but we were really good friends. We understood each other.
Wendy:	Do you feel closer to Hungarians and Romanians then?
Julianna Molnar:	Those ones I can really speak to. For example, the ones in Scarborough, they are Hung-, they speak Hungarian, they don't speak Romanian because they come, they are from Budapest.

Three of the participants expressed a view of themselves as independent, to varying degrees – Angela Huggins, Joe Brown, and Julianna Molnar. While this attitude of independence was stressed to the interviewer, it was not always observable in their actions, as seen in the reference to Joe Brown in section 7.3.2. In discussing the two observation sessions that had both involved visits to the same local pub referred to as 'the donut shop', Joe Brown confirmed that what I had observed – him spending a great deal of time on his own – was his typical behaviour.

Wendy:	Well, that you seem, you seem to spend a lot of time on your own, sitting on your own, is that what you usually do?
Joe Brown:	What sitting by myself?
Wendy:	Yeah.
Joe Brown:	Oh, I know people sitting there, I don't, I don't know who sit with me, I sit by myself, don't bother me.
Wendy:	Okay. Do you usually talk to other people?
Joe Brown:	I talk to other people. If, if, if I feel like, if I feel like sitting by myself, I sit by myself and read the paper.

Angela Huggins spoke of her independence as well as the safety and comfort she felt in her 'own little world', a phrase similar to the language used by Vittoria (1999) to describe the world created by care assistants working with people with dementia in residential care.

> Angela Huggins: …I, I am very happy by myself, I'm really not, not seeking some companionship even, nothing. I, I have my own little world, like I'm safe in it, it's like a cocoon you know, I'm safe in my little world there, it's just great and now I have my grandchild, that's my life. Yes, I'm very happy.
>
> Wendy: So tell me a little but about your, your world that you're safe in.
>
> Angela Huggins: Well I, first I'm independent enough that I can go wherever I want to, I don't have to ask permission. Because when I was married, it was, marriage it was like being in boarding school, sister may I do this, may I do that, you know and I thought ahh, not of my temperament, it didn't go, it didn't jive at all. But uh, I mean I, the, the years I spent in boarding school, it, I was more lonely than, than anything else, you know, but then I would get, I read a lot. In my apartment you'll say 'my god, is this a library'. I have books all over. So, I lose myself in my world, that's like my world.

This safe and familiar world described by Angela Huggins had been disrupted just prior to the research when it was determined that she should not be living alone and thus she was forced to move in with her daughter in Barrie - a much smaller city about 100 kilometres North of Toronto. Although she still spoke of herself as independent in this first interview (see above), this sense of herself was less evident in later interviews, in which she spoke of how much smaller her world had become in this much smaller, less ethnically and racially diverse, and more spread-out city, where she was a foreigner. This relocation, and resultant narrowing of her social world, was a direct result of having been diagnosed with dementia and labelled a risky person.   Although Angela

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Huggins was still 'living in the community', her movements were restricted by a lack of personal transportation and unfamiliarity with this new neighbourhood. Similarly, although Julianna Molnar did not live alone, she spoke of being on her own even when her husband Gyorgy was in the house as he spent a great deal of time on the computer. In the second interview, she told me with a laugh:

> My husband's on the computer more than he is with me!

Julianna Molnar returned to this theme of being alone, even in the company of others, during the final interview:

> I don't like to be alone. Uh, but the much of the time when Gyorgy is at home I am alone because he's at the computer and uh, and we are together only can I say when, when we are eating and usually if it is when we have supper, uh, we uh, we, uh, if it is cinema…we watch a movie together.

As has been shown in this section, the participants as a group experienced reductions and expansions of their social worlds, and this was related to the kind and extent of opportunities for social engagement that had been available to them prior to dementia, as well as other factors such as age, language, and relocation.

7.4.1 Mediating factors

As mentioned earlier in relation to Nancy Matheson (see section 6.3.3), access to financial resources and 'social capital' (Bourdieu, 1968) played a role in mediating people's experiences, particularly their opportunities for social engagement. While the most privileged older people with dementia – Gus Holden and Jim Heather – spoke of having withdrawn from past community involvement, they still had more opportunities for social interaction than the

more marginalized people in the sample, who had never had the extensive social networks, in the formal sense, that these men enjoyed. This is consistent with findings that older people living in deprived areas in the UK have high rates of exclusion from formal social relationships within their communities and low levels of engagement in civic affairs (Scharf et al, 2002). I had noted that Joe Brown appeared to hold the position of 'King of Kensington'[24] in his neighbourhood and that he certainly had an extensive informal network, yet these kinds of social relationships and interactions often are not captured in aging research that focuses on services and formal activities.

Nancy Matheson did not belong to any community groups and seemed to have limited opportunities for social engagement, apart from her family members and personal support workers. She could afford to hire two personal support workers (Barbara and Aissa), which increased the number and range of her social interactions. These workers, whom she referred to as her 'friends' helped Nancy Matheson with her ADLS and IADLs - her physiological and safety needs - and engaged her in conversation over the five hours they spent with her on their assigned days. In addition, Barbara accompanied her to the weekly film showings in the building, and they both took her for daily walks around the neighbourhood. Both Barbara and Aissa were invited to Nancy Matheson's 87th birthday party and Aissa attended, along with her husband

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[24] The King of Kensington was a popular CBC television program in Canada from 1975-1980 that featured a character names Larry King - a 'pillar of the community', font of local wisdom, and shopkeeper in the Kensington Market area of downtown Toronto; the role was played by Al Waxman, who was born in the community himself, and who never lost his association with 'the King'. Kensington Market was, and still is, a densely populated, multi-ethnic, working class neighborhood that has the best produce market, butcher's shop, cheese store, and second hand shops in Toronto. This was not the area in which Joe Brown lived, though it is similar and most Canadians would understand the reference to someone being like the 'King of Kensington'.

Frank, though Barbara was unable to make it in the end. The extent of involvement that Aissa and her own family have with Nancy Matheson can be detected in the picture below and the observation notes that follow, which detail conversations that occurred between the two interactions with Nancy Matheson cited in section 6.4:

Figure 7 'Nancy Matheson' with Aissa (HSW) at birthday BBQ

> After this interaction, I went and sat behind Aissa and Frank, as it was a good spot from which to observe Nancy. As I was sitting there, they engaged me in conversation and I learned that Frank is a limo driver and that they are both 'Arabians' who immigrated to Canada in 1971…. I asked if they came through Pier 21 in Halifax or whether it had been closed by then and Frank clarified that they were immigrants, not refugees, and said that they had come directly to Toronto… Aissa told me about her family, including the fact that she is a grandmother and that her grandson really likes Mrs. Matheson.

Had she not been able to afford her own personal support workers, Nancy Matheson would not have been able to remain in the condo that she spoke of

with such fondness (see section 7.3.3), and may have had to move into a care facility as Joe Brown was forced to do during the course of the research (see section 7.3.2).

At the second interview, as she looked at photographs of herself and her personal support worker Barbara from the first observation session[25], Nancy Matheson made it clear that Barbara played a very significant role in her life – referring to her consistently as 'a good friend'. It is obvious that Barbara's presence mediated Nancy Matheson's experiences of dementia.

> Nancy Matheson: Mm-hmm, mm-hmm, yeah, mm-hmm…I think this is when Barbara was giving me tips on how to stand up [looking at photo]. Uh-huh…Yeah, she's been a good friend. Mm-hmm…Okay now let's see, that's my friend Barbara, and I guess that's me at the end by the walker…
>
> Wendy: That's as we head out of the building.

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[25] Nancy Matheson looked at four photos during this section of the interview, two of which she did not give me consent to use when asked at the final interview.

Figure 8 'Nancy Matheson' leaving condo with friend Barbara (HSW)

Figure 9 'Nancy Matheson' walking with friend Barbara (HSW)

Nancy Matheson: Mm-hmm, yeah. She's been a good friend [little laugh]. Mm-hmm, yeah…boy the flowers look beautiful here don't? Mm-hmm.

Wendy: I think that's when you start singing *Follow the Yellow Brick Road* on the walk…

Nancy Matheson: Oh yes, because we were walking over a brick road. Yeah, mm-hmm, mm-hmm…Yeah Barbara's been a good friend [laughs again]…on our walk [looking at photo; laughs softly].

Wendy: Does this look like a fairly typical visit with Barbara? Some of the things that you normally do?

Nancy Matheson: Yes, I think so. Mm-hmm. Yep. She's the one I go to the movies with…mm-hmm…mm-hmm…yeah.

Ester Hernandez had very few opportunities for social interaction due to the degree of assistance she required with her activities of daily living and the financial strain her daughter was under[26]. Her life was restricted to dementia related activities and people – the dementia day program she attended three days per week; the personal support worker who came to her house for mobility exercises on the two other weekdays; and myself as a researcher for roughly 6 weeks. When the bus for the day program broke down, Ester Hernandez was not able to attend for over a week; and she could not come to the feedback session as it was too difficult for her daughter to arrange transportation, despite offers of assistance from myself and the reimbursement of travel costs from the Alzheimer Society of Ontario. No wonder Ester Hernandez had an active imaginary life, otherwise know as a 'tendency to confabulate'[27]. Her

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[26] Both of these issues were the focus of much discussion with Ester Hernandez's daughter and possibly the reason she had been so keen for her mother to participate in the research. While I expressed empathy during these conversations, I did not encourage her to discuss these issues during the research and waited until the end of the final interview to inquire about her sources of support and to refer her to the Alzheimer society and her mother's care coordinator at the community care access centre.

[27] Confabulation means 'making up answers to cover gaps in the memory' (Jacques & Jackson, 2000: 70). It would be interesting to look at how this medical discourse might be used to

opportunities for stimulation were so limited that it was surprising how well she was able to function and to resist efforts to disable her.

7.5 Gender differences

Although I was not looking for gender differences on their own, or separate from other identity factors, clear distinctions based on gender did emerge from the data in relation to experiencing dementia; for this reason, I chose to separate out gender in this analysis chapter. While I did discuss 'race', ethnicity, and class in particular with respect to the variability of social location (see section 6.2), these other identity constructs, for which there were at least three variables each, appeared to be more 'inextricably intertwined' (Andersen & Hill Collins, 2001b; Anthias, 1992; Bannerji, 1995a; Bhavnani, 2001; Brah, 2001; Crenshaw Williams, 1994; hooks, 2000a). Had I selected two particular ethnic and 'racial' groups and two social classes, I might have been able to present the results as ethnic, 'racial', and class differences; I would not have done so, however, as this would be inconsistent with an intersectional approach. I present the following gender differences with the caution that the sample size was small (eight people) and included more women (five) than men (three), as discussed in section 5.3.5; for this reason, these findings should be interpreted with caution and need to be supported by further research.

7.5.1 Women - accepting and masking

The most prevalent attitude amongst the women in the sample was a frank acceptance of memory problems, an approach that some of the women had

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pathologise or label as problematic everyday 'bullshitting' or story-telling, such as that undertaken by Joe Brown with his friends at the 'donut shop' (see 7.3.2).

employed in response to past troubles, such as the illness or death of a family member. In the first interview, Nancy Matheson explained that worrying about problems like memory loss actually makes them worse and that one should try and avoid any such expressions of self-pity.

> Nancy Matheson: ...I don't worry about it. I don't worry about it. If you worry and fret about it, I think it makes everything worse. If you just 'oh gosh, I've lost my memory', you know. No, no, no, you don't do that.
>
> Wendy: So you think that makes it worse…?
>
> Nancy Matheson: Oh yes, of course it does. Yeah, you'd feel so-, if you're sorry for yourself, then that's no good.

Julianna Molnar indicated a similar perspective in the second interview when she answered my question as to why she does not tell most people about her memory problems, with a simple question of her own: 'why should I be complaining?' As this was a gendered attitude, it could be an indication of support for the hypothesis that older women are more accepting of ill health and other problems encountered in later life because they have been socialized to accept their lot in life and to just get on with it (Ginn & Arber, 1995; Hughes & Metzuka, 1992). The concept of resilience, which will be discussed in more detail in chapter 8, is useful for understanding this gendered approach to problem management, as it refers to strengths developed in the face of structural disadvantage. Nancy Matheson stressed repeatedly the foolishness in 'fretting and fuming' about things that one has no control over; and in the final interview, she summarized her opinion thus:

> I mean there's no use fretting and fuming about it. That won't do you any good.

The women employed various strategies to downplay the significance of dementia as well; in this way, they may have successfully 'integrated' dementia into their lives (Keady & Nolan, 2003). For example, Bosse Knudsen, who described herself repeatedly as a 'people person' used humour to compensate for her inability to remember, as demonstrated in the following quote:

> No…I really don't worry about it, that I, that I can't remember so good. Just that, either sometimes, sometimes happens you know that there's something I have forgotten and then instead I'm, we just laugh about it, yeah.

It may be significant that Bosse Knudsen said '*we* laugh about it', rather than *I* laugh about it. The personal pronoun plural also was used by other participants in describing how they dealt with memory problems. In the following quote, Angela Huggins explained what happened when she forgot a doctor's appointment and tried to claim that her daughter had not told her about it:

> And I'll say, 'you never told me. I don't remember that.' And she says, 'Uh-huh. I know, old age setting!' And we make a joke about it. We don't argue about it.

This strategy of aligning oneself with others to dismiss the significance of dementia was seen in Bosse Knudsen's constant declarations that other people took her the way that she was, that they did not treat her any differently, as shown earlier in section 7.2. The disconnect I observed between the participants' views of their treatment by others and the actual words and actions of others with whom they interacted will be explored more fully in the next chapter on othering, particularly in section 8.4.

Several of the women also noted that they did not disclose their dementia status and in a sense chose to pass (Goffman, 1963). In a discussion of

whether she was treated any differently due to dementia, as other participants had indicated, Angela Huggins questioned the need to tell other people about her diagnosis, explained that non-disclosure ensured her continued status as a normal person (discussed in detail in section 9.5), and demonstrated that her strategies varied depending on the degree of familiarity she had with the person in question.

Angela Huggins:	Well, I mean I don't tell everybody if I go to the store shopping, I don't tell everybody, 'by the way… [coughs] by the way I have Alzheimer's.' So I don't see how I could be treated differently.
Wendy:	Okay, what about with your friends though. Do you tell them at all?
Angela Huggins:	Yeah, yeah, I make a joke…I'll say, um, um… let's think…someone was supposed to go to the show the other day and he didn't phone like he said, and I'll say, 'Ah, for God's Sake, what is it with old age…' I mean, I won't mention the word Alzheimer's but I'll joke about old age. Yes. I don't think that they even think that I have anything really wrong with me not to that extent. Because I really don't feel that way at all. I don't know. I mean if I see a good looking man coming down the street, I'm gonna look! You know, I mean I'm not dead yet! Let's face it. I, I'm not feeling sorry for myself, let's put it this way. And I'm aware of what is going on around me. It's not that I'm forgetting to set the table for dinner or something like that. I'm not forgetting anything like that.
Wendy:	Why do you not tell people?
Angela Huggins:	Because now that I'm in Barrie [mid-size city 100 kilometres North of Toronto], who am I going to tell? People that I don't know? You know, I don't know anybody here at all. Let's face it. So I don't have to…It's nobody's business. That's how I…It's nobody's business what I have…um, I, Avon. I have a little girl who I buy Avon from her and uh she hasn't noticed anything because I… I …you want to ask her but I mean why should I advertise something like that…I don't think it's necessary.
Wendy:	Okay. So it's nobody's business and it's not necessary.

Angela Huggins: Yeah. I go to a bakery shop in Toronto just before I came up here and still did my shopping as usual and nobody noticed anything different. They didn't have to say, 'can't you understand?' or whatever. I mean, nobody's treated me like that…

This section has shown that the women were more likely to resign themselves to having dementia, as opposed to fighting it, and that they felt that it was not worth worrying about. At the same time, the women employed various strategies to reduce the effect of their dementia on their relationships with other people, such as joking about memory problems and attributing them to old age, and passing for normal or not telling other people about their dementia status.

7.5.2 Men - controlling and being upfront

The men in the sample displayed a very different approach to dementia, which appears to be consistent with gendered behavioural norms that lead to men acting masterful and women powerless (Butler, 1990). A belief that one should be able to control one's memory problems and in this way overcome dementia was espoused by all three of the men, two of whom were multiply privileged and one of whom fell in-between multiply marginalized and multiply privileged, being marginalized on the basis of his class and 'race', and privileged on the basis of his ethnicity and gender. I was not able to explore the extent to which this response was related to the interaction of gender and class or simply gender, as I was unable to find another more marginalized male to test out this emergent theory, as noted in section 5.5 and detailed in footnote 13.

Jim Heather felt confident in the ability of researchers to conquer Alzheimer's disease in the near future, as the following exchange illustrates:

Jim Heather: So uh, it's strange disease. You know I, I have a definite feeling that within probably two to five years they'll uh, this will be a disease that, the Alzheimer part of it, will be, will be able to be conquered and uh…

Wendy: What makes you think that? Is that as a physician?

Jim Heather: What, the, the defeating?

Wendy: Yes.

Jim Heather: Well, I've been down to Toronto and seen the unit down there. Have you been there?

Wendy: Yes, at the Centre for Neurodegenerative Diseases?

Jim Heather: Mm, yes.

Wendy: I haven't seen the labs; I was there for a meeting.

Jim Heather: Yes, I've been through the labs and they're two or three people looking at different sides of it and it seems a pretty fairly complicated situation where there's um, there's two or three different ways of treating it possibly and uh and it's there's two or three different types of things that happen when the disease is getting underway. It's a bit complicated and that's why it's still around.

Despite having confidence in the researchers' ability to conquer dementia over time, Jim Heather struggled with the limitations imposed on him by his cognitive impairment and lamented the ineffectiveness of his own defences against an attack of this nature:

> …what um can we do or you know, you really feel that you've got no attack, from our point of view to prevent what's going to happen. We've [him and his spouse] not had any ability to, to um, do that, with attack, so far… Um, so um, I think that um as I say I think that it's [cough] very difficult to get around the feeling of defeat um as a result of the loss of human, brain dexterity.

An exception among the women, in terms of gendered responses to dementia, was Bosse Knudsen, who alternated between the strategies of dismissal used by the other women (see section 7.5.1) and the belief in one's ability to control dementia espoused by the men. Bosse Knudsen was one of the participants

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who fell in-between multiply marginalized and multiply privileged, being privileged on the basis of her 'race' and class, and marginalized on the basis of her gender and ethnicity, and she was one of the most cognitively impaired participants. These two things may explain her vacillation, or the fact that she did not hold firmly to one strong opinion or another. The quote below illustrates how her views were similar to the ones the males expressed:

> Bosse Knudsen: I, I try to not forget things.
>
> Wendy: Mm-hmm. How do you do that?
>
> Bosse Knudsen: I wor-, I just work harder on it, then think more about it.
>
> Wendy: So you're trying to control it?
>
> Bosse Knudsen: Hmm?
>
> Wendy: You're trying to control it?
>
> Bosse Knudsen: Yeah, yeah.
>
> Wendy: And is that how you've approached other things in life?
>
> Bosse Knudsen: Yeah.
>
> Wendy: Yeah, okay. How is that working for you?
>
> Bosse Knudsen: It's working good.

An oft-heard refrain from Joe Brown was:

> Well I tell you what, I remember what I wanna remember and what I don't wanna remember I forget.

And he expanded on this belief in a later exchange:

> Joe Brown: No. I remember what I wanna remember, okay. I wanna remember, I remember. I don't know, things I have to, things I have to…
>
> Wendy: So how do you do that though? How do you control that?
>
> Joe Brown: I guess you get it in your mind.
>
> Wendy: Yeah.

> Joe Brown: What you want there, okay now I was sitting there just now, I was sittin' here I was checking to see about my phone bills you know. Then I said I'm looking up at the thing, and I said oh, well I said I paid my phone bill last month so therefore I don't owe them no money, and now my rent's paid, I don't owe nobody no money.

Joe Brown's technique of 'getting it in your mind' is akin to Gus Holden's strategy of 'learning to lock something in wherever you can'; when Gus Holden made the latter statement in the second interview, he accompanied it with a gesture of turning a key beside his head.

In talking about the future, Jim Heather gave a sense of the rationale behind his strategy of confronting dementia head on, which entailed being upfront with other people about having memory problems:

> So um, I don't know what's ahead and uh I wished I didn't have to think about it occasionally but it's um it's very awkward to, but there's no other way I mean, you've got to confront things, confront them honestly and I think that uh that that is about the best we can do out of this.

This approach of being upfront (see section 8.3) was employed by Gus Holden as well, as was seen in the story of sharing his diagnosis with fellow cottagers in an effort to align himself with them (section 7.4). Not disclosing one's diagnosis and attempting to pass for normal did not seem to be an option for either Jim Heather or Gus Holden, both of whom felt that being upfront about their memory problems was the best approach. This could be related to their shared social class and associated societal expectations about the performance of professional men in both work and social settings. In fact, when I asked Gus Holden his perspective on the gender differences I had observed, he himself made this link to occupational background.

> No and because of my job and this is this not necessarily because
> I'm a man, it's just, I had to think ahead, plan something in my mind.
> I would have a speech to give or a uh, recommendation to put
> forward or something like that and I would, could be thinking about
> that on the way to a meeting and, and my mind, I would take my
> mind off that, right, talk to somebody uh, as I was going into the
> building and when I got to my, my time on the agenda, I would have
> no trouble. It, it would be tucked back there and I would explain or
> ask the questions, or make the suggestions and, if necessary, even
> follow through with a discussion on it. And uh, now, no, no, I couldn't
> do that now. Now uh, Sue [spouse] can do that now. Now whether
> that's because she's a woman or because she doesn't…

After I validated this occupational link and suggested a cohort effect as well, i.e. work expectations had been different for women than men in his generation, thus Sue did not have the same career opportunities, Gus Holden continued on with this argument and ended with a reference to losses:

> It was very much that way. Uh, almost everything I did that I can
> remember in my career, uh, there's the heading and I would, pe-,
> people would, I'd ask questions but I would develop that, it would be
> build it in my mind. So when the time, time came for me to write it
> down, to tell somebody else about it, or to even get more questions,
> ask more questions to fill it out, all the information I needed was
> there in my, in my head and uh, the words came, the words that I
> needed, the terms and everything like that. Uh, that's now missing.

As has been shown by the data in this section, the women and the men who participated in this research had very different approaches to dementia in terms of the degree of importance they accorded their memory problems, their approaches to ameliorating its effects, and their strategies for interacting with other people. Past research on subjective experiences of dementia has identified coping strategies including hiding memory lapses and going public (Keady & Nolan, 1995) and responses ranging from 'self-maintaining' to 'self-adjusting' (Clare, 2003), yet these have not been analysed for gender differences (Keady & Nolan, 2003). While my results indicate similar responses and strategies to people with dementia in past research, the significant finding

is that these were gendered behaviours and this is supported by emerging literature on identity roles in later life (Arber & Ginn, 1995). The extent to which these differences are due to gender alone or to gender interacting with social class is certainly an area for further investigation, as noted in chapter 6.

7.6 Conclusions

Several conclusions can be drawn from this chapter on experiencing dementia that build towards a grounded theory of the relationships between the experiences of older people with dementia and the intersections of 'race', ethnicity, class, and gender. First, the benefits of engaging with the white elephant (Albee, 1965) - in this case dementia - are clearly evident. Asking people with dementia about their experiences of living with a disabling condition such as this can generate rich data that not only challenges our existing knowledge base, but that also lead us towards a deeper and more complex understanding of this phenomenon called dementia. It is indeed possible, and it is extremely valuable to undertake these sorts of investigations, both for the researchers and the researched, as argued by researchers preceding me in this area (Keady & Gilliard, 1999).

Second, the problematisation of dementia occurs within a social and political context and is not transmitted to and/or integrated into the illness narratives (Kleinman, 1988) of all people with dementia in the same fashion. The extent to which dementia is conceptualized as a problem varies; dementia is not viewed as problematic by all those who are living with it and this is related to the social location of the affected individual, as well as the reactions of

significant others or other members of the participants' social worlds. The more privileged a person, the more likely they are to view dementia in a negative light; and the more marginalized an individual, the more likely they are to dismiss the significance of dementia and resist being viewed as the sum of their symptoms.

Third, there are indications in the data that dementia may facilitate, rather than hinder, self- actualization, as it affords people an expanded view of the universe and their place within it (Summerlin & Bundrick, 2000). This tentative finding builds on the large body of work to date that demonstrates the existing selfhood of people with dementia (Sabat, 2001), as well as emerging scholarship highlighting the agency of people with dementia (Hubbard et al, 2003; Cook, 2003; McColgan, 2001) and the importance of spirituality in dementia (Bell & Troxel, 2001; Snyder, 2003).

Lastly, this chapter on experiencing dementia clearly shows that diversity does make a difference. When we expand the pool of respondents by factoring in 'race', ethnicity, class, and gender, the picture that emerges of life with dementia is bound to be more nuanced and complex, as it was in this research. Not only do older people with dementia conceptualize dementia differently, but also their preoccupations, the impact it has on their social worlds, and the strategies they use to ameliorate it, all vary by social location.

Chapter - 8   Othering Dementia

8.1 Introduction

This chapter builds on the previous chapter on experiencing dementia to consider the interactive context of dementia. The purpose is to argue that othering is a significant feature of the interactions of older people with dementia in their social worlds; to enumerate the othering practices engaged in by the significant others of people with dementia; and to demonstrate the connection between social location and othering dementia. The latter argument expands on the link between social location and experiencing dementia established in the previous chapter.

8.2 Othering as a political act

There are at least two ways in which the concept of othering is used in sociological literature (Canales, 2000). The first denotes an interactive process of defining the self in relation to the other and taking the role of the other in order to understand oneself, as described by symbolic interactionists such as Mead (1967), Blumer (1962), Horton Cooley (1969), Goffman (1959), and Strauss (1997). The second use of othering refers to an overtly political negotiation of difference in which status as other is inscribed upon those who differ from the normative understanding of what it means to be a human being (de Beauvoir, 1997). Othering has been written about extensively, particularly as the concept applies to disabled people (Hughes, 2002; Morris, 1991; 1996; Oliver, 1990; 1996), minority ethnic and racialised people (Anderson & Hill Collins, 2001a; Brah, 2001; Kumashiro, 2000; Reimer Kirkham, 2003;

Rutherford, 1990; Young, 1990), and older people to a limited extent (Cohen, 1994). There have been a few studies looking specifically at othering practices within health care settings that have provided evidence that minority ethnic and 'racialised' service users and health care professionals are Othered in these contexts (Canales, 2000; Canales & Bower, 1998; Reimer Kirkham, 2003). Canales (2000) distinguished between inclusionary and exclusionary processes of othering and argued that, if the former -

> a process that attempts to utilize power within relationships for transformation and coalition building (Canales, 2000: 19) -

is practiced, it can overcome the latter. Although she defines othering in symbolic interactionist terms as 'how we engage with those perceived as different from self' (Canales, 2000:16), both these forms of othering draw on insider-outsider dichotomies and more political negotiations of difference. Reimer Kirkham (2003: 776) concludes that her own study:

> underlines the importance of uncovering, naming, and confronting those public scripts that say that certain people do not belong.

This argument shares similarities with that of Valentine (1998), who found that the invisibility and silencing of marginalized groups, in this case sexual and racialised minorities in Japan, through othering practices such as naming serves to deny their identity and as such is a powerfully destructive force.

The approach to othering associated with symbolic interactionism was first applied to dementia in the seminal work of Gubrium (1986a; 1986b; 1987) and Gubrium and Lynott (1985) on the social construction of Alzheimer's disease and is evident in research on the social interaction of people with dementia (Cook, 2003; Hubbard et al, 2002a; Li & Orleans, 2002; Lyman, 1998;

McGolgan, 2001; Vittoria, 1998; 1999; Williams & Roberts, 1995). A review of literature on the management of people with Alzheimer's disease in the late 1980s to early 1990s found that symbolic interaction was a 'predominant and consistent theme' (Moore, 1991) although explicitly sociological approaches to dementia care were rare at that time (Johnson, 1989). As noted, the popularity of symbolic interaction as a framework for understanding dementia has endured and now the lens has shifted away from service provider interactions with people with dementia towards people with dementia engaging with one another (Cook, 2003; McColgan, 2001).

It is the second meaning of othering, which can be traced back to Simone de Beauvoir's (1997) argument that women are treated as the Other[28], that the data in this study support and of which there has been little discussion to date in the dementia literature, although an associated term - 'marginalization' - has proven popular (Innes, Archibald & Murphy, 2004). For example, marginalization was a significant theme that arose in support groups for people with early stage memory loss in the United States and the authors suggest that ways to reduce marginalization should be an agenda for future research (The Group Members, 2003). Young (1990: 53) explained in her taxonomy of the five faces of oppression that:

> marginalization is perhaps the most dangerous form of oppression
> [as] a whole category of people is expelled from useful participation
> in social life.

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[28] It is difficult to pinpoint the origin of the concept of the Other, in its overtly political incarnation. De Beauvoir, with whom the Other is often associated, referred to woman as 'man's inessential other' (Barber, 2001: 71). She argued that 'he is the subject, he is the absolute – she is the Other' (de Beauvoir , 1997:16), yet attributed this usage to E. Levinas (de Beauvoir, 1997:16).

Although othering as a concept was not used explicitly in the brief article about the early stage support group (The Group Members, 2003), it is clear from the examples given that the intended meaning is closer to othering as a political act, than the more common usage referring to negotiated meaning between two or more parties. 'Being *the other'* is described by Madrid (2001: 25) as 'involving a contradictory phenomenon':

> On the one hand, being *the other* frequently means being invisible…
> On the other hand, being *the other* sometimes involves sticking out like a sore thumb. What is she/he doing here? If one is *the other*, one will inevitably be perceived unidimensionally; will be seen stereotypically; will be defined and delimited by mental sets that may not bear much relation to existing realities. *The other* disturbs, disquiets, discomforts. It provokes distrust and suspicion. *The other* makes people feel anxious, nervous, apprehensive, even fearful. *The other* frightens, scares.

It is more common in the literature to find references to 'the Other', such as the one above, together with descriptions of those who inhabit this category and what the experience is like for them, than explanations of the process of othering - how and why one comes to 'be othered' and 'to other' others. In this chapter, othering is treated as the analytical lens through which the interactive components of the experiences of older people with dementia in this study are best understood, as well as a material reality of living with dementia.

8.3 Othering practices

The silencing and social distancing to which people with dementia are subject in settings and groups to which they are known was noted in most of the participant observation sessions. When I mentioned these incidents to the participants at the follow-up interviews, more often than not they had not been aware of this othering process or they actively denied that they had been

treated any differently. This basic social process would not have emerged as significant had I relied on interviews alone; through using participant observation *and* interview methods, I was able to see for myself the ways that older people with dementia function in their social worlds, to elicit their perspectives on these social interactions, and to compare the two accounts (Lambert & McKevitt, 2002; Ikels et al, 1988). A few of the participants did reflect upon the othering I had observed when asked about this in the subsequent interviews. In the second interview with Julianna Molnar, I tried to ascertain the nature of her interactions with people in the building, whether they knew that she was having memory problems, and if they treated her any differently as a result of that knowledge.

Wendy: Okay. What do they know about your current life?

Julianna Molnar: These people who are there [referring to art class]?

Wendy: Yeah.

Julianna Molnar: They are some who are very…uh…they talk very nicely….There are some people who don't even notice me…Uh…on this floor there is…there are few….there are few people, men and women, who know me. They always say hello, ask me how I am etc. etc. And they see that… um…the time I'm walking more with more difficulty.

Wendy: So have your interactions with the people in the class or the people in the building, have those changed at all since you started having troubles with your memory?

Julianna Molnar: I have a good relationship with the woman who is on the 10th floor from Romania. There's a couple who are from Romania. And they are a couple who we met because we heard them on the elevator speaking Hungarian or Romanian. But the one that I go visit, there's only one. But I strictly see ?…Very rarely…very rarely the ones that speak Romanian sometimes they will come in.

