A Phenomenological Exploration of Autonomy and Related Psychological Needs
Among the Residents of a Memory Care Unit

by

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Dedication

I dedicate this dissertation to my children, husband, and beloved parents who encouraged me to pursue my dreams. I always aspire to make you all proud.

La Mia Familia

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Biographical Sketch

Mary Zagari K. MacLeod, LCSW-R, ACSW, CGP, ACS was born in Rochester, New York. She attended Nazareth College where she earned a Bachelor of Arts degree in Psychology and Education. She then continued to the University at Buffalo where she earned a Master of Social Work degree. She has worked full-time at the University of Rochester for several years as a Social Worker and Psychotherapist. She attended classes part-time at the Warner School of Education at the University of Rochester in pursuit of her Ph.D. in Education with a concentration in Counseling, Human Development, and Mental Health. Her area of interest is exploring wellness factors within gerontology; a population most endeared. She has collaborated on additional research projects and submitted the following publication: *Etiology and Management of Elder Self-Neglect*, Adult Span Journal (April, 2015).

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To my dearest and beloved children; remember your roots and never give up on your dreams.... find and follow joy.... I Love You.... Always and Forever. Ti Amo Sempre.... La Bella Momma....

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Abstract

The population of persons 65 years or older is the fastest growing age demographic in the United States. The number of older adults will continue to increase, as will the number who suffer from dementia. This rapidly growing population of older adults with dementia will challenge our healthcare system to provide quality long term residential care while maintaining patients' dignity, independence, and autonomy. The purpose of this study is to examine experiences of autonomy and other related psychological needs from the perspective of older adults who reside in a memory care unit of an assisted living facility.

Autonomy is associated with better health outcomes and quality of life (Williams, McGregor, King, Nelson, & Glasgow, 2005), yet little is known as to how it is experienced by older adults with dementia. Previous literature has focused solely on the benefit of autonomy and its contribution to greatly improving quality of life (Hellstrom & Sarvimaki, 2007). However, lacking in the literature are the perceptions of individuals with dementia whose autonomy and related psychological needs may be constrained for the purposes of safety and other pragmatics within a residential care setting. Exploring how autonomy and related psychological needs are experienced by those residing in a memory care unit will not only provide an understanding of this phenomenon, but also an insight into best practices in care for this population. The theoretical framework of Self-Determination Theory (SDT), particularly the Basic Psychological Needs mini-theory by Ryan and Deci (2000) served as a sensitizing framework for this qualitative descriptive study, which used phenomenological interviewing as an analytical tool.

As a result of this study, it is more clearly understood that autonomy and competence needs are powerful psychological needs despite fading memory and that reality is shaped and constructed by these individuals in order to retain these needs. A central finding of this study was the importance of allowing as much autonomy as possible within the scope of ones' capabilities. The five central themes which emerged were; *Autonomy: Real and Imagined, Implicit Belief of Competence, A Preference for Routine and Comfort, Nuanced Relatedness and Dealing with the Neurophysiological Effects of Dementia*. Additionally, these psychological constructs underscored self-identity and selfhood for the participants of this study. By providing valuable insight into this population's needs as a whole, training and education necessary within healthcare services would become more tailored leading to the implementation of a truly person-centered care approach in serving those with dementia.

Keywords: *Memory Care, Person-centered care, Negotiated care, Dementia, Qualitative, Phenomenology, Autonomy, Psychological Needs, Self-Determination Theory.*

Contributors and Funding Sources

This work was supported by a dissertation committee consisting of Professors: Kathryn Z. Douthit (advisor), with the Department of Counseling and Human Development, Warner School of Education. Silvia Sörensen, with the Department of Counseling and Human Development, Warner School of Education. J. Steven Lamberti M.D. with the Department of Psychiatry, University of Rochester Medical Center. All work conducted for this dissertation was completed by the student independently.

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Chapter 1- Introduction

1.1 Framing the Problem

In 2009, elderly adults aged 65 years or older represented nearly 13% of the US population, or 1 in every 8 American citizens. It is projected that by the year 2030, there will be about 72 million elderly individuals in the United States, or nearly 20% of the population (Department of Health and Human Services, 2013). With the first of the baby boomers turning 65-years-old in 2011, the number of older adults will continue to increase and about 1 in 5 of these older adults will be diagnosed with dementia (Karel, Gatz, & Smyer, 2012). In light of this surge in the number of individuals with dementia, there will likely be a simultaneous increased need for quality long-term residential care for elderly persons, so that as they age, despite any impairments, they can maintain as much dignity and autonomy as possible. This need to provide quality care while maintaining the autonomy and dignity of the individuals with dementia extends to those elderly individuals who are among the most compromised both physically as well as mentally, and provides the rationale for this study.

This research aims to challenge the commonly held assumption that older adults with dementia, who are receiving and dependent on care, no longer have a need or desire for autonomy. Dependency is often related to impairment and is commonly equated with vulnerability as well as the loss of autonomy (Morris, 2005). Lack of attention to autonomy and related psychological needs often has led to a paternalistic

conceptualization and execution of care, thus robbing dementia patients of the opportunities to fulfill this very fundamental human need. Boyle (2008) explained that older adults with dementia, due to their poor physical health and limited cognitive capacity, might no longer have the ability to exercise complete autonomy. However, as Boyle underscores, this does not mean they no longer have the need for autonomy and it may be that preventing them from feeling autonomous contributes toward depressed mood, apathy, anhedonia, and anxiety.

In addition to Boyle, other scholars such as Heggestad, Nortvedt, and Slettebo (2013a) have brought the issue of autonomy among individuals with dementia to light. These authors found in a Norwegian study that individuals within various stages of dementia and living in a nursing home, reported not feeling “seen or heard as individual autonomous persons” (p.1) in the context of preserving their personal dignity of identity; a construct linked to a person’s integrity, autonomy, self-respect, and social relationships. Lidz, Fischer, and Arnold (1992) state that although moderately to severely impaired individuals with dementia may not be able to make complicated choices or act consistently toward realizing long-term goals, they still have some capacity to choose what to eat and when to go to bed.

Although the need for autonomy among individuals with dementia has been raised by scholars such as those discussed above, whether or not that need actually exists is not clear. Hence, a concept that is central to the rationale for undertaking this research is that it is not known if and to what extent individuals with dementia continue to have the psychological need of autonomy. For instance, Mattiasson and Andersson (1997) found

that influencing daily routines was of lesser importance to nursing home residents than developing and maintaining social relationships, thus suggesting that autonomy may not be of primary concern for those in residential care settings. In fact, O'Neill (1984) suggests in his philosophical standpoint, that routines in care may relieve some individuals of the pressures of having to make their own choices. Therefore, lending support for the constructs of paternalism and partial autonomy within medical contexts such as in residential care settings. This study's purpose is to better understand how and if autonomy as well as related psychological needs are experienced for those in a memory care setting. Although the primary interest is on the experiences of autonomy, participants' other related psychological needs may surface. Given that my interest is to gain a phenomenological understanding of perceived and experienced autonomy and related psychological needs in a naturalistic setting, my research is designed utilizing a qualitative research framework, which is best suited for this aim (Miles, Huberman, & Saldaña, 2014).

The primary research question in this study is: How do older adults residing in a memory care unit of an assisted living facility experience autonomy and related psychological needs? The aim of the primary research question is to explore and describe the perception of autonomy and related psychological needs as experienced by individuals diagnosed with dementia who live in a residential care facility. Literature that addresses this issue in depth, from the perspective of the individual with dementia, is sparse. The use of a qualitative framework in exploring this area of study is particularly limited. The phenomenon of autonomy in older adults residing in a memory care unit has

not been studied extensively to date, which limits practitioners from fully understanding the depth and richness of these experiences in the context of providing quality care.

The framework of Self-Determination Theory (SDT), particularly the Basic Psychological Needs (BPN) mini-theory by Ryan and Deci (2000), informed this qualitative descriptive framework and will be discussed in further detail later in this chapter. This particular theory was selected because of its basis in humanism which is well-suited for a phenomenological framework. Also, this theory postulates that the basic psychological needs within BPN are universal regardless of age, gender, and culture. Deci and Ryan (2002) underscore the importance of Autonomy, Competence and Relatedness as the basic psychological needs, which are determinants of well-being. In this theory, the authors argue that all three needs are essential, as well as universal across various populations and age groups, and that if any is thwarted there may be a negative effect on well-being.

Key terms defined. For the purposes of this proposed study, the following terms are defined.

Alzheimer's dementia. *Alzheimer's* is a type of *dementia* that is progressive and irreversible in nature. Alzheimer's disease is the most common cause of dementia among older people (Alzheimer's Association, 2013).

Assisted living (AL). Facilities that are generally understood to be housing options that include personal care and health related services while providing long term care that maximizes independence and dignity (Mollica & Snow, 2002). There is no single accepted definition of *AL*, nor are there guidelines for distinguishing its operations from

other forms of care (Lewin-VHI, Inc., 1996).

Autonomy. *Autonomy* is “willingly doing something when not being externally controlled” (R. Ryan, personal communication, April 2015). Deci and Ryan (1985) differentiate the constructs of control and self-determination by stating “control refers to there being a contingency between one’s behavior and the outcomes one receives, whereas self-determination refers to the experience of freedom in initiating one’s behavior” (p.31). Autonomy is the vehicle “through which other psychological needs are actualized” (Ryan & Deci, 2017, p.97).

Autonomy: Real and Imagined. The perception of being self-determined as expressed by having choices, control, and independence.

Autonomy support. *Autonomy support* is the interpersonal behavior provided to identify, nurture, and build inner motivational resources. The opposite of autonomy support is controlling-ness (Deci & Ryan, 1985).

Baby boomer. A *baby boomer* is someone born during the demographic birth boom between 1946 and 1964 (Hughes & O’Rand, 2004).

Dementia. *Dementia* is a syndrome that results in a change in an individual's behavior and cognition (Ropper, Sameuls, & Klein, 2014). These changes are most often initially manifested as declines in recent or short-term memory and followed by other cognitive, emotional, and behavioral changes.

Elderly. Most developed world countries have accepted the chronological age of 65 years and older as a definition of *elderly* or older person (World Health Organization, 2015).

Instrumental activities of daily living. *Instrumental Activities of Daily Living* include activities necessary to reside in a community, such as shopping, managing finances, housekeeping, and meal preparation. Whereas, basic activities of daily living (ADLs), include activities of hygiene and personal care (Katz,1983).

Long-term care. *Long-Term Care* is a continuum of medical and social services designed to support the needs of people living with chronic health problems that affect their ability to perform every day activities (McCall, 2001).

Memory care. A *memory care* is a higher level of care in specialized care units for those with a dementia diagnosis, once called dementia units (Zimmerman et al., 2003).

Self-hood. A recognition that one's behaviors emanates from and are authored by the self (Ryan & Deci, 2017).

Self-identity. The concept of self-identity includes roles, identities, attributes, and preferences which an individual utilizes in describing him/herself (Cohen-Mansfield, Golander & Arnheim ,2000).

Understanding the baby boomers. The baby boom cohorts in the U.S. are defined as the individuals born in the years 1946 to 1964 (Hughes & O'Rand, 2004). As this population will be the primary focus for this study, understanding this cohort is warranted. This identified cohort most likely has a particular propensity to question the standards and expectations for behavior of people in their 50s and 60s, as its members were witness to challenging societal norms as in the civil rights and women's rights movements. They are the largest cohorts ever to enter middle age in Western society and

currently represent approximately one third of the total U.S. population (Whitbourne & Willis, 2006). Overall, they are healthier than previous generations of middle-aged adults, better educated, in possession of more disposable income to purchase products that will help them preserve their youthful appearance and products that will allow them to hold onto their identities, as well as their independence, for as long as possible (Whitbourne & Willis, 2006; Thomas, 2007). Thomas (2007) expounds by stating the following:

Baby boomers ...with a higher level of education than any previous generation, a higher level of wealth, and the well-established habit of re-inventing social norms, I think baby boomers are going to find the concepts of intentional communities and the approach to old age as a development stage instead of decline appealing and consistent with their values. (p. 3)

Therefore, it is highly likely that the aging population, particularly the baby boomers, will continue to value their independence for as long as possible. Yet little is known of how one's sense of freedom of choice, assertion of desire or will, and autonomy, are experienced, particularly after being diagnosed with dementia. This explains the nature of the problem that this research is designed to address.

Autonomy and autonomy support as sensitizing concepts. Autonomy and autonomy support will be highlighted in this study as sensitizing concepts. Charmaz (2003) has referred to sensitizing concepts as background ideas that inform

the overall research. The concept of autonomy is often considered synonymous with the notion of self-determination and as a constituent of well-being (Hill, 1989). Generally, the construct of autonomy refers to an individual's right or ability to govern oneself (Mele, 1995) and often has blurred lines of definition with the construct of perceived control, a term which will be discussed next. The term autonomy has little consensus as to its definition but is often considered to be a prerequisite to psychological well-being (Jacelon, 2007). The concept of autonomy support means that an individual in a position of authority (e.g., caregiver, family member) acknowledges the person's feelings and provides information and opportunities for choice, while minimizing the use of pressures and demands (Deci & Ryan, 1985). The need for autonomy has been shown to be central to people's well-being and is especially salient for older adults in institutional settings, as reported in a landmark study by Langer and Rodin (1976). In this study, nursing home residents who were encouraged to take responsibility, make decisions for themselves, and exert personal control were more alert, active, and happy than residents who were told the staff desired to care for them and make them happy.

Nonetheless, it follows logically that being autonomous contributes to having a sense of purpose. As a result, supporting a sense of well-being, Ryan, Huta, and Deci (2013) argue in their Self-Determination Theory, to be discussed in detail later, that eudaimonic approaches as opposed to hedonic approaches to wellness include a sense of meaning in one's life. Additionally, they theorized that eudaimonic living has positive effects of psychological wellness because it facilitates satisfaction of basic, universal psychological needs of Relatedness, Autonomy, and Competence. Through the construct

of eudaimonic living, autonomy as well as a sense of meaning and purpose are connected to psychological well-being.

The literature has focused almost exclusively on the benefits of autonomy and its contribution to improving quality of life, with one focus being the development of best practice approaches in person-centered care (Crandall, White, Schuldheis & Talerico, 2007; Hellstrom & Sarvimaki, 2007). Despite this, there is limited literature addressing the phenomenon of autonomy from a practice versus a theoretical perspective highlighting the day-to-day lived experience. Especially lacking in the literature, as noted before but worth stressing, is the perception of individuals with dementia whose autonomy may be constrained for the purposes of safety within a residential care setting. Past empirical studies that have informed this area of study are sparse and the ones that do exist are generally from the Eastern hemisphere as will be evident in the literature review portion of this paper. These studies will assist in substantiating the further work that needs to be done in helping to understand the psychological needs of older adults.

Autonomy as compared to perceived control. Despite its vagueness, Collins, Luszcz, Lawson, and Keeves (1997) defined perceived control as a perception of how much control one has over situations in one's life. Skinner (1996) attempted to collect and analyze control-related constructs in research literature and organize them according to their definitions. She admits that it becomes confusing for researchers when the same term, such as perceived control, is used to refer to different constructs, such as autonomy and self-determination, further adding to the lack of clarity as well as lack of consensus in defining these similar terms. In general, control has been defined solely in terms of

mean-ends or outcomes. Skinner (1996) argues that the “constructs related to autonomy are outside the proper domain of control” (p. 557). Deci and Ryan (1987) also relate the construct of perceived control to outcomes, but clearly state that the perception of control may not be equivalent to autonomy.

Deci and Ryan (1985) differentiate the constructs of control and self-determination by stating “control refers to there being a contingency between one’s behavior and the outcomes one receives, whereas self-determination refers to the experience of freedom in initiating one’s behavior” (p. 31). Autonomy is “willingly doing something when not being externally controlled” (R. Ryan, personal communication, April 2015). In other words,

one can perform a behavior such as picking up a stick if threatened by an outside force to do so and as a means to avoid being punished if the task is not performed (this is having perceived control because the outcome can be controlled), yet one does not have autonomy in the behavior because the person may not have wanted to perform the behavior but rather felt coerced to do it. (R. Ryan, personal communication, April 2015)

Generally, autonomy is thought of as one’s ability to make one’s own choices, to be one’s own person, and follow one’s own decided course of action (Mele, 1995). The opposite of autonomy is heteronomy, which refers to the feeling that one’s behavior is being coerced or controlled by external forces as in the example provided by R. Ryan

illustrating perceived control. Clearly, the precise nature of the role of autonomy is open to debate amongst philosophers, sociologists, politicians, theologians, and various other scholars. Ambiguity around the notion of autonomy persists in the sense that an overarching and universal definition of autonomy has never materialized.

Agich (2003) suggests that the term autonomy refers to a broad set of qualities not universally recognized and that its meaning is “irremediably context dependent” (p. 6). According to Smebye, Kirkevold, and Engedal (2015), autonomy is not equated with independence and rational decision making, but rather with self-identification. Several dimensions of the term autonomy have been defined such as the notion of “moral autonomy” which refers to an individual's capacity to impose objective moral law on oneself (Hill, 1989). Philosophers such as Kant claimed this capacity of “moral autonomy” as the fundamental organizing principle of all morality (Hill, 1989). Dworkin (1988) refers to “personal autonomy” as an individual trait that a person can apply to aspects of their lives that may or may not be concerned with moral obligations such as choosing coffee with cream or choosing tea.

Operationalizing autonomy for this study. In a medical, caregiver, or supported living context, maintaining respect for personal autonomy is considered a fundamental ethical principle (Beauchamp & Childress, 2001). As already discussed, defining the term autonomy can be challenging. Therefore, for the purpose of this study, and in keeping with the phenomenological framing as well as the constructivist lens of this study, an objective definition of the term autonomy is not what is being sought; rather the participant's lived experiences of autonomy as constructed by him or her within the

context of his or her living situation. As this is what is being pursued, a novel understanding has emerged of how autonomy is experienced for the participants of this study. The interview questions as seen in Appendix A were designed and constructed to elicit the participant's felt experiences and thus, the felt meaning of the definition of the term, autonomy, is what they constructed in their responses.

Understanding dementia. The term "dementia" is an umbrella term for a general, yet serious, syndrome that can be caused by a variety of conditions. Dementia is a syndrome defined by change in an individual's behavior and cognition (Ropper, Sameuls, & Klein, 2014). These changes are most often initially manifested as declines in recent or short-term memory and followed by other cognitive, emotional, and behavioral changes.

The prevalence of dementia worldwide is currently estimated to be about 35-36 million individuals; this number is projected to double by the year 2030, and more than triple by the year 2050 (World Health Organization, 2012). It is estimated that five million Americans in 2014 suffered from some form of dementia (Alzheimer's Association, 2014). Alzheimer's is a type of dementia that is progressive and irreversible in nature. Many dementias are progressive, meaning symptoms gradually, but persistently, get worse. Alzheimer's disease is the most common cause of dementia among older people (Alzheimer's Association, 2013).

Three-stage model. Although dementia affects memory, thinking, orientation, comprehension, learning capacity, as well as judgment, consciousness is not affected (World Health Organization, 2015). While dementia affects each person differently, there are some general signs and symptoms, which can be understood in three basic

stages: early, middle and late as described by the Alzheimer's Association (2014). The early stage typically has a gradual onset. Common symptoms of early stage dementia include forgetfulness, losing track of time, and becoming lost in familiar places. Most individuals in the early stage are able to live in the community but may require assistance on occasion.

In the middle stage of dementia, also known as moderate dementia, the nature and severity of the cognitive, emotional, and behavioral changes becomes clearer and more restricting. It often includes symptoms such as forgetting recent events, forgetting people's names, becoming lost at home, having an increased difficulty with communication, needing help with personal care, and experiencing behavioral changes including wandering and repeated questioning. At this stage, either most individuals will decide for themselves, or the decision will be made for them, that living in the community is no longer a safe and viable option. This particular group of individuals was selected for study because of their likelihood of being able to verbally communicate their desire and need for autonomy, while residing in a restricted setting for the purpose of safety. It was also speculated and later found in this study, that because of the restricted setting, the need and desire for autonomy becomes heightened and, therefore, more apparent.

In the late stages of dementia, one is near total dependence and inactivity. Memory disruptions may be serious and physical signs and symptoms may become more obvious. Symptoms include becoming unaware of time and place, having difficulty recognizing relatives and friends, having an increased need for assisted self-care, having difficulty

walking, and experiencing behavioral changes that may escalate and may include aggression. A higher level of care, such as a skilled nursing facility, may be required at this stage, as feeding, toileting, and ambulation become more difficult.

Seven-stage model. The Global Deterioration Scale (GDS) developed by Reisberg and colleagues utilizes a seven-stage breakdown to describe the cognitive functional states of those suffering from dementia (Reisberg, Ferris, deLeon, & Crook, 1982). According to this seven-stage adaptation, stage one describes no detectable memory impairments. In stage two, there is a very mild decline described by having memory problems, but these are generally not distinguishable from aging memory loss. In stage three, there is a mild decline where friends and family may begin to notice changes that the individual may have problems with planning, organizing, and remembering names of newly introduced acquaintances. These first three stages are referred to as the pre-dementia stages and are in general similar to the early stages as discussed previously of the three-stage model.

The middle stage of the three-stages model of dementia is comparable to stages four and five of the seven-stage adaptation. Stage four is a moderate decline where symptoms are apparent, and individuals may forget details of their life histories. Additionally, they may forget how to do simple arithmetic, making financial management difficult. In stage five there is a moderately severe decline where individuals may have significant confusion and begin to need help with many day-to-day activities such as dressing.

Stages six and seven are comparable to the late stage of dementia in the three-stage model. In stage six, there is reference to a severe decline characterized by unawareness of

surroundings, difficulty with communication, major personality changes, wandering, and loss of bowel and bladder functioning. Stage seven is the final stage and is a very severe decline where one is nearing death. These individuals may lose the ability to respond to their environment or to communicate. They need assistance with all care and often may lose their ability to swallow. Stages four through seven are referred to as the dementia stages in the GDS (Reisberg, Ferris, deLeon, & Crook, 1982). These stages of dementia not only affect the individual but also those who care for them. It is also warranted to mention the symptoms of sundowning as this will be referred to later in this study. Sundowning is a symptom of dementia such as in Alzheimer's disease. The term refers to confusion and agitation which may increase in the later hours of the day for some individuals (Alzheimer's Association, 2014).

The Diagnostic and Statistical Manual of Mental Disorders definition. Another dimension to the definition of dementia comes from its designation as a mental disorder in the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM 5, American Psychiatric Association, 2013). The diagnosis of dementia was recently renamed in the DSM 5 as Neurocognitive Disorder (NCD) in an attempt to help reduce the stigma associated with the word dementia (Warchol, 2013). In the DSM 5, criteria for NCD are significant cognitive decline, interference with independence, and these criteria are not attributed to another mental disorder. Interestingly, dementia crosses both paths of mental health as well as medicine, possibly lending itself to a dual level of stigmatization. However, there is some argument that the construct of dementia may be more socially constructed than medically derived (Harding & Palfrey, 1997). Pollitt (1996), for

example, argues that the relationship between psychopathology and cognitive decline may not be straightforward and that other variables may be involved such as personality, social, and environmental factors. In fact, Pollitt (1996) asserts that dementia is basically a Western diagnostic category devised from Western biomedical measures. He questions whether or not the phenomenon of dementia is universal; implying that the social cultural context in which dementia occurs influences how dementia and dementia care are viewed.

Addressing decision-making capability myths. Because cognitive abilities such as decision-making capabilities, as characterized in dementia, have been inextricably linked to autonomy, a deeper exploration of decision-making capabilities as well as the myths surround these abilities are warranted. The literature on decision-making capacity in older adults and people with dementia is quite clear in its assertion that these individuals, even if declared legally incompetent, should be empowered to make their own decisions, except for those decisions for which they lack a specific decision-making capacity (Grisso & Appelbaum, 1998; Pomerantz & de Nesnera, 1991). Thus, even individuals who have been legally declared incompetent can retain the ability to make certain types of decisions and exercise their ability to be autonomous. For example, an individual declared incompetent can still make decisions about whether or not they want to eat a certain food, go to sleep at a certain time, or if they want to listen to the radio versus watch tv. An individual who is incapable of making major decisions should not be denied the opportunities to make as many choices as possible, in light of existing capabilities. It is an ethical obligation of the caregiver to treat these individuals with

respect and allow them as much autonomy as possible within their abilities (Beauchamp & Childress, 2001). The presence of a dementing disorder in a person should not automatically lead to the conclusion within a care giving setting, that the person cannot participate in decision-making all together (Agich, 2003). This thinking is in line with the core theoretical framework of humanism, which will be discussed in more depth later in the chapter. Also, it is important to remember that a person's capacity to make decisions is not static. It is best understood as a fluid construct, which may change over time, with each individual, and with each situation (Grisso & Appelbaum, 1998; Pomerantz & de Nesnera, 1991).

Understanding assisted living facilities and memory care units. In light of the growing numbers of older adults, a shortage of nursing beds, and dissatisfaction with nursing home (NH) care, there was an increased and focused awareness over two decades ago of a gap in the continuum of care for ailing older adults (Zimmerman et al., 2003). The gap was primarily between the “independent senior housing that catered to the elderly population without any functional impairments, and nursing facilities” that cared for the chronically ill and compromised (Zimmerman et al., 2003, p.107). The gap was filled by development of the “first stand-alone assisted living (AL) facilities, which were modeled after Dutch residential settings” (Zimmerman et al., 2003, p.107). The general goals of an assisted living facility are to provide a homelike environment, independence, autonomy, and privacy to their residents. It is noteworthy that not all facilities successfully achieve these goals and this philosophy of care standard.

Because assisted living facilities are exempt from the licensing restrictions that regulate nursing homes (Mollica, 2001) and therefore lack federal oversight, significant variability has developed in the characteristics of the facilities themselves as well as the residents they serve. In fact, there is no single accepted definition of AL, nor are there guidelines for distinguishing its operations from other forms of care (Lewin-VHI, Inc., 1996). Assisted living facilities are generally understood to be housing options for long term care that maximize resident's independence and dignity while providing personal care and health related services (Mollica & Snow, 2002). Assisted living provides 24-hour supervision, as well as coordinated assistance for personal care needs on a scheduled and unscheduled basis. However, an assisted living facility is less apt to provide ongoing, 24-hour intensive nursing assistance for individuals who have complex or unstable medical conditions. The distinguishing characteristic of an assisted living facility, relative to other forms of long term care, is its philosophy of supporting the particular and changing needs of the individual while supporting lifestyle choices and minimizing the need to change residence. According to Mollica (2005), this move toward supporting aging adults in their home environment is termed "aging in place" (p. 2).

Regardless of the lack of standardization of guidelines and universal definitions, market pressure has resulted in proliferation of the AL industry, particularly stand-alone facilities (Zimmerman et al., 2003). These facilities can provide higher levels of care in specialized care units for those with a dementia diagnosis, such as dementia units, which are frequently known as memory care units, and can enable aging-in-place (Zimmerman et al., 2003). As previously mentioned, the lack of federal oversight and regulation has

led to a wide array of assisted living models, thus creating research challenges in determining “what types of service in which types of assisted living buildings are most effective for the diverse group of people who suffer from dementia” (Hyde, Perez, & Forester, 2007, p.54). Additionally, criteria for admission into a memory care unit also can vary from one facility to another (Hyde, Perez, & Forester, 2007). The “majority of people with dementia who enter assisted living facilities come from home or an independent-living retirement community” (Hyde, Perez, & Forester, 2007, p.54). Most often, “difficulty managing medications, and the need for help with instrumental activities of daily living are key reasons for moving into an assisted living facility” (Hyde, Perez, & Forester, 2007, p.52).

Hyde, Perez, and Forester (2007), in a meta-analysis, found that AL facilities have larger numbers of earlier stage dementia residents, whereas nursing homes have significantly greater proportions of profound and terminal dementia residents. Within these AL facilities, they found that nearly all dementia units used some system of exit control such as locked doors or alarms as a way to ensure safety. This raises the question as to how these practices can coexist with person-centered care, purported to be the philosophy of care within these facilities.

As noted previously, “central to the AL philosophy is a respect for the individuals who live in this setting and their continued rights as citizens and human beings” (Hyde, Perez, & Forester, 2007, p.51). Yet, this philosophy of care is tested when the “people served have cognitive impairments that compromise their ability to make or communicate decisions regarding their care and lifestyle choices” (Hyde, Perez, & Forester, 2007,

p.51). Hyde, Perez, and Forester (2007) found this to be a “unique paradox inherent in assisted living” (p. 51) and noted that the “medical versus nonmedical model debates are a symptom of this failure to recognize the dual nature of the assisted living product” (p. 51). This paradox is germane to this study’s research question of how older adults residing in a memory care unit of an assisted living facility experience autonomy.

