

5-2015

Experiences of Personhood in Dementia Within Long-Term Care Settings: A Meta-Ethnography

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Recommended Citation

Taylor, Rebekah E., "Experiences of Personhood in Dementia Within Long-Term Care Settings: A Meta-Ethnography" (2015). *Master of Social Work Clinical Research Papers*. Paper 537.
http://sophia.stkate.edu/msw_papers/537

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Experiences of Personhood in Dementia
Within Long-Term Care Settings: A Meta-Ethnography

By

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MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
St. Catherine University and the University of St. Thomas
St. Paul, Minnesota
In Partial Fulfillment of the Requirements for the Degree of
Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract

To date, few studies have explored the subjective experience of identity and personhood in individuals with dementia, particularly among those living in long-term care facilities. As the population in the United States continues to age and dementia becomes more prevalent, the need to understand the experiences of persons with dementia will only increase. This paper used Noblit and Hare's (1988) meta-ethnography to synthesize existing qualitative research on the experience of personhood in dementia in long-term care. Seven studies representing a variety of professional disciplines, qualitative methodologies, and geographic locales were included. A first level of synthesis identified four major themes relating to personhood in dementia: personhood *in their world*, personhood and maintaining *human connection*, expressing the *distinctiveness* of personhood, and personhood and *the role required in this place*. A second level of synthesis linked these four themes within an integrative framework. This framework describes the experience of personhood in dementia as one of adjustment, characterized by both reconciliation and disconnect between past and present selves. The findings of this study suggest that the narrative of loss of personhood in dementia be challenged and that both the past and present identities of persons with dementia be honored and embraced.

Keywords: identity, personhood, dementia, long-term care, meta-ethnography

Acknowledgements

I wish to thank my Research Committee Chair, Professor Mike Chovanec, and my Research Committee Members, Professor Mari Ann Graham and Georgia Lane, for reviewing this project. Each offered valuable expertise and honest feedback. Also, many thanks to Neptali Rodriguez and to my mother, Deborah Ruth, and step-father, Neil Tianen. Without their love, support, and assistance with childcare, this project could not have become a reality. Finally, I would like to thank Tristan, my son, for his patience and understanding during countless hours of research this past year so that Mommy could become a social worker.

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Introduction

The myths and fears about dementia—the stereotype of someone in the later stages of the diseases that cause dementia—give rise to the stigma that isolates us. You say we do not remember, so we cannot understand. We do not know, so it is OK to distance yourself from us. And you treat us with fear and dread. We cannot work; we cannot drive; we cannot contribute to society. I am watched carefully for signs of odd words or behaviors, my opinion is no longer sought, and I am thought to lack insight, so it does not matter that I am excluded.

(Bryden, 2005, p. 40)

In recent years, researchers and advocacy groups across the United States and around the world have warned—with a growing sense of urgency—that an Alzheimer’s disease epidemic is imminent. Today, Alzheimer’s disease—the most common form of dementia—is the 6th leading cause of death in the United States and is the only killer in the top 10 for which there is no prevention or cure (Alzheimer’s Association, 2014b). Found primarily in individuals over the age of 65, the disease kills an estimated 500,000 older adults each year. According to the U.S. Department of Health’s Administration on Aging, as a result of the aging of the Baby Boomer generation, the elderly U.S. population is expected to double by the year 2030, when 1 in 5 Americans will be over the age of 65 (Siegel, 1996). The number of oldest-old Americans, those over the age of 85, will see the greatest increase (Siegel, 1996), and within this cohort, 1/3 of individuals have Alzheimer’s disease (Alzheimer’s Association, 2014a, p. 16). The number of individuals over the age of 65 diagnosed with Alzheimer’s disease could triple from 5 million to nearly 14 million by 2050 (Alzheimer’s Association, 2014a, p. 21).

Alzheimer’s disease exacts a heavy toll not only on individuals with the disease, but on caregivers and our nation’s economy as well. According to the Alzheimer’s Association (2014a), caregivers of persons with dementia (PWD) provided nearly 18 billion hours of unpaid care—care worth more than \$220 billion—in 2013. Research shows that caregiving is often

physically and emotionally stressful; in 2013, the health care costs for caregivers of PWD totaled more than \$9 billion (Alzheimer's Association, 2014a). On a larger scale, in 2014, the cost of caring for individuals with Alzheimer's disease in the United States is expected to top \$210 billion. "Nearly one in every five dollars spent by Medicare is on people with Alzheimer's or another dementia" (Alzheimer's Association, 2014b, Cost to the nation, para. 2).

The impact of Alzheimer's disease and other dementias on a person's ability to live well independently means that many diagnosed individuals end up in long-term care (LTC) institutions, especially in the later stages of the disease process. Defined by the United States Department of Health and Human Services (2014) as the "range of services and supports . . . need[ed] to meet . . . personal care needs," ("What is Long-Term Care," para. 1) LTC is provided in a variety of settings including nursing homes, assisted living facilities, transitional care units, and long-term acute care hospital wards.

Although most older adults state that they would like to stay at home as they age, many in the later stages of debilitating conditions like Alzheimer's disease will require the around the clock care that LTC facilities, and nursing homes in particular, provide (Yoder, 2012). Among Medicare beneficiaries, individuals with Alzheimer's disease and other dementias have nearly nine times as many skilled nursing facility stays as individuals without dementia (Alzheimer's Association, 2014a, p. 45). Sixty-four percent of all Medicare beneficiaries living in nursing homes have dementia (Alzheimer's Association, 2014a, p. 48). The Administration on Aging (Siegel, 1996) predicts that the number of individuals suffering from conditions like Alzheimer's disease and requiring nursing home care "will rise sharply" by the year 2030 (Summary, para. 4).

As increasing numbers of older Americans with dementia require residential LTC in coming years, we can expect a growing need for qualified clinical social workers to provide

direct care and consultation in these facilities. To date, the best practices in nursing home dementia care have been born out of the movement known as “culture change,” created in response to works by Kitwood (1997a; 1997b) and others on the preservation of personhood in dementia. An international effort based on values of “choice, dignity, respect, self-determination, and purposeful living” (The Pioneer Network, 2014b, What is Culture Change?, para. 1), culture change seeks to make LTC institutions more homelike through “person-centered” care. Person-centered care has been defined as “a journey that moves decision-making directly to the individual, despite frailty, cognitive impairment, or the location in which services are provided,” (The Institute for Person-Centered Care, 2014, para. 2). It continues to revolutionize care for PWD in nursing homes and other LTC facilities. Social workers in particular are well-poised to be key players in the ongoing person-centered care revolution.

Although the implementation of person-centered care has improved the lives of countless individuals living with dementia in LTC, the concept itself is still “somewhat marginalized (Beattie et al., 2007, p. 121) and has yet to be concretely defined (Terada et al., 2013). The effectiveness of person-centered care remains to be clearly demonstrated and measured (Edvardsson, Winblad, & Sandman, 2008). These issues may be due, in part, to the fact that the concept of “personhood” itself remains difficult to define, especially within the context of dementia.

Most dementia research continues to focus on medical treatment of the disease and the hunt for a cure; entire journals are devoted to these topics, for example, the *Alzheimer’s Disease Research Journal*, *Alzheimer’s Research and Therapy*, and the *Journal of Alzheimer’s Disease*. Research on Alzheimer’s disease and other dementias outside the biomedical field, and within the social sciences in particular, has concerned itself primarily with the caregiver experience

(see, for example, Cox, 1995; Putnam, Pickard, Rodriguez, & Shear, 2010; Sanders & Adams, 2005; Sanders, Ott, Kelber, & Noonan, 2008; Swenson, 2004). Much less attention has been paid to the subjective experiences of PWD themselves (Milne, 2010). Such research is particularly lacking in the field of social work (Tanner, 2013).

What is needed to insure future provision of truly person-centered dementia care in our nation's LTC facilities is earnest research exploring the subjective experience of personhood in individuals with Alzheimer's disease and other forms of dementia. Researchers in the fields of nursing, psychology, and other health professions, and particularly those outside the United States, have contributed much to this important work (see, for example, Hedman, Hansebo, Ternstedt, Hellström, & Norberg, 2013; Robinson, Giorgi, & Ekman, 2012; Westius, Kallenberg, & Norberg, 2010). Most studies on the subject involve individuals in the early stage of dementia and those living in the community (Beattie et al., 2007).

Only a relatively small number of studies examining the subjective experience of personhood in dementia within the context of LTC have been published. These studies, as far as this author has found, have yet to be reviewed and synthesized. As Glaser & Strauss (1971) have noted, research synthesis is a critical exercise which insures that the valuable contribution of individual studies is not overlooked (as cited in Sandelowski & Barroso, 2007). Synthesis allows themes among studies to be recognized and connected in meaningful ways. In the current study, such connections could help a broader, and yet more nuanced, picture of personhood in dementia to emerge. The purpose of this paper is to synthesize the findings of qualitative studies on the experience of personhood in individuals with dementia living in LTC. The hope is that this study will identify concepts described in the experiences of PWD that could help form new

theory on the experience of dementia and inform future research and person-centered social work interventions in LTC facilities.

Literature Review

Personhood is defined as “the state or condition of being a person, especially having those qualities that confer distinct individuality” (Personhood, 2006). Operating with definitions like this one, researchers for years have attempted to measure and quantify personhood and determine if it remains in individuals with dementia. Many in academia and in society have asserted that it does not. But, in 1997, Thomas Kitwood (1997a) wrote a book called *Dementia Reconsidered: The Person Comes First* that began to change popular understanding of PWD and of personhood itself.

Kitwood (1997a) defines personhood as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being” (p. 8). This view of personhood—one that draws attention to the ways in which those interacting with PWD can positively or negatively impact an individual’s sense of identity—has revolutionized the care of people with Alzheimer’s disease and other dementias. Increasing concern for the person with the disease has also lead, in recent years, to more qualitative studies exploring the subjective experience of PWD. Unfortunately, though, there are few qualitative studies exploring identity and personhood in more advanced stages of dementia and among elders living in LTC. The studies that do exist represent isolated pockets of knowledge. For this reason, a synthesis of existing qualitative studies on personhood in dementia in LTC is needed.

This literature review surveys current and past literature on personhood in dementia, including both theoretical papers and studies on how the concept of personhood is changing dementia care and research. Studies on social constructionist, phenomenological, and political understandings of personhood in dementia are presented and discussed, as are the issues of stigma, social death, and ambiguous loss. The person-centered care movement in LTC and

specific person-centered interventions are described. The increasing number of memoirs, autobiographies, blogs, and artistic self-explorations of the experience of dementia is addressed. Finally, the growing body of academic literature on the subjective experience of PWD and existing syntheses on dementia are reviewed.

Theories on Personhood in Dementia

For millennia, individuals with mental illness and those society might today label “demented” or “cognitively impaired” have been shunned and treated as something less than full persons. As recently as the 1980’s, such individuals were often warehoused in dismal asylums where severe mistreatment and neglect were routine. Even in the present day, PWD find themselves labeled and excluded in many ways. The biomedical model pathologizes such individuals and robs them of their humanity, most effectively by the assertion that the biological process of dementia involves a loss of self (Kitwood, 1997a).

In the early 1990’s, scholars in the fields of psychology and sociology began to challenge the dominant discourse in medicine and academia that the disease of dementia destroys personhood. Kitwood (1997a) became most well-known for challenging this premise. He argued the case for personhood in dementia from a social constructionist perspective (Kitwood 1997a; Kitwood & Bredin, 1992), as did other pioneering scholars (Sabat, 1998; Sabat & Harre, 1992). Sweeting and Gilhooly (1997), for their part, explored the significant ways in which “social death” impacts identity in dementia.

Personhood in dementia has also been explored through a more phenomenological lens (Ashworth & Ashworth, 2003; Davis, 2004; Kitwood, 1997b; Moran, 2001). In recent years, some researchers have begun to call for a more political conception of identity in dementia (Baldwin, 2008; Bartlett & O’Connor, 2007; Behuniak, 2010). Though these theoretical

perspectives on personhood in dementia reveal markedly different understandings of the same issue, collectively they represent an important step forward in our society's discourse on cognitive impairment and the individuals who experience it. Each perspective has something to offer our understanding.

Personhood in dementia as social construct. The theory of social constructionism posits that reality—or rather, realities—are formed and given meaning through human interaction (Hutchison & Charlesworth, 2015). In dementia research, this theory has been used effectively to help define personhood and to show that social factors, not just biological disease, play a role in illness and decline in dementia (Kitwood, 1997a, 1997b; Kitwood & Bredin, 1992; Post, 2013; Sabat 1998; Sabat & Harre, 1992). Such an understanding of dementia has allowed researchers to critique powerfully the biomedical model that denies PWD the status of persons and to establish a new vision of what dementia care could look like.

In defining personhood from a social constructionist perspective, Kitwood (1997a) argued that personhood develops gradually in children as a result of social interactions with significant others and that personhood is nourished and maintained by social relationships throughout the lifespan (Kitwood & Bredin, 1992). Sabat and Harre (1992) preferred to use the term “self” and differentiated between the “self of personal identity” and outer, more vulnerable, public “selves” (p. 444). Yet all of these authors see identity in dementia as socially constructed. They believe that PWD can and do remain persons—with the help of compassionate others—even to the end stages of the disease. Where personhood is lost, the cause is more a result of “malignant social psychology” (Kitwood, 1997a, p. 46), a lack of “intersubjectivity” (Kitwood & Bredin, 1992, p. 269), or “excess disability” (Sabat, 1998, p. 38) caused by well-meaning others than organic disease process.

Social constructionist dementia research is fundamentally hopeful for it does not see the loss of personhood to the disease as inevitable. Sabat (1998) stated that although an individual with dementia cannot be cured, with help, they can “achieve some level of optimal functioning” (p. 40). Kitwood & Bredin (1992) argued the same, identifying twelve indicators of well-being in dementia including, for example, “the assertion of desire or will . . . the ability to experience and express a range of emotions . . . social sensitivity . . . humour . . . [and] . . . creativity and self-expression” (p. 281). These indicators of well-being will be seen in an individual with dementia who is still treated as a “Thou” and not an “It” (Buber, 1923, as cited in Kitwood, 1997a). Such well-being becomes possible when loved ones and care providers are “. . . open to surprises” (Post, 2013, p. 349) of ongoing identity in PWD and when we recognize that we (the ones who do not have dementia) are part of the problem and yet have great potential to be part of the solution (Kitwood & Bredin, 1992).

The impact of stigma on personhood. In his classic work, Goffman (1963) defines a stigma as “an attribute that is deeply discrediting” and “constitutes a special discrepancy between virtual and actual social identity” (p. 3). He discussed numerous examples of stigma borne by marginalized individuals, including those who are disfigured, flawed in character, or mentally ill. In the case of dementia, Goffman explained that the disease is so stigmatizing that it becomes a person’s sole identity; all other characteristics or aspects of the afflicted person are swallowed up by the label of the disease. Once an individual is diagnosed, the word “dementia” identifies that person and replaces all other identifiers. The person is no longer seen as a writer, a retiree, a dependable person, a great conversationalist. They are “crazy,” “forgetful,” “senile,” “a person with dementia.” PWD, then, have to deal not only with the disease process itself, but with the judgmental and dehumanizing attitudes of society (Kitwood, 1997a; Milne, 2010; Sabat, 1998).

The impact of social death on personhood. A sociologist named Hertz was the first to use the term “social death” (Sweeting & Gilhooly, 1997). The term grew to be more widely used in the medical community and in death studies in the 1960’s. Sweeting and Gilhooly (1997) describe social death in the context of dementia as a process in which “society may view or treat the dementia sufferer as a liminal or non-person, who is demonstrably making the transition from life to death” (p. 99). The three categories of persons most likely to be considered socially dead—the long-term terminally ill, the elderly, and those suffering from “loss of personhood” (p. 97)—“coalesce in the case of dementia” (p. 98). Brannelly (2011) agreed that PWD are particularly vulnerable to the phenomenon of social death, which occurs “when people are considered unworthy of social participation and deemed to be dead when they are alive” (p. 662). Most vulnerable of all are those persons with dementia living in LTC. Echoing Kitwood (1997a), Sabat (1998) argued that, as a result of the dismissive and dehumanizing treatment of others, an institutionalized elder with dementia “for all intents and purposes . . . does not exist” (p. 39).

Ambiguous loss and social death. The concept of “ambiguous loss,” meaningfully describes the grief loved ones of PWD experience and appears to confirm the notion that individuals with the disease are—at least in part—socially dead. A term first popularized in 1999, ambiguous loss is defined as “a relational disorder that occurs when a loved one is physically present but psychologically absent” (Boss, 2010, p. 144). Boss (2010) worked diligently and compassionately to express the ambiguity inherent in the experience and losses of dementia, and wrote of “flashes of return” (p. 138) and “the still-open door” (p. 141). Yet the language she most commonly used to describe the fate of the person with dementia, words such as “disappear,” (p. 138) “being lost,” (p. 138), “missing,” (p. 138), “fading away” (p. 144), and

“absent” (p. 144), fit neatly within Kitwood’s (1997a) description of the “standard paradigm” that views dementia as “the death that leaves the body behind” (p. 37). This view of dementia, from Kitwood’s perspective, serves to diminish the personhood of the PWD.