Wendy: Mm-hmm…So do any of these people know that you're forgetting things?

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Julianna Molnar:	The one that I, the one that I see, we're together once a week…
Wendy:	The one on the 10th floor?
Julianna Molnar:	The 10th floor….but there are things that I forget. It happens that I speak to someone…if they stop and um they say something else and then I forget what I was going to say. But then they know and I remember. It happens for example that I go to the kitchen to…for something. By the time I get there I forget why I went. And I have to wait for a bit to remember.
Wendy:	Am I correct in assuming that you don't tell people?
Julianna Molnar:	I tell this one…I let her know.
Wendy:	But nobody else…And why is that?
Julianna Molnar:	Why should I be complaining?

As Julianna Molnar only talked of her memory problems with her Romanian friend on the 10th floor with whom she visited weekly, the second observation session took place during one of these visits, with the Hungarian interpreter and Julianna Molnar's husband Gyorgy present as well. She stated during this visit that:

everyone in the building complains about their aches and pains.

Yet, in the prior interview (see above), she had told me that she does not disclose her memory problems to other people in the building for the very reason that this would be 'complaining.'

Confirmation by a participant of the othering I had observed is shown in an excerpt from my field notes, as well as part of an interview with Jim Heather. I witnessed Jim Heather being othered during the first participant observation session, which took place at an airport hangar where his eldest son Mike manages one of the family businesses:

Several people recognized Jim Heather and said hello and a few brief words. There was a customer there who was introduced to Jim Heather as Mike's father and by name and he obviously knew of Jim Heather by name as he nodded, saying "ahhh" and gave Jim Heather a look of admiration. However, as Mike and this man proceeded to discuss the work underway [which Mike had explained to Jim earlier], Jim Heather was left on the sidelines, an observer like me. Jim Heather exchanged a look and weak smile with me.

At the interview following this observation session, Jim Heather acknowledged that he had noticed a change in his interactions with the people at the hangar, who had been 'much more free and easy in discussing things with [him] and that sort of thing' in the past. When I asked him about the above exchange, he likened the man's reaction to that of other people when they learn that he has Alzheimer's disease:

Jim Heather:	I, I guess I've got used to it, uh and um I think I recognized that, that um he was, he was finding out something for the first time…
Wendy:	Um-hmm.
Jim Heather:	…that um, uh, yeah, it was certainly not the, the sort of way that you meet people normally, it's artificial uh, in a, in a way.
Wendy:	How is it artificial?
Jim Heather:	That um when you, when you meet a new person, they um, uh, it's, it's not the sort of way that you meet someone normally. You have to um indicate or feel that you've got to indicate that um to indicate the uh, the way that you can carefully give some sort of idea of, that there's some sort of abnormality…really.

Jim Heather felt that he had to declare himself as having an 'abnormality', that it was his responsibility to alert his conversation partner to his newly acquired deficits and hence, changed status as a person (see section 7.4). While this approach did not always prevent the awkward silences and turning away that are characteristic responses to the other (Rutherford, 1990; Young, 1990), it did

serve to alert other inhabitants of Jim Heather's social world to the possibility that they might not be understood and would need to adapt their conversational style accordingly.

Most of the interactions that I observed between Gus Holden and his significant others were marked by enabling, as opposed to disabling behaviour (Brody et al, 1971); this was undoubtedly related to the mild state of his cognitive impairment and his retained abilities (Wells & Dawson, 2000; Zgola, 1999). Zgola (1999: 93) lists the retained abilities of people with dementia as:

- Remember things from the distant past
- Hold an opinion or offer advice
- Perform habitual, over-learned patterns of behaviour
- Learn new habits
- Enjoy pleasurable sensory stimuli
- Respond to and express emotions
- Follow a logical train of thought

Gus Holden was still able to perform the role of 'dynamic conversationalist' and storyteller in social gatherings, which can be seen as an indication of a few of these retained abilities - performing habitual over-learned patterns of behaviour; responding to and expressing emotion; and holding an opinion or offering advice (Zgola, 1999: 93). His abilities to do these things was diminished, however, as will be discussed in section 8.6.

During the second participant observation session, which took place at a staff meeting at a clinic owned by Jim Heather and his spouse Patricia, Jim Heather used his position as chair of the meeting to talk about having 'Alzheimer's related problems and Parkinson's'. I was very moved by his choosing to discuss openly what he was going through, including his fears and the negative

reactions of others, and watched closely to see how the staff would respond to his disclosure. As I wrote in my field notes below, neither the staff nor his spouse responded to Jim Heather's words, much less acknowledged the feelings behind his words; instead, they silenced him and reproduced the othering he had spoken of in relation to other people and their reactions to his having Alzheimer's.

> Jim Heather then talked of his interest in 'this place' [the clinic]; about having been on the board for so long; how good it is for him to be 'part of the team'; and how he would be upset if he was not able to 'have a laugh with people' and 'keep up with what people are doing'. He ended by saying, with a smile on his face, 'it's a sad time, but there you go'. After his words, Elaine [staff person] raised the issue of the shredder again and a heated discussion ensued about this; there was neither an acknowledgement of Jim Heather's feelings nor a response to his words by any of the people present. Jim Heather sat and watched the action.

In discussing the reactions of the staff to his disclosure during our next interview, Jim Heather indicated that, having disclosed his 'abnormality', he could have been asked to leave the clinic, but since he has been around for a long time and there is no precedent, that would be an extreme reaction on their part:

Wendy:	And how, what did you think about their reactions…to what you had to say at the meeting?
[pause]	
Jim Heather:	I don't know um, I really not sure why, what, I've been doing this for so long that, and I know this people for so long, no one's been, I can only think of one person that's ever um told to leave um and that was, not anything to do with me, but there's the only person in the building so um. No, I can't think of anything.

As noted in section 7.4, Ester Hernandez has a much narrower social world than Jim Heather, with few opportunities for engagement that are not in some

way connected to her status as a person with dementia. It was rare for Ester Hernandez to be treated as a person, in the sense described by Kitwood (1997), and not surprisingly, her acts of resistance tended to be ignored as well. The second participant observation session took place at the apartment she shared with her daughter Maria and focused on the interaction between Ester, Maria, and Ester's personal support worker Paula. Paula had been contracted to help Ester with personal care; however, Ester objects to anyone other than Maria doing this intimate caring labour, and therefore, Paula assists with walking and other physical exercises instead.

> Paula told me that Ester used to sit and sleep [when Paula first started working with her], all hunched over in her chair, and that she is much more alert and mobile now. After hearing this, Ester said 'improving'. I noted at this point that Paula and Maria regularly talk over Ester, as if she is not present or does not understand what they are saying.

Ester Hernandez was one of the more cognitively impaired participants and as a result was subject to a great deal of excess disability (Brody et al, 1971): her daughter and other caregivers demonstrated a tendency to do for her, rather than allowing her to do for herself. This can be seen in a few photos from the two participant observation sessions, the first of her being fed at the adult day program and the second of her being assisted to walk in her apartment with her personal support worker.

Figure 10 'Ester Hernandez' being fed by Filipina day program staff member

Figure 11 'Ester Hernandez' being helped to stand by Paula (HSW)

Figure 12 'Ester Hernandez' being helped to walk by Paula (HSW)

Figure 13 'Ester Hernandez' being assessed by daughter and Paula (HSW)

In contrast, Nancy Matheson's support worker Barbara tried to maintain her client's independence as much as possible and while she did monitor Nancy's performance, she did not seem to be actively disabling her, as can be seen by my notes from the first observation session. As in the scenario with Ester Hernandez above, this interaction took place between Nancy Matheson and her support worker, in her own apartment:

> After she was ready, Barbara helped Nancy Matheson to her feet by holding steady her walker and pushing the little table out of the way, then grasping hold of Nancy's arm to steady her once she was out of the chair; she did as little as possible to help her and was quite unobtrusive about it. Nancy then decided to go to the washroom and spent a long time in there (~10minutes) before returning to us in the kitchen. While she was gone, Barbara talked about working with Alzheimer patients and said what a sad disease it is as people are 'dying in front of you.' She asked me how I found Nancy that day and I said fine and noted that she had repeated a few things, but that she does very well in conversation. Barbara told me how Nancy sees her as a friend, not a worker and how she needs to retain independence and control over her life.

Barbara's own words and my observation notes are supported by the photo showing Nancy walking on her own with Barbara maintaining a respectful distance, ready to provide help if asked, but not directing Nancy in any way (see figure 9).[29] At the end of the walk, the pair sat down for a rest and posed for a final picture.

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[29] Nancy Matheson did not give permission for the use of several pictures of her from the first observation session, most of which showed her being assisted by Barbara or possibly appearing to be 'frail and dependent' (see section 7.4.1).

Figure 14 'Nancy Matheson' and her friend Barbara (HSW) after the walk

Despite being treated by others as excessively disabled, Ester Hernandez continually surprised me with her insightful comments, that often were not heard or understood by her communication partners, perhaps since they were so unexpected from an older person with dementia who was thought to 'confabulate' and 'perseverate'[30] routinely, and to have little knowledge of the English language. An example of this is taken from the 'sunroom chatter' activity during the first participant observation session at the dementia day program that Ester attended three days per week:

> The group leader asked if anyone knew what a 'calling card' was and Ester said 'yes, you give your card and I'll see you'. The group leader did not seem to grasp the dual meaning of 'calling card' so I explained that Ester was referring to how in the past you would present your calling card when you went to visit someone at their home or office. The group leader said 'oh, that's a long time ago' in response and clarified this was a card used to make a telephone call.

I was impressed by the speed with which Ester Hernandez came up with the answer to this question and how well she articulated her understanding of the purpose of a 'calling card'. The group leader was not visibly impressed herself, nor did she acknowledge Ester's skilful performance, an act which may have increased Ester's status and visibility in the group, yet also could have drawn attention to the group leader's own lack of knowledge.

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[30] These are both terms for perceptual disturbances or communication acts associated with dementia, signs of which are looked for during assessment. Confabulation (see footnote 24 in section 7.4.1) is marked by the confident presentation of obviously untrue information in order to hide the fact that the answer is not known; it may be conscious or automatic; has been observed with many forms of cognitive impairment, though initially associated with Korsakoff's syndrome and can result from a disruption in the time-sequence of stored memories (Jacques & Jackson, 2000: 70 & 231). My first experience with confabulation was while working on a life history project in 1993: I interviewed an older man with Korsakoff's syndrome who was living in a long term care facility populated mainly by men who had been alcoholics and street people; by the end of the interview, he had two PhDs, was royalty, and had just married his care assistant. Perseveration refers to a 'difficulty in shifting from one subject to another' (Jacques & Jackson, 2000: 153); in more extreme cases, a word, phrase or story is repeated over and over again (ibid, 154); and it can happen with speech or actions (ibid, 179).

In many of the interactions I observed, particularly with significant others, these older people with dementia were continually reminded of their memory problems, they were tested and set up for failure, and their status as 'people with dementia' was reinforced. I was guilty of this myself, as noted in section 6.4: this can be seen in the line of questioning that I pursued with many of the participants. An example of this behaviour on the part of someone else is taken from the start of the first observation session with Bosse Knudsen, which took place at the dementia day program she attended every Wednesday. The nurse manager tested Bosse Knudsen by asking her whether she knew me, and what my name is, despite our having met only twice before, both times in her home.

> After I arrived, Frances (nurse manager) came out to the hallway between the administration offices and the day program room to meet me. When we entered the day program room, I noticed Bosse sitting at a table beside a woman and across from another woman who was folding napkins…

Figure 15 'Bosse Knudsen' sitting with friend at dementia day program

> Frances said 'I guess you remember Bosse' and asked Bosse if she knew me. Bosse smiled and said yes and then Frances asked her

for my name but, to save her the struggle to remember, I said 'Hi Bosse, it's Wendy'…

The action I took in this example above is not the normal behaviour of a researcher, as this was a purposive strategy to consciously affect the research process and, as such, is an indication of my efforts to make the research less oppressive for the participants (see chapter 5).

At the second observation session with Nancy Matheson, her son-in-law Dave, who is a special needs teacher, demonstrated to me the extent to which Nancy fell 'under the gaze' (Foucault, 1994b) of her significant others, who are on constant alert for signs of her cognitive impairment and very conscious of her gaze themselves:

> Dave came over to chat and told me that he thought Nancy was over-stimulated, adding that he could tell by her eye movement, that she was not sure where to focus her gaze. He told me that he visits her for 1-3 hours at a time during which they have long talks; he noted the problem with under-stimulation, as well as over-stimulation and said that he notices that her perseveration varies depending on her level of stimulation. I had not noticed Nancy perseverating at all that evening; indeed, I had not noticed any cognitive deficits at all.

Angela Huggins was being monitored constantly by her daughter Ashley who was a social worker with the Children's Aid Society (see section 7.3.2). During the first observation session, she asked her mother repeatedly what she had eaten that day:

> Angela said she was not hungry so Ashley asked her what she had eaten for lunch that day. Angela could not remember but noted that she had eaten two peaches an hour earlier and for that reason was not hungry. Ashley continued to ask her mother questions about her eating patterns and encouraged her to eat, without success. Ashley told me that her mother's appetite had decreased and that getting her to eat was a big struggle.

Despite Angela reporting that she was not hungry and 'that she had eaten two peaches an hour earlier', Ashley was not satisfied until she found evidence in the kitchen that her mother had eaten a meal earlier that day:

> When she noticed the dirty frying pan in the kitchen, Ashley figured out that her mother had eaten bacon and eggs for lunch and said that if she checked the bread, she'd probably find that she had toast as well. This triggered Angela's memory and she confirmed that this is what she had eaten for lunch that day.

An extreme example of how people with dementia are Othered comes from the second observation session with Bosse Knudsen at a seniors' group at the Seventh Day Adventist Church to which she and her husband belonged.

> While Bosse was meandering about, no one spoke to her; in fact they seemed to studiously ignore her. One woman came up to me to expand on her earlier comments about the futility of attempting to build on First Nations reserves [in relation to the guest speaker from Habitat for Humanity] and after we talked for a few minutes, I told her why I was there. A little while later, after she noticed me talking to Bosse, she pulled me aside, gave me a conspiratorial look and confided in me that 'you can't talk to her…dementia…she has dementia you know'. I repeated that I was doing my PhD on dementia and was there to observe Bosse, and walked away from her.

Not only was this woman treating Bosse as the other, but also she felt it her duty to instruct me in the techniques of othering so that I could conform to the practices of the group; my non-compliance disrupted her taken-for-granted assumptions about who should be othered and how this should be done. One other person disobeyed the group sanctions that day and this was the lay pastor who had greeted the three of us upon our arrival and later came up to talk to Bosse Knudsen and placed a hand on her shoulder. In the photo, Bosse Knudsen looks like the 'people-person' she purports to be; the photo is

significant though because this was the only person that I saw treat Bosse Knudsen as a person (Kitwood, 1997) during the entire three hours.

Figure 16 'Bosse Knudsen' with the pastor at the seniors' church group

Angela Huggins' daughter Ashley tried to role model othering practices as well during the participant observation sessions when she repeatedly inquired as to her mother's eating habits and medication compliance (see below) and turned to me as if to say 'see, I told you she's losing it' if Angela Huggins was unable to provide a satisfactory answer. By the end of the second observation session, I had been tainted with courtesy stigma (Goffman, 1963; MacRae, 1999) – transformed into another one of 'the kids' whom Ashley had to look after, making sure we all went to the toilet before getting in the car and planning our route home:

> Before we left the store, Ashley asked where the washroom was and the clerk said that it was on the next level up and gave her the key. She asked her mother if she needed to go to the bathroom and Angela said no. Ashley asked if she was sure and pointed out that 'it's been an hour and it'll be 45 minutes until we're back at the house.' She noted that I could look after Maya [granddaughter] while

they went together. Angela became angry at Ashley's badgering her about the washroom and Ashley said 'pretend she's not here', gesturing at me. Angela relented and said 'you're on' to me and pointed at Maya. I asked whether we should stay in the store and Ashley suggested I push Maya around the store in the shopping cart, which I did while they went to the washroom. When they returned, Ashley checked with me whether I needed to go to the washroom and I lied and said that I was okay. In truth I did need to go to the toilet, yet did not want to miss observing them.

…Once we were settled in the car and on our way again, Ashley listed our next activities: drive through Barrie, go to another drugstore for the knee brace, go by the house to take a family picture, and then home. She asked 'how does that sound kids?' and I wondered if I was one of the kids she was referring to. Not getting a response, she said 'Gramma?' and Angela said it sounded fine.

Figure 17 'The kids' - 'Angela Huggins' with her granddaughter Maya

Angela was aware of these othering practices adopted by her daughter and how this made her feel like 'a decrepit old lady', particularly Ashley's recently adopted habit of referring to her mother as 'Gramma':

Wendy:	So you described Ashley like a mother hen. Is that something more recent?
Angela Huggins:	Yeah, yeah, yeah, most definitely.
Wendy:	Yeah. I guess the same with the questions about the eating, the routine questions about what to eat…

Angela Huggins:	Yeah, and-and the pills. She will say, 'Have you had your pills?' 'No but I'll have it in a short while, I haven't eaten yet.' So I have to eat first and take the pills. And then she come back, 'All right, I'm' going to get the pills.' She-She's a mother hen, you know. And-and now she calls me Gramma. And it aggravates me no end! In the store, 'Gramma!' And I don't answer. And everybody's looking, 'Where's Gramma?' You know? I mean, good God call me mommy! You know, it is-it's just-it's just recently Sister Bonita she-because of the baby. But the baby doesn't call me Gramma, the baby calls me 'Nana.' So if she would even say, 'Nana.'
Wendy:	Yeah. Have you told her that? [laughs]
Angela Huggins:	Several times but she forgets. I feel like a decrepit little old lady, with a little cane you know coming down the street. Good Lord!

Many of the participants felt that their memory problems did not cause them to be treated any differently by members of their self-identified communities, and for some this was indeed the case. As I accompanied Joe Brown on a typical walk around his neighbourhood, I did not witness any of the people with whom he interacted treating him as a person with an 'abnormality'. Below is a long segment of my notes from this first observation session and a few of the photos from this excursion that together demonstrate the absence of othering in interactions between Joe Brown and the people he encountered in his neighbourhood:

> Upon leaving the building, Joe Brown said hello to an older Black woman who lives in his building and chatted with her as they walked along the street… [I] asked her if I could take a picture of them together as they walked. She said okay if Joe didn't mind. I took a picture of them as he was gesturing to a place across the street (see Figure 3). We passed a younger Black man at an instant-teller machine and Joe Brown held out his hat to him as if asking for money; the man did not react at all. I commented on this interaction and Joe said 'oh, I always bug him'. Soon after, we passed a younger Black woman who greeted Joe Brown with 'hey Joe, how you doin'' and I said something about him knowing a lot of people to which he responded 'I know everyone in [name of the community]'.

We entered the 'cash and save' which is a storefront bank and he greeted the tellers.

Figure 18 'Joe Brown' greeting bank tellers

He seemed to be more familiar with the middle-aged Black woman than the other two tellers [younger Asian man and middle-aged South Asian woman]… [and he] sat down on the bench opposite the counter where she was sitting behind a pane of glass and started to chat with her from this position.

Figure 19 'Joe Brown' talking to head bank teller

She engaged in conversation with him normally and I checked whether this is what he normally did (sit down and shout at her from across the bank) and both of them confirmed that this was their usual pattern of behaviour.

Figure 20 Head bank teller talking to 'Joe Brown'

Being treated as the Other was not a strong feature in the observation sessions with Julianna Molnar either; she and her husband had requested that I not mention memory problems to any of the people present at her weekly art class, however, and I was introduced to the instructor and other class members as 'a young friend of hers doing a PhD and with whom she is working on a project about older people and their lives.' The first section of my notes from this first participant observation session shows Julianna Molnar being treated 'normally', while the second indicates there may have been some knowledge of her dementia and hence, special accommodation was made for her, though this is far less obvious than it was for most of the other participants.

> As Rick [art instructor] appraised Julianna's work and gave her some
> guidance in terms of colour,

Figure 21 'Julianna Molnar' receiving suggestions from art instructor Rick

he asked her for a pencil to draw in the cat and she immediately produced one from her toolbox. Rick then pencilled in the size and location of the cat

Figure 22 Art instructor Rick drawing cat as 'Julianna Molnar' watches

while Julianna watched with keen interest. When I went to take a picture, she looked directly at me and smiled, as if posing for the camera.

Figure 23 'Julianna Molnar' posing for camera at art class

Rick did not appear to modify his behaviour in any way when interacting with Julianna and she did not demonstrate any communication deficits that may have tipped him off that she has memory problems.

Despite the absence of othering in this interaction, later in the same session, I noted Julianna being treated differently than the other class members and felt at the time that this may be due to her cognitive impairment:

Lorraine [class member] then made an announcement about the art show on June 18 that would be there in the building. Rick [instructor] came by and wrote in pencil 'Art Show June 18' on the back of Julianna's painting, saying 'just so you remember'. I did not notice him do this with anyone else in the class so wondered if he was aware of Julianna's memory problems.

This section has presented rich data on the othering practices engaged in by significant others and others within the social worlds of older people with dementia. As has been shown, these othering practices were a frequent occurrence at the participant observation sessions and were commented upon by some of the older people with dementia themselves. The specific techniques that are discernable in the examples given will be enumerated in the

section that follows, along with the presentation of other taxonomies of othering practices.

8.3.1 Techniques of othering

Othering practices are modes of behaviour that render some people invisible, inferior, invalid, deviant or other and reinforce the dominance of those who enact these practices – in other words, a basic social process. Techniques of othering are the everyday acts through which the dynamics of privilege and oppression are made real and visible; these are the tangible manifestations of othering. During the course of this research, the following techniques were observed[31]:

- Silencing
- Distancing
- Disabling
- Treating as invisible
- Avoiding/shunning
- Testing/monitoring
- Naming/labelling
- Infantilising
- Pathologising
- Reducing (to disease state)

There is a key difference between this list of techniques of othering and earlier catalogues of 'malignant social psychology' (Kitwood, 1990; 1997a); earlier formulations were essentially psychological and thus, omitted the social. Othering is a basic social process, however, so the techniques can not be understood outside of the social context – they are learned and transmitted socially, as was evident in the observation session with Bosse Knudsen when

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[31] This is by no means an exhaustive list; the techniques listed were the most frequent or salient examples to be found in the data.

the group failed to teach me 'to other' an older woman with dementia, despite their best efforts.

Kitwood (1990: 181-184; 1997: 46-47) catalogued 'malignant social psychology' (MSP) as:

1. Treachery
2. Disempowerment
3. Infantilisation
4. Intimidation
5. Labelling
6. Stigmatisation
7. Outpacing
8. Invalidation
9. Banishment
10. Objectification
11. Ignoring
12. Imposition
13. Withholding
14. Accusation
15. Disruption
16. Mockery
17. Disparagement

While this may have been a new list of 'malignant social psychology' and certainly has been valuable for efforts to enumerate the 'depersonalising tendencies' of care settings (Kitwood, 1997), many of these concepts have a long history in the sociology of deviance and are basically underpinned by labelling theory (Becker, 1963; Goffman, 1963; Lemert, 1972). As a sociologist, I would be more apt to locate my work within the latter tradition than the frequently a-theoretical and a-historical dementia literature. Not only did Kitwood (1990; 1997a) fail to acknowledge his intellectual ancestors in his work on MSP, but he actually psychologised sociological theory (Valentine, 2004, personal communication). The descriptions given for each of the 17 examples

attend to individual interactions and do not attempt to link these to social structures in any way. For example, invalidation is described as:

> failing to acknowledge the subjective reality of a person's experience, and especially what they are feeling (p 46).

Perhaps this was a case of adoption of terminology without a sound understanding of its intended meaning or an intentional definitional twist to make the concept more psychological. As Zola (1982) clearly demonstrated in his chronicle of living with a disability, invalidation is a social process that occurs through four steps:

1. Denial of sexuality
2. Denial of anger
3. Denial of vulnerability
4. Denial of potentiality

While these denials routinely occur during one to one interactions and the 'feelings' of both parties are undoubtedly affected, denials of this nature are also evident in the policies and practices of institutions and organizations, and need to be understood within this social context.

This section has clearly demonstrated that the techniques of othering used by significant others are connected to the basic social process of othering. The individual acts that reinforce the categorisation of older people with dementia as problematic are connected to policies and practices that support othering. While most participants denied awareness of differential treatment due to their memory problems, there was evidence of familiarity with the process of othering related to other identity constructs, such as 'race', age, and ethnicity, as will be shown in the next section.

8.4 Awareness of othering

As noted in section 8.3, few of the participants commented on the othering that I saw at the observation sessions and most denied this having occurred when I raised it in the interviews. There was, however, a greater awareness of othering practices in general on the part of two of the participants, namely Angela Huggins and Ester Hernandez. Angela Huggins was quite articulate about the discrimination she had faced throughout her life, both in the West Indies and in Canada. For this reason, of all the participants, she was most similar to the politically conscious women in past research on identity and oppression who spoke of themselves as intersectional beings (Mama, 1995a; Petersen, 2000; Sudbury, 2001). In the first interview, as she told me about growing up in the West Indies and how a person of mixed race such as herself is viewed there, she clearly demonstrated her knowledge of othering practices:

Angela Huggins:	Like I am, not a known entity but I have um, one sixteenth of the population maybe, 1/32 of, very far.
Wendy:	That's a change you're saying, it didn't used to be that way?
Angela Huggins:	No, no, it always has been like that but now they're mixing a little bit more, like, like Indians, we have a big Indian population and a Black population, they're the two majority races - the East Indian and, not red Indian, East Indian and, and the Negro. And uh we are just a little sprinkling in-between. So is, when, when, if I have an argument [laughs], like with, with another West Indian and she's Black, she say 'you, you red Ind-, you red niggers are so stupid' and I say 'and you Black people are so ignorant too', you know. We call each other names but, but…
Wendy:	Yeah, what does she mean by red nigger?

Angela Huggins: Because I'm more red than white or I'm not Black, so. It's a slur, it's a slur, definitely it's a slur. And uh, when the Americans, we, they have a base in Trinidad and um, I'd be riding my bicycle going to school and they would say, I would be riding my bicycle with other friends going home for lunch and they would be darker than I am. These Americans would say 'oh my god, look at that one, just like back in the States'. So I was getting it on all sides, all sides. It was very tough…'cause we even felt about Maya [granddaughter], if it's going to be like that you know with, we have to find a place where she has, doesn't have discrimination at all, but where do you find a place, where, where can you go?

Although more cognitively impaired than Angela Huggins and less forthcoming about her own experiences of discrimination, Ester Hernandez appeared to be conscious of othering processes as well, as demonstrated in the following interview during which she tells me that 'outsiders' in Canada are immigrants, old people, and Filipinos, much to my obvious surprise:

Wendy: Yeah, so what do you think life is like for this woman here?

Figure 24 Health Canada South Asian woman dancing with Asian nurse

Ester Hernandez: This woman?

Wendy: Mm-hmm.

Ester Hernandez: I think maybe that they are outsiders.

Wendy: They're which?

Ester Hernandez: Outsiders.

Wendy: Outsiders?

Ester Hernandez: Yeah, maybe.

Wendy: Why are they outsiders?

Ester Hernandez: Because they are not born in Canada.

Wendy: Because they weren't, they're not born in Canada?

Ester Hernandez: I think maybe.

Wendy: Let's, so, I have a lot of pictures here[32], I'll show you some of the other ones. So, they're outsiders (Figure 24), what would he be, what would he be?

Figure 25 Time Slips white man without glasses

Ester Hernandez: I don't know. I don't know. What's that face, it looks like outsider?

Wendy: He looks like an outsider too?

Ester Hernandez: This old, he's old.

Wendy: Because he's old?

Ester Hernandez: Yeah, old people, looks like Filipino.

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[32] I was referring to my 'deck of image cards' (see section 5.3.2.1) that I was still using at this point.

It became apparent, in a later interview, that when she was not wearing her glasses, Ester Hernandez assumed that the person she was speaking with or looking at in a picture was Filipino. Thus, in this interview segment above, she considered this older white man to be an outsider like the older South Asian woman in the picture she had been shown before because to Ester he appeared to be 'old people, looks like Filipino'.

Although Angela Huggins and Ester Hernandez were clearly aware of othering processes in relation to 'race', ethnicity, and age, neither of them fully assumed awareness of being treated differently on the basis of their dementia status, as this exchange with Ester Hernandez indicates:

> Wendy: Ester, some of the other older people I've talked to…
>
> Ester Hernandez: Heh?
>
> Wendy: …say that people treat them differently when they
>   forget things…does this happen to you?
>
> Ester Hernandez: I don't know that, I just know all the nice people. If you
>   are talking to someone older, somebody older who
>   does not seem to understand, yeah, do not shout ever,
>   that is one…

Ester Hernandez expanded on these views about the right way to interact with older people and, in the process, avoided referring specifically to herself and reframed forgetting things as normal behaviour for older people:

> You must tell in a nice way. Don't tell her with shouting like that.
> Don't you know that that old people don't know how to speak…old
> people, you must be kind to old people...and don't shout.

Angela Huggins did not tell people about her diagnosis and felt that there was nothing different about her behaviour that would indicate to other people that she had Alzheimer's, as seen in section 7.5.1 with the data about not telling

storekeepers and how she was 'just a beginning Alzheimer's patient…not way back on the list'. In response to the latter comment, I inquired as to whether Angela Huggins felt she might be subject to differential treatment as her dementia progressed. She strenuously rejected this idea:

> No, no, no…no…I'll be treated differently here [Barrie] because they think I'm a Black person, but as far as any other thing, no, no…

A blatant example of Angela Huggins being othered as a Black person from the West Indies is taken from lengthy segments of my notes on the interaction she had with her new family physician during the second observation session:

> The first thing the doctor said to Angela was 'is your heart crying out for Trinidad still?' Angela said yes and then he asked why she had left… Angela told how she came to Canada for school…and told him that the population of Trinidad is one million, when he asked. In response to his question as to her occupation, she said that she had two - dancing and nail technician. He seemed surprised that she had never smoked or drank, so she added that 'the music gets me going'… The doctor asked Angela if she still cooks and she said no and explained that she went to a boarding school at age 14 so never really cooked. The doctor, obviously trying to display his knowledge of 'the islands', said 'you should make conch soup.' Angela smiled at this and did not otherwise respond. While she did not ignore or dismiss his questions, she tried to give him the least amount of information as possible. He then asked her if she likes swimming in the ocean and she said 'oh yes, I'm a beach person.' They chatted about the geography of Trinidad a bit and she shared with him the rumour that Trinidad had been part of Venezuela at one time, which he seemed surprised to hear… The doctor said something about how nice Wasaga Beach is [popular beach near Barrie] and that Angela could go there and pretend she was in Trinidad. Angela dismissed this idea with 'there's no palm trees'… As we left he said 'if I need advice on Trinidad, I know where to go', to which Angela replied 'my pleasure.'

Angela Huggins was acutely conscious of the othering that she had been subject to in this interaction with her new family physician, which had included several sexist and ageist comments as well. In the subsequent interview, Angela Huggins indicated that she felt that the doctor's age was part of the

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problem, as he was at least 25 years her junior, and suggested how she might deal with his strong opinions in the future:

> He's still too young for me, yeah. He-he comes out very, very strong. I can see he tells me one thing and I might say, 'Well, uh, I-I've had that medicine before,' and he say, 'Well try it again.' And I'll say, 'Well, you're wasting my time.' You know, I-I'll answer him back… Well I mean I could be his mother, I mean I [inaudible] difference, you know, I could be his mother for sure. He came on very, very strong.

