Listening to the Voices That Matter Most:

Establishing Personhood in People Residing in Long-Term Care with a Diagnosed Dementia

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Abstract

This study sought to hear the voices of people residing in a long-term care facility (LTC), thereby recognizing the inherent worth in all people despite the constraints of dementia. Data were collected through the generation of field notes and through unstructured interviews conducted with four older adults diagnosed with a dementia, and living in a LTC facility in Northwestern Ontario. Discussion focuses on findings from these qualitative interviews. Situating the discussion within the context of personhood, this study offers an understanding of the extent to which the contours of personhood exist in people who have been diagnosed with a dementia, and identifies ways in which to support the continuation of personhood in persons living in LTC and diagnosed with a dementia. My thesis provides insights from residents in LTC and has implications for future care in a LTC setting. Care providers for older people diagnosed with a dementia or any other intellectual disability may also benefit from alternative perspectives on meeting the needs of this vulnerable population.

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This thesis is dedicated to special people who have positively impacted my life. A very special dedication goes to a special woman, my mother Suzanne Arseneau, who is no longer physically on this earth, yet continues to be a strong influence in my life. My mother always encouraged me to embrace life's journey, following my hopes and dreams. A huge thank you must be expressed to my daughters, Shannon, Kathleen and Jessica who never wavered in their belief in me, even when I doubted that this thesis would be completed. I thank these strong women for offering me, each in their own unique way, inspiration to the very end. Thank you also goes to my father, Guy Arseneau who unwaveringly supports me in everything I do. I would like to especially thank Michael Lee, who is the calming force in my life, who supported me while patiently waiting for the completion of this thesis.

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Chapter one: Introduction and Literature Review

> Sometimes we must change our perspective and then
> we see in retrospect that even the saddest occurrence
> can also conceal a valuable experience within it.
> (The Dalai Lama in Von Schoenborn 2004: 122)

This study focuses on adults living with a diagnosed dementia in a long-term care facility, to establish the ways in which they demonstrate the contours of personhood. Typically, all levels of care providers perceive dementia as being problematic, and heavily focus on matters which are neurological in nature (Cohen-Mansfield, Golander and Arnheim 2000). As well, research has found that mainstream societal views about dementia have consistently focused on negative assumptions about the condition (Downs 2000; Bond and Corner 2001; Sabat 2002b; Kontos 2004; Surr 2006b; O'Conner et al. 2007). For example, it is typical for people to assume that behavioural problems belong solely to the person with dementia rather than acknowledge any outside contributing factors. For those who subscribe strictly to a biomedical perspective, dementia is simply a disease comprised of expected losses and deterioration with no consideration for remaining abilities. Consequently, older adults diagnosed with a dementia are usually excluded from filling the role of research participant in dementia research (Bond and Conner 2001; Langdon, Eagle and Warner 2007).

My argument in this study is that even in the face of a diagnosis of dementia, people are persons who should not be conceptualized primarily as objects to be fixed by medical technology. In other words, those living with a diagnosed dementia exhibit "personhood" and ought to be respected as valuable members of society. The **concept of personhood** encompasses the domains of physical, psychological, spiritual, and social aspects of self (as discussed later in this chapter). My findings, based on conversations with research participants, show that the personhood of each woman shone through. In brief, the women in this study exhibited such things as reasoning capacity and awareness of surroundings; they demonstrated the capacity to discuss feelings and emotions, they were able to plan for the future, and they displayed insight into their physical and mental limitations.

This chapter begins with a review of the relevant literature, providing an overview of dementia, highlighting the domains of self attributed to personhood and a discussion of Sabat's (2002a, 2002b, 2008a, 2008b) theory of self. Insights from previous research are useful for understanding the context in which personhood is presently understood.

Dementia

Statistics show an increase in the number of people affected by dementia: it is currently estimated that 1 in 11 Canadian seniors have Alzheimer's disease (a type of dementia) or a related dementia. Furthermore, current trends project that within the next 25 years an additional million Canadians will develop Alzheimer's disease or a related dementia (Alzheimer Society of Canada 2005). Stephan and Brayne (2008) define dementia as "a group of syndromes characterized by progressive decline in cognition of sufficient severity to interfere with social and/or occupational functioning, caused by disease or trauma, and often associated with increasing age" (p.11).

Neurodegenerative changes in the brain (deficits and impairments) often affect the person's mood and behaviour. For example, familiar people, objects, and environments may no longer be recognizable to the person diagnosed with dementia. This person may become frightened, frustrated or feel threatened, and they may react by wandering, withdrawing from social interactions or becoming aggressive. Due to the nature of these neurodegenerative changes in the brain, most healthcare providers believe that a medical model of care is the best fit in providing care for those diagnosed with dementia (O'Conner et al. 2007; Bond and Corner 2001). Overall, society has much confidence in the powers of technology and biomedicine, and this generally results in responding to "negative" behaviours resulting from the dementia with standardized assessments and pharmaceutical interventions, rather than exploring and trying to find the meanings behind individual behaviours (O'Conner et al. 2007; Bond and Corner, 2001).

Bond and Corner (2001) critically review a range of theories considered relevant to the study of dementia with a goal of finding an approach to understanding the meaning of dementia while ensuring that respect for an individual's personhood is preserved. Traditionally, research related to health issues such as dementia have been dominated by clinical epidemiologists and supported by a positivist biomedical method of research which mainly focuses on pathological influences of dementia (Bond and Corner 2001). Growing evidence supports the need for interpreting and understanding rather than routinely managing and controlling problematic behaviours (Goldsmith 2002). A social phenomenon such as dementia requires qualitative inquiry into the psycho-social influences at work (Phinney 1998; Bond and Corner 2001). There is a need to be cognizant of many situational circumstances which strongly influence a person's behaviour but are mistakenly attributed to the person's disposition alone (Sabat 2002b). A degree of deterioration influencing the psycho-social progress of dementia can be directly attributed to the environment, attitudes and actions of others (Kitwood, 1997; Bartlett and O'Conner, 2007; Baldwin 2008). The person with dementia becomes disempowered, first by the diagnosis of dementia and second by the reactions of others, resulting in diminished dignity and sense of worth and the person becomes an object of care who is expected to conform to a "pattern of dementia type behaviour" (Goldsmith, 2002: 49). Functional abilities are negatively impacted when the physical, social and psychological needs of the person diagnosed with a dementia are not met.

Basset and Graham (2007: 550) point out that "a disease classification socially clusters people as similar" and ignores the differences among them. Kontos (2004) challenges researchers to think outside the dominant biomedical paradigm of dementia that only understands the consequences of Alzheimer's disease in terms of cognitive deficiencies and loss of self. Attitudinal beliefs that the mind and body can be treated separately, that the body is like a machine which can be fixed, and that technology can fix almost anything, ignore the psycho-social influences on the progression of dementia (Bond and Corner 2001). There is growing evidence that at least some of the negative consequences associated with dementia may be averted or delayed by an approach to care that respects and supports personhood (Kitwood 1997;Goldsmith 2002; Sabat 2008: Ward et al. 2008). Goldsmith (2002) further argues that low expectations in terms of functional abilities by care providers lead to an escalation of downward consequences. This facilitates both the continuation of low expectations and high dependency for the person diagnosed with dementia. A goal of care should be to strive for flexibility which maximizes a person's ability to use remaining abilities to function independently by offering graded assistance (Christensen & White 2006). Focusing on remaining functions allows the person with a diagnosed dementia an opportunity to engage in their social community on his/her own terms (Christensen & White 2006).

O`Conner et al. (2007) suggest that an interdisciplinary effort be integrated into the care of older people diagnosed with a dementia to take advantage of the benefits of both a biomedical and social model. A social model of care understands there are contributing factors caused by social processes and structures which create disabling barriers for individuals with impairments.

The aim of the social model is to relocate the problem from the individual to society (O'Conner et al. 2007; Priestley, 2003). By moving away from the popular explanations of biomedical perspectives, researchers have found that losses within the domains of self could be correlated to dysfunctional social interactions rather than be explained by the neuropathology of disease (Kitwood and Bredin 1992; Jacques and Jackson 2000; Bond and Corner 2001; Sabat 2002a).

Standard Treatment

Special care units were conceived in the early 1900s in response to an increasing need for housing cognitively impaired older adults (McLean 2007). Long-term care (LTC) homes in Northwestern Ontario are generally designed in such a way as to physically separate cognitive impaired people from others in the facility. Physical separations from others are typically achieved by placing people with cognitive impairments in a locked unit within an already established LTC facility. However, people with behavioural problems which are sometimes associated with dementia are further segregated by being placed in psychogeriatric units where care treatments generally include the use of pharmaceuticals rather than finding creative ways to address the undesirable behaviour.

These special care units are widely supportive of a biomedical philosophy of care which largely focuses on concrete bodily task-oriented care (McLean 2007). A biomedical philosophy of care creates an environment in which people diagnosed with dementia become objectified in that the focus of care is using treatments with the hope of fixing their brain. The reality of the progression of the disease process is that there is no cure for dementia, people die as a result of complications resulting from dementia (Chen et al. 2007). Meanwhile, these people continue to have the ability to express their feelings and are at risk of being devalued and infantilised (Bond and Corner 2001). Worth noting is McLean's (2007) research which was conducted over a period of two years in an innovative nursing home which had two special care units. These special care units followed separate philosophies of care, 1) a biomedical model and 2) a person-centred mode. McLean's (2007) study illustrated that people with a diagnosed dementia who resided on a biomedically orientated care unit showed evidence of decline, whereas those who resided in a person-centred unit of care showed evidence of improving or remaining stable.

When people are first moved to a LTC facility, they often experience relocation stress syndrome (Stones 2006), which has serious consequences yet is often neglected in the assessment of older adults living in LTC. Relocation stress syndrome refers to the symptoms and outcomes which results from voluntary or involuntary transfers from one environment to another (Stones 2006). Research supports that people diagnosed with a dementia have higher levels of relocation stress, because of memory impairments (Stones 2006; Moyle et al. 2007). Care services need to be more responsive to the person diagnosed with a dementia by attuning to signals which may be indicative of relocation stress syndrome.

Erving Goffman's (1961) ethnographic study exploring the subjective experiences of people living in a mental health hospital, led to his identification of the concept of "total institution" as being:

> a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life. (p. xii)

The concept of a total institution perfectly describes the typical LTC facility. Families are led to believe that this setting is the 'home' of their loved one who finds themselves living there. There is an expectation that a home will provide comfort and nurture the physical, social and emotional needs of the person residing in LTC with a diagnosed dementia. It is further assumed that within the LTC community, residents will in time adjust to the home and adopt staff as surrogate families. Stark reality finds residents of LTC placed into a regiment of strict routine care, addressing only basic physical needs. Predetermined wake up times, feeding times and bed times provide the resident with few or no opportunities to exercise personal choices. For example, in undertaking my own observations in a LTC facility, I often observed instances where several residents sitting in wheelchairs were placed in a semi-circle near a television. They all sat robot-like watching a show that was not of their choosing.

Experiences of Dementia

On the premise that limited attention has been given to the awareness and subjective experiences in people living in LTC with a diagnosed dementia, Clare and colleagues (2008a) engaged participants in unstructured conversations. Findings of their study suggest that the structure of contemporary LTC facilities offers little opportunity for residents to perform adequate levels of activities of daily living (ADL), to engage in activities which utilize cognitive skills and to engage in meaningful conversations. Drawing upon narratives of personal experiences, Small, Froggatt, and Downs (2007) argue that failure to acknowledge the self in people diagnosed with a dementia can only lead to low expectations and acceptance of task-orientated care offering little to no direct interactions with the person. Research indicates that people diagnosed with dementia are "without malicious intent, depersonalized, invalidated, and treated dysfunctionally in one way or another by healthy others" (Sabat 2002a: 26).

Kontos (2004) undertook an ethnographic study of selfhood for those with Alzheimer's disease. Using participant observation, her research was conducted in a LTC facility in Ontario, where she studied those who had a diagnosis of dementia with cognitive impairment ranging from moderate to severe. Kontos argues that the "presumed existential erosion of selfhood with

Alzheimer's disease is not simply the result of neuropathology, but is, to a large extent, the consequence of a certain philosophical inheritance" (p. 830). Deeply rooted biomedical assumptions associate cognitive impairments with the ensuing loss of personhood (p. 830). Paying particular attention to bodily movements, Kontos observed how "selfhood emanates from the body's power of natural expression, and manifests in the body's inherent ability to apprehend and convey meaning" (p. 837). Furthermore, Kontos found that research participants demonstrated awareness of their surroundings and actively engaged with others with definite purpose and meaning, in turn providing evidence of the social self which is "guaranteed through social interactions" (p. 846) Similar findings are noted in a recent study which found that persons diagnosed with a dementia strategically find ways to preserve their "self" by using coping strategies such as maintaining a positive attitude (O'Conner et al. 2007).

In a study exploring the meaning of everyday life as expressed by eleven people with a diagnosis of early dementia, Holst and Hallberg (2003) found that individuals are able to transmit meaningful communications. Reactions and adjustments to dementia differ from person to person and also depend on the context of the interactions and how others respond to and treat them. A confabulatory story narrated by a person diagnosed with a dementia is often readily dismissed as being absurd, yet it may in fact have a valuable message and at the same time serve as a means of reconstructing an identity (Holst and Hallberg 2003). Thus, it may be wise to consider providing care for older adults with a diagnosed dementia on a case-specific basis while "being attentive to the person's inner and changeable story, trying to interpret how they experience and react to the current situation" (p. 360). Holst and Hallberg's research shows that adopting only a biomedical understanding of dementia erases the humanity of the person who is diagnosed with a dementia, and the complexity and diversity of individual social experiences are missed.

Building on existing literature, Gwyther (1997) advocates paying more attention to the often neglected perspectives of individuals themselves who have been diagnosed with a dementia. In her study, Gwyther includes powerful quotes from the voices of individuals diagnosed with dementia. The voice of a 59 year old man who had been recently diagnosed with probable Alzheimer's disease brings to light the desire to maintain a sense of personhood. When asked how he wanted to be treated, he simply responded, "Well," and later he added "Alzheimer's isn't my whole life" (p. 18). In effect he desired to be recognized as a person, not a by-product of a disease. Similarly, Diane McGowin's (1993) autobiographical account of her experience in *Living in the Labyrinth: A Personal Journey Through the Maze of Alzheimer's* demonstrates her ongoing need for respect, not to be seen simply as a medical case as she journeyed through the flux of erratic emotions. McGowin struggled to maintain personhood in the face of her diagnosis. Many individuals who have been diagnosed with dementia find themselves faced with "stigma, altered self-image, restricted life style, social isolation, discrediting of oneself as a burden, and loss of control" (Gwyther 1997: 19). These problems could all potentially be addressed by considering subjective interpretations of quality of life domains rather than focusing on the limitations imposed by the impairment.