Personhood in dementia as phenomenon. Personhood in dementia has been conceptualized not only from a social constructionist perspective but from a phenomenological perspective as well. The phenomenological perspective is often informed by the works of philosophers such as Husserl, Heidegger, Merleau-Ponty, and Sartre and focuses on the inner experience of the person with dementia. Some researchers, while not strictly phenomenologists, have examined important dimensions of the experience of cognitive impairment. Moran (2001) in a study of three books narrating the experience of relatives caring for PWD, discussed the embodiment of identity in dementia, as have Kontos (2004) and Phinney and Chesla (2003). Kitwood (1997b) himself insisted on the necessity of accessing the inner experience of dementia and suggests six routes via which this might be accomplished: written accounts of PWD, interviews and group work, observation of PWD in day-to-day life, interviewing others with conditions similar to dementia, poetry, and role play.

Ashworth and Ashworth (2003) and Davis (2004) are more explicit in their phenomenological orientation to personhood in dementia. Through the use of an idiographic case study, Ashworth and Ashworth (2003) argued that PWD do not lose their personhood to disease but continue to meaningfully inhabit a “lifeworld” (p. 179) of their own. PWD may lose memory, but they remain persons with “intentionality” (p. 185). Respect for PWD and their lifeworlds must be lived out in concrete ways and not only given lip service with “rights talk” (p. 182), which in and of itself cannot guarantee respectful treatment. From the phenomenological perspective of Ashworth and Ashworth (2003), it is the responsibility of those surrounding the

PWD to commit to “human engagement” (p. 188), “bracket” their own “presuppositions” (p. 186), enter into the experience of the affected individual, and validate their sense of reality.

Using the phenomenological concepts of lifeworld and Heidegger’s *Dasein* or “being there” to critique Kitwood (1997a), Davis (2004) came to a very different conclusion than Ashworth & Ashworth (2003) as to the inner experience of PWD. Davis (2004) argued that there is “no meaningful awareness” (p. 373) in dementia and that the disease involves the “dismantling of the self until there is nothing left” (p. 375). Davis allows for the good that has come from Kitwood’s pioneering work on personhood in dementia, but argued that Kitwood’s position can cause guilt feelings and complicated grief in caregivers of individuals with cognitive impairment. He insisted that Kitwood admit the “loss of personhood” (p. 377-378) in dementia or risk unfairly condemning loved ones of those afflicted. If nothing else, Davis’ (2004) work shows what a range of perspectives there are to be found in the exploration of personhood in dementia research.

Personhood in dementia made political. No one denies the impact of Kitwood’s (1997a) work on dementia research and health care systems in Europe and the United States. His writings helped launch a movement of person-centered care in the medical and psychiatric communities and caused society at large to revisit its assumptions about self and identity in dementia. Yet there are those who feel the time has come to move beyond the personhood model of dementia care (Baldwin, 2008; Bartlett & O’Connor, 2007; Behuniak, 2010). Bartlett and O’Connor (2007) argued that the model of personhood is limiting. The model shifted the focus of dementia care and research from disease to the “immediate environment” (p. 110) of PWD to good effect, but now the focus needs to shift again to wider societal factors and

policies that impact these individuals. They contend that a more political model viewing PWD as citizens would be empowering and beneficial.

Baldwin (2008) and Behuniak (2010) agree that a more political model of dementia is needed. Unlike Bartlett and O'Connor (2007) though, Baldwin (2008) sees the notion of citizenship complementing personhood, not replacing it, and proposed that new, more positive narratives of dementia at both the micro and macro level will help link the personal and the political. Behuniak (2010) finds fault in both phenomenological and social constructionist conceptions about identity in dementia and suggested that a model of PWD as "vulnerable persons" (p. 237) who nonetheless retain their "rights, dignity, citizenship . . . [and] humanity" would be more beneficial (p. 237). All of these authors, despite the differences in their terminology and theoretical conceptualizations, nonetheless see the importance of making personhood in dementia political, in order that affected individuals be afforded the rights, protection, and respect they deserve.

How the Concept of Personhood is Changing Dementia Care

Although we as a society have a long way to go in our understanding of the experience of dementia and attitudes toward those living with it, much progress has been made since Kitwood's (1997a) work was published. The discussion started by Kitwood and others has led to a growing concern for PWD and their rights to good care and quality of life. Even where personhood as a construct or the presence of identity in dementia remains only dimly grasped, individuals and institutions are being caught up in the rising tide of care and concern for those with Alzheimer's and other dementias. Social workers, in particular, with their injunction to "respect the inherent dignity and worth of the person" and commitment to client "self-

determination” (National Association of Social Workers, 2008) have proven to be powerful advocates on behalf of PWD.

Person-centered care has become a movement. The concept of personhood in dementia has revolutionized care for this population in community settings and especially in LTC. Across the nation and around the world, social workers have “taken lead roles” (Social Work Policy Institute, 2010, “Culture Change in Nursing Homes,” para. 1) in the movement of culture change in LTC facilities. Defined as “the transformation of nursing homes from an ‘acute care’ medical model to a ‘consumer-directed’ model” (Elliot, 2008, Background section, para. 2) culture change is seeing rapid growth and may increase resident autonomy in many areas of life. This person-centered model of LTC replaces the impersonal medical model of traditional nursing homes with a home-like environment where resident choice, meaningful relationships and activities, and individualized care are prioritized.

Person-centered care positively impacts quality of life. Although the number of studies seeking to measure the effectiveness of person-centered dementia care in LTC facilities is limited, research has shown that such care does have value (Edvardsson et al., 2008). In one study, Terada et al. (2013) explored the impact of person-centered care on the quality of life, mental status, and activities of daily living (ADL) scores of PWD living in hospital dementia wards and “geriatric health services facilities” (p. 104) in Japan. Nursing staff at these facilities (which are equivalent to American transitional care units) completed questionnaires rating 216 residents.

Terada et al.’s (2013) study found that in geriatric health services facilities person-centered care affording PWD privacy; a home-like dining atmosphere; and freedom in decision-making, social communication, and possession of personal items is significantly correlated with

certain domains of quality of life. These four domains of quality of life, as measured by staff responses, were “positive affect, ability to communicate, spontaneity and activity, and attachment to others” (Terada et al., 2013, p. 105). The elements of person-centered care examined in this study did not significantly correlate to mental status or activities of daily living (ADL) scores. So while person-centered care was not shown to impact residents’ cognitive status or level of functioning, it did show that this kind of care may improve aspects of quality of life.

In contrast to Terada et al.’s (2013) study, Adams, McAllister, Moyle, and Venturato (2007) administered surveys directly to early-stage PWD living in LTC facilities and conducted in-depth interviews to measure their quality of life. Although the three Australian residential care facilities studied in Adams et al.’s (2007) research are not specifically labeled “person-centered” care facilities, quality of life concepts revealed in 33 resident questionnaires from these homes are consistent with those found in discussions of the outcomes of person-centered care. For example, residents with “better interpersonal relationships” and “higher self-esteem” experienced better quality of life (Adams et al., 2007, p. 179).

The positive relationships and high self-esteem of residents may not be directly attributable to the quality of care in the nursing home studied; however, the study results indicate that person-centered care concepts such as “encouraging positive interpersonal relationships by demonstrating an interest in PWD” and “treating PWD with dignity” (Adams et al., 2007, p. 179) could be utilized to foster good quality of life. Indeed, it seems that the shift from medical model nursing home care to a model built on person-centered concepts such as these has legitimized psychosocial interventions that improve quality of life (Ronch, 2002).

Models of person-centered care. Many person-centered care models have been touted for their success in improving the lives of PWD living in LTC. The Green House Project, for example, has been described by its proponents as “an evidence-based model for long-term care” in which “the person with dementia lives, grows, and thrives” (Ortigara & Scher McLean, 2013, p. 68-69). Green House homes are designed for 10-12 residents and offer a more home-like environment and increased staff attention than traditional nursing homes (The Green House Project, 2012). According to The Green House Project (2012), PWD living in Green House homes have shown “improvement in seven domains of quality of life (privacy, dignity, meaningful activity, relationship, autonomy, food enjoyment, and individuality)” (p. 1). Other culture change models include The Eden Alternative, Wellspring, and Planetree (The Pioneer Network, 2014a). In addition, organizations such as the Pioneer Network, Action Pact, Inc., and PHI (Paraprofessional Healthcare Institute) assist nursing homes in their journey toward more person-centered care (The Pioneer Network, 2014a).

Person-centered interventions. Specific person-centered interventions in nursing homes have also been shown to improve care and quality of life for residents, including those with dementia. Rader & Semradek (2003) examined one nursing facility (involved in a separate experimental trial) that successfully implemented a new program to “increase . . . pleasure and comfort” and reduce “resistive, self-protective behaviors” in residents with dementia during bathing (p. 270). They found that because the nursing home they studied possessed important attributes “necessary for successful culture change” (p. 273), its staff was able to implement new bathing practices (such as making shower chairs more comfortable, giving sponge baths in bed, and offering enjoyable diversions during a bath) when other facilities could not. The positive attributes of the nursing home included “a shared vision of how things could be different” and “a

belief that change was possible,” the “desire to return locus of control to residents,” and the commitment to “empowering” staff caregivers (p. 273).

A study by Barnes, Wasielewska, Raiswell, and Drummond (2013) found that “family-style dining,” (p. 448) a type of dining allowing residents in nursing homes to choose their foods and serve themselves, contributed to increased “communication,” “interaction,” and “higher levels of well-being” (p. 448). The authors also note that because of the observational nature of their study, residents with cognitive impairment were able to be included in a way they might not be able to be if direct questioning were involved (Barnes et al., 2013). Another study showed that a nursing home art group successfully allowed residents with severe dementia living in the memory care unit of a large nursing home to “identify” and “express” previously “uncommunicated emotions” (Bober, McLellan, McBee, & Westreich, 2002, p. 74). The results of these studies show the positive impact that the concept of personhood—and the resulting person-centered care and culture change movements—has had on dementia care in nursing homes.

How the Concept of Personhood is Changing Dementia Research

More and more, researchers in the social sciences and health professions are exploring the phenomenon of personhood and identity in dementia. Some studies have attempted to measure awareness (Clare et al., 2012; Clare, Rowlands, Bruce, Surr, & Downs, 2008a; Watkins, Cheston, Jones, & Gilliard, 2006) and sense of identity (Eustache et al., 2013) in dementia. Other studies have sought to identify factors that impact (Addis & Tippett, 2004; Caddell & Clare, 2010) and interventions that support (Caddell & Clare, 2010) identity, or to quantify role identities (Cohen-Mansfield, Golander, & Arnheim, 2000; Cohen-Mansfield, Parpura-Gill, & Golander, 2006). Even more encouraging, as more and more researchers have come to

appreciate the likelihood that some sense of self or personhood is preserved in dementia, they have begun to design studies focused on the subjective experiences of individuals with dementia (Beattie et al., 2007).

PWD have been involved in studies seeking their opinions and experience on countless subjects including: quality of life (Adams et al., 2007; Boelens-Van Der Knoop et al., 2006; Fukushima, Nagahata, Ishibashi, Takahashi, & Moriyama, 2005), care needs and satisfaction in residential facilities (Hancock, Woods, Challis, & Orrell, 2006; Janzen & Warren, 2005; Popham & Orrell, 2012; Train, Nurock, Manela, Kitchen, & Livingston, 2005), coping (Clare, 2002; Gillies, 2000; Preston, Marshall, & Bucks, 2007), resilience (Harris, 2008), and hopefulness (Wolverson (Radbourne), Clarke, & Moniz-Cook, 2010). PWD have been involved in research on life narratives (Steehan, Godderis, Grypdonck, De Bal, & De Casterlé, 2007; Usita, Hyman, & Herman, 1998), the social and relational experience of dementia (Beard, Sakhtah, & Imse, 2009; Hulko, 2009; Langdon, Eagle, & Warner, 2007; Svanstrom & Dahlberg, 2004), and their experiences of diagnosis (Robinson, Clare, & Evans, 2005), early-stage disease (Beard & Neary, 2013; Holst & Hallberg, 2003; Macquarrie, 2005; Robinson et al., 2012), and institutionalization (Aminzadeh, Dalziel, Molnar, & Garcia, 2009; Clare, Rowlands, Bruce, Surr, & Downs, 2008b). Other research has explored the thoughts of PWD on spirituality (Dalby, Sperlinger, & Boddington, 2011), the acceptability of lies and deception in dementia care (Day, James, Meyer, & Lee, 2011), and meaningful activities (Phinney, Chaudhury, & O'Connor, 2007). Increasingly, PWD have also begun exploring their own experiences of personhood and identity in research studies, in song, and through the writing of memoirs, autobiographies, and blogs.

Personhood from the Perspective of PWD

Memoirs, autobiographies, and popular media. Many have wondered: How do PWD experience their own identity and personhood as the disease process progresses? Fortunately, there are some individuals diagnosed with dementia who have courageously taken the initiative to explore publicly their own experiences. In January 2013, country music artist and television host, Glen Campbell, recorded his final song, a poignant look at his life with Alzheimer's disease called, *I'm Not Gonna Miss You*; he is now living in a LTC facility. Other PWD are writing blogs about their experiences, including Howard Glick (earlydementiasupport.blogspot.com), David Hilficker (davidhilfiker.blogspot.com), and a man known as Silverfox (parkblog-silverfox.blogspot.com/). There are also articles, autobiographies, and memoirs penned by PWD (see for example, Bryden, 2005; Debaggio, 2002; Friedell, 2002; Taylor, 2007).

Qualitative studies on personhood in dementia. The number of qualitative studies exploring experiences of personhood in dementia, just like the songs, blogs, memoirs, and autobiographies mentioned above, has increased significantly in recent years. Researchers from many disciplines are exploring how best to include the active participation of PWD in more studies, in order that we as a society might better understand their experiences and perspectives (Moore & Hollett, 2003; Nygard, 2006). These studies utilize qualitative methods of data collection and analysis, including, for example, in-depth interviews, ethnographic observation, and constant comparative analysis, to enter deeply into the subjective experience of personhood in dementia.

Early-stage/community-dwelling. Most of the qualitative studies on the experience of personhood in dementia concern individuals in the early stage of their disease process and those living with dementia in the community (Beattie et al., 2007). Beard (2004) studied issues of identity in patients newly diagnosed with Alzheimer's disease. Kuhn and Moss (2002) used a

case study to explore “autonomy and selfhood” in a woman with dementia living alone in her home (p. 17). Preston et al. (2007) focused their study on persons diagnosed with “mild dementia” with recent Mini Mental Status Examination (MMSE) scores above 18 (p. 132). Steeman et al. (2007) limited the participants of their study to individuals with “probable mild dementia” (p. 119). Beard et al. (2009) and Robinson et al. (2012) studied those in the pre-clinical or early stages. None of these studies explored the experiences of PWD living in LTC facilities. Other authors have included individuals with moderate to severe dementia in their studies on identity and personhood, yet these studies also did not involve PWD living in LTC (Hedman et al., 2013; Phinney & Chesla, 2003).

Persons with dementia in long-term care. Qualitative academic studies that include first-person accounts and ethnographic descriptions of personhood in dementia among individuals living in LTC comprise the sample used in this meta-ethnography. As previously stated, there are a limited number of these studies to be found (Beattie et al., 2007). Most of the studies that do exist hail from outside the United States, including studies from Australia, Belgium, Canada, Ireland, Israel, the Netherlands, Norway, Scotland, Sweden, and the United Kingdom. These studies most commonly originate from the professions of sociology, anthropology, psychology, nursing, and medicine. Rather surprisingly, the subject of personhood and identity in dementia has “received little attention within the domain of social work” (Tanner, 2013, p. 155).

A Need for Synthesis

Despite a growing number of studies and memoirs exploring the subjective experience of PWD in recent years, a shortage of research syntheses of these writings makes deep understanding somewhat elusive. Still, a handful of systematic reviews and other meta-syntheses

have sought to integrate important aspects of the experience of dementia, as reported in qualitative studies and autobiographies. Ablitt, Jones, and Muers (2009) reviewed the qualitative literature on “relationship factors” in dementia (p. 497). Another group of researchers conducted a systematic review of reviews on the needs of PWD living in the community (von Kutzleben, Schmid, Halek, Holle, & Bartholomeyczik, 2012). Steeman, De Casterlé, Godderis, & Gryndonck (2006), in their oft-cited meta-synthesis, reviewed qualitative studies on the experience of early-stage dementia. These reviews, while informative and focused on the subjective experience of PWD, were not aimed specifically at understanding the subject of personhood, nor did they seek to capture the unique experience of individuals living in LTC.

Three studies have sought to explore the experience of personhood in dementia by synthesizing findings from memoirs and autobiographies. Basting’s (2003) synthesis of three autobiographies has often been looked to by later researchers for its exposition of a strong and persistent sense of self in the writings of PWD. Ryan, Bannister, and Anas (2009) followed Basting’s lead, examining thirteen memoirs of dementia. They explored how PWD are able to “construct and project positive new identities” (p. 145) and re-forge social ties through their writing.

The Purpose of the Study

Personhood in dementia remains a concept over which academics and health care professionals disagree. The focus for some is on personhood in dementia as social construct; others view personhood in dementia from a more phenomenological perspective. Some forward-thinking scholars insist that personhood in dementia be viewed more politically in order that PWD be afforded the rights they deserve. Many informed by the biomedical model seem to deny that personhood remains in PWD at all.

However one defines personhood or related words such as self and identity, the impact of these words and the questions they raise in the context of PWD continue to change dementia care and research. What is personhood? What is the self? Does identity remain in dementia, or is the person “gone”? How does living in LTC affect sense of self among PWD? What if we could gain the perspective of PWD themselves on these important questions? How would that impact what we say we know? Building on these important areas of inquiry, the research question for this study is: How do PWD living in LTC experience their own personhood and identity?