When asked about the doctor's preoccupation with Trinidad after this, Angela Huggins suggested that he had viewed her as a travel agent

> Angela Huggins: Yes…he was probably planning a trip, I don't know.
>
> Wendy: [laughs] That's what it seemed like.
>
> Angela Huggins: I mean, those are questions you would ask a travel agent.

As has been shown in this section, while participants were often not conscious of othering practices related to their dementia status, the concept of othering was far from alien. Further, while some participants were able to resist attempts by other people to treat them as inferior due to their 'race', ethnicity, age, class, or gender, for example, a few of the participants appeared to have internalized the shame of having dementia and being thought of as a 'silly patient', as will be shown in the next section.

8.5 Internalized shame – 'we silly patients'

Both of the physicians in the sample gave evidence of having internalized the shame of being a cognitively impaired person and this was the impetus for a photo essay that I submitted to the *International Journal of Epidemiology* called 'From Doctor to 'Silly Patient': Seeing beyond the disease label (Hulko, 2005).

Julianna Molnar stressed the association between status and cognition and asserted her own authority as a doctor in the following exchange about whether the act of forgetting matters and why some people admit to it and others do not:

Julianna Molnar:	It matters that you forget, for sure…It matters that you forget that you don't…it doesn't feel good when I can't remember certain things…But there are some people who don't admit that they forget and then there are certain people who do admit that they forget.
Wendy:	Yeah, that's true. Why do you think that is?
Julianna Molnar:	Why do I think? Because I was a doctor (laughs).
Wendy:	(laughs) No, but why do you think that some people will admit it and some people won't?
Julianna Molnar:	(laughs) Well there are some people who admit to it and there are some people who deny it.
Wendy:	Mm-hmm. But do you have an idea or a theory yourself of why some people will admit to it and other people won't?
Julianna Molnar:	There are those who…not very many who would want to think…who would want others to think that they are smarter than they are.

She went on to tell me her fears about the future; about the progression of her dementia and the lack of value her life would hold should she become 'completely stupid':

Wendy:	Yeah, what does it look like to you? That place you don't want to get to.
Julianna Molnar:	I don't want to be completely stupid. (laughs slightly)
Wendy:	Yeah…'cause your mind is an important…
Julianna Molnar:	Then there's no point to live.
Wendy:	Well your mind is a very important part of who you are.
Julianna Molnar:	Yeah it's very important. I know that. And many times it really hurts me that there are certain things that I don't remember.
Wendy:	Mm-hmm.

> Julianna Molnar: But my memory is still good enough that I can…I
>   can….I can keep…I can maintain…I can't say that it's
>   not worth it to live.

Further strong evidence of internalized shame comes from the other physician in the group – Jim Heather, a man who was not only a surgeon and hospital administrator, but also a prominent local business person and a 'pillar of the community'. The latter designation carries more status and power than that given to people like Joe Brown and others like him who are viewed as their neighbourhood's equivalent of 'the King of Kensington'. At the final interview, after we had spoken about what it was like for him to be part of the research and I had thanked him for 'taking the time to talk with me and to share [his] experiences', Jim Heather told me:

> No I think that that was vital to get some idea of, more of what uh we
> silly patients are doing[33].

I used this quote in the title of this section and the associated photo essay (Hulko, 2005), as it so clearly demonstrated to me internalized shame – the eminent surgeon referring to himself as a 'silly patient'. In discussing his decision to withdraw from the board of the local hospital, Jim Heather referred to himself in a similarly negative light:

> I suggested that I felt that uh despite being on the board for three
> years, that I didn't want to be just a lamppost sort of standing in the,
> standing in the way of everyone.

This reference to oneself as a 'silly patient' and a 'lamppost' indicates awareness of the negative social status afforded older people with dementia and the internalization of this stigmatization (Goffman, 1963). The exchange

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[33] This comment did not appear to be said with any irony; however, as Jim Heather's bodily expressiveness has been restricted by Parkinson's disease, it can be difficult to read his emotional responses.

between Bosse Knudsen and myself during which she questions why I would want to speak with her and not with her husband, as reproduced in section 6.3, is another example of internalized shame. The excerpts from interviews with Jim Heather and Julianna Molnar indicate that those older people with dementia who have 'further to fall' or more social status to lose upon developing dementia – in this case physicians - are just as susceptible to internalized shame as their more marginalized counterparts, such as Ester Hernandez, if not more so.

Ester Hernandez demonstrated some awareness of being othered by those around her; particularly the infantilizing practices (Hockey & James, 1993) to which she was subject. In the second observation session, during which I had noted that her daughter Maria and the support worker Paula frequently spoke as if she was not present (see section 8.3), Ester Hernandez remarked on this herself:

> Ester then said 'she knows everything [gesturing to Maria], but the mother knows nothing'.

It is clear by the phrasing of this comment that Ester does not concur with this assessment of herself as lacking knowledge. From this example, I can not say that she has internalized the shame of having dementia, yet her refusal to admit to having dementia discussed in section 6.4 may be an indication of this. Why go to such an effort to avoid the label of dementia unless it is believed to carry a stigma (Allan, 2000; Goffman, 1963; MacRae, 1999)? The stigma may be internalized, or the awareness that it is seen as such by others could be enough to compel someone to deny having it. The strategic element to denials of dementia will be discussed in depth in section 9.5.

8.6 Resilience as a mediating factor

The degree to which participants were subject to othering as a result of their dementia status varied by social location, in much the same way as experiencing dementia differed for this diverse group of older people with dementia (see Chapter 7). The more privileged older people with dementia – Gus Holden, Jim Heather, and Nancy Matheson – generally were othered to a greater extent than those who were subject to marginalization on more than one domain, apart from dementia - Joe Brown, Angela Huggins, Ester Hernandez, Bosse Knudsen, and Julianna Molnar. It could be argued that the othering to which Bosse Knudsen and Ester Hernandez were subject was at least as pronounced as that of Jim Heather, Gus Holden and Nancy Matheson, as may have been the impression given by the data presented earlier. These two women were the most cognitively impaired of the participants, however, and for that reason, one would expect that they would be more likely to be seen as the other. The cognitive deficits of the more privileged older people with dementia were not as noticeable in comparison with older people with dementia generally, and the participants in this study specifically. Towards the end of the third and final interview as we discussed his 'slippery slope' analogy, I explained this to Jim Heather, whose communication abilities had been affected by both Alzheimer's and Parkinson's disease:

> Wendy: [laughs] So I certainly think that if you, we know that there's a relationship between education and Alzheimer disease in that education uh seems to be a protective factor so I would not be surprised if education also affects your progression, right.
>
> Jim Heather: In what way does it protect your…

Wendy:	Well, what we've talked about that you, I would think that you would progress in terms of your communicative abilities…
Jim Heather:	Mm-hmm.
Wendy:	…and your, your language skills that you would lose those more slowly…
Jim Heather:	Yes.
Wendy:	…because you're starting from a higher starting point.
Jim Heather:	Yes, I've, I've wondered about that uh previously and uh it's something I don't know anything about um and I hope that's true.
Wendy:	Well like I say I have, you communicate extremely well now and I know that it's, that you've had a number of losses in your communication abilities but compared to people uh with or without cognitive impairments, you communicate very well.
Jim Heather:	Mm.
Wendy:	Does that surprise you [laughs]?
Jim Heather:	No, nothing surprises me anymore…

My view of these older people with dementia as able communicators (Cook, 2003), was not always shared, however, as shown by the following exchange with Gus Holden in the second interview which followed the first observation session. It is clear that while I thought he had been a 'dynamic conversationalist' during the barbeque at his daughter's home with her family and several neighbours, Gus Holden was conscious of not having contributed as much as he would have in the past:

Wendy:	Did you find that your, that your interactions have changed in any way? You, you mentioned that maybe in the past you would have gone up and talked to, to Matt [neighbour].
Gus Holden:	Yeah, mm-hmm.

Wendy:	Are there other things? And you also mentioned that, although you appeared to be um, a dynamic conversationalist to me [laughs], that perhaps you might have been um, joking more and throwing out more or longer thoughts?
Gus Holden:	Yes, yes, because everybody else was carrying on a conversation and some of those things I know would have triggered a response from me that they, they would have understood. And uh, sort of you remember such and such, you timed that, that ladder and dropped the paint on my toes, or something like that, if that was a fitting com-, a comment [reference to an incident the barbeque].

There were several instances when Gus Holden was actively involved during this particular observation session, as captured in two pictures, the first having been taken after Gus Holden was shown how to release the valve on the coffee urn so that he could complete his task of pouring it, and the second when a neighbour brought her infant granddaughter over to say hello to him:

Figure 26 'Gus Holden' pouring coffee

Figure 27 'Gus Holden' with infant girl
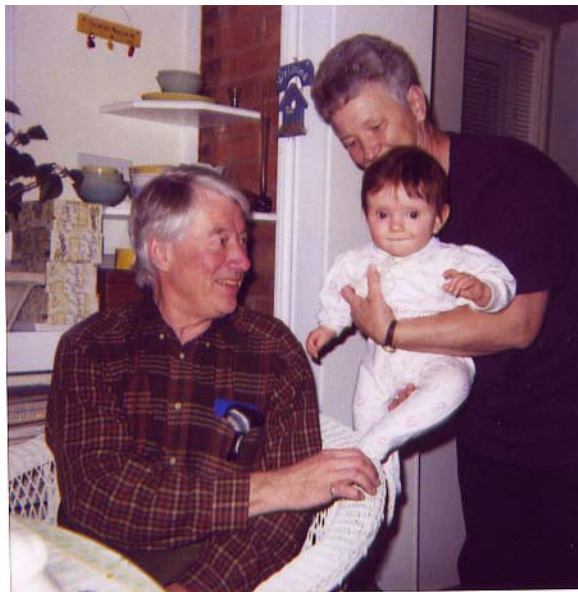
The one-on-one conversations that Gus Holden engaged in during this gathering were primarily with his son-in-law Dave, when he was not outside at the barbeque, and my former partner Chris, who had been invited to attend by Sue Holden and whom I had agreed to bring along, so that Gus Holden would have someone to converse with about science, the environment, and the university, among other topics of mutual interest[34].

The significant others of the more privileged people were acutely conscious of any deviation from the 'normal' (as in pre-dementia) behaviour of the older person with dementia in question and their standards for performance were so much higher, that minor failings were taken to be major deficits. This can be seen in the words and actions of Nancy Matheson's son-in-law at her 87th birthday party that I presented in section 8.3, as evidence of othering practices, as well as Jim Heather's rationale for withdrawing from his position on the board of the local hospital, discussed in section 8.4. In addition, significant others may become so accustomed to filling in the gaps for their partner with memory loss that when general information from the past is requested, they might mistake the request to be one for a specific memory of which they have no knowledge. A misunderstanding of this nature happened in the course of a discussion about hockey at the first observation session with Gus Holden, as can be seen in my notes:

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[34] This posed an ethical dilemma for me as I knew the participant's anonymity would be compromised by the inclusion of someone separate from the research who was not a part of their lives; yet, I was aware that bringing my partner would assist with efforts to normalize the research experience and that Gus would appreciate a new conversation partner. I explained my concerns when the invitation was extended and, based on our discussion, determined that the benefits outweighed any potential harms.

Around 6-6:15pm the neighbours began to arrive, bearing food, and there was some small talk about the previous night's hockey game and the fact that 5 overtimes is not the longest game in playoff history, it's the 4th longest. Gus talked of listening to hockey on the radio when he was a child and looked to Sue for help with the name of the apparatus. She replied gently 'I didn't know you then Gus', and he said 'no, I know' and indicated that he was looking for the name of something from that time period, not a specific memory. Eventually he came up with the name 'crystal-set' and told [another attendee] how he would listen to the hockey game under the covers with this radio.

The concept of resilience[35] is useful in helping to understand why the more marginalized participants did not appear to be Othered as frequently and indeed did not see dementia as particularly problematic, as explained in section 7.2. However, I am not using resilience as it is commonly referenced in the child psychology literature (Daniels, 2003, personal communication; Szalacha, Erkut, Coll, Fields, Alarcón & Ceder, 2003; Luther, 2003), where it is portrayed as an innate quality that if well developed enough, enables children who are victims of trauma to survive and thrive into adolescence and beyond. Resilience is definitely a sensitising concept (Glaser, 1978) in the social work field, as the belief amongst practitioners that people can benefit from adverse events fits well with a strengths perspective (McMillen, 1999; Saleebey, 1997) and the aforementioned definition of resilience is in operation. The psychological approach to resilience is exemplified by Foster's (1997) gerontological research demonstrating that resilience is 'surprisingly well-preserved throughout most of the life span' (p 189), in which resilience is said to refer to:

Positive changes in maintaining active or latent coping and adaptation capacities through various mechanisms (such as healing,

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[35] I was not able to trace the origin of this concept. I discussed this separately with two social work academics that use resilience in their published work, in the two distinct ways that I identify in this thesis; neither had the answer and one asked me to let her know if I found this out, as she thought it would be most helpful.

restitution, refinement and enhancement) that may not be immediately apparent but become evident over time (p 190).

Resilience has a parallel meaning within literature on marginalized or oppressed peoples (Blau & Brown, 2001; Brotman, Ryan & Cormier, 2003; Holstein & Minkler, 2003; Kirmayer et al, 2000; Littrell & Beck, 1999; Sonn & Fisher, 1998; Walters & Simoni, 2002), in which it is seen to be an *acquired* survival mechanism that results from experiencing discrimination on the basis of membership in a particular social group; and sometimes is termed 'cultural resilience' (Kirmayer et al, 2000; Sonn & Fisher, 1998; Walters & Simoni, 2002). It is this second meaning of resilience to which the data in this research refers and, while it was one of my sensitizing concepts at the outset of this research (Appendix D); it has taken on more significance than originally anticipated. Resilience defined in this way is meant to capture the strengths and resources of marginalized communities that are buried or overlooked in the multiple jeopardies tradition and other expressions of a 'deficit-thinking mentality' (Minkler, 1996), as many critical gerontologists have argued (Browne, 1995; Blakemore, 1989; Calasanti, 1996; Calasanti & Slevin, 2001; Dressel, 1991; Dressel et al, 1997; Ginn & Arber, 1995; Gonyea, 1994; Holstein & Minkler, 2003; Hulko, 2004; Levy, 1988; McMullin, 2000; Minkler, 1996; Victor, 1991; Vincent, 1995). The data presented in this chapter demonstrates the connection between social location and othering dementia and indicates that resilience may help to explain both the responses of the more marginalized older people with dementia as well as those of the people with whom they interact in their social worlds.

8.7 Conclusions

This chapter on othering dementia has shown that othering practices are a marked feature of the interactions between older people with dementia and members of their self-identified communities and that it is the explicitly political use of this term *blended* with the meaning within symbolic interaction that is most applicable to this data. Participants were often not conscious of having been Othered, although they may have shown awareness of othering practices in relation to identity factors, apart from dementia status, such as age, 'race', and ethnicity. The othering practices found in the data included silencing, treating the person with dementia as invisible, distancing, avoiding, testing and monitoring, naming/labelling, disabling, infantilising, and pathologising. The extent to which older people with dementia were subject to othering varied and was related to their social location with the more privileged participants experiencing a greater degree of othering and demonstrating more evidence of internalized shame than the more marginalized participants. As argued earlier, this can be explained by the performance expectations of the participants' self-identified communities, with the more privileged older people being pathologised for displaying any cognitive deficits whatsoever, no matter how minor, while their more marginalized counterparts seemed to be benefiting from a more expansive definition of normal within their communities and more tolerance for 'slippage'.

In addition, the concept of resilience as an acquired characteristic has been shown to be important, in that those people who have experienced discrimination/disadvantage in their lives prior to developing dementia, on the

basis of factors such as their 'race', ethnicity, class, and/or gender, seem to be able to apply this resilience to life with dementia – treating it as one more hurdle to overcome or just another thing to get on with. This may explain the gender differences found in the data as well, as noted in section 7.5.1. Finally, this chapter demonstrated the important role played by significant others in 'structuring and destructuring the course of illness' (Gubrium, 1987). Both enabling and disabling behaviours were observed during the course of this research, with the latter being much more common, and conceptualized as techniques of othering in this thesis. Yet, as has been shown, older people with dementia as a group did not passively accept othering practices, rather many of them resisted such efforts to diminish their status as persons, and this was connected to their social location. As described in section 8.5, Jim Heather accepted being seen as a 'lamp-post' or a 'silly patient', while Ester Hernandez resisted being seen as a person with a problem or one who does not know anything (see section 6.4 and 7.3.2). The strategic element to participants' responses to othering practices will be addressed in more detail in chapter 9.

Chapter - 9   Theorising Dementia

9.1 Introduction

The overall argument of this chapter on theorising dementia is that older people with dementia are active meaning makers, who strategically adopt certain theories of dementia as explanatory models (Kleinman, 1980) in order to avoid marginalization due to dementia. This chapter starts with an introduction to the everyday nature of theorising, followed by a discussion of theorising by the 'ageing enterprise' (Estes, 1979) and a review of the limitations of current dementia theorising, first introduced in Chapter 2. I will then describe the theories about dementia to which this group of people subscribed and the ways in which these theories correlate with their social locations. Next, the strategic nature of the dementia theorising undertaken by this diverse group of older people with dementia is presented, with particular reference to the normal aging theory and how the participants' theorising represents the acceptance and rejection of the biomedical paradigm. I conclude with insights into the reconciliation of emic and etic perspectives on dementia, arising from the words and actions of older people with dementia, which sets the stage for the concluding chapter of this thesis.

This chapter takes as its starting point the recognition that individual people are the experts on their own lives and that they routinely engage in theorising about themselves and their relationships to society. This activity is often referred to as meaning making in illness, or making sense of an experience (Askham, 1995; Kleinman, 1988a; Menne et al, 2002; Williams & Healy, 2001), yet these

are really acts of theorising that differ only from the work of 'theorists' in their conceptual elaboration and the legitimacy they are accorded. As noted in Chapter 3, there is an extensive literature base supporting the belief that definitions of and responses to illness, whether physical or mental, are influenced by culture; that normal and abnormal do not always mean the same thing within societies or cultural groups, let alone between them; and that 'illness narratives' (Kleinman, 1988a) that counter the dominant biomedical paradigm are rarely taken seriously. Health care professionals often refer to oppositional illness narratives - those that contravene or do not actively support biomedical beliefs – as 'folk narratives'. Several studies have situated this labelling in structures of power and domination, so as to contextualize meaning making in illness and to highlight the role and influence of power, not only in the creation of meaning, but also in the legitimating of meaning (Abrums, 2000; Goodman, 2001; Saris, 1995).

9.2 Everyday theorising

These arguments about the everyday nature of theorising rest on the work of a number of intellectual ancestors, namely Antonio Gramsci, Karl Marx, Alfred Schutz, and Dorothy Smith, together with sociologists who have applied this line of reasoning to older people (Auger & Tedford-Little, 2002; Gubrium & Wallace, 1990; Katz, 1996; Phillipson, 1998). While the endorsements of critical gerontologists such as Katz (1996) and Phillipson (1998) are significant, Gubrium and Wallace's (1990) conclusions about older people theorising age have not been subjected to further empirical testing, with the notable exception being the research in the Canadian Maritimes undertaken by Auger and

Tedford-Little (2002). Further, there is an abundance of work on the social construction of Alzheimer's (see chapter 2), yet older people theorising age remains an under-researched area (Gubrium, 2003, personal communication) – both topics of relevance to this thesis. While it was not something I set out to explore in this research, it became obvious fairly quickly that theorising was a significant component of the experiences of older people with dementia and that older people with dementia are active meaning makers, contrary to the popular (mis)conception. When I discussed my preliminary findings with one of the critical gerontologists referenced above (Katz, 2003, personal communication), I was referred to the article by Gubrium and Wallace (1990), which became a source of support for my findings and significantly influenced my analysis.

Although many sociologists have written about the everyday nature of theorising, influential writings by Gramsci (1971), Marx (1983), Schutz (1967), and Smith (1987) are particularly relevant to this chapter. I will briefly outline some of their key points that are relevant to this research before going on to discuss the everyday theorising of the older people with dementia with whom I worked. Gramsci (1971) argues that all people are intellectuals in that they philosophize about life, and arrive at understandings that have the potential to transform the world:

> …everyone is a philosopher, though in his own way and unconsciously, since even in the slightest manifestation of any intellectual activity whatever, in 'language', there is contained a specific conception of the world (p 323)…The active man-in-the-mass has a practical activity, but has no clear theoretical consciousness of his practical activity, which nonetheless involves understanding the world in so far as it transforms it (p 333).

This distinction between the populace who 'feel but don't always know or understand' and intellectuals 'who know but don't always understand and especially don't always feel' (Gramsci, 1971, as cited in Agger, 1979) underpins Gramsci's philosophy of praxis with its call for a dialectic between the masses and the intellectuals. Marx (1969)[36] called for an acknowledgement of the intertwined nature of theory and practice - praxis in Gramsci's terms - and, more importantly, the need to look for answers to theoretical questions in actual human practice:

> Social life is essentially *practical*. All mysteries which mislead theory to mysticism find their rational solution in human practice and in the comprehension of this practice (p 285).

For Marx, it is not enough to philosophize; intellectual activity must be channelled into action. Thus his famous concluding statement in *Theses on Feuerbach* (1969: 286) - 'the philosophers have only *interpreted* the world, in various ways; the point, however, is to *change* it' - is often seen as the origin of the concept of praxis (MacIntosh, 2003, personal communication). Latter day Marxists and feminists have defined praxis as:

> Reflection and action upon the world in order to transform it (Freire, 2001: 51).

> Thoughtful reflection and action that occurs simultaneously...the integration of knowing and doing (Kirby & McKenna, 1989: 34).

> The dialectical tension, the interactive, reciprocal shaping of theory and practice…at the centre of emancipatory social science (Lather, 1991: 172).

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[36] I have read slightly different versions of *Theses on Feuerbach* in three edited collections of Marx's writings (Agger, 1979; Feuer, 1969; Kamenka, 1983). I decided to use the Feuer (1969) reprinting of the Theses, as this translation is based on editions published by the Foreign Languages Publishing House in Moscow and Feuer's introduction to the collection indicated a thorough knowledge of Marx's work.

Schutz (1967) argues that human beings pre-select and pre-interpret the social world through a series of common-sense constructs of the reality of daily life; and therefore, this means that scientists are actually working with:

> constructs of the second degree, namely constructs of the constructs made by the actors on the social scene (p 6).

All of these interpretations are of course based on our own stock of experiences or what Schutz terms 'knowledge at hand' and this meaning making takes place in a social context; for, as Schutz (1967) notes, individuals are always:

> in a biographically determined situation, that is, in a physical and socio-cultural environment as defined by him/herself and within which s/he has a physical, moral and ideological position (p 9).

This means that, in the process of making social theory:

> Interpreters are inevitably caught up in the construction of models of models of models in recursive and reflexive fashion (Valentine, 1998: 277).

In her seminal work *The Everyday World as Problematic: A Feminist Sociology*, Dorothy Smith (1987) argues for an understanding of the social world, and the relations of ruling in particular, from the standpoint of women. She explains the origins of this counter hegemonic way of thinking thus:

> It is this essential return to the experience we ourselves have directly in our everyday worlds that has been the distinctive mode of working in the women's movement – the repudiation of the professional, the expert, the already authoritative tones of the discipline; the science, the formal tradition, and the return to the seriously engaged and very difficult enterprise of discovering how to begin from ourselves (Smith, 1987: 58).

In order to accomplish this work of ascertaining and valuing the standpoints of women, and other marginalized peoples, and connecting our lived realities to the relations of ruling, Smith suggests that we focus on 'the everyday world':

the world where people are located as they live, located bodily and in that organization of their known world as one that begins from their own location in it, is generated in its varieties by an organization of social relations that originate 'elsewhere' (Smith, 1987: 91-92).

The concept of problematic was developed by Smith to facilitate this link between the level of experience and that of conceptualization:

> to constitute the everyday world as that in which questions originate…and to explicate a property of the everyday world as a focus for sociological work (Smith, 1987: 91).

The 'active man-in-the-mass' (Gramsci, 1971), the 'wide-awake man' (Schutz, 1967), and yes, even women or 'ourselves' (Smith, 1987) are all seen to be actively making sense out of the social world. It is these 'first order constructs' (Schutz, 1967) that provide the foundation for the conceptual elaboration that sociologists and other social theorists do and for which the credit is often not shared. As my epistemological approach treated participants as 'co-creators of knowledge' (Fine, 1994), the results of this theorising are indisputably shared.

9.3 Theory from 'the ageing enterprise

Twenty-five years ago, the 'ageing enterprise' (Estes, 1979) was first identified and implicated in many of the problems encountered in later life, with the author referring specifically to:

> the programs, organizations, bureaucracies, interest groups, trade associations, providers, industries, and professionals that serve the aged in one capacity or another (Estes, 1979: 2);

and concluding that:

> the individual experience of aging is shaped by: (1) the perceptions, myths, and messages about aging that are communicated to old and young alike by media and opinion leaders, including gerontological researchers, and (2) the way a society treats its elders (directly or

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indirectly) via social policies on employment, retirement, health care, income, and the family (Estes, 1993: 292).

In a newer work referencing the ageing enterprise, Estes and her co-authors note that 'these different professional groups and interests are able to define questions about growing old to their own advantage' (Estes et al, 2003: 2). This argument is related to Gubrium and Wallace's (1990) contention that the intellectual products of the 'ageing enterprise' are very similar to the results of the everyday theorising of older people, an idea supported by one of the authors in earlier work (Phillipson, 1998). In their groundbreaking article 'Who Theorises Age?' Gubrium and Wallace (1990) provided rich data to support their claim that:

> …not just professional gerontologists theorise age; we all do to the extent that we set about the task of attempting to understand the whys and wherefores of growing old…[and] striking parallels can be found between the everyday theorising of ordinary men and women concerned with ageing and their more celebrated gerontological peers (Gubrium & Wallace, 1990: 132).

Despite the parallels between the products of the intellectual work of the 'ageing enterprise' and that of ordinary older people themselves, only the former has the authority or the legitimacy for its theories to be seen as such and then applied to the social world. Gubrium & Wallace (1990) referred to these 'two existing worlds of theory in human experience' as:

> ..one engaged by those who live the experiences under consideration, and one organized by those who make it their professional business systematically to examine human experience (p 147).

Attempts to replicate these results are not abundantly obvious through scanning the gerontological literature, despite the seemingly widespread belief that more work needs to be done on theorising age (Estes et al, 2003; Gubrium, 2003,

personal communication). An excellent example of the integration of theories from the ageing enterprise with the products of everyday theorising can be found in a gerontological text by Auger and Tedford-Little (2002). The authors, both Canadian social gerontologists, held eleven focus groups with older people, including Black and Mi'kmaw elders[37], in Nova Scotia to try and ascertain how older people feel about gerontology and about the aging experience. Not only did they ask general questions about the meanings of old age and aging, but they also tested out several gerontological theories on these groups of older people. Their results confirm the findings of Gubrium and Wallace (1990) about the close relationship between the ordinary theorising of older people and the 'scientific reasoning' of gerontologists.

The need to develop theory that is grounded in the experiences of older people themselves, and those with dementia in particular, was identified as an imperative at the outset of this research, as this has been one of the gaps in past theorising on dementia (Hulko, 2002). Harding and Palfrey (1997: 65), in their analysis of the social construction of dementia, sounded the caution against a-priori theory, noting that:

> we must be wary of imposing upon individuals and making them fit
> into off-the-shelf sociological theory.

The preceding statements about the ways in which people make sense of their social worlds and the fact that theories of older people mirror those of gerontologists, form the theoretical framework underpinning the following discussion of the third category – theorising - of this grounded theory on dementia and Intersectionality.

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[37] Mi'kmaw is a first nations community (aboriginal peoples) found in the Maritimes.

9.3.1 Theories of dementia

As I argued in Chapter 2 of this thesis and have stated elsewhere (Hulko, 2002; 2003), dementia theorising to date has been characterized by a preoccupation with ontological questions regarding the nature of dementia, such as 'what is it?', 'how did it come to be?' and 'what does it represent?' The way that dementia is viewed, undoubtedly affects the manner in which people respond to it as a social phenomenon (Robertson, 1990), as well as our everyday practices with individuals living with cognitive impairments. This is illustrated in the table in section 2.4, which I created in an attempt to delineate these various approaches to understanding dementia and their practical applications (Hulko, 2003), and to present the results in an accessible format.

This chart (section 2.4) had its debut at an invited lecture at the McMaster Summer Institute on Gerontology in June 2003 to an audience of over 150 health care practitioners and educators. I used it to help this group of people working 'on the ground' to understand the relationships between theory and practice in dementia care and to situate my own argument that dementia is best viewed as a 'bio-psycho-social phenomenon' (Hulko, 2003). The theoretical arguments I made that day appeared to resonate with the audience, many of whom shared case examples in support of my research findings; as a result, I was able to further elaborate the properties of what came to be the third category of this grounded theory - theorising.

The properties of the theorising category are that normal aging was the most prevalent theory of dementia amongst the research participants, with the only

exceptions being the most privileged participants – the two white Western upper class men – who believed that dementia is a brain disease. Katz (1996) explains in his seminal work on the formation of gerontological knowledge how the bio-medicalisation of aging (Estes & Binney, 1991; Estes et al, 2003) has created a real dilemma:

> On the one hand, the aged body, no matter how healthy and alive, was examined according to the pathological signs of senescence that separated it from the bodies of other ages; on the other hand, such pathological signs were considered to be normal in old age no matter how diseased or dying the body. Hence, in the discourse of senescence the aged body was neither diseased nor healthy but both normal and pathological since both conditions in old age were expressions of the same physiological laws (Katz, 1996: 44).

This dialectical reasoning which treats age-associated conditions like dementia as both normal and pathological was very much in operation amongst my research participants and represented both the acceptance and the rejection of the biomedical paradigm or 'the gerontological narrative' (Katz, 2003, personal communication); and is an example of the influence of the common assumption that older people are both 'ill' and 'not ill' (Thompson, 2001). A similar argument has been applied to children, with childhood being seen historically as a disease state that children can outgrow with proper care and attention (Hockey & James, 1993). Prior to explaining this dialectical reasoning about dementia in more detail, I will describe the theories of dementia that come 'straight from the horse's mouth' and that are shown to be influenced by the work of 'the ageing enterprise' (Estes, 1979).

9.4 Theory 'straight from the horse's mouth'

Angela Huggins understood the importance of getting the story 'straight from the horse's mouth' – older people with dementia in this instance – as indicated by her use of this expression in the final interview to cut short my unnecessary explanation of the rationale for talking directly to people with dementia:

Wendy:　　　　　Okay. So the reason I ask these questions is that this is something new that we haven't really talked to people themselves who are going through this. It's mainly been their caregivers that we've talked to. So we need to find out what the experiences have been like…

Angela Huggins:　Straight from the horse's mouth.

The theories about dementia that were put forth by the older people with dementia to explain what was happening to them were that (1) dementia is a brain disease and (2) dementia is part of normal aging. In the following subsections, I will give examples of these two competing, though by no means distinct and separate, ideologies and explain the clear associations with the social locations of these everyday theorists. After I have made clear the basic underlying premise and use of each of these theories and explained the ties to either the acceptance or the rejection of the biomedical paradigm, I will introduce the strategic nature of the theorising done by those participants who were marginalized on at least one domain.