In a recent exploratory study, researchers investigated the extent to which the perspectives of individuals diagnosed with dementia were included when focusing on quality of life domains within the context of care provided in a LTC. Older adults diagnosed with a dementia previously identified quality of life domains which are considered important. As well, a questionnaire was distributed to staff and recreationists working at psychogeriatric units, psychogeriatric day centres and meeting centres. A comparison of results suggest that professional caregivers and those diagnosed with dementia have different perceptions about the domains of quality of life that are important to older adults diagnosed with a dementia (Gerritsen et al. 2007). Financial issues, spirituality (access to religion), and being useful and giving meaning to life were the three significant domains which were paid less attention by professional caregivers. These findings are significant to personhood as they stress the importance of including the considerations of the person diagnosed with dementia when providing care. Researchers concluded that the psycho-social well-being of an older person diagnosed with a dementia can be challenged by the inadvertent tendency to depersonalize them.

Maintenance of a Sense of Self in Dementia

Jacques and Jackson (2000), both consultants in Old Age Psychiatry in the UK, address the complex nature of dementia, specifically what dementia is and what dementia is not. Lack of familiarity with the disease process of dementia can activate a fear which can then incite avoidance of interactions with individuals diagnosed with a dementia. Their focus is on how dementia affects a person's brain and how to address the reactions to the disease process of both the person with a diagnosed dementia and those who provide care. Furthermore, Jacques and Jackson (2000) state that by using a few general principles, such as setting reasonable goals, establishing priorities, utilizing an interdisciplinary approach to care, asking for help when needed, letting the older adult know what is happening, and engaging family members, caregivers can eliminate some of the stresses and barriers for older adults diagnosed with a dementia and their families. "For, at all stages of decline, it shows how 'success' that is limited, but no less real, can be achieved, even if the outcome always includes decline and eventual death" (Jacques and Jackson 2000: 348). Qualitative research suggests the possibility that people have awareness about them for much longer than previously presumed (Goldsmith 2002; Clare et al. 2008a). While some people still presume the progression to complete unawareness, others have an unshakeable belief that people diagnosed with a dementia retain insight through till their death (Goldsmith 2002). Awareness is especially likely to become apparent when the focus is on the self, on relationships with others or on the immediate environment (Clare et al. 2008a).

Personhood

The concept of personhood is of paramount importance in respecting the essence of a person's humanity. The concept is not only valuable in terms of framing interactions with an individual diagnosed with dementia, but also has the potential to be useful in the capacity of care planning (assessment and intervention) for all people living in LTC. For the purpose of my study, the concept of personhood encompasses the domains of physical, psychological, spiritual, and social aspects of self. The absence of robustness in any of these domains of personhood does not on its own equate to a reduction in personhood. It is the reactions of others to the loss of functions which places personhood at risk. Furthermore, each domain has a unique meaning for every person, therefore a reduction of function in one domain will not bring the same reaction for each person. Rather, there is an assumption that "each person has absolute value" (Kitwood 1997: 8) independent of the degree of functioning of a domain. However, in striving for a holistic approach to care for people living with a diagnosed dementia, it is important to consider the remaining function within each domain of personhood as well as the meaning assigned to a loss of function of a domain. Equally important is the need to pay attention to the body's natural ability to express and convey meaning by means of adopting the use of non-verbal cues (Kontos 2004).

Kitwood's (1997) work makes an important contribution to an understanding of personhood, stressing the importance of social interactions for a person's over-all well-being. Kitwood defines personhood as a "status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (p. 8). Kitwood further argues that "to see personhood in relational terms is, I suggest, essential if we are to understand dementia" (p. 12). Evolving over many years of dedicated research on dementia, Tom Kitwood, founder of the Bradford Dementia Group in the UK, combines theory and practice with the aim of developing person centred care. Despite the challenges and hard work which are ever present in dementia care, Kitwood (1997) challenges the biomedical view of dementia as a negative and hopeless deterioration of self.

A barrier preventing the attainment of acceptable quality of life levels for individuals with dementia is the lack of understanding of the effects of dementia on individual domains of personhood. Katsuno (2005) appropriately defines quality of life as "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her." Individuals with dementia are not a homogenous group and do not have the same needs; therefore, what will promote well-being for one, may not be beneficial to another (Bamford and Bruce 2000). Above all, the individual who has dementia is a human being and should not be treated as an object (Hendry and Douglas 2003). Giving individuals with dementia opportunities of having something to do and allowing choices congruent with their level of cognition are likely to lead to feelings of well-being and to retaining a sense of autonomy. It is a basic human need to feel wanted and accepted (Barnes 2004).

Physical Domain

It is very clear that people diagnosed with a dementia will experience debilitating losses with profound consequences. However, what is not clear is to what extent the people around the person diagnosed with dementia accelerate the progression of the disease. The progression of dementia eventually impacts a person's physical domain. In terms of health, researchers note that people with advanced dementia are predisposed to infections, fevers, aspiration and pneumonia, and they are not likely to be offered adequate pain management (Evers et al. 2002). The practice of dispensing analgesics to people diagnosed with dementia is often dismissed as unnecessary. Aggressive treatments given to people with severe dementia have been found to accelerate the rate of progression of the disease process. Furthermore, Evers et al. note that the inappropriate usage of antibiotics in end-stage dementia care can lead to iatrogenic outcomes such as renal failure, ototoxicity (adversely affecting hearing and balance), diarrhea, and behaviours requiring the use of restraints, and consequently prolong time to death.

The trajectory of functional decline in the last years of life varies significantly among different conditions. Although dying with a diagnosed dementia involves a lingering trajectory, the duration of the dying process is as variable as possible functional losses. Particularly important for people diagnosed with dementia is the significant impairment in functional ability throughout the last year of life in comparison to the experience of someone dying from cancer who experiences the same level of functional decline in just the last three months of life (Chen et al. 2007). Functional decline resulting from the progression of dementia offers little opportunity to worsen throughout the last year of life; in turn functional ability becomes a less reliable marker of terminal status (Chen et al. 2007). While each course of dementia is unique, typically death occurs in seven to ten years but can progress as quickly as three to four years or as slowly as fifteen (Nuland 1993). It is important to recognize conditions that could be treated resulting in improvement in function of the affected domain. With the ongoing introduction of new medical technologies, the primary goal is to fight to prolong life; therefore, it becomes problematic to determine when to move away from aggressive/curative approaches towards a palliative/comfort approach.

Psychological Domain

The psychological domain of personhood encompasses the emotions, habits, and personality of a person. Often there is a loss of former personality with the progression of dementia, altering the person such that he or she is no longer recognizable to family and friends. For many onlookers it is difficult, if not impossible to move beyond the changes in personality and to accept the emergence of new habits and behaviours. A neuropsychiatric perspective, commonly understood as the management of Behavioural and Psychological Symptoms of Dementia (BPDS) treats what are considered to be underlying pathologies of the brain. In contrast to a psycho-social perspective, BPDS understands difficult behaviours as being distinct from the reactions of the person to their declining abilities (Sabat 2008b). Consequently, by strictly adopting a neuropsychiatric perspective, care plans often adopt the use of pharmacological methods to treat what is considered to be inappropriate behaviour. Placing people with a diagnosed dementia into passive roles rather than attempting to understand their psychological changes and resulting behaviours diminishes their chance of achieving a good quality of life. Alternatively, when mindful attempts are made to "engage with a person as a person" (Sabat 2008a:84) and to understand the larger social context of that interaction, we can begin to see that the act in and of itself is not necessarily a product of brain damage but may be a response to dysfunctional social treatment (Sabat 2008a). It is counterproductive to try to influence a person with a diagnosed dementia to reorient him or herself to what we ourselves understand as reality or proper social behaviour. The challenging behaviour becomes a challenge for the caregiver to 1) recognize personal reactions to the behaviour, 2) find ways to best understand the problem behaviour and, 3) find ways in which the person can better cope (Goldsmith 2002). We are more likely to achieve better outcomes for all concerned by authentically working towards understanding and interpreting behaviour and through "interacting with them as persons" (Sabat 2008a).

What appears to be a much ignored aspect of the psychological domain is acknowledging the role that emotions play as a part of everyday life and recognizing that they are not simply an inevitable consequence of dementia (Rewston and Moniz-Cook 2008). Not considering the emotions of the person who engages in challenging behaviour can lead to further emotional distress. A wide range of negative feelings such as hostility, fear, panic, anger, embarrassment, and shame may then be experienced by the person diagnosed with a dementia, leading care providers to understand the behaviour as being problematic (Rewston and Moniz-Cook 2008). Four common reasons for emotional distress in people with a diagnosed dementia have been identified: "1) adjusting to having a diagnosis of dementia; 2) cognitive changes in perception and information processing; 3) personality and coping style; and 4) emotional distress of others." (Rewston and Moniz-Cook 2008: 252).

Equally important is that unattended emotional distress can potentially develop into anxiety and/or depression. The lack of understanding of the disease process often results in withdrawal from social interactions by both people diagnosed with dementia and by their family members, resulting in emotional pain (Katsuno 2005). The lack of social interactions, in particular the high degree of alone time which is spent in LTC doing nothing, could in turn obscure the amount of loneliness and sadness that the person with a diagnosed dementia is actually experiencing (Ward et al. 2008). The goal of care should always be towards remission of depressive symptoms. What people who are faced with a diagnosis of dementia need the most is repetitive reassurance and affirmation (Small et al. 2007) and validation that there is meaning associated with their expressions of emotions (Kitwood 1997). No matter how it is termed, challenging behaviours are most often a person's attempt at communicating and meeting physical, emotional or social needs (Small et al. 2007).

Social Domain

The social domain of personhood draws upon interpersonal relationships, culture, values, beliefs and interactions with various social systems. Moyle and colleagues (2007: 185) found evidence of the benefits of interpersonal relationships stating, "social networks, support and participation, no matter if they come from the inside or outside the facility, are important to happiness and well-being." An argument could be made suggesting that the social domain is an extremely important domain of personhood. Beginning with Kitwood and followed through in thinking by many current researchers, personhood is considered to be essentially social and facilitated through different social practices in relation to others (Cohen-Mansfield et al. 2000; Adams and Gardiner 2005; Bartlett and O'Conner 2007). Similar to any dysfunctional relationship, focus is more often placed upon the person who has been diagnosed with a dementia as being problematic, with no onus placed upon the other party of the interaction. It is important to recognize the impact of situational components (disease and social circumstances) of the interaction and the resulting behaviour of the person diagnosed with dementia (Sabat 2002b). Cohen-Mansfield et al. (2006) argue for a move away from binding the essence of personhood with cognitive ability. The uniqueness of each person diagnosed with a dementia blossoms when interactions with others allows identity to be creatively expressed (Cohen-Mansfield et al. 2006).

Adams and Gardiner (2005) distinguish between "enabling" and "disabling" dementia communication. Enabling dementia communication occurs when the person diagnosed with a dementia is permitted to express his or her own thoughts, feeling and wishes in the manner they are best able (Adams and Gardiner 2005). A disabling conversation occurs whenever participants of an exchange reinterpret what has been said through rephrasing or changing the meaning of the speaker (Adams and Gardiner 2005). Allan and Killick (2008) further expand on this by including the acts of interrupting the train of thought of the person diagnosed with dementia, using professional language and speaking outside of earshot about the person.

Communication is essential to being a person and to our ability to have relationships with others. Sabat (2008a) suggests using a multiple choice format in attempts of communication. This format provides a better opportunity for successful communication by facilitating the use of recognition skills which enhance the ability to make a choice. Key to this type of communication is the environment in which the interaction takes place. The person with a diagnosed dementia requires time to respond, in an environment with the least amount of distraction possible. With cognitive impairment it can be expected that communication may be filled with moments of silence and take longer than what is otherwise considered acceptable (Baldwin, 2008).

Literature promoting personhood in dementia reiterates time and again the importance of being able to accept the reality of the person diagnosed with dementia (Cohen-Mansfield et al. 2000; Goldsmith: 2002; Moore and Hollet: 2003). As Lloyd, Gatherer and Kalsy (2006: 1396) argue "views expressed by individuals at any given time represent some aspect of their reality and perspective." Allowing ourselves to accept a reality which is outside of an acceptable norm may go a long way toward producing a positive interaction with someone diagnosed with a dementia. With the progression of dementia, the person has absolute belief that what they are saying is the truth, and it becomes the challenge of the person without dementia to react to these perceived realities in a creative, positive, accepting, non-degrading manner (Hart 2003). Kitwood cautions, "it becomes unwise to dismiss any interactions between people who have dementia as meaningless or nonsensical" (1997: 95). Using "illogic logic" requires the suspension of belief in order for the person with dementia to feel safe and accepted in their own environment (Hart 2003). Dismissing people diagnosed with a dementia rather than attempting to understand their psychological changes and resulting disruptive behaviours diminishes their chance of having their personhood respected. By only paying attention to the deterioration that the disease process brings, we miss seeing the person at the centre of it all; the disease is all that is seen.

Spiritual Domain

Perhaps the most neglected domain of personhood which provides an individual with hope and a sense of meaning in life is the spiritual element. The ways in which spirituality is discussed in the literature are as variable as the assigned contextual definitions. One definition found in the literature speaks of spirituality in reference to dementia as, "our need and capacity for relationship to whatever or whoever gives meaning, purpose and direction in our lives" (Albinsson and Strang 2002: 169). Spirituality is an essential part of the humanity of all people (Puchalski 2007) which is not limited to a relationship with God. It could include other perceived higher powers and elements of nature (Albinsson and Strang 2002). In the context of sociology, spirituality has the capacity to create meaning in relationships, in turn alleviating some of the existential isolation often experienced by people diagnosed with a dementia. Menne and colleagues (2002) go further in stressing that interactions with the environment are an important factor in meaning making for individuals with dementia. For example, a feeling of peace can be achieved when nature is used as the source of spiritual comfort (Beuscher and Beck 2008). Katsuno (2003) and Beuscher and Beck (2008) both found that in the early stages of the disease, people diagnosed with a dementia often turn to spirituality as a method of coping.