Factors contributing to autonomy in residential environments. Well-designed physical space and enriching social environments intended to focus on enhancing quality of everyday life can help contribute to a sense of autonomy (Agich, 2003). Quality of life has been positively linked to certain building features, which support choice and control, community involvement, physical and cognitive support, comfort, and personal care; thus, creating a sense of normality and authenticity (State Government of Victoria, Australia, Department of Health, 2014). While it is important to mitigate danger by preventing people with cognitive impairments from being exposed to harmful situations, it is reasonable to make allowances for autonomy supportive activities, such as going for a walk outside or choosing what time to eat a snack. Creating structures of opportunities such as these can make a great difference in enhancing quality of life as well as in supporting autonomy (Hyde, Perez, and Forester, 2007). The challenge is to construct a setting that is safe while at the same time fostering as much individual choice as possible.

Well-designed building features that support choice and control do not compensate for the gaps in training of direct care workers, who are often not adequately prepared to provide autonomy supportive care. One review found that direct care workers received, on average, 75 hours of training that included little focus on issues specific or pertinent to

autonomy or dementia care (Alzheimer's Association, 2013). Furthermore, the fostering of positive relationships between the care provider and the individual allow the older adult to retain a perception of being in control (Kristensson, Hallberg, & Ekwall, 2010) and illustrate the importance of positive relationship building.

Kristensson et al. (2010) found that older adults, who were dependent on others and not informed of their care decisions often felt insecure. The feeling of insecurity ultimately led to conflicts with care providers. It is clear that multiple factors, such as the physical layout of the building, the quality of care, and the supportive relationships provided can determine how an older adult experiences support for their autonomy. Yet, the question that remains is how the older adults residing in a memory care unit subjectively experience their autonomy, support for their autonomy, and related psychological needs.

The person-centered care approach in relation to dementia care was developed as a way to interconnect the social environment and interpersonal interactions, in order to fulfill the psychological needs and well-being of those with dementia by honoring clients' choices as well as their autonomy (Willemse et al., 2015; Agich, 2003). Additionally, the person-centered approach is situated within a philosophical framework of providing service delivery that entails analyzing individual, team, or organizational practices with the goal of identifying areas requiring development to further an individual's autonomy. Person-centered care promotes greater patient responsibility by allowing patients to participate in the decision-making process, to the extent they wish to, and are able to; it

includes whoever is important to them in this process (Dow, Haralambous, Bremner, & Fearn, 2006).

Based on the research by Collopy (1988), Murphy (2007), Welford, Murphy, Wallace, and Casey (2010) and Clare, Rowlands, Bruce, Surr, and Downs (2008), it is clear that elderly residents and residents with dementia, continue to demonstrate a drive to fulfill their basic psychological needs as described by Self-Determination Theory (Deci & Ryan, 1985, 2000, 2008) and will be discussed later in more detail in the *Mini-theory within Self-Determination Theory* section of this chapter. In reviewing the suggestions by Clare et al. for improving conditions for people with dementia living in residential facilities, one can begin to see the relationship between the tenets of Self-Determination Theory and the needs of these individuals. These suggestions include:

1. Providing more opportunities for meaningful conversation and discourse with the residents. (Relatedness).
2. Offering choices and encouraging as much independence as possible for each person. (Autonomy).
3. Offering support for those experiencing depression, anxiety, etc. (Relatedness).
4. Maintaining continuity supporting the life roles of the residents such as allowing them more opportunities to engage in activities related to their work or hobbies. (Competence, Autonomy).
5. Eliminating boredom by encouraging meaningful activities. (Competence, Autonomy).
6. Encouraging a sense of community and belonging in the residents. (Relatedness).

7. Having the staff remain sensitive to the difficulties of living in a residential care facility. (Relatedness, Competence).

Controlled (extrinsic) motivation in residential care facilities. Residential facilities that house individuals with dementia tend to lean towards an authoritarian style of care, by exerting external control over their residents (Buron, 2008). A controlling environment such as this is high in external regulation and diminishes opportunities for intrinsic motivation in the residents (Deci, & Ryan, 1985). As discussed earlier in this paper, it is often erroneously believed that people with cognitive issues, as observed in dementia, automatically lack the capacity to make all decisions. While the need for external control in residential care homes that house a significant number of people with dementia is designed to ensure the safety of the residents, it is also important to remember that even individuals with moderate dementia can retain the ability to make certain types of decisions.

1.2 Theoretical Perspectives and Framework

Bronfenbrenner (1979) proposed in his Ecological Systems Theory that, in order to understand human development, the entire ecological system in which growth occurs needs to be taken into account as well as the person-context interrelatedness. In the context of dementia care, the macro-ecological perspective, which examines general attitudes towards aged individuals and ideologies of aging interact with and influence the micro-ecological systems, the systems in direct contact to the older adult such as family and care providers.

For this paper's purpose, the micro-ecological systems will be detailed with the understanding that the macro-ecological perspective of dementia care influences this system. The micro-ecological systems encompass the relationships and interactions an older adult with dementia has with their immediate surroundings such as family, residential care setting, and care providers. We begin this foundational understanding by examining care within a humanistic conceptualized viewpoint known to honor a person as a whole being, rather than a fragmented entity.

Humanistic framework. Humanism is a philosophical and ethical stance that emphasizes the value and agency of human beings. Martin Heidegger (1977), in attempting to express the simple essence of the truth of being, wrote “for this is humanism: meditating and caring, that man be human and not inhumane, ‘inhuman’, that is, outside his essence. But in what does the humanity of man consist? It lies in his essence” (p.86). Fundamentally, humanism is the study of the whole person, not only through the eyes of the observer, but through the eyes of the person being observed.

Western cultures tend to conceptualize dementia as an impairment and disability (Baldwin, 2005). As a result, dementia has often been depicted as a disease process and biomedical phenomenon with a trajectory of irrevocable decline related to neurodegenerative changes (O'Connor et al., 2007). However, with American health care viewed as impersonal and fragmented, there has been movement to redesign dementia care in the image of a more “patient centered practice rooted in humanistic psychology which holds that people are unique and multidimensional beings and that their

psychosocial and spiritual dimensions are as important as their physical health” (Love & Pinkowitz, 2013, p. 2).

Kitwood and Bredin’s (1992) influential work connected the sentiments and values of person-centered care specifically with dementia care. They believed the key psychological task in dementia care is that of keeping the sufferer's personhood intact by accepting the person as a human being, not as a diagnostic label. The central ideas of person-centered care foster practices in which people with dementia are treated as individuals by valuing them and looking at the world from their perspective (Gee & Scott-Multani, 2014). The question remains as to whether or not this premise of care is in fact being fully realized and implemented in contemporary practice.

Built upon this person-centered framework, the Eden Alternative is a philosophy of care developed in the early 1990’s by Dr. Bill Thomas, a physician specializing in geriatrics. This philosophy utilized the fundamental principles of identity, growth, autonomy, connectedness, and meaning to delivery of care (Tavormina, 1999). The support of autonomy is central to person-centered care (Happ, Williams, Strumpf, & Burger, 1996; Edvardsson, Winblad, & Sandman, 2008). According to Love and Pinkowitz (2013), there has been little progress made in creating policies, programs, and evidence-based practices to support transitioning to person-centered dementia care. Person-centered care is considered the gold standard of care (WHO, 2012), despite there being no common understanding or framework to define person-centered dementia care until initial steps were taken in 2012. While considerable progress has been made regarding a common understanding of person-centered dementia care, the question

remains of how to incorporate person-centered care within the bio-medically rooted mindset of the Western culture. In order to successfully accomplish integrating meaningful person-centered care within the Western culture, we may need to begin by dispelling misconceptions that older adult's lives have less value, promoting education by incorporating humanism into care practices, and holding firm to a value that all humans matter, regardless of their limitations, by embracing a more humanistic view which highlights autonomy and choice of the individual (Agich, 2003). Understanding how autonomy is experienced for those with dementia may allow care providers, policy-makers, and assisted living administrators the tools for implementing meaningful person-centered dementia care.

Understanding autonomy within the humanistic framework. Some scholars, such as Heidegger, have noted that autonomy can be used to refer to both a global condition (e.g., morality) as well as a more individual position such as personal choice (Heidegger, 1962). Heidegger, an existential thinker, conceptualized autonomy as a form of self-determination as well as a form of self-recognition. Making choices for oneself is important because one could not be recognized as an individual without the appreciation that one's behavior is a result of one's own initiative (Heidegger, 1962). By being autonomous, or at least feeling autonomous, as expressed by Heidegger (1962), it defines us as individuals and supports our sense of self (self-hood or personhood), and as a result, contributes toward our well-being; therefore, linking the construct of autonomy with the sense of self and well-being.

Other common definitions have lent themselves to reductionism in that they reduce the concept of autonomy to exclusively cognitive attributes, disregarding the remaining qualities of being human. These more cognitive definitions of the term autonomy are framed in the Kantian tradition, which stresses the importance of rationality, mental capacity, and competence. This Kantian framework does not directly relate to the basic premises of my study in that it disregards those with cognitive limitations. In this light, Sherwin and Winsby (2011) make the claim that equating autonomy to rationality may lead to the undervaluing and discrimination of older adults who lack capacity, have cognitive limitations, or who are dependent on others. Loss of cognitive and decision-making abilities should not be the defining points in having lost the quality of being human. In fact, humanist theories share in the contention that reasoning abilities alone do not substantiate the criteria for personhood.

Humanism and Self-Determination Theory. By the late 1950s, the two major paradigms driving clinical psychology were the psychodynamic and behaviorist paradigms. These paradigms tended to adopt a mechanistic view of human behavior and many psychologists were not satisfied with this approach. The third paradigm that evolved from this dissatisfaction was the humanistic movement. This movement was fueled primarily by Abraham Maslow (1943) and Carl Rogers (1959), although other theorists such as Otto Rank and Rollo May have been instrumental in promoting the humanist perspective (McLeod, 2007). Humanistic psychologists strongly believe in choice, free will, and self-determination, or self-actualization as characterized by Abraham Maslow (1943), as the important determinants of behavior and personality.

Their ideas are a reaction to the psychodynamic notion that instincts direct behavior and the behaviorist notion that the environment shapes personality. Thus, the humanistic model sought to put the control of people's lives back in their own hands. It concentrated on issues such as the need to meet basic human needs as food and shelter, but also on the human need to strive for other more abstract goals as in a sense of belongingness, creativity, and finding meaning in life. Hence, the humanistic paradigm did not deny the psychodynamic notion that people are motivated by drives or the behaviorist notion that the environment can help shape behavior; instead, the humanistic paradigm added a third element, innate motivation, to these notions. Motivation was a result of instincts or environmental pulls, but was also fueled by the need to become something more than a "cog in a machine" and a need to find deeper meanings to life and existence, something not well explained by the prevailing psychodynamic and behaviorist paradigms in psychology at the time.

Given their views, the humanists are often considered to have a more positive outlook on behavior and personality relative to the psychodynamic and behavioral theorists. The humanistic paradigm has been the foundation for a number of important theories relevant to the current discussion of autonomy and decision-making capacity in elderly dementia patients. The most relevant of these theories is aptly termed Self-Determination Theory (Deci & Ryan, 1991, 2000, 2008; Ryan & Deci, 2000, 2017). The central theme of Self-Determination Theory is that people have an innate drive towards personal growth that environmental conditions may either facilitate or thwart. This innate drive is consistent with the humanistic notion that people seek such things as

belongingness and relevance. There are optimal conditions that facilitate these innate motivations or innate needs which will be described next in the mini-theory within the Self-Determination Theory.

Mini-theory within Self-Determination Theory. These optimal conditions are defined by the satisfaction of the psychological needs for competence, relatedness, and autonomy, and collectively, these three elements comprise the foundation for the basic psychological needs sub-theory, a mini-theory, within the Self-Determination Theory (Deci & Ryan, 1985; Ryan & Deci, 2000, 2017). A strength of this theory in relation to my research is that it posits that these psychological needs are universal across age and culture, which makes it well suited for the purpose of exploring the psychological needs of older adults.

Competence refers to “our basic need to feel effectance and mastery” (Ryan & Deci, 2017, p.11). Relatedness refers to social needs of individuals such as the need to connect with others, interact with others, and show concern for others (Deci & Ryan, 2008). Autonomy refers to the need that individuals have regarding control over certain aspects of their lives and being able to make choices (Deci & Ryan, 2008) as well as being an active agent in the experience of behaving in accord with one's own interests or values (Ryan, Rigby, & King, 1993). Within the Self-Determination Theory, the universal nature of autonomy gives it applicability among individuals with cognitive deficits, such as those with dementia. An understanding of the need for autonomy is essential in the framework of this study.

Additionally, because the concept of autonomy for older people is minimally understood and not well developed in the literature (Murphy & Welford, 2012), the Self-Determination theory's definition of autonomy provides a broad and encompassing conceptualization from which to begin the exploration. According to Richard Ryan, "the issue of autonomy has both emotional and cognitive aspects, but explicit cognition is not required, as even infants have demonstrated the need for autonomy, by experiments undermining intrinsic motivation by external rewards" (R. Ryan, personal communication, October 15, 2014). In infancy, intrinsic motivation as displayed by the behavior one chooses to engage in without external forces is readily observable as exploratory behavior. Infant's observable behaviors were examined in a study conducted by Grolnick, Frodi, and Bridges (1984), where it was found that infants, whose mothers supported their autonomous behaviors in mastering a task, were more persistent than the infants whose mothers were more controlling. Thus, supporting the premise as communicated by R. Ryan that external control undermines intrinsic motivation, as early as in the infant years where cognitive abilities are not yet fully developed.

In more practical terms, Self-Determination Theory proposes that many things motivate individuals, but their primary psychological motivations include experiencing a sense of ability, being socially connected with others, and having choices in environments that they consider to be important to them (Deci & Ryan, 2000). It is a theory that supports the value of all humans by incorporating an individual's point of view regardless of their mental and cognitive capabilities. When these three psychological needs are adequately satisfied, individuals tend to exhibit optimal levels of

motivation, and harbor feelings of connectedness and well-being. Conversely, when these three needs are perceived as being thwarted, individuals begin to lose their motivation to actively involve themselves in aspects of their lives and may have a sense that they are not complete or valued. In applying this premise to an individual with dementia, it is foreseeable that these individuals may lose their sense of having value as well as lose their sense of well-being, if not supported in their need for competence, belonging, and autonomy.

In cases of a severe lack of these three psychological needs, individuals can become mentally or physically disabled (Deci & Ryan, 2000). Although these needs are psychological in nature, without the psychological nourishment provided by satisfaction of basic psychological needs, Deci and Ryan posit that individuals will begin to experience a sense of discontinuity, periods of amotivation, and physical and mental disharmony over time. Satisfying one or two of the three would not suffice; “each of these three needs plays a necessary part in optimal development so that none can be thwarted or neglected without significant negative consequences” (p. 229).

Consequently, the three psychological needs nurture an overall mental sense of completeness as a person. As discussed by Clare et al., (2008) this sense of completeness can be diminished in individuals with dementia who are not supported by caregivers and family in experiencing all of these psychological needs.

Despite the strengths of the Self-Determination Theory for use in exploring the needs of older adults, it does have its limitations. Although this theory claims that specific psychological needs are universal, this claim has been a source of debate. Keller

(2012) mentions that varying cultural environments can ascribe different meanings to the terms autonomy and relatedness, depending on the contextual demands of that cultural milieu, which, in addition, can change over time. For example, non-Western families are more inclined to support communal psychological autonomy with social responsibilities prioritized over individualized autonomy. In contrast, Western families focus primarily on individuals and their inner states. Chirkov, Ryan, Kim, and Kaplan, (2003) argue against this and support the notion of autonomy being a universal need by differentiating the construct of autonomy within Self-Determination Theory from the constructs of individualism, independence, or separateness. This is an example of how a macro-ecological perspective can influence the micro-ecological systems, as discussed previously. Despite these points of debate, Self-Determination Theory does provide the framework as well as the justification for exploring how the psychological need of autonomy in older adults with dementia is experienced. Additionally, by better understanding the phenomenon of autonomy from the perspective of the psychological needs of those with dementia, future care such as innovative programs/practices, care provider development, and policy/system changes can be tailored to meet the demands of quality care.

1.3 Analytical Framework

Epistemological framework. Epistemology is the explanation of how we know what we know (Crotty, 1998). In other words, epistemology is a theory of knowing (Sprague, 2010). Exploring and identifying one's theoretical framework as a researcher challenges us to define what we know and, more importantly, how we think we know. A

constructivist perspective situates belief in a subjective reality: What each individual believes to be true is real to that individual, at least for that moment. It also incorporates the socio-cultural aspects of perception and cognition. The individual places meaning on his or her beliefs, which are shaped by local culture, and then acts accordingly. In other words, truth for the individual is constructed and not found. According to Sprague (2010), the world and the societies within, are socially constructed because they are products of ongoing human activity.

Qualitative methodology is largely founded on a constructivist philosophy as it is designed to elicit the meanings behind behaviors, in order to best understand the participants' construction of reality. The essence of constructivism is to encompass the subjective and to make meaning of one's reality. Individuals' interpretation of events is considered important (Miles & Huberman, 1994) and provides the framework for a phenomenological analysis. Phenomenological methodologies are related to constructivism in that they are focused on understanding a phenomenon in a comprehensive and holistic way by acknowledging the constructed and contextual nature of human experiences in allowing shared realities to coexist (Thorne, Kirkham, & O'Flynn-Magee, 2004). Therefore, it is substantiated that this epistemological framework, a phenomenological analysis, is best suited in underpinning the methodologies needed to understand the primary research question under study.

In this approach, truth, in terms of one's reality, is viewed as provisional and emergent rather than static and linear (Thorne, 2008). Individuals do not exist in a social vacuum and the social constructivist view recognizes this reality (Thorne, Kirkham, &

O'Flynn-Magee, 2004). Truth and reality are created via symbols, such as words and actions (Sprague, 2010). In other words, shared meaning becomes truth. This approach is relevant to my research question in that it takes into account how the researcher understands reality while exploring the participant's subjective views through phenomenological interviewing methods. Phenomenological interviewing, to be discussed in more detail later, is a method of questioning which employs descriptive as well as a structural approach as a means to explore experiences (Bevan, 2014). In order to provide meaningful person-centered care, the participant's reality must be understood, even if it is grossly different than the researcher's and care provider's reality, so that emotional and psychological needs of the participant can be met. The researcher cannot truly know how the participant experiences reality except through use of words and actions, which the researcher subjectively interprets.

In general, the constructivist lens allows room for the researcher's role and reactions to what is observed because meaning is created and constructed, not simply discovered (Sprague, 2010). A researcher is not simply an observer, but rather a participant within the process of research (Thorne, 2008). The researcher's presence can change the dynamics of being observed and this may, in turn, help create meaning. The constructivist epistemology and qualitative methodology are best suited for research where capturing individual meaning becomes an important element, as is the case with my research question. Therefore, the constructivist lens supports the methods of a qualitative design and phenomenological interviewing to capture the lived experiences of those under study.

My primary research question is best explored using the postmodern framework and lens because it lends itself to allowing for multiple explanations of how the world for older adults residing in a memory care unit can be experienced. The phenomenological interviewing method, as mentioned previously, is situated in a postmodern framework and utilizes the theoretical underpinnings of constructivism and subjectivism. Because it is germane to my research question, it is salient to note that Mak (2009), who was interested in studying subjective well-being, found that individuals with cognitive impairments, such as those with mild to moderate dementia, are able to provide reliable information regarding their internal emotional state. In other words, an individual with cognitive impairment may be able to provide reliable information as to whether or not they feel autonomous within a context. Digby, Lee, and Williams (2016) found that information provided by participants with dementia may not always be straightforward or factual but represents the individual's feelings at that particular time, demonstrating "genuine authenticity" (p. 8). In addition, this finding further substantiates the use of a phenomenological interviewing approach in eliciting rich data in understanding the phenomenon under study. Furthermore, incorporating Self-Determination Theory (Ryan & Deci, 2000, 2017), provides a sensitizing framework in the phenomenological understanding of how autonomy is experienced within this population.

Epistemological implications. Thus far, I have given justifications supporting the benefits of a qualitative approach for use in understanding the complex nature of how individuals with dementia experience autonomy and related psychological needs in a

residential care setting. According to Creswell (1994), a qualitative study is defined as an inquiry process of understanding a social or human problem, based on building a complex, holistic picture, incorporating detailed views of informants, and conducted in a natural setting. It is of great importance to have congruence between selected qualitative methodology and the theoretical framework in designing research (Maxwell, 2013).

Maxwell (2013) states that the purpose of theory is to draw attention to what one sees, as well as to shed light on relationships, that may otherwise go unnoticed. He does caution that, “no theory can illuminate everything” (p.50). However, it can guide inquiry and the rationalization for exploring a particular phenomenon.

Thus far, I have provided a rationale to support the premise that the need for autonomy continues to exist in the dementia population and that little is known and understood in regard to the phenomenon of autonomy in dementia. According to Thorne (2008), qualitative research is designed to generate empirical knowledge of a contextual understanding of a human phenomenon for which measurement is inappropriate or premature. Because so little is known or understood about autonomy and older adults with dementia, applying quantitative measurement at this point would yield data with limited validity.

1.4 Methodological Overview of the Research Study

Research participants in this study are adults, aged 65 and older, who are in early late to middle stage dementia and who reside in a memory care unit of an assisted living facility. The aim of the study is to answer the research question: How do older adults residing in a memory care unit of an assisted living facility experience autonomy and

related psychological needs? I have used a phenomenological interviewing approach, a method to be described in detail later, as well as observations of residents and staff to answer my research question. These methods have been instrumental in obtaining data that describe these individuals' lived experiences.

1.5 Conclusions

There is an ethical obligation to recognize that people with cognitive limitations, such as dementia, are human beings who have basic innate needs that are physical, mental, emotional, and psychological. Self-Determination Theory, aligned with humanistic and organismic theories, offers a framework supporting person-centered care and insight into what particular psychological needs are important in maintaining the mental well-being of all people, regardless of age or limitations.

A thorough analysis and a solid framework has been provided regarding the notion that qualitative methodology, grounded in humanism, is best suited for exploring my primary research question with the ultimate goal of contributing new knowledge to an unexplored phenomenon. This method is based on the epistemological and ontological frameworks that support human realities as subjective and constructed within a context. The phenomenological interviewing approach, with its constructivist's and phenomenological roots, provides solid underpinnings from which to explore the phenomenon of autonomy and related psychological needs for older adults residing in a memory care unit.

Chapter 2 -Literature Review

2.1 Overview of the Relevant Literature

The literature to be discussed next illustrates the importance of autonomy as well as the importance of supporting autonomy. The reviewed literature is divided topically and involves overarching generalizations regarding the experience of autonomy and autonomy support, as empirical data directly linking these areas of study to those with dementia residing in memory care units are lacking. However, having a view of autonomy as it relates to one's environment, the care giver perspective, as well as other cognitive disorders closely related to dementia lend support that directly exploring how autonomy is experienced, specifically for those with dementia residing in a care facility, is an area that requires further exploration.

This chapter attempts to answer the question of how previous studies have, from various perspectives, captured the experience of autonomy in older adults. In addition, the literature reviewed in this chapter will demonstrate that this answer is quite elusive and will highlight the sparse attention in prior research addressing the lived experiences of autonomy for individuals residing in memory care units. Obstacles such as recruitment difficulty, language deficits, and credibility of subjective information may all play a role in this limitation of literature (Penrod et al., 2007). There is, however, considerable attention given to the support for autonomy, as it is examined for those in residential care facilities from various perspectives, such as from the residents' and from the care providers', for those with dementia and similar cognitive challenges. Prior research will

be discussed in terms of its relevance, application in practice, contribution, as well as gaps in contributing to the knowledge base, as it relates to the phenomenon of autonomy by individuals residing in memory care units. Within the discussion of the relevant literature, there will also be mention of how methodological approaches have expanded the field of knowledge being discussed as a means to support my study's contribution to the scholarly conversation.

I begin by exploring the literature that addresses the meaning of autonomy from the caregiver, the resident, and other relational perspectives as a way to lend weight to the pursuit and refinement to my area of study. My study assists in closing the gap in the literature by adding a phenomenological vantagepoint of how autonomy is experienced by those residing in a memory care facility. Next, I explore the literature addressing specific factors that have contributed to autonomy such as the effects of the environment and communication styles before detailing literature that offer suggestions on how to maximize autonomy for residents. I conclude the chapter with summarizing literature particularizing the need and benefits of autonomy for populations with cognitive deficits similar to those with dementia, such as individuals with traumatic brain injury, developmental disabilities, and schizophrenia. The purpose of incorporating these other closely related populations is twofold. One is to demonstrate the stark contrast in the volume of literature for these populations in comparison to older adults with middle-stage and more advanced dementia. The other purpose is to examine how autonomy is experienced for those with cognitive deficits and limitations, as these are not exactly, but

closely related to the cognitive challenges of those with dementia as demonstrated in decreased problem-solving abilities, difficulty with abstract thinking, and poor judgment.

Literature review of autonomy among older adults in residential care. This section begins by exploring the literature found after a search via Pro Quest. Key terms such as memory care, dementia, cognitive deficits, autonomy, agency, older adults, well-being, quality of life, personhood, and autonomy support. The literature was reviewed and the most relevant articles to my research question were selected.

The literature exploring personhood and quality of life for older adults has shown a growing trend over the last several years, particularly in European countries. This growing trend emerges from the theoretical framework of person-centered care which is founded on the ethic that all human beings have value and are worthy of respect despite their disability (Epp, 2003). Additionally, it stresses that individual care is best provided when tailored to the individual's changing needs. Again, the data addressing this issue from the perspective of the older adult with a diagnosis of dementia are extremely limited. However, my research aides in providing key insights as to how autonomy is experienced directly by those with this diagnosis.

The majority of the literature exploring the notion of autonomy in older adults residing in a residential setting is descriptive and framed in terms of quality of life, well-being, and life satisfaction rather than specifically and solely addressing the perception of, or need for, autonomy. One primary issue noted is that the term autonomy is generally not associated with older adults with dementia because the term is usually contextualized as referring to independence. It is often assumed to rely heavily on

cognitive abilities as well as reasoning capabilities. Another salient issue is that there is no operational definition of autonomy, as discussed in detail earlier. Perhaps, as Welford, Murphy, Wallace, and Casey (2010) suggest, autonomy should be context dependent because of its nature being dynamic rather than static. My findings in my research lend support to this notion and will be discussed at a later point in this paper.

Through the process of examining the literature, a larger number of the articles found originated from the United Kingdom (UK), Netherlands, Sweden, and Canada. These articles were empirical studies utilizing the perceptions of those under study. In comparison, there were very few articles specific to this topic originating from the United States (US). This comparison is noteworthy in that it illustrates the importance of research and how research is conducted, in relation to dementia, based on global conceptualizations of this diagnosis. One article from the US was written by Collopy (1988) and another, discussed in more detail later, by Kasser and Ryan (1999) which illustrates empirical findings in a mixed method study. The article from Collopy (1988) was a conceptual piece, which was a review of case studies, highlighting the need for autonomy while explaining the differences of decisional and executive autonomy. Collopy (1988) as well as Kasser and Ryan (1999) highlighted the importance of self-determination and autonomy for those in residential settings. Kasser and Ryan (1999), to be discussed in detail later, found that autonomy and relatedness are central to older adults' well-being in institutional settings; thus, supporting the importance of retaining these needs for residents. Similarly, Collopy (1988) detailed how individuals involved in long-term care could experience self-determination while still being subjected to the

supervision and rules that long-term care providers enforce for resident safety. Collopy (1988) discussed a tension in self-determination based on decisional autonomy and executive autonomy. Decisional autonomy is composed of the ability to make decisions without outside coercion or restraint, whereas executive autonomy is the freedom to act on decisional autonomy.

Decisional autonomy can exist without the freedom to execute choices such as for those individuals who are incapacitated, constrained or prevented from acting (Collopy, 1988). For example, an individual could possess decisional autonomy over certain types of choices such as what time to eat dinner, but be restrained in their executive autonomy by the rules and regulations of an external force such as living in a residential home that enforces limits on opportunities to make and execute decisions. There is a distinct difference between being autonomous in actions and being autonomous with decisions. My research highlights and contributes toward the understanding of and distinction between these two.

Residents of long-term care homes, according to Collopy (1988) should be able to make certain choices regarding their activities of daily living where they only require no assistance or minimal assistance (e.g., bathing, eating) and should be able to surrender executive autonomy in instances where total assistance is required. Other relevant potential determinants, according to Collopy (1988), which are applicable to patients with dementia, include such notions as direct versus delegated autonomy. Here the polarity is deciding between being able to act on one's own (direct) versus giving the authority to have others direct for them (delegated).