9.4.1 Dementia as a brain disease

The two multiply privileged men in the sample – Gus Holden and Jim Heather – were the only participants who supported the brain disease theory of dementia. At first glance, this is not unexpected from Jim Heather, as he had been a physician; the other former physician in the sample – Julianna Molnar - did not

believe that her memory problems were pathological in nature, however, suggesting that intimate knowledge of the medical establishment does not account for this finding. I asked Jim Heather in the final interview whether he thought being a physician made a difference to his approach towards dementia, which was to be upfront about his diagnosis (see section 7.5.2), and although his initial reaction was dismissive, he did feel that physicians have extra understanding:

Wendy:	Do you think that has anything to do with your being a physician? Taking that approach?
Jim Heather:	Um, would I do it if I was a clockmaker or something?
Wendy:	[laughing] Well, I just, perhaps…
Jim Heather:	Hmm.
Wendy:	If, if you were anything other than a physician, right?
Jim Heather:	I think some people would whether they were a physician or not have um that sort of approach but not necessarily very many…'cause they don't understand probably to the same extent that we do and…
Wendy:	What is that like, having this extra understanding?
Jim Heather:	It makes it easier in some ways and in some ways it makes it harder.
Wendy:	How, how does it make it easier?
Jim Heather:	That um, uh we understand, we understand more fully um what's, what's happened to us and um I find that um, that uh other people [early stage support group members]…didn't have quite the same approach. Um, the people there were uh less likely to say, say um, uh, to be frank about it as to what we've got.

The frankness referred to by Jim Heather in this exchange was not all that obvious in my interactions with the participants, almost all of whom avoided the use of any of the words in the dementia lexicon, and Jim Heather himself talked around Alzheimer's (see section 6.4). Jim Heather's 'extra understanding'

caused him difficulties as well, particularly now that his knowledge and expert status had been compromised by memory loss, as shown in his reflections on a visit to the Alzheimer research labs in Toronto, in the company of the early stage support group.

Jim Heather:	Yes. And uh, it was easy for me to, to um be able to absorb what we were being told and rather difficult for the people to um, to uh absorb what information that they were being given. And uh, I've had um, a background of um…of uh interest in, in um, neurophysiology and I felt very upset really when I was doing it, doing the trip through the labs, that here I was I'd been an expert and I barely knew what, much more than some of the people could be expected to know, they knew about as much as I did about it I think.
Wendy:	The people working there or the people you were on the tour with?
Jim Heather:	People that are on the tour, very few of them were able to absorb it, the information. And uh, they had as much knowledge that they picked up, by now they may have lost, it may have disappeared again, but they um had an amount of knowledge which would be miniscule compared with the amount I had when I was doing the degree in neurophysiology.
Wendy:	What was it that was upsetting about that?
Jim Heather:	That I'd lost all the, lots of information that I had when I was um, when I was in that sort of work.

Jim Heather's extra understanding and expertise as a physician is not the same as Julianna Molnar's, however; Julianna Molnar had a very different approach to dementia than Jim Heather, as seen in her answer to the same question about the effect of her medical background on life with dementia:

Well, it's natural that what you worked in, it's more difficult to forget the profession you worked in, the things you worked in. But now there are a lot of changes. How can I know the brand new medicines? And there are certain things that we really used and now people don't even know about it.

While her answer was not unrelated to the question, in that she referred to professional knowledge and noted that she might not be up to date on the latest medicines, Julianna Molnar clearly did not see herself in the role of the patient. Thinking at the time that she had not understood the question, I tried rephrasing it in the hopes of getting her views about going from doctor to 'silly patient' (Hulko, 2005):

> Wendy: But do you think that because of your background, even though you're not working now, that that might make it more difficult for you to have problems with your memory?
>
> Julianna Molnar: It doesn't feel good that I can't remember certain things and I don't remember certain things that happened to me or when I was young. My memory has gotten worse quite a bit but I'm aware. But I'm aware.

As indicated by these examples and expanded upon in section 9.4.3, although these two participants shared the same professional background and similar medical knowledge, this had not led them to hold the same understandings of dementia. Clearly, other aspects of their social locations, such as their gender and ethnicity, played a role in theorising dementia, in the same way it did for experiencing and othering dementia, as shown in chapters 7 and 8. Before I discuss the role of social location further, however, I will demonstrate the use of the brain disease theory and show how it indicates acceptance of the biomedical paradigm.

References to the pathological nature of dementia were expressed by the two multiply privileged men in an unquestioning tone that underscored just how taken for granted the 'standard paradigm' (Kitwood, 1997a) remains today. Jim Heather talked at length about the search for a cure and often turned 'the

clinical gaze' (Foucault, 1994b) on himself, as was seen in the exchange from first interview that was excerpted in section 7.5.2 and that ended with these words.

> Jim Heather: The um other disease I've got is uh the Parkinson's and uh that's been treated fairly well, it's been…you can keep a fairly reasonable level of neurodegeneration in um with, with it but it still gets them in the end. So it's not a…perfect situation either.

In this passage (see section 7.5.2 and above), Jim Heather expressed his faith in the ability of scientists to conquer the disease, which was discussed as a gendered belief in section 7.5.2; referenced the complicated nature of dementia and scientific research seeking to unlock its mysteries; and indicated his own knowledge of neurodegenerative processes. Although Gus Holden used the language of cancer, rather than brain disease, and does not have the same familiarity with medical language as Jim Heather, his words clearly indicate that he also sees dementia as a pathological state, and not as a normal part of aging:

> Wendy: …why do you think this is happening to you?
>
> Gus Holden: [pause] Alzheimer's?
>
> Wendy: Mm-hmm.
>
> Gus Holden: Well, uh, it's cancer of certain uh [intake of breath], systems in my body. That, that's not word for word but uh, that's what uh I was told. I, I didn't know about it and then, uh, what's her name, oh dear, here's where my…
>
> Wendy: Dr. [name]?
>
> Gus Holden: Yes, yeah. It is, was very good about explaining it and interpreting it for me and the, uh, she wasn't sure if I was initially but it's been getting worse and I went through the various tests and things like that.

Gus Holden's words describing the second time he came into contact with people with Alzheimer's while at the family cottage (see section 7.4) demonstrate the micro-level application of the 'alzheimerisation of aging' (Adelman, 1995)[38] and indicate some of the benefits of heightened public consciousness of the association between dementia and later life:

> …main thing was we were going from the uh, the shore, across to a party. And in going, I was with a group of about half, heard somebody mention Alzheimer's or something and I said 'yeah, I've got Alzheimer's' and all of a sudden there were five of us that had Al- I think it was five of us, that had Alzheimer's in some form. I had just started I guess you would say. Actually, no, I didn't even know that I had Alzheimer's. I was losing my memory as I said, I have a terrible memory now and then that broke one of the others, they had, and then somebody started, said 'well so and so had, had Alzheimer's'. It wasn't, it probably wasn't as, oh, I don't know, it didn't seem bad to me, it seemed to be fine and getting along famously.

When I questioned Jim Heather about his use of the expression 'slipping' in reference to his awareness of the signs and symptoms of dementia, he explained that this was an euphemism for being on 'a path of decline' that he had used in the past when talking about his own patients. This is another example of Jim Heather turning the 'clinical gaze' (Foucault, 1994b) upon himself.

Wendy: You, you've mentioned an expression to me a few times, the, slipping, you've used that word 'slipping' and you talked about a slippery slope now as well.

Jim Heather: Yes.

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[38] This term was first used by Adelman (1995) to critique the disproportionate amount of funding spent on Alzheimer's disease research by the National Institute on Aging in the United States. Adelman argued that this huge investment in dementia research was occurring at the expense of broader gerontological research interests and basic science in particular; and that the 'alzheimerization of aging' was an example of the 'application of trickle-down economics' (529) and 'successful science advocacy' (531). Adelman did not use this phrase to refer to the way that fear of Alzheimer's disease has infected the public consciousness and reinforced the association between aging and dementia, however, although his work is clearly located within this critical tradition (see Binney & Swan, 1991; Bond, 1992; Cohen, 1998; Gubrium, 1986; 1987; Herskovitz, 1995; Holstein, 2000; Hulko, 2002; Leibing, 2002; Lyman, 1989; Robertson, 1990).

Wendy:	Can you tell…
Jim Heather:	It' just, it's just…
Wendy:	...me some more?
Jim Heather:	…something that you, it's a word we used quite a bit in talking about some pa-, patients that um. Slope, the slippery slope was the, the person that'd got on this path of to, of decline for example, person with cancer and um, it, it's a euphemism I suppose to describe a patient's um, being on the slippery slope.

A little while later I returned to this idea of slipping to confirm that Jim Heather applied this concept to himself, not only to his patients:

Wendy:	So you see yourself then on a path of decline?
Jim Heather:	Yes. And uh it's, there's, I realize that there's a slope. I picture the slope and a picture of the expression is a useful way of describing, describing what the, what is going on.

As is clear from the data presented in this section, the two most privileged participants fully accepted the brain disease theory and used it as their 'explanatory model of illness' (Kleinman, 1980). Further, the prevalence of the biomedicalisation of aging and the influence of the gerontological narrative is evoked in their descriptions of interacting with members of the 'ageing enterprise', as well as other laypeople or ordinary theorisers such as themselves. This adoption of the biomedical paradigm occurred in spite of the fact that I had explicitly attempted to limit effects of this nature by choosing to work with a community-dwelling, non-institutionalized population (see Chapter 5 for further discussion).

9.4.2 Dementia as normal aging

The normal aging theory was the most popular theory of dementia amongst the participants, which on its own is unsurprising, as this has been the case in past research on subjective experiences of dementia (Gillies, 1997; 2001; Keady et al, 1995; Keady & Gilliard, 1999; Phinney, 1998). Every participant who was marginalized on at least one domain, whether 'race', ethnicity, class or gender, invoked the normal aging theory to explain the cause of their memory problems. The use of the normal aging theory is exemplified by the following quote from Angela Huggins, one of the multiply marginalized participants, from the first interview when I asked her why she thought this was happening to her:

> I just think I'm getting older and, and I just, my memory isn't as good as it was 'cause my mother was just the same…and nobody thought of putting her in an institution or anything like that…

In the second interview, which occurred several months later, when I asked her where her ideas come from, Angela Huggins credited her doctor as an additional source for the normal aging theory that she applied to Alzheimer's.

Angela Huggins: Because I associate old age with Alzher-Alzheimer's with old, older people. I don't think young people get it, really. It's more for older people.

Wendy: Is that based on your personal experiences knowing older people?

Angela Huggins: No, no. When I was told about Alzheimer's I thought, Oh no, this doctor's crazy. What is she talking about? I couldn't believe it. It threw me for a loop. I mean I accept it now because I realize too, when Ashley [daughter] tells me I'm losing it you know, I sit here and I can't remember something, I think 'Oh God, she's right.'

…

Wendy: So if I were to ask you for your theory of why this is happening to you, would you say it's because you're getting older?

Angela Huggins: (inaudible) 'cause the doctors don't seem so concerned about it; It's not like I have cancer or something like that, you know. It's just, it's just uh, it's just, just a thing that happens when you're getting older.

Bosse Knudsen varied in the extent to which she acknowledged being cognitively impaired, as noted in section 7.2. She denied knowledge of Alzheimer's disease in the manner of Ester Hernandez (see section 6.4), yet did admit to having memory problems and being forgetful. The rationale Bosse Knudsen provided for her memory problems varied as well, as can be seen by a few of the explanations that she produced, all in the same interview:

Well, that I can't tell you. I don't know. [pause] I don't know it's just, I guess that's just the way I am.
…
I just think that days are different.

Later on, Bosse Knudsen told me that other people dismiss with laughter her memory problems as they believe they are caused by age, so I explored with her how she feels about this age association:

Wendy: So people attribute it to age and say it's…?

Bosse Knudsen: Yeah.

Wendy: …because of age?

Bosse Knudsen: Yeah, Yeah.

Wendy: What do you think about that?

Bosse Knudsen: Well it could be that, that it is, yeah. I never really think about why.

Wendy: You don't think about why it's happening?

Bosse Knudsen: Yeah, yeah. I don't.

Wendy: Why is, why do you think?

Bosse Knudsen: I, I don't wanna fuss about it and that's it. That's not really big thing to me.

In this sequence of explanations we can see Bosse Knudsen normalizing her forgetfulness and asserting her personhood; indicating the variability of life with dementia; agreeing with the normal aging theory; and explaining that she's never really thought about why it's happening because it's not a big deal to her. For Bosse Knudsen, theorising about dementia is linked to experiencing dementia - if it's not a big deal or simply a nuisance, why worry about the cause? The variability of dementia was noted by Jim Heather as well; though this had not shaken his opinion that Alzheimer's is a pathological brain disease.

> Um, so uh and it very, the other thing, the disease itself, both of them [Alzheimer's and Parkinson's] vary quite a bit. It depends on what, what you've been eating I think, and did you take all your pills, which I've, haven't done…since uh this morning [gets up to look for pills].

Although Ester Hernandez would not openly admit to having dementia in any of the interviews (see section 6.4), she did reference normal aging theory during the second participant observation session when her daughter pressed her to explain her memory problems:

> Then Maria asked her 'how come you can't remember?' and Ester said 'it's been a long time'.

Nancy Matheson – the only multiply privileged woman in the sample – usually chose to assert her individuality, and hence her incomparability; she did use the normal aging theory to align herself with other older people, however, and, through doing so, asserted her status as a 'normal older person':

> …but it doesn't bother me because I think it happens to everyone, you know.

There were a few novel theories as to what causes dementia offered by two people involved in the research, and these most closely align with psychological theories of dementia. During the observation session when Ester Hernandez

claimed that her forgetfulness is related to how long she has lived, her daughter Maria pinpointed a past emotional upset and Ester's inability to recover from it, as the reason for her mother's memory loss, as detailed in my notes:

> Maria thinks that her mother's memory loss is connected with Maria's youngest daughter's elopement at age 18 when she became pregnant. The two girls used to come over to the apartment while Maria was at work and Maria believes that Ester spoiled them. After the elopement, Maria was so upset that she stopped talking to the girls. Ester keeps thinking of them and Maria thinks this incident caused her memory loss.

Joe Brown regularly used the normal aging theory - 'every dog has its day' being his mantra in later life; yet, on one occasion, he told me that past emotional upset caused by a woman can affect a man's mind when he gets older, a theory that seemed rather incredible to me at the time:

Joe Brown:	…I say, a lot of men, a lot of men, get married you know and, and especially if their wife's cheating on them you know, I think, I think when they get, if they stay with them women long enough, as they get older, I think it affects them.
Wendy:	They what?
Joe Brown:	I think it affects their mind.
Wendy:	It affects the mind?
Joe Brown:	Yeah, I think so, I think so, I...
Wendy:	That's your theory huh?
Joe Brown:	Huh?
Wendy:	That's your theory is it?
Joe Brown:	Yeah, I think so, I think so. Because I know, I know because I, I know, I know about, I know, I know a guy.

Unlike Jim Heather and Gus Holden, it was not doctors that Joe Brown most often referred to as his source of 'received wisdom' about aging and dementia;

rather, it was a group of 'old men' that he hung around with when he was a 'young guy' growing up in Nova Scotia:

Wendy:	So where do your ideas fr-, about Alzheimer's come from? The things that you just told me about what…
Joe Brown:	Well, I know, I know this from when I, I know this from people that had old-timers when I was a young guy, see.
Wendy:	When you were young?
Joe Brown:	I know this from the old people, you know. I used to know, when I was a young guy, I used to be messing around with nothing but old men, okay.
Wendy:	I know, you've told me that before.
Joe Brown:	Old men, all the old men.

Although his doctor had helped him to understand that 'every dog has its day' in relation to his diminished sex life in later life - a subject he spoke about frequently (see section 7.3.2) - he was first taught this lesson by another one of these 'old-timers', this time in Toronto after he had moved to the city in his late teens:

> You know, I tell you a story, I remember when I was a kid in Toronto, this old man used to tell me, this guy was about my age [now], an old guy, he used to, I would go, if I'd go to the store for him, I'd come back and I'd sit down and he'd say you know Joe, he'd say son, he says enjoy yourself when you're young, he says when you get my age he says, it's all in your mind, not in your pants [laughs].

As has been shown, there were two main theories proposed by the participants to explain their memory troubles/Alzheimer's disease/dementia – brain disease and normal aging. Some of the connections to the biomedicalisation of aging have been indicated, as well as the fact that 'received wisdom' came from different sources. In the next section, I explain the connection between dementia theorising by the participants and the degree of acceptance and

rejection of the biomedical paradigm or the 'gerontological narrative' (Katz, 2003, personal communication).

9.4.3 Acceptance and rejection of the bio-medical paradigm

The different uses of the metaphor of cancer by a number of the participants is illustrative of the influence of the bio-medical or 'standard paradigm' (Kitwood, 1997a). As the reader may have noted in section 9.4.1, those who supported the brain disease theory of dementia and who were the most privileged, both made use of the metaphor of cancer in theorising dementia. Gus Holden referred to Alzheimer's as 'a cancer of certain systems in [his] body' and Jim Heather likened the 'path of decline' associated with dementia to the 'slippery slope' travelled by patients with cancer. Angela Huggins, who was one of the multiply marginalized participants and who supported the normal aging theory, stressed that what she has is 'just a thing that happens when you're getting older' and that 'it's not like [she has] cancer or something like that', which she thought would be more concerning to the doctors (see section 9.4.2). Cancer is undisputedly a pathological disease (Stacey, 1997) and was referred to directly by a few of the participants whose family members had died of cancer, including Gus Holden, whose son had died in adolescence of brain cancer. The differential use of the word 'cancer' by research participants is evidence of this dialectical view of aging – as both normal and pathological (Katz, 1996) - and corresponds to the link I have established between everyday dementia theorising and the social locations of the theorists. Two very different theories of dementia are supported by reference to the same disease state – it's not like cancer; and it is like cancer. This difference of opinion within my sample

parallels the dispute that raged about Alzheimer's in the early part of the last century (Cheston & Bender, 1999; Dillmann, 2000; Fox, 1989; Gubrium, 1986; 1987; Leibing 2002; Robertson, 1990; Shenk, 2001) and that still resurfaces every now and again - is Alzheimer's due to normal aging or is it a brain disease? The question that is raised by these results is: do we need to choose? What advantages might there be in espousing this dialectical view? The strategic nature with which the participants used the normal aging theory will help us to better understand these questions and thus is addressed in the next section.

9.5 The strategic use of normal aging theory

As was indicated in section 7.4 with respect to Ester Hernandez and her awareness of othering practices, there was a strategic component to the actions of those older people with dementia who had experienced marginalization on the basis of one or more aspects of their identity prior to being diagnosed with dementia. This strategizing was most apparent with respect to dementia theorising, as will be shown in this section of the thesis.

Unlike the other former physician in my sample – Jim Heather - who ascribed to the pathological view of dementia – or brain disease theory – Julianna Molnar drew on the normal aging theory and referenced her credentials as a medical doctor to legitimate her view that dementia is part of normal aging:

> I know very well, I was a doctor. I know well that at a certain age,
> there are certain things that are forgotten and your brain not working
> as it used to. For at a certain level, at a certain level, I think it's
> normal but I don't feel good about it.

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The claim that Julianna Molnar used this theory in a strategic way is supported by the fact that she showed awareness of the marginalization to which older people with dementia are subject and for this reason did not tell people about her memory problems (see section 8.3). As explained in section 8.3, Julianna Molnar and her husband had requested that I not mention memory problems to any of the people present at her weekly art class and for this reason I was introduced to the instructor and other class members as:

> A young friend of hers doing a PhD and with whom she is working on a project about older people and their lives.

Attributing her memory problems to aging was a way for Julianna Molnar to retain her status as a 'normal' older person, to avoid the othering that she knew she would be subject to, should people in her building find out about her dementia status. She offered several explanations for why she does not disclose her dementia status to her neighbours, yet did not expressly acknowledge her awareness that she would be treated differently. This can be seen in comments that she made about the people in her building at several points during the second interview, starting with her Romanian friend Maria, who is one of a small number of people that is aware that Julianna Molnar is experiencing memory loss.

Julianna Molnar: Maria I just met here in this building. We've lived here for 15 years; it's going to be 15 years in the fall. She moved here I think maybe a year before. We got to know each other quickly because we speak Romanian quite well.

Wendy: I think you told me that she knows, that she's one of the few people that knows that you're having some trouble with your memory?

Julianna Molnar: Yes, she's aware that my memory has gotten worse. A little bit.

Later on Julianna Molnar suggested a lack of familiarity with most of the people in the building as an explanation for why she does not disclose her memory problems:

> I am not in very good terms with a lot of people. We know each other, we say hello, maybe a few words here and there, but if we see each other, but we are not together enough.

Towards the end of the interview, after Julianna Molnar had told me how much she enjoyed the research experience because of the opportunity it gave her to talk to 'intelligent people', she pointed out one of her educated neighbours and indicated that ethnic differences are a factor inhibiting interaction in the building:

> That man who's coming in [pointing to television that shows the front entrance of building], he was a teacher. He is I think a year older than I am. He's from Iran but he completed his university in Paris and he likes to meet with us and talk to us. It's only on the outside when we meet; we don't go to each other's house or places. For him it's very different and he has a very different culture than we do. That's natural. And there are a few who are Muslim and then they turn their head when they see us.

As can be seen from these quotes, there are an array of factors influencing whether to tell and how much to tell 'the normals' when one has a discrediting attribute such as dementia (Goffman, 1963). Awareness of the othering that could ensue is a strong incentive to remain silent and pass for normal as long as possible (ibid); this passing is a strategic act and not an indication of internalized oppression, much like Kanuha (1999) found in his study of lesbian and gay men of colour. Passing was typified as: dissociation, omission, mutual pretence, and playing with the audience (Kanuha, 1999: 34); and four conditions relevant to the decision whether or not to pass were identified (p 31): (1) fit; (2) risk and safety; (3) relationship with audience; and (4) motivation and energy. While these conditions certainly applied to the older people with

dementia in this research, based on my observations, I would not have expected to see or hear about examples of 'playing with the audience'. However, perhaps that is exactly what Ester Hernandez was doing, as indicated in the data presented below.

The best example of the strategic use of normal aging theory comes from the most cognitively impaired older person in the sample. In the interview excerpt below, Ester Hernandez alternated between English and Tagalog and the interpreter was not as literal in her translations as she had been in the previous interview.

Wendy:	Ester…have you ever heard of something called Alzheimer's disease?
Ester Hernandez:	Alzhe-?
Wendy and Interpreter:	Alzheimer's.
Ester Hernandez:	Alzheimer, I just take something, for example.
Wendy:	Have you ever heard of that?
Ester Hernandez:	No, what does that mean? What's that mean?
Wendy:	It's a disease that people get when they're older…when they, they forget things.
Ester Hernandez:	They are contigous, contagious?
Wendy:	No, it's not contagious
Ester Hernandez:	That is not contagious?
Wendy:	No, it's not contagious; it's not that kind of a disease. It's in your head…It's when changes happen in your brain.
Ester Hernandez:	Me, I don't know…walking a lot… an old person walking around…
Interpreter:	[explains that Ester Hernandez thinks this means somebody who is sick in the head, somebody crazy].
Wendy:	No, not really like that.
Interpreter:	[tells her it is not mentally crazy]

Ester Hernandez:	What is the sickness, what is Alzheimer's?
Interpreter:	[asks Wendy if she can interpret it in a simpler way as she thinks Ester Hernandez is getting more confused]
Wendy:	It's…it's when your memory doesn't work very well, when you have little memory [words suggested by the interpreter].
Ester Hernandez:	No, I don't have that.

This piece of data clearly illustrates Ester Hernandez's denial of general knowledge of Alzheimer's disease, as well as the applicability of this label to herself. Her question as to whether or not Alzheimer's is contagious and her avowal that she does not have this sickness that affects your memory proved to be the most important features of this exchange, as will become evident upon reading the notes below about the events that followed.

> After about an hour, I determined that there was no point in continuing with the interview as it had not been fruitful up to that point and both myself and Ester Hernandez were getting tired. However, we had to remain until Maria [Ester's daughter] returned, which was [half an hour later]. After I stopped the tape, we talked about singing and dancing. The interpreter sang the Philippines national anthem and Ester Hernandez sang the words that she could remember, following the interpreter's lead. The interpreter stopped since she could not remember the words and Ester told her in Tagalog that she had contaminated her with her forgetfulness.

From these notes, we see that this 'profoundly impaired' woman, who denied any knowledge of Alzheimer's and refused to admit to having memory problems, had remembered our conversation about whether Alzheimer's is contagious or not and then used this information, after the interview, to joke with the interpreter that she had 'contaminated her with her forgetfulness.' This is a clear example of the strategic behaviour that people with dementia are capable of performing, in order to protect their status as 'normal older people'

and avoid the stigma (MacRae, 1999;Goffman, 1963) associated with dementia and the othering to which a person with dementia is subject (see Chapter 8).

9.6 Reconciling emic and etic perspectives

As mentioned in Chapter 3, there are two different approaches to cross–cultural psychiatric research, the emic and the etic approach, terms that are derived from anthropology. The etic approach assumes that mental illness is universally similar and thus classification and measurement systems should apply globally, even though most are Western products. The Mini-Mental State Examination (Folstein et al, 1975) is a prime example of this in the dementia field. Conversely, the emic approach starts from the perspective of the local culture and tries to understand phenomena from within that context (Patel et al, 1995a).

Thus an emic perspective represents an 'insider's perspective' (Braudy Harris & Sterin, 1999), based on subjective, local knowledge, while an etic perspective is the outsider's view – that of the ageing enterprise (Estes, 1979). The latter approach is that which has been most often used to develop theory on ageing and dementia, and is that which this thesis has shown to affect dementia experiencing, othering, and theorising. We have a dilemma now though, as the etic perspective on dementia has clearly influenced the emic one, in the manner of Gidden's (1993) 'double hermeneutic'. Giddens (1993: 170) explained the complexities of this cross-contamination of thought processes – the double hermeneutic – as follows:

> Sociology, however, deals with a universe which is already
> constituted within frames of meaning by social actors themselves,

and reinterprets these within its own theoretical schemes, mediating ordinary and technical language. This double hermeneutic is of considerable complexity, since the connection is not merely a one-way one; there is a continual 'slippage' of the concepts constructed in sociology, whereby these are appropriated by those whose conduct they were originally coined to analyse, and hence tend to become integral features of that conduct (thereby in fact potentially compromising their original usage within the technical vocabulary of social science).

The dialectical theory of dementia arising from this double hermeneutic process of theorising dementia is different than Kitwood's (1990) proposed theory of 'the dementing process in old age', with its focus on 'the dialectical interplay between neurological and social-psychological factors' (Kitwood, 1990: 162). The dialectical theory arising from this grounded theory study proposes that dementia is both normal and pathological, in much the same way that the 'biomedicalisation of aging' (Estes & Binney, 1991; Estes et al, 2003) or the 'discourse of senescence' (Katz, 1996) has turned old age into both a normal and a pathological state. Katz (1996) suggested a clear link between the discourse of senescence, the growth of the Alzheimer's movement, and professional efforts at 'disciplining old age':

> But what it is the AD movement if not the biomedicalisation of senile dementia stripped of its social and economic dimensions? In other words, the discovery of AD's proliferation may have more to do with how it is used to facilitate disciplinary alliances than with its actual epidemiological spread. In this way, as in the earlier formation of the discourse of senescence, new representations of the aged body become resources for the professional expansion of gerontological knowledge (p 113-114).

Faced with a dialectical theory of dementia as both normal and pathological, a theory that has come 'straight from the horse's mouth', do *we* accept it or reject it? If we choose to embrace the dialectic *and* wish to diminish the influence of the biomedical paradigm, perhaps conceptualizing dementia as a bio-psycho-

social phenomenon offers a way forward that best evokes the complexities and uncertainties of dementia and that reconciles these emic and etic perspectives.

9.7 Conclusions

This chapter has shown that older people with dementia are active meaning makers who engage in theorising dementia and do so in a strategic manner. The particular theories used by the participants to explain their memory problems do not represent the range of dementia theorising that exists to date (see Table 1 in section 2.4). None of the participants referred to dementia as a psycho-neurological condition, or a disability, or a social construction. Although several of the participants noted the significance of psychological and sociological factors in terms of experiencing and othering dementia, the theories espoused by the participants were those that biomedicine has been in conflict over since Alois Alzheimer first described the clinical features of the patient Frau D and Kraepelin named the condition she was suffering from Alzheimer's disease (Dillmann, 2000; Fox, 1989; Gubrium, 1986; 1987; Leibing 2002; Robertson, 1990; Shenk, 2001). Rather than choose between these dominant theories of dementia, a dialectical theory of dementia that positions dementia as a bio-psycho-social phenomenon serves to disrupt this false dichotomy and reinvent the 'discourse of senescence' (Katz, 1996) as a strategic theory derived from the integration of emic and etic perspectives.

Chapter - 10   Conclusions

10.1 Introduction

In this final chapter, I will demonstrate how the aims of this thesis have been achieved and then draw together all the theoretical arguments presented thus far into a grounded theory of dementia and intersectionality.   After accomplishing this task, I will raise some of the implications for policy, practice, and research.   While the implications are directed primarily at the fields of dementia and aging and few examples are given, I hope that the reader will be able to see the applicability to parallel fields and to spot additional implications.

Throughout this thesis, I presented numerous theoretical insights discovered while doing grounded theory research into older people's experiences of dementia and the intersections of gender, class, ethnicity, and 'race'.   The research question – what are the relationships between older people's experiences of dementia and the intersections of 'race', ethnicity, class, and gender – was answered in full with the results having been encapsulated in the three categories of the grounded theory: experiencing dementia, othering dementia, and theorising dementia.

The first research aim of exploring older people's experiences of living with a cognitive impairment was met through interviews, photography, and participant observation with older people with dementia and their significant others.   The consideration of 'race', ethnicity, class, and gender and their intersections, as well as the dynamics of privilege and oppression, was evident not only in the

composition of the sample, but also by the way in which I used intersectionality/social location as a lens through which the experiences of the various research participants were compared.

The second research aim of developing a theory of older people's experiences of dementia and intersectionality was met through the use of grounded theory research, the results of which were detailed in the preceding chapters on experiencing dementia, othering dementia, and theorising dementia. After attending to the third research aim in the next paragraph, I will attempt to distill all this theorising into a succinct theoretical statement and an accompanying diagram that is both comprehensive and comprehensible, and to demonstrate the fit, workability, relevance, and modifiability of the grounded theory.

The third research aim of critically reflecting on the research process was met through the use of a reflective journal, peer debriefing, and the solicitation of feedback from the participants, among other strategies and techniques. These tools, combined with my own constant questioning of self and others, enabled me to attend to the ways in which the research was affecting all of the parties involved and to assess not only the outcome (grounded theory), but also the process (emancipatory/anti-oppressive research). As was clear by the responses of the participants, not only was this a non-traditional way of doing research, but it also was a more inclusive and highly enjoyable experience for those involved and it had a positive impact.

10.2 Grounded theory on dementia and intersectionality

As has been shown throughout this thesis, new and varied views of dementia surface when the concept of intersectionality is applied to dementia research; and these perspectives pose challenges to our assumptions about what it is like to experience a phenomenon such as dementia. The grounded theory arising from this study explains the complex nature of the relationships between the subjective experiences of older people living with dementia and the intersections of class, ethnicity, 'race', and gender. The main argument presented is that there is a connection between social location and lived experiences of dementia; these relationships can be observed across and within the categories of experiencing, othering, and theorising; and dementia is a bio-psycho-social phenomenon that is understood by those living with it to be both normal and pathological.

As has been argued, in order to be relevant and connected to the lives of real people and phenomena, theory needs to be grounded and 'straight from the horse's mouth'. The use of a-priori theories about social life, particularly aging and dementia, created primarily by white Western upper middle class men, must be halted. These theories cannot adequately capture the lives of those whose social locations differ from the theorists. We must start to value the meaning making – the everyday theorising – that older people and other marginalized peoples engage in themselves and expand our disciplinary canon to reflect this wealth of knowledge.

Associated with this latter point is a critique of the concept of intersectionality. Although I find tremendous value in an intersectional analysis and will continue to use this theoretical concept in my own work, I feel that it is simply a theoretical concept and level of analysis that primarily exists in the minds of theorists and can be alienating to those whose lives it is meant to capture. Therefore, I argue that intersectionality should be treated as a theoretical lens and a metaphor for the interaction of complex and intertwined identity constructs; however, it should not be introduced into our conversations with marginalised people if they are not familiar with this term. To do otherwise, would be to superimpose the alienating discourse of academia onto the sphere of ordinary life.