A study done by Puchaski (2007) found that spirituality had a relational capacity to provide a sense of connectedness to others while ensuring the essence of being by respecting the inherent worth of all people, inclusive of those diagnosed with a dementia. She also found that people in LTC had the basic human need for love and concern which requires more than the instrumental aspects of dementia care. Instrumental dementia care, which focuses on physical needs, is a more familiar way of providing care and one which does not require the care provider to step into positions that requires comfort with silence and acceptance of the unknown. Puchaski (2007) concludes that it is "easier to adjust pain meds than to take time to hold someone's pain and listen to deep distress and hopelessness" (p. 39).

Literature further indicates that older adults are at risk of pervasive suffering when care providers approach psychosocial and spiritual care at the end of life solely from a biomedical perspective (Nakashima and Canda 2005). Many staff are often uncomfortable with addressing spiritual, existential, death and dying issues and find themselves minimizing spiritual/existential concerns, avoiding the subject matter or changing the subject (Albinsson and Strang 2002; Nakashima and Canda 2005). Allowing the voices of people with dementia to be heard facilitates a process whereby they can work through the acceptance and/or denial of their dementia, justify their loss of roles, address emotional outcomes resulting from the return of past traumas, and express grief when they are feeling useless (Lawrence 2003; 2007). Addressing these uncomfortable issues can go a long way in fulfilling spiritual needs. Hearing their stories offers a glimpse into what Lawrence (2007) describes as an ongoing legacy of life through dementia. Knowing what is important in terms of spirituality, for the person diagnosed with dementia, acknowledges their personhood. Care plans should include the investigation of spiritual history. Through proper history taking, care providers can learn how spirituality matters to the person and perhaps most importantly derive what kinds of interventions are the most relevant to the person (McCurdy 1998; Lawrence 2003; Stuckey and Gwyther 2003). It has long been discussed in literature that spiritual needs are essential to the well-being of people with dementia, offering a source of comfort and support, yet it still remains the most neglected domain of personhood.

Self

Adopting a social constructivist perspective, self is understood as being socially constructed and assured through social interactions. Therefore, "self is not a given property of the person, a function of cognition or personality, but is created or diminished in interaction and relationships" (Small et al. 2007: 110). Different disciplines circumscribe how the concept of self is to be understood. A sociological perspective understands the self as a social construct which is created via social interactions in everyday life. According to George Herbert Mead:

> The self has a character which is different from that of the physiological organism proper. The self is something which has a development: it is not initially there, at birth, but arises in the process of social experience and activity, that is, develops in the given individual as a result of his relations to that process as a whole and to other individuals within that process.
> (Mead 1934:135)

The disease process of dementia in and of itself has little to contribute to the loss of self, rather the experience of loss of self is related to the process of communicating with others, and the actions of others. In essence, for a person diagnosed with dementia, loss of self is an attack on their personhood, in that one's status is relegated to that of a sick dependency role and the context of the relationship changes with little opportunity to develop one's self. Significant to dementia, loss of self can lead to excessive disability which goes beyond what would be expected from organic pathology alone (Sabat 2002a).

A social constructionist perspective asserts that self is not dissolved during the progress of dementia, rather the degree to which self is diminished can to some extent be attributed to the behaviours of others (Sabat and Harré 1999; Bond and Corner 2001; Holst and Hallberg 2003; Dorenlot 2005). Research findings suggest that social selves are constructed by multiple personae, which are built upon individual personalities and life histories which then persist and flourish only with the cooperation of others (Sabat and Harré 1999; Cohen-Mansfield et al. 2000; Holst and Hallberg 2003; Small et al. 2007). Accordingly, the continuity of the expression of self for an individual diagnosed with dementia must be supported by strong interpersonal relationships allowing for the voice of the individual diagnosed with a dementia to be heard (Surr 2006a). Researchers argue that individuals diagnosed with dementia are not "empty shells" and it is possible to conduct research on dementia while building upon the strengths of individuals with a diagnosed dementia (Hellström et al. 2007). It can then be argued that interactions with others facilitate the expression of self for people diagnosed with a dementia in both negative and positive manners, depending on how their daily social interactions unfold.

Inspired by a book discussing the loss of self, Sabat and Harré (1992) set out to explore issues pertaining to dementia within the scope of a social constructionist theory of the nature of the self. An analysis of the book *Alzheimer's Disease: The Loss of Self* by Cohen and Eisdorfer (1986), combined with a dialogue exchange which was witnessed between a person diagnosed with dementia and a person without a diagnosis of dementia, led to their finding that people who were diagnosed with a dementia engage in adaptive interchanges within the context of their environment while working towards sustaining their presented selves. Sabat and Harré explain that:

> One's personae or selves are presented discursively by ensuring that one's public performances conform to the requirements of the person-types that are recognized by one's fellows. Each community has its repertoire of recognisable and acceptable person-types. (p. 445)

Sometimes these exchanges are accomplished in creative yet unconventional manners. It was found that selves belonging to people diagnosed with a dementia were presented to "conform to, or satisfy, the needs of the caregiver" (Sabat and Harré 1992: 448). In examining the talk of those diagnosed with dementia, they found them making use of indexical terms such as "I", "me" and "my," which they took as verification, from a constructionist viewpoint, that an intact self exists within the realm of dementia.

Sabat's Theory of Self

Sabat (2002a) introduces a constructionist method of analysis which looks at the expression of self in terms of three separate forms which are called *Self 1* , *Self 2, and Self 3* (See appendix A). *Self 1* represents our personal identity which can be expressed both verbally and in the case of aphasia through miming. Guided by our lived experiences, the expression of *Self 1* is manifested through the use of personal pronouns. Personal emotions and experiences influence how we engage in conversations and the circumstances in which we choose to reveal certain aspects of our lives. This thesis provides evidence that people diagnosed with a dementia are able to clearly display their intact *Self 1*. *Self 2* is comprised of one's physical and mental attributes, as well as one's understanding of his/her attributes. A person diagnosed with dementia risks having newly acquired attributes, such as memory problems, becoming the central focus of his/her communications. Frequent focus on negative attributes often results in the increasing loss of remaining valued attributes of *Self 2* (Sabat 2002a). *Self 3* is comprised of the various social personae marked by unique patterns of behaviours which we present to others dependent upon the social situation in which we find ourselves, requiring the cooperation of at least one other person. However, when major focus is placed on the newly acquired dysfunctional attributes of *Self 2* (e.g., memory loss), healthy others may restrict *Self 3* of the person diagnosed with a dementia to that of a sick role and to all of the negative implications a sick role brings (Sabat 2002a). For example, if *Self 1* begins to continuously feel misunderstood by healthy others, the individual will either begin to disengage from social interactions or begin to respond aggressively. The person with dementia is then assigned an attribute of being a patient with behavioural problems or worse, assumed to be incapable of communicating. Both of these scenarios conform to the requirements of the disease process which are constructed under the assumptions that only ongoing deterioration is possible. Alternatively, *Self 3* will flourish if *Self 1* is given the opportunity to focus on the individual's remaining positive *Self 2* attributes, and not be discouraged by the decrease in function of past attributes.

Conclusion

There is a need to step back from the label "dementia" and understand the behaviours unfolding of people living with dementia. It is evident from current literature that as a whole, we continue to reiterate the same types of problems and issues with few changes in practice. Much of the literature speaks to the impact of the experience of dementia on formal and informal care providers despite the fact that the main "actor" in this story is indeed, the person living with a diagnosed dementia. The next chapter will discuss the methods used to hear the voices of residents in LTC who have been diagnosed with a dementia

Chapter Two: Methods

> Although expressive language impairment can make communication more difficult within qualitative interviews it does not make it impossible.
> (Lloyd et al. 2006: 1396)

The scope of this study is not to provide a wide breadth of perspectives from people diagnosed with a dementia. Rather, the intent is to gain insight into the existence of personhood in people with a diagnosed dementia in LTC, and to allow their voices to be heard during the research process. When researchers explore the phenomena of dementia, they must keep in mind that although the ultimate goal is "to construct a full interpretive description of some aspect of the lifeworld" (van Manen 1997: 18) the researcher also needs "to remain aware that the lived life is always more complex than any explication of meaning can reveal" (van Manen 1997: 18). I will show that it is only by conversing with and focusing on the subjective experiences of people residing in LTC with a diagnosed dementia that evidence of personhood can be established. Furthermore, their voices should be considered when addressing their needs. My guiding research question can be stated as: To what extent are the domains of personhood evident in older adults who have been diagnosed with a dementia while residing in long-term care (LTC)?

An interpretive qualitative analysis is appropriate for this research because it adopts an interactive humanistic approach which is apt to facilitate hearing the voices of the residents. The goal of this study is to provide a representation of my understanding of what the participants had to say while keeping an open mind that the subjective world is not fully accessible. In this study, I adopt an interpretive analysis that is flexible and accepts respondents as the primary experts regarding their experiences, and therefore I am especially interested in learning from them

(Brocki and Wearden 2006). Interpretive analysis facilitates a process in which individual accounts of the older adult diagnosed with a dementia can be expressed and in turn provide evidence of the domains of personhood. The contours of each domain are very broad and are not expected to be evident in the same way for each person. For example, the physical domain may be evident in observed pain; there may be evidence of awareness in the psychological domain; the social domain may be demonstrated by the person's awareness of her surroundings and the spiritual domain may be expressed as a need to find meaning and purpose in life.

A Reflexive Note

> The researcher does more than affect ongoing social life: his weltanschauung – worldview- shapes the entire project. From early curiosity all the way to writing the final report, the researcher's personal biography is the lens through which he sees the world. (Rossman and Rallis 2003: 10)

I am not personally experiencing the effects of a diagnosis of dementia, therefore I must be aware of what personal attributes I bring into the interview process that will inhibit or positively influence how I conceptualize my research project, design my study and interpret my data. Being in the role of a researcher it is necessary to recognize my part in creating the thematic accounts of my interviews.

My initial exposure as a volunteer on a dementia unit in a LTC facility elicited feelings of uneasiness and to some degree fear. These reactions motivated me to seek understanding of the social world in which people diagnosed with a dementia find themselves. My assumptions about living with a diagnosed dementia in LTC are based on personal observations while volunteering and have created suspicions that the voices of the residents are unnecessarily silenced. I have overheard derogatory remarks addressed towards the residents and have witnessed long periods of time where no interactions are made with the residents. Despite my belief that most people have good intentions, I intuitively sense that there seems to be something missing or not quite right in how care is provided to people with dementia. Several interactions have led to my assumptions that many individuals on the dementia units are very lonely, sad and misunderstood. It is my belief that all people deserve to be heard and treated with respect despite their differences.

There is a widely accepted belief that women are raised to be primary caregivers and furthermore are nurturing and caring. Following this belief, as a female, I was socialized by a very loving mother and continue to value the concepts of caring, compassion, and empathy and try to incorporate these in my daily life. As a middle aged female with caring attributes I may have contributed positively to the rapport that was established with my respondents. Being an older researcher may have also impacted the willingness for the residents to participate in the interviews. Upon the conclusion of one interview, I requested permission to return to conduct another interview later. The respondent replied, "I don't suppose I have the right to say no." This raised concerns for me: What would cause this respondent to feel this way? Did she perceive me as an authoritative figure? Is this simply a result of her past work experience of adhering to rules and regulations? This brought to light the need to ask permission at each interview, and pay attention to body language which may contradict the verbal response.

I am open to learning new things yet cautious not to impose my own understandings onto the experiences of others. I readily admit that I seek the positive in every situation, however I remain cognizant of the seriousness and complexity of dementia. However, I do desire to understand and represent to the best of my ability a glimpse into the life of an older adult diagnosed with dementia who resides in LTC. I believe emotions are a part of who we are and what we choose to do. As a researcher I follow a prescribed method of inquiry but in the end, parts of me, “matters of the heart,” have found their way into the final outcome of my analysis. I feel privileged to have had the opportunity to have conversations with people diagnosed with a dementia.

Process of Recruiting Participants

Due to my involvement with a larger research project on end-of-life care for people with dementia in LTC, a study funded by the Canadian Institutes for Health Research, and led by Dr. Mary Lou Kelley of the Centre for Education and Research on Aging and Health (CERAH) at Lakehead University, I had access to administrative staff at that LTC facility, which is located in Northwestern Ontario. Consequently, I asked the Director of Care at the LTC facility to help with identifying potential participants for my own research. A diagnosis of any type of dementia was a criterion that the Director of Care was to consider when identifying participants. The Director of Care of the facility identified eight possible candidates to be part of my study. I was provided with a list of the names and contact information of family members who were designated power of attorney (POA) for the people residing in LTC. Consent was given to interview four residents who have been diagnosed with a dementia and reside on what is termed a “dementia unit”. Neither gender nor age was a consideration in the recruitment of participants for this study.

I chose to use this small sample size so that I would be able to capture subtle nuances of meaning which may provide insights valuable in the context of recognizing personhood in people diagnosed with a dementia (Brocki andWearden 2006). I make no claim about the generalisabiltiy of this study but suggest that the findings are applicable to persons within a similar context (Brocki and Wearden 2006; Holst and Hallberg 2003). The premise that knowledge comes from experience and that each person's unique perspective matters supports my decision of having four participants within this study. The four participants were not chosen in any particular order, they were chosen based on the first four POAs to consent to having their family member interviewed. Two family members declined permission to interview their family member saying that they did not believe that the resident was capable of participating in any type of conversation. The four consenting POAs were provided with an information letter and consent form (see Appendices B & C) outlining the purpose of the study. Once written consent was obtained, I was introduced by the POA to their family member. The resident, however, was still asked whether he/she was willing to participate in each interview. Both residents and POAs were assured that the participation of the resident in the research is completely voluntary, they could withdraw at any time, and it would in no way affect their care at the facility.

Participant Characteristics

My sample consists of four females who are living their final phase of life in LTC with a diagnosed dementia. I assigned pseudonyms to each participant and subsequently used these pseudonyms in all field notes, interview transcripts, and written reports. The participants are in the middle-old (aged 75 to 84) and the frail-old (aged 90 and over) categorization of age (Chappell, McDonald and Stones 2008). At completion of the data collection the youngest participant was 82 years of age and the oldest participant was 96 years of age. Diagnosis of the selected participants included mid stage and early stage vascular dementia (VaD); mid stage Alzheimer, mid/late stage Alzheimer. Interestingly, not all of the POAs readily admitted to a diagnosis of dementia for their family member. One POA commented that their mother's memory was fine for her age, attributing any cognitive difficulties as a normal aging process.

However, all participants are residing on a designated dementia ward and a personal conversation with the Director of Care confirmed a diagnosis of dementia for each of the participants (personal communication, February 6 2009). The participants are described in more detail below.