Mutually agreed-upon norms by residents, their families, and caregivers pertaining to when authority should be given to others for decision-making can lessen the burden of a resident feeling that they have no control to act on their own, according to Collopy (1988). Additionally, Collopy (1988) offers a potential solution for residents in long-term care facilities to balance the need for an individual to retain a sense of self-determination while delegating specific decision-making tasks to caregivers in order to allow the resident to be safe and secure. The need for an individual to retain a sense of self-determination adds merit to the notion that there is a tension at play in institutional settings with safety and autonomy needs. There is a question which yet remains, as is evidenced by the gap in the literature, specifically addressing how best to elicit these data from the residents' perspective, particularly those with dementia. My study helps in closing this gap in the literature and specifically addresses the tension between safety and autonomy needs.

A salient point highlighted in this study is that individual care is best provided when tailored to the individual's changing needs, further lending merit to the need for person-centered care. These data emerged after careful review and description of case studies, which are often used in a qualitative methodological approach as a means to gain deeper meaning of phenomena not yet fully understood. This lends support to the method of incorporating case studies, as conducted in my study.

From the caregiver perspective. In Ireland, Murphy (2007) led an exploratory qualitative study by collecting data from over 300 nurses working in long-term care facilities. The aim of Murphy's (2007) study was to explore the nurses' perceptions of the

factors that facilitated and hindered quality care for senior citizens residing in long-term care. Van Manen's principles of hermeneutics guided this study, which allows basic themes, such as interpretation and dialogue, to be highlighted (Van Manen, 2014). The findings indicated that a philosophy promoting independence and autonomy in the residents, homelike social environmental conditions, person-centered care, knowledgeable staff, being familiar with the particular individual, and a multidisciplinary approach to care were facilitating factors. Contrarily, a lack of patient choices, hurried interventions or lack of time, and resistance by the patients to change or being bound to routines were hindering factors to successful patient care. Thus, the presence of or lack of self-determination was viewed by nurses in this study as a significant factor leading to quality care for elderly long-term care residents.

The opportunity for self-determination was seen as facilitating quality care and the removal of self-determination was viewed as hindering quality care from the perspective of the nurses. This study adds to the knowledge base that it identifies self-determination as a salient factor for quality care from the nurses' perspective. The design utilized in this study helped in reaching deeper into the understanding of what constitutes quality care, even though the notion of quality care is subjective. However, this study does not involve the perceptions of older adults with dementia but rather of the care providers. Although studied from a caregiver perspective, this research was included in the review to demonstrate the importance of self-determination as a quality-of-life factor because there have been limited studies exploring this specific topic from the perspective of older adults with dementia.

From the resident perspective. Also from Ireland, Welford, Murphy, Wallace, and Casey (2010) used a concept analysis framework to examine available literature to determine the aspects of autonomy that are important to elderly individuals in residential care facilities as opposed to patients in hospital settings. Concept analysis utilizes an eleven-step method for conducting research by using rigorous questioning in order to understand concepts within a context; given that concepts are dynamic and not static in nature (Wilson, 1963). The term under question for this particular study is autonomy.

Welford et al. (2010) found what they called “six key attributes of autonomy” (p. 1226) to be described in detail later but basically included; encouraging resident decision-making, resident delegating care needs, negotiated care planning, open and respectful communication, culture of flexibility, and maintaining dignity. Similar to Collopy’s (1988) conceptual article, Welford et al. (2010) highlight the value of self-determination for those in residential care settings. Welford et al. (2010) illustrate that the distinction between hospitalized patients and residential care individuals be of importance. These authors note that hospitalized patients are often in a temporary situation and may be able to withstand short-lived suspensions of emotional needs, whereas individuals in a residential care facility are in their homes where they expect their needs to be met. There are obvious differences in the needs of residential care facility inhabitants from patients in temporary settings. This highlights the importance, as my study does, of focusing on the needs of those who are residing in long term care facilities such as an assisted living facility, which is often viewed as home.

Additionally, these researchers attempted to operationalize the term autonomy in residential care for older people by drawing on existing debates and discussions within the literature. Ultimately, a universally accepted definition for autonomy has yet to be adopted. It is likely that without this universal understanding of the meaning of autonomy, true person-centered care cannot be fully realized. This was an argument initially supported by the author of this paper. However, since completing the study, this author now supports a more nuanced definition of autonomy which is specific to the individual receiving care. Autonomy may need to be viewed as a fluid dynamic specific to the individual's needs and in the context of their living situation. Specific to the Welford et al. (2010) study, it revealed "six attributes of autonomy" (p. 1226) valued by elderly residential care inhabitants:

1. Residents believe that they should be involved and encouraged in decision-making activities as long as they are able to do so.
2. When residents delegate their needs to others they believe that they should do so based on their own right to self-determination.
3. Based on the above, the delegation of choices/needs is best accomplished through negotiated care planning which is a cooperative venture between the resident, their family, and the staff.
4. Any delegation of autonomy should include input from important family members or significant others wherever possible as a means of ensuring resident dignity.

5. Residential unit policies should be flexible and aimed at maintaining the dignity of the resident.

6. Relationships are most meaningful when the staff is consistent (thus they are familiar with the residents), motivated to be of assistance to the residents, and foster relationships aimed at enhancing the residents' ability to remain autonomous.

While the aforementioned studies have illustrated the value placed on self-determination and autonomy in residential care inhabitants, they did not establish the need for self-determination in individuals who are diagnosed with dementia. As a result of Welford et al. (2010) work, attributes of autonomy that are meaningful to residents were elicited. The next study explores the notion of self-determination for those specifically with dementia.

Empirical evidence to support the notion of self-determination for those specifically with dementia was provided by Clare et al., (2008) from the UK where they analyzed the results of unstructured interviews of 81 individuals with moderate to severe dementia living in ten different residential care homes. The results of the interviews were subjected to interpretative phenomenological analysis. Because direct accounts of the subjective experiences of those living with moderate to severe dementia are rare (Clare et al., 2008), this study was one of the few directly related to my research.

Clare, Rowlands, Bruce, Surr, and Downs (2008) were able to capture the residents' feelings of isolation, uncertainty, sense of worthlessness, and fear by identifying common themes that emerged from the interviews. For instance, one theme

was that the residents seem to lack a sense of being consulted or confided in regarding being placed in the home and in their daily decisions, both of which led to a general feeling of lacking control.

The lack of control experienced by residents was associated with both their perceived loss of self-determination and losses in their cognitive and physical functioning due to their dementia illnesses as well as the normal course of aging. These losses were associated with a great deal of unhappiness and despair. However, even with great losses in their ability to engage in self-determination, these individuals still tended to produce themes in their interviews that illustrated the need to continue to be self-determining such as "I'll be alright; I'll manage," and "I am still somebody" (Clare et al., 2008, p. 716). These are basic statements that represent a need for the individual, even for those residents with moderate dementia, to maintain control and a sense of self-determination in their lives, according to Clare et al. (2008). Such optimistic self-determining attitudes helped the residents to cope with their distress fostered by feelings of uncertainty and a lack of control related to their lives in residential care.

Clare et al. (2008) study clearly illustrates and supports that there is still a drive/need towards a self-determined purpose and identity even in moderate to severely demented individuals; an extremely salient point in regard to my study. It highlights the need to understand how autonomy and related psychological needs are experienced for this population from a subjective standpoint, as done in my study. However, two issues distinguish this study from my study: 1) it explores self-determination as a whole rather

than focusing exclusively on the notion of autonomy and 2) it is a study conducted in the UK and thus may not be applicable to conditions in the US.

Autonomy support. Based on their findings, Clare et al. (2008) strongly suggested that it is important for caregivers working in residential homes for the elderly and demented individuals to attempt to find ways to support autonomy and self-determination. In doing so, caregivers would allow these individuals to maintain a sense of self, which would maximize the mental and physical well-being of the residents. These suggestions include:

1. Providing more opportunities for meaningful conversation and discourse with the residents.
2. Offering choices and encouraging as much independence as possible for each person.
3. Offering support for those experiencing depression, anxiety, etc.
4. Maintaining continuity supporting the life roles of the residents such as allowing them more opportunities to engage in activities related to their work or hobbies.
5. Eliminating boredom by encouraging meaningful activities.
6. Encouraging a sense of community and belonging in the residents.
7. Having the staff remain sensitive to the difficulties of living in a residential care facility.

By comparing the conclusions of Murphy (2007), Welford et al. (2010), and Clare et al. (2008), it is evident that people with dementia have similar needs for self-determination when compared to non-demented individuals in residential care. Although, these articles focused primarily on control, decision making/choice, and general sense of self-determination, they lay the groundwork for the foundational claims that these individuals continue to have significant psychological needs aside from their physical care needs. These rich and meaningful claims add merit toward pursuing further knowledge in how autonomy is experienced for those with dementia; a gap in the literature which my research addresses.

Specific measures of autonomy in residential care. This section turns to a mixed method study utilizing two constructs of the three psychological needs of Self-Determination Theory, which was conducted in the US by Kasser and Ryan (1999). The study found that autonomy and relatedness are central to older adults' well-being in institutional settings. Consistent with Self-Determination Theory, Kasser and Ryan defined autonomy as related to volition and choice rather than a feeling of independence. This study used structured interviews and survey data from various measures such as a life satisfaction Likert survey with 50 nursing home residents. The correlational analyses allowed them to conclude that personal autonomy was significantly inversely related to mortality at a one-year follow up. In other words, individuals who felt autonomous died later than individuals who did not feel autonomous. These perceptions whether positive or not were then correlated to levels of depression and life satisfaction using quantitative methods.

Kasser and Ryan (1999) study offers insight into the notion of autonomy specifically, although not for individuals with dementia. This study added to the body of literature in that it directly examined the older adults' perspectives by use of interviews about aspects they considered vital to well-being such as relatedness and autonomy. Parallels between this study and my own area of study are that it was conducted in the US and it specifically defines the term autonomy in a broad and encompassing way as feeling one's actions are volitional.

Autonomy, well-being, and sense of self. Additional literature was identified that is specifically relevant to the topic of autonomy, well-being, and sense of self within a structured/controlled setting for older adults. A few of them specifically address populations with cognitive deficits such as dementia. One article focused on the importance of the relationship between the care providers and the residents. Overall, my general review of the literature selected showed consensus that person-centered care that stresses the benefits of autonomy for older adults within structured settings is of value toward well-being (Custers, Westerhof, Kuin, Gerritsen, & Riksen-Walraven, 2012). However, there was also a consensus that, although this understanding about person-centered care is present and valued, it is not routinely utilized in day-to-day practice. Additionally, there were suggestions that more studies are needed from the client perspective, an obvious gap in the literature and one my research addresses, in order to better understand their views on what autonomy means to them and how it may influence their daily care. Because most studies were conducted from the caregiver or family viewpoint, there is a limitation in expanding our knowledge base. The articles

from the caregiver and family viewpoint, with their unique perspective, do add guidance and a starting point in the understanding of what may be needed or valued for those with dementia. The next study addresses the importance of the care relationship and the impact it has on well-being illustrating the notion that well-being is supported by the quality of care provided.

Relationship between residents and care providers. Kristensson et al. (2010) wrote from a qualitative perspective using open-ended interviews with people who were identified as being heavily dependent on the health care system by repeated hospitalizations or frequent contact with their physicians. The study demonstrated the detrimental effects of older adults losing control over their life situations. The data from the interviews were analyzed using a content analysis method comprised both of manifest and of latent levels of concerns. The manifest level concerns the surface of the text, whereas the latent level concerns deeper meanings from the text. Specifically, the study looked at how older adults experience health care in relation to power, given the fact that older adults tend to rely on healthcare systems heavily. In the process of interviewing fourteen older adults, it was found that by having a positive relationship between the care provider and the individual, it allowed the older adult to retain a perception of being in control. Older adults who were dependent on others and not informed of what was happening in their care had feelings of insecurity and ultimately conflicts with care providers, potentially affecting well-being. This study is not specific to individuals with dementia living in an assisted-living setting. However, it does add to the understanding of the importance and impact of how care is delivered in the context

of power inequalities. Additionally, it highlights the importance of the relationship between older adults and care providers and the effect this relationship may have on well-being; a construct which has been connected to autonomy (Ryan, Huta, & Deci, 2013). The use of content analysis may not be the best suited for older adults with dementia due to potential expressive language limitations since this method adheres strictly to “counting responses” and “using a template analysis style” (Sandelowski, 2000, p.338). Therefore, this method may be too rigid to use with this population where thoughts and language can possibly wander off topic lending support to a descriptive methodology as utilized in my study.

Baltes and Baltes (1986) also focus on the interaction of discourse analyses specifically in control-related factors within care institutions. These authors assert that passivity in elderly cannot be taken as evidence of loss of control but rather as a result of institutional environmental responsiveness. In other words, if dependent behaviors are immediately attended to by care providers while independent behaviors are ignored, then there is a significant decrease in autonomous functioning.

Residential care and its effects on residents sense of self and well-being.

Hellstrom and Sarvimaki (2007) conducted a qualitative study in Sweden that highlighted the importance of self-determination for older people living in sheltered housing. The study shows how living in a particular setting could decrease self-determination; further adding to the knowledge that context can influence how self-determination is experienced. This study depicted 11 people living in five different housing facilities and found that the “overall theme was disempowerment, which implied

an environment that does not strengthen individual self-determination” (p. 413). For example, when residents had an opportunity to make decisions, the staff only accepted them if they agreed with the decisions. Contrary to the notion of self-determination, a paternalistic view among the staff was detected (Hellstrom & Sarvimaki , 2007).

Hansebo, Hedman, Ternestedt, Hellstrom, and Norberg (2012) found in their qualitative work that people with mild to moderate Alzheimer's took on the perspectives of others when they were being treated offensively. In other words, their sense of self and self-esteem had devastating effects following being treated poorly by care providers.

As a result of the small sample size of the Hellstrom and Sarvimaki (2007) study, and the fact that it was conducted in Sweden, it is difficult to generalize the findings to other populations and cultures, but it is related to the population in my study.

Nevertheless, the researchers offered viable solutions which may be applicable with other populations, such as education and training of staff in helping to mitigate the negative effects that attitudes of staff can have on the residents. The Hellstrom and Sarvimaki (2007) study also highlighted the importance of the subjective standpoint of older adults living within a structured setting; thus, valuing the meaning individuals place for themselves rather than meanings and values placed for them by their providers and caregivers. The rationale for seeking the understanding of subjective meaning is to help in the development and implications for practice. This particular study detailed suggestions on how to increase residents' sense of autonomy within these settings and listed education and training of staff as an example of how to help shape practice.

Effects of communication style on resident. Another study selected was a qualitative study from the UK conducted by Milne (2011). This study is relevant to my study in that it is relatively current and explored the subjective experience of individuals with moderate to severe dementia living in a care home. The researcher used multiple methods to capture her data such as in observations, videos, and focus groups. She showed how ageism, i.e., negative views toward older adults, does affect care, and was able to link communication style of the care provider with how residents felt afterwards. When care providers used verbal and nonverbal positive communication, warm and friendly in nature, it resulted in the person with dementia feeling happy and relaxed, which contributed toward well-being. This communication style supports the dignity of those being cared for, according to Randers and Mattiasson (2004). Negative and neutral communication left residents feeling distressed, withdrawn, and at greater risk of developing challenging behavior (Milne, 2011).

The research by Milne showed that although the self is affected by dementia, “manifestations of selfhood and identity persist, even in late stages of the illness along with the capacity to develop positive therapeutic relationships” (Milne, 2011, p. 78). The data elicited within the Milne study illustrate an important point in relation to my study in that they highlight the obvious psychological need for quality of life by stressing well-being, making choices, autonomy, and independence in individuals who have a diagnosis of dementia. In addition, this study substantiates the need for research in understanding how residents view quality of life, as this study is one of a few capturing the lived experience of those with dementia. Again, Milne’s study illustrates how the relationship

in a structured environment, particularly with people with dementia, can influence the feelings and behaviors of the residents. Although these findings are not generalizable, this study from the UK assists in highlighting the gaps in the literature and confirms that there is a need to understand the experiences of older adults with dementia.

Flexibility of individual needs. A study conducted in the Netherlands by Custers et al., (2012) utilized interview methods with structured questions as a means to investigate the residents' experiences of relatedness, autonomy, and competence, as described by Self-Determination Theory. This portion of the study utilized qualitative methodology as a way to capture lived experiences. Additionally, the residents were asked to respond to a questionnaire, rating on a 5-point scale the importance of the three basic needs, a quantitative dimension of the study. This study illustrated that residents are different in their needs for autonomy, relatedness, and competence. A limitation in the context of relating these data to my research is that the 150 participants were not cognitively impaired. However, this study helps to support the notion that individuals' needs may be best served by being matched to providers who can meet their particular needs and the idea that the care system needs to be flexible in providing care; all qualities within the person-centered approach to care.

In combination, these studies give support to the notion that older adults living in a structured setting with dementia value the patient/staff relationship, person-centered care, and have the ability to retain a sense of personal control and autonomy, which in turn, affects well-being. Future qualitative research, with phenomenological methodology capturing the lived experiences of how psychological needs, such as

autonomy, is experienced for older adults with dementia from their own perspective, is needed to close the gap of our limited understanding and appreciation of this phenomenon (Milne, 2011). Once these needs are better understood, care can be better matched to the individuals' needs, thus providing a truly meaningful person-centered approach. My research aids in closing this gap of knowledge which, in turn, then supports improving best practices of care that are truly person-centered.

2.2 Literature Review of Autonomy with other Populations

As a result of the sparse literature specifically exploring the psychological needs of those with dementia in a residential care setting from their own perspective, various disease processes where cognitive processes may be impaired were explored to assist in substantiating the reasoning for my research. These disease processes, such as traumatic brain injury, stroke, developmental disability, and schizophrenia, although not identical to dementia, are similar in that they are included in the DSM, have cognitive challenges and limitations associated with them, have societal stigma attached that entails the perceived need for care, and may influence one's freedom in making choices for oneself.

Unfortunately, because of these factors, these individuals may not be readily afforded the opportunities to give their subjective input on treatment received from care providers and from society in general, which may impact their sense of well-being.

The literature to be discussed next highlights the fact that individuals with disorders that share features of dementia demonstrate a psychological need for autonomy that contributes toward well-being. The majority of the studies selected utilize a qualitative design in order to capture the lived experiences of those being studied as I

have done in my study. The first study highlights the subjective experience of those with brain injury and was selected because of the use of qualitative methods as well as the data that this method extracted, specifically data regarding personal autonomy.

Traumatic brain injury. According to Conneeley (2003), eighteen individuals with traumatic brain injury who were interviewed six months after rehabilitation identified several factors linked to their subjective experience of quality of life; the top three were sense of well-being, functional status, and personal autonomy. The qualitative design method enabled the researchers to gain an understanding of the experience of quality of life by those affected by traumatic brain injury. The similarities in diagnosis may be used to point to similar processes in speculating that autonomy needs may be comparable for those with dementia.

In France, Mazaux et al. (2002) conducted phone interviews to assess the psychosocial outcome of seventy-nine individuals ten years after their brain injury. These individuals were described as young adults who were severely impaired and lived with their parents or in high-cost nursing homes. The researchers specifically asked for the participants' life satisfaction and subjective feelings regarding quality of life by using the Glasgow outcome scale. Sixty-seven percent of seventy-nine individuals were satisfied with their sense of autonomy. This study utilized a mixed method approach in that it used interviews to elicit details as well as the Glasgow scale to quantify results. However, a limitation of this study is that the data are vague and general. The term autonomy for this study lumped together physical, social, and psychological constructs. One salient point to be gleaned is that there is research for this particular population for

which their subjective views of quality of life, well-being, and autonomy were explored, despite their cognitive limitations, unlike for those with the diagnosis of dementia.

Another point is that despite having cognitive limitations, the participants' felt sense of autonomy was extracted and used as valuable data. This similar premise can be applied for those with dementia in understanding their felt sense of autonomy, as done in my study. Individuals, who have suffered strokes, as illustrated next, clearly identified factors that constrained their autonomy while residing in a nursing home.

Stroke. In a grounded theory study utilizing concept analysis conducted by Proot, Crebolder, Abu-Saad, Macor, and Meulen (2000) in the Netherlands, researchers described a model of changing autonomy needs for patients with strokes while in a nursing home. It was explicitly stated “a qualitative research method was chosen because there is very little known about the concept under study” (p. 463). The researchers asked the residents to define autonomy and utilized this definition throughout their interview.

Proot et al. (2000) found that autonomy needs changed for the individuals in a nursing home. After admission, being in an unfamiliar environment and being unfamiliar with the care routine, appeared to constrain the stroke patients' autonomy. This awareness of decreased autonomy led patients to compare their situation to their lives beforehand. As a result, these individuals had a profound sense of loss particularly with a loss of identity. Patients felt it was difficult to have any sense of control and choice because of the unfamiliar environment and practices. This sense of loss and uncertainty due to unfamiliar surroundings and care practices is descriptively similar to the experiences of those with dementia. They found that staff giving support and

attentiveness facilitated autonomy over time, but it was also noted that an extreme in attentiveness constrained autonomy. This particular study supports the notion that staff attention and flexibility to the changing needs of their patients are vital in supporting autonomy.

Developmental disabilities. Wehmeyer (2001) helped introduce the idea that people with mental retardation not be excluded from the promotion of self-determination by highlighting that they are worthy of respect and dignity, despite the perception that these individuals are not capable nor independent. According to Wehmeyer and Abery (2013) and Wehmeyer and Garner (2003), self-determination has now become part of the demands made by people with developmental disabilities in the self-advocacy movement and these ideas have been incorporated into the disability rights and empowerment crusade. For this population, a strong self-advocacy movement group has ensured that the individual's need for self-determination is preserved, promoted, and included as a criterion for best practice in the field. In general, the movement has been to turn away from institutional care settings for this population and has worked to promote and enhance the environment in ways that foster more opportunities for self-determination and support within community settings.

In a review of their work over the past several decades, Wehmeyer and Abery (2013) provide a synthesis of findings pertaining to efforts in promoting self-determination for those with intellectual and developmental disabilities. The majority of their work utilized a quantitative design with regression analyses to determine that choice opportunities were the strongest predictors of self-determination and that

intelligence scores did predict whether a person lived in a more or less restrictive setting. The authors acknowledged that choice opportunities are easily measured, but realized more research is needed to explore the impact that the environment has on these factors as they suggest that environment may play a more important role in promoting self-determination than do personal characteristics such as intelligence. This is an important finding as it may also relate to older adults with dementia and their environment either hindering or supporting the promotion of self-determination.

Wehmeyer and Garner (2003) found that intellectual capacity was not a significant contributor to either self-determination or autonomous functioning for this group and that opportunity to make choices contributed positively to greater self-determination and autonomy across all levels of cognitive functioning. These findings may be similar for older adults with dementia who may fluctuate in cognitive functioning level and their capacity for understanding. In contrast to those with intellectual and developmental disabilities, older adults who can no longer care for themselves are typically placed in institutional settings where opportunities for self-determination are minimally promoted and advocated for as best practices in the field of providing care. Hopefully, my research will aid in making changes in this area and support opportunities for self-determination for those living in memory care settings.

Wehmeyer and Garner (2003) examined the self-determination and autonomous functioning of 301 adults with intellectual and developmental disabilities by using a 72-item self-report scale, which measures characteristics such as autonomy and self-regulation. These scales were administered with the assistance of a primary contact

person for each of the study participants. A multivariate analysis technique, a form of structural equation modeling, was conducted to provide the results of the data by investigating variable relationships. Multiple variables were observed for similar patterns of responses as they related to a latent variable. The variables were indicators for self-determination, severity of intellectual impairment, locus of control, life choices, as well as living arrangement, either independent or congregate. This design was well matched for the research question the authors aimed to answer as it gave an understanding to the relationships of the variables under review. For example, people with severe intellectual impairments were less self-determined than their peers with mild intellectual disabilities. There were also significant differences between people in the severe disability group and those in the developmental disability group on locus of control scores. Of note, this method would not generate the type and depth of data necessary to answer my research question in my study because of its inability to gather the perspective of the individual within their environment. However, this study may suggest that an individual's severity of impairment may impact their sense of being self-determined in their level of locus of control. Initially, from a speculative standpoint, I believed a similar finding may also apply to severity of dementia impacting one's sense of self-determination and locus of control. However, since conducting my study, I found this speculation to not be supported as the need for autonomy was consistent throughout various levels of impairment.

Schizophrenia. Schizophrenia is another disabling condition for which research has illuminated the importance of autonomy in individual's lives. In a study by Roberts,

Warner, and Brody (2000), eighty-four patients with a clinical diagnosis of schizophrenia were invited to participate in a structured interview and asked to complete a 5-point Likert rating their attitudes related to motivation to participate in research. These scores were compared to the personal views of psychiatrists and the psychiatrists' predictions of patient views as related to participation in research. The qualitative design was the best-suited method to elicit the data of interest because it provided data specific to personal views and compared the views of the patients to the views of the psychiatrists. The study showed that generally, across attitudes, patients supported research participation more than psychiatrists predicted they would. In other words, the study supported the idea that "there is a necessity of exploring, not presuming, the perspectives held by individual patients with respect to clinical research...psychiatrists' personal views and their predictions of patients' views were strongly weighted toward personal autonomy" (p.73). Therefore, despite the fact that these individuals had a schizophrenia diagnosis, this study suggests they valued having a choice/autonomy in their ability to participate in research more than their psychiatrists believed they did. The speculation that older adults with dementia may have a desire in having opportunities to make choices that are greater than predicted or presumed by health care professionals is supported by this study. In another study to be discussed below, personal autonomy is explored with individuals with schizophrenia.

In a conceptual piece of literature, Sass (2011) explores in depth that people with schizophrenia do have a diminished sense of agency and autonomy, in terms of experience and action. As a result of this, Sass (2011) suggests that individuals with

schizophrenia may think and act in ways that suggest exaggerated autonomy, as a way to experience a heightened form of personal agency. He strongly argues against the notion that particular psychological disorders, such as schizophrenia, automatically characterize a diminished sense of autonomy. This is a point also relevant to the population of older adults with dementia. In addition, Sass (2011) acknowledges that there have been authors who have not provided a definition of the term autonomy, thus making it difficult to understand the meaning ascribed in these philosophical and technical discussions. The larger point here is to illustrate that there is available literature, both conceptual and empirical, exploring the subjective need for and experience of autonomy for varying disabilities.

The literature is not only plentiful and mostly from the US as depicted in Table 1, but also illustrates the focus placed in conducting research specifically addressing the concept of well-being within these various disabling conditions such as traumatic brain injury, stroke, developmental disability, and schizophrenia. In stark contrast, the literature exploring the need for and experience of autonomy for older adults with dementia is limited in the US strongly suggesting that person-centered care for this specific population needs further exploration. Digby, Lee, and Williams (2016) stress the importance of including those with dementia in research to further the knowledge base of their experiences. Not only does this lack of exploration in the US demonstrate a gap in the literature, but also in our understanding and appreciation for the phenomenon of autonomy in individuals with dementia. My study is a step toward this important initiative.

2.3 Summary of Literature

Table 1

Author/Year	Country	Methodology	Summary
Langer and Rodin/ 1976	USA	Value of choice/Quantitative-questionnaire	<ul style="list-style-type: none"> inducing a greater sense of personal responsibility in people in a nursing home, who may have virtually relinquished decision making, either by choice or necessity, produces improvement in health
Heggestad, Nortvedt, and Slettebo/2013	Norway	Phenomenological and Hermeneutic approach	<ul style="list-style-type: none"> Qualitative design-dementia residents in nursing home-not being seen or heard-threat to dignity
Collopy/ 1988	USA	Conceptual/case study review	<ul style="list-style-type: none"> Decisional and executive autonomy Care tailored to individual needs
Murphy/ 2007	Ireland	Hermeneutics phenomenology/Qualitative	<ul style="list-style-type: none"> Nurses in nursing homes viewed quality care as care enabling

			self-determination
Welford, Murphy, Wallace, and Casey/2010	Ireland	Self-Determination/Qualitative – concept analysis	<ul style="list-style-type: none"> Importance of autonomy in elderly in residential vs., hospital settings
Clare, Rowlands, Bruce, Surr, and Downs/2008	United Kingdom	Self-Determination/Qualitative-Interpretative phenomenological analysis	<ul style="list-style-type: none"> Older adults with severe dementia in residential settings felt isolated, worthless, and lacked control
Kasser and Ryan/1999	USA	Self-Determination theory and Socio-emotional selectivity theory/ Mixed Method	<ul style="list-style-type: none"> Autonomy and relatedness are key to well-being for older adults in institutional settings
Custers, Westerhof, Kuin, Gerritsen, and Riksen-Walraven/2012	Netherlands	Self-Determination and person-environment congruence models/Mixed method	<ul style="list-style-type: none"> The match between individual needs in nursing homes and the fulfillment of these needs by the environment is crucial for well-being.