In chapters two through four of this thesis, we learned that the theoretical products of 'the ageing enterprise' (Estes, 1979) have progressed outwards from the individual to the individual in society, yet have neglected older people's views on aging and being old; that inequalities in later life are persistent, interactive and patterned by socio-demographic variables; that theories of dementia relate primarily to ontology and represent partial, atomistic views; that the dynamics of privilege and oppression affect our lives with and without dementia; and that despite the omission of the voices of marginalized people in tales of subjective experience of dementia, there are indications that social location does impact on experiences of dementia.

Chapter five offered methodological insights, including how to steer a path through the great Grounded Theory divide, what grounded theory can look like when infused with feminist and anti-oppression sensibilities, how to

operationalise intersectionality, ways to access subjective experiences and observe social worlds, and what it means to make research less oppressive for research participants and more inclusive of their voices and experiences. In Chapter 6, we started to see the dismantling of key assumptions about dementia. The data presented countered the view that people with dementia lack insight, and showed that a reluctance to discuss dementia and avoidance of words from the dementia lexicon can be seen as purposive acts on the part of older people with dementia.

Chapter 7 presented the properties of the first category of the grounded theory – experiencing – and began to construct the argument that there are relationships between older people's experiences of dementia and their social locations. It was shown that complex insights can be gained through talking with older people with dementia about their experiences; this rich data counters commonly held assumptions about life with memory problems; dementia may facilitate self-actualization; and diversity does indeed make a difference. Through chapter 8, we were introduced to the second category of the grounded theory – othering – and learned that othering practices are frequent occurrences in the context of dementia; the extent to which people with dementia are subject to othering is related to their social locations; and the concept of resilience is important for understanding differential experiences of marginalization due to dementia. The penultimate chapter presented the third category of the grounded theory – theorising – and argued that older people with dementia are active meaning makers who theorise about their dementia experiences, and do so strategically. The next section will build on the

conclusion reached in chapter 9 that older people with dementia propose a dialectical theory of dementia that positions dementia as both normal and pathological, and integrates emic and etic perspectives. The result is a theory of dementia as a bio-psycho-social phenomenon.

10.3 Dementia as a bio-psycho-social phenomenon

As has been indicated thus far, the biological features of dementia - degree of cognitive impairment, symptomology, medical interventions - are not the sole factors affecting dementia experiencing, othering, and theorising for older people living with dementia. Bosse Knudsen and Ester Hernandez were the most cognitively impaired of the participants, yet were not othered as often (see section 8.6.1) due to what some would term their social-psychology – being a 'people person' and using humour in the case of Bosse Knudsen, and denying the label of dementia and drawing attention to other biographical features such as having been a dancer and a teacher for Ester Hernandez. This can also be seen as a sociological dimension - the result of resilience developed through a lifetime of discrimination based on identity factors such as their 'race', gender, and ethnicity.

The results of this research indicate that dementia is best viewed as a 'bio-psycho-social phenomenon' (Hulko, 2003), as the biology, psychology, and sociology[39] of the individual in question affect the way that this phenomenon is experienced, responded to by others, and made sense of by the person with

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[39] While 'psychology' and 'biology' are used in their unadulterated disciplinary forms to refer to individual characteristics, as in the biology or the psychology of Mrs. X, 'sociology' is almost always presented in an altered form, such as the social context or the socio-cultural environment. Because I don't see any reason not to, I am using the term sociology in the same way that psychology and biology commonly appear in reference to people.

dementia him or herself. Julianna Molnar implicated sociology in particular when she told me in the second interview that social isolation and lack of communication with others increases the likelihood of forgetting *everything* for those who already are experiencing memory loss:

> Those people who are forgetting about things…I would say…I think it really adds to it if somebody takes away…like you are not communicating anymore, you're not with people anymore…In order for you to keep your memory to some extent, you need people because otherwise you forget everything.

All people need to be surrounded by others, especially older people at risk of social isolation such as those with dementia (Alzheimer Scotland Action on Dementia, 2001). The presence of fellow human beings can encourage 'rementia' (Sixsmith et al, 1993) and the retention of abilities (Zgola, 1999: 93), the latter being reminiscent of the strengths perspective in social work (Saleebey, 1997) whose aim is to shift a social worker's focus from pathology and problems, to strengths and challenges. A paradigm shift of this nature is exactly what Kitwood (1995; 1997a) and others have long been advocating for in dementia and which many have thought attainable through the adoption of the social model of disability.

Marshall indicated the 'naturalness' of a holistic way of thinking about dementia amongst those who work directly with people with dementia when she referred to dementia as 'the most complex biopsychosocial disease' (1999: 90) in an article about what service planners and policymakers need from research. At a dementia seminar in Edinburgh soon after I arrived in Scotland to start my PhD, Jacques (2001) argued for a more holistic approach to dementia to avoid the polarization of the medical model and the social model; and I suggested that

perhaps he was calling for a bio-psycho-social approach. Based on the audience reactions, this appeared to be unfamiliar terminology or not the usual way of thinking about dementia in the UK; although I did notice that the other social worker in the room nodded in understanding. The ambiguous relationship between social work and bio-medicine is evident by the fact that a social work monograph on the application of the personhood concept in work with older people with dementia drew heavily on sociological theory, yet framed dementia as a disease from the outset (Bryan, 2001).

There are important differences between calling dementia a 'bio-psycho-social phenomenon' and closely associated terminology such as a 'bio-psycho-social disease' (Marshall, 1999) or a 'psycho-social condition', for example. While Marshall (1999) used an expression that included all three elements – biology, psychology, and sociology – she retained the word disease and in doing so, indicated possible support for the view of dementia as pathological and not normal aging. Even if Marshall had used the word 'disability', as she has done elsewhere (Marshall, 1998), this simply would have indicated another ontological position that is taken to be oppositional to the medical model. The same would have been the case with condition or illness, which are both euphemisms for disease, though meant to indicate an emphasis on the patient's or emic perspective, rather than the physician's or etic one (Conrad & Kern, 1981; Emami et al, 2000; Kleinman, 1988a). Finally 'social construction' is far too expansive a claim on its own, as it rejects the possibility of any biological features in dementia and denies the bodily experience of symptoms and behaviours (Phinney, 2003), although it accomplishes the important task of

implicating the social world. The word phenomenon is sufficiently neutral on its own, and when combined with bio-psycho-social, allows for equal emphasis on all three components – and it allows for a holistic approach that reflects the theories of older people with dementia that what they have is both normal and pathological.

Three themes were evident in my earlier review of dementia theories (Hulko, 2002): prior theorising on dementia has not been based on the lived experiences and viewpoints of people with dementia themselves – it has not come 'straight from the horse's mouth'; dementia theories have failed to account for the socio-cultural context of people with dementia, the intersectional nature of identities, and the interaction between these realms; and future sociological theorising on dementia and intersectionality needs to be grounded in an analysis of the structure and function of privilege and oppression in order to adequately account for the experiences of people who are simultaneously oppressed on the basis of multiple and intersecting identity categories. Clearly a more holistic approach to dementia is needed to build a theory of dementia that adequately accounts for the variability of experiences. This research supports the view that a bio-psycho-social approach may be the most appropriate model for understanding the ontological and phenomenological nature of dementia. The timeless words of John Dewey (1939) explain the rationale behind this approach:

> It is my conviction that many perplexing problems now attendant
> upon human old age have a psycho-social origin …Biological
> processes take place in economic, political and cultural contexts.
> They are inextricably woven…We need to know the ways in which
> social contexts react back into biological processes... (As cited in
> Achenbaum, 1997:22)

The bio-psycho-social approach is often referred to by health care practitioners (Dowrick, May, Richardson & Bundred, 1996) and its adoption has been recommended for aging research (Innui, 2003). It has been shown that psychosocial aspects of health can be taught successfully to medical students (Burch, 1980-81) and easily applied to clinical practice (Egger, 2001). However, despite these expressions of support, this integrative approach has not been well evidenced in practice (Dowrick et al, 1996; Egger, 2001) and has yet to be applied to efforts towards achieving a greater understanding of the nature and/or experience of dementia. Referring to dementia as a phenomenon, and a bio-psycho-social one at that, takes the debate further, into the realm of ontology. It moves beyond *an approach to* dementia, towards *a grounded theory of* dementia.

The model below illustrates this phenomenon called dementia as being comprised of the elements of biology, psychology, and sociology.

Figure 28 Dementia as a bio-psycho-social phenomenon
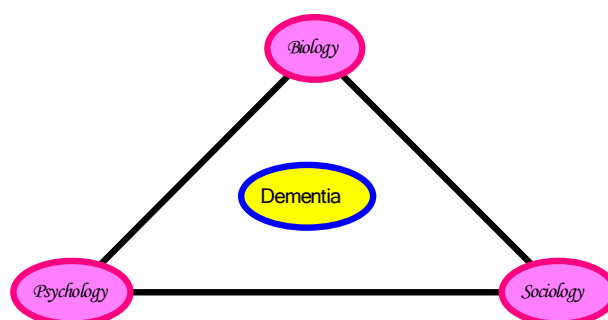
In terms of the contributions of each element, biology can be seen to be causative as it refers to the degree of cognitive impairment, symptomology, and specific medical interventions such as pharmacotherapy; psychology is a mediating element made up of factors like personality traits, psychic resources,

self-awareness, and 'challenging behaviours'; and sociology, also mediating, can be seen in one's identity and social location, the social world surrounding the person with dementia, including interactions with significant others and health care professionals, and structural forces, such as the dynamics of privilege and oppression. This holistic approach to dementia is grounded in the voices and experiences of older people with dementia themselves and reflects their everyday theorizing about this phenomenon that they believe to be both normal and pathological. Coming from people with dementia themselves, this conceptualisation of dementia as a bio-psycho-social phenomenon overcomes some of the weaknesses of past theorising about dementia.

I did not set out with a definition of dementia for this thesis, as I was not entirely comfortable with the biomedical one that I had been exposed to as a health care professional; nor was I satisfied with social constructionist perspectives, as they seemed to deny bodily experiences of dementia and the very real problems resulting from cognitive impairment that I had witnessed when working with people with dementia. This critique of the social construction of dementia is similar to that of feminist disability activists who pointed out the limitations of the social model of disability due to its neglect of impairment (Crow, 1996; Morris, 1991; 1996). The way that the social model of disability has been adopted within the dementia field (Bartlett, 2000; Kitwood, 1995; Marshall, 1998; Pool, 2000) appears to answer the call for a sociology of disability and impairment (Hughes & Patterson, 2000), one that acknowledges the social construction of disability while attending to the bodily experiences of impairment, essentially an approach that is integrative. It has less to say about

the ontology of dementia, however, as the focus is more on how we should respond to dementia than what dementia is, especially for the people who have it.

As has been argued in this section, biology alone can not account for the variability of dementia experiencing, othering, and theorising amongst this group of older people with dementia. The eight older people with dementia with whom I worked on this research ranged in age from 73 to 87 years, with 77 years being the average; five of them were women and three were men; three were considered to be multiply privileged, three fell in-between multiply marginalized and multiply privileged, and two were multiply marginalized, on the basis of their 'race', ethnicity, class, and gender; six of the eight were born outside Canada and had immigrated in adulthood; all had been diagnosed with some form of dementia, primarily Alzheimer's disease, with mixed dementia and dementia non-specified being the other diagnoses; and the degree of cognitive impairment for this group ranged from mild to moderate-severe, with the majority being moderately impaired. The range of dementia experiencing, othering, and theorising amongst this diverse group of older people cannot be accounted for by a variation in the biological features of dementia alone, as shown by the data presented in this thesis. The psychological and sociological aspects of dementia are just as important if we wish to achieve a complete and necessarily complex picture of subjective experiences of dementia, and one that reflects the dialectical theory of dementia as normal and pathological that has come 'straight from the horse's mouth'.

10.4 Implications for research, practice, and policy

Several implications arise from this grounded theory of dementia and intersectionality, as I expected at the outset (see chapter 5). The implications that I am presenting are divided into research, practice, and policy, with the recognition that there are overlaps between these different domains. Future research will have to address these implications, which are only briefly highlighted.

10.4.1   Research

This thesis has demonstrated that it is not necessary to choose between Glaser and his followers on one hand and the Strauss and Corbin school on the other, in order to do grounded theory research. It is possible to steer a course through all the dogma and infighting and produce a workable alternative that deserves the grounded theory official stamp. Moreover, grounded theory research that conforms to feminist principles and that makes use of anti-oppressive research methods is achievable. It must be stressed that this is a different way of doing grounded theory, and as such, it could be considered by current practitioners as too different or not at all different[40]. While the form of grounded theory that I describe in this thesis is less dogmatic and more reflexive than originally prescribed (Glaser & Strauss, 1967), I believe that adhering to the basic strategies (see chapter 5) and conducting research in an ethical and rigorous manner ensures congruence with the tenets of Grounded

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[40] See, for example, Glaser 's (2002) response to Charmaz's (2000) article distinguishing between objectivist and constructivist grounded theory; Glaser (2002: para 1) claims that 'Constructivist Grounded Theory (GT) is a misnomer' as he believes that grounded theory has always been constructivist, despite clear arguments that this is a new approach to creating knowledge using grounded theory strategies (Charmaz, 2000; Clarke, 2003).

Theory; at the same time, it allows for grounded theory research that makes more sense to researchers and research participants.

Not only did this thesis show that it is entirely possible to talk to older people with dementia about their experiences, whatever their level of impairment and insight, it also proved that strategies to reduce power differentials, such as participant validation, using verbatim quotes and long narratives, and process consent, can be used successfully with older people with dementia. Prior to using these practical strategies, the researcher must first conceptualise 'vulnerable old people', such as those with dementia, as active meaning makers (Russell, 1999). Furthermore, this thesis proved that it is possible to obtain approval from a hospital ethics committee for critical social science research that uses anti-oppressive methods and employs an emergent research design.

The therapeutic benefits of sharing one's stories of dementia were evident at several points during the research process, and this unexpected outcome was commented upon by several of the participants as well. As Kleinman (1988a) argued, I too found that research can fill a therapeutic void, in that there is not always time in a clinical encounter for us to encourage story telling, yet we know that it is beneficial for people to be able to share their illness narratives with receptive listeners. The therapeutic effect could be seen as one measure of success, as could the instances of catalytic validity (Lather, 1991), such as when Jim Heather told his staff about what it is like to have Alzheimer's and how he had been treated, after having discussed his experiences in two interviews with me. This moment of catalytic validity – 'the degree to which the research process re-orients, focuses, and energises participants towards

knowing reality in order to transform it (Lather, 1991: 68) – is captured in the photo below of 'Jim Heather' acting contrary to our expectations of a 'silly patient'.

Figure 29 'Jim Heather' chairing the staff meeting

10.4.2   Practice

At the Toronto feedback session, I was asked by the daughter of one of the participants, who was a social worker herself, why adult day programs don't run groups where people with dementia can talk about what they are going through. This is such a simple idea, yet rather revolutionary for dementia care. When support groups are offered for people with dementia, as opposed to their caregivers, they tend to be directed at people in the early stages and/or those with early onset dementia (Cheston, Jones & Gilliard, 2003; The Group Members, 2003). For those who are not eligible to attend these groups, we are

often so focused on activity programming and keeping people busy (Katz, 2000) that we neglect to discuss the phenomenon that brings people together for a full day, or half a day. The photo below depicts the activity schedule at a dementia day program and evokes the busyness that is so common in dementia care, perhaps driven by a fear of idle hands:

Figure 30 Activity schedule at dementia day program
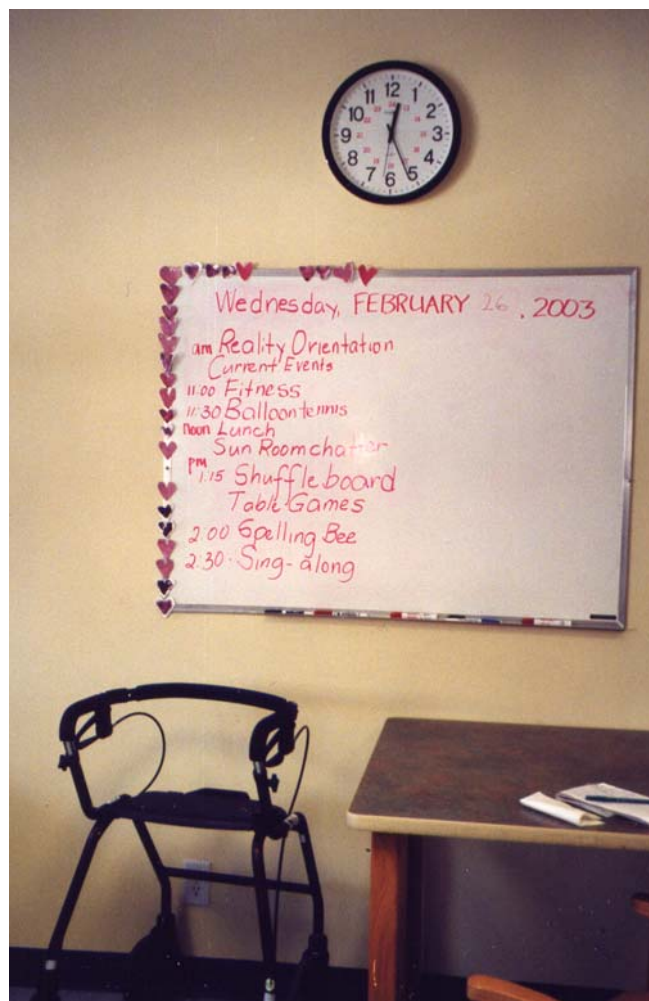
I suggest that 'over-programming' might have more to do with our own discomfort with the topic of dementia and less to do with concern for the delicate emotions of people with dementia, as older people with dementia find it beneficial to talk about their experiences (see chapter 6; Bartlett & Cheston, 2003). It is entirely understandable to feel afraid to initiate a discussion that

could go in any direction, raise uncomfortable emotions, and might not achieve resolution. When the environment is one in which talking to people is viewed as slacking, as not really working, and not a valid activity in its own right, there is not much incentive to explore the therapeutic benefits of talking about life with dementia. It has been argued that 'we risk marginalising some voices because they're too painful for us to hear – we hear them already in our work, in our lives, as we think (or try not to think…) about how we shall be when it is our turn, if it is to be our turn' (Cheston, 2004: 167). This avoidance of the topic of dementia might be owing in large part to cross-contamination from long-term care facilities, with their preoccupation with bed-and-body work (Gubrium, 1997) and activities of daily living (Beck et al, 2000), and the lack of funding and recognition of the need for counselling services for older adults in general.

In addition to 'life with dementia' groups at adult day programs, we could make better use of the social work profession, by actually having social work positions at local Alzheimer societies. Social workers could provide one to one counselling for people with dementia, which is not widely available at present, after which point people might decide to join a group of their peers. Gus Holden only felt ready to join a support group after he had the experience of talking with someone individually about his experiences, yet the only option in his community that is available to him as a person with dementia is an early stage support group. Angela Huggins noted how valuable it would be for those who are having a really hard time with dementia to talk to others. We know that not everyone is a group person and that individual counselling should precede group work, yet support services for people with dementia have not been

designed in this way, as they have been add-ons to services for caregivers, who were the primary client base of the Alzheimer Society for many years. It should be noted, however, that not all social workers will be suited to this type of work, nor will they be skilled in using a reflexive approach, simply by virtue of their professional background. Bryan (2001) concluded her monograph about person-centred social work with older people with dementia thus:

> By examining the person centred care approach and use of 'self' as a social work method, it was found that the qualities defining the method were not a generic condition of all social workers, but a rigorous, reflexive philosophy that was hugely demanding to practice (p 41).

An even more radical approach that is suggested by the findings of this thesis is to stop intervening in the lives of people with dementia, to stop making something problematic that is not viewed as a problem by the majority of the people who have it. If dementia is not hell for everyone who has it, why are we acting as if it is? Rather than adopting a policy of non-intervention per se, we should view this as an opportunity for community development – with a twist. It is apparent that the communities of the multiply marginalised older people with dementia have something to teach to the members of the social worlds of the multiply privileged older people with dementia. A transfer of knowledge and skills in 'human relations' and a more expansive definition of normalcy needs to take place and this time it should come from acknowledging the strengths of marginalised communities, rather than emphasising their disadvantages (Minkler, 1996; Saleebey, 1997).

People with dementia have started to advocate for themselves, and through doing so, to counter the negative, hopeless images associated with dementia

(Friedell & Bryden, 2002; McKillop, 2001; Robinson, 2001). For example, the Dementia Advocacy and Support Network (DASN) is a virtual community of people with dementia that started as a support group for people with dementia and has grown into a very strong lobbying and advocacy organization (DASN, 2004). While this is a very promising direction, we do need to ensure that the growing number of self-advocates are actually representative of older people with dementia and reflect the diversity of views about experiencing, othering and theorising dementia that are captured in this thesis.

10.4.3   Policy

At the policy and practice interface, the idea of creating dementia-friendly communities (Alzheimer Scotland Action on Dementia, 2001; Marshall, 1999) is certainly worth promoting and what this might look like should be explored in depth. This campaign is meant to address the reality that the majority of people with dementia live 'in the community'; indeed, they are 'not just receiving health services, but are moving about in our towns and cities like the rest of us' (Marshall, 1999: 93). It is within their own social worlds that people with dementia are marginalised on the basis of their dementia status and it is within their social worlds that people with dementia are subject to disabling behaviours. Raising awareness about dementia and increasing sensitivity towards people who have dementia would go a long way towards achieving full citizenship rights for people with dementia (Cook, 2003; Innes, 2002). Associated with a community level response such as this is the policy of relinquishing control over resources to the communities that are in receipt of them, as in the independent living movement. Perhaps the communities of the

more marginalised older people with dementia – that seem to be far more accepting of difference or eccentricity - are unconsciously putting into action the policy of normalisation that has been championed by the learning disabilities movement. In line with this shift, we need to alter our funding structures to ensure that psycho-social interventions receive as much funding as medical interventions; and that we move away from the medical focus on 'diagnosis, drugs, and doom' to a more social emphasis on living life to the fullest.

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Appendix A

Making the links: Social theories, experiences of people with dementia, and intersectionality

WENDY HULKO*

Introduction

The intent of this chapter is to introduce a new area of social science inquiry into the field of dementia - intersectionality/interlocking oppressions - and to apply this to an analysis of the literature to date on subjective experiences of dementia. This particular investigation is sociological in nature, however, critical theorists, practitioners and educators have been 'talking intersectionality' across several disciplines for over a decade. The concept is rooted in Freire's (2001) depiction of oppression as a structure of domination in which all humans participate, both as oppressors and as the oppressed. In the 30 years since the first publication of Freire's seminal text on oppression, terms like multiple, simultaneous, interdependent and interlocking have been affixed to the root word 'oppressions' in an attempt to broaden the theory to include systems of inequality other than class and to do so in a way that consciously avoids the 'add and stir approach' (Dressel, 1991). Freire himself was engaged in this work as noted by Macedo (2001) in his introduction to the 30th anniversary edition of *Pedagogy of the Oppressed:* "Freire's later works make it clear that what is important is to approach the analysis of oppression through a convergent theoretical framework where the object of oppression is cut across by such factors as race, class, gender, culture, language and ethnicity"(p 15).

Intersectionality/interlocking oppressions as a theoretical concept and level of analysis resides in a decidedly critical terrain that seems not to be marked by disciplinary boundaries and positioning, but by a shared sense of the emancipatory potential of theory that is derived from lived

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experiences and subjugated knowledges[1]. The introduction of this way of thinking about identity and difference is attributed to critical legal theorists (Crenshaw, 1994;1989; Delgado 1995), although it surfaced in broader feminist and anti-racist writings of the same period (Andersen and Collins, 1995; Bannerji, 1995; Bishop, 1994; Stasiulis, 1990). Since then it has been adopted by social work (Carniol, 2000; Dominelli, 1997; Mullaly, 1997; Oliver, 1996; Thompson, 2001) and eventually made incursions into critical gerontology (Dressel, Minkler and Yen, 1997; Estes, 2001; Vincent, 1995). A distinction was made between the micro-sociological concept of intersectionality and the macro-sociological concept of interlocking oppressions by Collins in 1995:

> First, the notion of interlocking oppressions refers to the macro level connections linking systems of oppression such as race, class, and gender. This is the model describing the social structures that create social positions. Second, the notion of intersectionality describes micro level processes - namely, how each individual and group occupies a social position with interlocking structures of oppression described by the metaphor of intersectionality. Together they shape oppression (as cited in Dressel, Minkler and Yen, 1997, p 583-584).

Intersectionality is used to point to the ways in which multiple and complex identity categories such as gender, 'race'[2], ethnicity, class, age, able-bodiedness, sexual orientation and faith/religion interact to shape individual life experiences. We cannot compartmentalise people and investigate, for example, how either ''race'' or class contributes to individual experiences of a particular social phenomenon, as we are all 'racialized' and classed and interact with the world as holistic beings. This chapter on dementia and intersectionality treats interlocking oppressions as the structural framework that shapes and constrains the

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[1] I use subjugated knowledges in the Foucaultian (1994) sense of "naive knowledges, located low down on their hierarchy, beneath the required level of cognition or scientificity", oppositionally situated in relation to dominant and dominating scientific discourse (p 41). See Leibing (1997) for an excellent example of the explanatory power of subjugated knowledges in relation to dementia in Brazil.

[2] I use 'race' in quotation marks to denote that I subscribe to the view that race is a social construction . Moreover, it should remain an important focus of sociological analysis as long as the values ascribed to this term and the resulting hierarchies remain in existence, shaping all our experiences of privilege and oppression. For a clear articulation of this position, see Crenshaw (1994).

Appendix A

identities and the experiences of people with dementia as they try to make meaning of their lives as intersectional beings.

The application of this analytical lens to dementia represents a progression from the preoccupation with the self/person that has characterised much dementia theorizing and research since the groundbreaking work of Kitwood (1990) and Sabat and Harré (1992). It is also a move towards the concept of identities - as intersecting, fluid and problematized - and an attempt to excavate and accord central importance to subjugated knowledges (Foucault, 1994*)* regarding identities and lived experiences of dementia. Emergent interest in identity follows a decade of heavy criticism of the predominance of biomedicine in the field of dementia (Binney and Swan, 1991; Bond, 1992; Downs, 2000; Herskovits, 1995; Holstein, 2000; Lyman, 1989; Robertson, 1990). Social scientists and others have been arguing for alternative approaches to dementia that focus on the person, not only the disease/disability, and many have contested the belief that dementia is an organic condition, seeing it instead as a social construction (see Harding and Palfrey, 1997). Although there is this aforementioned trend in dementia concerned with personhood (Kitwood, 1997a; Kitwood and Bredin, 1992) and selves (Sabat, 2001; Sabat and Harré, 1992), this has not been approached with an understanding of identities as multiple and intersecting. Rather, 'identity' is used interchangeably with 'selves' and 'person' and is constructed as both universal, in that we all are presumed to have one, and particular, in that we each have a unique, personalized one. The way in which identity categories interact with one another and the broader socio-cultural context of dementia is essentially ignored in these largely psychologically-oriented approaches to understanding dementia. These approaches do, however, represent progression from bio-medical models that see pathology as central and exclude both psychological and socio-cultural factors.

If one ascribes to the belief that dementia is a disability, it is relatively easy to see that dementia represents an intersectional state of being, as it resides most often at the intersection of age and able-bodiedness with prevalence increasing as it does with age. Add to this gender, 'race', ethnicity and class and the picture no longer lends itself to individualistic theories that appear to view people as homogeneous beings apart from their biology and/or psychology. As there is a lack of

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theorizing and research in dementia on how older people with dementia conceptualize their experiences in relation to intersectionality, literature must be drawn together from fields that are often disconnected: critical gerontology, mental health and illness, disability studies, critical race studies, women's studies, social work, cultural anthropology and legal/human rights theory. Making these links enables connections to be made across different experiences of intersectionality and interlocking oppressions. This chapter will apply the foregoing analytical discussion to the literature to date on subjective experiences of dementia. Prior to embarking on this however, a few theoretical distinctions are necessary in order to substantiate the position that we do not yet have an adequate explanation for this particular realm of human experience.

Dementia theorizing

Several ontological theories regarding dementia have been put forward. However, phenomenological perspectives remain a major, acknowledged gap in the literature. Given the lack of experiential theories, the focus here will be on theories that address the nature of dementia. It is noted, however, that in order to begin to understand dementia, we need to ask the people who are labelled as such about their experiences and then generate theory from these answers, rather than imposing a meta-theory on observed /described phenomena. Current theories on dementia may be loosely classified as: (1) dementia as a brain disease, (2) dementia as a normal part of the aging process, (3) dementia as a psycho-neurological condition, (4) dementia as a disability, (5) dementia as a mental health problem, and (6) dementia as a social construction. This fairly recent proliferation in the number of theories, or alternative conceptualizations of this phenomenon we call dementia, is closely related to dissatisfaction with the ability of the medical model to adequately account for the variability and diversity of symptoms and behaviours found in people with dementia. The arbitrary manner in which dementia was classified as a brain disease assists us in understanding the dissatisfaction with this model as an explanatory theory and will be briefly reviewed below.

Appendix A

Dementia as a brain disease

The medical model sees dementia as a brain disease and has been the dominant paradigm in this field since Kraepelin named an amalgam of symptoms and associated behaviours Alzheimer Disease (AD) in 1910 and classified it as a distinct subset of senile dementia (Cheston and Bender, 2000; Dillmann, 2000; Fox, 1989; Gubrium, 1986; Herskovits, 1995; Holstein, 2000; 1998; Leibing 2001; Robertson, 1990). This naming served to differentiate AD from senile dementia, a decision which Alois Alzheimer himself disputed at the time as he believed that what he had witnessed clinically was not the result of a distinct disease process, but rather a variant of senile dementia. A related debate, which predated this declaration of AD, was whether any distinction could be made between senile dementia and normal ageing. These scientific deliberations fell largely dormant until the early 1970s when AD was 'rediscovered' by medicine and psychiatry and agreement was reached to treat AD as an organic condition that is both related to and distinct from senile dementia. This led to the reintroduction of the general category of dementia in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) in 1994. As Cheston and Bender (2000) state, this "re-creation of Alzheimer's disease...has served to place people with Alzheimer's disease within a constricting explanatory framework in which they tend to be perceived as diseased brains rather than as social beings with active mental lives" (p 44). There is undeniably an association between dementia and ageing in that incidence and prevalence rates increase with age, however this does not support the belief that dementia is a normal part of the aging process. Contemporary theorists view dementia as a pathological condition that primarily strikes individuals at random. In this sense, the brain disease theory is akin to the personal tragedy theory heavily criticized in disability studies (Bond and Corner, 2001; Oliver, 1996) which sees disability (dementia) as a tragic quirk of fate that leaves the affected individual subject to the pity of others. The resulting societal responses focus on assisting the individual to adapt, rather than fundamentally altering social structures to accord disabled people full citizenship rights. The discovery of a pathological brain represents just such a personal tragedy in the world

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of biomedicine, a tragedy that medicine is driven to avert through the discovery of a cure.

Questions of normalcy and critiques of the biomedicalization of dementia

Aging is not a condition, but rather a process. Although various conditions may attach themselves to older people as they age, it is questionable whether the process of aging itself can be said to cause a condition such as dementia. There are compelling arguments that aging has been turned into a condition through a process of medicalization (Estes and Binney, 1991; Robertson, 1990), and the same process has been said to have solidified the location of dementia 'under the gaze' (Foucault, 1975) where it is then subject to regulation by the medical profession (Bond, 1992; Lyman, 1989; Robertson, 1990). As Dillmann (2000) concludes, dementia can be thought of as "a subset of the changes identified by the usage of the concept of aging [and] this subset is the result of a normative decision to evaluate a particular area of the range as 'abnormal'" (p 151). This process of ascribing phenomena with a designation of normal or abnormal certainly applies to dementia, just as it has operated in the past for 'madness' and 'senility' (Foucault, 1965). Indeed, the determination of whether dementia and other conditions that connect brain and behavior exist as facts or whether we have created them relies on an understanding of the creation of 'the other' and the designation of behavior as normal or abnormal.