Audrey

Audrey was 82 years old at the time of completion of data collection. She was admitted into the LTC home in February, 2007, at the age of 80 years. Audrey was diagnosed with mid-stage vascular dementia (VaD). Audrey was recently widowed and had one son and two daughters. Audrey lived most of her adult life within Northwestern Ontario. She used to work for the Ministry of Education. Audrey shared a room with another resident. Her room was filled with mementoes of her family.

Brenda

Brenda was 96 years old at the time of completion of data collection. She was admitted into the LTC home in March, 2007, at the age of 95 years. Brenda was diagnosed with mid-stage Alzheimer's disease. She had resided in various communities in Northwestern Ontario during her adult life. Brenda was widowed and had two sons and one daughter. Brenda's work experience ranged from working in the health care field to working as a sales clerk in a department store. Brenda resided in a spacious private room with large windows which provided an airy quiet living area. There were various mementos from home throughout her room, including family photos.

Catherine

Catherine was 81 years old at the time of completion of data collection. She was admitted into this LTC home in June 2005 at the age of 78 years. Catherine was diagnosed with early-stage vascular dementia (VaD). Catherine was a long time widow who had also experienced the death of one son and one daughter. Six sons and one daughter were still living. Catherine lived most of her adult life in Northwestern Ontario. Her work history was not available as there was no history sheet in her room. The subject of previous work experience did not come up during conversations. Catherine shared a room with another resident. Her room was somewhat stark in comparison to other living areas, however there were several home-drawn pictures which were likely drawn by grandchildren.

Deirdre

Deirdre was 91 years old at the time of completion of data collection. She was admitted into this LTC home in August, 2004 at the age of 87 years, Deirdre was diagnosed with mid/late stage Alzheimer disease. Deirdre was widowed and had one son, one daughter and three step-daughters. Deirdre spent part of her life in Manitoba prior to residing in Northwestern Ontario. Deirdre's work experience included various trade jobs. Deirdre shared a room with another resident, with her bed positioned alongside of the window. There were several photos and pictures on the walls.

Research Design and Data collection

Interviews for the purpose of this study are understood as being "conversations" with the residents. Conversations facilitate a more friendly relationship, enabling the resident to feel comfortable in participating in the research process. Holst and Hallberg (2003) have established that structured questions can be confusing and threatening to people who have been diagnosed with a dementia. People diagnosed with a dementia are better able to express their own thoughts and feelings within the context of a conversation rather than by answering questions from a structured interview guide (Clare et al. 2008; Surr 2006a).

By following a structured approach, the researcher risks missing the true nature of what the participant is trying to express, particularly for people diagnosed with a dementia (Becker 1999). Standardized, structured methods of inquiry can be too restrictive regarding the scope of information to be collected during the interview. It is extremely important for the interview process to reflect the interests of the person diagnosed with dementia. The person may associate a structured interview with assessments on which they did poorly in (i.e. assessing memory) and may also feel like they are being judged.

Instead of structured interviews, I used a non-directive interview style with open-ended questions. I utilized minimal probes to help ensure that I did not interject my own frame of reference into the conversation. My intent was to allow the flow of the conversations to be determined by the resident, as much as possible, allowing their voice to be heard. In the face-to-face conversations, it was important for me to accept what my participants had to say as being important. Dementia researchers need to resist the impulse to establish a "truthful portrayal" of the target of study (Phinney, Chaudhury, and O'Conner 2007). To truly accept my participants as having absolute value, issues of finding words or confabulation are not relevant since their experiences and descriptions of reality are honoured and accepted (Moore and Hollett 2003). The goal of study should not be to judge the correctness of what had been described by a person diagnosed with dementia, but "rather to provide another window on their involvement in everyday habits and practices" (Phinney et al. 2007: 386). Through narration we are able to make sense of the social world. Therefore, it would be disrespectful to dismiss the uniqueness of a person's understanding of the world simply due to the fact is does not meet your understanding. The content of the conversation being told may be a glimpse into what the person diagnosed with dementia deems valuable (Steeman et al. 2007). The challenge becomes to find the ability to step outside of one's conceptual ideas of what constitutes reality and accept what is being said within the context of the conversation, to find meaning behind the words.

Kuhl (2002) argues that it is only in learning how to be with another person and hear what is being said that it is possible to see the person, not the disease. Moyle et al. (2007) have identified the importance of being attentive to all individuals as people. People diagnosed with a dementia are too often dismissed as being irrational and having nothing of importance to say. Following the assertion that one person's conversation is important to expand current understandings of an issue (dementia) by offering a unique different perceptive, I held onto my primary focus of hearing only the voices of the residents. Despite having access to existing data from staff and family I stayed focused on what the residents had to say. Conventional methods of research which seek confirmation from others greatly diminish the voice of the person diagnosed with dementia, overshadowed by care providers. As discussed by Lloyd et al. (2006: 1391), "supplementing with additional data suggest that interview accounts provided by individuals with dementia alone were deemed insufficient." Baldwin (2008) further suggests that "to be unheard, unrecognized, unremembered is absolute death." Currently, literature on dementia continues to be widely concentrated on the perspectives of family members and professionals.

The Interview Process

Each time I returned to the LTC to talk with a participant, it soon became evident that she did not remember me from our previous session. However, two participants indicated that my voice seemed somewhat familiar to them. I was then careful to re-introduce myself as a university student doing research at the start of each session. I informed the resident that I would like to talk to them a little bit about this place and about their happiness and satisfaction while respecting their decision whether or not to proceed with the interview. I did not dictate the course of the interview in order to facilitate freedom for the respondent to talk about whatever was important to her. I utilized an unstructured conversational interview approach whereby a single entry question was presented and I asked the resident to respond freely. Although I opened each conversation with a general question inquiring about how the resident's day was going, my role then became to be an active listener and bear witness to what was being conveyed. Once a topic was introduced by the participant I followed up with questions as needed, being careful not to influence the direction of the conversation yet careful to be alert to emerging themes.

Due to the nature of dementia, conversations varied in length and were conducted over the course of several weeks and at various times during the day. I avoided going to the facility whenever I had flu or cold like symptoms to avoid inadvertently contaminating an already vulnerable population. In addition, I was prevented from visiting the facility during a week when it was closed to visitors due to a gastrointestinal outbreak. There were also times when it was simply not appropriate to engage the resident in an interview, either because the resident was in pain, was involved in an activity, or was outside the facility for personal reasons. Morning time was not a good time to conduct interviews, there was too much activity going on with resident care.

The number of recorded conversations with each participant ranged from two to six, with a total of fifteen transcripts. My intent was to gather evidence of the expression of personhood for each woman, rather than show that all domains of personhood were evident, and it was not my intent to continue data collection until thematic saturation was reached. Thus, I conducted only enough interviews to allow me to show that participants were indeed able to express personhood. As well, time constraints were a factor regarding the number of interviews I was able to conduct.

Thirteen conversations were conducted during the early afternoon and two were conducted in the evening. The conversations lasted three to forty-one minutes. The discrepancy in length of conversations can be accounted for by the uniqueness of each participant's ability to engage in conversation at the time I chose to visit the facility. I regarded each participant as a person and no matter how little she was able to actively engage in a conversation, what she did have to say was important. I consciously worked to embrace the individual differences of my participants and to not dismiss what they had to say based on their limitations. This is in line with Lloyd et al. (2006) who argue that a consequence of not making an effort to hear what a person has to say in effect suggests depersonalization of that individual. I was attentive to signs of discomfort which suggested to me that the conversation should be terminated. For example, when talking with one participant I noticed that she appeared to be tiring from working hard at memory recall, therefore we concluded the conversation and I helped her return to the common room.

The conversations were completed between May 20, 2008 and February 17, 2009 at the LTC on the ward where the resident resided. Six interviews occurred in the family room located on the floor. The family room offered a private setting with no interruptions. Four conversations occurred in the resident's room. This provided me with the opportunity to observe their personal environment. Three conversations occurred in the dining/activity room which proved to be a lot noisier due to background noise. Two conversations were conducted in the hallway. There was one instance where the interview process was disrupted by nursing staff doing routine personal care for the residents. This disruption did not appear to distract from the interview. On one occasion during a conversation one resident showed interest in the recording device. I asked her if she would like me to show her how it worked. After the conversation was completed I rewound the tape and let her hear the conversation. This appeared to satisfy her curiosity as she did not ask about it in future interviews.

During the conversations I paid particular attention to non-verbal cues expressed by the participant and also made observations regarding the setting. After the conversations I utilized a contact summary form to make note of my thoughts on how the interview went (see appendix D). A contact summary is a form used to summarize in a reflective manner the main points of the interactions with a contact (Miles and Huberman 1994). During this reflection period I also noted my own feelings going away from the interview. These notes were helpful in instances when I needed clarification of what was said during the interviews. I mailed thank you notes to each of the participants at the conclusion of the interviewing process.

Data Analysis and Interpretation

Ongoing analysis is conducted both during and after several months of interviewing sessions. After each interview session I found a quiet spot to reflect on what had transpired and make additional descriptive analytical notes. Keeping thorough details of the interviews enables a thick descriptive analysis. On a regular basis I reviewed the notes to maintain familiarity with the transcripts.

Post interview reflection led to the identification of possible themes which were derived from my memory. For example, at the conclusion of all conversations with Brenda I sensed without a doubt that her home had special meaning for her. Also, at the conclusion of an interview with Audrey I was fascinated by how much she framed her conversation within the context of an educational institution. I was guided by my impressions and when I began the coding process I looked for representations of themes within the text of the transcripts to see if what I had sensed was represented in what was conveyed by the resident.

I also kept a journal to track my thoughts during this process of collecting data. I frequently discussed findings of this research and my ideas with several people who work in the gerontological field. While discussions focused on the themes I identified, there was agreement that these themes represented a description of the phenomenon of personhood with a diagnosed dementia in LTC. The concept of community practice is explained below:

> In the research field, the community of practice is composed of immediate colleagues with whom you share your work. Working together and sharing your work strengthens your learning as you move through the research process. You subject your work to scrutiny from this community, eliciting the tough questions and exploring possible answers that deepen your understanding and make your study robust. (Rossman and Rallis 2003: 34-35)

I transcribed each individual transcript verbatim. I then read and reread the transcribed data several times to become familiar with different aspects of the data and be attentive to what the data were revealing about the lived experience of the older adult residing in LTC who has a diagnosed dementia. I also listened to the taped interviews again to call to mind the details of the interview. I was able to visualize nonverbal gestures, facial expressions and body language, as well as to be reminded of the tones in speech of my participants. I used contact summary sheets previously mentioned above to reorient myself to a particular contact, and coded them as part of the analysis. I organized the analysis around emergent themes derived from each individual transcript rather than by pre-determined constructs. However, I was guided by post interview impressions in that I looked for representations of themes derived from my memory of the conversation. For example, after each conversation with Brenda I strongly sensed her sadness at not being in her own home. Upon analyzing the transcripts I identified a theme relating to the importance of home within the text.

I organized the data by using a coding technique whereby line by line I looked for representations of things said within the conversations which could identify themes. Coding allowed me to identify emergent themes rather than find themes associated with existing literature. I inserted each code in the margin next to the section of data it related to. I then created a list for each resident of all the key points and grouped them into initial emerging themes. If I detected a new theme in the next transcript belonging to the same resident, I went back to see whether it had been missed in the preceding transcripts. I carefully chose to name each code to reflect the context of the resident's words. I reread the transcript which an emergent theme was derived from was reread to ensure that is was represented in the transcript. I was not looking to see whether each theme held true for each resident, my goal was to represent what each resident had to say as meaningful in and of itself. Finally, I performed a last rereading of the transcripts to verify that my interpretations were found in the resident's statements.

Once I analyzed each grouping of interviews separately I proceeded to seek similarities within the literature. More specifically, I was looking to see whether the identified themes were found in the original model of dementia care that I created.

Conclusion

There is a need to stop, listen, and be present for the person despite their diagnosis of dementia. Adopting a method of research which includes hearing the voices of the residents may shift attitudes away from focusing on dementia as a disease without a cure towards focusing on the whole person and their continued strengths. Research continues to find that there is limited attention to the subjective experience of residents diagnosed with dementia who reside in LTC (Moyle et al. 2007; Clare 2008b). The next chapter presents what the participants had to say about living in LTC with a diagnosed dementia.

Chapter Three: Key Themes

> It would be impossible to prove otherwise, and dismissive to state than an individual with dementia no longer has a life, or is no longer an individual. (Lawrence 2007: 559)

This chapter presents themes that emerged during the analysis of each individual's set of transcripts, and discusses the significance of these themes. The aim of my analytical process was to find themes conveying each participant's subjective experience grounded in their own words. In general, what becomes clear in examining themes found in each participant's set of transcripts is that each maintains a reality for herself that allows her to express her contours of personhood. As discussed in the previous chapter, participants are referred to by pseudonyms to ensure anonymity.

Data Collection with Audrey

As previously stated, a diagnosis of vascular dementia was a contributing factor to Audrey's admission into LTC in 2007. I collected four taped conversations and two informal, non-taped conversations with Audrey. The longest conversation lasted twenty-seven minutes, while two conversations each lasted five minutes (one taped interview and one non-taped) for a total of seventy-eight minutes of conversational time. Audrey was 82 years of age at completion of the interviews. On most occasions, she was very receptive to participating in conversations, actively engaging with me, and having a good sense of humour. One conversation occurred in the evening, while others were at various times during the afternoon. On another occasion that I had planned on conversing with Audrey, I arrived to find her sleeping and snoring in her chair outside of the elevators. I was unsure of what if anything I should do. I did not want to touch her or speak out to wake her in fear that I would startle her. As I looked around I noticed staff going about their duties, unconcerned that she was sleeping in this area. I returned several times during the time span that I was at the facility and she did not awake from her nap

Audrey was described by staff and family as being a 'colourful character' who had the ability to tell "quite the story." However, I would argue that her stories were her way of holding on to the person who had previously worked for the Board of Education. This seemed to be her way of making sense of where she was and what she was doing. I recall leaving the first conversation noticing how comfortable Audrey seemed to be with describing her daily activities as occurring within an educational setting. During conversations she often made reference to rules, regulations, kids, teachers and classrooms.

My observations led me to believe that Audrey was quite comfortable living in this facility. For example, she was never in her room when I went to see her. I always found Audrey out and about in the halls, or as Audrey would describe her wanderings, she liked to "just scoot around." She expressed no negative concerns about the facility. Rather, when I asked her if she liked the place that she was at she told me, "It's good." I then asked if this was her home and she replied, "No this is not my home, my home is in [states the name of the city]." She was clear, in other words, that the facility was not her home.