Kristensson, Hallberg, and Ekwall/2010	Sweden	Power dynamics/Qualitative- content analysis	<ul style="list-style-type: none"> Older adults' perception of being dependent on health care and providers
Hellstrom and Sarvimaki/2007	Sweden	Self-Determination-human value/Qualitative-content analysis	<ul style="list-style-type: none"> Older adults' feelings of disempowered in their living situation of sheltered housing
Hansebo, Hedman, Ternstedt, Hellstrom, and Norberg/2012	Sweden	Social Constructionist theory/Qualitative-content analysis	<ul style="list-style-type: none"> Negative effects that attitudes of staff can have on older adults in structured living setting
Milne/2011	United Kingdom	Subjective experience/Qualitative dementia-specific observational tool- interviews-focus groups	<ul style="list-style-type: none"> Experiences and perspectives of residents with dementia living in a care home-care provider effects
Conneeley/2003	Britain	Quality of life/Qualitative- longitudinal	<ul style="list-style-type: none"> Quality of life factors for people with brain injury

Mazaux et al./2002	France	Rehabilitation/Mixed Method-phone interviews- Glasgow outcome scale	<ul style="list-style-type: none"> Factors contributing toward life satisfaction for those with severe brain injury
Proot et al./2000	Netherlands	Rehabilitation/ Qualitative- concept analysis, interviews	<ul style="list-style-type: none"> Defined autonomy individually. Changing autonomy needs for stroke patients in nursing home
Wehmeyer and Abery/2013	USA	Disability rights- Empowerment/Self- Determination/ Social- Ecological/Quantitative- regression analysis	<ul style="list-style-type: none"> Promoting and enhancing environments that ensure self-determination for those with developmental disabilities
Wehmeyer and Garner/2003	USA	Disability rights- Empowerment/ Self- Determination/Quantitative	<ul style="list-style-type: none"> Opportunity to make choices for those with developmental disabilities contributed positively to self-determination
Roberts, Warner, and Brody/2000	USA	Ethics/Qualitative-structured interviews	<ul style="list-style-type: none"> People with schizophrenia have the ability to decide to participate in research,

			whereas, their psychiatrists (care professional) did not believe they had the ability
Sass/2011	USA	Psychopathology/Conceptual	<ul style="list-style-type: none"> The diagnosis of Schizophrenia in itself should not lend itself to a characterization of having a diminished sense of autonomy

2.4 Conclusions

A comprehensive and synthesized analysis concerning current literature has been provided, exploring autonomy, autonomy support as well as other related psychological needs with older adults, and those with dementia, as well as those with similar disabilities. Based on the empirical evidence to date, it is supported that people with dementia retain the motivation to fulfill basic psychological needs as described by the Self-Determination Theory. Existing literature also indicates that there is significant variation in the motivation to fill these needs in the elderly and those with dementia. However, the presence of variation in a group does not mean that these needs should be ignored or that the application of total external control for all people with dementia

should be the preferred course of action for managing individuals with dementia in residential care.

If the goal of residential care is to allow individuals, through person-centered care, to function and thrive to the best of their capabilities, then caregivers must allow residents the opportunity to continue to live their lives to the best of their abilities, despite their cognitive challenges. There is an ethical obligation to continue to recognize that even people with dementia have basic innate needs that are physical, mental, emotional, and psychological. As clinical rationale supports that satisfying innate psychological needs result in better health outcomes, there is both an ethical and clinical rationale for supporting autonomy among older adults with dementia as their needs dictate.

Various empirical studies have been explored that support the notion of older adults' need for growth and well-being, but few address the needs of those with dementia. Thus, I extrapolated from the aforementioned literature and suggest that the Self-Determination Theory can offer a valid theoretical framework in helping to inform, support, conceptualize, and provide the basis for truly meaningful person-centered care from a universal perspective. This theory is well equipped in addressing psychological needs, which are important in maintaining the physical and mental well-being of people regardless of age, culture, and their physical or mental capabilities. The Self-Determination Theory provides a universalist and trans-cultural account of optimal human functioning that cuts across cultures and supports wellness in all humans (Ryan, 2011). It is in this context that this study has been formulated and conducted, as a means

to add to the scholarly conversation in understanding autonomy and related psychological needs, from the perspective of those with dementia.

Chapter 3-Methodology

This research was framed utilizing the research question: How do individuals residing in a memory care unit of an assisted living facility experience autonomy and related psychological needs? The aim of the research question was to explore, utilizing a phenomenological interviewing approach, the perception of autonomy and related psychological needs as articulated by individuals, diagnosed with dementia, living in a residential care facility. Although the primary interest has been on the experiences of autonomy, participants' other related psychological needs arose and were captured from the data. Qualitative research methods, because of their flexibility and iterative processes, are a suitable form of research methodology to begin the exploration of a phenomenon within a relatively underexplored context and to gain deeper meanings (Miles, Huberman, & Saldaña, 2014). Also, according to Bogdan and Biklen (2011), qualitative methods best solicit the views of those who are marginalized, such as older adults with dementia. Additionally, qualitative data analysis searches to describe general statements about relationships and themes present within the data. Therefore, the use of a qualitative design is substantiated in exploring the meaning of autonomy and related psychological needs in older adults with dementia.

3.1 Investigator Assumptions/Positionality

To strengthen the quality and trustworthiness of research, the researcher must adopt a reflexive attitude and be aware of how their role, assumptions, and biases may influence the observations and findings (Heggestad, Nortvedt, & Slettebo, 2013b). The primary

instrument for data collection and analysis in qualitative research is the researcher herself, both as a human instrument and as the primary research tool. Because of this, there is a responsibility for reflexivity in considering one's own biases, limitations, and views. Therefore, for this study, in the interest of full disclosure and of guarding against unethical or unintentional influences, I examined my perceptions and realized I had several assumptions and biases stemming from my own experiences about how cognitive deficits affect autonomy in the context of dementia care. As part of this study, in order to neutralize my biases, I used brackets, in the text during observations, interviews, and journaling to capture my thoughts and feelings to the fullest extent possible.

To begin, my first experiences with those with dementia came from my peripheral dealings with two of my grandparents who suffered from dementia and were cared for directly by my father in his house. Because my experiences were as a distal observer and not as a direct caregiver, I naively believed that individuals living with dementia simply lived for the moment with no pain or regrets and, therefore, were unable to experience a sense of loss, even the loss of their own memories. I had witnessed my grandparents as content and they often spoke of their previous life with joy. Because of this assumption, I imagined that individuals with dementia, at times, relinquished their need to hold on to a once cherished sense of autonomy that they may have experienced in their younger years prior to suffering the devastating effects of dementia. I believed they enjoyed being cared for by others and had no need to make their own choices any longer. This desire to make choices vanished along with their memories. I also assumed that an individual who had a high need for autonomy in their younger years, such as my grandfather did, may have a

more difficult time later in life, after a diagnosis with dementia and especially during lucid moments, in dealing with restrictions placed by a structured environment. For example, I witnessed that my grandfather would insist that he fix an electrical outlet as he believed he knew better than my father. My grandfather was accustomed to fixing things around the house. He became angry when my father took away his tools and denied him these opportunities for safety reasons. These moments led to some conflict, but they only occurred during lucid moments. Therefore, my suspicion was that individuals with dementia who had a strong need to hold onto a sense of autonomy often lead to disruptive or aggressive behaviors when experiencing lucid moments or when feeling their choices were being taken away.

Later, some of my assumptions and biases were further solidified while some were challenged after directly caring for my father who developed symptoms of dementia. I found that individuals with dementia, especially during lucid moments can, and do, experience a strong sense of loss, even of their own memories. My beloved father struggled to hold onto every shred of autonomy. Working with his need for autonomy rather than blindly taking it away from him for safety reasons, I found that providing care and supervision could be negotiated. For example, in the early stages driving was an issue of concern and through family discussions which included him, it was negotiated that he limits his driving to daylight hours and utilize familiar routes. He eventually agreed because he was willing to negotiate this to retain his ability to drive for as long as safely possible. The line of what was safe and what was not at times became blurred and could vary with time; this line was often fluid in nature.

As the illness naturally progressed, I offered choices of which foods he chose to eat first rather than simply stating it was time to eat. For a brief moment, I fell into a routine and started to feed him without asking his preference and he said firmly “you can’t make people do what they don’t want”. This statement jolted me back into honoring his personhood and his need for autonomy, a lesson I have never forgotten and has been the foundation for this study.

As discussed, my personal assumptions arose from personal experiences in dealing with family members who suffered from various stages of dementia, but the fact is that it is difficult to know how this illness affects each individual at any given moment. In other words, generalizations are just that, generalizations, and cannot provide a blanket understanding of how this illness affects each individual. To further confound this, the limited understanding we have is further highlighted by the fact that there is a paucity of empirical research in this area which explores how one experiences a need for volition and choice while in the midst of this disease. I had hoped for and was privileged to find that the outcomes of this study provided a glimpse of understanding how autonomy is experienced for this population. Although the findings may not be generalizable to all individuals with dementia, it is variable and idiographic; thus, supporting the notion that care needs to be personalized and fluid in nature, lending itself to a truly person-centered approach to care.

3.2 The Use of Phenomenology

Guba and Lincoln (1994) argue that questions of paradigm must be understood and examined before the development of research methods. My research question is grounded

in a paradigm supporting a qualitative method with a phenomenological mindset in that it stresses the importance of the participant's perspective in relation to their experiences. Phenomenology seeks to understand the essential nature of basic human truths accessible through the understanding of human subjective experiences. A phenomenologist works through to deeper essential structures of what it means to be human by accepting that all knowledge is an interpretation (Thorne, 2008). Researchers in a phenomenological mode attempt to understand meanings of events and interactions of ordinary people in particular situations (Bogdan & Biklen, 2011). In other words, there is an attempt to place no assumptions in understanding what things mean to the people being studied, thus explaining why the positionality of the researcher needs to be explored and unearthed. The exploration of my personal biases and assumptions are salient in exploring my research question of understanding if and how the construct of autonomy is experienced in older adults residing in a memory care unit of an assisted living facility. As a researcher, one must be prepared to be open to understanding without these preconceived assumptions.

Reality is understood only in the form in which it is perceived, according to constructivism. An example of this is illustrated by the reality experienced by an older adult with dementia in that if this individual believes it is time for them to go to work, although in actuality this is untrue, then their reality is the reality for them at that particular time. By using qualitative methods such as interviews, observation, and field notes as I have done in my study, a researcher attempts to understand the way people think and feel about their world as they are experiencing it.

3.3 Phenomenological Interviewing

A method for interviewing within the descriptive phenomenological framework of research is phenomenological interviewing. This is an in-depth form of interviewing that is grounded in the philosophical tradition of phenomenology and is a means to capture lived experiences in order to develop a world view (Marshall & Rossman, 2016). This method entails a structured approach that utilizes questions to contextualize experiences as well as to elicit the meaning behind an experience (Bevan, 2014). In keeping with the fundamental phenomenological concepts, this method recognizes that human experiences are complex, fluid, often experienced inter-subjectively, and contain meaning.

Phenomenological interviewing is a two-tiered method of first obtaining an individual's description of an experience and then secondly the meaning of the experience. Generally, the first interview focuses on an individual's life history and context. The second interview, aims to reconstruct experiences as well as reflections on the meaning of those experiences. Personal knowledge of a given phenomenon by the researcher is acknowledged, but set aside by critical self-questioning in a reflective process. However, Brevan suggests that clarification of a phenomenon may entail the use of “imaginative variation” (p. 141) which is used in the analysis of the data. Imaginative variation is a process in which the researcher can uncover parts of the data in attempting to clarify an experience. In other words, it allows the researcher the ability to discover data, which adds to the clarity and stability of the phenomenon under investigation while remaining grounded in the original context and experience. This method of interviewing provides structure but is not restrictive in examining an individual's lived experience.

3.4 Study Details

Target population. The target population for this study is individuals between the age of 65 and 89 and living in a memory care unit of an assisted living facility in the Northeast. Individuals who reside in these specialized units are in the late early and in middle stages of dementia. Those with later stages of dementia typically transition to skilled nursing facilities due to their higher physical care needs. The population of memory care unit residents was specifically selected because of the heightened tension between the potential need for autonomy and the restrictions placed for safety purposes. Prior studies indicate that lack of freedom and independence are viewed as “restrictive” in a communal living situation (Milne, 2011, p.80).

Individuals in middle stage dementia may have periods of lucidity with the potential to generate quality interviewing and rich data in relation to their experiences. It is relevant to note that Byrne-Davis, Bennett, and Wilcock (2006) as well as Mayhew, Acton, Yauk, and Hopkins (2001), found that people with moderate or severe dementia were able to talk about quality of life in meaningful ways. Heggstad et al. (2013a) expressed the importance of giving voice in research to older adults with dementia. They also found it was important to ask interview questions of those with dementia that appeal to their feelings and experiences rather than their intellectual capacities, an approach I incorporated in my study, by modifying questions to focus on feelings rather than thoughts. Individuals in early stage dementia have not been included in this study primarily because they are more likely to live independently either at home or in senior housing (Alzheimer’s Association, 2013) suggesting they may have more opportunities

for making their own choices. On the other end of the spectrum, individuals in late stage dementia were not selected because of the increased likelihood of communication difficulties in later stages of dementia (Reisberg, Ferris, deLeon, & Crook, 1982).

Unit of analysis. Of note, the term participant and the term subject are used interchangeably in this study but refer to those who participated in the study. Individual participants (subjects), as the unit of analysis, were studied using several data sources, e.g., the data used to study participant #1 will include a) participant #1 interview one (P1, I1), b) participant #1 observation one (P1, O1), c) participant #1 interview two (P1, I2), and d) participant #1 observation two (P1, O2). Additionally, in Chapter 4, participants' quotes are identified according to unit of analysis as mentioned and whether or not the data source was gathered in the a.m. or p.m. hours. The a.m. and p.m. delineation assisted in identifying differences due to sundowning symptoms. Sundowning typically occurs in those with memory impairments and often occurs in the evening hours. Symptoms may include increased confusion, agitation, and decreased lucidity.

Cases or unit of analyses were then compared and contrasted to each other as whole units as a means of making connections and recognizing the diversity among the individuals (Maxwell, 2013). In keeping with the descriptive methodology and in an effort to gain rich integrated data, commonalities amongst individual experiences lent themselves toward a composite summary of their collective subjective experiences as a means to better understand the totality of the phenomenon (Giorgi, 2005). If a participant, family, or staff member chose to opt out of the study at any point, no further

data were retrieved from that individual. However, this did not occur in the study although each staff, participant and their families were given the option.

Sample size and characteristics. Inclusion criteria were being between age 65 and 89, residing in a memory care unit of an assisted living facility, having the ability to speak English, and being able to verbalize and answer general questions relating to feelings and experiences (Heggestad et al., 2013a). Exclusion criteria included those residing in a memory care unit under age 65, those over age 89, those who have been appointed a legally authorized representative to make decisions, other than a health care proxy or power of attorney, such as a legally appointed guardian, those unable to verbalize needs and desires, and those with severe and consistent disruptive behavioral issues such as verbal outbursts or aggressiveness sufficient enough to preclude the appropriateness of interviewing. However, those with occasional disruptive behaviors were not excluded, as it is feasible that this behavior may be a result of frustration regarding their lack of autonomy. Thus, relevant data would have been missed if these individuals were excluded from the study. Nonetheless, it was made clear that in any cases where individuals with occasional disruptive behaviors were involved in the study and it was believed by those providing care for the individual that participants' behaviors repeatedly escalated as a direct result of the individual's involvement in the research process, the individual would be withdrawn from the study. This was particularly pertinent if those providing care believed that there was any harm being caused because of being involved in the study. Of note, no participants were withdrawn from the study due to disruptive behavioral issues.

A phenomenological analysis study is generally conducted utilizing small sample sizes, and because of the case by case detailing, allows the focus of the study to specify perceptions and understandings of a particular group of people rather than making more general claims (Osborn, 2007). Smith, Flowers, and Larkin (2009) suggest a small number of participants, between three and six, with a total of four to ten interviews per research project. They support the notion of “quality and not quantity” (p. 51), which is attained by concentrating on a smaller number of cases as well as total number of interviews. For this study 7 participants residing in the memory care unit, two male and the remainder female, were identified by the key informant as being able to endure the process of being interviewed by not displaying distress for several (2 separate) short interval semi-structured interviews (15-120 minutes) over the course of 2 ½ months. Five of these participants (one male and the remainder female) were ultimately enrolled in this study.

Within a phenomenological study where rich data are elicited, Morse (1991) estimated that a total of five to six participants was a reasonable sample size. Because it is typical for an assisted living dementia unit to have a total of 23 to 25 residents at any given time, selecting five participants willing and able to participate in semi-structured interviews several times was realistic, as well as feasible. For the purpose of saturation, having four to eight participants willing to be interviewed several times allows one the opportunity to gather rich data (Morse, 1991). Saturation is achieved when the researcher has “pursued the variance required to make certain theoretical claims...or express confidence that no new variations on the theory will emerge” (Thorne, 2008, p. 98).

Having 5 participants who were able to be interviewed several times each, as well as observed on several occasions, provided data to the point where it was believed saturation was achieved as no other new themes emerged from the analysis.

Informed consent and assent. Conducting studies with a population considered to be vulnerable, makes the achievement of a reliable informed consent challenging. However, research may proceed with such vulnerable participants if additional safeguards are in place to minimize the risk of harm and exploitation (Silverman, 2011). Informed consent is the process where the researchers clearly communicate with the participant, who is of legal age and competent, to ensure that the individual understands expectations. Assent is the agreement and willingness of someone not able to give legal consent to participate in the activity. Additionally, a proxy consent is then required of this individual and incorporates a legally designated person to assist the client in decision making processes. Once participants were identified by the key informant, I read them a brief script summarizing the study as well as their involvement, and then asked for assent to participant in the study in the presence of the key informant of the facility and their family member.

Silverman (2011) suggests that asking probing questions to assess the participants understanding of the research enables a safeguard process for vulnerable participants. Only on one occasion was it necessary for the researcher to ask probing questions to ensure the participant understood their involvement in the research. This participant gave verbal assent but did not want to sign the assent section of the consent form. A proxy consent, an informed consent by the legal representative as identified by the key

informant, was then obtained by the researcher for each of the five participants.

McKeown, Clarke, Ingleton, and Repper (2009) support the notion that individuals with dementia must not be excluded from research, but caution that capacity to consent to research participation must be explored, even if eventually leading to a “proxy consent” (p. 1937) by a relative or close care provider.

Informed consent from the participants’ families was also obtained. Several family members of the study participants were involved in the observation portion of the study and were observers during the interview portion of the study. Therefore, their informed consent was needed. However, information from the families was used only in reference to the participant and the participant’s response to interview questions. Staff involved in providing care for the study participants, agreed to consent by a letter of acceptance and support from the assisted living facility administration granting permission to proceed with the research. Study participants as well as the families of the participants were told they were free to withdraw from the study at any point, if desired, and their data from the date of withdrawal would not be used in the study and would be destroyed. No participants or their families chose to withdraw from this study at any time. All study participants, their families, and staff were offered anonymity, assuring their identities remain protected. Only after receiving RSRB approval and prior to initiating the study, consent forms were reviewed and signed by all involved participants and their families.

Setting for data collection. The setting identified for data collection was in an established adult assisted care facility in a suburban area of a medium-sized city in the northeast portion of the United States. The healthcare facility has various levels of care

within it including supportive apartments, assisted living, and a small, secured dementia care unit within its assisted living facility. This particular assisted living facility had a mix of individuals with physical and cognitive impairments and the memory care unit is home to those individuals with mid-stage dementia symptoms who have been identified by family or care providers as no longer being able to care for themselves in an independent setting. These individuals either pay privately or have long term care insurance to live in this setting.

As previously referenced, there are typically 23-25 individuals within the memory care unit at any given time. At the time of this study, there were 23 females and 2 were male. Each resident has his or her own bedroom and there is a communal area for activities and a separate dining area for meals. The doors are locked, and staff and families must enter a code to exit or enter the area. There are approximately 4-5 aides during the day and evening shift and 2 nurses per shift within the dementia unit. There is a small office attached to the congregate area where the nurses obtain medicines and dispense them either in the communal area or in the private rooms of the residents. Most of the residents are ambulatory but may need assistance, on occasion, with activities of daily living, such as eating or toileting. Approximately one third of the residents use walkers and about half use canes to ambulate. One resident used a wheelchair. Despite this, most residents do not have any major physical or mental health impairments, which typically require a higher level of nursing care. However, one participant in the study was awaiting placement in a higher level of care due to her declining medical health and increased need for supervision.

Recruitment strategy. The participants were selected via a purposive, criterion, and convenience sampling technique (Thorne, 2008), with assistance from the administration staff or “key informants” (p. 91). The key informant is another name for the cultural liaisons or gatekeepers, all of whom are familiar with the ethos of the facility. An approved screening form was provided to the key informant to assist in screening participants.

The key informant had the initial discussion with the subjects and their legal representative for participating in the study. The key informant also pre-selected subjects in the memory care who she knew had legal representatives in order to sign consents and take part in the study. These preselected participants were reviewed individually in consultation with the assisted living staff/cultural liaison, as well as potential participants’ families in helping determine which individuals would be able to endure the process of research participation including two short interview periods (thirty minutes or less) as well as two separate observation periods (180 minutes or less). Enduring the process of research participation entails not displaying any behaviors which indicate distress or agitation outside of the individual’s normal range of behaviors as identified by the key informant or gatekeeper.

Batchelor-Aselage, Amellia, Zapka, Mueller, and Beck (2014) discuss the importance of utilizing a “gatekeeper” (p. 17) in residential facilities to identify prospective participants. These authors define “gatekeepers” as the persons who are working directly with the individual with dementia and who are able to identify the legally authorized representative, such as a health care proxy or power of attorney, for

that individual (p. 17). For this study, the gatekeeper was the same individual as the cultural liaison and key informant. She was a key administrator of the assisted living facility who was familiar with the residents, their behaviors, as well as the culture of the facility. She had been employed at the facility for close to 20 years and deemed to be invaluable, for the purpose of this study.

Individuals were selected utilizing the inclusion and exclusion criteria mentioned earlier. The selected individuals, as determined by the key informant who knew these individuals and as a means to minimize any bias selections, were determined to be able to tolerate short periods of interviewing (thirty minutes or less) and also to have the likelihood of lucidity. For example, if an identified participant had a pattern of becoming increasingly disoriented toward later evening hours (sundowning), the interview was scheduled earlier in the day.

Once preselected individuals were identified by the key informant, the researcher then reviewed these subjects to confirm that these individuals fit the criteria established for participation in this study. The approved recruitment script which briefly gave details of the study was read to the pre-selected individuals and their legal representative in person or via phone for the purpose of determining a subject and their legal representative's willingness to participate in this study. Once participation was confirmed, the approved informed consent and assent (of the subjects) form was completed by the researcher in the presence of the key informant at an agreed time and date at the facility location.

Process of data collection. As previously mentioned, data for this study were collected by the researcher over the course of 2 1/2 months via interviews of residents; observations of selected study participants, their families and involved staff; and researcher field notes. More specifically, 5 residents in a memory care unit, one male and four females, were involved in 2 separate (one in the am and one in the pm for each participant) short, semi-structured interviews (15-120 minutes each), using a phenomenological interviewing method. Roulston, DeMarrais, and Lewis (2003) support the notion of keeping interviews short, especially for those with cognitive deficits. Digby, Lee, and Williams (2016), state that the nature of the dementia condition may lead to tangential conversations and as a result the interviewer must be flexible as well as adaptable in probing areas of interest for the participant rather than following predetermined questions in a rigid format. They also stress the importance of capturing the essence of the views of the participants as these are rich data, rather than extracting the factual aspects related to their experiences.

A piloting of the first interview research questions (Appendix A) was performed with participant one in order to determine ease of use and understanding of the questions. After interview one, the interview data were audio recorded, transcribed, and analyzed utilizing Atlas.ti. software. Additionally, multiple readings of the text were conducted to determine whether rich data could be collected to assist in answering the research question. The process and the results were discussed in detail with the research facilitator. After a thorough review and discussion, the research questions were deemed appropriate and thus the research process continued with the selection of other identified participants.

Once all participants were identified and consents completed, the interviews were audio recorded and later transcribed by the researcher. Additionally, the researcher kept a journal noting obvious body language, tone of voice, facial expressions, and mannerisms as well as researcher reactions to the process. Interviews have been found to be the “gold standard” of data collection for exploring an individual’s lived experiences (Sandelowski, 2002, p. 105). Mak (2009) asserts that significant challenges in studying those with dementia include possible diminished insight as well as impaired communication abilities. These challenges thus support the use of observational methods to elicit and supplement other data.

After the first interview session with each study participant, each participant was individually observed in the community area for 1-2 hours each, on two different occasions, at approximately a 2-week interval between sessions, over a one-and-a-half-month time span for any indications of experiences of autonomy, autonomy support, and related psychological needs. These observations occurred during breakfast, lunch time, dinner hour, and planned group activities. One session occurred in the morning and one occurred in the late afternoon for each participant. Observations were conducted as an unstructured observer as a way to experience the naturalistic setting by not “separating the researcher from the researched” (Mulhall, 2003, p. 307). Mulhall explains that the purpose of an unstructured observer is to acknowledge the importance of context in that the whole social setting is recorded and by entering the field with “no predetermined notions as to the discrete behaviours that they might observe” (p. 307). The role of the researcher, as an observer, was disclosed to those who asked, participants who have

signed assent and consent and their families, as well as to the staff. A limitation in this is that knowing the researcher's role may influence naturalistic behaviors. However, having covert observations may elicit unwanted fear in the residents and possibly cause unnecessary distress. Data were not gathered from residents who were not study participants or individuals who have chosen to no longer participate in the study. Interactions that study participants had with other residents were captured with the focus being solely on the participants' responses.

Additionally, assisted living staff, such as aides and nurses, as well as the participants' family members were observed during interactions with particular attention to behaviors that allowed participants to make their own choices, versus behaviors that inhibited choices, were noted along with the participants' reactions. Data gathered during the interaction of a study participant with staff or family are solely focused on the responses from the participant. The staff and family observations helped in highlighting potential discrepancies between observations and interview data from the study participants and generated either confirming or disconfirming evidence (Maxwell, 2013).

Operationally defining autonomy and autonomy behaviors were challenging within the phenomenological nature of this study. One of the underlying precepts in any phenomenological study is that the individuals participating in the study will have an idiographic understanding and experience of the phenomena. As a point of departure, behaviors suggesting that individuals are un-coerced with their choices within the fluid nature of their environment were highlighted. Conversely, behaviors that suggested resisting compliance with a directive from staff or family and/or possibly verbalizing a

desire to have a choice in a matter or explaining why they do not wish to comply, are considered data supporting a desire for autonomy.

Following the first observation portion of the study, the second round of interviews with the study participants then occurred. By conducting initial interviews before the observation period, it allowed the study participants to become familiar with the researcher, with the goal of reducing anxiety for the participants (Hellstrom, Nolan, Nordenfelt, & Lundh, 2007). According to Beuscher and Grando (2009), establishing rapport with older adults with dementia is crucial to the interview process. As a result, older adults with dementia who became familiar with the researcher's presence prior to an interview were less anxious and more apt to participate in the study. Digby, Lee, and Williams (2016) stress the importance of the interviewer displaying a calm and attentive manner in order to have a successful engagement. I found this approach to be extremely helpful in eliciting deeper meanings during interviews and observations as it helped in facilitating trust toward the researcher. This trust enabled the researcher to offer calming assurance to the participant, if any slight indications of distress were noted.

The second round of interviews following the observation period allowed for questions that elicited meaning of observed experiences. This sequence is supported by the phenomenological interviewing method. Seidman (2013) posits that in-depth interviewing is “the best avenue of inquiry” (p. 10) to gain understanding of peoples lived experiences and the meaning they place on those experiences.

As previously mentioned the phenomenological interviewing approach is a two-tiered method in that it obtains descriptions of context and is followed by questions that

elicit meaning (Bevan, 2014). Prompts for questions during the resident interviews (as seen in Appendix A) were designed in a ladder approach starting with general close-ended questions which provided descriptions and context information, and proceeded to slightly deeper and more structured questions (Price, 2002). The open-ended questions provide an opportunity in understanding how the residents experience residing in a memory care unit of an assisted living facility, while being extremely mindful of keeping interviews short. It was necessary, at times, to utilize neutral probes and prompts in the interviews to elicit more data. Questions covered perceptions of autonomy and what that meant for the individual. These questions were modified from the Autonomy Support Climate Questionnaire, the Self-Determination Scale, and the Basic Psychological Needs Scale obtained from the Self-Determination Theory website. These instruments have autonomy and related psychological needs relevant material embedded in their questions and are used as a means to capture these constructs.