Early treatises on the creation of 'the other' in relation to ideas of normalcy may have been concerned with ostensibly different subject matter, for example 'madness' (Foucault, 1965), 'stigma'(Goffman, 1963) and 'deviance' (Becker, 1963), yet the common thread is the identification of a situation that has been problematized by society and that subsequently results in discrimination of those who are classified as 'others', in this case people with dementia. Recently the term 'senility' has been reclaimed as a rejection of the medical classification of dementia, which is thought to be concerned only with the pathological. The use of the word 'senility' is a political act meant to signal a concentration on the physiology, political economy and social relations that structure loss and decay of the body and its voice (Cohen, 1998;

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Traphagan, 2000). The term, however, cannot escape its contested past in which it was equated with the aging process and as a result senility was seen to be an expected part of the aging experience. The degree to which dementia and senility are believed to be qualitatively different conditions is still under debate and although we may think now that the former term represents an advance in medical thinking and social awareness, it may just be a surface appeasement. That is to say, the response to dementia has not improved in terms of removing the stigma and engaging with 'the other' in a meaningful way. At the meta-level, the political economy of social relations of domination and difference has not been structurally altered by adoption of the clinical term dementia. Poverty, marginalization, and social exclusion are seen as 'non-medical issues' and through their omission from under the gaze, the aging process is effectively depoliticized (Robertson, 1990). Once we deconstruct the use of the words and the conditions they describe, we may come to the conclusion as stated above that it is all about the social construction of the 'other' and if that is the case, then society is necessarily implicated. And as Sayce (2000) states in referring to mental illness in general, "purely genetic explanations let society off the hook" (p 92).

Dementia as a psycho-neurological condition: the inclusion of the mind

Given the concerns with the reductionist, and quite possibly unscientific brain disease theory, it is no surprise that a move to a theory that took into account individuality and personality characteristics was embraced by those concerned more with the care than the cure of people with dementia. Kitwood's concept of personhood (Kitwood, 1990; 1997a; 1997b; Kitwood and Bredin, 1992;) and Sabat and Harré's corresponding focus on selfhood (Sabat and Harré, 1992; Sabat, 1998; 2000; 2001) was readily embraced and people eagerly adopted what they saw as a social-psychological approach, not the integrative theory that Kitwood proposed (Pool, 2000) that sees dementia as the interaction of both neurological and social-psychological domains. By factoring in the mind, Kitwood postulated that it is possible to observe some degree of 're-mentia' (Kitwood, 1997a; Kitwood and Bredin, 1992) and research

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has indeed supported this hypothesis (Sixsmith et al, 1993). Kitwood does not disavow the influence of pathology, rather he adds another component - the social-psychological - and asks that we view dementia first as a disability and then as an illness (Bartlett, 2000; Kitwood, 1997a). He has expanded the notion of what constitutes dementia and developed a method of assessing both well- and ill-being in dementia and an approach to care based on this synthesis of social-psychology and neurology (Kitwood and Bredin, 1992; Pool, 2000). At the same time, Sabat and Harré (1992) and Sabat (1998; 2000; 2001) were busy accumulating proof of the existence of selves in people with dementia, selves that seemed to persist well into the disease process and whose maintenance was shown to be dependent on the actions of others in their environment.

Personhood as defined by Kitwood (1997a) refers to a standing or status that is conferred on an individual by others in the context of a relationship, thus it is said to "emerge in a social context" (Kitwood and Bredin, 1992, p 275) and Sabat and Harré acknowledge that social constructionist theory (Sabat 2000; Sabat and Harré, 1992) forms the backdrop for their research on selfhood. However, neither Kitwood's nor Sabat and Harré's work truly enters into the social realm. It stays not only at the level of the individual, but at the basic psychology of the individual, leaving little room for an articulation of the role and influence of intersecting identities based on class, gender, 'race' and ethnicity. Another limitation of this theory is that it is not grounded in experiences of people with dementia; people with dementia were not asked how they would explain dementia (Harding and Palfrey, 1997), although this has been endorsed as a direction for future research (Kitwood 1997a; 1997b).

The personhood/selfhood concept and the accompanying theory of the interaction of brain (pathology, development, activity) and psychology is important to this project on dementia and intersectionality as it expands on the bio-medical notion of dementia as solely a brain disease, it champions the importance of understanding the person behind the disease and in doing so, lays the groundwork for further explorations of the nature of identity and the socio-cultural context of dementia. Dementia can be seen to challenge our notions of normalcy (Kitwood, 1997b) and encourage us to better understand what it means to be a

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person (Kitwood, 1997a). Our next step should be to explore what it means to be a person with multiple and intersecting identities, a person of a certain 'race', ethnicity, class and gender, an exploration that would take us into the sociological realm of understanding dementia. Kitwood (1997a) intimates this direction in his conclusion that the paradigm he espouses "brings into focus the uniqueness of each person, respect for what they have accomplished and compassionate to what they have endured" (p 135). The question of endurance in the face of discrimination is central to the following theory which views dementia as a disability and which is in essence a sociological theory.

Dementia as a disability and the connection to mental health and illness

Disability theorists and activists have not addressed dementia or mental ill health specifically, however it is becoming increasingly common in dementia and in mental health and illness to turn to the social model of disability championed by Oliver (1996; 1990) as a more adequate paradigm for understanding cognitive impairment (Bartlett, 2000; Gwilliam and Gilliard, 1996; Sayce, 2000). The attractiveness of the social model of disability is that it does not see impairments as problematic, rather it postulates that society has problematized impairment. Society is seen to disable people in the way that people with impairments are unnecessarily isolated and excluded from full participation in society (Oliver, 1996); society has not shifted attitudes and adapted environments to accommodate those who differ from the norm (Phair and Good, 1995). This is a move completely away from brain disease theory into the realm of the social, towards a political economy of disabilities. However, Oliver sees a clear distinction between theories and models and does not refer to the product of his thinking as a theory. He calls it a model since he believes models aid in understanding (Oliver, 1996) and do not seek to explain as theories do. There are differing opinions as to what distinguishes a theory (McMullin, 2000). This semantic distinction has not been as critical in dementia, and so this model has been adopted as an explanatory theory - a theory of how dementia should be viewed, not how it is caused. Naming dementia as a disability moved dementia theorizing to a focus on society, away from

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the brain, or the brain and behavior combined. The realm of the social leads us to questions as to how society shapes and constrains the experiences of people with dementia through our conceptualization of this disease/illness/disability and the interaction of relations of domination. It is this question that Oliver poses in his suggestion that the way forward on a theoretical level for disabilities is the creation of social oppression theory, developed by disabled people, and in this way grounding the theory in the experiences of people living with impairments, who are consequently disabled by society (Oliver, 1990). Oliver further highlights the need for an analysis that sees oppressions as intersecting and acknowledges that the social model of disability does not address this issue (Oliver, 1996). The imperative for the future is that theory be derived from the experiences of the people under study, a need that was identified earlier in relation to future dementia research. Initial indications are that it is natural for people to talk in the language of intersectionality, as the following quote demonstrates: "As a black disabled woman, I cannot compartmentalize or separate aspects of my identity in this way. The collective experience of my race, disability and gender shape and inform my life" (Hill, 1994, as quoted in Oliver, 1996). The concern expressed in the quote of the dangers in and futility of sectioning off parts of oneself is at the heart of an intersectional analysis. Aligning dementia with disability places cognitive impairment in a socio-political context and moves towards an understanding of the status of being disabled as an outcome of relations of subordination and privilege.

An analysis of intersecting oppressions is central to Liz Sayce's (2000) investigation into the discrimination and social exclusion of people with mental health problems and how to overcome this state of affairs. Her finding that people with mental health problems, referred to as users/survivors, are socially excluded, and that this intersects with other forms of discrimination, is based on extensive research with users/survivors, mental health professionals, policy makers, disability activists, advocates and lawyers in the US and the UK. She concludes that the disability inclusion model (based on the social model of disability) is the most likely model to lead to social inclusion and full citizenship rights as it places users/survivors as a minority group in society, it is inclusive of differences within the group in terms of decisions about whether to receive treatment or not, it acknowledges intersecting identities and it

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builds alliances with other groups to address simultaneous discrimination. Her rationale for focusing on oppression/ discrimination, rather than 'stigma' for example, is that the latter stays at the level of the individual and the former points to patterned or systemic exclusion from social and economic life (Sayce 2000). The adoption of the disability model by users/survivors, being people who are socially excluded due to mental health problems, lends further credence to its applicability to dementia.

The influence of sociology: dementia as a social construction

Sociologists have been criticized for not engaging with the needs and concerns of older people with mental health problems (Pilgrim and Rogers, 1999). Indeed Sayce (2000) identifies older people with mental health problems as those among the unheard voices that we need to actively seek out and suggests that mental health groups should build alliances with older people's groups in order to increase their strength as social movements. Although there is little evidence of sociological theorizing on dementia specifically, sociological theories have been applied to the study of dementia (Bond and Corner, 2001) and this link has not always been recognized[3]. The impact of work that has applied a sociological perspective to dementia has been profound in terms of our understanding of the social construction of Alzheimer's disease (Gubrium, 1986; Harding and Palfrey, 1997) and the purpose it has served for the "Alzheimer's Enterprise"(Binney and Swan, 1991), the biomedicalization of dementia (Bond, 1992; Lyman, 1989; Robertson, 1990) and the emphasis on lived experiences of dementia (Froggatt, 1988; Lyman, 1989; Lyman, 1998; Bond 1992; Bond and Corner, 2001; Robertson, 1991; Vittoria, 1998). Dementia as a subject matter seems to have "fallen through the cracks between social gerontology and medical gerontology, with neither specialty paying much attention to the social forces that affect the conceptualization and experience of the disease"(Lyman, 1989, p 599). This in turn has led to a lack of social theories of dementia.

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[3] For example, Kitwood's (1990) description of malignant social psychology draws on the sociology of deviance, namely labeling theory (Becker, 1963; Lemert, 1972), and Goffman's (1963) work on stigma; Sabat and Harré's (1992) and Sabat's (1998 & 2000 & 2001) work on selfhood is grounded in social constructionist theory (Berger and Luckmann, 1966).

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In line with the question of normalcy addressed earlier in relation to the brain disease theory and the biomedicalization of dementia, social constructionists view normalcy as a socially negotiated designation (Harding and Palfrey, 1997; Pilgrim and Rogers, 1999) based on social constructions of unwanted or deviant behavior. This theorizing is derivative of Thomas Szasz's 1961 thesis *The Myth of Mental Illness* (Szasz, 1994) and Berger and Luckmann's (1966) seminal work *The Social Construction of Reality* in which they state that "questions of psychological status cannot be decided without recognizing the reality-definitions that are taken for granted in the social situation of the individual...psychological status is relative to the social definitions of reality in general and is itself socially defined" (p 196). Rather than biology or physiology, it is society that is seen to create mental illness through its definition of normative behavior. The resulting label of abnormal is applied differentially and it has a variable effect on those to whom it is applied based on factors such as their 'race', ethnicity, class, gender and age (see Cohen, 1995). Harding and Palfrey (1997) question to what extent dementia is a label applied to people who resist oppression through an assertion of their individuality and their independence. Pilgrim and Rogers (1999) claim that "it is the roles and context of people's situations that influence the type and rate of mental distress" (p 40). Referring to the social construction of senility in particular, Traphagan (2000) states that it is a "matter of human identities as they change and are negotiated between and among people over their lives" (p 186) and stresses that this social construction is not universal, it is culturally mediated. For this reason, anthropologists, such as Traphagan (2000) and Cohen (1998), refer to senility as culturally, rather than socially, constructed. Viewing dementia as a social construction is helpful in that it speaks to the political economy of dementia - the interaction of the political, the economic and the social structures, and their impact on human experience. It runs the risk, however, of negating the very real experience of disorientation, memory loss, diminished judgement, and other symptoms endured by people with dementia. Further, it does not adequately explain the role of intersecting identities, nor does it place people in a socio-cultural context that differentially supports or disables them based on where they lie on the dual axes of privilege and oppression. For older people with dementia who are experiencing the

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intersectionality of age and disability, without even factoring in other dimensions of their identities, there is a need for theory that is grounded in their lived experiences and that further develops our understanding of the intersecting nature of oppression.

Implications for future theoretical developments

Three themes have run through this review of dementia theories: (1) prior theorizing on dementia has not been based on the lived experiences and viewpoints of people with dementia themselves; (2) dementia theories have failed to account for the socio-cultural context of people with dementia, the intersectional nature of identities, and the interaction between these realms; and (3) future sociological theorizing on dementia and intersectionality needs to be grounded in an analysis of the structure and function of privilege and oppression in order to adequately account for the experiences of people who are simultaneously oppressed on the basis of multiple and intersecting identity categories. From this theoretical review, we now move onto the literature on subjective experiences of dementia and its relevance to our understanding of dementia and intersectionality.

Subjective experiences of people with dementia

The movement to hear the voices of people with dementia started with a few pioneers who stated in legitimating fora that perhaps dementia researchers should place less emphasis on caregiver coping, stress and burden and start to examine what people with dementia are experiencing (Cotrell and Schulz, 1993; Cotrell and Lein, 1993; Froggatt, 1988; Lyman, 1989; Robertson, 1990). This probably was not a revelation for a number of people working directly with individuals with dementia who had come to realize experientially that "perhaps the PDWADs [persons diagnosed with Alzheimer's disease] themselves...have something to tell us about what it means to be human in the face of such dissolution, if we but ask and listen" (Robertson, 1990, p 436). Nevertheless, a movement was born that sought to understand the subjective experiences of people with dementia, through eliciting their perspectives and observing their social interactions. Resulting research has covered biomedical concerns of diagnosis, symptoms and treatment; the psychological arena of cognitive change and its impact on performance, affective states, loss and coping mechanisms;

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anthropological investigations into cross-cultural definitions of and attitudes towards dementia; and sociological questions about the nature of being in the world and the influence of structural factors and institutions such as work, the family, the state and what Estes (1979) termed "the aging enterprise". These sociological questions are perhaps the least researched, as instrumental concerns have taken precedence for those who might have explored these larger issues, e.g. social work researchers.

Subjugated knowledges

The pioneering researchers acknowledged that their proposed line of inquiry would be fraught with difficulties, primarily in terms of methodology. In addition, the assumption that people with dementia are not 'reliable historians' or 'credible witnesses', even about/to their own lives, was omnipresent and as such could be found in surprising quarters. I recall in 1997 discussing my interest in 'hearing the voices of people with dementia' (see Goldsmith, 1996) with a social work professor whose commitment to feminist research I respected and shared. I was not surprised that she queried my proposed methodology as I was accustomed to her intellectual rigor and precision. However, her attempts to dissuade me from research of this nature seemed to arise from a judgement that we cannot learn anything from people with dementia because they are unable to phrase their answers in a way that we can understand and/or that would be considered legitimate by the research community. This dismissal seemed inconsistent, not only with her epistemological standpoint, but also with growing evidence to support the refutation of similar arguments that have been applied to "almost every oppressed and disempowered group in society" (Proctor, 2001), examples being people with disabilities and children. A direct link seems to be made between cognition and validity in a demonstration of what has been aptly termed "cognitive superiority" (Shepphard, 1991, as cited in Harding and Palfrey, 1997, p 42). Although used by Shepphard to refer to the exclusive control of experts over the diagnosing (defining) of dementia, cognitive superiority translates to the belief that if someone's cognitive capacities are impaired, anything they tell us should be viewed as suspect. Moreover, emotional responses are not seen to

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carry as much weight as cognitive responses, if any at all, which greatly impacts upon people who communicate primarily through non-verbal means, such as those with advanced dementia. This attitude of cognitive superiority effectively means that a person with dementia does not have the power or authority to define his/her own experience. Maybe the unspoken problem is that asking people with dementia about their experiences might lead us to question and potentially re-evaluate our definitions of normalcy and abnormality and leave us with an uncomfortable doubt in our own cognitive superiority. It is within this context that we can understand this recent move to hear the voices of people with dementia and the composition of the group of individuals we have heard from to date.

Knowledge sources

The literature reviewed takes the form of personal accounts (see Boden, 1998; Davis, 1989; Henderson, 1998; McGowin, 1993; Rose, 1996), narratives produced with the involvement of a supportive other (see Killick and Cordonnier, 2000; Living Archive Project, 2001; McKinlay, 1998; Snyder, 1999; Zabbia, 1996), qualitative research studies (see Chatterji, 1998; Cohen, 1995; Cheston, 1996; Cotrell and Lein, 1993; Froggatt, 1988; Gillies, 2001; Keady et al, 1995; Labarge et al, 1998; Leibing, 1997; Lyman, 1998; Mills, 1997; Phinney, 1998; Proctor, 2001; Sabat, 2001; Sinason, 1992; Snyder, 2001; Sutton, 1994; Vittoria, 1998) and stories posted on Web sites or available in hard copy for the purpose of raising public awareness (see Alzheimer Society of Toronto, 2000; Ashley, 2001; Booth, 2001; Pauline and Mica, 1996; Shelia, 2000). Past research into subjective experiences of dementia has employed various methodological approaches, such as ethnographies, case studies, clinical observations, participant observations, focus groups, and semi-structured and structured interviews; has taken the person with dementia and/or their caregivers/family members as the primary subject(s); and has occurred in a number of different field settings, for example, care facilities, homes of people with dementia, neighborhoods, hospitals, and adult day programs. This body of literature (personal accounts, narratives produced with the involvement of a supportive other, qualitative research studies, and stories posted on internet sites) is

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reviewed critically in the following sections in terms of who is telling these stories of dementia, what these stories tell, whose voices are still silent/silenced and how untold experiences might differ.

Who is telling these stories of dementia

Although there has been exponential growth in work of this nature and thus many sources now exist, some troubling generalizations can be made regarding the voices that we are hearing: younger people in their forties to sixties who are well-educated, white, married, professionals, with strong religious or ideological beliefs and supportive families, who would be classified as early stage[4] in terms of their disease progression. These are generalizations and as such will not be applicable to all sources cited nor to all narratives produced by or with the involvement of individuals with dementia. The explanatory purpose of grouping this set of characteristics is to evoke a sense of the dominant voices that have captured the public consciousness and thus have come to speak for a marginalized group of people with varied experiences as a whole and intersecting identities as individuals. A promising exception is the recent book by Lisa Snyder called *Speaking Our Minds: Personal Reflections from Individuals with Alzheimer's* (1999). For her exploration of the subjective experience of Alzheimer's disease, Snyder has "deliberately chosen people of different ages, ethnicities, and educational and professional backgrounds" (p viii) and these biographical details come through in the narratives. It is apparent however that the seven people whose lives are showcased in the book have not been asked in the taped, in-home interviews, whether and in what way these controlled-for identity constructs shape their experiences of dementia. The influence of strong religious and/or ideological beliefs is evident in all but one of the narratives and may be a consequence of the author's decision to pursue this specific line of questioning (Snyder, 1999, p viii). The role of religious beliefs will be returned to in a later section of this paper, as it is a recurrent theme in many of the personal accounts published to date.

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[4] Downs (1997), in a cogent review of the emerging trend in dementia research of looking at the person with the disease, notes that the emphasis has been on people in the early stages of dementia.

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What these stories tell us about identities, problematized and intersecting

I have looked at Snyder's (1999) collection of experiences of dementia in depth for two reasons: (1) it is groundbreaking in that the author set out to hear voices of people with dementia, diversified her sample in terms of age, ethnicity, educational and professional background, and has published the results in a format that is accessible to the public; and (2) the narratives indicate the influence of gender, age, and class on the interviewees' experiences of dementia *despite* the author's inattention to this - she did not ask about this according to her notes (Snyder, 1999: viii) and does not analyze its appearance in the narratives either in this journalistic tale or in a recent academic piece based on the same research (Snyder, 2001). Owing to Snyder's noted attention to identity constructs in her sample selection, it is logical to presume that these accounts have the most likelihood of furthering our understanding of dementia and intersectionality. As the excerpts indicate, gender, age and class may be important to these individuals in terms of how they make meaning out of their experiences of dementia. Moreover, ethnicity may factor in as well, although its role and influence was invisible in the narratives presented in the book. The information given does not give us a fulsome picture, but it does raise the possibility that identity categories do shape individual experiences of dementia in an intersecting fashion. There are indications in the words of Snyder's (1999) interviewees that they may conceptualize their experiences in terms of identity categories, age being the most pronounced, with gender and class showing up as well.

Age and gender

Age seems to hold explanatory power for many people with dementia, as evidenced by personal accounts of and research with individuals with dementia. Some researchers have noted the influence of age in their analysis of the data while others have not, yet often the influence can be picked up in the narratives of the people with dementia that are included. As an example of the first approach, Gillies (1997) found that the 20 older people with dementia she interviewed about

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their experiences attributed their memory problems to old age, "it's an age thing" and "I put it down to age" being common statements (p 26). As very few of these people had been told their diagnosis, this finding should be interpreted with caution. Further support for this age association is presented in Phinney's (1998) study of experiences of early dementia in which three of the five people who were interviewed at length and observed in their own homes "interpreted their experiences in the context of themselves growing older" (p 13). Examples of the secondary types, in which the interaction of age and gender or age alone shows up in the data presented, although it is not analyzed by the researcher, are numerous. I have chosen a few to illustrate this point: A 78 year old woman in Cheston's (1996) study reportedly stated: "Sometimes I've got to sit there and just think, or close my yes until it comes back. Then I'm alright and off I go again. But then I'm getting older..." (p 595). Christopher Young, a prominent Canadian journalist until his retirement in 1996, writes about being 78 years old and living with Alzheimer's disease that "People of my age know that age [sic] is not a permanent contract....It is a much greater tragedy when younger people are stricken with Alzheimer's...We older ones expect problems...(Young, 2000, p 31).

Snyder (1999) reflects on how one participant named Jean had "courageously examined her roles and identity as a female [and] had participated in a demolition of the boundaries traditionally surrounding women in an evolving Western society" (p 68) over the course of her life. The continuing influence of her identity as a woman can be seen in some of the following excerpts from her narrative: "If I'm in a group of women with whom I am comfortable, I'm not as likely to have a problem" (p 60); "The women who helped me out - they were saints. They were the sweetest, loveliest women. I'll never forget them" (p 64); and "I guess there are people out there handling this marvelously [sic]. But it just isn't me. I want to cry and whine and kick! Not as ladylike, I must admit" (p 71). Age as an identity construct may be influential as well in Jean's experience, as the following quote with respect to her rationalization of early symptoms of memory loss indicates: "I'd think, 'well, I'm almost 70'" (p 60). Her ideas of 'age-appropriate behaviour' further shape her decision-making now: "I think living alone at this point now is something that is just plain old. I want some interaction

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with people" (p 74). Age intertwines with gender in the following quotes about Jean's relationship with the women's movement, now: "I was very active in the women's movement, and all these women I know are still working. They're much younger than me, and they're all busy" (p 67), and in the past: "So these women became my family. Age didn't mean anything. Nothing meant anything except our belief in ourselves...The whole feeling was really sisterhood" (p 67).

A few samples from John Killick's life history and poetry work with people with dementia evoke a sense of the dislocation and marginalization experienced by older people with dementia, especially older women: a well-educated woman named Alice who is in her mid-80s and lives in a care facility states: "As you well know, I'm being held prisoner here. My sister has stolen my life. Now I'm old and expected to dream my time away" (Killick, 1996, p 291); and in the poem The Bad Home (Killick and Cordonnier, 2000, no p #), a line reads: "I'm too old to do anything. I'm just a dustbin". This sense of being shunted aside and objectified is echoed in the words of a 78 year old woman named Betty in Snyder's (1999) study who highlights the importance of seeing the person behind the disease in all his/her complexity and seeking the meaning of the experience for people with dementia. She describes the attitude of health care professionals: "They know the diagnosis, but they don't take time to find out what it truly means for that person....A person with Alzheimer's disease is many more things than just their diagnosis. Each person is a whole human being (Snyder, 1999, p123-124). Lastly, these haunting words from the poem Openings (Killick and Cordonnier, 2000, no p #): "It's really scary when you're an old woman".

Gender, age, and class

As seen in the earlier quotes, an 82 year old man named Booker explains his dementia in terms of his age: "Time brings this disease on and I've been going on a while now. You come to an age when your system changes" (Snyder, 1999, p 101). Interestingly, a younger woman Consuelo, aged 33 years, who has tested positive for the Gene responsible for early onset Alzheimer's disease, does not seem to think that age would make a difference to her experience: "I don't know if it's harder

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at my age than it would be I were 70. Maybe it would be the same. But I always expected to get ill or have Alzheimer's when I got older, not now when I'm in my thirties" (Snyder, 1999, p 148). Although Consuelo does not problematize age, social class may have an influence on the way she conceptualizes her experience, as the next quote illustrates: "But I'm more educated than the rest of my family, so I thought I wouldn't get it. Then I recalled that my uncle was a lawyer and he had the disease. So, your schooling doesn't matter. You can go to college and still get Alzheimer's" (p 138).

Another older interviewee (aged 70 years) named Bob indicates the influence of gender with respect to his adaptation to changing roles within the family: "Poor Erika [Bob's wife] has to do all the driving, thinking, and putting things together. Instead of my doing things for her, now she's the one who jumps in and gets things done" (Snyder, 1999, p 85). This indication of the influence of gender roles is also evident in Cotrell and Lein's (1993) study in which the female caregivers "engineered their spouses' retirement in such a way that they could gracefully retire without 'losing face'" (p 125) and thereby avoid stressful situations. However, the women with dementia continued to "perform cognitive tasks that were frustrating and stressful for them" (p 125) as their male caregivers did not plan and execute face-saving avoidance strategies on their behalf. Questioning the concept of gender and the persistence of its importance in her life as a person with dementia who is acutely aware of her lack of worth as a human being, Diana Friel McGowin asks the reader "If I am no longer a woman, why do I still feel I'm one?" (1993, p 123).

Gender is a variable that to date has been largely ignored by qualitative researchers addressing the nature of experiences of dementia, with the exception of a recent study by Proctor (2001). In this qualitative exploratory study, the author looked at gender and power in relation to the service experiences of four older women with dementia in a day hospital. It is unusual in its focus on gender and power dynamics and in the application of this emphasis to the research process itself. The method of data analysis employed was developed specifically to uncover the voices and experiences of disempowered individuals, originally adolescent women (Brown and Gilligan, as cited in Proctor, 2001). Through repeated and varied listenings to the data, hidden truths are

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uncovered that may be missed through conventional data analysis that is not attuned to power in the relationships.

The author (Proctor, 2001) notes how one woman named Marion had difficulty making herself heard with the doctors and how she had interpreted this as owing to her lack of education: "I was going to a doctors. I said 'Oh, don't tell me there's going to be one asking a lot of questions'.... I aren't right well educated you know and I haven't learnt big words or 'owt like that" (p 371). Another woman in describing why she relates differently to the doctors and nurses than she does with the other patients states that "There's always a difference. They're higher up" (p 372). The influence of class is clearly evidenced in the words of these two women, although it is the role of gender that is under investigation in this study. Gender is often intertwined with age as the voices of older women noted earlier demonstrate and indications from Proctor's (2001) study are that class needs to be explored as an identity construct that intersects with other aspects of one's identity as well. This is supported by a recent study (Leibing, 1997) of a middle class population in Rio de Janeiro, Brazil. Rio de Janeiro is home to the country's highest proportion of older people, many of whom have mental health problems. The research looked at the illness narratives employed by 52 caregivers of Alzheimer patients and found that respondents believed that in addition to genetic factors, the ill person's biography and personality played a role in their current status as Alzheimer patients; stress, loss and a hard life were thought to bring on the disease. The findings indicate that the social context is important to subjective explanations of dementia and that the caregivers' responses could be perceived as "a wider societal way of coping in a world which does not seem to have space for everybody" (Leibing, 1997, p 236). It is possible that gender played a role with adherence to strict gender roles being observed in the sample - the women were mostly housewives and the men were primarily in the military - and the women with dementia more likely to be described as happy personality types. The role and influence of gender is not clear however, as the explanations as to cause of the disease did not vary by gender. Cohen (1995) found differences in perceptions and explanations of behavioural and personality changes in old age by the gender and class of the older person in question, but not by the respondent, although this was not the case for all

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conceptualizations of aberrant behaviour. This ethnographic research was undertaken in four neighbourhoods in Banaras, a city in India with a high concentration of older people and pronounced stratification by social class. The finding that "old voices in Banaras are heard primarily as extremes of power or abjection" (Cohen, 1995, p 323) leads Cohen to conclude that what is needed to move forward in our understanding of the social construction of 'senility' is a phenomenology of the voice, which means *"to take the act of listening seriously"* (p 320, emphasis in original).

Religion

The first published personal account of living with dementia was written by an American evangelical priest named Robert Davis (1989) and could be said to have shaped the way that subsequent true stories of dementia have been framed and interpreted. For example, his use of the word journey to describe his experience of dementia has been repeated in several accounts that followed (Crisp, 1995; MacKinlay, 1998; McGowin, 1997; 1993); it figures prominently in the title - *Each Person's Journey is Unique* - of a recent article in which a number of these insiders' tales of dementia are reviewed (Laurenhue, 2001); and Keady et al (1995) found from their in-home interviews with six people in the early stages of dementia that this is an apt description of the experience, adding that it is a journey largely into the unknown. A related theme of spiritual redemption and acceptance of God's will is echoed in many of the stories of dementia that followed Davis' account (Bailey and Darling, 2001; Brennan, 1995; Cheston, 1996; Living Archive Project, 2001; MacKinlay, 1998; McGowin, 1993; Phinney, 1998; Snyder, 1999; Zabbia, 1996) although none of these views of people with dementia demonstrate quite the same degree of fervency as Davis (1989), exemplified by the following quote: "Perhaps the journey that takes me away from reality into the blackness of that place of the blank, emotionless, unmoving Alzheimer's stare is in reality a journey into the richest depths of God's love that few have experienced on earth" (p 137). Davis decided to write his story in order to "be the voice for all those victims who lost their ability to communicate even before they knew what was bringing on all these devastating changes" (p 18). He

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sees himself as a spokesperson for people with dementia, believing that he has the ability "to personally express what the countless voiceless people are feeling" (p 18). At the end of the book, his belief in redemption and the healing power of heaven is so strong that his "heart develops a strange homesickness for heaven" (p 156) where he will be "made complete" and "have new abilities [such as a new mind] that are wonderfully magnified" (p 155).

Two examples from the subsequent literature evoke the influence of religious beliefs that was first evocatively described by Davis: Phinney (1998) reports that one of the women she interviewed in her study into the experiences of people with dementia "felt that Alzheimer's was God's way of 'making her slow down'" (p 13) and Cheston (1996) reports that a participant in the psychotherapy group that he co-facilitated and videotaped stated "I always say God's on one shoulder and my husband's on the other shoulder, so you'll never walk alone" (p 595). Interestingly, one of the first articles calling for research into the experiences of people with dementia concluded with the suggestion that future research should address "the effect of strongly held religious or ideological beliefs, and of the presence of close affectionate relatives, or a confidante, on maintaining the self" (Froggatt, 1988, p 136). I am not aware of research that has taken up this call, although both of these themes are visible in a close reading of the literature published to date, as the examples above indicate, and interest in the self clearly abounds (Bender et al, 2000; Crisp, 1995; Jonas-Simpson, 2001; Herskovits, 1995; Kitwood, 1990; 1997; Kitwood and Bredin, 1992; Mills, 1997; Sabat, 2001; 2000; 1998; Sabat and Harré, 1992; Small et al, 1998; UBC Dementia Research Collaborative Working Group; Vittoria, 1998).