Audrey's Themes

Four major themes emerged from my conversations with Audrey which provide a glimpse into her understanding of her life in LTC. The first theme, *"This is where we learn"* illustrates Audrey's way of holding on to the part of her life which most likely held special meaning to her. The second theme, *"My brain is not working"* articulates the awareness Audrey had of her difficulties in finding the right words to convey what she was trying to get across to me. The third theme, *"I am okay"* seemed to be expressed by Audrey in a tone suggesting that she was convincing herself that despite her awareness of the difficulties with her brain she was indeed okay. The fourth theme, *"I always want a fair shake"* conveys Audrey's need to be treated fairly and with respect.

Theme 1: "This is where we learn"

I always went away from conversations feeling as though I had learned a lesson. For example, my first conversation with Audrey discussed the consequences of behaviours, rules and regulations, and the need for respect. In all six conversations, Audrey talked as though she was living in an educational institution. She clearly pointed out to me that she is staying in a place where she learns and that her room was where she studied. She referred to her living environment in terms of having a nice class, a very nice room, nice kids and a nice teacher. "This is where our learning is coming from. This is where we learn, yeah I like it here." She also told me that school occupies her time during most of the day. Audrey's need for learning became clear with comments such as: "what's important to me, I want to [searching for words] to study stuff." She elaborated that she wanted to study things that she felt were important to herself and to everybody else. She told me, "I feel that they are important and my friends are willing to, are willing to study these subjects because they are important." There was no clear indication of what things were important to study, however the importance of learning was a theme raised in each of our conversations.

Theme 2: "My Brain is not working"

The one thing that stood out while conversing with Audrey was her awareness of her "brain not working'." During our conversations there were many pauses as Audrey appeared to be concentrating on finding her words. The following statement illustrates Audrey's awareness of her difficulty in expressing her words and also her apparent need for confirmation of the normalcy of this difficulty: "Sometimes I have trouble finding my words, doesn't that happen to you?" I answered Audrey in the affirmative, confirming that I too have experienced trouble with finding words. By the fifth interview, nine months from the first interview, I noted an increase in Audrey's struggle to find words, however she continued to reassure herself that this was okay. During this conversation Audrey was trying to recall something and in exasperation stated, "Ah, my brain won't work. It makes me feel stupid." In an effort to encourage confidence in her existing abilities I told her that I did not think she was stupid and that she was doing the best that she could. Later on in the conversation she once again caught herself struggling with finding words to express her feelings. In time Audrey was able to tell me, "I always feel like that, a dumbo." I questioned why she felt like a dumbo and she responded, "I don't know, I am not, I am not up to par there [points to head], but it feels that way, it's silly to feel like that." Throughout the conversations Audrey always took ownership of her struggles, "Oh yeah, I often have some trouble with my words; and this brain [pointing to head] just doesn't want to tell me what it is either." It could be argued that Audrey actively engages in establishing personhood.

Theme 3: "I am okay"

It soon became evident while conversing with Audrey that she was trying hard to remain positive while coping with her increasing memory difficulties. Throughout the conversations she would periodically tell me that she was okay. One time Audrey told me, "I think I am, I think

I'm doing okay; I should say as well that I feel like I am, [pause] I am okay." However there were times when she really had to try hard to recall memories. At one point during a conversation Audrey inquired about what I studied and I responded that I enjoyed learning about people who were aging. I then asked if she had anything important to tell me about getting older and she responded:

> I should be able to at this stage of my [struggle with words], but I feel that I haven't experienced enough to tell you anything about the experience. I don't think I have. I feel like I haven't done anything, but that's not so.

Audrey demonstrated her interest in wanting to believe that everything is okay while being aware that she has difficulty in recalling past events. During another conversation with Audrey she was describing a scenario where the task for students was to figure out answers to prepared questions from the contents of a book that had been read. She noted that the kids were getting pretty good about it and then told me, "You gotta be able to keep going!" Her continued attempts to find the words to convey what she was thinking did indeed demonstrate that she was able to keep going!

The last time that I went to the facility I found Audrey in the hallway near the nursing station. At this particular time Audrey declined to come to a quiet place to converse with me but was open to conversing in the hallway. She appeared agitated and eventually told me that she was very concerned about something she thought she had done wrong. Audrey was waiting to speak to someone who could clarify what she had done wrong. She told me:

> My day is going lousy. Yes, I – I did something stupid last week and this week and [struggling with thoughts] I don't remember what it was, I wish I could, it was something really stupid anyway. It was stupid, I don't know.

It was quite clear that something was bothering Audrey that day. As was typical in prior conversations, Audrey framed this experience in an educational context. She explained being "stupid" in the context of there being a problem with some papers at school and that she did not deserve a grade. After being able to voice her frustrations about having a lousy day, Audrey conceded that things were not going so well but at the same time she felt that she was okay. She told me, "I am okay, I am not excellent or anything like that."

Theme 4: "I want a fair shake"

This particular theme appeared throughout all conversations with Audrey, which led me to recognize that it was important to her to be treated fairly and feel respected. She first introduced the term "fair shake" into the conversation when she told me that as a child she wanted to be given a fair shake. Within the context of our conversation, fair shake was spoken in terms of being given a chance to try to do things and have the help when necessary. The vulnerability created by changes resulting from the progression of Audrey's diagnosis stresses the need for fair shakes. When I asked if she still wanted a fair shake she responded, "Of course, I, I always want a fair shake." She further told me that at the present "there isn't lack of a fair shake" and she also added, "I get ah I get ah I get as much help as I want and everything." During another conversation Audrey relayed to me that the "teachers were considerate of us." Within the context of how Audrey frames her conversations, I understood her to be telling me that the nursing staff were considerate of the residents. Overall, Audrey indicated that people treated her well and that she had no problems with her stay at this facility. Audrey told me, "I think it's nice, this is a nice place, I think I will stay here for a while." During another conversation Audrey introduced the word "fairmanship". When I asked her what she meant by that term, she told me, "fairmanship, well that would mean being able to do things on their own."

Audrey demonstrated determination in conveying the importance of being respected to execute a degree of independence in trying to do things on one's own.

Audrey's Expression of Personhood

Audrey created a sense of continuity and purpose in her life by filling her days with activities that were significant to her, mainly those which mimic a school context. In support of personhood, Audrey found a way to actively create a scenario to make sense of her new social world. Her choice to incorporate family and friends into her understanding of the activities of her daily life within an educational setting served as her coping mechanism. Another noteworthy issue supporting personhood was the importance to Audrey of maintaining the ability to continue to do things on her own, or in her terms, *fairmanship*. Her descriptive choice of words to describe doing things on one's own enabled her to express her view.

Of my four participants, Audrey was the one in whom I noticed the most changes in her physical appearance and ability to communicate. I noticed the decline over the course of the several months that passed between the first and the last two times that I went to converse with Audrey. As we made our way to the family room to have our first conversation Audrey paused to straighten up her blouse commenting that it was only right that she looked respectable. This remark made a marked change in her overall appearance noticeable. Also, during our last conversation I noted that Audrey's speech was not as strong, her voice was much softer spoken. Audrey was also moved over to the dining room side which was allocated to residents in need of more care.

There were many instances during our conversations which Audrey demonstrated awareness of being in a social world and at times being objectively evaluated. In retrospect, I wonder whether Audrey's bout of distress where she described herself as being "stupid" was a response to her awareness of her deterioration. Audrey's designation of the negative attribute "stupid" is evidence of personhood in that she exhibits the ability to express feelings of how she viewed herself in response to how she perceived others evaluated her. Our conversations offered an opportunity for Audrey to speak and be heard. She simply required the time to work through her thoughts and to have active listeners with lots of patience to be there for her.

Data Collection with Brenda

As previously stated, a diagnosis of mid-stage Alzheimer's disease was a contributing factor to Brenda's admission into LTC in 2007. I collected four conversations with Brenda, each varying in length. The shortest conversation lasted eighteen minutes whereas the longest lasted forty-one minutes for a total of 109 minutes of interview time. Brenda was 96 years of age at the completion of the interviews. There was only one occasion when I went to converse with Brenda that I could not locate her anywhere on the ward. Staff indicated that she may have gone out to have her hair done. One other time she was in the dining room and I wheeled her back into the room where we then had a conversation. On most occasions, Brenda was very receptive to participating in conversations, however she actively engaged with mixed emotions. During the conversations Brenda appeared to have little trouble articulating her thoughts and finding words. Brenda adjusted the position of her chair to face me and actively engage in conversation. However, from time to time she adopted a melancholy demeanour, turning her head away to stare out the window, as she expressed a longing to return to her home or appeared disinterested in the conversation at hand.

Brenda's Themes

One main theme consistently emerged from the conversations with Brenda which reflect her thoughts about her life in LTC: there's no place like home. Brenda mentioned many incidents which indicated the extent of difficulty that she was having with adjusting to the transition of moving from a much loved home to living in a LTC facility. During one conversation Brenda wistfully stated, "life just seems to change," as she attempted to make sense of the changes which have occurred during her life span. Conversations with Brenda provided insight into her struggle with wanting things to remain as they have always been.

Theme: "There's no place like home"

Brenda articulated her desire to return to her own home even after residing in the LTC facility for a period of almost two years. There were thirty-two recorded instances of Brenda expressing her desire to go back to her home. Our entire first conversation was focused around this desire. She told me:

> It isn't like your home. There is something about your home. I will be moving back there. What is most important to me is getting home and being at home, instead of up here. At home you'd probably be among family.

She also stated, "I think it would be a better life than up here," suggesting that her perception of quality of life in her present environment did not meet her expectations. For the most part, Brenda had no specific complaints about the facility itself, only that she was too far up (being on the 3rd floor). In every conversation Brenda made comments expressing her displeasure of the location of her room. Brenda told me: "This is the part I don't like about living here, because it is too far away from the ground. I've never been on a height like this before." The staff was referred to by Brenda as being hard workers, she did not speak of them as nurses or caregivers. “Well, people are very good. I have no complaints on it, but, they are, they seem to be you know the type that can work.”

At the end of each conversation I asked Brenda whether it would be alright to return another time. She always said yes, but always cautioned that she may not be there since she expected to be going home. Brenda told me:

> I am not staying in here very much longer. I am going to my own home. I asked my son to supply me with some things you know to put, to move. I liked my own house and I am planning on moving there at any time.

At times it was evident by the tone of Brenda’s voice that her patience was fading and annoyance was setting in. During one conversation she commented with determination in her voice, “Oh, I’d like to get home and I’m going home!” Later during this same conversation, with annoyance in her voice she stated, “I’ve been wanting to move for I don’t know how long.”

Although Brenda did not always have a good sense of the time line of past events she was able to recount some meaningful times in her life. On two separate occasions she talked about her husband and how his illness led to them moving into the home that she persistently told me she was moving back to. “Oh we used to live, my husband died, passed away here, and we moved into our own home there and that was quite a few years ago now. [sigh] And life, it just seems to change.” On another occasion she told me:

> Oh I liked Atikokan, and we lived there for quite a few years and my husband took sick and he had to see a doctor here in town every week so I decided to sell and we were lucky to get a house as fast as we did. And I still have my house, yes, and then he passed away.

Perhaps one of the more challenging life altering changes for a person is the loss of mobility. Brenda introduced this topic by describing a sore back from sitting so long in her wheelchair and how one becomes "tired of sitting like that." She told me, "I don't really like it but you learn, I have to have it, the wheelchair."

Brenda also commented, "how much can you do in a chair?" reiterating her dependence on her chair. As well, Brenda showed awareness of the consequences of her mobility limitations which prevented her from doing the two things most important to her: 1) going home; and 2) having a dog. From Brenda's perspective, it was because of her mobility restriction that she was not able to get home and was not able to have a dog. For example, during our third conversation the discussion soon centred on Brenda's desire to go home. Upon questioning her as to her ability to return to her home, Brenda responded:

> I don't know, but if I don't get home I am going to run away! Oh yeah, well my home really isn't that far away. But I could, what am I talking about, I can't walk. Yeah, I can't walk, how am I going to run away?

With this comment, Brenda demonstrated her awareness and ability to reason. During another conversation Brenda spoke of trying hard to get a dog that she wanted, and she recognized that it was not feasible to have a dog at her current place of residence. As she said, "this is no place for the dog here, so when I go home." Talking about getting a dog seemed to give Brenda something to look forward to. For Brenda the visit from the dog was the highlight of her day, definitely something to look forward to in the midst of her trying to figure out how to return to her own home.

Brenda's Expression of Personhood

Conversations with Brenda centered on her anticipation and hope of going back to her home, yet at the same time she often slipped into expressing feelings of disappointment and resignation to remaining at the LTC facility. Most significant is the continuous references she made to her displeasure with her room location. She was able to accurately place herself in a location and articulate strong feelings on this issue, something she could not do if she had not been aware of her surroundings.

A life review technique can be used with elderly people to promote a sense that one is managing well despite their circumstances, but this is a rarely used coping technique within LTC settings with people diagnosed with dementia (Neimeyer 2000; Goldsmith 2002; Williams and Keady 2006; Egan et al. 2007). However, this technique was used serendipitously with Brenda during our conversations. Brenda was able to use our conversations to reflect on meaningful times in her life in turn affecting her mood in a positive manner. Brenda eloquently contrasted what her life used to be like in comparison to her present circumstances, conveying the meaning that life in LTC held for her. However, the conversations provided a fascinating glimpse into Brenda's life. Brenda demonstrated ownership of her feelings and desires both through verbal expressions and through gestures. Throughout the conversations Brenda often had a brilliant smile with light refreshing laughter. Her eyes lit up whenever the conversation turned towards dogs, birds and other animals. On the other hand, Brenda exhibited moments of melancholy as she pensively looked out the window. For the most part, Brenda preferred spending most of her time in her room, with the exception of taking part in group meals. She spoke of the value of having time alone once a person reaches her age, "I stay in my room most of the time, the older they are, the quieter they would like to be."