Beuscher and Grando (2009) acknowledge there may be communication challenges with those individuals with dementia, but offer some remedies such as “simplifying the structure of questions, allowing ample time for responses, using reminiscence, and redirecting dialogue” (p. 6) in order to remain on task. I frequently allowed time for a response and at times was asked to repeat the question, which I did in a relaxed and calm manner. Because of the nature of the dementia diagnosis, which may affect recall ability, the use of observations in addition to the interviews were important in augmenting interviews by providing direct cues for daily events. Observations of body

language, tone of voice, and facial expressions were captured in the sidelines of note taking during interviews and observations.

Data analysis. A qualitative research study involves a continuous interplay between data collection and data analysis (Strauss & Corbin, 1998). For this reason, I began analyzing data following the first interview to begin identifying patterns, and to facilitate subsequent data collection. The two primary sources of data for analysis are field notes detailing observations, and transcribed interviews along with notes regarding researcher “reactivity”, i.e., reactions the researcher may have that influence the data (Maxwell, 2013, p. 124). Analysis involved data immersion through repeated readings and deep-level thinking of the transcribed interviews as well as data obtained from the observations. Additionally, all collected data were analyzed and processed using Atlas.ti computer program software by using a manual coding method within the software which included both a first cycle and a second cycle (Miles et al., 2014).

The first cycle consisted of the initial review of the data and used an open descriptive coding technique (Saldaña, 2013). Coding is an interpretative act that allows the research process to transition from data collection to data analysis. Descriptive coding summarizes in a word or short phrase the basic topic of a passage and is deemed appropriate for virtually all qualitative studies (Saldaña, 2013). In its essence, descriptive coding is an approach in transforming data into manageable form specifying what was seen or heard with little scrutinizing by the researcher. Text from the interviews was studied line-by-line and major descriptive themes were extracted producing a list of 50 initial codes. Interpretive descriptive coding as described by Thorne (2008) allows an

“underlying shared intent” (p.145) to be captured. For example, when a specific word, such as the word, “limited”, is captured, further interpretation is needed to understand the intent of the word given the context: would limited be intended to mean in a physical sense or to mean lack of options? Allowing Atlas.ti to automatically code would have not enabled nuanced meanings to be captured. Thus, explaining the researcher’s decision to use the manual coding option within the Atlas.ti program. Additionally, the first cycle of coding was conducted between rounds of interviews to guide the inquiry for deeper meanings during the second interviews with each participant.

The first cycle generally leads to a categorized inventory of the data's contents, which establishes the groundwork for the second cycle coding. During the first cycle of coding which includes organizing, sifting, and sorting of the units of analysis, arose initial codes such as control, choice, power, routine, compliance, and denied. Often these initial codes overlapped and were redundant in meaning leading to the second cycle of coding.

The second cycle coding entailed further analysis and interpretation, and grouped summaries into smaller categories, themes, or thematic constructs such as autonomy, competence, connectedness, security, and safety. In addition, the second cycle utilized a sensitizing concept of Self-Determination Theory construct of autonomy as a general guiding lens in developing categories and pattern codes with theoretical constructs (Miles et al., 2014). As previously stated, Charmaz (2003) has referred to sensitizing concepts as background ideas that inform the research. During the second cycle, the construct of autonomy was used as a category, not as a predetermined code but rather as

a way of informing, connecting, and organizing initial codes such as control, choice and denied into a unified conceptual grouping. It was particularly noted if a pattern or theme emerged after developing categories in the second cycle of coding which related to the theoretical constructs of autonomy and to the experience of making one's own choices. Key concepts and codes which emerged such as controlled, constrained, choice, power, safety, and independence were of particular interest and were determined for the purpose of this study to be autonomy relevant thematically. A parallel process was employed to focus on related psychological needs that emerged through the inductive process.

The relationship between the first and the second cycle coding was analyzed for similarities and differences (Saldaña, 2013). The emerging categories were used to organize and group codes into meaningful clusters, ideally “between 10 to 15” (Hsieh & Shannon, 2005, p. 1279). Depending on the relationship between the subcategories or clusters, they were combined to organize a smaller number of categories or themes which helped in explaining patterns in human relationships and behaviors. Maxwell (2013) suggests not just focusing on similarities but instead looking for patterns to connect statements and find commonalities in order to produce a coherent integrated whole, as in a collective experience. The ultimate purpose is to give meaning to the phenomenon under study.

Although Bowen (2006) supports the notion that “sensitizing concepts can be effective in providing a framework for analyzing empirical data and, ultimately, for developing a deep understanding of social phenomena” (p. 20), steps need to be taken to minimize bias. To assist in minimizing imposition of undue bias related to pre-formed

theoretical constraints at this stage, the use of memo writing was utilized as a practice of reflexivity in analyzing the researcher's role as well as possible influences and biases on the study. This will be discussed in greater detail in the, *Threats to the Study and Ensuring Trustworthiness*, segment of this paper.

3.5 Data Storage and Security

As long as the human subjects' research project was considered active, care will be taken to protect data storage. Paper records, such as consent forms and determination to consent forms, are kept in a locked file cabinet within a locked office accessible only by the researcher. All digital records are stored in a password-protected file. Digital recordings of interviews as well as the transcripts are also kept in the password-protected file. Upon completion of the research, all records will be retained no longer than a three-year period, as required by RSRB, and at that point all data will be destroyed by means of shredding and deletion of electronic files. All necessary safeguards, encryption, and security measures were taken for data security, safety, and confidentiality. These measures to adhere to professional codes within the research areas, support research integrity (Pimple, 2002).

3.6 Threats to the Study and Ensuring Trustworthiness

Planning and predicting possible threats to this study during each decision opportunity helped to contribute toward the integrity of the whole (Thorne, 2008). Because qualitative data analysis is often a continuous and iterative process (Miles, Huberman, & Saldaña, 2014), there are multiple opportunities to ensure that data collection is held to rigorous standards. These standards help to establish trustworthiness

of the research results. According to Morse, Barrett, Mayan, Olson, and Spiers (2002), it is the responsibility of the qualitative researcher to ensure verification strategies during the inquiry process by identifying and correcting errors before they are built into the developing model.

Researcher bias and reactivity are two of the major threats to validity according to Maxwell (2013). The biases and assumptions that I mentioned previously in the *Investigator Assumptions/Positionality* section of this paper were obviously a threat to this study in that they may have colored the way interactions were perceived. How these threats were managed and avoided in this study will be discussed shortly. Another threat to this study was the potential bias of looking at this phenomenon solely through the lens of the constructs of autonomy, more specifically, the Self-Determination Theory. In addition, the reactions that the residents in assisted-living, their families, and the staff had toward me as a researcher, and in turn, my reactions to them, also known as reactivity, may have played a role in affecting the validity of the data. Interestingly, Becker (1970), found that there is less influence from the observer on a participant's behavior than from the setting itself. From the researcher standpoint, one must be willing to reflect on one's values, behaviors, experiences, and positionality within the research, as I have done previously, to identify how these may influence the collection and interpretation of data (Paterson, 1994).

Reflexivity. The practice of reflexivity is an opportunity for the researcher to engage in analysis of one's own role in the research process and is a vital tool in increasing trustworthiness, as well as integrity in qualitative research (Finlay, 2002).

Reflexivity can be accomplished by use of memos, such as jottings of reflective thoughts, preconceptions, or questions as the study unfolded and throughout the research process, which I actively utilized, in order to help mitigate threats of biases and potential reactivity as discussed previously. Finlay (2002) also notes that reflexivity is particularly useful in trying to explain how individuals make sense of their social world and their place in it by providing context to experiences, which is extremely relevant to this particular study.

Peer debriefing. The use of peer debriefing groups during the first coding cycle, such as the classmate cohort groups I attended, assisted in avoiding the tendency to process data prematurely, or in a biased manner. I avoided gathering and analyzing data in isolation, and relied on key committee members and peers for input. Working in isolation makes it difficult to discern if information gathered is biased based on preconceived notions.

Member checking. Utilizing member checks, also known as respondent validation, is an important tool in helping to clarify and understand a participant's interpretation of an experience (Maxwell, 2013). Utilization of member checks was instrumental when interviewing residents, observing residents, their families, and staff for the purpose of clarifying and understanding differences or similarities in the perception of observations as they compared to the interview data. An example of this was asking a participant to clarify or explain their feelings following an interaction where a facial expression suggesting dissatisfaction was noted by the researcher. My initial assessment of the dissatisfaction was confirmed but it was important to use the member check tool to validate my finding.

Triangulation. Another approach in ensuring trustworthiness, triangulation, is the use of multiple data sources to examine the phenomenon under study. By combining different sources such as observation and interviews, richer and more valid data were obtained (Heggestad et al., 2013b). According to Maxwell (2013), the use of triangulation “reduces the risk of chance associations and of systematic biases due to a specific method” (p. 128). Triangulation in this study involved multiple observations, repeated interviews of residents, memos, and audit trails such as a personal reflective journal. By combining all of these techniques, rigor and validity were added to my study with the goal of strengthening the relationship between the conclusions and reality (Maxwell, 2013).

Other strategies, which were used in this study to test the validity of the conclusions and address potential threats to the conclusions, are intensive involvement by repeated observations, over a one-and-a-half-month span, and interviews over a two-and-a-half-month span (Maxwell, 2013). Repeated observations and interviews through long-term involvement of a combined period of over three-months, by use of multiple interviews, are not only important in reducing validity threats, but are also key strategies for use with this population in gathering rich data.

3.7 Risks /Benefits of the Study

The risk to the participant was minimal but may have included stress in answering research questions. Answering these questions not only was a disruption to the natural flow of the milieu of the assisted living facility but may also have highlighted a perceived sense of lacking autonomy whereas this may have been unnoticed before. As a protection

against this risk, participants who appeared agitated or stressed were given a break for as long as they needed, as well as given the option to discontinue participation. This occurred in one session of an interview and after a few minutes with some comforting words, the interview continued. The participant was struggling with her memory, could not find the words to express herself (aphasia), and ultimately attempted to lighten her distress by using humor. Her struggle was acknowledged and normalized by the researcher, which eased her distress. Another risk is the breach of confidentiality in the event that research records are lost or stolen. Names and other identifiers will be kept in a secured locked file cabinet and password protected on an electronic file as a way of protecting against this risk.

The benefits of this study for the participants are minimal but may include an opportunity for added socializing as well as an opportunity to validate the individuals' experiences by active listening. The overall benefit of the study is to gain an insight and understanding of how autonomy and related psychological needs are experienced by older adults who reside in a memory care facility. This knowledge can help expand the body of literature, and highlight applicable implications for practice, such as in the development of teaching and training for staff that care for these individuals.

Chapter 4-Research Findings

The previous chapter summarized the methods used for the completion of this study, whereas this chapter will focus on the analysis and findings of the study. I will also discuss, for the purpose of clarity, how data were organized into meaningful categories/themes from the multiple codes identified. Additionally, I will discuss the thought processes in the groupings of the data into the five primary themes that ultimately emerged.

4.1 Data Analysis Overview

I began analyzing data following the first interview in order to start the process of identifying patterns and to inform subsequent data collection. Data analysis and data collection occurred simultaneously. I extracted codes, gleaned from significant phrases and descriptive statements, from the original individual interview transcripts and observation sessions, which was consistent with the purpose of providing data for the research question: How do older adults residing in a memory care unit of an assisted living facility experience autonomy and related psychological needs?

I created a Word document listing meaningful units and associated codes. Meaningful units are groupings of words that ultimately lead to the development of the codes and are relevant to the study's aim. Specifically, meaningful units are excerpts from observations or interviews which explicitly address the research question. Examples of meaningful units were: "Why would someone tell me what time to go to bed? ...what the hell?...I go when I want!" (codes emerged from this unit such as

control, dignity, power, and feelings) (P4, I2, p.m.), “making my own decisions is a want and a need, it’s just me” (codes emerged such as identity, choice, need) (P5, I1, a.m.), “I can’t remember, that’s why I’m in memory care” (codes emerged such as inability, memory loss, insight) (P2, I1, a.m.), “I’m well taken care of” (codes such as comfort, meeting needs) (P3, I1, a.m.) or “I can make meals but I can’t walk into the kitchen here and start messing it up and serving everyone...so, so I’m able to do it but you see, we don’t have to” (codes such as ability, choice, competence, control, restrained) (P4, I2, p.m.).

Ultimately, forty-two primary code words emerged that were relevant to the research question. Examples of code words are: choice, emotions, dignity, inability, routine, humor, ignored, pride, power, insight, inward and loneliness. Code words were chosen both by reflecting on the words of the older adults in the context of which they were spoken, and by observing their inflections, facial expressions, body language and other observations noted. For example, if a participant showed sadness through facial expression or body language or displayed anxiety by the act of pacing, it was captured and coded under the primary code of emotions. During my observations, I documented my reactions and placed them in brackets []. This often helped in supplying meaning and context. Because of the communication impairment caused by the dementia process, verbal data from the interviews were occasionally limited and their precise meanings unclear. Therefore, data from the interviews and observations needed to be subjected to hermeneutic scrutiny (Kitwood, 1997). This meant that their words, as well as their social and symbolic context of their living situation, were documented via observations,

and as per Kitwood, repeatedly re-read and examined using subjective interpretation to actively explore their intended meaning.

The interview and observational transcripts along with the forty-two identified codes were then input into Atlas.ti software, which facilitated a systematic organization of the data. The Atlas.ti software assisted in the organization of the data as well as in the retrieval of data based on either the individual participants or other units of analysis. The method of constant comparison between participants as well as other units of analysis (Glaser & Strauss, 1967) was used to sort and analyze the forty-two codes into larger, more encompassing categories. The Atlas.ti software was instrumental in this analysis stage. Also during this analysis stage, transcripts were read repeatedly and closely, ultimately leading to the preliminary understandings and findings to be discussed in this chapter. The process of coding was repeated until further readings did not produce any new findings. The iterative nature of constant comparison elicited descriptive themes that cultivated similar meanings held by the participants. This contributed to understanding how these individuals experienced autonomy and related psychological needs.

Once the primary codes were organized into larger categories, they were eventually condensed into themes in the qualitative descriptive tradition as described by Sandelowski (2000). Codes with similar attributes were eventually merged into seven larger categories related to psychological needs. The seven categories that emerged were: 'sense of self/identity', 'making choices' 'loneliness/isolation/familiarity/security', 'competence/ability', 'restrained/restricted', 'belonging/family' and 'insight into

memory loss'. A search for similarities and differences between the categories was conducted, and overlapping categories were then grouped together for thematic similarities. For example, the categories 'making choices', 'restrained/restricted' and 'sense of self/identity' were grouped into the larger theme of Autonomy: Real and Imagined. These seven categories eventually led to the development of five primary themes.

The five primary themes that emerged represented key aspects of the experiences under study that reoccur throughout the findings (Charmaz, 2003). Charmaz viewed the development of themes as collections of larger units of analyzed data (e.g., codes, categories) from which themes are extracted through a meticulous and iterative analysis of data content. Theme analysis is the attempt to create order and to thoughtfully elicit the meaning of what has been disclosed through interviews, field notes and observations. Appendix A illustrates the questions asked for Interview One and Interview Two which helped elicit data for the development of the themes. The aim then is discovering themes, which are essential to the phenomena under study.

Thematic representations of the content categories were used to reveal particular aspects of how participants experience autonomy and related psychological needs. The themes are '*Autonomy: Real and Imagined*', '*Implicit Belief of Competence*', '*A Preference for Routine and Comfort*', '*Nuanced Relatedness*', and '*Dealing with the Neurophysiological Effects of Dementia*'. Appendix B summarizes how collected data were grouped into categories and themes specific to each of the five participants. Additionally, it provides a demographic sketch for each of the five participants.

During my analysis, I consulted a member of the dissertation committee as well as fellow students with expertise in qualitative research to ensure that my coding process was thorough and comprehensive. This collegial process assisted in maintaining the trustworthiness and integrity of the study. Lastly, an analysis and interpretation of the content categories was performed as a way to understand the meanings of these themes in the context of the participants' lived experiences and their environment.

Composite summary of experiences versus variations in individual experiences. Not every participant provided data reflecting all five of the fundamental themes. Giorgi (2012) argued that development of themes is a vital step as the “phenomenological approach is holistic” (p. 5), and the goal is to identify the essence of the experiences through a composite summary through collective subjective experiences. The approach of developing a composite summary through collective experiences is a fundamental component in this study. Additionally, it is important to note that counter examples, which are examples that show the effects of the absence of a construct under study, are illustrated and discussed as well. Stake (1995) refers to counter examples in case study research as cases that acknowledge a variability or modification of the generalization. In addition to counter examples, in vivo confirmatory incidents arose during data collection specific to the construct of autonomy. In vivo confirmatory incidents illustrated the effects of being denied opportunities for autonomy by restricting choices and, as a result, highlighted the need for autonomy. These examples will be discussed accordingly and lend support for the core themes by better understanding the totality of the phenomenon under study.

4.2 Brief Overview of the Five Participants

This section contains a summary of each of the five participants identified by their pseudonyms. In depth detail of the participants' demographics is not necessary as the individual findings and their backgrounds are not what is being pursued. Nonetheless, the background information of the participants does provide context and situates the participant in relation to their quotes, which in turn contributes toward a deeper understanding of each participant.

Debbie. I begin with participant # 1(P1), Debbie, who is a Caucasian female, widowed, uses a walker and has worked at her family business full-time. She is described by the key informant (see Chapter 3 for description of 'key informant') as having a "good sense of humor but uses her humor to cope with her memory issues." The informant also indicates that "she gets frustrated with herself over her memory loss and raises her hands to her head in frustration." Although she has lived at this facility for just over a year, the key informant added that Debbie "often misses her home throughout the day, gets anxious and then tends to keep to herself either by going in her room or falling asleep in the common area."

Marianna. Participant # 2 (P2), Marianna, is a Caucasian female, widowed, uses a walker, has lived at the facility for approximately 1 1/2 years and is waiting to go to a higher level of care in a nursing home because of her "memory declining", according to the key informant. This suggests that she is further along in her dementia and, therefore, her memory loss is more severe than some of the other participants. She tended to remain in confused states of consciousness rather than fluctuating in lucidity as the other

participants of the study. In hindsight, she may have been too advanced in her illness for this study, although she did meet the inclusion criteria. She has a large number of children in the area, has worked various jobs throughout her life and is described by the key informant as having a “serious and somber disposition.” She also “tends to keep to herself but doesn’t isolate in her room, just won’t say much.” The key informant reports that “she experiences sundowning in the evening, and at times has become agitated displaying behaviors such as screaming and crying.” Sundowning in dementia and Alzheimer’s disease has been characterized as worsening of agitation or confusion symptoms late in the day. The key informant also reports that this participant “doesn’t struggle with her memory issues or is embarrassed by it but accepts it for what it is.”

Venecia. Participant # 3 (P3), Venecia, is also a Caucasian female, widowed, has been at the facility just over one year, uses a walker; has three children, (one of whom has died) and worked full-time throughout her life. She is described by the key informant as “prim and proper” and “likes routine and uses it to hide her memory deficits and make her feel safe.” The key informant reported that she “initially missed home when she moved in, put up a fight, but now has adjusted and is more cooperative.” The key informant also reported that Venecia is considered “more advanced in her dementia as compared to some others” and “mostly minds her own business.”

William. Participant # 4 (P4), is a Caucasian male, walks independently, is widowed, has been at the facility just over two years, and has two children in the area. He ran his own business for many years. William did not finish high school, but he did go back for his GED, which per the key informant “He was proud of accomplishing.” The

key informant describes him as “a gentleman but doesn't like to be told what to do, and gets angry if frustrated.” She also describes him as “very dignified and proud.”

According to the key informant, he has adjusted to his living situation, “likes to keep to his routine”, and is often polite, but keeps people “at arm's length away.” She also stated, “he uses humor to connect with others, hide his memory issues and he often spends a lot time in the common area.”

Marybeth. Participant # 5 (P5), Marybeth, is a Caucasian female, uses a walker, is one of many children, is widowed, has been at the facility just over seven months and has three children who visit frequently. She graduated high school and worked full-time most of her life. She is described by the key informant as “being mostly in good spirits but gets sad daily and states she wants to go home.” The key informant also reported that she is “angry at her son for putting her here as she doesn't feel she belongs here.” She occasionally has symptoms of “sundowning at night when she gets angry, struggles more with her memory and wants to be left alone.” The key informant notes that during the day “you wouldn't think she belongs here because she’s very social with the others.”

4.3 Five Core Thematic Categories

Under each thematic category are the details of the meaningful units and codes that ultimately led to the development of the five core themes. I captured the way participants experience these constructs through their words and observed behaviors. The interview questions/prompts are displayed in Appendix A. It is difficult to know the intention of the participants during their expressed reactions and therefore, for the purpose of this study, these reactions will be taken at their most generally implied

meaning and supported with as much observational evidence as possible. Several times, I did not have the opportunity to ask follow-up questions and thus, had to rely heavily on the observational data for analysis purposes.

Questions for Interview One were more general and were for the purpose of developing an understanding of the context of the living environment. Questions for Interview Two were more specific and included questions which focused on autonomy as well as competence. The questions focusing on autonomy included terms such as *who decides* and *how would you feel if someone decided*. The questions that I intended to focus on competence asked about *ability* in performing a task. However, the term ability can have two meanings; one meaning would relate to capability and another would relate to freedom. Specifically, one can be capable of actions, behaviors and outcomes, or one can choose or be granted the freedom to engage in actions and behaviors that produce certain outcomes. Again, without asking follow-up questions for clarity, it is unknown what meaning the participants intended. Thus, the context of the statements as well as other observational data were relied upon for analysis and interpretation of the participants meaning.

Autonomy: Real and Imagined. The most predominant finding was that all of the five participants in this study expressed a belief that they were making their own choices and perceived that they were retaining control over their lives while residing in the memory care unit. A number of quotes presented below indeed confirm the notion that some aspects of autonomy were experienced by participants. However, as the life that was lived prior to the onset of dementia became dramatically restricted, it was clear that

individuals clung tightly to the notion of retaining a freedom of choice, *even when the reality of dementia-related constraints necessitated a loss of that freedom*. According to Deci and Ryan (1985) autonomy is thought of as a volitional process where one has freedom to make one's own choices, hence the choice of theme, 'Autonomy: Real and Imagined'.

These participants had no difficulties in verbally expressing their freedom to make their own choices in a clear and cogent manner as illustrated by the following quotes: "I can arrange my room. I can arrange my closet, *if I want*" (P1, I1, a.m.) and "They don't tell me what to do" (P3, I1, a.m.). Participant #2, Marianna, who is awaiting placement in a nursing home, which suggests that her symptoms of dementia are more advanced, was able to express her ongoing belief of her own autonomy despite her advanced symptoms: "Yeah, I always decide what I want to do" (P2, I1, a.m.). Participants varied in the degree of importance for this desire or perception but, nonetheless, it was evident and clearly expressed by all the participants in this study.

The central theme of 'Autonomy: Real and Imagined' included varying codes such as: having choice, having control, feeling independent, having power, and having a sense of self. I found greater thematic similarities rather than differences amongst all the participants. All the participants expressed the need and desire for autonomy, and they perceived that they retained their autonomy, even when that autonomy had, in reality, been lost to the restrictions of a memory care unit. Thus, despite their memory loss, this perception that autonomy persisted remained intact for these participants.

The construct of ‘Autonomy: Real and Imagined’ was often closely intertwined with a ‘Implicit Belief of Competence’, the theme to be discussed next. Because the flow of the interview generated a confluence of these two themes, some examples of Implicit Belief of Competence were included and identified in this section of the document on Autonomy: Real and Imagined. For the purpose of this study, examples of Autonomy: Real and Imagined include instances having to do with choices, wishes, desires, and intent. In the context of coding, these examples were labeled when a statement, or part of a statement, was made in context of choice and emphasis was being placed on choice rather than on ability in performing an action. However, instances in which the context focused on action, behaviors, outcome, and ability were coded as referring to capability rather than freedom, and labeled Implicit Belief of Competence. The word “implicit” is used here to underscore the notion that it became clear to me, when reviewing the data, that the study participants may not have understood my question as a competence question. For example, when a participant was asked if they were “able to make their own meals”, it is not clear whether the respondent was interpreting the meaning of the word ‘able’ to be ‘allowed’ or ‘capable’. Thus, I have chosen the theme ‘Implicit Belief of Competence’ to reflect the potential ambiguity in interpretation of data. Competence, as defined by Ryan and Deci (2017), is a need to feel one is able to master tasks. It addresses the belief that a person has in being able to accomplish an outcome. Because it is the perception and belief of, rather than the successful outcome of, autonomy and competence, it is difficult to know with certainty the participants’ intended meaning often resulting in an overlap of these two constructs. Nevertheless, the construct of autonomy

was not always interconnected with the construct of competence. Examples of Autonomy: Real and Imagined are in these quotes: “If you wanna eat something, you can eat it, if you don't wanna (eat) it you leave it on your plate” (P1, I1, a.m.) and “They don’t tell me what to do” (P3, I1, a.m.). The second statement is a standalone example of Autonomy: Real and Imagined as it is about volition. The first statement illustrates Autonomy: Real and Imagined as it is in the *choice* of eating something or not.

Clarifying the nuanced distinctions despite communication challenges. The context of statements and their implied meaning was captured and determined by me at the time of data collection. I captured observed behaviors to help in determining the intended meaning at the time of interview. Many of these behaviors were placed in brackets to assist in understanding the implied meanings. I, however, acknowledge the ambiguity in determining the intended meanings. This is of particular note with the communication challenges the participants may have been experiencing, the short-interview time frames to avoid inducing anxiety, and the inability to ask clarifying questions. Further complicating the matter, is the fact that autonomy related questions were asked during the same interview as competence related questions. Despite these challenges, given the fact I was immersed in the interviews and observations, which I captured from my own perception as the researcher, I felt I would be doing the data an injustice by not presenting the fact that participants were including the notion of competence in their responses. Therefore, I felt it was important to include the possibility that the participants of this study believed in their own competence. For clarity, I have placed in parenthesis the construct which I determined at the time of the interview based

on surrounding evidence and behaviors. If there was ambiguity of the response being intended as Autonomy: Real and Imagined or as an Implicit Belief of Competence, I then state both.

Autonomy in relation to self. Being autonomous is one of several basic psychological needs and has also been found to have a strong link with self-identity. Making choices for oneself is important because one could not be recognized as an individual without the appreciation that one's behavior is a result of one's own initiative (Heidegger, 1962). The feeling of being autonomous, Heidegger (1962) states, defines us as individuals and supports our sense of self. According to Smebye, Kirkevold, and Engedal (2015), autonomy is not equated with independence and rational decision making, but rather with self-identification. These authors support that what people identify with and value are an integral part of the decision-making process and that this aligns with a person's sense of self rather than their rational decision-making abilities or independence. This notion of autonomy as a sense of self is reflected in many of the participants' experiences, as will be illustrated in the quotes to follow.

Debbie made it clear that she valued her autonomy by the fact that she feels she can express her own opinions. Her statements also demonstrate a connection with how she self-identifies. She has no problem expressing her opinions, as seen below.

Interviewer: Do you feel you're able to
express your own opinions?

Interviewee: Yes.

Interviewer: Okay. Can you tell me more about that?

Interviewee: Well, sometimes I get mouthy [laughs]. But
I feel as if I can, nobody can criticize this.

(P1, I2, p.m.)

When she was asked about a possible restriction in her making choices, she responded strongly proclaiming her need for independence.

Interviewer: Okay. How would it make you feel if your bed
time was picked for you?

Interviewee: Oh, I wouldn't like that.

Interviewer: Can you tell me why?

Interviewee: Well, I have to have some independence!

(P1, I2, p.m.)

Overall, Interview One was a broader and more general inquiry, and Debbie responded accordingly with more generalizations about her freedom to make choices and the implicit belief in her competence, as seen in the quotes below. She emphasized the action in arranging her room and closet rather than the choice of doing so. She verbalized these needs as being important to her sense of self by stating it was important to think for oneself. At one point, although she struggled with her memory, she was able to clearly articulate the importance of being able to make independent choices.

Coz I want to be independent. Is that a good word
for it? I can arrange my room. I can arrange
my closet. They don't tell me what to do.

Well, if I don't wanna go someplace, I tell them I don't
wanna go. I can keep it up here, I mean.. [she struggled at
this point trying to find the next word, as she pointed to
her head and showed frustration on her face]. I think it's
gotta be important to you to think for yourself.

(P1, I1, a.m.)