Whose voices are still silent/silenced

As has been shown through this review, we have not heard from traditionally marginalized groups of people such as ethnic and "racial" minorities, lesbians/gays/ bisexuals, poor people, and uneducated people. The influence of 'race' and ethnicity on subjective experiences of dementia is a relatively unexplored domain (Bowes and Wilkinson, 2001) although interest in 'race' and ethnicity has been growing in the areas of risk and prevalence, assessment, service provision and caregiving

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(Anderson and Brownlie, 1997; Innes et al, 2001; Patel et al, 1998; Yeo and Gallagher-Thompson, 1996). Lisa Snyder (1999) identified ethnicity as one of the bases upon which she diversified her sample, however it seems that she is using ethnicity as a polite word for 'race'. We are given hints through the author's narrative about the "racial" background of two of the respondents in a way that asks the reader to integrate their assumptions into the text. We presume that Consuelo is Mexican-American as she has a Latin name, as does her husband Juan, and since she spent part of her childhood living in Mexico while commuting to school in her native United States. We also surmise that Booker is African-American when we learn that his father was emancipated from slavery at age nine. The meaning for Consuelo and Booker of these ascribed identity categories is not explored. No clues are given as to the 'ethnicity' of the five other people with dementia that are profiled, leaving us to assume that they are all white and are not members of any ethnic minority groups. The other research studies covered in this review report on factors such as gender, age, diagnosis, marital status and family status, past occupation and sometimes faith in terms of the composition of their samples. The lack of information on 'race', ethnicity, sexual orientation and abilities leads us to assume firstly, that the participants are all white able-bodied heterosexuals from the majority ethnic community and secondly, that this information is not relevant for understanding subjective experiences. Further, if the information is given at all, it is reported in a descriptive fashion; these identity constructs are not seen as worthy of investigation either holistically or separately. We will not know whether and in what way an individual's unique and intersecting identity shapes their experience of dementia until we include these sorts of questions in our research design and ask them directly of the people whose lives we are studying.

How experiences of dementia may differ if we look at intersecting identities - Striving for normalcy

Another theme that runs through the literature and that is relevant to this project on dementia and intersectionality is that of striving to be normal, normal usually taken to mean 'pre-morbid' or 'without dementia'. Phinney (1998) found through interviewing five people with dementia

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and their spouses and observing them at home that two themes emerged: being unsure and trying to be normal. Trying to be normal involved efforts to maintain continuity in their lives despite the presence of dementia and strategies were classified as self-monitoring, keeping an active mind, staying engaged and downplaying. Phinney (1998) also discovered that her queries that were related to corporeal experiences of symptoms and disease were substantially less important to her interviewees than the "broader experience of living with Alzheimer's in terms of its meaning to them and their concerns" (p 14).

Comparing oneself to others in terms of normalcy and striving for normal status is prevalent in personal accounts of living with dementia and could reflect motivations for publicizing one's private troubles - yes to make it a public issue (Mills, 1959), but also to normalize the experience, to hold onto the status of oneself as a normal human being. Christopher Young (2000, p 31) writes, "I live a fairly normal life, yet it is not the same". Normal, but different - this sentiment echoes the voices of disability and mental health activists. Diana Friel McGowin (1993) takes her construction of self as normal a step further in establishing her past life as one of normalcy, perhaps to provide additional support for a continuation of this status. She states at the outset of her book that her account is one of "an average family with nothing more than life's typical problems" (p 11) and towards the end of the book enumerates several problems that she and other people with dementia encounter because "we look okay" (p 125). This theme of striving for normalcy is important to dementia and intersectionality for the simple reason that for marginalized peoples - older people, women, ethnic and "racial" minorities, poor people, lesbians/gays/bisexuals, disabled people, people with mental health problems - striving for normalcy is the stuff of daily life. It is *extra*ordinary for most oppressed people to be seen and treated as normal, to have a powerful voice, to be part of the dominant discourse, to be seen to have legitimate knowledge claims. With this understanding, the importance of locating this type of research within an analytical framework of intersectionality/interlocking oppressions and of making links across experiences of oppression becomes clearer.

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Implications for future theory and research

Through a review of dementia theorizing and the literature on subjective experiences of dementia, it has been shown that identity as a concept has not been addressed to any extent and certainly not within an understanding of how people are simultaneously situated and describe their experiences in terms of their intersecting identities. This gap in the literature exists for three reasons: (1) the dominant voices telling their stories of dementia do not, by and large, include marginalized people - ethnic and "racial" minorities, older people, lesbians/gays/ bisexuals, disabled people, poor people, uneducated or minimally educated people – who may conceptualize their experiences differently than the mainstream voices; (2) when identity constructs i.e. gender, age and class are referred to, they usually are not problematized or seen as salient concepts in furthering our understanding of experiences of dementia; and (3) the striving for normalcy theme in the dominant discourse does not leave space for those who were likely concerned about their full human rights before/apart from their diagnosis of dementia, those who were striving already. As a starting point, future dementia theorizing and research needs to move beyond a limited focus on the self/person, towards an awareness of and investigation into identity. The next step would be to build in an understanding of intersectionality/interlocking oppressions – meaning an analysis of how we are all differentially located on axes of both oppression and privilege and how this is determined by where we are situated and situate ourselves in terms of our own intersecting identities. Only then do we have the possibility of unearthing the subjugated knowledges that lie buried under the dominant dementia discourse - le savoir des gens (Foucault, 1994, p 41) - that should serve as our guide to and through this realm of human experience.

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How does who you are as a person shape living with memory problems?

A research project by Wendy Hulko, MSW, PhD Candidate
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Gender:
- assigned at birth
- based on our sex parts
- man or woman

'Race':
- label others give to us
- based on our physical appearance (mainly skin color)
- Black, white, Asian, mixed, Aboriginal

Ethnicity:
- self-chosen
- group of people we identify with or feel part of
- based on shared clothing, dress, food, religion, language, birthplace, etc.

Class:
- determined by self and others
- based on education, occupation, income, access to status and resources, etc.
- lower or working class, middle or managerial class, upper or professional class

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Introduction

The aims of this chapter are to introduce the concept of intersectionality, highlight its relevance for social science research on dementia, and address methodological issues arising from a grounded theory study of dementia and intersectionality. This chapter is based on research that was in progress at the time of writing; and that was concerned with subjective experiences of dementia in later life, particularly the influence of one's social location on this life process. Explorations of the subjective realm of dementia are fairly recent (see Braudy Harris 2002; Downs 1997; Proctor 2001; Wilkinson 2002; Woods 2001), despite researchers having highlighted this gap well over a decade ago (Cotrell and Schulz 1993; Froggatt 1988; Lyman 1989). Moreover, this body of research is incomplete, as minimal attention has been paid to the influence of identity categories such as age, class, gender, 'race'[2], and ethnicity (Disman 1991; Downs 2000; Hulko 2002). Socio-cultural factors such as one's gender, 'racial', ethnic, and class identity impact on one's world view and life course and are thus an important consideration in seeking to understand what it is like to live with dementia.

Despite the growing voices of people living with dementia, these have largely excluded the input and participation of people who belong to traditionally marginalised groups (Hulko 2002). We will not know whether and in what way an individual's unique, complex, and intersecting identity shapes their experience of dementia until we include these questions in our research and ask them directly of the people whose lives we are studying. Moving away from selfhood and personhood, into the realm of identity, calls for an analysis of intersectionality - a metaphor for the entanglement and interaction of multiple and complex identity categories. If we are to move beyond narrow conceptions of personhood that are now claiming space alongside biomedical views of dementia and for which credit is due Tom Kitwood and his colleagues striving towards a 'new culture of dementia care' (see Kitwood 1997;1990; Kitwood and Benson 1995; Kitwood and Bredin 1992), we must expand the epistemological and ontological bases of dementia research, embrace lessons from parallel knowledge traditions, and develop theory that is grounded in the voices of people experiencing this phenomenon. This chapter introduces a study that was designed to achieve these aims and uses it as a case study to highlight emerging issues for social science research in dementia. After an introduction to the concept of intersectionality, I present findings from the literature related to dementia and intersectionality, focusing on dementia theorising, subjective experiences of dementia, identity factors, and social location. I then describe the research project, discuss methodological issues that have arisen, and conclude with

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[2] I use 'race' in quotation marks and racialized people (Fanon 1963) to denote that I subscribe to the view that race is socially constructed (see Haney López 1995). Moreover, it should remain an important focus of sociological analysis as long as the attributes ascribed to different 'races' and the resulting hierarchies remain in existence, shaping our experiences of privilege and oppression (see Crenshaw Williams 1994).

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comments about the potential implications of a grounded theory of dementia and intersectionality, and key questions that have arisen from the study.

Intersectionality – Meaning and use of this concept

As I have discussed elsewhere (Hulko 2002), intersectionality as a theoretical concept and analytical perspective has been used by scholars and activists in critical legal theory, feminism, anti-racism, and more recently, social work and critical gerontology. Intersectionality is used to point out the reality that we are all holistic beings, inhabiting multiple and complex identities that should not be teased apart into separate units of analysis (Anderson and Hill Collins 2001; Bannerji 1995; Brah 2001; Dressel, Minkler, and Yen 1997; Lorde 2001; Woodward 1997). Further, we each possess different degrees of oppression and privilege based on our relative positioning along axes of interlocking systems of oppression, such as racism, classism, sexism, ethnocentrism, and ageism. Where each of us lies in relation to the center and the margin (hooks 2000) - our social location - is determined by our identities, which are necessarily intersectional. Intersectionality is related to key sociological concepts such as identity, social location, subjectivity, and the self, all of which have been a focus of intense interest within the dementia field in recent years. There are two approaches to the study of identity/subjectivity, with one approach seeing identity as 'fixed and transhistorical' (essentialism) and the other treating identity as 'fluid and contingent' (Woodward 1997). This study takes the latter approach, using the terms identity and subjectivity interchangeably, recognizing that the former has a political meaning (Bannerji 1995) while the latter denotes status as a subject and signifies the coming to voice of oppressed peoples (Mama 1995).

'Intersectionality' and its corollary 'interlocking oppressions' have been applied to human rights claims/discrimination cases (OHRC 2002) in the critical race theory tradition (Crenshaw Williams 1994; 1989; Delgado 1995; Delgado and Stefancic 2001). However, this has not been accompanied by empirical research to date. Intersectionality may feel right and make sense intuitively as a way of thinking about our multiple selves, and may appear theoretically and politically attractive as it leads us away from fruitless attempts to find the ultimate oppression to which all others can be reduced. However, it needs to be bolstered by empirical research, a task made daunting by the fact that it is a very difficult concept to operationalise, and efforts to do so are rarely discussed (see Hulko 2003). Nevertheless, it represents an important development in thinking about identity and difference and could offer valuable insights for dementia research.

Knowledge to date about dementia theorising, subjective experiences, identity, and social location

Given the dearth of literature specifically related to the topic of dementia and intersectionality, the literature review that I undertook for this project involved extensive reading in the substantive field of dementia, as well as sampling of material from related disciplines and parallel knowledge fields. I sought out knowledge about subjective experiences of dementia, as well as concepts, evidence, and theories that could potentially assist in the development of a grounded theory of dementia and intersectionality. Since I have detailed elsewhere my findings related to dementia

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theorising and subjective experiences of dementia (Hulko 2002), I will summarize this material and then give an overview of the literature related to identity and social location.

Dementia theorising has been largely ontological in nature, focused on what dementia is or how it should be viewed and thus the question of how dementia is experienced has been largely overlooked (Hulko 2002). The absence of phenomenological perspectives on dementia is an acknowledged gap in the literature and accounts for my attention to ontological theories of dementia in this review. The divergent and overlapping dementia theories that have been put forth to date see dementia as: (1) a brain disease; (2) normal ageing; (3) a psycho-neurological condition; (4) a disability; (5) a mental health problem; and (6) a social construction. While this proliferation of theories is indicative of growing disaffection with the medical model (Bond 1990; Estes and Binney 1991; Lyman 1989; Robertson 1990), chiefly for its inability to adequately explain this phenomenon called dementia (see Leibing 2002), theories which address the social and environmental context of dementia have not been free of some of the limitations of their predecessors. The brain disease and normal ageing theories were the first explanatory theories of dementia put forth and have yet to be reconciled with one another, despite the fact that both are rooted in the bio-medical paradigm. The psychological and sociological theories that followed did not alter the ontological course of dementia theorising in that they are not grounded in the voices and experiences of people living with dementia, nor do they take into consideration identity factors and social location. It appears that the next step should be to try to develop theory through the active engagement of people with dementia themselves, taking into consideration their socio-cultural context (Downs 2000).

In my search for information on subjective experiences of dementia, I reviewed personal accounts, narratives produced with the involvement of a supportive other, qualitative research studies, and stories posted on Web sites or available in hard copy for the purpose of raising public awareness (see Hulko, 2002). I looked closely at who is telling these stories of dementia; what these stories tell; and whose voices are still silent/silenced. Then I asked myself how untold experiences might differ. I found that the 'typical' person with dementia in these published accounts was a middle-aged (40 to 60 years old), well-educated, white, married professional in the early stages of dementia, with strong religious or ideological beliefs, and a supportive family. The voices that are missing in the dementia literature are those of minority ethnic and racialised people, poor people, uneducated or minimally educated people, and lesbian/gay/bisexual/two-spirited people; and while the voices of older and disabled people do appear, this is certainly not a dominant feature. Identity was rarely treated as a salient variable in the literature and was certainly not viewed as multiple, complex, and simultaneously expressed. When identity categories, such as age, gender, and ethnicity were mentioned at all, it was in a descriptive fashion in that any influence these factors might have on subjective experiences was not analysed. Yet despite this omission, through a close reading of the texts, I was able to discern class, gender, religion, and age effects in the views and stories told by people living with dementia and found evidence of intersectional thinking on the part of the respondents. With regards to how untold stories might differ, a predominant theme in the literature was that of 'striving for normalcy', with normal being used to refer to life before/without dementia.

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This theme does not leave space for those who might have been striving for normalcy prior to a diagnosis of dementia or who reject societal definitions of normalcy.

From reviewing the literature on meanings of health, illness, and disability cross-culturally; identity and oppression; 'race'/ethnicity and dementia; class, gender, and dementia; and inequalities in later life, I garnered further insights that shaped this study. For example, conceptions of illness show similarities and differences across and within cultures and certain concepts are helpful to understanding how individuals make meaning of their experiences, including illness narratives (Kleinman 1988) and exploratory maps (Williams and Healy 2001). While insiders' perspectives such as these are valuable, they should be critically analysed, considering the temporal and socio-cultural context in which the teller lives and the tale is told. Researchers in turn need to design studies in a way that connections can be made between subjective meaning making (individual experiences) and the social forces that both support and impede these efforts (social structures), a longstanding problematic in sociology (Smith 1987).

Research on 'race'/ethnicity to date has focused on: comparative risk, incidence and prevalence rates for various racialised groups; challenges in assessment and diagnosis in a multicultural context; provision of services to minority ethnic and racialised people with dementia and their caregivers; caregiving amongst minority ethnic and racialised groups; and the meanings of dementia for certain minority ethnic and racialised groups. There is an obvious gap in that lived experiences of dementia have not been a concern for researchers interested in 'race'/ethnicity and dementia and, interestingly, many 'racial'/ethnic differences fall away when education is controlled for (Yeo 2001), a finding which indicates the entangled nature of identity categories.

Another factor that may prove to be the unspoken, yet most salient, variable in dementia research is class, and it may be that people belonging to the upper class are more fearful of dementia (Hellebrandt 1980) because it represents more significant losses in terms of their social roles, while those from the lower class are accustomed to dealing with adversity and dementia represents one more challenge to overcome. Gender may prove to be significant in terms of adherence to or liberation from gendered identities in the context of dementia and the ways in which gender relations mediate experiences of dementia for both men and women. It may be difficult, however, to ascertain men's views of the influence of their gender as it seems that they are not accustomed to thinking of themselves in this way, unlike women who are said to possess epistemic privilege (Whitehead 2001). This is akin to Du Bois' theory of double consciousness (1953) which postulates that oppressed people, being conscious of the dynamics of privilege and oppression and their own relative positioning, are able to see both the privilege of their oppressors and the way that efforts to sustain that privilege result in their own oppression. Thus, it may be unfamiliar for white people to talk about the effect of their 'race' on their experiences, as most do not recognize their whiteness as having an influence, particularly in terms of privilege.

It appears that social location has an influence in terms of people's conceptualisations of their experiences and that privilege and oppression need to be considered as dialectical, rather than oppositional (Bishop 2002; Freire 2001). This means that we need to interrogate privilege as well as oppression, as social life is relational and it is the same power dynamics shaping privilege as oppression, including

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the relative amount we each hold and the meaning this has for our life experiences (Calasanti 1996). Several critical gerontologists note the importance of looking at forms of oppression as interacting with one another in complex ways; and as rooted in processes of domination and subordination; plus viewing marginalised peoples as having strengths; and as actively resisting oppression (Browne 1995; Blakemore 1989; Calasanti 1996; Calasanti and Slevin 2001; Dressel 1991; Ginn and Arber 1995; Gonyea 1994; Levy 1988; McMullin 2000; Minkler 1996; Victor 1991; Vincent 1995). A key concern arising from the literature on intersectionality/interlocking oppressions, however, is that this is a difficult concept to operationalise and thus, there is a lack of empirical research to substantiate all the theorising and personal reflections. Trying to address this gap clearly requires creativity and a willingness to take chances with one's research design and data collection tools, particularly interview questions, along with reflexivity in the field to follow possible leads, weave together threads of meaning, and make connections between individual experiences and social structures. These are all lessons that apply to this project on dementia and intersectionality, which I will describe in the next section.

Grounded theory research into subjective experiences of dementia and intersectionality
      It became apparent after a thorough review of the literature that this project could not be anything but exploratory in nature and qualitative in design, and that grounded theory methods (Charmaz 2000; Glaser 2001; Glaser and Strauss 1967; Strauss and Corbin 1998) could best address the research question - what are the relationships between older people's experiences of dementia and the intersections of 'race', ethnicity, class, and gender. The research aims, which reflect the feminist, critical gerontology, and anti-oppressive social work stance I brought to this project, were:

- To explore older people's experiences of living with a cognitive impairment, taking account of 'race', ethnicity, class, gender and their intersections and the dynamics of privilege and oppression
- To develop a substantive theory of older people's experiences of dementia and a formal theory of dementia and intersectionality, grounded in the voices and (inter)actions of older people with dementia
- To critically reflect on the research process, particularly the roles and effects on the researcher, the researched and the emerging theory, and the applicability and effectiveness of anti-oppressive research methods

      Using grounded theory meant that the research design would be emergent and this would require me to be reflective, reflexive, and able to tolerate a degree of uncertainty. For example, the size and composition of the sample and the interview questions evolved throughout the course of the project, based on the results of the simultaneous collection and analysis of data and my reflections on the effectiveness of the methods I was using. The other grounded theory strategies I used were: two step data coding process; comparative methods; memo writing to construct conceptual analyses; sampling to refine emerging theoretical ideas; and integration of the theoretical framework (Charmaz 2000, p.510-511). I was determined that this would apply from conception through completion in the classic grounded theory tradition (Glaser and Strauss 1967) and wanted to avoid a mistake noted in the literature (Glaser 2001; Strauss and Corbin 1994) whereby researchers claimed to have used a grounded

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theory approach when it is little more than inductive analysis. The generation of theory that is grounded in the data – not merely conceptual description - is the hallmark of grounded theory research (Glaser 2001) and "all three aspects of inquiry (induction, deduction and verification) are absolutely essential" (Strauss 1987, p.12) in order to achieve this result. Through engaging in grounded theory, infusing it with anti-oppression sensibilities, and reflecting on my experiences throughout, I hoped to add to these and other methodological debates about this popular and seemingly misunderstood method of research. The themes in the literature and the suggestions put forth for doing research with people with dementia, together with my own experience in dementia care and research, informed the design of this project.

My data collection tools included interviews, participant observation, and photography with older people with dementia who ranged from multiply oppressed to multiply privileged, and focus groups with their significant others. I used conversation aids such as images of older people and third party questioning to increase both comfort and familiarity with the questions and to help to unlock subjectivity, and photographs of my research participants that I took at the observation sessions and in their homes, as well as family pictures that they shared with me, to stimulate thinking about life with memory problems. My sample evolved throughout the project in accordance with theoretical sampling (Glaser and Strauss 1967), and was comprised of older people with dementia in two different communities who were recruited through a local geriatrician and the Alzheimer society in one community, and a clinic for older people at an acute care hospital in the other. Over the course of a month, I would do three semi-structured interviews of 30 minutes to an hour and half with a participant, interspersed with two observation sessions of about two hours at a setting or event of their choosing. The interview questions were designed to stimulate self-identification in terms of identity and social location and to evoke thoughts on living with memory problems. I used a Polaroid camera as I felt this would be more dementia-friendly than a digital camera or a 35mm camera, primarily for the instantaneous photo developing, and the size and appearance of the photographs. As a result of this, I was able to speak with my participants about the events, people, and objects captured on film at the time that they occurred and I could leave behind a record of the time that we spent together to serve as a memory aid for my next visit. I used a computer program to assist with the data analysis - N*VIVO - and once I became comfortable with its operation, it enabled me to organize all of the data collected and to perform functions such as linking documents, embedding visual data and memos, and modelling relationships (Lonkila 1995; Richards 2000). More details of my methods will be offered in the subsequent discussion of the methodological challenges I encountered.

Methodological challenges and attempts to address them

Several methodological challenges have arisen in the course of this research project on dementia and intersectionality and while they are specific to this project on dementia and intersectionality, they offer insights for other research endeavours in dementia. In this section, I will raise the issues and describe my attempts to address them; this is a work in progress and this will be addressed in more depth in a forthcoming paper (Hulko 2003). The challenges I encountered relate to: (1)

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configuring the sample; (2) translating sociological concepts; (3) describing the project; (4) designing interview questions; and (5) being reflective and reflexive.

In configuring my sample, I had to resist the pull towards essentialism that seems to arise in research related to identity and difference. I knew that my participants, as a group, should represent various social locations, rather than different mathematical configurations of the variables of 'race', ethnicity, class, and gender. However, I was not sure how to accomplish this so I played with different algebraic formulas in an effort to devise a 'diverse sample' and considered using Ragin's (1994) truth table method of quantifying data when researching diversity. I was able to reject this process of essentialising people with its ostensible goal of simplifying complexity/diversity once I came upon an alternate method that was more in line with my research aims and still resulted in a sufficiently diverse sample. My approach calls for the selection of people who lie at different points on the axes of oppression and privilege, based on their 'race', ethnicity, class, and gender. In this way, similar/shared social locations, ranging from multiply privileged to multiply oppressed, rather than individual characteristics, form the basis upon which the sample is stratified. I was aided by a tool that is popular in anti-oppression workshops for graphically determining one's own social location. In this exercise, multiple axes of oppression and privilege are drawn in a form reminiscent of the spokes of a wheel and each is labelled with a different identity construct, i.e. age, gender, class, sexual orientation, 'race', ethnicity, religion, (dis)ability, language, health status. The centre of the circle represents privilege and the outside represents oppression/marginalisation (see hooks 2000). The task is to situate oneself on each of these axes in relation to the margin and the centre and, through doing so, to become (more) conscious of the degree of privilege and oppression one owns and that makes the everyday world problematic (Smith 1987), more so for some than for others. I did not plan to make these diagrams with my participants, rather I used the socio-demographic information I was given to construct a diagram for each participant and then located each of them along a continuum from multiply oppressed to multiply privileged. This process necessarily took place over the course of the project as people entered the project at different points and I assessed the composition of my sample.

The second challenge I had to deal with on an ongoing basis was in the translation of sociological concepts. Theoretical questions had to be translated to research questions, and then turned into interview questions, that could be expressed in everyday language. The questions asked of participants had to be understandable and respectful at the same time, while still derivative of the original theoretical concepts to enable back translation. For example, the title of my thesis 'Dementia and Intersectionality: Exploring the experiences of older people with dementia and their significant others', became 'How does who you are as a person shape living with memory problems?' on the information leaflets and consent forms. To ensure that my materials would be understandable to older people with memory problems, I checked the readability statistics in MS Word and edited these documents repeatedly until the information leaflet was at a grade four level and ratio of 86/100 for reading ease, and the consent form was at a grade five level and ratio of 76/100 for reading ease. The standard is a grade seven to eight level with a ratio of 60-70/100 for reading ease. Sociological concepts can be complex and since these are not often the terms we use to describe ourselves, it was very difficult to explain this research in written and verbal

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form. The following excerpt from the information leaflet for research participants lists factors upon which people differ or how we are all unique and represents my attempt to translate gender, ethnicity, 'race', and class into plain language:

- whether we are a man or a woman
- the languages we speak, food we eat, and clothes we wear
- where we come from
- how old we are
- how other people see us
- the schooling, jobs, and money we have or had
- how easy or hard life is for us

'Race' is not easily identifiable in this list; the language I have used could be thought to refer to age or disability. This probably has more to do with my own discomfort over using certain words or phrases, such as skin colour, that may be more descriptive, yet indicate acceptance of the ideology of racial differences.

Describing the project was a concern not only for my interactions with research participants, but also with each of the interpreters that I worked with and all the gatekeepers, meaning "those individuals in an organisation who have the power to grant or withhold access to people or situations for the purposes of research" (Burgess 1984, p.48). The gatekeepers I had to pass through in order to speak with older people with dementia included the research director and research committee, program manager, geriatricians, professional and administrative staff, and public affairs department at one recruiting site; the Alzheimer Society executive director and support counsellors, and a geriatrician and administrative staff at the other site; the people in charge at the various observation settings; and the significant others in both locations in the case of those people whom I was told not to contact directly. I demonstrated my legitimacy/credentials in order to gain access to research participants and to build rapport with gatekeepers, yet essentially had little control over which of their clients they chose to refer to me. At first, most gatekeepers interpreted my research as being solely about minority ethnic and racialised people - the Other - and tended to place greater emphasis on language and 'race'/ethnicity than either gender or class. As the inclusion of privileged people is equally as important in seeking to understand the dynamics of privilege and oppression (Calasanti and Slevin 2001; Lee 1993) and hence was critical for my study, I had to continually explain to the gatekeepers what I was attempting to do, why, and how they could help me, while being attentive to any misinterpretations that might have been transmitted to potential participants. For example, one recruiting site left me a message that they had 'one for race, one for race and class, and one for ethnicity'. I interpreted this as meaning these people were marginalized on these grounds and privileged on the basis of the factors not mentioned, and clarified the next time we talked that each of us has a gender, class, 'race', and ethnicity.

The challenges in designing the interview questions relate to my interest in facilitating self-identification and the expression of subjectivity on the part of my research participants. This was in the hopes of avoiding mislabelling people or placing too great or too little importance on an aspect of their identity. To try and achieve this goal, I posed general questions such as 'tell me some important things about yourself'; 'when you think of yourself, what image comes to mind'; and 'how would other people describe you'. These questions did not elicit the responses I was hoping for at the

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beginning of my research as more often than not, participants referred to personality characteristics. I realized that I had to be more direct with my questioning, as in 'what is it like to be an old Filipina woman'. I used images of older people who were diversified by ethnicity, 'race', class, and gender and asked questions about the people in the pictures such as 'what do you think of him/her'; 'who has the best/worst deal in life'; and 'who is the most/least like you'. I had difficulty overcoming my own reservations about being insensitive or too personal and using language that I was not comfortable with such as 'old' or asking questions of a Black man that seemed self-evident such as 'so why is he a brother' in reference to a picture of another Black man.

The last challenge is that of being both reflective and reflexive, which essentially means 'being on' at all times, continually analysing and responding to insights derived from the research process. Reflection represents the critical introspection the researcher undergoes and reflexivity the action that flows from this; the latter being akin to 'praxis' in Marxist terms (see Kirby and McKenna, 1989). These terms are often conflated in methodological discussions, however, with researchers referring to the importance of reflexivity in the sense of documenting one's reactions to the research and situating oneself in the research process, yet not giving any evidence of their methods having been modified on the basis of these reflections. For this project, I carried a reflective journal with me in which I recorded thoughts on the research process; made notes on most encounters, particularly the initial one which was the information and consent meeting; introduced new questions and/or put aside the pictures if they didn't appear to be achieving the desired result; developed an interview guide prior to each encounter based on my analysis to date; and consulted with peers about my techniques and results. Despite all of these efforts, I feel that I could have been even more reflexive if I had the time and concentration to thoroughly reflect, and the freedom from institutional expectations or constraints, such as those imposed by the recruiting site, ethical review committee, and funders.

Conclusion - possible implications and key questions
At the time of this writing, the data collection and analysis was still in progress and therefore, possible implications are tentative. A grounded theory of dementia and intersectionality could further our understandings of lived experiences of dementia in later life, and address the socio-cultural context of dementia. It may well lead to further questions about how to design and deliver services that are based on the desires of users, rather than on the opinions of providers about what older people with dementia need; and it could raise the controversial issue as to whether we should be intervening in their lives at all. As this research project drew on parallel knowledge traditions and crossed disciplinary boundaries, the findings are likely to have implications for several fields of study and various disciplines; and the implications could be for any level of scholarly activity such as theory, research, policy, and practice. As the potential audience is wide and the research-policy-practice interface important to me, I plan to disseminate the findings widely, which will necessarily entail publishing in multiple genres (DeVault 1999; Fine et al 2000) to ensure that all those who may benefit from having the information have access to it (Kirby and McKenna 1989). For my research participants, I committed to preparing a summary of one to two pages in an accessible format and to sharing this information with them verbally, in a group format or one-on-

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one sessions. Some dementia researchers might question the purpose and utility of sharing results with participants as the nature of their cognitive impairment may preclude any understanding of that which is presented to them. Yet, as Elaine Robinson (2002) writes of her experience taking part in research, "it would be very disheartening for us to spend our time taking part in interviews or providing written material only to find that we never hear from those conducting the research" (p 106). I only hope that the emerging theory makes sense to the people upon whose experiences it is based and that it can be presented to them and others in an accessible format that will empower, rather than alienate. If it does not make sense, then does their cognitive impairment impede their ability to understand or has the researcher not accurately reflected their perspectives and experiences? This is a question that researchers are forced to grapple with in seeking to involve participants meaningfully. Do participants need to talk about themselves as intersectional beings or is this the lens and the methodology that the researcher brings to the project? Working with the concept of intersectionality can be cognitively demanding due to the complexity and may require a politically conscious subject. If that is the case, we may set ourselves up for failure if we try to move beyond our analytical frame as researchers using an intersectional perspective and look for evidence of intersectional thinking in the words and actions of our participants. These are some key questions that have arisen to date and for which it is hoped some answers may emerge. Through presenting this work in progress as a case study and detailing the methodological issues that have arisen in working with the concept of intersectionality, perhaps other researchers may encounter useful insights for their own work and choose to grapple with these and other complex questions.