Methods

Meta-Ethnography

This study is qualitative in design and used Noblit and Hare's (1988) process of meta-ethnography to synthesize qualitative studies on the experience of personhood in dementia among individuals living in LTC. According to Noblit and Hare (1988), meta-ethnography is a form of literature review that uses metaphors in a process of finding "analogies between . . . accounts" (p. 13) and "translating the interpretations of one study into the interpretations of another" (p. 32). Significantly, the data used in meta-ethnography are the original researchers' interpretations of findings, not the interviews or other data that make up the findings themselves. In meta-ethnography, according to Britten et al. (2002), interview responses and other raw qualitative data are often called "first order constructs" (p. 211). The original authors' interpretations of raw data are "second order constructs" (p. 211). "Third order constructs" are the product of meta-ethnographic synthesis (p. 211).

Meta-ethnography is more "inductive" and "interpretive" than other types of literature reviews and meta-syntheses (Noblit & Hare, 1988, p. 16). According to Noblit and Hare (1988), "A meta-ethnography synthesizes the substance of qualitative research, while meta-analysis synthesizes the data" (p. 81). Its use of metaphor allows for an understanding of "how things might connect and interact," (p. 18) "without being either overly reductionistic or falling prey to aggregate theories of synthesis" (p. 23). For this reason, meta-ethnography is an ideal methodology for researchers seeking to explore human experience more deeply. It allows for theorizing about the connections between qualitative studies, without losing the unique context and contribution of each individual paper. Meta-ethnography was chosen as the methodology for the current study because of its purposeful focus on the experiences and views of the individuals

studied (Atkins et al., 2008) and its potential to develop new understandings of phenomena based on the interpretations of existing qualitative work.

How meta-ethnography has been used. Today, meta-ethnography is considered one of the more accepted forms of qualitative synthesis (Campbell et al., 2003). Meta-ethnography has its origins in the field of education, yet has increasingly been used in health care and other fields to study a wide variety of subjects, for example, fathers' experiences of becoming parents (Chin, Hall, & Daiches, 2011), patients' experiences of antidepressants (Malpass et al., 2009), vaginal practices in sub-Saharan Africa (Hilber et al., 2012), and the treatment views of substance-abusing women (Hines, 2013). Although dealing with incredibly diverse subject matter, researchers conducting meta-ethnography are always interested in "how qualitative researchers interpret and explain social and cultural events" (Noblit & Hare, 1988, p. 7).

In at least three known studies, meta-ethnography has been employed to explore issues in dementia. Tränvag, Peterson, and Näden (2013) synthesized studies examining healthcare professionals' views on dignity-preserving dementia care. Prorok, Horgan, and Seitz (2013) explored the health care experiences of PWD and their families. Page and Keady (2010), in the only meta-ethnography inclusive of issues of personhood in dementia that this author could find, described how nine authors with dementia experienced themselves and their disease.

The aims of meta-ethnography. "Firmly based in the interpretive paradigm" (Noblit & Hare, 1988, p. 11), meta-ethnography is meant to inform the development of new conceptualizations and new theory. Surprisingly, meta-ethnography has not often been used in the field of social work. More of this kind of research is needed in order to illuminate the experience of dementia and to inform professionals of best practices with PWD. For, undoubtedly, great skill and understanding are needed "if concepts of personhood . . . are to have

meaning in social work practice with people with dementia” (Tanner, 2013, p. 166). Yet solid answers are unlikely to be found. This meta-ethnography represents but one possible interpretation of the studies synthesized. Rather than reaching definitive conclusions, the hope, according to Noblit and Hare (1988) is to “achieve the goal of enhancing human discourse” (p. 18).

The phases of meta-ethnography. There are seven phases to meta-ethnography. These are: 1. Getting started, 2. Deciding what is relevant to the initial interest, 3. Reading the studies, 4. Determining how the studies are related, 5. Translating the studies into one another, 6. Synthesizing translations, and 7. Expressing the synthesis (Noblit & Hare, 1988, p. 26-29). As the work of meta-ethnography proceeds, “the phases overlap and may be parallel” (Noblit & Hare, 1988, p. 29). Phases 1 and 2 incorporate sampling procedures. Phase 3 involves data collection. Phases 4, 5, and 6 represent data analysis procedures. Phase 7 represents the dissemination of findings. The phases of the process are described below within the more traditional research headings of Sampling, Data Collection, Data Analysis, and Dissemination.

Sampling

Getting started. The first phase of meta-ethnography is to identify an area of interest that could be explored through the use of qualitative methodology. For this study, the initial question of interest was: What can qualitative studies reveal about the subjective experience of dementia? As suggested by Campbell et al. (2003), the interest behind this question—in contrast to the interests underlying more quantitative synthesis efforts—concerns the human experience of disease. A cursory look at the literature on this question revealed that the topic area was much too broad. An exploration of the experience of dementia could include a wide variety of issues such as relationships, spirituality, coping, and meaningful activities. Furthermore, as previously

discussed, while much has been written about the experiences of individuals with early-stage dementia living in the community, there has been less of a focus in the literature on the subjective experience of those PWD living in LTC. As a result, the focus of this study was narrowed to PWD living in LTC and the topic area restricted to the experience of personhood and identity in dementia.

Deciding what is relevant. The second phase of meta-ethnography is to decide what studies are relevant to the topic area. Despite the name of the methodology, Noblit and Hare (1988) do not require that the studies synthesized be ethnographies. Authors who have followed in Noblit and Hare's footsteps encourage the inclusion of studies with diverse qualitative methodologies (Campbell et al., 2003) as well as papers representing a variety of professional disciplines and "schools of thought" (Booth, 2001, p. 4). Most importantly, the synthesis involved in meta-ethnography does not need to be "exhaustive" (Noblit & Hare, 1988). Rather, a diverse group of papers relevant to the research question are included; quantity is not primary.

Unlike meta-ethnographies that include only studies with direct participant interviews and quotes (see Monforte-Royo, Villavicencio-Chávez, Tomás-Sábado, Mahtani-Chugani, & Balaguer, 2012, for example) this meta-ethnography incorporated ethnographic, participant-observation studies as well. This decision was made because of the growing consensus that a variety of research approaches are needed to explore the experience of people with advanced dementia (Beattie et al., 2007). Indeed, Kitwood (1997b) includes observation as one of his "six access routes to the subjective experience of dementia" (p. 16). Similarly, Kontos (2004) understands dementia to be embodied and suggested that one must look beyond what is said to gain understanding. The aim here was not to discount the spoken voice of the person with

dementia, but rather to become more intentionally aware of the many ways the experience of such an individual may be communicated.

Search strategy. The author of this study conducted a literature search for peer-reviewed articles on the subjective experience of dementia between July and August of 2014 using the following databases: Academic Search Premier, Alt HealthWatch, Cinahl, Consumer Health Complete, EBSCO MegaFile, Embase, ERIC, Family Studies Abstracts, HealthSource Nursing/Academic, MAS Ultra, PsycINFO, PubMed, Social Work Abstracts, and SocINDEX. The author also searched Google Scholar and the journals *Ageing International*, *Alzheimer's and Dementia*, *Clinical Social Work Journal*, *Dementia (2005-2014)*, *Generations*, *Gerontology*, *Gerontologist*, *Health & Social Work*, *Journal of Aging Studies*, *Journal of Gerontological Social Work*, *Nursing Older People*, *Qualitative Health Research*, and *Qualitative Social Work*. Key words used for the search included: *Alzheimer's*, *dementia*, *experience*, *experience of dementia*, *experience of Alzheimer's*, *subjective experience*, *perceptions*, *interviews*, *nursing homes*, *long-term care*, *ethnography*, *voice*, *institutionalized*, and *phenomenology*. An initial 69 articles on the subjective experience of dementia were identified in these searches. Many were eventually excluded because they were not focused on PWD living in LTC. In January of 2015, the author conducted a follow-up search of the database Academic Search Premier using the keywords "experience of dementia" and scanned the titles of 1,890 articles. In addition, the citations of fifteen key papers were searched by hand. The author set 1997 as the earliest year allowable for papers, as this was the year when Kitwood (1997a) authored his book, *Dementia Reconsidered*. Articles on the experience of dementia from the patient's perspective were very rare before that time.

A purposive sampling strategy was used to identify relevant papers for this meta-ethnography. In terms of sample size, Noblit and Hare (1988) used 2-6 papers for their meta-ethnographies. Subsequent meta-ethnographies that this author found include between 6 (Chin et al., 2011) and 44 (Atkins et al., 2008) studies. The current study synthesized 7 papers. This sample size was determined as studies were appraised for quality, relevancy, and degree of author interpretation (studies representing strictly descriptive research would likely be difficult to synthesize using this methodology). As stated above, the sample intentionally includes both ethnographies and other qualitative methodologies. Also of particular interest for this study was the inclusion of papers varying in terms of type of LTC setting and author profession.

Quality appraisal. It might fairly be said that meta-ethnography and qualitative research synthesis as a whole have an uneasy relationship with the notion of quality appraisal. Some meta-ethnographies do not assess for quality using criteria checklists (see Chin, Hall, & Daiches, 2011, for example). Other meta-ethnographies incorporate or advocate the use of quality assessment in some form but do not necessarily exclude studies based on negative assessments (Atkins et al., 2008; Booth, 2001; Flemming, Graham, Heirs, Fox, & Sowden, 2013; Malpass et al., 2009; Monforte-Royo et al., 2012). For their part, Noblit and Hare (1988) reject a more quantitative understanding of research synthesis, stating that studies ought not to be discarded as a result of flaws in methodology. Rather, “the worth of studies . . . is determined in the process of achieving a synthesis” (p. 16). The importance here is placed on the contribution of each individual study to the research topic, not on flaws that might exclude it from a different form of synthesis.

For this current study, the quality of studies was appraised in three steps, not for the purpose of omitting papers, but, as Malpass et al. (2009) have said, to “test’ the contributions of

the papers at a later stage” (p. 158). First, two key questions borrowed from Malpass et al. (2009) and Campbell et al. (2003) were asked: Is the study qualitative in design? Is it relevant to the topic of the meta-ethnography? Second, the oft-cited Critical Appraisal Skills Programme (CASP) Qualitative Checklist tool (CASP, 2013) was used to assess the studies (See Table 1).

Table 1. CASP Qualitative Research Checklist

- | |
|--|
| <ol style="list-style-type: none"> 1. Was there a clear statement of the aims of the research? 2. Is a qualitative methodology appropriate? 3. Was the research design appropriate to address the aims of the research? 4. Was the recruitment strategy appropriate to the aims of the research? 5. Were the data collected in a way that addressed the research issue? 6. Has the relationship between researcher and participants been adequately considered? 7. Have ethical issues been taken into consideration? 8. Was the data analysis sufficiently rigorous? 9. Is there a clear statement of findings? 10. How valuable is the research? |
|--|

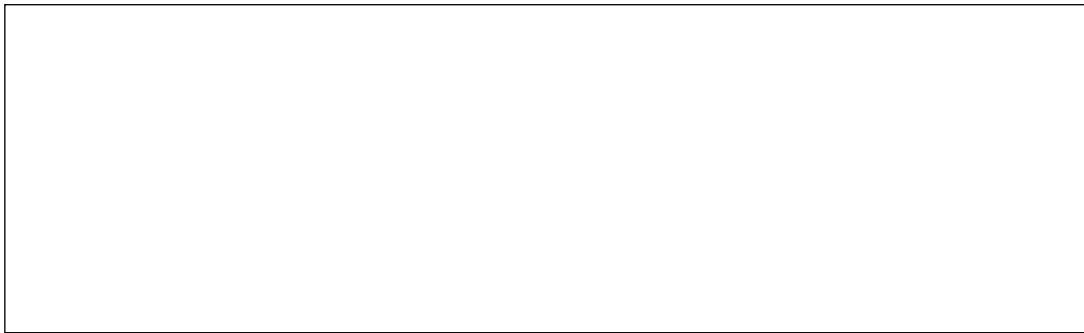
Critical Appraisal Skills Programme (CASP) 5/31/13

One point was awarded for each positive response on the CASP checklist, with 9 being the highest possible score. Third, based on the CASP results (Questions 1-9), CASP Question 10 (“How valuable is the research?”) was answered, and each paper in the sample was categorized according to a modified version of Dixon-Woods et al.’s (2007) schema.

The modified version of the Dixon-Woods et al. (2007) schema is shown below in Table 2. In keeping with Noblit & Hare’s (1988) directive not to omit papers based on methodology alone, the original category, “FF-Paper to be excluded on grounds of being fatally flawed” (Dixon-Woods et al., 2007, p. 44) was removed. The two papers placed in the “?” category were

included, despite initial concerns about the relevancy of the studies; their placement in this category provided important insight that helped assess the value of the papers later in the process. For the purposes of this study, the only papers automatically excluded were those that were not qualitative, those not relevant to the study, and those containing so little author interpretation that a meta-ethnographic synthesis would be difficult or impossible.

Table 2. Assessment Categories for Qualitative Papers



Dixon-Woods et al. (2007), p. 44

Data Collection

The third phase of meta-ethnography is to read the studies. This step requires a close reading of the papers to be synthesized so that the researcher can become comfortable with the language and concepts in each. According to Noblit and Hare (1988), “. . . extensive attention to the details in the accounts” will allow for the “noting of interpretive metaphors” (p. 26). Metaphors (i.e. second order constructs) are the key to meta-ethnography, and not just any metaphor will do.

Citing the work of Brown (1977), Martin (1975), and House (1979), Noblit and Hare (1988) instruct that the best metaphors are those with the most “economy, cogency, range, apparency, and credibility” (p. 34). In other words, the metaphors chosen by the meta-ethnographer should be simple, convincing, encompassing of content, demonstrative, and believable, in order to make an effective synthesis possible. By way of example, in Noblit &

Hare's, "School Principal's Synthesis," the metaphors of "freedom to make no serious mistakes," "patience," "prudence," and "maintaining the system" are chosen to complete the meta-ethnography (p. 41). If satisfactory metaphors such as these cannot be identified in the studies to be synthesized, according to Noblit and Hare (1988), new metaphors may need to be created.

The author read the studies to be synthesized in chronological order, as many researchers have suggested (Campbell et al., 2003; Malpass et al., 2009; Monforte-Royo et al., 2012). Each paper to be synthesized was read multiple times, with special attention paid to the Results and Discussion sections of the papers. This is important because meta-ethnography uses authors' interpretations as its data, and interpretations are most often found in these sections. The author composed "a list of the key metaphors, phrases, ideas, and/or concepts (and their relations) used in each account" (Noblit & Hare, 1988, p. 28). The author used the researchers' own words as metaphors (Tränvag et al., 2013). The researchers' words, in turn, were rooted in the direct quotes or expressions of the PWD studied. For the sake of clarity, a table adapted from Tränvag et al. (2013), Monforte-Royo et al. (2012), and Hilber et al. (2012) showing identified first order constructs (raw data/quotes), second order constructs (metaphors), and third order constructs (this author's overarching themes or "translations," as described in Phase 5 below) is included in Appendix A.

Data Analysis

Determining how the studies are related. The fourth phase of meta-ethnography is to determine how the studies are related. According to the methodology of meta-ethnography, there can be three different types of relationships or "translations" between studies: "reciprocal . . . refutational . . . [and] line-of-argument" (Noblit & Hare, 1988, p. 36). Reciprocal translations involve metaphors that are essentially equivalent; refutational translations engage interpretations

that are in conflict with one another; and lines-of-argument translations not only determine relationships between studies but offer a larger interpretation of what these relationships mean.

To determine what type of translations might exist between the papers, the key metaphors drawn from each study were written down side by side in columns on a grid. In this way, the connections and dissimilarities between studies were more readily noted (Campbell et al., 2003). Mindful of “both content and context” (Hilber et al., 2012, p. 1312) in the studies, at the end of this phase, the author developed a tentative idea of how the studies are related.

Translating the studies. The fifth phase of meta-ethnography is to translate the studies. The translations between studies in meta-ethnography are accomplished in a way similar to the “constant comparative method” of grounded theory (Glaser & Strauss, 1967, as cited in Noblit & Hare, 1988, p. 63). The constant comparative method involves reading and re-reading texts to find connections and conflicts between them. Padgett (2008) describes this process as “searching for patterns but also remaining alert to negative instances and irregularities” (p. 155). The benefit of grounded theory is that theorizing develops from the data. This process is fundamentally inductive and avoids the “restrictions of a preexisting theory” (Monette, Sullivan, & DeJong, 2011, p. 226).

Translations between the studies being synthesized were created by separating identifiable themes, concepts, and metaphors into categories. The key through this process of looking for connections and forming groups of themes was to reduce the data while “ensur[ing] that the essence of individual study findings [is] retained” (Flemming et al., 2013, p. 1026). Metaphors identified in the earliest study were compared to metaphors in the second study, then these metaphors were compared with the following study, and so on. Categories formed in early comparisons were maintained unless a new category was identified as more representative of the

connections between studies. Throughout the process, different categories or translations were tested (based on the adequacy of metaphors mentioned above) until a final list of four translations (See Appendix A) was decided upon. This process represented a “first level of synthesis” (Flemming et al., 2013, p. 1025).