After some probing, Debbie specifically described that her ability to make choices is “a
necessity” (P1, I1, a.m.) and when asked why this was the case she stated, “because you
have to keep your mind working.”

(P1, I1, a.m.)

As an example of how she would feel about not being given a choice, Debbie stated the
following with a chuckle,

Interviewer: How would it make you feel if someone
picked breakfast for you?

Interviewee: Well, I prefer to pick my own [laughs].

(P1, I2, p.m.)

The residents of this facility are allowed to choose one of two choices of prepared foods for breakfast, lunch and dinner every day.

The psychological need to retain a sense of autonomy was articulated by the participant who was the most advanced in her memory loss, Marianna. The quote below demonstrates Marianna's altered sense of reality. She displayed no psychological struggle with her memory loss. She recalled her parents as if they were still living. Despite her advanced memory loss and altered sense of reality, she was able to describe her desire and need for Autonomy, as well as her Implicit Belief of Competence.

“Yeah, I do everything [referring to performing actions in the community area] that I'd like, like go ahead. Ummm, mention that to my parents and that-- they say well that sounds good and that's it.”

(P2, I1, a.m.)

Marianna refers to *we* below making it unclear if she meant her parents, the other residents, or her family. I did not have the opportunity to ask a follow-up question in order to clearly understand her meaning of *we*. However, she is able to clearly articulate that she can make her own choices based on her perception and belief, even in the midst of her advanced dementia.

Interviewer: You can make your own choices and how you want to do things?

Interviewee: Yeah, [Inaudible]. It's nothing to do, sure we
can [?]. (P2, I1, a.m.)

When asked in a slightly different way, she answers affirmatively again with some assistance as seen below. It may be argued that the interviewee was led to her response in the following quote. However, as I was physically present and witnessing facial and body language, I relied on the observational data through her facial expression indicating frustration and movement of her lips forming the word “decision” as she attempted to communicate at that given moment.

Interviewer: Do you feel you can decide how to do the
things you want to do?

Interviewee: Yup.

Interviewer: Can you tell me more about that?

Interviewee: Mh hmm. Anything that is, I make my own
.... and teach [?] uh things.

Interviewer: Your own-- you were going to say decisions?

Interviewee: Yeah.

(P2, I1, a.m.)

Marianna was asked more specific questions regarding autonomy and competence in Interview Two, which occurred in the evening. During this time, she was experiencing an increase in agitation making it difficult to keep her focused on the questions at hand, but she was able to answer the questions affirmatively, as seen below. She also expressed displeasure at the thought of being denied an opportunity to make her own choice.

Interviewer: Who decides what time you go to bed?

Interviewee: Me! [she verbalized loudly and firmly]

Interviewer: Yeah. You say that with such a conviction?

Interviewee: [Laughs].

Interviewer: How would you feel if someone picked your bedtime for you and said, “you have got to go to bed, it is 7 0' clock”.

Interviewee: I am liable to tell them what to do [she gave a stern look indicating displeasure and shook her head to indicate ‘no’].

Interviewer: Like what? Mind your own beeswax or something like that?

Interviewee: Yah.

Interviewer: Are you *able* to make your own meals?

Interviewee: Yeah. (Implicit Belief of Competence-as she believed she could perform this action)

Interviewer: So, you would go in the kitchen area here and make

what you want?

Interviewee: Well, I have never done it. I just go

ahead and make what I want. (Implicit Belief

of Competence and/or Autonomy: Real and

Imagined)

(P2, I2, p.m.)

Of note, residents of this facility are not allowed in the kitchen area and not allowed to prepare their own meals. The key informant also had shared that Marianna cannot dress herself without assistance. This point is made to illustrate the discrepancy between one's actual ability and one's desire, belief or perceived reality. Marianna does, however, express wanting to choose what she wants to wear and what time to go to bed. She also retains the Implicit Belief of Competence that she can perform the action ("make what I want") for an outcome of preparing her own meals. It is also possible, she is for face-saving purposes, retaining the idea of autonomy and competence as important dimensions of her identity.

The emotional impact of being denied something desired (in vivo confirmatory incident) was clearly evident in the narrative below from an excerpt of observational notes when Marianna expressed displeasure.

Marianna stated she wanted cream of broccoli during dinner but was told it was cream of cauliflower by the server. She said she didn't want it.

She said aloud “if they don't have it I don't get it.”

She sat as the others ate their soup and she didn't have any.

She looked down and appeared sad. I observed her displaying a faint frown on her face. [I felt sad for her as the reality was that she wasn't asking for much and as a result went without dinner].

(P2, O2, p.m.)

For one participant, asking questions regarding making one's own choices triggered memories of the past. The narrative she chose to describe her need for making choices was drawn from past experiences rather than the present. During Venecia's interview, as seen below, she immediately referenced her life before moving into the facility when asked about making her own decisions.

Interviewer: Do you feel it is important for you to
make your own decisions?

Interviewee: Well, as long I think they were
reasonable. Well, there's nothing
really to tell, you know. I did what I
wanted to do and I wasn't doing
anything wrong.

Interviewer: When is this?

Interviewee: You know back then, when I was a
wife and mother. I drove everywhere.

Interviewer: What was it about driving a car?

Interviewee: More freedom. I, I got out the front
door and I got in my car and I went
where I wanted to go! [she smiled]

(P3, I1, a.m.)

When asked more probing questions in relation to the present, Venecia's responses detailing examples of autonomy were more focused, as demonstrated below.

Interviewer: Do you feel you make your decisions
for yourself now?

Interviewee: Yeah. They don't tell me what to do.

Interviewer: Right. Can you give me an example of
something you decide for yourself?

Interviewee: I decide what I like to eat and that, you
know. Yeah. I don't ask for a lot. I
can watch TV if I feel like it and if I
don't, I nap a little and whatever. I do
what I wanna do. (Autonomy: Real and

Imagined) I'm not caged in here or anything.

If I wanna go out, I go out. [she points to
outside] (Autonomy: Real and Imagined)

(P3, I1, a.m.)

The reality is that she cannot leave the unit when she wants as there is an entry and exit code to enter in the security panel to allow the doors to open. However, she believes she can come and go as she chooses, suggesting a choice, Autonomy: Real and Imagined. Clearly, there is a need to believe she can leave when she wants, and this has become her reality. The several excerpts above lend support for a nuanced understanding of how autonomy is experienced as it defines these participants as individuals as well as supports their sense of self despite their diminished capacity. This has been a substantial and significant finding in this study.

During Interview Two which was tailored to be more specific, Venecia was asked more detailed questions and she was able to respond accordingly. She did not become upset or angry when presented with a situation of not being allowed her to make her own decision, but instead answered in a matter-of-fact fashion exerting her sense of self and identity, as seen below.

Interviewer: How would it make you feel if your
bedtime was picked for you?

Interviewee: Well, I don't think they would, really.

Interviewer: Okay. How would you feel if they did

make the bedtime for you?

Interviewee: Oh, I wouldn't let them tell me to go to
bed at six o'clock or something [self-
advocacy]

Interviewer: Who decides what time you go to bed?
You're pointing to yourself.

Interviewee: Yeah. I could go really early if I want.
If I wanna stay up later, I stay up.
(Autonomy: Real and Imagined)

Interviewer: Are you *able* to make your own meals?

Interviewee: I can if I want to (Autonomy: Real and
Imagined and/or Implicit Belief of
Competence)

(P3, I2, p.m.)

This narrative above highlights the perception of autonomy being intertwined with the belief of competence as well as with one's sense of self and identity. This is in line with the findings of Clare et al. (2008) discussed earlier in the paper, who concluded that there is still a drive/need towards a self-determined purpose and identity, even in individuals with moderate to severe dementia.

The one male participant of the study provided an understanding of how he experienced autonomy. William expressed his perception of autonomy or rather, his

right to have autonomy, with a tone of “of course” as seen below. He also expressed his Autonomy: Real and Imagined in the context of his Implicit Belief of Competence routinely. For example, he stated, “I do what I want to do, you know” as he pointed to activities around the room such as the craft center, the piano, and the board games. He believed he could and should make decisions and believed he was capable of performing an action/activity, if he chose. He expressed these beliefs as a matter of certainty. He also clearly expressed that his Autonomy: Real and Imagined is a part of who he is, as seen below during Interview One.

Interviewer: Do you feel you can decide how to do things
the way you want?

Interviewee: The way I want? Oh certainly, yes! I do what
I want to do, you know. (Autonomy: Real and
Imagined and/or Implicit Belief of Competence)

Interviewer: Do you feel you make decisions for yourself?

Interviewee: Absolutely! (Autonomy: Real and Imagined)

Interviewer: It's important for you to make your own
decisions?

Interviewee: Ugh sure, why not? [in a tone of voice suggesting
disbelief in not making his own decisions]

Interviewer: Why is it important?

Interviewee: Because I'm me! (self-identity) I don't want

to be doing something. Like someone says,
 “you get your ass over here”—excuse me
 lady.

(P4, I1, a.m.)

The narrative above also lends supports, as earlier examples did, that there continues to be a drive/need towards a self-determined purpose and identity even in individuals with moderate to severe dementia as Clare et al. (2008) concluded. This notion will be further discussed in detail in Chapter Five.

In Interview Two, when asked about making his own meals, William recognized there may be limitations to doing this. He stated he could perform the act of making meals if he chose (Implicit Belief of Competence) but did not want to make a mess or cook for everyone (Autonomy: Real and Imagined-choice in doing it), as seen below.

Interviewer: Okay. Are you *able* to make your own meals
 here?

Interviewee: Well, I can make meals but not without
 messing it here. One way or the other I make
 my own, yeah. (Implicit Belief of Competence)
 I don't know how you mean.
 I'm not going to walk in at the kitchen and
 serve, cooking for everybody. (Autonomy: Real and

Imagined-choice to not do so)

(P4, I2, p.m.)

William again expresses strong Autonomy: Real and Imagined in Interview Two, at the same time as expressing his sense of self, as seen below. The tone of voice he expressed during this interview suggested that he was horrified at the possibility of not having a choice regarding what he could do for himself. An alternate explanation of these statements would be that he had a strong need to *appear* autonomous to the interviewer rather than having a strong need to *feel* autonomous. Thus, suggesting the need to appear autonomous may to some extent be socially constructed possibly serving as a means to connect with as well as be accepted by others. Although the intention is unknown, the narrative below demonstrates the emotional importance of and the value placed on being autonomous.

Interviewer: Is it important to make your own decisions?

Interviewee: Oh yes, it is. I can do what I wanna

do (Autonomy: Real and Imagined-referring to
freedom of choice in making his decisions).

I don't know who would come against it, who
would tell me different?

Interviewer: I see. So, tell me, who decides what time you
go to bed? You raised your hand.

Interviewee: When I feel like it. (Autonomy: Real and Imagined)

When it's a good time, I wanna go to bed.

Interviewer: Does anyone here ever tell you what time to
go to bed?

Interviewee: No.

Interviewer: Okay.

Interviewee: Who would try to do that? Maybe, I'm
talking about just the people that are here
and... I wouldn't agree with that, you tell me
where I wanna go, no. What the hell! [voice louder
and taut. He was horrified in thinking someone
would tell him where to go].

(P4, I2, p.m.)

During an observation, as noted in the excerpt from observational notes below, William displayed doing what he wanted with little regard to who was around and who spoke to him, thus portraying in action his desire not to be told what to do, a sentiment he had verbalized above. Because his behaviors matched his verbal expressions, it is less likely that he simply wanted to project an image of appearing autonomous to the interviewer and lends credence to the notion that he internally believed in his desire and/or right to be autonomous.

He looked dignified as he sat in his chair. He looked around and noticed a staff person threw out a newspaper. He then stood up as the group activity was going on around him. When the staff person asked him where he was going, he ignored her as he walked over to the garbage and took out the newspaper from it. He walked unaided into the bathroom located off the community area.

(P4, O2, a.m.)

I would speculate that the fact that this participant had an extensive history of owning and running his own business for many years contributed to his high degree of desire for autonomy. It is also possible that his high degree of autonomy gave him some of the tools he needed to own and run his own business. These factors may explain and support the notion that his autonomy is strongly intertwined with his sense of self, which is tied to his ability to advocate for himself.

The fifth participant to demonstrate her Autonomy: Real and Imagined, which was often intertwined with the Implicit Belief of Competence, was Marybeth. To reiterate, she displayed the greatest difference in her memory loss from the morning interviews as compared to the evening interviews. She had a history of sundowning and often became agitated, angry, and weepy in the evening hours. During our first interview, Marybeth was clear, organized in her thinking and I internally questioned why she was placed in a memory care unit, as I had not observed her in the evening hours yet. However, by the

second interview and observation in the evening hours, I observed the effects of her dementia where she displayed some irritation and agitation.

Despite this fluctuation in dementia symptoms, Marybeth was clear in her desire to make choices for herself when she stated, “I still want to be in charge with my life” (P5, I1, a.m.). She went on to describe, as seen below in a morning interview, how autonomy was a part of her personality.

Interviewer: Do you feel you can decide how to do things
the way you want to do them?

Interviewee: Yes, yes, yes. (Autonomy: Real and Imagined)

Interviewer: Why is it important for you?

Interviewee: Because I, I'm that type of person, that's my
personality. (Identity)

Interviewer: So, would you say it's a need or a want to
make choices for yourself?

Interviewee: Oh I would like to say it's a need and a want,
I would like to be in charge of my life and
do what I choose to do. (Autonomy: Real and
Imagined and identity)

(P5, I1, a.m.)

The observation below details a challenge to autonomy, an in vivo confirmatory incident, of a situation which could have escalated into a conflict quickly. It undoubtedly reveals a clear example of being denied an opportunity for autonomy and the effects of this. It began when Marybeth adamantly stated her desire to have dessert before dinner. When presented with a compromise, she was able to engage in a solution that helped avoid a conflict with the staff while simultaneously giving her what she wanted. The contentious interaction was quickly diminished after providing her with a rationale for having some nutrition before eating dessert. The below text from observational notes during observation # 2 and the implications for practice of this observation will be discussed in greater detail in Chapter Five. Again, researcher reactions are in brackets.

Two staff people were busy taking dinner trays off the large tray holder that held all the meals and one staff person went around to each resident asking if they wanted chicken cordon bleu or a turkey sandwich with soup.

Marybeth stated,

I would like to have dessert
before dinner please

One of the staff persons looked over at her and said,

No, that's not how we do things.
You need to eat your dinner first.

The staff proceeded to pass out plates to the others. Marybeth sat there

with no food in front of her as the others around her ate. She looked over at me quickly. [With an awareness of potential bias, I note that my suspicion at that time was that she may have felt some awkwardness because our discussions have been about choice and here she was being denied a choice].

Marybeth looked sad at first and sat quietly with her head down.

She then asked firmly in an angrier than sad tone,

Why not?

She was ignored by both staff people who glanced at her and were busy working [At this point, I felt proud of her for standing up for herself and questioning the status quo. I was curious how this situation would play out as I was observing and taking notes at the same time, I also internally struggled with the choice of whether or not to intervene].

Marybeth asked louder,

Why can't I just have dessert,

if that is what I want?

I don't see what the big deal is?

Again, she was ignored. When the staff person asked Marybeth what she would like she stated,

I would like to have dessert only tonight,
what are the choices?

The staff person looked at her with disdain [I imagine because Marybeth was making her job difficult for her] on her face and stated,

You know we have to eat our dinner first
before dessert, now what would you like
chicken or a turkey sandwich?

Marybeth did not respond but looked downward and had a frown on her face. [I felt embarrassed for her and sad that she could not make such a simple request and that she was spoken to as a child would be, I then decided to intervene]. I said to Marybeth,

How about we make a deal, you have a few
bites of dinner, and I'll get you a dessert?
You know, if you have a
little dinner it might help with blood sugar
and that kind of stuff.

She said,

Oh, you are right ok, I'll have a few bites
of the chicken, then.

[I thought she was glad that she was not being ignored and was relieved that she was

willing to be flexible, as long as someone was flexible with her in offering her choices].

To lighten the mood and to help avoid her feeling embarrassed, I joked about the small portion sizes and how it would be an appetizer for me. Marybeth chuckled and had a bite as we talked. She said,

It's not bad, you know I'm glad you told me
about the blood sugar thing,

I knew that but I'm glad you reminded me.

After about half of her plate was eaten, she asked me what was for dessert.

I don't know, but I can go ask if you like.

She said,

Yes, would you please?

I went back to Marybeth and stated her choices. She said,

Oh yes, cherry pie, that sounds lovely.

[Her smile warmed my heart]. I went and took a pie off the counter as the staff was placing them on the counter now. [I also instinctively knew I had an invaluable piece of data for my study which illustrated the impact of being denied autonomy in the face of having a strong desire to be able to make choices. It was also an example of how autonomy can be maintained by negotiating care needs].

(P5, O2, p.m.)

Hyden, Lindemann, and Brockmeier (2014) support the notion that when one's autonomy is tampered with, there is an associated feeling of humiliation or loss of respect, which lends supportive evidence for my suspicion that Marybeth may have felt some emotional response, possibly embarrassment, in the excerpt above. I also acknowledge that my own sense that she was specifically feeling embarrassed could be a projection and that a more nuanced understanding of Marybeth's experience of that moment could only come through more probing follow-up interview questions.

Implicit Belief of Competence. As already introduced in the section above, another core theme that emerged was Implicit Belief of Competence. As previously stated, Ryan and Deci (2017) define competence as a need to feel efficacious in tasks and behaviors one has endorsed. Note, the key word in this definition is *feel* and there is no mention of accomplishing or completing the tasks or actions desired. Code words and categories identified for this theme were words such as can, able, do, capable, ability, and competence.

As mentioned in Chapter Two, Collopy (1988) stated that there is a distinct difference between being autonomous in actions and being autonomous with decisions. Because reality is often self-constructed for these participants due to fading memory, their belief that they are autonomous with decisions does not always align with being autonomous with actions. These participants' belief that they are competent, regardless of fact, is their own perception. At times autonomy and competence have been difficult to separate into distinct constructs based on participants' narrative, yet they are subtly different psychological needs heavily dependent on context.

Implicit Belief of Competence has been identified as a separate core theme because, although often interconnected with autonomy, it is its own construct. I found a select few meaningful units referring strictly to the construct of competence without the construct also being linked to autonomy and making one's own choices. For example, William stated, "Well, I can make meals but not without messing it here. One way or the other I make my own, yeah" when asked about making his own meals. Similarly, when asked about making her own meals, Marianna stated, "Well, I make it myself and bring it here". In reality, participants are served all meals, but they both believed they could perform the task of meal preparation, if they wanted. Other examples are when participants believed they were able to successfully perform self-care needs such as bathing, dressing, brushing one's teeth, and combing one's hair when in reality they were unable to perform these actions. These examples were predominantly illustrations of competence.

Furthermore, the construct of competence was found to be prevalent for all the participants as was Autonomy: Real and Imagined despite diminished capabilities. Participants believed they were competent in actions when in reality they were not able to perform them or restricted from performing them. An alternative explanation may be that these participants wanted to be perceived as being competent. Either way, the notion of competence was relevant for these individuals.

The quotes below illustrate examples of Implicit Belief of Competence as well as the strong interconnection of this construct with Autonomy: Real and Imagined during an evening Interview Two with Venecia. Again, residents are not allowed to cook for themselves and do not have access to the main kitchen. When she was asked if she was

able to make her own meals, the context of the response stressed both the choice as well as the ability to do so if she chose. The key informant also shares that Venecia needs assistance in bathing and dressing herself.

Interviewer: Okay. Are you able to dress yourself?

Interviewee: Yes. (Implicit Belief of Competence)

Interviewer: Tell me how you do this.

Interviewee: I wash and then I get my clothes on. (Implicit Belief of Competence)

Interviewer: You picked your clothes the day before or the morning of?

Interviewee: Probably in the morning if I feel like it, you know. (Autonomy: Real and Imagined)

Interviewer: Okay. Are you able to make your own meals?

Interviewee: I can if I want to. (Autonomy: Real and Imagined-choice and/or Implicit Belief of Competence- ability)

Interviewer: Okay. How would you do that?

Interviewee: Well, if I got the facilities, I'd do it.

Interviewer: Okay. What facilities?

Interviewee: Well, they got a stall over, a toaster and things like that.

(P3, I2, p.m.)

The quote below demonstrates Debbie's Implicit Belief of Competence as well as her Autonomy: Real and Imagined in making her own choices. Of note, her examples below were actions she was, in fact, able to choose and to perform with reminders from staff.

Interviewer: Do you comb your hair every day?

Interviewee: Oh, yes. (Implicit Belief of Competence- action)

Interviewer: And you use a brush or a comb?

Interviewee: Oh, brush usually.

Interviewer: And how do you do it?

Interviewee: I just brush it back. It's how I want it.

(Implicit Belief of Competence
and/or Autonomy: Real and Imagined)

(P1, I2, p.m.)

Participant two, Marianna, who is awaiting a higher level of care, was able to clearly articulate her belief that she can accomplish things as illustrated below.

Interviewer: So, can you tell me a little bit about your morning routine here?

Interviewee: Hmm. I get up, I clean my teeth and get ready and come here. [chuckles]. Good enough? (Implicit Belief of Competence)

Interviewer: Okay and what do you do here in the morning?

Interviewee: Oh shit! Yeah, I know but uhm. I can't remember, that's why I'm in memory care.

Interviewer: It's okay. It's okay.

Interviewee: Uh, how would I word it? You do it or you do it one of this. [background talk of other residents-included because it may have distracted her].

Interviewer: It's okay, we can move on, you want to move on?

Interviewee: Yeah.

Interviewer: Yeah, it's okay. All right. What kinds of foods do you typically have for lunch here?

Interviewee: Oh, not too much. Ah, sandwich, couple of sandwiches--that's about it.

Interviewer: Okay, and you like the food?

Interviewee: Yeah.

Interviewer: It's pretty good?

Interviewee: Well, I make it myself and bring it here.

(Implicit Belief of Competence)

Interviewer: Okay. All right.

(P2, I1, am)

I asked the key informant if Marianna was, in fact, able to perform the above tasks of brushing her teeth and getting ready and was told she needed reminders as well as assistance with these tasks. It was interesting to note her brief moment of lucidity leading to her insight of knowing she can't recall, thus explaining why she's in memory care. However, later in the same interview, she struggled with and stumbled on her words, "Uh, how would I word it? You do it or you do it one of this," before stating she makes her own sandwich, which is not feasible in the memory care unit. Despite this, she believes she can perform these actions. The above example illustrates the variability in fluidity of memory loss and capabilities within the same person within a short period of time.

Marybeth was clear in her describing her Implicit Belief of Competence and Autonomy: Real and Imagined by her desire to perform any tasks that she likes/chooses when she stated the following,

Interviewee: I like to do the things that I like to do... like

going shopping (Implicit Belief of Competence)
 and as long as my children are willing to take
 me, I'll do it. But I also do things that
 they like to do.

Interviewer: Okay, okay. But it's important that you
 have a say on things?

Interviewee: Oh definitely! (Autonomy: Real and Imagined)

(P5, I1, am)

It is likely that because the interview was held in the morning during her most lucid time, she was able to recognize there are limits to what she is capable of doing as well as limits to her choices as she knows she relies on her children to take her to events.

During an evening interview with Marybeth as depicted below, she revealed her Implicit Belief of Competence by highlighting the ability and act of picking out and selecting an outfit for the day. The below text was in the context of a conversation focusing on her abilities rather than choice. She also noted that she preferred to keep her routine the same as she did at home. This example serves to highlight Implicit Belief of Competence as well as the desire to maintain routine, a need to be discussed in more detail in the next section, A Preference for Routine and Comfort.

Interviewer: Uh-huh. Do you pick out your own clothes
 every morning?

Interviewee: Oh, absolutely -- yes. (Implicit Belief of
 Competence)

Interviewer: The night before or the day of --

Interviewee: No, I get up like I would at home. I do
everything that is exactly the same thing. (A
Preference for Routine and Comfort)

(P5, I2, pm)

William expressed a similar sentiment about his Implicit Belief of Competence as well as A Preference for Routine and Comfort. He was vague in his response but was clear in his perception that whatever he decided to do was his choice and he believed he was capable of performing the action/activities he chose. When discussing which activities he chooses to do when he gets visitors, William made the following statements.

Interviewer: Okay. What do you do when they are here?

Interviewee: I just *do* anything I *want*. (Implicit Belief of
Competence and/or Autonomy: Real and
Imagined) You know. Just routine [he pointed to
various familiar activities around the room such as
the books, playing cards, and the board games]
whatever the heck.

(P4, I1, a.m.)

A Preference for Routine and Comfort. Meaningful units and code words

relevant to routine and comfort were prevalent for all the participants and thus warranted its own thematic category. The central theme of “A Preference for Routine and Comfort” included meaningful units or codes such as routine, familiarity, meeting needs, consistency, self-soothing, familiarity, predictability, continuity, comfort, and being provided care. Routine is a strategy used to organize activities along different axes of time in an orderly predictable and familiar pattern and has been found to serve adaptation by providing comfort, continuity and support for one’s identity especially during stressful situations (Zisberg, Young, Schepp & Zysberg, 2007). The desire to continue with and retain routine as well as a tendency to be drawn toward comfort was not overtly or verbally expressed but rather it was witnessed during observations through behaviors suggesting the need to fulfill these needs for all the participants.

On several occasions it was observed that when residents struggle with their dementia symptoms, thus highlighting a stressful situation and feelings of vulnerability, the emotional need for comfort, self-soothing, safety, continuity, stability, familiarity, and routine was also present, if not heightened. Feil (1993) supports the notion that in the context of dementia, universal needs such as the longings for safety, love, comfort, and purpose emerged and by validating rather than ignoring these needs and feelings anguish is reduced.

In prior research, familiar places and rituals such as everyday routines contributed toward well-being and a sense safety and security for those in residential settings dealing with chronic illnesses (Årestedt, Benzein, Persson & Rämngård, 2016). These authors

found that consistency and stability created a feeling of being at ease, especially when facing experiences that invoke feeling of threat or vulnerability. This lends support for the notion that the choice to continue with a routine and be drawn to familiar patterns of behavior aid in providing some sense of predictability, comfort, and continuity when feeling uncomfortable or vulnerable.

In the observation below, Debbie illustrates the importance of maintaining routine, as well as consistency, by selecting the chair she always uses in the dining room. Her choosing to continue with this familiar routine may suggest a way of fulfilling her need for predictability, comfort, and continuity or it may have simply been a way for her to sit closer to someone she liked, or it may be a combination of the two.

When lunch was announced, she got up from her chair and walked. She walked on her own to the dining room. She sat herself in the chair she always sits in the dining room and waited to be served as she has in the past. (routine, familiarity)

(P1, O2, a.m.)

Sitting in the same chair and location that one is accustomed to in the dining room or communal area is a consistent routine I noted with all the participants, including William. On one occasion, I witnessed a participant asking a family member to move out of her chair although there were other available chairs nearby, suggesting that using one's own chair is valued in day-to-day routine. The need/desire to feel a sense of continuity and predictability can be reflected in physical space such as sitting in the same chair.

The participant below, Marybeth, discussed her morning routine when asked to describe it and stated [by sitting up straighter and had a smile on her face that gave the appearance of her feeling positively about her routine at home], it's "just like I did it at home" (P5, I1, a.m.), suggesting support for the psychological importance of keeping predictable patterns of behavior relative to the patterns established at home. She has a choice to not follow the same pattern of behaviors as she did at home but nonetheless chooses to continue the patterns.

Interviewee: And I wake up around, oh I don't know 7:30,
around 7:30.

Interviewer: Okay.

Interviewee: And I get up and go into the bathroom and the
first thing I do is go to the bathroom.

Interviewer: Okay.

Interviewee: And then I uhmm have a cup of coffee and
after that I decide on what I'm going to wear
and get dressed. (routine, choice, predictability,
familiarity)

(P 5, I1, a.m.)

The participants, Debbie, Marianna, and Venecia, as noted below, illustrate an important nuanced finding in that they did not mind being cared for in certain areas they have perceived as areas they have willingly chosen to give up, such as in the routine of preparing and being served food. Debbie made it clear that “I have done enough cooking through the years,” suggesting, she did not mind no longer needing to cook and therefore, chose the act of being served food as acceptable to her. In other words, it is possible that these participants have chosen to view some activities as ones they have chosen to no longer want to do for themselves, versus activities being denied them. Pirhonen (2017) found in his work that delegating one’s agency to others voluntarily is more acceptable than having one’s agency restricted by others. Therefore, being cared for in specific ways through what is viewed as a delegated care task makes it more acceptable because it is perceived as being chosen by the participants. Simply, delegating one’s autonomy is a choice and therefore a version of autonomy.