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Appendix D Conceptual baggage/sensitising concepts

The results of the initial free-flowing process through which I extracted 41

concepts from my personal concept bank:

> oppression, marginalisation, social exclusion/inclusion, resistance,
> incompetency/incapacity, frailty, othering/marking, alterity/double
> consciousness, internalised oppression/false consciousness,
> mediating structures, subjectivity/reflexivity, ageism/sexism/
> racism/classism/heterosexism/ableism/ethnocentrism/sectarianism,
> feminisation of ageing, biomedicalization of ageing, social
> construction of reality/race in particular, apocalyptic demography,
> subjugated knowledges, epistemic privilege, diaspora,
> acculturation, adaptation/adjustment, ghettoisation,
> personhood/selfhood, confusion/disorientation, confabulation,
> misrecognition, aphasia/apraxia/agnosia, excess disability,
> cognitive superiority/hypercognitive culture, illness narrative,
> awareness contexts, explanatory models of illness, emic and etic
> perspectives, lived experience, social location, counter hegemonic,
> hegemony-ideology, intersectionality, interlocking oppressions,
> reductionism, embodiment

The 35 concepts that I added while reading through the reflexive journal I had

been keeping since starting this project in late September 2001:

> senility, structured dependency, political economy of ageing,
> disengagement, stigma, disease, disability, impairment,
> polyvocality, identity, labelling, cultural appropriation, critical,
> community, discursive/discourse, emancipation, participation,
> ontology, epistemology, normalisation, continuity, liberation,
> agency-structure, resilience, storytelling, institutionalisation, moral
> career, racialisation, essentialism, gatekeeping, insight,
> dominance-subordination, VOICE, liminality, positionality

Appendix E - Possible interview questions (Dec 12/02)

A. Identity and social location (race/ethnicity, class, gender):

- Tell me about your background (class, 'race'/ethnicity, gender)
    - Birthplace
    - Ethnic ancestry
    - Cultural traditions
    - Growing up
    - Immigration
    - Relationships, marriages, births, deaths
    - Family, friends
    - Neighborhood, community
- How did this lifestyle you've described change over the years, up to the point you started having problems with your memory?
- What was life like before you started having memory problems?

- When you think of yourself, what image comes to mind?
    - What words describe you as a person?
    - How do you think others see you?
    - If you were lost and someone was looking for you, how would they describe you to a police officer?
    - What 'walk of life' would you say you come from?
    - What groups of people do you identify with?

Using deck of image cards:
- Who has the best deal in life? Why? (set picture aside)
- Who has the worst deal in life? Why? (ditto)
- Who is most like you? Why? (ditto)
- Who is least like you? Why? (ditto)

- Tell me some important things about who you are as a person.

B. Subjective experiences of dementia:

What is it like to have memory problems?

How does your being a (insert words used in answer to earlier questions) shape your experience of living with memory problems?

How do you feel this compares to other people's experiences?

Using deck of image cards:
What do you think having a memory problem is like for him/her?
How is it the same for you? How is it different for you?

Appendix F – Social location diagrams (excerpts from reflexive journal)

Below is a page from my reflexive journal (July 2002) documenting 'my brainwave' – the idea of using the axes of privilege and oppression in lieu of a demographic face sheet to document their social locations. I later expanded on this, using it as a tool to configure my sample.
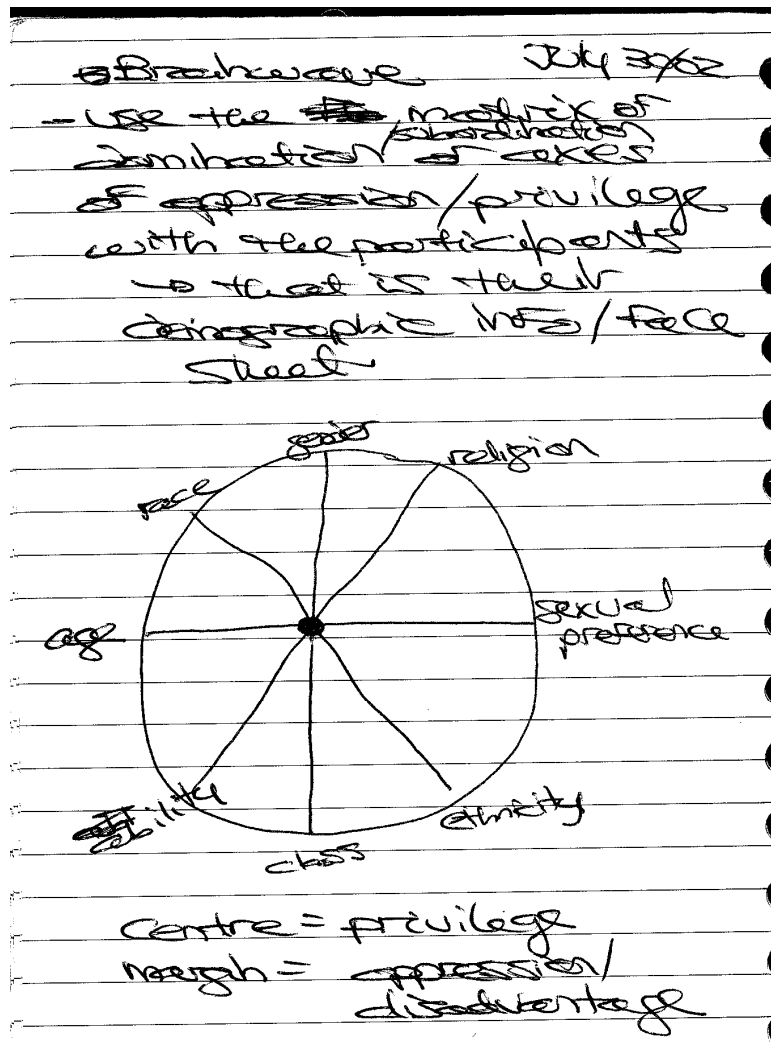
In the next set of excerpts from my reflexive journal (January 2003), the diagrams on the left were created for the first four participants – 'Jim Heather' (top left), 'Bosse Knudsen' (top right), 'Joe Brown' (bottom left) and 'Ester Hernandez' (bottom right); and the diagram on the right was drawn for 'Angela Huggins'. Also on the right is the line along which I plotted participants to ensure the sample represented a continuum of social locations from multiply marginalised to multiply privileged.
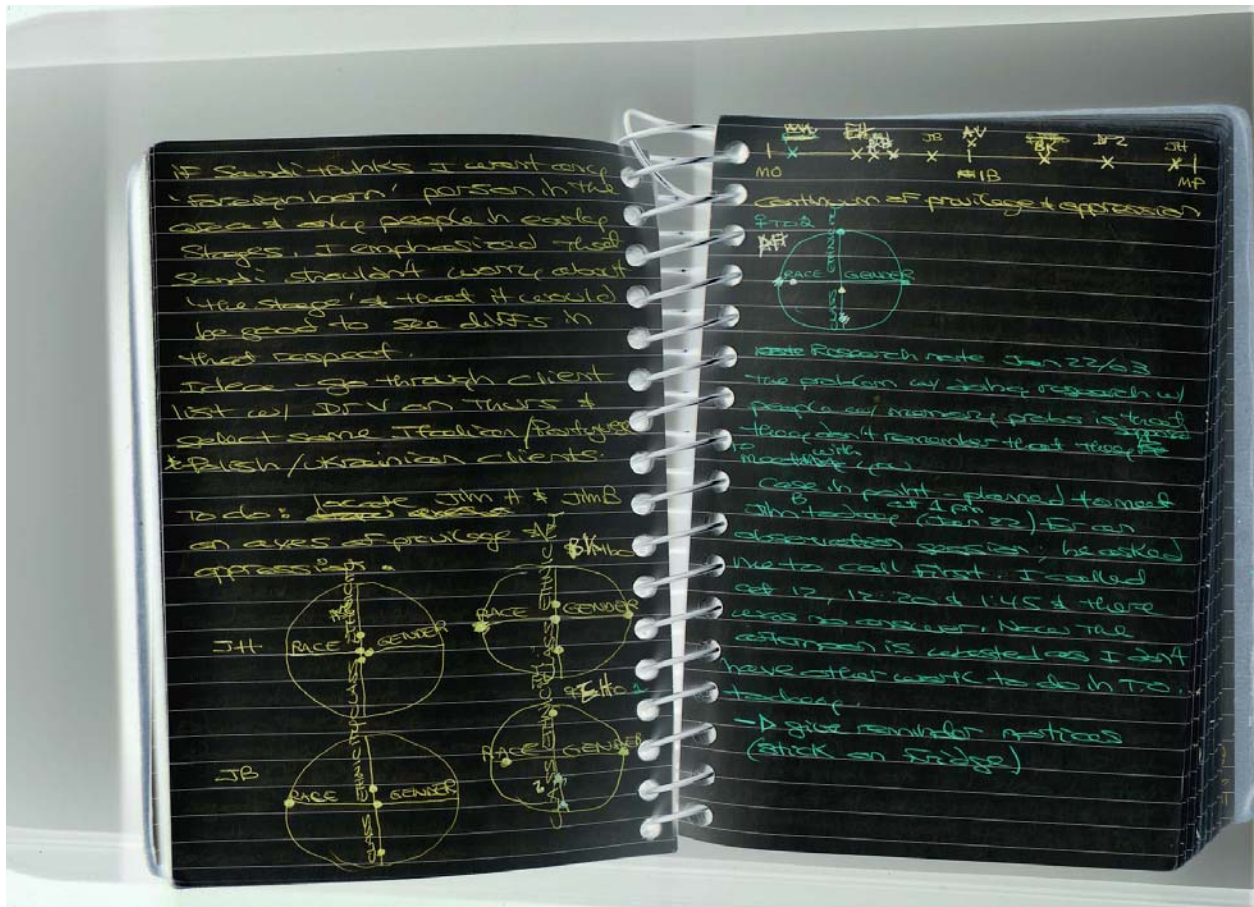
Below are diagrams that I constructed for potential participants (March 2003) as I tried to determine which of these people might best fit the theoretical sampling criteria. The diagram in the upper left hand corner was constructed for a woman in Peterborough who declined to participate; she was replaced by 'Nancy Matheson', who shared her multiply privileged status. The diagram directly below this one was drawn for 'Gus Holden', another one of the multiply privileged participants and the one in the middle of the bottom row represents 'Julianna Molnar', an in-between participant.
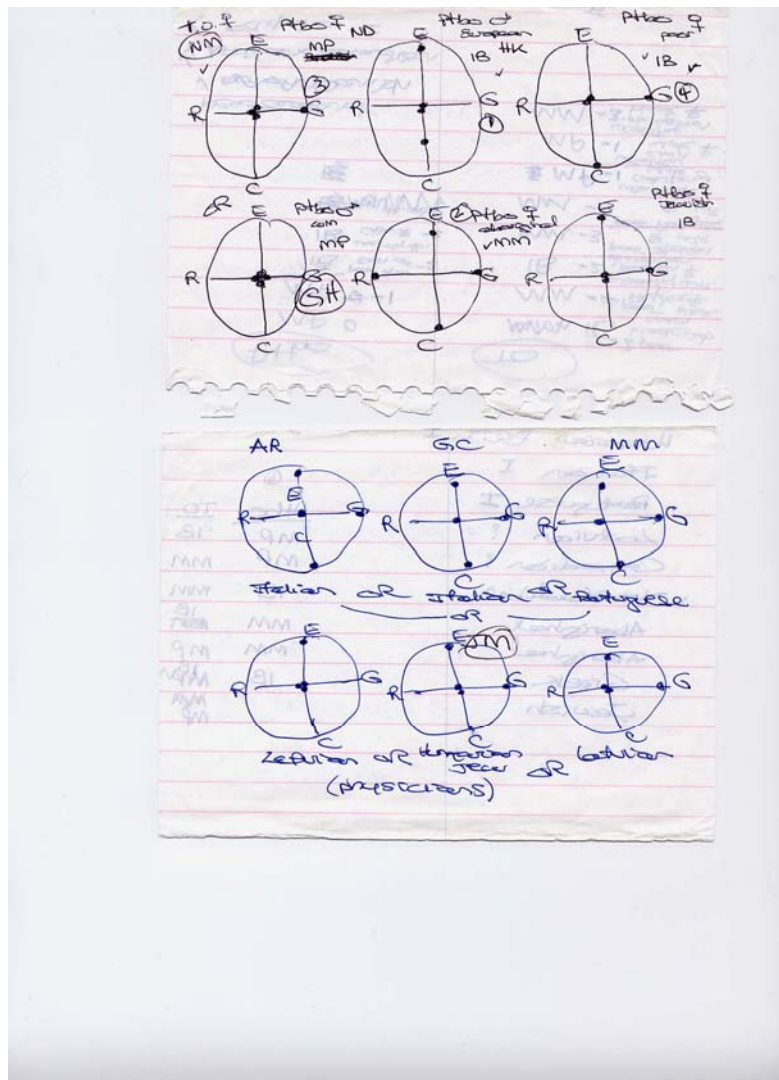
Appendix G - Possible interview questions (April 14/03)

A. *Identity and social location (race/ethnicity, class, gender):*
   1. Tell me some important things about yourself.
      o What words describe you as a person?
      o Tell me a bit about your background (birthplace, ethnic identification, education, occupation, religion, family)
      o What should other people know about your life story?

   2. When you think of yourself, what image comes to mind?
      o How would others describe you to a stranger?
      o What groups of people (community) do you feel part of?
      o What 'walk of life' would you say you come from?

Deck of image cards:
For people with moderate to severe cognitive impairment, communication difficulties, and those who are not self-aware/reflective; ask them to sort the images into piles or give them contrasting images
- What do you think of her/him?
- What do you think his/her life is like?
- Who has the best/worst deal in life? Why?
- Who is the most/least like you? Why?

B. *Subjective experiences of dementia:*
   1. What is it like to have trouble with your memory? (What would it be like to have trouble with your memory?)
      - In what ways has Alzheimer's (being forgetful) affected your life?
      - How about your sense of yourself as a person?
         o Has that changed at all? If so, in what way?
      - Tell me about forgetting. (What would it be like to forget things)?
      - Describe to me a typical day.
      - How important to you is your memory?
      - Tell me about being old/getting older.

   2. How has being a (insert self-description) affected your life up to now?
      - How does this relate to having Alzheimer's (being forgetful)?
      - What about being older? Does being a (insert self-description) make a difference in any way? If so, how? If not, why not?

   3. Why do you think this is happening to you?

   4. How do you think what you are going through compares with other people's experiences?
      o Is it the same? Different? In what ways? Why?

PHOTOESSAY

From doctor to 'silly patient': seeing beyond the disease label

Photographs and text by Wendy Hulko

This photoessay is based on a grounded theory study of the relationships between older people's experiences of dementia and the intersections of 'race', ethnicity, class, and gender, undertaken from September 2002 to August 2003 in Ontario, Canada. The research methods included interviews, participant observation, photography, and focus groups with eight older people with dementia, who were selected through theoretical sampling. Ethical approval was obtained from the relevant research and ethics committees; pseudonyms were self-selected by participants; and consent was negotiated throughout the research process, including consent to take photos at home and during the observation sessions, and to use them in publications arising from the research.

Presented here are the words and images of the two research participants who are former physicians (a cardiovascular surgeon and an internal medicine specialist). The selected verbatim quotes below, taken from individual interviews with 'Julianna Molnar' and 'Jim Heather', indicate a strong capacity for self-reflection and an awareness of societal attitudes towards 'silly patients'. Their reflections may encourage other medical practitioners to see beyond the label of dementia.

The photographs that follow show 'Julianna Molnar' and 'Jim Heather' during the course of the research project—two active, engaged older people with dementia. These visual portrayals of everyday life with dementia may seem at odds with images of frailty and incompetence that are most often used to depict 'silly patients', such as those diagnosed with dementia.

Receiving instruction at the weekly art class for seniors

Department of Sociology, Social Policy and Criminology, University of Stirling, UK and School of Social Work and Human Service, The University College of the Cariboo, Canada

'I didn't know about Alzheimer's…I was a different type of medical doctor…I know well that at a certain age, there are certain things that are forgotten and your brain not working as it used to. For, at a certain level, at a certain level, I think it's normal but I don't feel good about it.' Julianna Molnar

Telling stories about family photographs displayed at home

'…and um I'm concerned about [my wife] um having the same feeling, you know is this going to be steep or shallow or what is it going to be and how is it going to affect both of us and what, what's, what um can we do or you know, you really feel that you've got no attack, from our point of view, to prevent what's going to happen.' Jim Heather

Working on another painting for the art show

'I don't want to be completely stupid [laughs slightly]…But my memory is still good enough that I can…I can….I can keep…I can maintain…I can't say that it's not worth it to live.' Julianna Molnar

Chairing a staff meeting at the clinic (with spouse)

'I suggested that I felt that uh despite being on the board [of the local hospital] for three years, that I didn't want to be just a lamppost sort of standing in the, standing in the way of everyone.' Jim Heather

Arranging a visit with Romanian neighbor (with Hungarian interpreter)

'It doesn't feel good that I can't remember certain things and I don't remember certain things that happened to me or when I was young. My memory has gotten worse quite a bit but I'm aware. But I'm aware.' Julianna Molnar
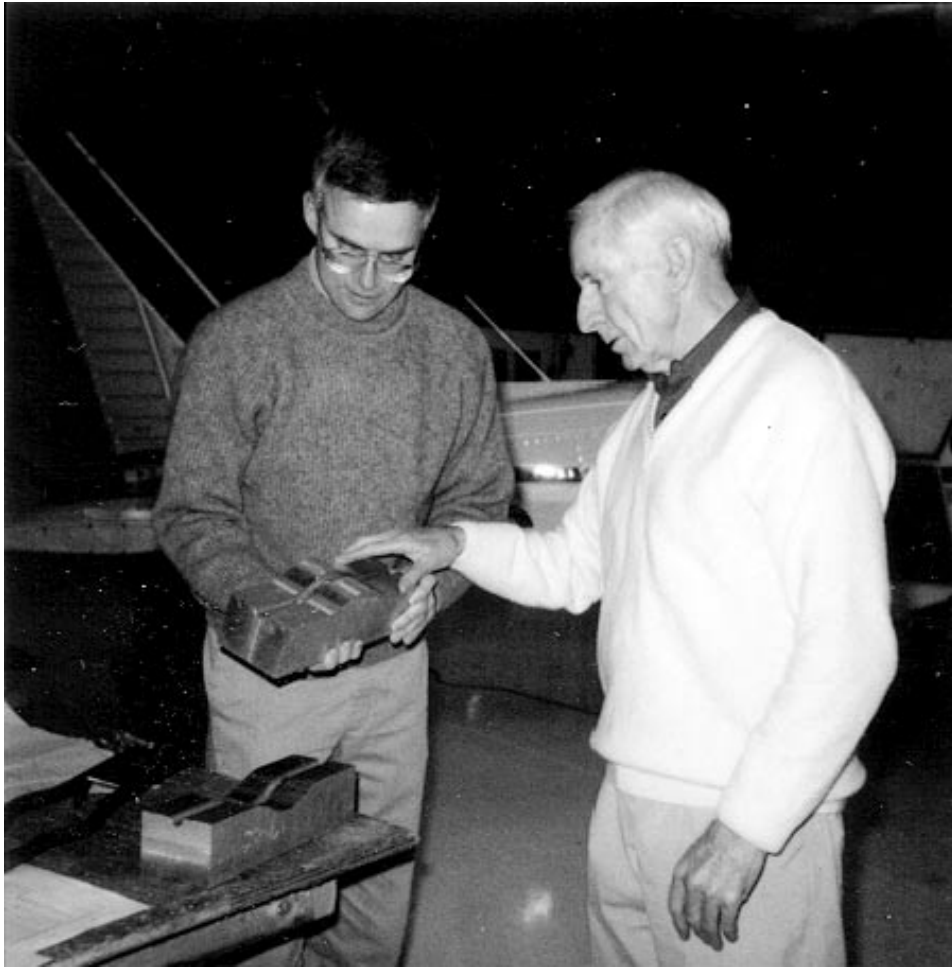
Learning about a tool created to fix an airplane (with eldest son)

Wendy (researcher): 'Thank you. I really appreciate your taking the time to talk with me and to share your experiences.'
Jim Heather: 'No I think that that was vital to get some idea of, more of what uh we silly patients are doing. So, uh, all the very best.'

Taken together, these representations—in words and images—of two former physicians *living* with dementia, and *reflecting* upon their changed social status, reinforce the need to see beyond the disease label to the actual person.

Dementia and Intersectionality
Proposed Research Project

PhD student with experience in the dementia field in Canada would like to speak with persons with dementia from diverse ethnic, 'racialized', class and gender groups between September 2002 - May 2003

Methods:
- Qualitative (grounded theory) research
- three short (20-30 min) interviews and two two hour observation sessions with persons with dementia
- Focus groups with significant others

Ethical Issues:
- University/agency ethical approval to be obtained
- Consent from participants to be negotiated throughout; proxy consent if advisable
- All views and observations to be kept confidential
- Anonymity of participants to be ensured

If you know anyone who would be interested in sharing their experiences of dementia, please contact:

Wendy Hulko, MSW, PhD candidate
Applied Social Science, University of Stirling, Scotland

e-mail: wendy.hulko@stir.ac.uk

phone (as of Aug 30): (705) 748-0564 (Peterborough)

LOGO

How does
who you are as a person
shape living with
memory problems?

A research project by Wendy Hulko, MSW
Department of Applied Social Science
University of Stirling, Scotland

UNIVERSITY OF STIRLING

Information sheet for research participants

Appendix J

Each person is one of a kind because of:

- whether we are a man or a woman
- the languages we speak, food we eat, and clothes we wear
- where we come from
- how old we are
- how other people see us
- the schooling, jobs, and money we have or had
- how easy or hard life is for us

I would like to know these things about you, as they relate to having memory problems. This research project is to try and find out what life is like for people with memory problems. This will happen by talking to you and other people in similar situations. This may not benefit you personally but I hope it will help other people to know what it is like to have memory problems. My university is paying for this work. I will write about it and share what I learn with you, your family, and the public. I hope to become a university professor when I finish this work.

Please read this information about this work. Think it over and talk to other people if you like. Then decide whether you want to be part of it or not. Even if you say yes now, you can change your mind later. You don't have to give a reason for your answer. Your decision will not affect any help you are getting. If you do say yes, I will ask you as we go along if you feel okay with it. You can stop at anytime.

What will happen?

I will talk with you for half an hour on three different days.

I will make notes and use a machine to tape our talks. This will be in a place where you feel most at ease.

We'll talk about who you are as a person and what it is like to have memory problems. I will show you photos to go with the questions.

I would like to see a photo of you or an object that is special to you. This will help me know you better as a person. I hope these things will help the questions make more sense.

I will come with you to an event or place that is important to you. I will take pictures and make notes about what I see there. We will talk about the pictures.

I will talk to someone that you tell me is important to how you see yourself as a person. This will be in a group after we finish our work.

When all the work is done, I will let you know what I found out. If you like, you can pick some photos of yourself for me to show to other people.

If you are upset after one of our meetings, you can call me or Dr. [name] to talk about it.

Appendix J

Your privacy

To protect your privacy, a fake name that you make up will be attached to my notes about you. This name will be used in anything that I make public. Other details of the work that can be linked to you will be changed as well. I will keep everything safe and private in a locked cabinet and in my computer.

What happens next?

I will answer any questions that you have in person or over the phone. If you decide to be part of this work, we can meet to talk about it.

You can reach me by mail, telephone or e-mail:
Wendy Hulko
[address of recruiting site]

 Telephone:
[number of Dr's office at recruiting site]
(416) 967 5900 ext. 238 (Alzheimer Society of Ontario)
(705) 748 0564 (Peterborough office)

 E-mail: wendy.hulko@stir.ac.uk

Thank you for reading this leaflet.

Appendix K

Logo

How does
who you are as a person
shape living with
memory problems?

A research project by Wendy Hulko, MSW
Department of Applied Social Science
University of Stirling, Scotland

UNIVERSITY OF STIRLING

CONSENT FORM

This consent form is only for participation in the research project
named above. Please return one copy to Wendy. Send it to the
address on the back of this form or give it to Wendy in person.
Keep the other copy for yourself. A third copy of this form will be
placed in your medical record to be kept private by [name of
recruiting site].

Appendix K
How does who you are as a person shape living with memory problems?

Your name: _____

Please circle yes or no for each statement below

I looked at the purple information sheet and talked about it
with Wendy and _____
                        (Fill in name of other person)   YES/NO

I have an idea of what this work is about and it sounds
okay to me   YES/NO

I know that I can stop being part of this work at any time
and do not have to say why   YES/NO

I am aware that my decision will not affect any help that I
am getting here or anywhere else   YES/NO

I know that everything I tell Wendy and that she sees will
be kept private, except if someone is hurting me   YES/NO

I realize that this work means three meetings and two
visits to other places with Wendy over the next few months
                                                   YES/NO

Appendix K

I agree to Wendy using a machine to record our
conversations   YES/NO

I agree to Wendy observing me at a place that I select
                                                       YES/NO

I agree to Wendy taking notes and pictures of me
                                                       YES/NO

I agree to Wendy using pictures that I choose in her work
that she shares with the public   YES/NO

I agree to take part in this work   YES/NO

Your signature: _____

Name and signature of Substitute Decision Maker or
Witness: _____

                _____

Today=s date:_____

Appendix K

[name and position of doctor] is supervising this study. The Research Ethics Board has reviewed the ethical aspects, physician compensation issues and financial aspects of this study and has given its approval. If you have any questions about your rights as a research participant, you may contact [name and phone number of Chair of the Research Ethics Board].

If you are hurt while taking part in this study, free care will be given to you. If this happens, please contact [name and phone number of Patient Care Manager].

For information about the study, and to be part of it, please speak with [name of supervising doctor] or contact:

Wendy Hulko
[address of recruiting site]

c/o Telephone:
[phone number of doctor's office at recruiting site]
(416) 967 5900 ext. 238 (Alzheimer Society of Ontario)
(705) 748 0564 (Peterborough office)

 E-mail: wendy.hulko@stir.ac.uk

Appendix L – Working Hypotheses

Based on initial coding (4/10/03 - 2:52:13 PM)

1. Social location does make a difference in terms of perspectives on memory problems (whether one problematizes it or not) and in turn how one adapts to it, ie whether accommodations are seen as necessary.

5/1/03 - 4:09:41 PM I have been explaining this hypothesis to people in terms of Maslow's hierarchy of needs for a few months now and even discussed this with Sue and Jim in February. I was suprised, therefore, to realize that I had not written about this yet and that's how this addition to the memo came about. The connection is that those who are more oppressed seem to focus on physiological and safety needs in relation to dementia, while those who are more privileged talk about belonging and self-esteem needs. I'm not sure if anyone has written explicitly about how social location impinges on one's ability to progress up Maslow's hierachy of needs (the pyramid) and need to check this out, as well as getting the original reference for Maslow's hierachy. This idea has not lost strength as I've progressed with my research; my hypotheses are becoming more complex, yet this simple framework still 'fits' and 'has grab' [GT terms]. Almost everyone recognizes Maslow's hierachy when I mention it and understands the connection to my research when I explain my research findings to date.

2. How much privilege and/or disadvantage one has had affects how others respond to them with the more privileged folks being othered more often and more marginalized folks being treated 'normally' more often. Resilience mediates marginalization due to dementia. That said, social location also determines the people one interacts with and the range of activities one engages in, with these being more limited and more dementia related (less normal) for the less privileged people. Although the MP men (JH and GH) say they have withdrawn from people and activities, they still seem to have fuller social lives and more opportunities for non-dementia related interactions that have the potential to support other aspects of their identities.

The third hypothesis was edited on 4/15/03 - 7:23:20 PM

3. Normal aging is the theory of dementia espoused by all participants, except the MP men - JH who was a physician and GH who was a university administrator. The adoption of the normal ageing theory does not represent a passive acceptance of ageist societal norms, rather it is a strategy used to ensure one's at least partial inclusion and to avoid being labeled abnormal, which would likely lead to institutionalization or other forms of social exclusion. Normalizing dementia/memory problems protects against the risks of being found incompetent, namely losing one's independence and home, for those who are marginalized already. By contrast, the brain disease theory seems to be important for the MP men to believe in as a way of explaining their inability to do what they used to do; their sense of their own mastery or capability while not openly acknowledged is such that it's as if the only thing that could set them back in any way would be a disease, not age itself. Aging is more positively valued for men than for women, other factors being the same, with an older man holding more esteem than an older woman, therefore aging is

not a bad thing perhaps, but disease is. The other folks recognize that old people are devalued because they forget things for example so they buy into this stereotype as way of fitting in.

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4. Definition of dementia - a bio-psycho-social phenomenon that mainly affects older people.

Biological - (causative) degree of impairment, symptomatology

Psychological - (mediating) psychic resources, personality characteristics, self-awareness, adaptation and resilience

Social - (mediating) socio-cultural environment, one's social location, structural factors

Appendix M – Attributes Table for Research Participants

Pseudonym	Group	Age	Gender	'Race'	Ethnicity	Social class	Cognitive status	City
Jim Heather	MP	74	Man	White	New Zealander	Professional/ Upper Class	AD – mild to moderate	Ptbo
Joe Brown	IB	76	Man	Black	African-Canadian	Working/ Lower Class	Dementia – mild to moderate	T.O.
Bosse Knudsen	IB	76	Woman	White	Danish/ Scandinavian	Middle Class	AD - moderate	Ptbo
Ester Hernandez	MM	76	Woman	Asian	Filipina/ South Asian	Working/ Lower Class	AD – moderate to severe	T.O.
Angela Huggins	MM	74	Woman	Mixed	Trinidadian/ West Indian	Middle Class	AD mild	Barrie (T.O.)
Julianna Molnar	IB	83	Woman	White	Hungarian Jewish	Middle Class	AD mild	T.O.
Gus Holden	MP	73	Man	White	Anglo-Canadian	Professional/ Upper Class	AD mild	Ptbo
Nancy Matheson	MP	87	Woman	White	Anglo-American	Professional/ Upper Class	AD mild to moderate	T.O.

MP – Multiply privileged; closer to privilege than disadvantage on three or more axes
IB – In-between; closer to privilege on two axes and closer to disadvantage on two axes
MM – Multiply marginalized; closer to disadvantage than privilege on three or more axes
Ptbo – Peterborough
T.O. – Toronto

Appendix N – emblematic photos of participants

'Jim Heather'

Pictured with his eldest son, learning about a new tool to fix an airplane (first observation session)

'Joe Brown'

Pictured at his local hangout ('the donut shop'), reading the Metro (free daily paper) and drinking a pop (first observation session).

'Ester Hernandez'

Pictured singing and dancing along with the Tagalog interpreter in her home (second interview)

'Bosse Knudsen'

Pictured with her husband at the senior's church group, smiling and being a people person (second observation session)

'Angela Huggins'

Pictured with her daughter and granddaughter outside the site of their new home (second observation session)

'Julianna Molnar'

Pictured painting at seniors' art class (first observation session)

'Gus Holden'

Pictured checking for frost damage on opening day at the family cottage (second observation session)

'Nancy Matheson'

Pictured with her eldest daughter during her 87th birthday party at her daughter's home (second observation session)

Appendix O

How does who you are as a person shape living with memory problems?

A research project by Wendy Hulko, MSW, PhD Candidate
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Results of the project so far (July 28, 2003):

- Views on memory loss range from it being 'not a big deal' to 'hellish.'

- Experiences of memory problems are affected by a person's background and lifestyle:
  - For many people, it simply does not matter. These tend to be the people who have had to deal with discrimination in their lives due to their 'race', ethnicity, class, and/or gender.
  - Those for whom it makes a big difference are people who have had more advantages in life as a result of their 'race', ethnicity, class, and/or gender.
  - Some people are more focused on basic and safety needs, while others are more concerned with self-esteem and belonging needs. This depends on the amount of advantage and discrimination one has had in life.

- Most people say their memory loss is a normal part of the aging process.
  - This seems to be a strategy to avoid being seen as different and to still be considered 'normal.'
  - The more privileged men say the opposite - that it is a brain disease.

- There are differences between women and men's experiences.
  - Women tend to accept their memory problems, believing that one should grin and bear it; that there's no sense in worrying, complaining, or feeling sorry for yourself.
  - Men seem to believe they should be able to control their memories and are striving to conquer the disease.
  - Women hide their difficulties, do not tell other people, and joke about what is happening to them.
  - Men tend to be more upfront about their memory problems.

- Being part of the research was a positive experience for everyone.
  - People enjoyed the opportunity to talk about what they are going through and to hear about the experiences of others.

Thank you for being part of this project!