Synthesizing translations. The sixth phase of meta-ethnography is to synthesize translations. After the translations are developed between the studies, the translations are then compared. This phase involves what Noblit and Hare (1988) call a “second level of synthesis” (p. 28) beyond the initial formation of translations. It is at this stage of meta-ethnographic synthesis that the development of new theory becomes possible. In this study, the four translations between studies were analyzed and a lines-of-argument relationship was established. The resulting synthesis allowed for a new conceptualization of the experience of personhood in dementia among individuals living in LTC.

Dissemination

The seventh and final phase of meta-ethnography is to express the synthesis. The findings and discussion section of this study represent phase seven of the process. The presentation of this material in May of 2015 will also be a part of phase seven. In keeping with Noblit and Hare’s (1988) direction, the hope is that the writing in this study—and especially the translations developed—will be accessible to the target audience of the work. This study’s audience will primarily be composed of social work students, professors, health care professionals, and community members. Some of these individuals will already be engaged with important issues of dementia and LTC. Others will likely be unfamiliar with this subject area. The intention is for this study to be digestible and edifying for novice and expert alike and for its content to be applicable to clinical social work practice.

Conceptual Framework

Inductive Research

The current study is an example of inductive research. As such, the data in this study—specifically, qualitative researchers’ interpretations of experiences of personhood in dementia—form a starting point from which concepts and theory can be developed. In other words, “inductive approaches permit the data to shape the theory rather than having a preconceived theory impose meaning on the data” (Monette et al., 2011). According to Noblit & Hare (1988) meta-ethnography “does not require a prior conceptual framework” (p. 37). For this reason, no rigid set of concepts related to the specifics of this inquiry is presented here. Even key terms such as “personhood,” although previously discussed and briefly defined, may take on new and unexpected meanings within the context of the qualitative studies synthesized in this study. Perhaps new words for personhood will arise in the process. In short, this study begins with the data within the papers to be synthesized. Nonetheless, for the sake of transparency, a few remarks on the theoretical orientation of the author might be helpful.

Interpretivism and Phenomenological Gerontology

Both interpretivism and phenomenological gerontology have inspired this work. Interpretivism rejects a strictly positivist worldview and pursues “an explanation for social or cultural events based upon the perspectives and experiences of the people being studied” (Noblit & Hare, 1988, p. 12). Understanding the perspectives of PWD through the synthesis of qualitative studies is the aim of this project. The interpretivism employed here insures that the perspectives of the researchers studying the experience of dementia are considered as well.

Some key concepts of phenomenological gerontology also helped motivate the author to carry out this current study. Just as interpretivism rejects strict positivism, phenomenology

counters materialism, and specifically the medical model that, at times, with its focus on disease and objective results, “ignores the person that animates the body, and the life world that contextualizes the person” (Powell, 2014, p. 23). For many decades, the medical model has been the primary lens through which society has viewed and understood dementia. Within this positivist model, dementia has been viewed too narrowly as a physical disease, a collection of symptoms, and a scientific puzzle to be worked out. There is a need to view dementia more holistically and for the perspective and experiences of older adults diagnosed with Alzheimer’s and other dementias to be considered. This study sought to address a gap in the literature by accessing and synthesizing the perspectives of PWD living in LTC. Phenomenological gerontology informed this pursuit by offering “a corrective to the seeming dominant emphasis on bio-medical conceptualizations of aging” (Powell, 2014, p. 24).

Researcher Bias

Noblit and Hare (1988) understood that in meta-ethnography, researcher bias must be addressed directly and openly. Inevitably, “The analyst is always translating studies into his own worldview. A meta-ethnography based in notions of translating studies into one another will inevitably be partially a product of the synthesizer” (p. 25). Only by acknowledging this at the outset of the synthesis can the researcher be true to the process of meta-ethnography. This faithfulness to the process, in turn, allows for the creation of a meta-ethnography that transparently explores the intersection between the human experience of the individuals studied and the interpretations of researchers seeking understanding.

This study’s author has seven years of experience working with PWD and their families in LTC facilities. Based on this experience, the author’s belief is that self and personhood remain in dementia, despite disease. One often hears comments made, even by well-intentioned

family members and professionals, that indicate a person with dementia is no longer fully a person. “Her body is alive, but she is long gone.” “I know he’s not dead yet, but the person who was my father isn’t here anymore.” Such beliefs often keep loved ones from visiting their family member with dementia because, “They won’t know who I am or remember my visit anyway.” Yet, conversation and time spent with PWD reveal what appears to be an intact sense of self, even late in the disease process. This perception motivated the research question of the current study.

To minimize the impact of researcher bias in this meta-ethnography, the author formed a committee of academics and professionals who read this manuscript and offered critical feedback on its processes and conclusions. Some committee members were chosen based on their divergent views on personhood and dementia and their ability and willingness to challenge the author. Others were chosen because of their status as relative “outsiders” to the subject of dementia and thus their contribution of a fresh and critical perspective. The hope is that the committee review process contributed to the rigor of the study and helped make the results produced more meaningful.

Findings

Of the eleven studies rated using CASP, four were excluded from the meta-ethnography. Two of the studies were excluded (Clare et. al, 2008a; Clare et al., 2008b) because they represented mixed methods studies and two (Chatterji, 1998; Golander & Raz, 1996) because they did not explore in depth the subjective experience of the PWD included in the study. The remaining seven studies used as data in this research project had CASP scores ranging from 6-9, and four of the studies were determined to be “Key Papers.” (See Table 3).

Table 3. Categorization of Studies According to Quality

	Li & Orleans (2002)	Kontos (2004)	McColgan (2005)	Granheim & Jansson (2006)	Surr (2006)	Nowell, Thornton & Simpson (2013)	Heggestad, Nortvedt, & Slettebø (2013)
Is the study qualitative in design?	YES	YES	YES	YES	YES	YES	YES
Is the study relevant to the topic of the meta-ethnography?	YES	YES	YES	YES	YES	YES	YES
Is there enough author interpretation to make a meta-ethnographic synthesis possible?	YES	YES	YES	YES	YES	YES	YES
1. Was there a clear statement of the aims of the research?	YES	YES	YES	YES	YES	YES	YES
2. Is a qualitative methodology appropriate?	YES	YES	YES	YES	YES	YES	YES
3. Was the research design appropriate to address the aims of the research?	YES	YES	YES	YES	YES	YES	YES
4. Was the recruitment strategy appropriate to the aims of the research?	YES	NOT SURE	NOT SURE	YES	YES	YES	YES
5. Were the data collected in a way that addressed the research issue?	YES	YES	YES	YES	YES	YES	YES
6. Has the relationship between researcher and participants been adequately considered?	NO	NO	YES	YES	YES	NOT SURE	NOT SURE
7. Have ethical issues been taken into consideration?	NOT SURE	NOT SURE	YES	YES	YES	YES	YES
8. Was the data analysis sufficiently rigorous?	YES	YES	YES	NOT SURE	YES	YES	NOT SURE
9. Is there a clear statement of findings?	YES	YES	YES	YES	YES	YES	YES
10. How valuable is the research? (KP, SAT, ?, IRR)	KP	KP	?	SAT	KP	KP	?
CASP TOTAL:	7	6	8	8	9	8	7

The two papers initially thought to be not relevant to this study (McColgan, 2005; Heggstad, Nortvedt, & Slettebø, 2013) made a significant contribution to the synthesis; however, it is possible that these two studies skewed the results of the meta-ethnography as they are focused more on the negative impacts of institutionalization and issues of dignity than personhood per se.

Description of Studies Included

The seven studies included in this meta-ethnography are presented in Table 4 below. The studies were published between 2002 and 2013 and were conducted in seven different countries (The United States, Canada, Scotland, Sweden, England, Wales, and Norway) by researchers from the disciplines of sociology, public health sciences, nursing, the social sciences, and psychology. A variety of LTC settings are represented in the studies including secured Alzheimer's units (Li & Orleans, 2002; Heggstad et al., 2013) and dedicated Alzheimer's floors (Kontos, 2004; Surr, 2006), nursing homes and residential apartments specifically for individuals with dementia (McColgan, 2005; Graneheim & Jansson, 2006; Surr, 2006), nursing homes for the general population (Surr, 2006; Heggstad et al., 2013), and an inpatient dementia care setting (Nowell, Thornton, & Simpson, 2013). Three of the studies are ethnographies (Li & Orleans, 2002; Kontos, 2004; McColgan, 2005); the remaining four studies represent a variety of other qualitative methodologies. All of the studies explore the subjective experience of personhood and identity in PWD living in LTC.

Table 4. The Sample: Studies Included in the Meta-Ethnography

Source Paper N=	Professional Discipline	Country	Setting	Sample/Demographics	Method	Purpose of Study
Li & Orleans (2002)	Sociology	United States	Secured Alzheimer's unit of a senior living facility	4 residents (3 women, 1 man), age 78-94, all diagnosed with Alzheimer's disease	Ethnography, participant observation and interviews	To determine whether a sense of personhood remains in PWD living in care facilities, despite their disease.
Kontos (2004)	Public Health Sciences	Canada	Orthodox Jewish LTC facility in Ontario, Alzheimer's floor	13 residents (10 women, 3 men), all Eastern European Jews, with moderate to severe cognitive impairment	Ethnography, participant observation	To explore selfhood in Alzheimer's disease in a Canadian LTC facility

McColgan (2005)	Sociology	Scotland	nursing home for PWD	9 residents (8 women, 1 man)	Ethnography, participant observation and some taped interviews	To look at the impact on nursing home residents of a surveillance culture and their responses to it.
Granheim & Jansson (2006)	Nursing	Sweden	a residential home (six wards of apartments and common living space, with nursing care) for PWD in Sweden	3 residents (1 woman, 2 men) diagnosed with dementia and with a history of "disturbing behavior"	10 conversational interviews interpreted using a phenomenological hermeneutic methodology	To explore the meaning of living with dementia and disturbing behavior in an institution.
Surr (2006)	Social Science/ Dementia Studies	England/Wales	residential care homes	14 PWD (13 women, 1 man), 72-94 years old, living in 4 residential homes in England and Wales, MMSE scores of 20 or less.	Unstructured interviews analyzed with an interpretive biographical approach	To examine the relevance of a socio-biographical theory of self to PWD living in residential care.
Nowell, Thornton, & Simpson (2013)	Psychology	England	Dementia care inpatient settings	white British 62-87 years old, 3 female, 4 male, length of stay 14-112 days, Alzheimer's disease, vascular, alcohol-related dementia, frontal-temporal dementia	Interviews and interpretive phenomenological analysis	To explore the subject of personhood by investigating the experience of PWD
Heggestad, Nortvedt, & Slettebø (2013)	Nursing Sciences	Norway	Two nursing homes (a locked special care unit for PWD in a small town and a larger general unit in a nursing home in a larger town)	5 residents (4 women and 1 man), aged 84-94,	Participant observation and qualitative interviews. Phenomenological and interpretive hermeneutic approach.	To determine how life in a nursing home affects PWD's experiences of dignity

How the Studies are Related

Translating the studies: A first level of synthesis. As each of the studies in this meta-ethnography explores the same general topic area, it was possible to create reciprocal translations between them as a first level of synthesis. In other words, "each study [was] translated into the terms (metaphors) of the others and vice versa" (Noblit & Hare, 1988, p. 38). A total of 201 metaphors (second order constructs) were identified in the seven studies and are presented in the Findings and Discussion sections in italics. Upon reading and re-reading the studies, it was determined that these metaphors could be grouped into four overarching themes (third order constructs) relating to the experience of personhood in dementia within long-term care settings:

- 1) Personhood *in their world*
- 2) Personhood and maintaining *human connection*
- 3) Expressing the *distinctiveness* of personhood
- 4) Personhood and *the role required in this place*

These four themes are labeled with those metaphors—*in their world* (Li & Orleans, 2002), *human connection* (Li & Orleans, 2002), *distinctiveness* (Kontos, 2004), and *the role required in this place* (McColgan, 2005)—found during the synthesis to be most encompassing of the content of related metaphors across studies. To complete the reciprocal translation of the studies, subtle similarities and differences among metaphors within the four themes were explored and are detailed in the “Translating the Studies” section below. The first, second, and third order constructs identified during the synthesis are displayed in Appendix A.

Creating lines-of-argument: A second level of synthesis. After the reciprocal translation of the studies was complete, additional relationships among the four themes, or third order constructs, were observed. For this reason, a lines-of-argument synthesis was attempted. Effectively ordering the results of the reciprocal translations “into a new interpretive context” (Noblit & Hare, 1988, p. 64), this second level of synthesis revealed a new understanding of the experience of personhood in dementia in LTC settings.

According to the seven studies in this meta-ethnography, the experience of personhood in dementia within LTC settings is one of adjustment, characterized by both reconciliation and disconnect between past and present selves. The themes of personhood *in their world* and expressing the *distinctiveness* of personhood describe this state of adjustment and instances of reconciliation and disconnect between past and present selves. The themes of personhood and maintaining *human connection* and personhood and *the role required in this place* identify social and institutional supports and barriers to the reconciliation of past and present selves among PWD.

Translating the Studies: Four Themes on Personhood

Theme 1: Personhood *in their world*.

Li and Orleans (2002). In their ethnography, Li and Orleans (2002) studied PWD in a locked Alzheimer's unit at a senior living facility to determine whether or not personhood persists in dementia. They found that *in their world* (p. 234), in other words, in the world of the residents studied, personhood does appear to remain. The *separate world* (p. 236) the authors speak of refers both to the *distinctive culture and social reality* (p. 233) of the residents with dementia and to their inner worlds of experience.

According to Li and Orleans (2002), the Alzheimer's unit is a *social organization* (p. 233) jointly created by residents and staff. It is a unique place full of forgetful people who themselves are *forgotten to some extent by the larger society* (p. 234). Each day in the unit offers residents a predictable schedule of activities and interactions. By virtue of their disease, the residents in the unit are members of a *collective culture* (p. 234).

Internally, the residents are described as being on *journeys to different places of being* (p. 242). Their dementia causes them to be *beyond and yet here with us* (p. 242). One resident, Marion, "lives in her own world of music" (p. 241). George and Ebber spend hours each day sitting in silence beneath a tree in the courtyard, holding hands and seeming to "understand each other perfectly in their own *separate world*" (p. 236). Based on their observations, Li and Orleans (2002) refer to the internal experience of dementia as *relatively free* (p. 241) and largely characterized by *calmness, passivity, innocence, and pliancy* (p. 242). The authors were able to observe the full personhood of the residents *by focusing primarily on being* (p. 242) and not seeing the changes in them *as deteriorations from some desired state* (p. 242).

Kontos (2004). Kontos' (2004) ethnography, set in Chai Village, a Canadian LTC facility, differs from the other studies in this meta-ethnography in significant ways. The author's focus on the embodiment of personhood in Alzheimer's disease is unique. She writes of the

world of PWD not so much as a place, but as a way of being. In contrast to Li and Orleans (2002), Kontos (2004) writes that the residents of Chai Village *were not operating in their own private worlds* but rather were *participants in a common world* (p. 840). Kontos' (2004) observations reveal that selfhood in PWD living in LTC can be seen in their physical way of *being-in-the-world* (p. 846). Rather than supporting the common notion that selfhood is based in cognition, Kontos' (2004) research shows that selfhood can be seen *below the threshold of cognition* (p. 837) in the bodies of PWD *engaged with the world* (p. 836). Kontos (2004) found evidence of selfhood in the *coherence and unity* (p. 840) and *fluidity and abandonment in movement* (p. 834) of the residents, as well as in their *grasp of the environment* (p. 839), and in the *body's affinity with its surroundings* (p. 839).

McColgan (2005). The primary goal of McColgan's (2005) ethnography was to explore the "surveillance culture" (p. 411) of a nursing home in Scotland and the "resistance strategies" (p. 411) residents with dementia employed in order to create home and privacy for themselves. Using participant observation and unstructured interviews, the author found that residents, though physically present in the nursing home, were often *reflecting on another place* (p. 423) usually *from a time before* (p. 423). For some residents, these reflections took the form of expressed *frequent longings for home* (p. 428). Other residents walked the halls of the nursing home constantly as though *seeking something familiar* (p. 423). One resident, Alice, expressed that she was *ready to go home* (p. 425) by donning her coat and sitting in the lounge as though waiting to leave the place. McColgan (2005) explains that "home" for the residents was *symbolic of independence* (p. 422) and *strongly linked to identity* (p. 422), while the nursing facility was synonymous with a lack of freedom. In support of this notion, one resident named

Isobel stated, “I don’t want to be classed as just a person as this . . . I would rather be classed a different place” (p. 421).

Graneheim and Jansson (2006). In this Swedish nursing study of persons living with dementia and “disturbing” (p. 1397) behavior in residential care, the authors found evidence of the unique internal worlds PWD inhabit. Similar to Li and Orleans’ (2002) notion that PWD are *on journeys to different places of being* (p. 242), Graneheim and Jansson (2006) noted that residents were *on their way to places that symbolize a freedom* (p. 1402). Although at least one resident in Graneheim and Jansson’s study expressed the sense of internal freedom that Li and Orleans mention, saying that he was able to “take it easier now” and be “just an ordinary man” (p. 1401), many other residents felt “empty,” (p. 1401) and, like the residents in McColgan’s study, were *longing to get to a better place* (p. 1402). Most often, the places the residents longed for were *remembered* (p. 1401) places. When speaking of their daily existence, the residents in this study quickly shifted *between the present and the past* (p. 1400). Deceased family and friends were *experienced as alive* (p. 1400).