The several excerpts below may also lend further support that choosing to be cared for through delegated care tasks and feeling a sense of continuity through predictable and familiar routine patterns possibly are intertwined with the basic need to feel one has a choice (have autonomy).

Interviewer: So, you would go in the kitchen area here and
make what you want?

Interviewee: Well, I have never done it.

Interviewer: Okay, do you think you could?

Interviewee: I don't want to. (Autonomy: Real and Imagined)

Interviewer: No? Why not?

Interviewee: I have done enough cooking through the
years. (believes she has chosen to be relieved of
this task)

(P1, O2, a.m.)

and,

She took her time and didn't look rushed eating her food [in
the dining area along with other residents, she looked
content] (familiar routine of prepared food given to her and
eating in dining area connected to feelings of being
content)

(P2, O2, p.m.)

and,

“Well, I get everything I need. There's nothing I'm
lacking.” [participant describing, she doesn't lack for
anything in the facility and has delegated her needs to the
staff, feels cared for]

(P3, I1, a.m.)

It was a striking observation to note that for all the participants, verbally or through action, there was a desire for as well as a choice in maintaining routines. When specifically asked about his daily morning routine William stated, “I just do anything I want.” (P4, I1, a.m.) The key informant had stated “he likes to keep to his routine” when describing what William does during the day. Although William’s response was brief and to the point, it highlighted an acknowledgement that he chose to do anything he wanted for his morning routine (autonomy) and he was able to clearly express this. The several statements from participants discussed above, lend support to my assumption that the notions of routine and familiarity may aide in promoting feelings of comfort and continuity as well as supporting one’s desire for autonomy. By choosing whether or not to continue with a routine or to delegate a care task that once was a familiar routine such as preparing meals, one exercises one’s need for autonomy. Williams’s activities in his routine were perceived by him to be his choice rather than him being dictated; thus, routine was interrelated less with need in terms of dependency and loss of independence but rather with control/choice for him.

According to the nuanced patterns noted in the participants’ narrative as a collective group, it lends support for the notion that there is value to maintaining routine and familiarity which may contribute towards a sense of autonomy as in the study by Årestedt, Benzein, Persson, and Rämgård (2016). Nonetheless, the participants of my study have verbalized and/or behaviorally illustrated that they choose to continue with or

allow a routine to occur and believe that this choice is within their control rather than believing that these choices are made for them, parallel to the work of Pirhonen (2017).

As Feil (1993) suggests, the need for comfort, predictability, and routine are universal needs that are heightened especially during times of vulnerability. The key informant had shared that Debbie rarely sits in the common area, but when she does, she routinely appears to fall asleep during group activities or will get up and go to her room. To recall, Debbie was the participant who always wanted to meet in her private room for interviews and, therefore, seeing Debbie out in the community area was unusual and not a common occurrence. The key informant also shared with me that Debbie often became frustrated with her “mind not working right, then gets frustrated and wants to be left alone.” It is possible that the familiarity of Debbie’s room may have provided comfort for her particularly during times of her feeling vulnerable. Yet, it is also possible that resorting to her room provided her some needed retreat from the stimuli in the communal area.

Nuanced Relatedness. The central theme of Nuanced Relatedness has several subsections such as *Choosing Degree of Relatedness*, *Making Compromises* and *Preserving Familial Relationships*. This central theme included varying codes such as family, closeness, compromise, connection, accommodation, belonging, acceptance, and humor. The term nuanced highlights the subtle distinctions in having this need met. There was strong visual and verbal evidence for all the participants needing to belong and feel connected to others, as seen in the statements listed below;

“They make me feel like I belong here and they're ... I don't find anybody not likeable” (P5, I1, a.m.) [when discussing the staff], “We sit and visit and talk and find out what's going on with the family and who's doing what, where and whatever” (P3, I1, a.m.) [when discussing what she does during family visits], “they're very very welcoming” (P3, I1, a.m.) [describing the staff], and “Oh, thank you, do you want some candy, Miss?” [as he smiled] (P4, O2, a.m.) [Using playfulness and humor in an attempt to connect to another resident as she walked past].

Choosing Degree of Relatedness. The need to feel connected was often intertwined with freedom to make the choice (autonomy) to be alone if desired or needed, similar to the other central themes which were often intertwined with the construct of autonomy. There appears to be a need to choose when to be with others and when some alone time is desired or needed. The need to connect with others or disconnect from others was a fluid and dynamic construct. The following observations and quotes are counter examples of the need to connect with others: “She did not talk to the others and just focused on her meal” (P1, O2, a.m.) [during the breakfast meal in the dining room], “Yeah, tell them not to bother me” (P1, I1, a.m.) [referring to the other residents], and “She sat by herself and then stood up by herself with her walker and went to her bedroom alone”. (P2, O2, p.m.) [during a group activity in the group room].

There is some observational evidence that led to my questioning whether this need or desire to be alone arose during moments of struggling with dementia symptoms that in

turn may heighten feelings of vulnerability. Pirhonen (2017) found in his study that residents in an assisted living facility sometimes isolated themselves from others to avoid feeling awkward in their company. Participants use of private time offered them an opportunity to make a choice in reducing the level of external stimuli, possibly, as observations suggest when feeling insecure, awkward or emotionally vulnerable. At times, participants turned inward (by closing off from others) either physically or mentally as a way to disconnect from interactions or their environment. There are numerous possible reasons for this including fatigue, apathy, and not feeling well. This desire to be alone when struggling with dementia symptoms will be discussed in more detail in the Dealing with the Neurophysiological Effects of Dementia section of this paper.

There are varying degrees of freedom for these participants in this setting to make the choice to be left alone when desired. For example, the activities person in the facility strongly encouraged all participants to partake in the scheduled activity. The activities person made personal and concerted attempts to engage participants. This was noted in an observation, “She smiles, touches several ladies on their shoulder and jokes with them [the activities person is very friendly and warm]” (P2, O2, p.m.). However, these participants can choose to remain engaged in the activity or not. When discussing group functions and activities at the facility, Debbie made it clear that she sets the tone of level of interaction when she stated, “They, they don't tell me I got to do this, or I got to do that. Yeah, they know and leave me alone” (P3, I1, a.m.). When no activity is planned at the facility, participants are free to engage or not engage with others.

In the community area with other residents, the participants were observed being selective in their social interactions. It was these observations, that when one chose to end social interactions, by either physically removing themselves from the situation or simply closing one's eyes to end a conversation, which lend support for the central theme of Nuanced Relatedness as also an expression of one's choice. Nevertheless, there are a number of possibilities as to the motives for behaviors such as closing one's eyes such as fatigue and medication side effects. Again, it is the totality of the data observed and gathered from all the participants that led to my noticing patterns of behaviors that have led to my assumptions. The excerpt below from an observation of Debbie is an illustration of the possible need to control, through various behaviors, one's interaction with others.

When a discussion occurred in the community area where she was sitting toward the back and paying attention, Debbie put her head down suddenly and focused on her knitting instead, appearing as if she didn't want to participate any longer. She then got up and walked away. After about 15 minutes she walked out of her room on her own with no walker and sat with the others in the community area. She leaned to the side of the chair and appeared to fall asleep by closing her eyes.

(P1, O1, p.m.)

Marianna displayed a similar pattern of behavior as illustrated in the several observations below. Marianna was observing an interaction in the community area, and when asked if she wanted to “join in,” she verbally stated “no.” She behaviorally reinforced this by removing herself physically from the community area. For reasons unknown, she made the choice to disengage from relating with others around her by sitting by herself. Later, she stood up by herself with her walker and went to her bedroom alone.

(P2, O2, p.m.)

and,

Marianna watched quietly as the other members played bowling. She sat and watched attentively as she placed her leg on her walker. Activities person asked, “You don't want to participate?” and subject said, “Nope I don't.” Activities person said, “Ok maybe later then.” She sat quietly watching the other members with her fingers near her mouth. She moved her walker back as another member

walked past and bumped into her with her walker. The activities person said, “Ok let’s all stretch now.” Subject watches but didn’t stand up. She leaned forward to watch the others as they participated. She bent her head to watch but didn’t participate. She stood up and walked to her room with her walker without saying a word.

(P2, O1, a.m.)

Marianna decided to leave the social gathering and walked away. There is a myriad of possibilities as to why she chose to leave the room, such as she was tired of watching, she did not feel she could participate, or she wanted to avoid potential embarrassment or feelings of awkwardness. Either way, she exerted control and choice (autonomy) by removing herself from the situation.

Venecia, as illustrated in an observation below, remains connected with the activities person and follows her direction as best she can. As a reminder, Venecia was described by the key informant as “more advanced in her dementia as compared to some others”. When Venecia, along with the others were asked to touch their toes and Venecia couldn’t do this, she blurted out a memory from her childhood. The timing of her recalling this memory may have been random or it is possible it may have been a way to self-soothe or distract from not being able to perform the task as she was asked to do, and thus connected with the others in a way she felt she could.

The activities person says, “Ok let’s stretch.” Venecia stands up and stretches her arms out and rotates neck to stretch. She watches her neighbor to see if she's following also. She sits down after the activities person says to sit. She kicks her leg up as directed. “Let’s march now and lift our arms,” directs the activities person. “Now let’s touch our toes,” which she could not do. Venecia then states abruptly, “Yes, I used to play hopscotch when I was younger, you drew on the sidewalk.” She smiled as she recalled this memory. [I had the sense she wanted to share what she could do during a moment when she was unable to participate]

(P3, O1, p.m.)

The participants of this study decided when, how and to what degree they participated in social gatherings and activities. They regulated their behavior either by disconnecting from the activity by dozing off or by physically removing themselves. Either way, they often exerted choice of when to engage with others and when to withdraw.

Making Compromises. The construct of Nuanced Relatedness was also intertwined with the ability to compromise and at times, not complain/accommodate, in order to get along with others and to retain a positive connection with the staff. Meaningful units such as avoiding conflict, being congenial and not causing a disruption were illustrated in

the following statements: “Whatever they serve, I eat. I’m not a complainer” (P1, I1, a.m.) (Made in reference to not causing problems for the staff) and “Well, um, whatever they want me to do, I try to do”. (P1, I1, a.m.) (again, referring to the staff), “Mostly, I go along *unless they are stepping on my toes* [emphasis added]” (P4, I2, p.m.) (referring to the staff and she stressed the point that if she felt they crossed a line by “stepping on her toes”, then she would speak up), and that it is “Very seldom that we disagree” (P2, I1, a.m.) when discussing interactions with the staff. This ability to compromise suggests an intact ability to negotiate relationships in order to get social needs met by being congenial and conflict avoidant, yet being willing to speak up if feeling this “line is crossed.” Also, it suggests having a mental threshold of what one is willing to tolerate (compliant) or not, and then making the choice of when to assert one’s demands and advocate for oneself (autonomy). Nevertheless, choosing the degree to which one is willing to compromise in relationships affects how one negotiates meeting one’s need for relatedness.

Preserving Familial Relationships. The construct of Nuanced Relatedness also incorporates the desire for familial connections. No participants verbally expressed feelings of loneliness or a desire for more contact with other residents or staff. Many of the participants expressed a desire for more family interaction and connection and some reported that family doesn’t visit frequently despite their frequent presence. It was mentioned by several participants that their family did not visit as often as they would like either because of busy schedules or inconvenience, as in the comments below by Venecia.

Interviewer: Good. Does your family visit in the evening time here?

Interviewee: Well, it's kinda hard for them I think, you know. I, I'm well taken care of. They know it [chuckles].

(P3, I1, a.m.)

Of note, her son was sitting behind her but out of view. She had talked with him a few minutes earlier.

The comments below display some disappointment from Marybeth because of family not visiting enough. She states she would have liked her son to visit more than he has thus far. This statement expressed her desire for more interaction with him.

Interviewer: Does your family visit in the evening time?

Interviewee: No.

Interviewer: No?

Interviewee: No. In fact, I was thinking, I thought maybe my son would have been here, he's only been here once.

Interviewer: Okay.

Interviewee: My son and I thought he would have been here more than that. My son, xxxx was here, he's my older son. And my son, xxxxxx, I don't think xxxxxx was here at all.

Interviewer: Okay. When is the last time that they visited you?

Interviewee: Probably a good seven days ago.

(P5, I1, a.m.)

Her older son visits several times a week according to the key informant.

In the narrative below, Marianna's reality is in her remembered past. Yet she is able to express her present desire to accommodate her mother by meeting her at home because her mother does not like to travel. It is likely that Marianna's mother is no longer living but she speaks of her as if she is still alive. Although Marianna is more advanced in her memory loss, she is still able to express a desire to see her family more, as they "very, very seldom" visit. However, the key informant stated, "Her daughter is here all the time".

Interviewer: Okay. When does your family usually visit?

Interviewee: Very, very seldom. Ummm, my mother doesn't like traveling and that's so I go home all the time.

(P2, I1, a.m.)

Alternatively, William was clear in not seeing his family recently and discussed it in a matter-of-fact tone with little emotion, as discussed below.

Interviewer: Does your family visit in the evening time?

Interviewee: No.

Interviewer: No?

Interviewee: No.

Interviewer: When's the last time that they visited you?

Interviewee: Well, you know couple of weeks or week, yeah that's all.

(P4, I1, a.m.)

Because of his abrupt and short answers as well as the stoic expression on his face as he responded, these observations suggested that he did not wish to discuss this topic any further. I was unable to obtain any information on the frequency of family visits for William from the key informant. The precise intent behind William's words was difficult to know as I did not know the reality of how frequent family visited and no follow-up questions were asked at that time to avoid the possibility of upsetting him. Nevertheless, it was evident that this was a subject he did not want to discuss further.

The examples of dialogue thus far support a desire and need for relatedness, especially with family. It was evident, as the dialogues above have illustrated, that there is a longing and desire for more contact with family. The relationships with family were obviously meaningful and could not be replaced by the staff or other residents. As noted above with Venecia, she mentioned that it was difficult for family to come in to visit. Despite her son sitting behind her and speaking to her a few moments earlier, I had the impression Venecia had forgotten he was there. Therefore, it was possible that family was visiting more frequently than the participants had mentioned but that they didn't recall. Although the frequency of their family visits was outside of the participants' control, their

frequent expressions for their desire for family to visit was within their control. It is possible that the desire to have family near and the desire for them to visit frequently highlights the psychological needs that these relationships fulfill. The intertwining of all the core themes of this study and the reality of a diminished memory will be discussed in more detail in the next section of this chapter. Each of the core themes were closely intertwined with the other themes and, thus, isolating them completely, at times, was not feasible.

Dealing with the Neurophysiological Effects of Dementia. Although the theme of Dealing with the Neurophysiological Effects of Dementia is not a psychological need, it unexpectedly emerged as a central category for all the participants, whether they were struggling to retain the limited memory they did have (Debbie and Marybeth) or were at such an advanced point that the loss of memory and other symptoms of dementia were no longer distressing to them (Marianna and Venecia). It became evident in this study that understanding how one deals with the neurophysiological effects of dementia affects how one has one's psychological needs met. This construct emerged through repeated observational evidence and may be important in understanding the context of Autonomy: Real and Imagined, Implicit Belief of Competence, A Preference for Routine and Comfort, and Nuanced Relatedness. As in A Preference for Routine and Comfort, Dealing with the Neurophysiological Effects of Dementia was not overtly discussed during interviews but rather captured during observational periods.

Of the five participants, participant #1-Debbie and # 5- Marybeth struggled the most with their dementia, and both vacillated with the Neurophysiological Effects of

Dementia within the same day and sometimes within an hour's time. Debbie had insight into her issues with memory as evidenced in her statement "I-I can't. Today, it's not working" (P1, I1, a.m.) as she pointed to her head and clutched her fists together suggesting frustration. For all the interviews, this participant wanted to meet in her room with a staff person present, which was honored. She had a tendency to isolate herself and the key informant shared with me that she thought it was because she did not like to embarrass herself out in the community area because of her memory loss. Debbie was observed in the community area several times where she interacted with others minimally and then abruptly disengaged by looking downward or closing her eyes, as in this one observation below.

A discussion was occurring in the community area where she was sitting toward the back and paying attention, she put her head down and looked like she didn't want to join in any longer because she looked down and focused intently on her knitting instead. She had made the choice to disengage from interacting.

(P1, O1, p.m.)

Marybeth, as discussed previously, was extremely lucid in the daytime and was found interacting with others in the community area. She frequently engaged in a cogent manner in activities during the day as depicted in the morning observations below.

During these times of lucidity, as illustrated in the several examples below, she was able to fulfill her needs for both autonomy and competence.

The activities assistant told the group it was time to bowl and Marybeth said, “Wow, we keep busy.” She played bowling willingly, and the activities person said, “It's your decision if you want to play.” She rolled the ball on the table. “Oh, my God -- why does it go to the left”. “Come on you can do it,” the activities person said as she directed her to play a round of bowling (Marybeth displayed autonomy and competence by choosing to continue to engage in this activity).

(P5, O1, a.m.)

and,

They were asked by the activities staff what was important for well-being. Marybeth stated, “Making the right choices was important for well-being and good health, family is important for well-being too” (relatedness). When asked what kind of choices she can make Marybeth said, “Well, I can't order Pontillo's pizza if I want”. The activities person said, “No you can't, but you can wear the clothes you want” (autonomy).

(P 5, O1, a.m.)

However, by evening, Marybeth displayed sundowning behaviors with agitation, irritability and weepiness. I observed her during an evening observation of another participant, sitting alone in the community area. Marybeth asked people as they walked by to call her son for her because she was “stuck here by accident.” She was weepy and irritable as she continued to ask other residents to help her call her son, a familiar person. The staff noticed her but ignored her. Marybeth was clearly distressed in the observation discussed. When she displayed behaviors suggesting she was distressed, it is possible she may also have been feeling vulnerable emotionally.

During an evening observation period as discussed in the excerpt below, I witnessed Marybeth more introverted and self-preoccupied than she normally displayed during daytime hours. She appeared to be struggling with the neurophysiological effects of dementia.

The evening began with the activities person asking the group to come sit in the community area in order to play bowling with plastic pins on a table. Each member took turns throwing the ball. When it was time for Marybeth, she didn't stand up like the others had done prior but rather talked about her past life (something familiar) before moving into the facility. She stated, “my mother put clothes on the clothes line when I was younger, and my wedding dress was washed and put there.” The activities person

asked her if she wanted to play a game of bowling and Marybeth didn't respond but instead, looked down and blushed. Her facial expression and her blushing provided observational data to support that she was possibly embarrassed and was perhaps having a difficult time with her memory. I recalled that the key informant had previously told me that when she "struggles more with her memory ... [she] wants to be left alone." While the activities person asked the next person to play, I got up and sat next to Marybeth. I slowly put out my hand and she held it, which suggested to me she recognized me enough (familiarity) to trust me or she needed some comfort and took the opportunity to have her needs met.

(P5, O2, p.m.)

Again, in contrast to the morning observation, the evening observation excerpt as depicted below illustrates Marybeth being more introverted and paying more attention to herself and her own needs which are in her control and with which she is familiar, rather than participating in the group activity in which she normally would participate during the daytime.

Marybeth came back with the staff person and said she didn't want to get her hair done. She sat in the back of the

room looking at her nails. She waved her hands in the air to ensure her nails were dry and ignored the staff person as she was focused on her nails. Her facial expression was displaying focus on her own needs and demonstrating little awareness of her surroundings and what was happening. The other residents were moving toward the dining room as she sat disconnected from the events in her environment.

(P5, O2, p.m.)

A book by Baker (2007) describes the need for those residing in a nursing home to have a sense of belonging to a place in order to experience well-being. She identifies the three psychological processes which contribute toward this sense of place as being familiarity, attachment, and identity. Baker describes the disorientation that occurs from one being displaced from one's home as undermining one's sense of belonging. This observation suggests that there is a searching for opportunities for familiarity to sustain one's sense of identity and belonging. It is also feasible that as one's disorientation heightens there is a heightened sense of vulnerability and threat to self; as a result, one's need for familiarity, stability, comfort, continuity, and safety increases as well.

One possible interpretation of the observations discussed thus far, based on Baker's (2007) insights, is that Debbie had a tendency to seclude herself, either physically or mentally, during a moment when struggling with her memory, as I had observed her doing during the interviews in her room. Yet, it is also conceivable that the behaviors

Debbie displayed were the results of executive function limitations commonly found in people with dementia. However, it is also conceivable that these behaviors may have been a way to save herself from feeling embarrassed, humiliated, or awkward, as the key informant had shared. It may be that her room offered her comfort as well as enabling her to feel secure and safe during moments of feeling emotionally vulnerable. It is also possible that struggling with one's memory may be experienced as a loss of control for this participant, thus explaining why she chose a routine and familiar task such as knitting, and often wanted to meet in her room.

Marybeth displayed a pattern of behavior, as discussed above, which was similar to Debbie where she blushed during a group activity and then held my hand, suggesting when her feelings of insecurity or vulnerability were increased, her need for familiarity and comfort grew as well. Godwin and Poland (2015) found when a person feels most vulnerable and threatened, the need for contact with a familiar person may result in wandering behavior. This reflects a search for something or someone familiar and safe, especially in a place or during a time that appears strange and frightening. They also posited that in dementia we see the person's raw attempts to remain safe and secure despite being stripped of the layers of socialization and ability to fully communicate needs. Future studies focusing exclusively on this observed phenomenon may be valuable and will be briefly discussed later.

William as noted previously, did not appear to struggle with his memory but rather held onto his reality of his once lived life as a way of existing in the present, which demonstrated his need to retain autonomy and competence, as seen below. The narratives

told by patients do not always follow logic, but the deviations from reality may express a truth more revealing of who they see themselves to be (Fivush & Haden 2003). Also, Romanoff and Thompson (2006) found that the ability to reinterpret past experiences in the light of current conditions, can be utilized to fulfill a need for patients by giving them a sense of control. In other words, hanging onto the past through narrative accounts, may affirm one's continuity of self.

As displayed in the below excerpt, William keeps his answers to questions short, possibly as a way to limit expressions of his dementia symptoms, yet is consistent in expressing his autonomy and competence.

Interviewer: Do you feel you make
decisions for yourself?

Interviewee: Absolutely!

Interviewer: Can you give me example?

Interviewee: Ugh huh. Just anything I want.

(P4, I1, a.m.)

In contrast, Participants #2 (Marianna) and #3 (Venecia), were described by the key informant as being more advanced in their memory loss. There were no observational sessions for any of these participants indicating that they were struggling with memory loss; in other words, they did not fluctuate in lucidity. For example, Venecia also did not appear to struggle with her memory but rather accepted it and integrated it into her daily activities. It was evident that she remained in her remembered past as her present state of reality, as seen in the observation noted below.

She suddenly recalled activities and then a humorous memory from her youth and retold it in her activities group, although they were not discussing these topics at the time.

Activities person says,

“Ok let’s stretch”.

She stands up and stretches arms out and rotates neck to stretch. She watches her neighbor to see if she's following also. She sits down after the activities person says to sit. She kicks her leg up as directed.

“Let’s march now” and lift our arms,”

directs the activities person.

“Now let’s touch our toes.”

But she doesn’t follow along. Venecia states,

“Yes, I used to play hopscotch when I was
younger, you drew on the sidewalk”

She smiled as she recalled this memory but was not following along with the rest of the class. Instead she told the following story,

I remember I worked in the telephone company. It
was a fun job-- people would ask for naughty
numbers, we knew who they were, these were the
days of the party lines. Well I heard the naughty stuff

on the party line. It was fun a lot of good people and
even some of the old crabby ones too.

(P3, O1, p.m.)

In contrast to those who struggled with their memory, Venecia did not self-isolate or withdraw from activities. Instead, she used humor and recalled memories, possibly as a means to deal with her distress/awkwardness of not following along or possibly as a means to connect with others because she was unable to or chose to not follow along. Perhaps Venecia's recollections are not as filtered as they are for others because she is less attuned to social conventions as a result of her dementia.

According to the key informant, Marianna was the most advanced in her illness and as a result of this she was awaiting nursing home level care. This participant lived in her own reality, as has been noted earlier. Marianna's self-awareness of her memory loss rarely fluctuated. In other words, she did not appear to be grasping the gravity of her memory loss and therefore, was not distressed by the loss of it. It is possible that there is no need for "face saving", a need to be perceived a particular way by others, at this point of the illness. As illustrated below, she was able to interact meaningfully with others, as she sang a lullaby to her daughter. During this observation, I presumed that she most likely displayed this behavior in the past as a doting mother taking care of her young daughter. Recalling it may have brought her a sense of familiarity and comfort. She had a smile on her face as she swayed from side to side gently as she lovingly looked at her daughter.

She sat with her daughter who was visiting and sang the song,

“You are my sunshine, my only sunshine

You make me happy when skies are gray

You'll never know dear, how much I love you

Please don't take my sunshine away”

quietly to her daughter. Her daughter sat up to leave and kissed her mother. Marianna said to her daughter who she obviously recognized,

“take care now”.

She then shifted her attention and watched quietly as the other members played bowling. She sat and watched attentively as she placed her leg on her walker.

(P2, O1, a.m.)

During an interview, Marianna was able to answer the question but had difficulty elaborating any details. She then drifted into her own reality as seen below.

Interviewer: Okay. Is it important for you to make your
own decisions for yourself?

Interviewee: Mm hmm.

Interviewer: It is?

Interviewee: Yeah.

Interviewer: Okay, tell me why?

Interviewee: I don't know-- it's just that we do it that way.

[she recalled it was something she did but

could not elaborate, she looks downward and did not

make eye contact with interviewer]

Interviewer: Okay. Does it make you feel good?

Interviewee: Oh oh, once in a while when like something
will come up, something, I can't remember it
but anyways and that I would ask my parents
about something and they always they tell
me. [she was in her own reality and
avoided eye contact with interviewer while being
asked a question and while she responded]

(P2, I1, a.m.)

As depicted above, Marianna unexpectedly began speaking about her parents, something she was familiar with during a time she struggled for her answer. This offers another example of one resident seeking familiarity and security in the midst of feeling confused. In speaking about familiar people (her parents) Marianna may have attempted to maintain a sense of control when feeling insecure and vulnerable, as her behaviors involved looking down and avoiding eye contact with the interviewer on several occasions. Godwin and Poland (2015) suggest that dementia could move emotions either way, unleashing previously repressed memories or calming sources of previous anxiety, and that while imaginary accounts are usually dismissed as confabulation by care providers, they may provide people with personal satisfaction by fulfilling their needs.

In the work by Fazio (2008), it was suggested that older adults with Alzheimer's disease utilize some safe guards for self-protection in order to maintain a positive sense of self and well-being. He states several forms of self-protection such as, identification with a particular role even though we no longer assume that role (such as in the example given by Marianna who sang a soothing lullaby to her daughter), memories of more successes than failures, and recollection of information about our past constructed through suppression and selective recall (the examples by Venecia and her sudden recall of playing hopscotch as a child and working at a telephone company during a group activity). These safe guards serve to support a positive sense of self and well-being, according to Fazio (2008). The examples of dialogue (refer back to the quotes) illustrate that these safe guards persist for the purpose of fulfilling psychological needs. Despite this, it is difficult to know the precise explanations and intent behind participants' behaviors and dialogue, I have offered my conjectures based on patterns of behaviors and data from the participants as a collective whole with supportive evidence as needed, yet keenly aware of the fact that they are speculative.

Additionally, the excerpts discussed thus far lend supporting evidence for my analysis that there may be a tension at play between the need for Autonomy: Real and Imagined which supports the sense of self and the fear of losing one's autonomy as a threat to self through one's loss of memory and diminished capabilities. This observation was an unexpected finding and is slightly outside the scope of this study as dealing with the neurophysiological effects of dementia is not a psychological need. However, Dealing with the Neurophysiological Effects of Dementia was found to have an impact

on psychological needs and, for this reason, considered pertinent enough to add as a central theme in this study. Nevertheless, this phenomenon lends itself to further investigation and study in the future as mentioned previously. A relevant and pertinent finding in this study is that despite the struggle with memory loss or not, it is evident that older adults have a need to retain a need to retain a sense of autonomy, which is the main focus of this study. Appendix C offers a summation of the central concepts of this study along with the core themes.

4.4 Summary

The constructs of Autonomy: Real and Imagined and Implicit Belief of Competence have been discussed separately as has the interconnectedness of these two constructs. Additionally, as the discussions earlier illustrated the construct of Autonomy: Real and Imagined was so prevalent that it was found to be interwoven through the constructs of Nuanced Relatedness as well as A Preference for Routine and Comfort. The interconnectedness of these constructs in this study lends supports to the idea that Autonomy is the vehicle “through which other psychological needs are actualized” (Ryan & Deci, 2017, p.97). Dealing with Neurophysiological Effects of Dementia emerged as a contextual explanation in understanding the fluidity in how these constructs are experienced in relation to each other for this population. These perspectives enlightened us to their first-hand experiences and needs in the context of their living situation so that best care practices can be fully realized.