Data Collection with Catherine

As previously stated, a diagnosis of early stage vascular dementia was a contributing factor to Catherine's admission into LTC in 2007. Without being able to articulate what event had led her to reside in this LTC facility, Catherine was aware of having lived there for approximately three years. An award for Senior's Month 2008, designating Catherine as the recipient, was posted on her bedroom wall. This was awarded to her for being an inspiration to others. Catherine could not articulate why she was the recipient. I conducted two conversations with Catherine, each lasting for sixteen minutes in length for a total of thirty-two minutes of interview time. Each conversation was conducted in the family room with the door closed for privacy. On both occasions Catherine presented a very positive attitude despite the instances of her need to search for words. She communicated in a playful manner, often laughing and making light of her limitations. She often commented on having difficulty thinking about what she should say next. When I noticed that Catherine appeared to be tired of communicating, perhaps due to the difficulty in expressing her thoughts, I escorted her back into the common room. She appeared to be quite comfortable in the common room, content to sit and watch game shows on TV.

Catherine's Themes

On both conversational occasions, Catherine acknowledged the merit of having residents participate in research which focused on them. She further explained, "I think that it could help, maybe come along with something." When asked to expand on how things could change to make things better for residents she told me, "Not that I can find so far. Not really, not right now because I can't say whether it's too much going on or not enough." Catherine presented herself as a very content woman who was comfortable in her surroundings.

Two themes emerged from the conversations with Catherine: 1) "I am trying to think" and 2); "I am quite content to be there." The first theme, "I am trying to think" demonstrates her awareness that something was not quite right with her cognitive abilities. For example she often stated, “It’s not working up there.” The second theme, “I am quite content to be there.” speaks to the comfort level that Catherine had in living in LTC.

Theme 1: “I am trying to think”

Despite Catherine’s continuous efforts at “trying to think,” she always displayed a positive attitude. Catherine indicated a willingness to converse with me, however, her facial expressions provided evidence of her tiring from the exertion of trying to remember. At one point the conversation led to me inquiring about her past work experience, but she had difficulty responding. She told me: “I, wait a minute, I am trying to think, what did I do? It is really when you think of it, hmm, all of a sudden I go blank.”

At this point I asked how she felt when her mind goes blank. In keeping with her overall positive attitude and resiliency she responded: “Not too bad I guess, I just keep on it, and get better. Yeah, that’s the best way to do it anyway.” I was once again aware of the extent to which Catherine put forth an optimistic attitude and communicated to her that I thought she had a good attitude. Catherine replied, “I have a pretty good attitude [chuckles].” Winding up a conversation, I asked Catherine if there was anything else she would like to tell me at this time.

> I can’t think of it at the moment. I am trying to think, I should be able to say something but I can’t. No, not at the moment, at the time because it is not working very good up here [points to her head].

Theme 2: “I am quite content to be there”

Catherine commented that the LTC facility was a good place to live and furthermore, that she was happy living there. She told me, “I am quite content to be there. I enjoy it anyways. Why

I am, I don't know [chuckles]." Catherine expressed that overall, her social interactions with other residents were good. This could be a factor in creating her feelings of contentment. Catherine was not bothered by the residents whom she felt were a bit troublesome to get along with. She felt that it was normal to get along better with some over others, and something that happens everywhere. During one conversation Catherine spoke about her interaction with residents:

> Oh yeah, I don't have no problems with them. Well, we get along okay, the people I know there. Well, some of them can be a little bit not too good to get along with but that's okay too.

It becomes questionable whether Catherine's contentment is at times blended with feelings of resignation. Catherine alluded to there being little opportunity to engage in activities and by default often settled down to watch television. I inquired as to whether she watched a lot of television and Catherine responded, "Yeah, I do that quite often, what else is there to look?" When I asked Catherine to describe the kinds of things she had been doing that day she replied, "Not a heck of a lot really, quiet today." Knowing that the facility offers recreational activities, I then asked Catherine if she could tell me about them. She responded:

> Ah, yeah quite a few things happen alright, but ah sometimes it's not that, how would you say, not that well, it's going on to a month already waiting for it to happen.

I then asked whether she often had to wait for things to happen. She answered in a matter of fact tone that sometimes you do have to wait for things happen. She then provided an example of an activity she would like to pursue. She told me:

> I was hoping to do something. Well, I never was good at sewing or doing your, how would you say, not sewing, just something, for myself, get myself something to use.

Once again Catherine appeared to be tiring of conversing so I escorted her back to the common room. I wheeled Catherine's wheelchair to the spot that she wanted to be. I thanked her for having this conversation with me and we exchanged goodbyes.

Catherine's Expression of Personhood

Conversations with Catherine provided a glimpse into the resiliency that is possible to shine through in the midst of the challenges one faces within the scope of the disease process. Catherine was able to articulate how she felt about social interactions with other people living in the facility. She was able to make a connection and view the nature of relationships in a group situation as being similar in other group environments, commenting that some people are easier to get along with than others. She was cognizant of human nature's way of not always necessarily getting along the same with everybody but to still make the best of the situation. Even though Catherine exhibited a positive attitude throughout the conversations, she also made references to the lack of having something other than television to occupy her time. Conversations with Catherine illustrated a woman who was accepting of the circumstances in her life while still able to voice her dislikes in a respectful manner. The most significant evidence of personhood demonstrated by Catherine was her willingness to be a participant in this research.

Data Collection with Deirdre

As previously stated, a diagnosis of mid-late stage Alzheimer's disease was a contributing factor to Deirdre's admission into LTC in 2004. Deirdre was 96 years of age at completion of the interviews. I collected three conversations with Deirdre. The shortest conversation lasted for three minutes whereas the longest conversation lasted twenty-one minutes, for a total of twenty-seven minutes of interview time. However, conversations with Deirdre did not go as smoothly as planned. In part this was due to the level of pain that Deirdre appeared to be experiencing. On a subsequent visit there was something unsettling about her overall demeanor. Deirdre appeared agitated and had a haunted look in her eyes. Her clothes were a bit disheveled and she had a look of concern on her face and rubbed her hands together in a nervous fashion. When conversing with Deirdre her eyes tended to drift in many directions. Direct eye contact only occurred when I presented a question to her. Conversations with Deirdre required that I pay close attention to what she was saying. Her speech was soft and low in tone. My observations led me to believe that Deirdre often experienced feelings of distress. She often exhibited anxious behaviours, both in body language and in her tone of voice.

Deirdre's Themes

During one of our conversations I soon became aware, from watching her facial expressions, that Deirdre was experiencing a high level of pain. Prior to the termination of the conversation she made a noteworthy statement. The common room, where Deirdre was sitting, is located directly beside the dining area in an open concept style. During one of our conversations, staff was tidying up after a meal and in turn creating some loud noise. After hearing a particularly loud noise Deirdre told me: "Oh there we go, that always happens." This statement is indicative of how different noise levels are bothersome to Deirdre. It immediately came to mind that the noise level could possibly be reaching her threshold for the acceptance of noise in relation to the level of pain she was experiencing. At this point I ended the conversation, communicating to Deirdre that I would find a nurse who could address her pain concerns.

My analysis of our conversations yielded two themes for Deirdre: 1) pussy willow courses and 2); all day waiting. Deirdre established the first theme during one of our conversations which was entirely centred on a pussy willow course. The second theme was created during our last conversation where it became clear that Deirdre was anxiously waiting for someone to arrive.

Theme 1: "Pussy willow course"

Once I introduced myself as a university student, our conversation was centred on taking courses. From this point forward Deirdre spoke of her experience with pussy willow courses. I soon noticed Deirdre was a bit agitated. She did not appear to be in physical pain, as she had appeared to have been during our previous conversation, but seemed to be experiencing emotional distress. I asked her if something was bothering her and she replied, "I don't know, I don't know but it's not the university at all, I don't go there." I then asked how she was feeling today and she replied that she was "just terrible." She situated her distress in the past in that she indicated that she was worried about her kids waiting for her to play with them. Then she continued to tell me that she wasn't sure what she had done in university. Although the conversation continued on the topic of pussy willow courses, Deirdre never indicated whether the course she was speaking of throughout the conversation was offered by a university.

The remainder of our conversation was centred on what Deirdre referred to as the pussy willow course. I asked Deirdre to explain what the pussy willows taught her. She told me, "well that's just it, I've just got back from them [the courses] and the pussy willows [points to wall], there's a pussy willow and there's a pussy willow. With this comment, I realized that Deirdre was seeing something that I could not see, pussy willows on the wall. She went on to say:

> There's a man that gave me a course to take, take the course and take the pussy willow course. Well, I haven't seen him since. I don't know what he's doing.

Within the next portion of conversation, Deirdre raised the issue of having support when taking courses. She went on to talk about taking the course with a friend who was nervous about taking it by herself. She told me, “I guess she is scared to take the course cause till she gets in with somebody that she knows.”

I realized that Deirdre was tiring and probably would not be able to provide me with a concrete explanation of what her pussy willow course was about. Towards the end of the conversation Deirdre once again pointed to the wall showing me where the pussy willows were located. She went on to tell me about a man who was telling her that the pussy course was not real. She then told me that she argued that the course was real and that she wanted to take it. She told me, “I said, ‘well big deal.’ I said, ‘I want to take it.’ I said that’s what’s on the wall” [she was looking towards the wall and showing me that there were pussy willows there]. Deirdre appeared to be associating her vision of pussy willows on the wall with part of the pussy willow course. I did not try to dissuade Deirdre that there was no such thing as a pussy willow course nor did I let on that I could not see any pussy willows on the wall.

Theme 2: ‘All day waiting’

The final conversation with Deirdre was held in the common room where I found her alone at the dining room table. She appeared anxious and her clothing was somewhat dishevelled. I noticed what could be described as a haunting look in her eyes. Once again she was envisioning things that I could not see. For example she thought the salt shaker was a teapot. I began the conversation by inquiring about her well-being. She spoke of a man for whom she was waiting. She told me, “I have been here all day waiting for him to come and take me to his place." She could not tell who the man was. I continued to notice that Deirdre was somewhat anxious and again asked about her well-being. She replied,

> I feel alright, but I'd feel much better if he'd let me go, but where would I go? Oh I feel if they came with me and they are feeling like this too and she says it's crazy that you don't come, pity myself.

Deirdre then talked about being "awfully lonesome" and stated she wanted her daughter to come visit. She said, "I hope because I am awfully lonesome, but I am not lonesome because I've got them." It was not clear who 'them' are. At this point Deirdre appeared to think that her daughter was away at university taking a course. Wringing her hands, she said, "Well, I don't know what to think. My daughter is gone away, she's gone to taking some, take courses." Deirdre seemed to be quite distressed about her daughter being away. Deirdre was confused about the present reason for her daughter's absence. No matter the reason for her daughter's absence, Deirdre was obviously distressed.

Deirdre's Expression of Personhood

The first conversation with Deirdre began in the common room where I found her to be sad. She told me that she was disappointed because, "I don't get to do the things that I like to do, just what they want me to do." Although Deirdre did not clarify what or to whom she was referring, her comment demonstrates that Deirdre still had ownership of her feelings and that no matter to what extent her desires were realistic, they were nevertheless real to her. This interaction also raised the question, to what extent does a resident have a say in choosing how they want to spend their day? For example, if Deirdre was feeling a lot of pain, did she have the power to choose to go back to her room and lay in her bed which has a therapeutic mattress? Leaving the common room, I noticed that Deirdre was unable to return to her room unattended.

There was some degree of ambiguity in the conversations with Deirdre. However, I was able to establish subtle understandings in her cryptic way of speaking. Conversations with Deirdre stressed the need for patience and willingness to be there as a witness to her words. Even if things were not always clear to me, I observed a degree of awareness on the part of Deirdre that I was there to hear her. She rightfully dominated the conversation, occasionally looking up at me, and continued talking as I was trying to leave the room.

Conclusion

Conversations with Audrey yielded the greatest variety of themes, while conversations with Brenda, Catherine, and Deirdre yielded only one or two themes each. Nine themes were developed and grounded in each woman's own words. Problems with memory recall were captured in two themes, "My brain is not working" and "I am trying to think." At first glance themes such as "I am okay," "I always want a fair shake" and, "I am quite content to be there" suggest that overall, the participants experience a sense of well-being and respect for their personhood. However, degrees of distress were evident in all conversations. Themes such as "There's no place like home" and "All day waiting" are suggestive of possible problems within the contours of personhood. Such comments may be indicative of feelings of loneliness, despair, or frustration, all which can lead to depressive states or aggressive behaviors. "This is where we learn" demonstrates creativity in trying to make sense of a significant change in one's life. Both Audrey's use of an educational framework in her conversations and Deirdre's discussion of the "Pussy Willow Course" theme requires one to step outside of the box and consider possible unconventional explanations. As previously mentioned, the women did not remember previous conversations per se. However with the exception of Deirdre, the women were consistent in what they had to say during each interview. The women uniquely provided me with a glimpse into their lives as people, each sharing their likes and dislikes in their present environment. Each woman was clearly able to interact with me and share what was important to them. The following chapter will relate my research findings to the existing literature which discusses personhood in dementia care.

Chapter Four: Discussion

> My every molecule seems to scream out that I do, indeed,
> exist, and that existence must be valued by someone!
> (Diana Friel McGowin 1993: 114)

My study used a conversational method of data collection to provide evidence that personhood is present in people diagnosed with dementia in LTC. Conversations are a tool to reveal what aspects a person with dementia considers to be of value (Steeman et. al. 2007). Four women were given an opportunity to lead conversations centred on the topic of their choice. This process allowed me to listen to the voices of the residents and at the same time observe the ways in which they expressed their personhood. To reiterate, personhood is framed around the contours of physical, psychological, spiritual, and social aspects of self which are dependent on the social relations with others. This chapter compares and contrasts findings from the conversations in my own research with existing literature. Without a doubt, by moving away from a biomedical perspective of dementia, my study found that personhood is evident in people who have been diagnosed with a dementia and are residing in LTC. Although each woman was at a different stage regarding the categorization of their diagnosed dementia, they were all able to provide insights into their worlds.

Addressing the physical domain of personhood, conversations with Audrey and Catherine frequently brought to my attention the reality of experiencing cognitive difficulties as a result of dementia. The extent to which the women were aware of the changes occurring in their brain was demonstrated by the frequency with which they voiced such comments as "my brain is not working" and "I am trying to think." In order to normalize their memory loss as something which is common to all and not an inevitable consequence of dementia (Langdon et al. 2007; Steeman et al. 2007), it was not unusual for one of the women to ask me if I also had trouble finding my words. Also, similar to participants in other studies, Audrey offered an explanation for her cognitive difficulties by telling me that her brain was not working (Clare et al. 2008a).