Surr (2006). This study out of the United Kingdom used unstructured interviews to explore the ways in which self is preserved in PWD living in residential care. Similarly to Li and Orleans (2002), the findings of this study suggest that PWD living in LTC settings inhabit a distinct social world of their own. Surr (2006) writes of the *narrower social context and community* (p. 1726) of the four residential homes she studied. Within these homes there was *limited contact with the social world and community outside* (p. 1725). Significantly, Surr (2006) found that despite the narrower world they inhabited, the majority of residents were able to maintain the social roles that had previously been important to them in their current situation.

The *desirable social roles* (p. 1727) carried out within the world of the residential homes assisted in the maintenance of personhood for the residents.

Nowell et al. (2013). In this unique study of PWD residing in “ward settings” in England (comparable to long-term acute care hospitals in the United States), the residents can be seen as inhabiting a world of *transient personhood* (p. 402), a personhood that exists across time and space. Much like McColgan (2005) and Graneheim and Jansson’s (2006) studies, PWD in this study longed for and at times seemed to experience *a return to the past* (p. 402). Similar to Surr (2006), these residents would *draw on past roles and status* (p. 401) to maintain personhood in the present. They thought of *home as a securely attached place* (p. 401) and spent time *revisiting past experiences* (p. 401) in order to get along in their current circumstances. The past, in fact, offered them *security and familiarity* (p. 401). One resident, Lily, described this process of reaching for the past and for the familiar as “putting a big jigsaw together, making the pieces fit” (p. 401).

Heggestad et al. (2013). In their exploration of experiences of dignity in dementia within nursing homes, the authors of this Norwegian study write eloquently on issues of personhood in the world of dementia. The study’s use of participant observation and qualitative interviews uncovered in the participating residents a sense of *homesickness* (p. 887) similar to that found in McColgan (2005) and Nowell et al. (2013). Residents with dementia felt as though they were *merely visitors* (p. 889) in the nursing home and, like the residents in Graneheim and Jansson’s (2006) study, would *long for a physical place they belong* (p. 889). One resident interviewed for Heggestad et al.’s (2013) study explicitly linked notions of home and personhood when she said of home: “that’s *where you’re known*” (p. 888).

Theme 2: Personhood and maintaining *human connection*. The metaphor of *human connection* drawn from Li and Orleans' (2002) study captures well the theme found in all seven papers: relating to others is an important aspect of the experience of personhood in dementia. Li and Orleans (2002) found ample evidence that PWD *maintained their relationships* (p. 234) with residents, family members, and staff despite their disease. *Love and care continued* (p. 235) among residents who expressed affection and concern for one another in words and gestures. The authors saw residents console one another, cheer for one another during games, and wait expectantly for one another at certain times of day. Many residents clearly cared about physical self-presentation to others; many exhibited an *eagerness to be with people* (p. 235). They relied on one another and, significantly, appeared to use *relationships as self-identifiers* (p. 237).

Kontos (2004), like Li and Orleans (2002) found evidence of the importance of human relationship among PWD living in LTC. She contends that the *social aspects of the body* (p. 845) are key to selfhood in dementia. These aspects are seen in the *affection and physical contact* (p. 833) between residents, in their *communicated affirmation* (p. 834) of one another, and in their clear *mastery of a common code* (p. 842). Caring among residents was seen in their *open and gentle presence* (p. 833) with one another and in their *responding to vulnerability in others* (p. 834). One especially poignant example of a kind response to vulnerability is seen in an exchange between a resident named Dora and another resident. When this other resident began to cry and yell out, "I want to go home!" over and over again, Dora reached out, and gently holding the resident's arm, sang her a Yiddish lullaby.

Perhaps because of McColgan's (2005) focus on resident strategies to create privacy in nursing homes, her study includes less content on the importance of human relationship than the others studies in the meta-ethnography. Still, the metaphor of *having a blether* (p. 423) emerges

as an apt metaphor for social connection in her study. *Blether* is a word used in Great Britain to refer to idle chat or conversation. The residents in McColgan's (2005) study assembled twice daily for tea and a *blether*. These were important parts of the day for most residents and offered a chance to express personhood socially. McColgan (2005) refers to these tea times as *public ritual* (p. 428) that offered *a system of support* (p. 428) and *familiarity ... from a time before* (p. 423) the nursing home.

Graneheim and Jansson (2006) use the words *mutual togetherness* (p. 1402) to refer to the human connection among residents and between residents and staff in their study. The authors admit that moments of "togetherness" were only "occasional" (p. 1401), due to what they perceive as the breakdown of relationships among individuals with dementia and "disturbing" behavior. Graneheim and Jansson write that the residents' *social selves come and go* (p. 1402) depending on the type of interaction they experience with other residents and with care providers. Interactions in which residents were *included* (p. 1401), *invited to participate* (p. 1401), *accepted . . . as equals* (p. 1402), and *needed and appreciated* (p. 1401) are discussed as experiences of togetherness.

Surr (2006) considers *relationships with others* (p. 1724) to be critical to the experience of personhood among PWD living in residential care. Residents' relationships with their children, in particular, offer *recognition, attachment, and positive regard* and contribute to the preservation of self (p. 1724). *Positive relationships* (p. 1728) within the nursing home afford *a sense of security* (p. 1725) and *a feeling of being included* (p. 1724). For one resident, Brenda, a romantic relationship with another resident served to bolster her sense of self. Having a partner in the nursing home created a *nurturing and strengthening environment* (p. 1725) in which she could flourish.

According to Surr (2006), *desirable social roles* (p. 1728) within the nursing home are also very significant in the support of personhood. Such roles allow residents opportunities for *caring* (p. 1727) and *helping others* (p. 1727) and enable them to *continue to work in the present* (p. 1725). Surr (2006) points out that those residents who did not maintain positive relationships and roles in residential care struggled to maintain a sense of self.

Although Nowell et al. (2013) write at length about social comparison and the tendency of PWD to separate themselves from others in long-term hospital settings, they acknowledge that, for the residents they studied, *the ward experience was shared* (p. 404). At certain times, *being a part of the group* (p. 404) in the ward could offer a sense of identity for residents; undeniably, *similarity would afford a sense of belonging* (p. 403). For some of the residents with dementia there was *a desire to find commonality* (p. 403) with others. Sharing the experience of dementia with others seemed to make their situation less frightening and more bearable.

Heggestad et al. (2013) write of *being seen and heard* (p. 886) as essential to experiences of dignity and identity among PWD in nursing homes. In their study, participant observation and qualitative interviews revealed that most residents felt as though they were not being treated as *individual autonomous persons* (p. 881). The residents expressed a desire to be *taken seriously* (p. 886) and to know that *someone listens to our will and wishes* (p. 888). Their longing for home was interpreted by the authors not only as a longing for a place but as a longing for human connection. The residents are searching *for someone they belong to* and, even more importantly, *someone who may confirm them as persons* (p. 889).

Theme 3: Expressing the *distinctiveness* of personhood. In Kontos' (2004) study, the metaphor of *distinctiveness* (p. 844) refers to the uniqueness and individuality of each resident with dementia. Kontos (2004) experienced her study participants as *distinctive individuals* (p.

844) because of their *tendencies and inclinations* (p. 842) to act in certain ways. In other words, each PWD was unique and responded to situations in particular ways. The residents' actions revealed *innovation* (p. 844), *spontaneity* (p. 844), and *creative capacity* (p. 845), signaling the presence of *embodied selfhood* (p. 845). A resident named Dora exemplified her unique selfhood in her tendency to burst into song; Edna would always stop and gaze at the paintings on the wall during her walks; and Abe spontaneously danced when invited by a staff member. There was not only a sense of uniqueness and innovation in these actions but a real *coherence of selfhood* (p. 845). Each resident expressed *a unique synthesis of movement* (p. 840).

In Li and Orleans' (2002) study, the distinct individuality of residents with dementia is described with the metaphor of *idiosyncrasy* (p. 238). Like Kontos (2004), Li and Orleans (2002) provide examples of the *unique identities* (p. 238) of their study participants. A resident named Larry was always whistling. This was his idiosyncrasy and a sign of his identity. Another resident, Marion, had played piano all her life and always responded powerfully and enthusiastically to music; she also played facility games "in her own way" (p. 235), refusing to follow the rules.

Each of the residents in Li and Orleans' (2002) study revealed *distinctive sources of gratifications and frustrations* (p. 241). Expressing themselves as *individual beings* (p. 238) seemed to be a way of coping with life in the nursing home. Some would *create a fabled past* (p. 235) to preserve a sense of personhood, others would choose regularly *not to do something* (p. 237) that was suggested to them. All of these examples support the authors' contention that *self-generating conduct* (p. 236) was an important way in which residents maintained and expressed personhood.

The distinctiveness of the residents with dementia in McColgan's (2005) study can be seen in the *identity claims* (p. 429) they make to resist the anonymity of institutionalization. The residents wanted to *project a suitable self-image* (p. 412) and to show themselves to be different than *staff labels* (p. 429) suggested. In everything, they would *resist the institutional image presented* (p. 422). The residents did this, for example, by sitting *always . . . in the same chosen seat* (p. 423). A resident named Alice would wake up early to sit in a certain spot in the lounge. After meals, she would hurry back to that spot to insure that no one else would take it; she spent most of her days in that one chair in the lounge. By doing so, Alice was able to *claim ownership and distance from others* (p. 428) thus *constructing an identity* (p. 428) tied to a certain area rather than to the nursing home. Li and Orleans (2002) might refer to Alice's sitting as *idiosyncrasy*. Whatever one calls it, Alice's claim of a specific seat (p. 429) allowed her some measure of *privacy* (p. 429), *control* (p. 429), and a certain *distancing from the group* (p. 429). Her *just sitting* (p. 428) allowed her to maintain her personhood.

In their study, Graneheim and Jansson (2006) found that residents with dementia and "disturbing" behavior made clear attempts to assert their individuality and maintain their selfhood. One way in which the residents did this was to compare themselves to other residents they considered *really sick* (p. 1400). All three of the residents interviewed for the study *consider[ed] themselves as healthy* (p. 1401) and *not at the same level* (p. 1401) as the other residents with dementia, although they too were in fact significantly impaired. Their experience was one of *being placed among 'fools'* (p. 1400). One resident, John, spoke of the need to converse with residents who were less cognitively impaired in order not to become *like the others here* (p. 1401). In a sense, then, denying the severity of one's own dementia preserved a sense of personhood. Furthermore, the "disturbing" behavior of the residents in and of itself may

have been an expression of personhood. The behaviors that the study participants exhibited, such as wandering, screaming, not accepting the residential home as home, crying, and trying to escape represented attempts to *communicate their story* (p. 1402) and *maintain their self* (p. 1402).

Surr (2006) found that for PWD living in residential care the sense of *having been someone* (p. 1728) was key to maintaining a sense of an individual self. Residents revealed their uniqueness in *the creation and telling of a life story* (p. 1728) and in sharing with others the unique roles through which they had *contributed to society* (p. 1726). A resident named Charles spoke of his work for a car company as “the biggest part of [his] life” (p. 1726). Several female residents spoke with great pride and the same *sense of contribution to self* (p. 1726) of their roles as mothers.

Surr (2006) confirmed the relevance of a socio-biographical approach to self in dementia with the findings of her study. The residents studied in four different nursing home settings used *story as an attempt to communicate* (p. 1728) and understand themselves in the present. They clearly viewed the present *in the context of their past* (p. 1728) as the poignant example of a resident named Josephine shows:

(Josephine): . . . my husband was musical. He conducted, always conducted the anthem in the choir. We had a big choir in Reedon, in the chapel, you know, and er . . . he always got up and conducted the anthem, as they sang it, you know, and one time he did it and down he went on the floor, and a couple of the men from the . . . thing went to help him up and he was dead . . . That’s why I’m living here now. Mm. Miss him terribly, you know. (p. 1727)

Josephine was able to make sense of her present circumstances, of her living in the nursing home, by the telling and re-telling of this story. *Epiphinal events* (p. 1728) like these in the lives of residents served as meaning makers and stabilizers of selfhood.

Much like in Graneheim and Jansson's (2006) study of a residential home, Nowell et al. (2013) found that residents in hospital dementia care settings compare themselves favorably to other residents in order to maintain a sense of their own individual personhood. As one resident named Jimmy stated clearly, "I am the same but different" (Nowell et al., 2013, p. 402). The authors found residents *delineating differences* (p. 403) as Jimmy did with this statement for the purpose of stressing *their very individual role* (p. 402) as *an individual outside of this group* (p. 402). Like in Surr's (2006) study, residents would *draw on past roles and status* (p. 401) in their interactions with others. In the context of Nowell et al.'s (2013) study though, they did so specifically to *separate themselves* (p. 403) from others, especially those acting in bizarre and unwelcome ways. Doing so allowed them to *manage their own uncertainty* (p. 403) about their disease and circumstances and to *bolster self-esteem* (p. 403).

In their study, Heggstad et al. (2013) contend that PWD are *whole and unique persons* (p. 888) who *know who they are and what they have been* (p. 888). One powerful example shared to support this contention is the story of a severely impaired, largely non-verbal resident named Asta:

In the unit where Asta lived, all the residents, except her, had their own key to their private room. One day when the head nurse came in to the living room, Asta walked straight ahead to her and asked her loud and clear: "Can anyone tell me why I can't have my own key to my room?" The head nurse seemed to be surprised by this question from Asta, and it seemed as she did not expect her to express her wishes so clear. (p. 886)

Here Asta shows what the authors refer to as the *individual identity, which exists behind the disease* (p. 888). Although Heggstad et al.'s (2013) aim was to explore experiences of dignity among PWD and not identity per se, their study examples speak powerfully to the experience of personhood in dementia.

Theme 4: Personhood and *the role required in this place*. The metaphor *the role required in this place* (p. 422) comes from McColgan (2005). It is derived from the author's

commentary on interviews with a resident named Isobel who resisted being *classed as a person with dementia* (p. 421). The nursing home is described as a place where residents are subject to *categorical placement* (p. 421) based on disease and given a *specific identity and status* (p. 429). Residents in the nursing home are seen as *passive recipients of care* (p. 419) and *lack[ed] the esteem of others* (p. 421). The *institution strip[ped] residents* (p. 429) of personal autonomy and identity; it was a place *devoid of choice and privacy* (p. 420). Isobel had a sense of *how others saw her* (p. 422) and how the nursing home *defined* (p. 421) her. She resisted all that the nursing home represented. She longed to fill a role different from the one required by the nursing home.

In their study, Li & Orleans (2002) describe poignantly how PWD are often *characterized only by losses* (p. 243). In this study, although the family members of residents with dementia visited their loved ones at least weekly and although some were able to honor and embrace “the patients’ *transforming selves*” (p. 241), many could not *attribute anything but sorrow* (p. 241) to PWD. This was sometimes true of staff as well. As a result, there was a *pervasive melancholy* (p. 241) in the Alzheimer’s unit of the facility.

Societal notions of the importance of competence and accomplishment caused family members to value mainly *the past of the person* (p. 240) with dementia and to view them *in terms of their losses and deficiencies* (p. 241). The *contrast of the past and present* (p. 240) was very painful for the residents’ family members. One son spoke of his difficulty accepting his mother’s dementia, saying he was always *remembering the way it used to be* (p. 240). A daughter spoke of her experience of her mother’s dementia as the *loss of a person* (p. 239). The role required of PWD in LTC, then, can be perceived in the context of Li and Orleans’ (2002) study as one of diminishment and *deterioration . . . from some desired state* (p. 242).

In Graneheim and Jansson (2006), the experience of living with dementia and disturbing behavior in a residential home is described as being *overprotected* and *treated like a child* (p. 1400). One resident, John, expressed his frustration with such treatment after a caregiver insisted on accompanying him on a walk outside the ward:

Yes, I become furious . . . and I tell them that I walk anywhere . . . in London, in Paris and in Berlin . . . I don't need a nanny . . . but here, in a hole, I am not allowed to go out on my own because I could get lost . . . it is a hell of a life. (Graneheim & Jansson, 2006, p. 1400).

The residents in Graneheim and Jansson's (2006) study did not want to be placed in the childlike role that the residential care home seemed to demand. They did not want to be positioned as *inadequate, confused and helpless* (p. 1402). *Locked up in the ward*, they missed the freedom (p. 1400) of the outside world and wished to be listened to by staff. The residents felt constrained by the rules of the home and directions of their caregivers. Again, in John's words, ". . . they have their orders and I have my wishes" (p. 1400). For the participants in this study, living with dementia and disturbing behavior in LTC meant being treated like children and *losing meaning* and *feeling empty* (p. 1401). Despite moments of togetherness, the residents experienced a *collapse of relations to self and others* (p. 1401).

In Surr (2006), *social roles* (p. 1726) are presented as crucial to the preservation of self in PWD living in residential care. Work and family roles and *current caring roles* (p. 1727) in the residential homes appeared particularly important for PWD. Significantly, Surr (2006) found that most residents in the four residential homes studied were able to maintain these roles and thus avoid the loss of self that institutionalization can cause. Still, those residents who stood out as different from others, who were difficult for staff to deal with, who were no longer in contact with family, and who held other *undesirable roles* (p. 1728) in the homes struggled to maintain a

sense of self. These unfortunate residents experienced *social exclusion and stigmatization* (p. 1725) and felt *powerless and ignored* (p. 1725).

One resident, Olga, did not develop any *real friendships* (p. 1725) with her fellow residents nor a *close bond* (p. 1725) with facility staff, perhaps because of her nationality or a sense of her general unlikeability. As a result, she *never settled into the home or seemed at peace* (p. 1725). Another resident, Ethel, exhibited behaviors that staff found very challenging. These behaviors may have represented Ethel's attempts to express selfhood; however, because of the difficulty they caused in the home, they were responded to with a *lack of validation* (p. 1725) from the staff. It seems then that *the role required* by PWD in the residential homes Surr (2006) studied is a positive social role that requires at least a minimal ability to connect with others. Residents unable to assume such a role experienced a negativity that *undermine[d] self* (p. 1728).

In Nowell et al.'s (2013) study, PWD living in hospital dementia wards occupied *impersonal* (p. 399) roles in which they felt *unknown* (p. 399). A *one size fits all approach* (p. 406) was evident in the hospital wards studied as was *the central role of rules* (p. 399). In the words of one resident, Lily, "It's a lot of filling up time here, you have to do as you're told. You can't always have your own way" (p. 400). According to the authors, a certain amount of *reflective thinking* (p. 400) was required in order for residents to become *socialised to the environment* (p. 400) of the wards and to *fit the system* (p. 399). "Individuals less cognitively able" (p. 400) were expected to be at even higher risk of being viewed as *no longer having the qualities of a person* (p. 400). Given the *lack of choice* (p. 399) and *lack of respect and trust* (p. 399) offered to the residents in Nowell et al.'s (2013) study, *compromised personhood* (p. 399) was a real risk for many.

In their study, Heggstad et al. (2013) wrote that PWD are often *seen and treated as a diagnosis* (p. 888). Defined by their illness, they occupy a role that is *totally dependent* (p. 886) on others. *Institutional frames* (p. 889) such as *routines* (p. 889) and *locked doors* (p. 889) reinforce the fact of the residents' illness and can bring on *a feeling of captivity* and *homesickness* (p. 887). In the words of a resident named Grete, "Materially, it is good to live here. We get everything we need. We get food, clean clothing and so on, but . . . You know it is like a prison without bars . . . I feel like a prisoner. I have no freedom" (p. 887). Another risk, too, when PWD are treated "as a diagnosis" and forced to live in institutions that are more medical than home-like, is that residents will come to feel as though they are *merely visitors* (p. 889). Unable to accept a role of permanent dependency and a place that does not feel like home, they imagine themselves as passersby instead.

Of the seven studies in the meta-ethnography, Kontos' (2004) paper alone did not contain metaphors that fit with the theme of *the role required in this place*. Kontos (2004) does, in a more general way, discuss public and scientific perceptions of dementia as an experience of "fear, dread, and loss" (p. 845). She also explores the popular societal assumptions of the "passivity of the body" (p. 829) and the "loss of agency" (p. 829) in dementia. In a sense, then, Kontos (2004) is speaking to the "role" PWD play in society as a whole. Although Kontos' (2004) ethnography was set in a Canadian LTC facility, she does not explicitly address the negative impact institutionalization can have on personhood in dementia. To honor the methodology of meta-ethnography and to avoid undue over-generalization between studies, this author did not attempt to synthesize Kontos' (2004) study on this theme.

Creating Lines-of-Argument: Connecting the Four Themes

A second level of synthesis, or “lines-of-argument” synthesis was made possible in this meta-ethnography with the help of a concept identified in an outside source. In an article describing her experience of early Alzheimer’s disease, Truscott (2003) wrote: “I am daily in a state of adjustment, trying to reconcile the old me with the new me . . .” (p. 12-13). These words, despite being penned by a woman with early-stage Alzheimer’s living in her home, aptly describe the experience of personhood in dementia among those living in LTC, as presented in the seven studies of this meta-ethnography. Although another author, Post (2013), wrote that in dementia, “the idea of a total disconnect between the then self and the now self is false” (p. 352), yet the construct of past and present selves faithfully represents the experiences of PWD in the studies synthesized.

Each of the four themes derived from the studies in this meta-ethnography speaks of the experience of personhood in dementia as one of adjustment, characterized by both reconciliation and disconnect between past and present selves. Within this lines-of-argument synthesis, the themes of personhood *in their world* and expressing the *distinctiveness* of personhood describe this state of adjustment and instances of reconciliation and disconnect between past and present selves. The themes of personhood and maintaining *human connection* and personhood and *the role required in this place* identify social and institutional supports and barriers to the reconciliation of past and present selves among PWD.

Personhood in their world: A state of adjustment. In the seven studies synthesized for this meta-ethnography, the theme of personhood *in their world* captures the state of adjustment in which PWD in LTC live. PWD perhaps appear to inhabit *a separate world* (Li & Orleans, 2002, p. 236) because internally they experience life from a liminal space *between the present and the past* (Graneheim & Jansson, 2006, p. 1400). They are, as Kontos (2004) wrote,

participants in a common world (p. 840), often preoccupied with places, feelings, and people *from a time before* (McColgan, 2005, p. 423). There is a society that offers *limited contact* (Surr, 2006, p. 1725) with the outside world. Their experience is one of longing and uncertainty (Heggestad et al., 2013) in which they are *beyond and yet here with us* (Li & Orleans, 2002, p. 242). Nowell et al.'s (2013) words, *transient personhood* (p. 402) perhaps best describe the experience of self in dementia within LTC. PWD experience selfhood both as it was in the past and as it is now. They seem to struggle, both consciously and unconsciously, to adjust to this reality and find internal reconciliation between these past and present selves.

In their world PWD often *return to the past* (Nowell et al., 2013, p. 402). These journeys to times gone by may indicate either a disconnect between past and present selves or an effort at reconciliation, depending upon the person and the situation. At times, LTC may represent such a *strange environment* (Nowell et al., 2013, p. 401) to PWD, it may be so unfamiliar to them, that they seek an escape from the present. Their feelings of *homesickness* (Heggestad et al., 2013, p. 887) and fear, which sometimes cause wandering and calling out, may indicate a failure to adjust and be reconciled with the present self. At other times, *reflecting on another place* (McColgan, 2005, p. 423), and “storytelling” about the past (Surr, 2006, p. 1728) may reveal more successful attempts “to cope with the ‘here and now’” (Nowell et al., 2013, p. 401).

In McColgan's (2005) study, one resident, Alice, attempted repeatedly to disconnect from her present self and situation by putting on her coat and sitting in the lounge “ready to go home” (p. 425). Conversely, in Nowell et al.'s (2013) paper, a resident named Lily described her attempts, not to disconnect, but to be reconciled with her past and present self. Lily spoke of these efforts at reconciliation as “putting a big jigsaw together, making the pieces fit” (p. 401). Putting together the puzzle of self, for many residents, helped “to diminish the feelings of

confusion and helplessness” (Nowell et al., 2013, p. 401) they experienced in the world of dementia.

Kontos (2004) and Li and Orleans (2002) offer a glimpse of what reconciliation of past and present selves in PWD might look like. On a most basic level, such reconciliation can be seen in Kontos’ (2004) descriptions of embodied selfhood. According to Kontos’ (2004) work, selfhood exists *below the threshold of cognition* (p. 837). It could be argued, then, that in the bodies of PWD, the past and the present self are united quite naturally and in a certain sense cannot be affected by the disease.

There is a *coherence and unity* (Kontos, 2004, p. 84) and *fluidity and abandonment in movement* (p. 834) in PWD that suggest a kind of body memory is at work. In one episode in Kontos’ (2004) study, when a health care aide said, “Hello, Gorgeous” to a resident named Florence, Florence responded with a sensual shake of her hips (Kontos, 2004, p. 834). Here, the embodied union between the past and present self is made apparent. Florence’s past self (who remembers receiving compliments and the response they might elicit) and her present self (whose sense of *being-in-the-world* allows her body to move in meaningful response to stimulus) responded as one to the aide. In that moment, Florence was reconciled internally and at peace. This state may be what Li and Orleans (2002) were referring to when they wrote of the *calmness, passivity, innocence, and pliancy* of PWD (p. 242). In such moments, PWD indeed appear to be *relatively free* (p. 241) in their *different places of being* (p. 242).

The distinctiveness of personhood and adjustment in dementia. Similarly to the theme of personhood *in their world*, the theme of the *distinctiveness* of personhood reveals the state of adjustment in which PWD live and their experiences of past and present selves. The residents in the studies included in this meta-ethnography asserted their own *distinctiveness* either as a means

to disconnect from the present self or in order to achieve internal reconciliation. In Nowell et al.'s (2013) study, residents relied heavily on their own *past roles and status* (p. 401) to individuate themselves and distance themselves from present difficulties. In Surr's (2006) study, residents' knowledge of *having been someone* (p. 1728) contributed to their adjustment in the present. In their study, Li and Orleans (2002) described at least one resident who *create[d] a fabled past* (p. 235) in order to stand apart.

In Nowell et al.'s (2013) study, standing apart from other residents with dementia appeared to be very important to many PWD in LTC because doing so helped *manage their own uncertainty* and *bolster[ed] self-esteem* (p. 403) in the face of a frightening disease. These hospital dementia ward residents did all they could to *separate themselves* (p. 403) and define themselves as *outside of this group* (p. 402). They found many ways of *delineating differences* (p. 403) between themselves and other residents with dementia. In Graneheim and Jansson's (2006) study, residents with disturbing behavior, unable to reconcile themselves to the reality of the present, *consider[ed] themselves as healthy* (p. 1401) and spoke of their coming to a LTC facility as *being placed among 'fools'* (p. 1400).

Some residents in the studies synthesized, rather than looking to the past or separating themselves from other residents with dementia, asserted the distinctiveness and power of their present self as a way of finding reconciliation within themselves. McColgan's (2003) study offers the best examples of this kind of adjustment to dementia. Alice, for example, always sat in the same spot in the lounge opposite the clock (p. 423). Rebecca pretended she was putting on makeup to avoid attending activities in which she did not want to participate (p. 424). Jane kicked a doctor who attempted to examine her without speaking to her and explaining who he was (p. 425). Each of these actions revealed the distinctive personalities of the residents carrying

them out. They also represented attempts to guard personhood in the present, thus bringing into the current moment the autonomy and agency expressed by the residents in the past.

Clearly within the theme of the *distinctiveness* of personhood one again can see, if only briefly, what reconciliation between past and present selves in dementia might look like. In Kontos' (2004) study, in the *innovation* (p. 844) and *spontaneity* (p. 844) of Dora's singing, Lily's looking at each painting on the wall, and Abe's graceful dance with a staff member, a sense of freedom and clear awareness of self can be seen. These residents, to borrow Heggestad et al.'s (2013) words, *know who they are and what they have been* (p. 888). Such moments of freedom show that adjustment to life with dementia is possible; reconciliation between past and present selves can come, and will even last, if PWD in LTC are given the support they need to maintain this inner acceptance and peace.

Human connection: A support for adjustment and reconciliation. The themes of personhood and maintaining *human connection* and personhood and *the role required in this place* represent the second half of this lines-of-argument synthesis. These themes reveal how the persons, institutions, and society surrounding PWD can either support or hinder their efforts at reconciling past and present selves. Attention will first be given to human connection.

In each of the seven studies synthesized in this meta-ethnography, human connection appears vital to PWD in their attempts to adjust to disease and reconcile their own past and present selves. This contention is supported by Surr's (2006) finding that "*positive relationships* were supportive of self" (p. 1728) in residential care, while "*negative relationships* served to undermine the self of participants" (p. 1728). In other words, positive connections with others facilitated internal reconciliation while negative relationships and interactions could cause residents to disconnect. In most of the studies, connections with other residents and

opportunities to care for others appeared especially significant in helping PWD embrace their current selves.

The residents in Li and Orleans' (2002) study *maintained their relationships* (p. 234) despite cognitive impairment. Kontos (2004) referred to *the social aspects of the body* (p. 845) that made such relationships possible. In McColgan's (2005) study, residents offered one another *a system of support* (p. 428), and for one resident in Surr's (2006) study, a romantic relationship with another resident offered the *nurturing and strengthening environment* (p. 1725) she needed to adjust and thrive. In Graneheim and Jansson's (2006) paper, moments of *togetherness* (p. 1402) were important to residents. *Being included* (p. 1401) helped one resident with disturbing behavior adjust to dementia and embrace his present self. In Philip's words, "I take it easier now . . . you may be yourself. Just an ordinary man" (p. 1401). Similarly, in Nowell et al. (2013), the *sense of belonging* (p. 403) and *being part of the group* (p. 404) can be interpreted as having afforded residents the chance to adjust to the present. Residents who were "ostracized" by others for whatever reason, like Olga in Surr's (2006) study, "never settled into the home or seemed at peace" (p. 1725). Denied human connection, these residents could not adjust or find reconciliation within.

For most PWD in these seven studies, as relationships continued, *love and care continued* (Li & Orleans, 2002, p. 235). In Kontos (2004), when Dora held another resident's arm and comforted her with a Yiddish lullaby, she offered both *affection and physical contact* (p. 833) and meaningfully *communicated affirmation* (p. 834). Such *responding to the vulnerability in others* (p. 834) was likely beneficial not only for the recipient of such kindness, but for the giver of care and concern as well. Roles of *caring* and *helping others* (Surr, 2006, p. 1727) allowed

many residents some degree of continuity in their sense of self as kind and generous individuals. These roles allowed for the reconciliation of past and present selves.

Human connection between PWD in LTC and their family members also appears significant. As Surr (2006) found, relationships with children, in particular, offered *recognition*, *attachment*, and *positive regard* (p. 1724) for residents with dementia. Visits with children no doubt afforded PWD some sense of a connection to the past and a sense of connection to lifelong roles, if not explicit memories. According to Li and Orleans (2002), family members, just like PWD, must learn to adjust to the effects of the disease and to their loved ones' *transforming selves* (Li & Orleans, 2002, p. 241). The less time family members spend thinking about the past and the more successful they are in making "efforts to adjust" (Li & Orleans, p. 240), the better their loved one with dementia will adjust. The authors' notion here is that the individual with dementia be viewed by others "as a full human being in the moment" (p. 242). The more PWD are treated as full persons the more they will come to accept themselves as such, reconcile their past and present identities, and adjust to life with dementia.

Just as it is between PWD and their fellow residents and family members, human connection between PWD and LTC staff is important and supports adjustment to disease and a changing self. Graneheim and Jansson suggested that staff members and residents who have *accepted each other as equals* (p. 1402) are party to a powerful relationship that can *enhance a sense of self* (p. 1402). In Surr's (2006) study, positive relationships between residents and staff afforded *a sense of security* (p. 1725) in PWD. Similarly, Heggestad et al.'s (2013) identify *being seen and heard* (p. 886), *taken seriously* (p. 886), and treated as *individual, autonomous persons* (p. 881) by LTC staff as key to PWD's experiences of dignity. Again, the more PWD

see themselves treated respectfully and with dignity, the better able they are to adjust and to embrace their current situation and their own changing self.

The role required in this place: A barrier to adjustment and reconciliation.

Unfortunately, as has been well borne out in the literature, PWD in LTC often are not afforded the basic dignity, support of selfhood, and aid in adjustment they deserve. PWD experience this lack of support and respect not only from LTC staff, but from family members and society as a whole. The theme of personhood and *the role required in this place* reveals this finding.

According to Nowell et al. (2013), the *impersonal* (p. 399) nature of LTC hospital settings is “incongruent with a respect for personhood” (p. 399). As a result, in such settings, *personhood is unavoidably compromised* (p. 399). Li and Orleans’ (2002) research in a care facility supports this notion. They found that in the facility they researched, PWD were viewed largely *in terms of their losses and deficiencies* (p. 241). McColgan (2005) found that the nursing home she studied *strip[ped] residents* (p. 429) of “independence, autonomy, and identity” (p. 429). Heggstad et al. (2013) too speak of the *institutional frames, routines, and locked doors* (p. 889) of LTC. When PWD in LTC have to adjust “to *fit the system*, rather than the reverse being true” (Nowell et al., 2013, p. 399), they often disconnect, intentionally separating themselves from the present situation and all that institutionalization represents. In such cases, little support for the vulnerable, changing self of dementia is to be found. Thus, adjusting to disease and reconciling past and present selves becomes nearly impossible.

The role required of PWD in LTC acts as a formidable barrier to adjustment and internal reconciliation. This role is one *characterized only by losses* (Li & Orleans, 2002, p. 243) and imbued with *sorrow* (p. 241). To borrow Kontos’ (2004) words, the role assumes “the passivity of the body” (p. 829). PWD are thus seen as *passive recipients of care* (McColgan, 2005, p. 419)

who are like children. They are *inadequate, confused, and helpless* (Graneheim & Jansson, 2006, p. 1402) and *totally dependent* (Heggestad et al., 2013, p. 886). PWD are *unknown* (Nowell et al., 2013, p. 399) in LTC and *seen and treated as a diagnosis*” (Heggestad et al., 2013, p. 888). When a resident with dementia is assigned such a role, in Graneheim and Jansson’s (2006) words, “she or he will take this position” (p. 1402).

Discussion

The findings of this meta-ethnography suggest that personhood persists in dementia and is meaningfully expressed through the words and actions of PWD living in LTC settings. By providing evidence of the interpersonal and institutional effects on PWD's self-understanding, the findings also support a social constructionist view of personhood in dementia within LTC settings. In a first level of synthesis, a reciprocal translation of the studies revealed four third order constructs that help describe the experience of personhood and identity in dementia: personhood *in their world*, personhood and maintaining *human connection*, expressing the *distinctiveness* of personhood, and personhood and *the role required in this place*. In a second level of synthesis, a "line-of-argument" was developed that united the four third order constructs within an integrative framework. This line-of-argument revealed the experience of personhood in dementia to be one of adjustment, characterized by both reconciliation and disconnect between past and present selves.