On the other hand, there comes a time when individuals with dementia truly believe that the information that he/she has at the moment is valid and will likely react negatively to opposing perspectives (Hart, 2003). As previously suggested, it may be more prudent to find a creative way to maintain the conversation. An alternative suggestion reported in the literature to help understand what a person with dementia is trying to communicate is as follows, "it may help if we realise that these stories are very much like dreams, which seem to be a mixture of fact and fantasy; yet seem real enough when we are having them" (Goldsmith 2002: 60). For example, this theory would understand Deirdre as being both a storyteller and central character of a dream who is relaying the concepts of her dream, which had significant meaning to her. Through necessary embellishment which is required to make a good story, Deirdre presented her story of her experience with a pussy willow course (Goldsmith 2002). This story may have served as a way for her to work through her anxieties or may simply have been a story with a specific message to relay. Alternatively, her story offered an opportunity for her to capture an audience willing to spend the time to sit and listen.

Another aspect of the physical domain of personhood was addressed when affirming her identity, Brenda often good-naturedly stated that she had nothing to complain about, yet at the same time she was aware at a practical level of the need for her to reside in LTC. As much as she articulated the desire to return to her own home, she was aware of physical restrictions standing in her way. Brenda demonstrated awareness in relation to her body, reflecting on her capabilities via her discussions of mobility. Brenda went back and forth between her desire to going home and realizing the necessity for her to reside in LTC. Brenda had an understanding that she could not go home due to her mobility concerns, yet did not give up on the idea of going home one day, in the near future. Futuristic goals delineating something for Brenda to look forward to, such as returning to her home, whether or not going home was realistic, created a coping strategy to sustain her optimism (Clare et al. 2008).

Personal wellbeing and resiliency are significant factors in addressing the psychological domain of personhood. Research has established that "indicators of relative well-being are part of our shared experience, they have face validity; that they are, or can be present in severely demented persons is an empirical observation" (Kitwood and Bredin 1992: 282). The women who participated in this study exhibited a wide continuum of emotions throughout the conversations. For the most part the women presented positive attitudes, showing the resiliency they all had in the face of their personal challenges. Exhibiting personal attributes of determination and resiliency, the women in this study (except Deirdre) always stated that they were okay even after speaking of something that had been bothering them. "The concept of resiliency conveys the idea that individuals can overcome negative outcomes despite the presence of significant risk factors" (Nakashima and Canda 2005: 121). For example, Audrey's cognitive difficulties could be designated as being her significant risk factor, whereas her determination to keep on trying was her way of overcoming negative outcomes.

Audrey generally seemed to have a positive attitude towards the challenges of her cognitive difficulties, however, on one occasion she seemed very distressed. Negative responses have been associated with feelings of being worthless, a lack of being valued, loneliness or shame, overall being in a relative state of ill-being (Kitwood and Bredin 1992; Steeman et. al 2007). Nevertheless, Audrey's ability to express an array of emotions shows that she was faring well and exhibiting behaviours much like anybody else would. This sort of observable behaviour is indicative of her relative well-being (Kitwood and Bredin 1992; Goldsmith 2002). Similar to participants in a study by Steeman et al. (2007), Audrey did not present the whole conversation in a negative fashion. The interactive process of the conversation provided Audrey with an opportunity to alter her mood from one of despair and self-loathing to a more positive state of well-being.

Similar to a participant in Clare et al.'s (2008a) study, Audrey expressed her awareness of her emotions by stating that she also had a feeling that she was okay. Audrey's descriptive account of her feelings is reflective of her intact ability to derive a subjective point of view of her overall well-being, an important attribute of the psychological domain of personhood. Also, Audrey's stated desire for a fair shake along with her stated subjective feelings of receiving a fair shake, being treated with respect and dignity, further positively influenced her overall well-being.

Catherine's second theme, *I am quite content to be there,* suggests that she had to some extent adjusted well to her LTC environment and was able to feel content within the context of her new environment. Catherine's self rated contentedness can plausibly be understood in terms of her psychological makeup so that she may be like those studied by Kitwood, who entered the dementia experience with "intense and poignant awareness of what is happening to them, and who remain highly open to their experience, without evasion or blame" (Kitwood 1997: 72). Supported in the literature, there is no absolute correlation between physical or cognitive impairments and a decrease in quality of life impacting domains of personhood (Moyle et al. 2007). Research findings also show that quality of life is given higher positive ratings by people diagnosed with a dementia than by their caregivers, and that impairments associated with dementia do not necessarily result in a decrease in quality of life (Train et al. 2004; Gerritsen et al. 2007; Moyle 2007; Steeman et al. 2007). These findings challenge assumptions that the experience of dementia can only be constructed as negative. A decade ago, Woods (1999) cautioned that we not "lose sight of the opportunities for the human spirit to emerge in the midst of undeniably difficult circumstances" (p. 38).

Although it is desirable to achieve a sense of personal well being, caution is necessary so that one does not dismiss the reality of occurrences of ill-being such as distress. For example, the instance where Audrey exhibited a high degree of distress could be understood in terms of her feeling distressed over what was happening to her, and her lack of ability to control what was happening. In terms of expressing personhood, Audrey creatively, actively worked to create a scenario (studying things) to make sense of what was going on. Furthermore, in the limited time I was able to spend with Deirdre I was able to observe a resident who did not present herself in a way indicative of overall well-being. However, this is not to say that she was devoid of personhood, but suggests that not all domains of Deirdre's personhood were being adequately addressed. In particular, Deirdre's psychological domain seemed to be most adversely affected. Deirdre was often found to be alone and in some sort of emotional distress upon arriving for each conversation. I wondered how often Deirdre and others in similar states were left alone to repeatedly rehash in their minds whatever was bothering them. I did not notice anybody else approach Deirdre for the duration of our conversation. It did not seem right to me that Deirdre was often alone, feeding off of her anxious thoughts. Emotional pain can be associated with "cognitive changes in perception and information processing" (Rewston & Moniz-Cook (2008: 252). Conversations with Deirdre did not provide enough evidence to be certain whether she was experiencing emotional pain or if her anxious behaviour was a result of her personality and coping style. No matter the cause of her distress, the question is raised: to what extent did Deirdre experience loneliness and furthermore, how was this addressed within her care plan?

It was noted in the literature review that for some people residing in LTC, conversations with staff were limited to receiving service and care, contradicting the assumption that they consider LTC facilities to be their home (Clare et al. 2008). For example, rather than referring to staff in familial-like terms, Brenda spoke of staff in terms of being hard workers. This is simply another indication that Brenda did not consider herself to be in a home environment. Similar to the participants in a recent study, Brenda spoke of her living in LTC as doing the best in a situation in which she had little control and "suffering the resulting thoughts and emotions" (Clare et al. 2008: 716). The implication of suffering through thoughts, as noted with the scenario with Deirdre, is that there is an adverse influence on one's psychological domain of personhood. As mentioned earlier, it is common that newly admitted people to LTC will experience a degree of stress as a result of being dislocated. It is also theorized that the distress will decrease over a twelve week period of time (Stones 2006). However, Brenda has resided in LTC for approximately two years with no apparent indication of resigning herself to the fact she will be residing in LTC for the remainder of her life. One only needs to reflect on their own emotive responses to significant life events to begin to understand the effect of a major move for an elderly individual. "The transition from home to a residential care setting will take people away from their normal routine and opportunities for engaging in behaviours that have meaning" (Moyle et al. 2007; 185).

Spirituality, the most often neglected domain of personhood, offers a person the opportunity to have meaning and purpose in his/her life. Spirituality can provide a coping method for the person diagnosed with dementia, a way to feel connected, and develop an overall feeling of peace and emotional well-being. All in all, "patients want and need more than technical aspects of medical care; they need love and concern, and this is what spiritual care is grounded on." (Puchalski, 2007: 38). The women in this study did not explicitly discuss spirituality, rather their references were subtle and made in the context of meaning, purpose and direction in life. Conversations with Brenda which were essentially conveyed in the manner of telling stories of her life serendipitously had the effect of providing her with a coping mechanism, the life review. Her behavioural responses (light laughter, shine in her eyes, and a smile on her face) were similar to those of participants in a recent study which found that the act of reviewing one's life can amount to finding meaning in one's life while also sharing with others who you are as a person (Clare et al. 2008; Lawrence 2007). "It is these meaningful exchanges that bring hope and purpose amid the devastation of dementia" (Stuckey and Gwyther, 2003: 295).

Regarding the social aspects of personhood, Catherine recognized the merit of providing input to those who are researching dementia (McGowin 1993; Gwyther 1997; Goldsmith 2002; Phinney et al. 2007). Katsuno (2005) suggests that much of the public opinion is negative which unfortunately shapes public consciousness of the disease and further contributes to the negative stereotypes and stigmatizing of individuals with dementia. Conversations with Catherine are indicative that people with dementia are in fact able to and want to be productive members of society. Participating in research is a means for people with a diagnosed dementia to be useful member of society. Alternatively, for some participants inclusion in research can be an altruistic means of helping others who will be diagnosed with a dementia (Langdon et al. 2007).

The social domain of personhood is evident for all the women in this study. All the women willingly participated in interactions with me and made references to their social worlds.

It must be emphasized that the women in this study provided strong evidence that they ought to be treated with respect. For example, Audrey's display of self-awareness in her discussion of "being stupid" could only take place because she was aware of being in a social world. In other words, one cannot assign attributes to oneself without recognition of acting in a social context. Furthermore, in keeping with Sabat's (2002) theory of self, an intact self was clearly evident in all the women given their constant usage of the indexical 'I' in their conversations. Each woman in this study acted in unique ways in order to ensure the perseveration of self.

Preservation of self via engaging in activities was both commented on and acted upon by the women in this study. Audrey was actively engaged in the preservation of self by incorporating her past working experience as she framed her experience in LTC in an educational setting (Bassett and Graham 2007; O'Conner et al. 2007; Phinney 2007). Catherine identified the desire to engage in an activity which would be useful to her, something for her to use, such as something she could sew. Participants from a recent study also spoke of engaging in leisure and recreational activities which were important to them, bringing enjoyment and pleasure (Phinney et al. 2007). The lack of activities which sometimes leave the women with nothing more to do than watch television is indicative of living in a "total institution" environment. It should be noted that the nature of her disease process may be skewing her sense of time between activities. However, it should also be recognized that residents need to fill the time in-between activities in a more stimulating manner.

Although it was not clear to whom Brenda had previously been talking, she told me, "they asked questions and I answered them." Her voice gained strength as she further stated in no uncertain terms, "I answered them my way." In the next breath she told me, "at my age, well now, you know, when we answer them it doesn't make much difference." Interestingly, on the one hand Brenda exhibits the ability to assert herself, letting it be known that what she has to say is of importance, whereas her next statement asserts that older people's answers are irrelevant simply due to their age. This scenario speaks to the issue of whether people residing in LTC feel a sense of being valued or are they readily being dismissed as being nonsensical? Rather than the conversations being nonsensical, Bond and Conner (2001:104) suggest, "they create their own reality and language to describe the presentation of self by the person with dementia." Conversations with these four women provide a very unique experience to my data collection. Goldsmith (2002) beautifully describes the motivation I had to continue the conversations with the women even though they were sometimes challenging:

> It is not acceptable at an early stage, nor even at a later stage for that matter, to write off a person's ability to communicate just because we find it difficult to comprehend what they are trying to convey to us. If there is a problem in understanding then the responsibility lies with us to ensure that we are doing everything possible to facilitate communication (p.52).

Goffman's (1961) concept of a *total institution*, whereby residents become casualties of the institutional regime, can be used to explain many of the observed behaviours in a LTC setting. During our first conversation Deirdre indicated that she had few opportunities to make independent choices throughout her day. Deirdre often appeared anxious, and this anxiety seemed to be exacerbated by finding herself spending *all day waiting* for things such as going to her room, waiting for visitors, waiting to go somewhere, or receiving pain medication. It is the nature of an institutional setting to have rigid standards and set agendas such that the people who are living there have a limited ability to do as they wish. Rather, they are expected to conform to the rules and regulations. In essence, "institutions offer distinct senses of who and what we are, what we were, and can be" (Holstein and Gubrium 2000: 13). It is not surprising, therefore, that LTC residents such as Deirdre would express negative feelings such as anxiousness.

Moreover, there is a self-fulfilling prophecy at work in such situations (Watzlawick, 1984), as the daily lives of residents are assessed by LTC staff on the basis of their observed limitations and weaknesses. Watzlawick (1984) further suggests that assessments are used in future decisions and actions (care plans) which reproduce conditions for the expected event. For example, if it was noted during the assessment of memory that the person has increased difficulties, extenuating circumstances (i.e. time of day or preceding interactions which may affected his/her mood) are generally of no consequence. This person will then have fewer expectations placed on him/her, leading into the self-fulfilling prophecy that dementia is simply a disease comprised of expected deterioration. Consequently, it is easy for staff to avoid engaging in time consuming interactions which can enhance feelings of value for residents, once a person is designated as an object to be managed by physical care.

Unfortunately, negative aspects of institutional care have long been recognized and are not considered to be of any consequence due to frequent assumptions that people with dementia lack awareness of their situation (Clare et al. 2008). However, the people in Clare et al.'s study (2008), who had a diagnosis of dementia, illustrated that they continue to have awareness of their situation. It is not necessary to assume people diagnosed with dementia are incapable of exhibiting personhood, as they are capable of engaging in social interactions and expressing their needs. What is needed is to have the time, patience and creativity to interpret the needs of people living in LTC with a diagnosed dementia. However, the reality is that a LTC institution is by nature a business which employs workers who are often torn between meeting the demands and expectations of the employer, and treating the people they are responsible to care for with compassion (McLean 2007).

Conversations with my participants raised the question: To what extent does a person living in LTC have a choice regarding how they want to spend their day? For example, if Deirdre was feeling a lot of pain, did she have the power to choose to go back to her room and lay in her bed? Leaving the common room, I noticed that Deirdre was unable to return to her room unattended. Therefore, I would guess that she could only go back to her room to lie down if she was able to catch the attention of a sympathetic staff person (personal support worker or nurse). A safe assumption could be made that this would be extremely difficult to do given that the duties of staff are not organized to ensure that they pay close attention to what residents want at any particular point. Given staffing shortages, staff do not have time to listen to what residents have to say or provide them with much needed stimulus. Another question is raised as to what types of activities are offered in the facility and to what extent are the preferences of the person living in LTC considered? For example, if one of the women wanted to sew and had mentioned this to staff, do the personal wishes of residents count for much and are they seriously considered? It is understood that sewing can be a complicated activity, however, with a bit of creativity and patience, activities can be adapted to fit the abilities of the people living in LTC.