The First Level of Synthesis

Personhood in their world. The theme of personhood *in their world*, drawn from Li and Orleans (2002), describes how PWD experience personhood in the context of their own unique reality, from a place of "being" (Kontos, 2004, p. 846) and "seeking" (McColgan, 2005, p. 423), *between the present and the past* (Graneheim & Jansson, 2006, p. 1400). This theme is found in the seven studies of this meta-ethnography and in other literature on the subject of dementia. In their theoretical work, Ashworth and Ashworth (2003) spoke of the "lifeworld" (p. 179) of the person with dementia as a place that may seem strange to others but that is very real and meaningful for the person experiencing it. Similarly to Kontos (2004) and Li and Orleans (2002), Ashworth and Ashworth (2003) also spoke of "a deep simplicity" (p. 199) in the existence of PWD. Phinney and Chesla (2003) and Svansson and Dahlberg (2004), in their

studies of community dwelling PWD, wrote of the world of dementia in a more negative way. Phinney and Chesla (2003) described it as “a world that did not make ready sense” (p. 290) to its inhabitants. Svanstrom and Dahlberg (2004) remarked that PWD and their spouses became “strangers in their own world” (p. 677).

Personhood and maintaining human connection. The theme of personhood and maintaining *human connection* illustrates the importance of *mutual togetherness* (Graneheim & Jansson, 2006, p. 1402), *relationships with others* (Surr, 2006, p. 1724), *affection and physical contact* (Kontos, 2004, p. 833), and *being seen and heard* (Heggstad et al., 2013, p. 886) to the experience of identity in PWD. Several other studies in the literature also speak to the importance of human relationships in dementia. Edvardsson and Nordvall (2007), Terada et al. (2013), and Adams et al. (2007) all found social relationships to have a positive impact on PWD living in institutions. Preston et al. (2007) found social elements in the positive coping strategies of individuals with early-stage dementia. In a systematic review of studies exploring relationship factors in dementia, Ablitt et al. (2009) found that many important elements of human relationship remain in dementia. They found that “love, emotional warmth and closeness, and affection” (p. 501) continue, and that “a sense of mutuality” (p. 501) is particularly important. This calls to mind both Li and Orleans’ (2002) metaphor, *love and care continued* (p. 235) and Graneheim and Jansson’s (2006) observation of mutuality between staff and residents as beneficial to maintenance of self. Post’s (2013) work too supports these metaphors in its suggestion that “tenderness” and “affective closeness” (p. 361) are critical to the sense of selfhood in PWD.

Expressing the distinctiveness of personhood. This theme, expressing the *distinctiveness* of personhood, incorporates metaphors such as *idiosyncrasy* (Li & Orleans, 2002,

p. 238), *their own identity claims* (McColgan, 2005, p. 429), *having been someone* (Surr, 2006, p. 1728), *delineating differences* (Nowell et al., 2013, p. 403), and *whole and unique persons* (Heggestad et al., 2013, p. 888) to make the case that individual identity remains in PWD living in LTC. The studies in this meta-ethnography and many studies in the literature thus reject the notion of the “dismantling of the self” (p. 375) put forward by Davis (2004) and others. Caddell and Clare (2010), Cohen-Mansfield et al. (2000), and Westius et al. (2010) all found in their research that a distinct self is maintained in dementia, despite cognitive losses. Basing his belief on twenty years of work with PWD and caregivers, Post (2013) concurs. Significantly, Beard (2004) found, as did the authors in this meta-ethnography, that the distinctiveness of personhood is not simply naturally preserved in dementia but that individuals diagnosed with dementia work actively to preserve their own identities. Perhaps most clearly of all the distinctiveness of identity in PWD can be seen in the courageous memoirs left to us by individuals themselves who have the disease (see, for example, Bryden, 2005; DeBaggio, 2002; Taylor, 2007).

Personhood and the role required in this place. The theme of personhood and *the role required in this place* speaks to the many ways in which the *impersonal* (Nowell et al., 2013, p. 399) nature of LTC facilities and attendant labels for residents such as, *powerless* (Surr, 2006, p. 1725), *inadequate* (Graneheim & Jansson, 2006, p. 1402), and *totally dependent* (Heggestad et al., 2013, p. 886) impact PWD and their sense of identity. The findings of this meta-ethnography support earlier research claiming that the attitudes and practices of individuals and institutions can have a negative effect on PWD and their conceptions of self (Brannelly, 2011; Kitwood 1997a, 1997b; Kitwood & Bredin, 1992; Milne, 2010; Post, 2012; Sabat, 1998). In today’s medicalized society, to borrow Baldwin’s (2008) words, “persons with dementia are first and foremost ill” (p. 223). If PWD are treated this way, then, according to Brannelly (2011),

“personhood . . . cannot be facilitated” (p. 669). Indeed, in Edvardsson and Nordvall’s (2007) study with residents of a psycho-geriatric facility, PWD felt as though they had no worth. In Aminzadeh et al.’s (2009) research, some PWD relocating to LTC recognized the “restrictive” and “rule-bound” (p. 491) nature of many residential care facilities and seemed to sense in advance the role they might be required of them there.

The Second Level of Synthesis

Describing the state of adjustment in dementia. In this meta-ethnography, the themes of personhood *in their world* and expressing the *distinctiveness* of personhood describe the experience of adjustment in dementia. The experience of adjustment, for example, can be seen in Li and Orleans’ (2002) metaphor of *journeys to different places of being* (p. 242) and McColgan’s (2005) *constructing an identity* (p. 428). In literature outside this meta-ethnography, researchers have described the state of adjustment in dementia as well.

Turning to the first theme of “in their world,” Edvardsson and Nordvall (2007), for example, described the inner world of PWD living in a psycho-geriatric ward as constantly changing in regards to time, place, and social identity. Just as the residents in McColgan’s (2005) study were seeking *something familiar* (p. 423), those in Edvardsson and Nordvall’s (2007) study “searched for comprehension” (p. 494). They found a measure of comprehension by returning to the world of the past, just as the residents in most studies in this meta-ethnography did (Graneheim & Jansson, 2006; Heggstad et al., 2013; Li & Orleans, 2002; McColgan, 2005; Nowell et al., 2013; Surr, 2006).

The second theme, expressing the *distinctiveness* of personhood, speaks to the experience of identity adjustment in dementia, as do many other recent research studies. Rather than use the word “adjustment” to describe this process, some authors speak of continuity and discontinuity

of self in dementia (Cohen-Mansfield et al., 2000; Page & Keady, 2010; Preston et al., 2007). Cohen-Mansfield et al. (2000) found varying degrees of continuity in the self-understanding of the nursing home residents they studied. Preston et al. (2007) found that PWD attempted to maintain continuity of self either by accepting their disease or by denying it. Similarly, in Steeman et al.'s (2006) systematic review of early-stage dementia, PWD sought to adjust to their illness through both "self-protection" (denial and distancing) and "self-adjustment" (adapting to the disease) (p. 736). Finally, Eustache et al. (2013), in their research in a French care home, found that identity adjustment in dementia centers on the concepts of "sameness" and "selfhood" (p. 1464). "Sameness" refers to the person one has "become over time" (p. 1465), while "selfhood" describes who a person is "now in the present" (p. 1465). According to the study's findings that PWD could not report their ages accurately, "sameness" or "distinctiveness" is better preserved in dementia than the "selfhood" of the present.

Instances of reconciliation and disconnect between past and present selves. In the studies of this meta-ethnography, within the themes of personhood *in their world* and expressing the *distinctiveness* of personhood, one can cite numerous examples in which the PWD studied experience either reconciliation or disconnect between past and present selves. For example, in Graneheim & Jansson (2006), Philip's quote cited earlier, "I take it easier now . . . you may be yourself" (p. 1401) suggests a moment of reconciliation. Conversely, Isobel in McColgan's (2005) study displays a disconnect between past and present selves when she states, "I don't know what happened to make me like this" (p. 421). Examples similar to these can be found in the research literature on experiences of dementia as well.

In the literature, reconciliation between the past and present selves of PWD has been characterized by a purposeful commitment to living in the present (Basting, 2003; Hedman et al.,

2013; Robinson et al., 2012). This involves accepting the limitations of the disease (Basting, 2003), focusing on the positive (Beard, 2004; Hedman et al., 2013), and, according to the PWD in Robinson et al.'s (2012) study, "letting go" (p. 299) and "adopting an "open and receptive stance to . . . illness" (p. 231). By doing so, some PWD are able to adjust to their disease and find the *freedom* (Graneheim & Jansson, 2006, p. 1402) that so many struggle to achieve.

The research literature shows not only instances of reconciliation between the past and present selves of PWD, but evidence of disconnect as well. Such disconnect perhaps can be explained by the inability of some PWD to reconcile the changes caused by their disease with what Preston et al. (2007) called the "prior sense of self" (p. 133). A common experience for PWD, it seems, is knowing that one is different now but being unable to understand how the difference came about (Robinson et al., 2012). The sense of "sameness" and "selfhood" Eustache et al. (2013) spoke of that is "well nigh impossible to dissociate in healthy people" (p. 1465) is disconnected in PWD. A strong sense of the self of the past remains; however for some PWD, "updating . . . those self-representations that are related to the present" (p. 1465) is more difficult. This separation between past and present selves causes a feeling described in the literature as living "halfway" or "in between" (Henderson, 1998, as cited in Basting, 2003, p. 94). The fear is that "a chasm" might open up that "would forever separate" the PWD "from the past" (Baldwin, 2008, p. 223).

Supports and barriers to reconciliation between past and present selves. In this meta-ethnography, the themes of personhood and maintaining *human connection* and *the role required in this place* address the supports and barriers to reconciliation between past and present selves in PWD. *Human connection*, not surprisingly, appears to aid in the reconciliation of past and present selves. In Surr's (2006) study, for example, an intimate relationship provided a

female resident with a *nurturing and strengthening environment* (p. 1725). This woman appeared particularly at peace and content in the present, despite her disease. Conversely, the residents in McColgan's (2005) study were described as having been *strip[ped]* (p. 429) of autonomy and dignity by *the role required* in the nursing home and thus found it very difficult to reconcile themselves with the reality of their present selves.

The research literature also offers evidence that human connection supports internal reconciliation in PWD and *the role required* by many LTC institutions impedes it. Steeman et al. (2006) found in their systematic review that when PWD, with the help of their families, were able to accept their diagnoses, the process could "be dealt with more positively" (p. 735) and be viewed as "more of a challenge than a threat" (p. 735). Human connection and emotional support, like that offered to a woman interviewed in Hulko's (2009) study of community-dwelling individuals, allows PWD to feel that others "accept" (p. 137) them and gives them the peace and confidence to continue on.

Unfortunately, when individuals and institutions do not accept PWD as they are in the present, the process of reconciling past and present selves becomes much more difficult. Cohen-Mansfield et al. (2006) found that family members, in particular, are guilty of "underestimation of the present" (p. 755) when it comes to their relatives with dementia. In this study, family members believed that dementia had a greater effect on current identity than it actually did. In another similar study, Cohen-Mansfield et al. (2000) found that although family members, when discussing the past, could come up with numerous positive identifying traits for their relatives with dementia, nearly 75% of family members interviewed could not identify a single positive attribute in the present. Milne (2010) found that negative views like these can be internalized by

PWD and negatively impact the way they see themselves. Indeed, the negative attitudes of others, according to Robinson et al. (2012) make it harder for PWD to adjust.

Implications

The lie of dementia. Post (2013) wisely wrote that “a person with dementia is rarely as gone as we superficially suppose” (p. 357). If the results of the current study are correct, the distinctiveness of personhood indeed remains in dementia, even in its later stages. The unique identities of PWD are preserved as is their need for human connection and love. Yet, PWD in some ways inhabit a world all their own; they may at times feel as though they are lost between the past and the present. They struggle daily to adjust to their disease, to hold on to their memories and yet make peace with their current situation.

Unfortunately, the dominant narrative of dementia, what Bryden in her memoir called, “the lie of dementia” (p. 170) denies the full humanity of PWD and thwarts them in their efforts to adjust and embrace the present. According to Baldwin (2008), “The narrative of people with dementia losing their personhood degrade[s] and dominate[s]” (p. 224). Forced to internalize this narrative and the negative roles required in LTC and in society as a whole, PWD have little hope of adjusting to life with their disease.

Effectively “defined” (McColgan, 2005, p. 421) by society and “staff labels” (p. 429), the lives of these unfortunate individuals begin “losing meaning” (Graneheim & Jansson, 2006, p. 1401). In cases where the toxic effect of labeling, catastrophizing, and discounting continues unchecked by the positive effects of human connection and support for the internal process of reconciliation and adjustment, “a collapse of relations to self and others” (p. 1401) can occur. It is at this point that so many PWD are considered absent. Undoubtedly, PWD are irrevocably transformed by their disease; however, just as Kitwood (1997a) and others warned us nearly two

decades ago, lack of support for the individual's selfhood (on the part of family, friends, LTC staff, and society) can be an equally destructive force.

Changing the dominant narrative and caring for PWD. PWD need help: the help of social workers, of family members, of society as a whole, to reconcile the before and the now of who they are. They need help to form and maintain what Post (2013) called the "enduring" self (p. 349). To help PWD embrace their own "enduring" selves or what Bryden (2005) called a "new identity" (p. 170), society will need to change the narrative of dementia, begin to view dementia as "more of a challenge than a threat" (Steeman et al., 2006, p. 735), and make a purposeful commitment to living in the present (Basting, 2003; Hedman et al., 2013).

A role for clinical social work. Clinical social workers, in particular, with their wealth of mental health knowledge, holistic theoretical orientation, and commitment to "the dignity and worth of the person" (NASW, 2008) are uniquely poised to improve the lives of PWD living in LTC. Through direct practice and advocacy efforts at the micro, mezzo, and macro level, clinical social workers can help change the societal narrative of dementia. Defending the personhood of vulnerable clients with dementia through the education of staff and family members, implementing person-centered care interventions in LTC institutions, and conducting and disseminating research on personhood in dementia will all contribute to this effort.

With the help of clinical social workers in consulting, supervisory, and direct care roles, person-centered care ideas and interventions within LTC settings will need to continue to advance. These interventions should prioritize and facilitate human care and connection between residents, staff, and others. They should honor the individual and promote "a continuation of self and normality" (Edvardsson, Fetherstonhaugh, & Nay, 2010, p. 2614), guiding the system to fit the person and not the other way around. Identity as PWD construct and understand it should be

honored (Cohen-Mansfield et al., 2000). Assessment tools and recreational activities should be used to identify those “enduring” aspects of self that PWD themselves choose to highlight. In this way, the focus of care could remain on what PWD can do now (Beard, 2004) and what they have now (Ashworth & Ashworth, 2003), not on what has been lost. This could help social workers meet PWD where they are and at the same time restore staff and family members’ faith in the goodness of the present.

Limitations and Recommendations for Future Research

A meta-ethnography is not meant to involve an exhaustive literature search. The purposive sampling utilized in this study undoubtedly missed studies that could have made a significant contribution to the work. Furthermore, it must be acknowledged that those studies included in the synthesis may involve inherent bias toward the preservation of self and personhood in dementia. For it is perhaps unlikely that researchers interested in identity in dementia would study the subject at all if they thought personhood did not, at least in some form, persist despite disease. The narrow focus of this meta-ethnography on personhood within LTC facilities may also have skewed the results. Certain concepts, such as the negative impact of institutionalization on personhood, may have been overrepresented as a result of the purposive sampling employed in the search strategy. A more general research question about the subjective experience of dementia may have produced more surprising, and also more fruitful, results. Furthermore, a more diligent effort to find disconfirming evidence to the thesis presented herein may have been wise.

The criticism may be raised that the work of meta-ethnography is far removed from the data of the original studies synthesized, in this case, the words and actions of persons living with dementia. Noblit and Hare (1988) acknowledge that meta-ethnography involves “interpretations

of interpretations of interpretations” (p. 35). While this level of abstraction is perhaps no different than that found in many quantitative studies, it does need to be explained.

Meta-ethnography is a methodology that rejects positivism. It “should be viewed as an interpretation and, as such, subject to critique and debate” (Noblit & Hare, 1988, p. 35). For this reason, the findings of this study are not generalizable to other PWD in other LTC settings. Indeed, this study represents only one possible understanding of the subject at hand. Ultimately, though, the goal of meta-ethnography is not to accumulate evidence or definitively answer a question. Rather, it invites “readers to find the universal lessons of a particular, yet ‘strange’ culture” (Noblit & Hare, 1988, p. 79). In this case, the culture we seek to understand is that of PWD living in LTC. Accessing their experience was the goal of this study. Recognizing, however, that the subjective experience of any one person can never be fully known by another, the author is content “not to achieve closure, but to enable discourse” (Noblit & Hare, 1988, p. 77).

The interpretations in this meta-ethnography are limited in that the researcher did not have any other individual verify the cogency or appropriateness of the metaphors pulled from the studies or assess the degree of faithfulness of the final synthesis to the studies. In future research, it would be wise for meta-ethnographies to be conducted with, minimally, a second researcher in order to avoid confirmation bias and other pitfalls.

Further qualitative studies on the subjective experience of PWD in LTC are certainly needed. Much more remains to be discovered about how these individuals view their lives, their experiences, and their own personhood. Future research into personhood in dementia could also explore how experiences of identity differ between community dwelling and facility dwelling individuals and between persons with early-stage dementia and persons in the later stages.

Quantitative research studies would also be a good follow up to this meta-ethnography as they could allow the metaphors and third order constructs formulated herein to be tested for saliency in the lives of PWD.

Conclusion

This research project represents—to this author’s knowledge—the first meta-ethnography focused on the experience of personhood in dementia within LTC settings. As such, it addresses a significant gap in the literature. The study successfully synthesized seven studies on personhood in dementia at two levels. First, the study identified four third order constructs that were critical to understanding the experience of PWD in the LTC settings studied. These constructs: personhood *in their world*, personhood and maintaining *human connection*, expressing the *distinctiveness* of personhood, and personhood and *the role required in this place* offer powerful insight into the nature of identity in dementia. Second, the study produced a new theoretical framework for understanding the experience of personhood in dementia and how it is supported and diminished in LTC settings. According to the findings of this study, personhood clearly remains in PWD living in LTC. Furthermore, supporting Kitwood’s conclusions of the late 1990’s, personhood in dementia appears in many ways to be socially constructed. This means that although we, as professionals, family members, and a society are part of the problem when it comes to the diminishment of identity in PWD, we also have the potential to be part of the solution.

I choose a new identity as a survivor. I want to learn to dance with dementia. I want to live positively each day, in a vital relationship of trust with my care-partners alongside me. By rejecting the lie of dementia, and focusing on my spirit rather than my mind, I can be free of fear of loss of self, and in so doing can also help you to lose your fear that you are losing me.”

(Bryden, 2005, p. 170)

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**Papers synthesized in this meta-ethnography.*

Appendix A

First, Second, and Third Orders Constructs Identified in the Meta-Ethnography

Third Order Constructs (Translations)	Study	First Order Constructs (Raw Data)	Second Order Constructs (Metaphors)
Personhood in their world			
	Li & Orleans (2002)	Marion "lives in her own world of music" p. 241, George and Ebber "understand each other perfectly in their own separate world" p. 236	"in their world" p. 234, "separate world" p. 236, "distinctive culture and social reality" p. 233, "social organization" p. 233, "they forgot and they were forgotten to some extent by the larger society" p. 234, "collective culture" p. 234, "journeys to different places of being" p. 242, "beyond and yet here with us" p. 242, "relatively free" p. 241, "calmness" "passivity" "innocence" "pliancy" p. 242, "by focusing primarily on being" p. 242, "as deteriorations from some desired state" p. 242.
	Kontos (2004)	"Anna shouted 'shah' and then waited for Abe's response. Abe shouted 'bah', and Anna shouted 'shah', establishing a repeated pattern" p. 836, "A Health Care Aide approached Florence . . . And said enthusiastically, 'Hello gorgeous! You look great!' Florence lifted her arms above her head and shook her hips from side to side and then pushed her hips forward and backwards in brisk, accentuated movements" p. 834-835	"were not operating in their own private worlds" p. 840, "participants in a common world" p. 840, "being-in-the-world" p. 846, "below the threshold of cognition" p. 837, "engaged with the world" p. 836, "coherence and unity" p. 840, "fluidity and abandonment in movement" p. 834, "grasp of the environment" p. 839, "the body's affinity with its surroundings" p. 839
	McColgan (2005)	Alice expressed that she was "ready to go home" p. 425 by donning her coat and sitting in the lounge as though waiting to leave the place. Isobel stated, "I don't want to be classed as just a person as this. I would rather be classed a different place" p. 421	"reflecting on another place" p. 423, "from a time before" p. 423, "frequent longings for home" p. 428, "seeking something familiar" p. 423, "symbolic of independence" p. 422, "strongly linked to identity" p. 422
	Graneheim & Jansson (2006)	Philip said, "I take it easier now . . . You may be yourself. Just an ordinary man" p. 1401	"on their way to places that symbolize a freedom" p. 1402, "being in an empty world" p. 1401, "longing to get to a better place" p. 1402, "remembered better places from the past" p. 1401. "changed between the present and the past" p. 1400, "deceased are experienced as alive" p. 1400

	Surr (2006)	Resident, Kathleen (of her role in the nursing home): ". . . And I've come to work here, which I love, I like the people, I like the set up, in fact I thoroughly enjoy everything about it" p. 1726	"narrower social context and community" p. 1726, "limited contact with the social world and community outside of the home" p. 1725, "desirable social roles" p. 1727.
	Nowell, Thornton, & Simpson (2013)	Lily described this process of reaching for the past and familiarity as "putting a big jigsaw together, making the pieces fit." p. 401, Peter: "It's like living at my mum's." p. 401	"transient personhood" p. 402, "a return to the past" p. 402, "draw on past roles and status" p. 401, "home as a securely attached place" p. 401, "revisiting past experiences" p. 401, "security and familiarity" of the past p. 401
	Heggstad, Nortvedt, & Slettebo (2013)	Berit: "Home is where the family is, your things. Everything happens at home; that's where you're known. But it is very nice to be here too" p. 888.	"homesickness" p. 887, "merely visitors" p. 889, home is "where you're known", "long for a physical place they belong" p. 889
Third Order Constructs (Translations)	Study	First Order Constructs (Raw Data)	Second Order Constructs (Metaphors)
Personhood and maintaining <i>human connection</i>			
	Li & Orleans (2002)	"Katherine presented herself as kind, polite, and considerate . . . She always tried to talk to people next to her" p. 234, George and Ebber "held hands when they walked into the building, expected each other at the table for meals, and waited for each other" p. 236, "Residents cooperated . . . Cheered for each other" p. 237	"maintained their relationships" p. 234, "love and care continued" p. 235, maintain "human connection" p. 241
	Kontos (2004)	"After breakfast, Dora was in her wheelchair in a line-up of residents against the wall in the hallway. The resident next to her was crying out, 'nurse, nurse', and then started to weep and repeated the same phrase over and over, 'I want to go home'. Dora reached over and placed her hand gently on top of the resident's forearm. Holding her hand there, she sang, <i>Tumbalalayka</i> , a Yiddish lullaby." p. 834	"social aspects of the body" p. 845, "affection and physical contact" p. 833, "communicated affirmation" p. 834, "mastery of a common code" p. 842, "open and gentle presence" p. 833, "responding to vulnerability in others" p. 834,

	McColgan (2005)	"Residents loved, at these times, to sit with a cup of tea and have a 'blether.' They always wanted to sit with someone and have a cup of tea with them . . .socially, it was a significant part of the day for residents" p. 423	"having a blether" p. 423, "public ritual" p. 428, "a system of support" p. 428, "familiarity . . . from a time before" p. 423
	Graneheim & Jansson (2006)	"Philip said, 'I go on well with the care providers . . . Sometimes they ask for my knowledge and I enjoy giving information" p. 1401, John (speaking of a fellow resident): "And there is a lady here . . . We sit at the same dining table . . . and you can talk to her too. You need somebody to talk to in a place like this" p. 1401	"mutual togetherness" p. 1402, "social selves come and go" p. 1402, "being accepted" p. 1401 "being included" p. 1401, "invited to participate" p. 1401, "accepted . . . as equals" p. 1402, "needed and appreciated" p. 1401, "enhance a sense of self" p. 1402
	Surr (2006)	Brenda (speaking of John): "Very good friends we [her and John] are . . . He'll do anything for me. Yes, he will." p. 1725	"relationships with others" p. 1724, "recognition" "attachment" positive regard" p. 1724, "positive relationships" p. 1728, "a sense of security" p. 1725, "a feeling of being included" p. 1724, "nurturing and strengthening environment" p. 1725, "desirable social roles within the home" p. 1728, "caring" p. 1727, "helping others" p. 1727, "to work in the present" p. 1725
	Nowell, Thornton, & Simpson (2013)	Peter: "I've found that people here are like me, that aren't sure about what is going on . . . It makes me fee more saner." p. 403, Peter: "Everybody's friendly . . . So it's a big family. Yes. Yes, a big family. I'm used to lots of people." p. 401	"the ward experience was shared" p. 404, "being a part of the group" p. 404, "similarity would afford a sense of belonging" p. 403, "a desire to find commonality" p. 403
	Heggstad, Nortvedt, & Slettebo (2013)	Eli: "What's worst is . . . And I understand that they are busy, but if they just run through the corridor, and maybe someone will say, 'can I have that?' -and it could be pills or something - and they cannot, because they don't have time to answer, you know. And those kinds of things, it makes you feel a bit 'down'" p. 886	"being seen and heard" p. 886, "individual, autonomous persons" p. 881, "taken seriously" p. 886, "someone listens to our will and wishes" p. 888, "someone they belong to" p. 889, "someone who may confirm them as persons" p. 889

Third Order Constructs (Translations)	Study	First Order Constructs (Raw Data)	Second Order Constructs (Metaphors)
Expressing the distinctiveness of personhood			
	Li & Orleans (2002)	"in her own way" p. 235, "Larry whistled all the time, which had become part of the life of the facility. It identified Larry . . . [who] was once a respected high school music teacher" p. 238, "(Marion) hummed along with almost every song played, although she could not produce any of the words. She referred to Matthew playing the piano, saying, "I know what he is doing. I played that thing all my life. I know it." "George liked to wear his cowboy's hat and sit outside under the tree" p. 236	"idiosyncrasy" p. 238, "unique identities" p. 238, "individual persons" p. 234, "individual beings" p. 238, "distinctive sources of gratifications and frustrations" p. 241, "individual beings" p. 238, "create a fabled past" p. 235, "choose . . . not to do something" p. 238, "self-generating conduct" p. 236
	Kontos (2004)	"Dora, for example, sang on her own accord, while Edna when strolling down the hallway often stopped to look at the paintings on the wall." p. 844, ". . . When Abe was prompted by a member of the staff to take her hand, he slowly danced to the song being played on the radio" p. 844.	"unique synthesis of movement" p. 840, "distinctiveness" p. 844 "distinctive individuals" p. 844, "tendencies and inclinations" p. 842, "innovation" p. 844, "spontaneity" p. 844, "creative capacity of embodied selfhood" p. 845, "coherence of selfhood" p. 845
	McColgan (2005)	"Alice liked to be the first up in the morning . . . and arrived in the lounge before anyone else. Taking up her regular seat opposite the clock on the wall, she waited . . . Alice did appear to do a lot of waiting, but she always did it in the same chosen seat" p. 423	"their own identity claims" p. 429, "project a suitable self-image" p. 412, "staff labels" p. 429, "resist the institutional image presented" p. 422, "always...in the same chosen seat" p. 423, "claim ownership and distance from others" p. 429, "constructing an identity" p. 428, "privacy" p. 429, "control" p. 429, "distancing from the group" p. 429, "just sitting" p. 428
	Graneheim & Jansson (2006)	John spoke of the need to converse with residents who were less cognitively impaired in order not to become "like the others here" p. 1401	"residents who are really sick" p. 1400, "considered themselves as healthy" p. 1401, "not at the same level" p. 1401, "being placed among fools" p. 1400, "communicate their story" p. 1402 and "maintain their self" p. 1402

	<p>Surr (2006)</p>	<p>Charles: "I worked for Mullins Motors, making cars . . . that's my . . . biggest part of my life" p. 1726, Josephine: "Mm. They're good, three good girls, you know, my daughters. Well, I supp' I don't, I'm not boasting about them at all, but it's partly the way you bring them up, isn't it. Don't you think?" p. 1726, (Josephine): ". . . my husband was musical. He conducted, always conducted the anthem in the choir. We had a big choir in Reedon, in the chapel, you know, and er . . . he always got up and conducted the anthem, as they sang it, you know, and one time he did it and down he went on the floor, and a couple of the men from the . . . thing went to help him up and he was dead . . . That's why I'm living here now. Mm. Miss him terribly, you know." (p. 1727)</p>	<p>"having been someone" p. 1728 "the creation and telling of a life story" p. 1728 "contributed to society" p. 1726, "sense of contribution to self" p. 1726, "story as an attempt to communicate" p. 1728, "in the context of their past" p. 1728, "epiphinal events" p. 1728</p>
	<p>Nowell, Thornton, & Simpson (2013)</p>	<p>Jimmy: "How can I put the two together? I am the same but I am different" p. 402</p>	<p>"delineating differences" p. 403, "their very individual role" p. 402, "an individual outside of this group" p. 402, "draw on past roles and status" p. 401, "separate themselves" p. 403, "manage their own uncertainty" and to "bolster self-esteem" p. 403</p>
	<p>Heggstad, Nortvedt, & Slettebo (2013)</p>	<p>"In the unit where Asta lived, all the residents, except her, had their own key to their private room. One day when the head nurse came in to the living room, Asta walked straight ahead to her and asked her loud and clear: 'Can anyone tell me why I can't have my own key to my room?' The head nurse seemed to be surprised by this question from Asta, and it seemed as she did not expect her to express her wishes so clear." p. 886</p>	<p>"whole and unique persons" p. 888, "know who they are and what they have been" p. 888, "individual identity which exists behind the disease" p. 888</p>

Third Order Constructs (Translations)	Study	First Order Constructs (Raw Data)	Second Order Constructs (Metaphors)
Personhood and the role required in this place			
	Li & Orleans (2002)	<p>Jeff (of his mother with dementia): "I am very sensitive . . . I just have a little trouble to accept it. Remembering the way it used to be. That makes it harder." p. 240</p> <p>Mary Ellen (of her mother with dementia): "The most discouraging thing is I don't have her [Mother] any more to spend time with . . . It's disappointing. Loss of a person in your life . . . The person is not there. They don't know who they are, and who their family is, what they have done in the past. They cannot remember one minute from the next. " p. 239</p>	<p>"characterized only by losses" p. 243, "the patients' transforming selves" p. 241, "attribute anything but sorrow" p. 241, "pervasive melancholy" p. 241, "the past of the person" p. 240, "in terms of their losses and deficiencies" p. 241, "contrast of the past and present" p. 240, "loss of a person" p. 239, "deterioration . . . from some desired state" p. 242</p>
	Kontos (2004)	////////////////////////////////////	////////////////////////////////////
	McColgan (2005)	<p>Isobel: "I don't know what happened to make me like this . . . I don't want to be classed as just as person as this . . . I would rather be classed a different place" p. 421</p>	<p>"the role required in this place" p. 422, "categorical placement" p. 421, "a specific identity and status" p. 429, ""passive recipients of care" p. 419, "lack[ed] the esteem of others" p. 421, classed as a person with dementia" p. 421 "insitution strip[ped] residents" p. 429, "devoid of choice and privacy" p. 420, "defined" p. 421 "staff labels" p. 429, "disarray caused to individuals" p. 430, "staff obsessive and disruptive" p. 430, "tried to discourage possession of one area" p. 426</p>
	Graneheim & Jansson (2006)	<p>John: "Yes, I become furious . . . and I tell them that I walk anywhere . . . in London, in Paris and in Berlin . . . I don't need a nanny . . . but here, in a hole, I am not allowed to go out on my own because I could get lost . . . it is a hell of a life." (Graneheim & Jansson, 2006, p. 1400). John: ". . . they have their orders and I have my wishes" (p. 1400).</p>	<p>"overprotected" and treated like a child" p. 1400, "inadequate, confused and helpless" p. 1402, "locked up in the ward" p. 1400, "missed the freedom" p. 1400, "losing meaning" and "feeling empty" p. 1401 "a collapse of relations to self and others" p. 1401</p>

	<p>Surr (2006)</p>	<p>Olga (in response to the question, Do you like living here?): "Not here . . . I do not very much, you know, because it's not for me, you know, it's not mine, it's the others they're having plenty there. So . . ." p. 1725 Ethel: " . . . When there's a lot of women there's always something wants darning [sewing/mending] or doing something with it. But I told them and nobody's bothered to ask me so I can't go on me knees and beg so I'll have to just wait and see if anything materialises." p. 1725</p>	<p>"social roles" p. 1726, "current caring roles" p. 1727, "undesirable roles" p. 1728, "social exclusion and stigmatization" p. 1725, "powerless and ignored" p. 1725, "real friendships" p. 1725, "close bond" p. 1725, "never settled into the home or seemed at peace" p. 1725, "lack of validation" p. 1725, "undermin[ed] self" p. 1728</p>
	<p>Nowell, Thornton, & Simpson (2013)</p>	<p>Lily: "It's a lot of filling up time here, you have to do as you're told. You can't always have your own way." (p. 400). Ken: "You're living by their rules and regulations. You have to abide by their rules and regulations and I think that confines everybody in here to those aspects." p. 399</p>	<p>"impersonal" p. 399, "unknown" p. 399, "one size fits all approach" p. 406 "the central role of rules" p. 399, "reflective thinking" p. "socialised to the environment" p. 400, "fit the system" p. 399, "no longer having the qualities of a person" p. 400, "lack of choice" p. 399, "lack of respect and trust" p. 399, "personhood is unavoidably compromised" p. 399</p>
	<p>Heggestad, Nortvedt, & Slettebo (2013)</p>	<p>Grete: "Materially, it is good to live here. We get everything we need. We get food, clean clothing and so on, but . . . You know it is like a prison without bars . . . I feel like a prisoner. I have no freedom" (p. 887)</p>	<p>"seen and treated as a diagnosis" p. 888, "totally dependent" p. 886, "institutional frames" p. 889, "routines" p. 889, "locked doors" p. 889, "a feeling of captivity" p. 887, "homesickness" p. 887, "merely visitors" p. 889</p>