Conclusion

Conversations with the women in this study offer a view of real problems that they face in their journey of living in LTC with a diagnosed dementia. There are noteworthy findings in my study which are congruent with current research. There is a growing consensus that there is a need to move beyond applying only a biomedical perspective in dementia care and research. My study supports other findings which suggest domains of personhood need to be addressed which go far beyond the physical/medical needs of a person. The preliminary understandings from my study have identified sufficient cause for further investigation which seeks the perspective of any person diagnosed with a dementia. The concluding chapter discusses direction for future research.

Chapter Five: Conclusion

> If we fail to believe that the person with dementia is still a person in their own right, then we may easily fall into the habit of treating them as less than a person.
> (Goldsmith 2002: 66)

Adopting only a scientific understanding of dementia loses the humanity of the person who is diagnosed with a dementia, missing the complexity and diversity of individual social experiences. My thesis demonstrates the importance of finding ways in which to support the continuation of personhood in persons living in LTC diagnosed with a dementia. The importance of being attentive to all the domains of personhood cannot be stressed enough. In particular, care planning needs to go beyond physical care and be more inclusive of the social and spiritual domains of personhood. It is necessary to adopt best practices which allow others the time and energy to be directed into truly listening and making honest efforts to interpret what the person with cognitive impairment is saying and/or needing. Care providers need to be allotted flexibility in their duties to allow time for meaningful conversations to occur with the people diagnosed with a dementia.

The attitudes that promote and fuel the social construction of dementia as a problem need to be challenged and there needs to be a new way of understanding which embraces the uniqueness of the person with dementia. Effort should be made to place the person before the disease. In our busy lives we often forget that it is the simple things that can bring us happiness and create psychological well being. "A simple touch of the hand, a hug, and pat on the back, shoulders, or knee can bring a smile or alertness in the eye of a previously expressionless and sad face" (Hendry and Douglas 2003: 101). It is not unusual to find people residing in LTC who are left in hallways or in common rooms, in their wheelchairs with the wheels locked, restricting movement. At the least, it would be wonderful if the people who passed by them would acknowledge their existence. Imagine what a difference it would make in their day! It is imperative that health-care professionals, formal caregivers, and researchers all work as an interdisciplinary team with individuals who have dementia to improve their quality of life while respecting the person despite the diagnosis of dementia. At a practical level inclusion of people with a diagnosed dementia in research serves as a tool for consideration of humanized care planning (Cohen-Mansfield et al. 2006).

This study also had a significant finding of the importance of making available activities which do not necessarily require the participant to use higher cognitive functions or participate in oral communications. Similarly, a participant in Phinney et al's (2007) study identified a need for activities which did not place too high of a demand on her which she could do alone and not feel embarrassed if things did not go smoothly. Catherine's cognitive difficulties, in particular her constant need to try to remember, could be successfully addressed with types of activities being incorporated into life enrichment programs attuned to the needs of the people living there. Resident biography charts (missing from one of the women's room at the time of this study) would also be a helpful aide in identifying activities to match both former and new found interests (Kitwood 1997; Surr 2006; Egan et al. 2007; Lawrence 2007).

Although this study was comprised of a small sample size, the findings are useful in terms of contributing to theoretical models of dementia care. There is sufficient cause for further research which focuses on personhood by listening to the voices of people diagnosed with dementia. The ways in which the women demonstrated the contours of personhood (psychological, physical, social and spiritual) include, among other things: awareness of and expression of pain; insight into their own physical and cognitive changes; ability to reason and plan; awareness of their surroundings; ability to express and discuss of feelings and emotions; the ability to communicate; and the need to find meaning and purpose in life – look to the future. This study used direct subjective accounts from women living with moderate to late stage dementia to demonstrate that personhood is indeed present despite a diagnosis. It is hoped that the findings from this study will encourage other researchers to include the voices of the people diagnosed with a dementia when conducting research about dementia. By only relying on medically focused research and medical definitions of dementia there is the risk of people who are now, more than ever, in need of empathetic support from society.

Additional qualitative research can build evidence to inform potential changes in how care is provided to people diagnosed with a dementia who are living in long-term care. There is nothing to lose with these efforts and everything to gain – a more complex understanding of dementia care. At the least, some of the negative understandings of dementia may be swayed towards a more positive understanding when plans of care are more supportive of individual personhood; care that facilitates transformation and development throughout the various stages of dementia.

Findings from this study are not exhaustive, rather they offer an alternative understanding of important issues related to dementia. This study is useful in providing food for thought in how we think about dementia as a disease. This thesis speaks to the importance of recognizing the role of a social model of care for people who are residing in LTC with a diagnosed dementia. The perspectives offered in this thesis are not meant to only serve academic interests; they could serve to benefit many others with dementia if we take notice and act on them and consider the practical importance of respecting all domains of personhood when providing care. Without a doubt, dementia is a very personal experience which no two people experience in exactly the same way. Years of living shape the unique experiences of each person, differentiating one person from the other. We must continue to find ways to better understand the inner world of the person diagnosed with a dementia. Are we listening to the voices which matter most?

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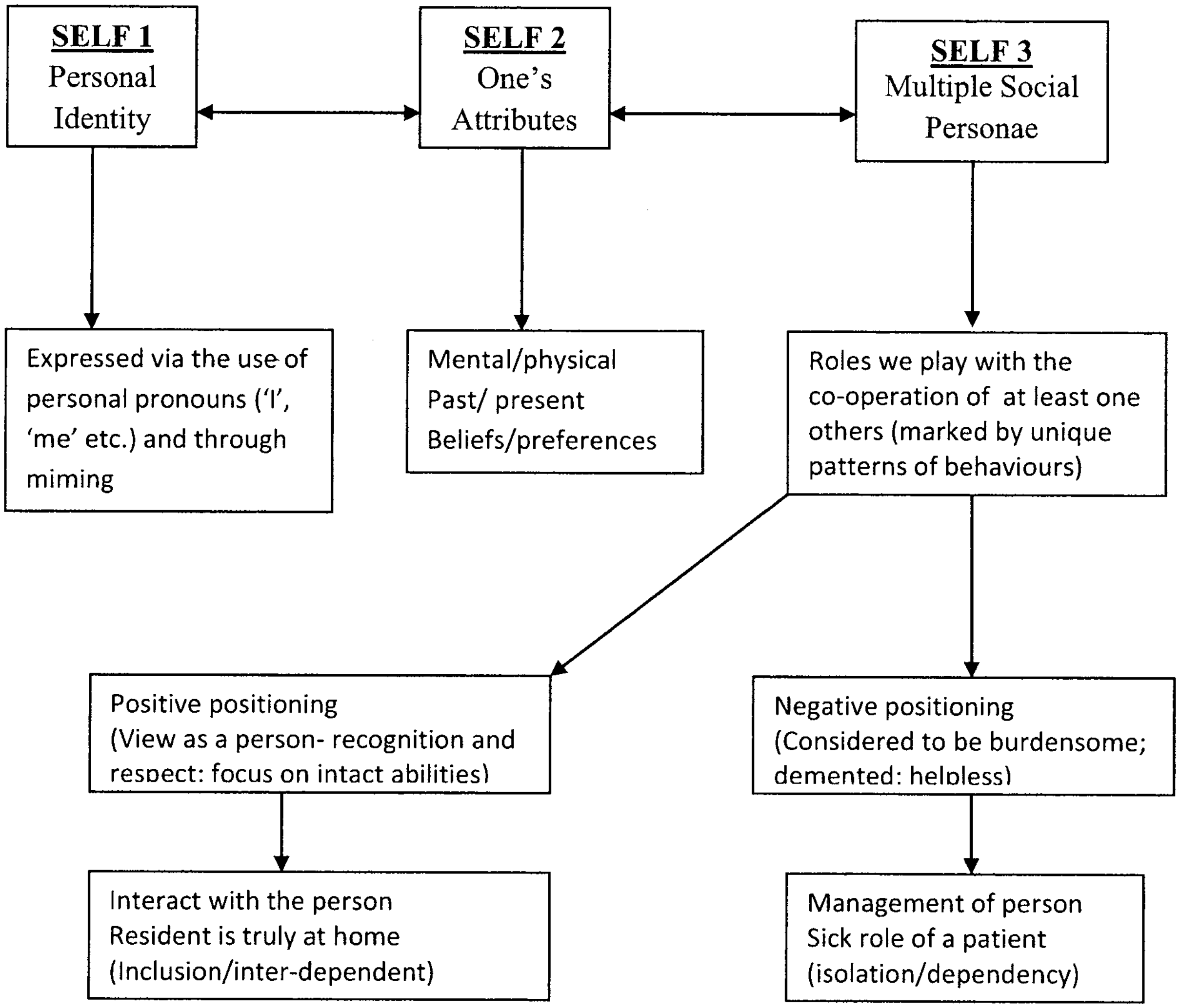
Appendices

Appendix A

Illustration of the 3 Aspects of Self Presented by Stephen Sabat



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Appendix B

Information Letter for Power of Attorney

Dear Family Member and/or Power of Attorney:

As Power of Attorney of your relative [name of relative] living at Bethammi Nursing Home, we are writing to ask for your consent for your relative to participate in a study that we are doing concerning palliative and end of life care for people with dementia. This research is being conducted by Dr. Mary Lou Kelley, Lakehead University, Dr. Jean Kozak, University of British Columbia, Dr. Michael MacLean, University of Regina, Dr. Joanie Sims-Gould, University of British Columbia, Dr. Elaine Wiersma, Lakehead University, Sonja Habjan, Lakehead University, and Lise Arseneau, Lakehead University.

We are doing this research to better understand the experience of dying with dementia in a long-term care facility. As evidenced by an extensive literature review, there is little information on the experience of dying with dementia in long-term care. The purpose of this study is to explore the subjective experience of dying and end of life care for persons with dementia in long-term care from multiple perspectives. Understanding the current state of end of life care for persons with dementia can assist facilities in providing more appropriate support and provide direction for future research.

The purpose of this letter is to inform you of what your family member's participation in the study entails, and to ask for your consent for your family member to participate in the study. We will be conducting a series of interviews to better understand the experience of dying with dementia from multiple perspectives. We would like to interview numerous staff from various areas, including health care aides and personal support workers, nurses, recreation staff, social work, management staff, medical staff, and spiritual advisors and clergy. We would also like to interview a few residents and family members as well as volunteers.

We would like to ask your family member to participate in an interview with one of the researchers or a focus group discussion. This would involve engaging in a discussion with the researcher about his or her experiences living at Bethammi Nursing Home and quality of life. These discussions would be scheduled sometime during the week of March 2, and will be tape-recorded with your permission. These discussions will last approximately 30 to 90 minutes. During the interview and focus groups, all answers are acceptable and will be valued. Confidentiality and anonymity of interview participants is guaranteed, but cannot be guaranteed for the focus group participants because of the group format. However, all focus group participants will be encouraged to respect the privacy of individuals taking part in the group.

We recognize the possibility that the nature of the conversation may be difficult for your family member, and the interviewer will be sensitive to this. If you decide to give your consent for your family member to participate in this study, we will be asking you to sign a consent form. This form will state your consent on behalf of your family member to participate in an interview with one of the members of the research team. Participation in this study is completely voluntary and you and your family member may choose not to participate. All participants, including your family member, may also choose to withdraw from this study at any time. Any decision not to participate or to withdraw from the study will have no impact on your family member's care at Bethammi.

All information gathered throughout this project, including field notes from observations and the interview transcripts will be kept strictly confidential and accessed by only the researchers. In order to protect the anonymity of the facility and all participants, pseudonyms for the facility and all participants involved in the study will be used in all notes taken throughout the project and in written and oral reports of the project. All data from the study will be securely stored at Lakehead University for up to seven years. A summary of the study and presentations will be distributed to the facility after summer 2008.

This study has been approved by the Research Ethics Board at Lakehead University and the Board of Directors of St. Joseph's Care Group. These offices are available for any concerns and comments pertaining to this study and can be reached by contacting either the Lakehead University Research Ethics Board at (807) 343-8283, or the St. Joseph's Care Group Chair of the Board Ethics Committee at (807) 343-4300, extension 4723.

Should you have any questions about this study, please feel free to contact Mary Lou Kelley at (807) 766-7270.

Thank you for your interest and involvement in this project. We look forward to working with your family member and others at Bethammi Nursing Home.

Sincerely,

Dr. Mary Lou Kelley
Director
Centre for Education and Research on Aging & Health

Appendix C

Declaration of Informed Consent—POA

I have read the information letter provided by Mary Lou Kelley and the research team, describing the purpose of the study. My consent for ______________________ [name of family member] to participate is made under the following conditions:

1. That I have read and understood the information in the study cover letter.
2. My family member's involvement includes participating in an interview or focus group that will take approximately 30 to 60 minutes to be scheduled during the week of [???] and will be scheduled at a time convenient for him or her during that week.
3. My family member's participation is completely voluntary and all data collected will be used solely for teaching and research purposes.
4. All information will be kept strictly confidential, accessed only the researchers involved in the project. Pseudonyms for the facility and all participants involved will be used on all documents pertaining to the study and in all oral and written reports of the project. My family member's name will never be used.
5. Confidentiality and anonymity of focus group participants cannot be fully guaranteed due to the group format. However, all participants will be encouraged to respect the privacy of individuals taking part in the group.
6. My family member may withdraw from the study at any time by simply notifying one of the researchers, and may refuse to answer any questions during the interview or focus group. My family member's withdrawal from the research will have no impact on his or her care at Bethammi Nursing Home.
7. It is not anticipated that my family member will experience physical or psychological harm.
8. The findings of the research will be prepared for publication at professional conferences and journals.
9. Data will be published in aggregate form, and no individual participants will be identified in published results without their explicit consent.
10. All data will be securely stored in a locked filing cabinet at Lakehead University for seven years.
11. My family member and I may request an executive summary of the findings upon completion of the study. These will be available through Lakehead University after summer 2008.

This study has been reviewed by the Research Ethics Board at Lakehead University and has received ethics clearance. The Office of Research Ethics at Lakehead University is available for any concerns and comments pertaining to this study.

Consent for ______________________ to Participate in an Interview or Focus Group

Name of POA____

Signature of POA____

Date ____

Signature of Researcher ____

Consent for the Interview or to be Audiotaped

Name of POA____

Signature of POA____

Date ____

Signature of Researcher ____

Appendix D

Contact Summary Form

Time of Visit:

Today's Date:

Participant:

Researcher:

1. What were the main issues or themes that struck you in this contact?

2. Summary of information received (or failed to get) on each of target questions

3. Anything else which struck as being salient, interesting, illuminating or important

4. What new or remaining target questions do you have in considering the next contact with this site?