In summary, I found that Autonomy: Real and Imagined was oftentimes interconnected with the construct of Implicit Belief of Competence. As Clare et al.

(2008) found, autonomy is interconnected with one's sense of self, and my study reinforces this observation. For many of the participants in this study, the need to belong, Nuanced Relatedness, was evident and the ability to negotiate relationships was utilized in order not to feel left out, not to disrupt the order of things and to feel connected with others. Additionally, having the freedom to choose whether or not to interact with others was central for these participants. This freedom allowed them the prerogative to control their level of interactions with others around them, highlighting the drive and need for autonomy within this construct. It was evident from the participants of this study that there was a longing and desire for more contact with family. Most likely these relationships help fulfill psychological needs for the participants in a way that the relationship with staff could not.

For this group of participants, there was A Preference for Routine and Comfort although this need/desire varied in degree for each participant and at various moments of struggling with memory loss. Routine, comfort, stability, familiarity, and predictability were important determinants in fulfilling the need/desire for comfort and continuity. The male participant referenced routine several times and the key informant mentioning "he likes to keep to his routine". Having their needs met contributed towards the feelings of continuity and the drive and need for autonomy was often central in helping them meet their needs.

The Dealing with Neurophysiological Effects of Dementia was central for all the participants in this study as they were residing in a memory care unit. Those who were struggling with their memory loss, appeared at times to have a desire to turn inward and

to self-isolate, possibly as a way to self-soothe, provide a feeling of being in control of events, or as a means to find continuity. For those who had insight into their memory loss, I observed that participants sought familiar routines, activities, people, or places during times of feeling vulnerable or distressed by memory loss. Those participants who were more advanced in their illness and were no longer cognizant of memory loss, such as Marianna, lived in their own reality and less frequently demonstrated a heightened need for turning inward or toward familiarity. However, these participants did continue to exert their desire for and need for autonomy, a central finding of this study.

As a care provider, being flexible in providing for and enabling one's need for autonomy, relatedness, and competence is essential in supporting the psychological needs of the residents they serve. It is also essential to provide predictability and routine through continuity when memory loss may serve to increase a resident's anxiety or fear. The care provider is entrusted with the role of providing specialized person-centered care that can vacillate from minute to minute and from resident to resident. The delicate balance of providing day-to-day care through the constructs of flexibility and continuity, based on the thematic findings of this study, will be discussed in further detail in the *Implications of Findings* section of Chapter Five of this paper.

Overall, this study highlights the idea that care providers need to support these participants' reality in their need for Competence, Relatedness, Comfort, and Routine by supporting their desire for and need for Autonomy. It is evident that the psychological needs discussed remain centrally important to these individuals across realities and despite fading memory. The need for autonomy and competence was so robust that it

shaped reality for many of these participants. Their narrative was consistent in including their desire and need for autonomy and competence. These psychological constructs have been strong contributors in driving selfhood even in the midst of diminished memory. Chapter Five will conclude this paper by exploring the significance and implications of this study, as well as limitations and potential future research directions.

Chapter 5- Discussion and Implications

5.1 Discussion

It is well known that the population of persons 65 years or older is the fastest growing age demographic in the United States and that predictions point to a concomitant increase in the number of individuals diagnosed with dementia (Karel, Gatz, & Smyer, 2012). This rapidly growing number of older adults with dementia will challenge our healthcare system to provide quality, long-term residential care while maintaining patients' dignity, independence, and autonomy. The purpose of this study was to examine experiences of autonomy and other related psychological needs from the perspective of older adults who reside in a memory care unit of an assisted living facility. Exploring how autonomy and related psychological needs are experienced for those residing in a memory care unit not only provided an understanding of this phenomenon, but also potential insight into best practices in care for this population. This research aimed to challenge the commonly held assumption that older adults with dementia, who are dependent on care, no longer have a need or desire for autonomy. Morris (2005) posits that dependency is often related to impairment and is commonly equated with vulnerability as well as the loss of autonomy. The theoretical framework of Self-Determination Theory (SDT), particularly the Basic Psychological Needs mini-theory by Ryan and Deci (2000), served as a sensitizing framework for this qualitative descriptive study.

Lack of attention to, and support of autonomy and related psychological needs often has led to an authoritarian and overprotective conceptualization and execution of care, thus heightening the potential of robbing dementia patients of the opportunities in fulfilling these fundamental human needs. My study identified five themes; *Autonomy: Real and Imagined, Implicit Belief of Competence, A Preference for Routine and Comfort, Nuanced Relatedness and Dealing with the Neurophysiological Effects of Dementia*. Understanding these themes for the participants aided in a deepening of understanding of how these constructs interacted with one another, as well as understanding of how they are experienced for those residing in a memory care unit.

Boyle (2008) explained that older adults with dementia, due to their poor physical health and limited cognitive capacity, might no longer have the capacity to exercise complete autonomy. However, as Boyle underscores, this does not mean they no longer have the need for autonomy, as my study supported. Additionally, Boyle asserts that preventing individuals from feeling autonomous contributes towards depressed moods, apathy, anhedonia, and anxiety. My study not only supports these notions expressed by Boyle, but also reinforces what Lidz, Fischer, and Arnold (1992) state, i.e., that although moderately to severely impaired individuals with dementia may not be able to make complicated choices or act consistently toward realizing long-term goals, they still have some capacity to choose what to eat, what activities to participate in, and when to go to bed. The participants in my study had a psychological need to feel autonomous and were clearly able to make these choices within their capabilities.

Being autonomous, or at least feeling autonomous, as defined by Heidegger (1962), depicts us as individuals and supports our sense of self (self-hood or personhood). This kind of independence contributes toward well-being; therefore, linking the construct of autonomy with the sense of self and well-being. According to Smebye, Kirkevold, and Engedal (2015), autonomy is not equated with independence and rational decision making, but rather with self-identification. I found the construct of autonomy to be associated with the sense of self on multiple occasions as previously discussed in depth in Chapter 4.

Also, as discussed before, Agich (2003) suggests that the term autonomy refers to a broad set of qualities not universally recognized and that its meaning is “irremediably context dependent” (p. 6). This offers a possible explanation of why autonomy was often found to be interconnected in this study with the construct of competence. Although competence refers to the ability to carry out an action or the perception that one has the ability to carry out an action, it was often found in this study to be dependent on situation and context. The choice (autonomy) of wanting to act on an identified action (competence) was also often context dependent. As Welford, Murphy, Wallace, and Casey (2010) suggest, autonomy is context dependent because of its nature being dynamic rather than static. The construct of competence was similarly experienced in this study as often being context dependent and thus, the feeling of competence within the individual is also dynamic in nature rather than static.

Furthermore, in a quantitative study by Radel, Pelletier and Sarrazin (2012), a strong interplay between autonomy and competence was found. They found that

individuals acted to restore their autonomy only if they felt competent to do so in the situation, and if they had low feelings of competence in a situation, these individuals relinquished their need to restore their autonomy. Although, Autonomy: Real and Imagined was often found alongside Implicit Belief of Competence in my study, the nuanced relationship between these two constructs found by Radel et al. was not present.

As discussed in earlier, well-being is salient for older adults in institutional settings, as reported in a landmark study by Langer and Rodin (1976). In this study, nursing home residents who were encouraged to take responsibility, make decisions, and exert personal control for themselves were more alert, active, and happy than residents who were told the staff desired to care for them and make them happy. My study suggests that feeling autonomous, or perceiving oneself to be autonomous, was an essential inherent psychological need as the theory of Self Determination claims.

Ryan, Huta, and Deci (2013) argue in their Self-Determination Theory that eudaimonic approaches as opposed to hedonic approaches to wellness include a sense of meaning in one's life in order to be considered living well. Additionally, they theorized that eudaimonic living has positive effects of psychological wellness because it facilitates satisfaction of basic universal psychological needs of relatedness, autonomy, and competence. Through the construct of eudaimonic living, autonomy, as well as a sense of meaning and purpose are connected to well-being. Collopy (1988) as well as Kasser and Ryan (1999) have also highlighted the importance of self-determination and autonomy for those in residential settings. My study also lends support to the importance

of autonomy as it was seen as a strong psychological need among the participants thus, further supporting it as an element needed for well-being.

Alternatively, Mattiasson and Andersson (1997) found that developing and maintaining social relationships as well as maintaining routine was of greater importance for cognitively competent nursing home patients in a nursing home in Sweden than personal autonomy which they described as individual priorities. However, Kasser and Ryan (1999) found that autonomy and relatedness are central to older adults' well-being in institutional settings; thus, supporting the importance of retaining and supporting these needs for residents. Additionally, as previously noted, my general review of the literature selected showed consensus that person-centered care that stresses the benefits of autonomy for older adults within structured settings is of value toward well-being (Custers, Westerhof, Kuin, Gerritsen, & Riksen-Walraven, 2012). There was also a consensus in the selected literature that, although this understanding about person-centered care is present and valued, it is not routinely utilized in day-to-day practice. Furthermore, there were suggestions in the reviewed literature that more studies are needed from the client perspective, an obvious gap in the literature and one my research addresses, in order to better understand their views on what autonomy means to them and how it may influence their daily care.

My study found that supporting autonomy and maintaining familiarity and daily routines were of paramount importance to the participants. This is comparable to what Clare et al. (2008) found in their study which found that feelings of uncertainty and a lack of control fostered distress for those residing in a residential care facility. At times

in my study, supporting autonomy and maintaining routine appeared more predominant than maintaining social relationships/relatedness. Although these constructs were not analyzed quantitatively in my study, from a qualitative standpoint the issue of relatedness, excluding familial relationships, was not as relevant for any of the participants as were the constructs of routine, familiarity, autonomy, and competence. This was determined by the frequency this code word appeared during the analysis of data. Additionally, these results may have occurred because relatedness was not questioned to the degree as was autonomy and competence. However, my study did not raise questions regarding routine and familiarity, yet these constructs emerged. It may be that the diagnosis of dementia had an influencing factor in this difference of findings. Nevertheless, these discrepancies between studies highlight the importance of uncovering the values of the residents and making these the priorities for institutions to fulfill.

As discussed earlier, Collopy (1988) detailed how individuals involved in long-term care could experience self-determination while being subjected to the supervision and rules enforced for resident safety by long-term care providers. Collopy (1988) identified a tension in self-determination based on decisional autonomy and executive autonomy. Decisional autonomy is composed of the ability to make decisions without outside coercion, whereas executive autonomy is the freedom to act on decisional autonomy. Decisional autonomy can exist without the freedom to execute choices for those individuals who are incapacitated, constrained, or prevented from acting (Collopy, 1988). For example, an individual could possess decisional autonomy such as the choice

to have dessert before dinner, but be restrained in their executive autonomy by the rules and regulations of an external force such as life in a residential home that enforces limits on decision opportunities. There is a distinct difference between being autonomous in fulfilling a desired action and being autonomous with making decisions and choices. My research contributes toward the understanding of and distinction between these two in that a participant could believe they had a choice in preparing a meal but in reality, were not allowed to do so. Clearly, my study has shown there is value in supporting residents' decisional autonomy. However, policies need to be flexible enough to allow care providers the ability to act accordingly by allowing them the ability to make changes in routine or practices of care to meet an individual's needs at the time it is provided.

A study similar in nature to mine was conducted by Milne (2011), as discussed earlier. This study explored the subjective experience of individuals with moderate to severe dementia living in a care home. Milne showed that when care providers used verbal and nonverbal positive communication, it resulted in the person with dementia feeling happy and relaxed, which contributed toward well-being. This communication style supports the dignity of those being cared for, according to Randers and Mattiasson (2004). Negative and neutral communication left residents feeling distressed, withdrawn and at greater risk of developing challenging behavior (Milne, 2011). An example of negative communication and the consequences was discussed in Chapter 4. Here a participant was denied the opportunity to have dessert before dinner as she had requested.

The research by Milne (2011), previously discussed in Chapter Two, showed that although the self is affected by dementia, “manifestations of selfhood and identity persist, even in late stages of the illness along with the capacity to develop positive therapeutic relationships” (p. 78). The rich data elicited within the Milne study illustrate the fulfillment of psychological needs by stressing well-being, choices, autonomy, and independence in individuals who have a diagnosis of dementia. Milne’s study illustrates how the relationship in a structured environment, particularly with people with dementia, can influence the feelings and behaviors of the residents. This also supports the contextual and dynamic nature of the constructs of autonomy and competence as discussed earlier. This research (along with mine) aimed to fill the gap in the qualitative research which explores how autonomy and other psychological needs are experienced for those residing in a memory care unit. My findings indicate that these participants had a profound psychological need for autonomy and competence, which was sometimes intermixed with their sense of self, suggesting that self-perception or identity are both still present for my study participants. They desired social contact with others, but this need was reduced at various times for some of the participants. This is referred to in my study as *Nuanced Relatedness*.

Some observational sessions led me to question that when there were indications one was feeling vulnerable or distressed often leading to self-isolation, these events coincided with struggling with memory loss. This theme was identified as *A Preference for Routine and Comfort*. In the present study, I speculate that the preference for comfort and routine are derivative of the needs for safety and security. Ryan and Deci (2000)

claim that “people come to desire psychological safety-security when they experience thwarting of the basic needs, or in other words, threats to the self” (p.325). In other words, safety and security become motives in response to feeling insecure. The desire for safety and security would become heightened when basic needs are not being fulfilled or during times of there being a threat to self. This directly coincides with what was found in my study. When individuals felt a threat to the self, either by feeling vulnerable from memory loss, having decreased autonomy, or decreased competence (basic need diminished), their need for familiarity, which provided protection, stability, safety, and security, increased. Ryan and Deci (2000), when addressing the constructs of security and safety, at the psychological level, did not view these as basic needs but rather as deficit motives. In other words, they viewed the desire for psychological safety and security as being heightened when one experienced a thwarting of basic needs or a threat to the self. Similar to what I had observed on several occasions when my participants were struggling with their dementia symptoms (threat to the self), the emotional need for comfort, security, familiarity, safety and routine seemed to also be present. As expressed by Heidegger (1962) previously, by being autonomous, or at least feeling autonomous, it defines us as individuals and supports our sense of self. Therefore, the opposite of this also has merit, in that a restriction of autonomy (a basic need) would create a threat to one’s sense of self.

The aim of this study was to develop a fuller and richer understanding of what it means for people with dementia to experience autonomy and other psychological needs. The nature of phenomenology is to elicit rich narrative in order to understand meaning

for the participants. Due to the nature of the dementia diagnosis, rich and in-depth narrative was not possible, but as a collective whole, this study was able to understand their experiences through dialogue and observations. As mentioned earlier in this paper and in keeping with the descriptive methodology, commonalities amongst individual experiences lend themselves to a composite summary of their collective subjective experiences as a means to better understand the totality of the phenomenon (Giorgi, 2005). The individuals participating in the study had an idiographic understanding and experience of the phenomena under study. These participants clearly demonstrated their need and desire for autonomy. In part due to the style of questioning, the need for autonomy often was intertwined with other psychological needs such as competence, relatedness, and the need for familiarity, safety and security, despite fading memory. These psychological constructs were powerful and underscored self-identity and selfhood for these participants. The constructs shaped these individuals' reality and the narratives associated with these constructs.

The next section will focus on how the findings of this study offer support in providing education and training for dignity-enhancing, person-centered care for care providers. This training concentrates on the present and offers the guideposts of flexibility and continuity as needed by the individual being provided care. In my study when individuals felt a threat to self, either by feelings of vulnerability from memory loss or highlighted inabilities to be autonomous or competent (basic need diminished), their need for familiarity which provided protection, stability, safety, and security increased and was labeled A Preference for Routine and Comfort. It is during these

moments that staff can recognize and provide opportunities for continuity in order to meet the individual's needs. For example, a staff member could offer to look at family photos or talk about familiar people and places. Providing opportunities as this may be a way for a care provider to support an individual's continuity of identity through the past and familiar. Care needs to be viewed on a continuum based on what the individual needs are at any given time. The continuum is not necessarily a dichotomy but rather a means to view needs that may at times become entangled and offers the care provider an opportunity to decipher between these needs with primary focus always being on the one being provided care. For example, when an individual is needing to fulfill their need for autonomy by expressing the desire to make choices, staff can find opportunities to allow the individual to make selections such as what channel to watch on tv or which snack they may like. When an individual is seeking comfort and safety, staff can find creative ways to provide consistency or reassurance. From a system perspective, residential care homes may need to develop policies that enable direct care providers the flexibility to provide such nuanced person-centered care. Successful negotiation of the balance between flexibility and continuity, although challenging due to the everchanging nature of dementia, is the key goal for staff in providing person-centered care.

5.2 Implications of Findings

Overwhelmingly, all five participants of my study highlighted the importance of allowing as much autonomy as possible within their capabilities. Beauchamp and Childress (2001) had also suggested this to be an ethical obligation of caregivers who provide care to these individuals. However, complicating this is the fact that people's

capacity to make decisions is not static but rather a fluid construct, which may change over time within each individual and with each situation (Grisso & Appelbaum, 1998; Pomerantz & de Nesnera, 1991). As previously mentioned, Hyde, Perez, and Forester (2007) found a “unique paradox inherent in assisted living” (p. 51) and noted that the “medical versus nonmedical model debates are a symptom of this failure to recognize the dual nature of the assisted living product” (p. 51) of providing safety at the same time as providing person-centered care. This paradox extends itself to how best practice care should be provided to adults residing in a memory care unit of an assisted living facility. From the interview and observational data, it is evident that individual care is best provided when tailored to the individual’s changing needs, further lending merit to the need for person-centered care.

One such option was to match providers to individuals whose needs may be best met by those care providers. In Custers et al., (2012) study, they illustrated that residents are diverse in their needs for autonomy, relatedness, and competence. Custer’s et al. study helped to support the notion that individuals’ needs may be best served by being matched to providers who can meet their particular needs. The care system needs to be flexible in providing these care needs. Although I support the notion of care systems needing to be flexible, I do not believe it is always practical on a day-to day basis to match providers with individuals being provided care.

Welford et al. (2010), identified “six key attributes of autonomy” (p. 1226). These six attributes are the following: resident decision-making, resident delegation of care needs, negotiated care planning, open and respectful communication, culture of

flexibility, and maintenance of dignity. Welford et al. understood that autonomy needed to be viewed as a fluid dynamic construct specific to the individual's needs and in the context of their living situation. I offer a variation from Welford et al. (2010) work and suggest a continuum of care model based on the findings of my study.

Continuum of negotiated care; the balancing of flexibility and continuity. I

suggest a modified variation from Welford et al. (2010) based on a continuum of negotiated care model with Autonomy (flexibility) on one end of the continuum and the delegation of Autonomy (continuity) on the other end of the continuum, as seen below in Figure 1. Again, these needs are not necessarily in opposition to one another but can appear as opposing needs to an untrained eye. By viewing these needs as opposing one another, it can heighten the inherent paradox within assisted living facilities of providing safety at the same time as providing person-centered care. As an alternative, the continuum of negotiated care model offers care providers a means to recognize various needs with the goal of negotiating fluctuating care needs with the central focus being on the person being provided care.

The dealing with the neurophysiological effects of dementia was central to all the themes and thus placed within the continuum arrow as seen below. The term continuity was chosen because of its ability to describe continuous action and unbroken patterns, but also allow for fluidity and adaptability which is needed to meet the needs of this population. The everchanging needs of those with dementia can remain fixed for a brief period of time requiring continuity and stability for that given time until the needs change again. Negotiated care as Welford et al. (2010) suggest is

the goal in providing individualized care and despite the everchanging needs of this population can be obtained. The continuum of negotiated care model presented addresses the challenge in constructing a setting that is safe, while at the same time fostering as much individual choice by fulfilling needs as possible. The focus of care becomes the residents and their needs at a particular moment in time rather than the needs of the institution.

Figure 1 Continuum of Negotiated Care Model

While it is important to mitigate danger by preventing people with cognitive impairments from being exposed to harmful situations, it is reasonable to make allowances for autonomy supportive activities such as walks outside, music or tv channel selections, or food choices. Creating structures of opportunity for autonomy such as these can make a difference in supporting quality of life (Hyde, Perez, and Forester, 2007). However, to create structures of opportunity there needs to be flexibility in policies for these institution, as well as for the individual care providers.

Although residents of long-term care homes, according to Collopy (1988), should be able to make certain choices regarding their activities of daily living where no assistance or minimal assistance is required (e.g., bathing, eating), they should also be given the choice to surrender executive autonomy in instances where total assistance is essential. However, choices leading to harm to the individual or others will require intervention. This is the other end of the continuum where there may be a heightened need for consistency, familiarity, stability, safety, and security by giving the individual the authority and choice to have others direct for them (delegated care). However, the care provider cannot assume the continuation of this delegation and must always be attuned to the need of the individual's need to reinstate their autonomy. Because institutions are focused on safety and liability, they have a tendency to take away autonomy long before it becomes life-threatening to do so. These institutional regulations force individual care providers into restricting resident autonomy which may be particularly harmful to the residents during moments of lucidity.

Promoting autonomy for people with dementia requires ongoing commitment with practical attention to dignity-enhancing and person-centered care practices in day-to-day encounters. Using a continuum of negotiated care lens for care givers may be a way for them to negotiate care and to understand there are moments that require flexibility as well as continuity. This framework will enable the fostering of positive relationships between the care provider and the individual, and allow the older adult to retain the perception of being in control (Kristensson, Hallberg, & Ekwall, 2010). However, this quality of care cannot be provided without development of innovative and progressive programs/practices, care provider training, care provider development with sensitivity dialogue, and policy/system changes.

5.3 Significance of Research

My study helped close the gap in our understanding of how psychological needs, such as autonomy, are experienced for older adults with dementia. As a result of this study, it is more clearly understood that autonomy and competence needs are powerful psychological needs despite fading memory and that reality is shaped and constructed by these individuals in order to retain these needs. Because these needs are better understood, care can be better matched to the individuals' needs, thus aiding in a more meaningful person-centered approach. A dynamic and continuum approach to care may be what is needed for creating a purposeful environment, which allows for flexibility as well as continuity.

The significance of this study was to aid in understanding how, in the context of autonomy, residents respond to and experience current practices in dementia care. In this

light, the study provided insights that could ultimately contribute to innovative care opportunities. The findings of this study suggest that basic psychological needs such as autonomy, competence, relatedness, and safety/security are important determinants for individuals residing in a memory care unit. Therefore, it follows that care needs to be individually tailored to assist in fulfilling these needs.

In an attempt to promote dementia care practices that are strength-based rather than deficit focused, Welford and Sweeney (2015) offer practical suggestions such as determining level of ability for each activity of daily living, rather than designing care plans from an assumption of dependency. I expanded the work of scholars, such as Welford and Sweeney, by providing a significant contribution to this growing field with a nuanced understanding of the patient experience in current dementia care practices. Most importantly, the data from this study support a desire for autonomy and as a result, the need for autonomy is now better understood. The findings of my study may also prove beneficial to other populations with diminished cognitive capabilities such as those with developmental challenges or those with brain injuries. As a result of my study, health care professionals and the residents of a memory care unit may be able to better negotiate care, making person-centered care more than a tokenistic strategy, but rather a reality in daily practice (Welford & Sweeney, 2015).

5.4 Trustworthiness

I used several methods to enhance trustworthiness, data integrity, and data reliability. Methods to enhance trustworthiness included reflexivity and peer debriefing. I was reliant on peer debriefing throughout the process of data collection, analysis and

processing as a means to minimize threats to trustworthiness. During peer debriefing, there were times where there was not a consensus among the members. This was especially prevalent with regard to the interpretations of the autonomy/competence data where there was much debate on the nuances that differentiated actions and the desire to act as either autonomy or competence. The group members eventually came to a mutual consensus in distinguishing these two constructs for the purpose of data analysis. Examples of reflexivity were captured and separated by brackets [] during the study process. These insights were meant to capture my assumptions and reactions as a researcher so that any biases and preconceived assumptions could be revealed and minimized. Also, I frequently utilized the practice of reflexivity by engaging in memo writings. This is a process of analysis in one's own role in the research process and is a vital tool in increasing trustworthiness and integrity in qualitative research, according to Finlay (2002).

5.5 Limitations of Current Study

First, my ability to capture the true essence of what 'experience' means for these participants was hampered by their verbal limitations, forcing me to rely on the observations as well as subjective interpretations of those observations. For example, I kept interviews brief out of caution to not induce agitation and anxiety in the participants, and I often was unable to ask follow-up questions to more accurately capture the participants' intended meaning specific to abilities. Without follow-up clarifying questions it was not possible to determine whether the participants' intended to highlight their freedom of choice or their capabilities when responding to questions

addressing autonomy and competence. However, due to language, expressive, meta cognition limitations as a result from dementia, it is uncertain that the level of abstraction necessary to answer such follow up questions with the precision necessary would have been present; an inherent limitation with this population. Therefore, this study would have benefited from more observations to make up for the lack of richness in each individual's data. As a result of limited follow-up questions, data were processed through the researcher's lens, which added a layer of subjectivity to the data findings.

Another limitation was that several of the questions designed to elicit data regarding competence may have been overly simplified. Consequently, I missed opportunities to gather richer data regarding this construct. I found that questions such as "are you able to dress yourself?" and "how do you comb your hair?" were overly simplified and may have been perceived as belittling to my participants' own sense of ability and competence. However, the overall simple structure of interview questions and the allotment of time for responses allowed them to control the tempo of the conversations.

The presence of the researcher, which can influence the data, was also a limitation. The participants, staff and families may have responded differently as a result of the researcher's presence; thus, influencing the data. It is possible that participants wanted to appear autonomous and competent in order to retain a positive portrayal to others. However, it is unknown to what degree, if any, this limitation may have influenced the data.

One more limitation was that the scope of the current study was small. While I was able to draw a small sample within one facility, this sample does not represent the larger population of people as a whole who live in memory care centers. Similar to most qualitative research, the data gathered do not have “generalizability” (Maxwell, 2013, p.137) to other people within the facility under study, as the selection of those studied may be biased toward those who are able to better communicate. In addition, the data do not generalize to populations of older adults residing in a memory care unit of a different assisted living facility. For example, autonomy, competence, and relatedness needs of individuals in other dementia centers could be stronger or weaker, they could be experienced or expressed differently, and there may be other needs that emerge that do not overlap with the ones found in this sample.

In other words, despite the consistency in the data that were gathered as a collective group, the data is only specific to the participants of this study. However, through this study I successfully elicited valuable data despite the richness of it. Most importantly, this small sample size was beneficial in terms of developing a clear understanding of how these individuals experienced autonomy and other psychological needs within this specific memory care unit.

A final limitation was not having an objective measure of dementia severity. I relied on the assisted living facility admission criteria to determine admittance into their memory care unit. Knowing the dementia severity may have been instrumental in further understanding how individuals in the facility with advanced symptoms responded differently than those with moderate symptoms. It is possible that those with advanced

symptoms in this facility may have had certain psychological needs which were more salient for them than those with moderate symptoms. Additionally, because dementia severity was not measured, the findings of this study cannot be generalized to any specific level of dementia or generalized to the diagnosis of dementia.

5.6 Future Research

It was the aim of this study to expand the work of scholars such as Welford and Sweeney by providing this growing field with a nuanced understanding of the patient experience in current dementia care practices. Most importantly, as the data from this study supports a desire for autonomy, the inherent need for autonomy is better understood. Health care professionals and the residents of a memory care unit may be able to better negotiate care, making person-centered care more than a tokenistic strategy but rather a reality in daily practice (Welford & Sweeney, 2015).

Within the current study, I focused solely on those participants within a selected facility. There would be value in exploring psychological needs for those in a memory care setting in other types of institutions, as well as in nursing homes or day care centers. Care provided in other settings may further our understanding of how context affects the experience of autonomy for this population. Future studies could also focus on expanding the observations made in my study in which individuals who appeared to be struggling with their memory were also more inclined to self-isolate and retreat to familiar patterns. We may learn that there is a correlation between what is experienced for these individuals in terms of vacillating memory loss and what they may need from

their environment at a given moment. By understanding this more, person-centered care could be more fully realized.

A valuable next step may be to work toward a broader scale study, to include other settings and a larger participant base. This could inform policy and healthcare practices in the future. More qualitative research is needed to further explore how others residing in a different memory care unit experience autonomy and other relevant psychological needs, adding a broader scope to this phenomenon. Policy changes may include flexibility to those who provide direct care, allowing them to make best practice decisions based on the client's changing needs rather than being restricted to institutional guidelines.

Additionally, future studies should also include those with more advanced symptoms of dementia as a means to compare and contrast findings, but also to elicit the salient meanings specific for this population. Due to communication constraints of this population, care would need to be given in the questioning of specific constructs and follow up questions so that rich data could be collected. Nonetheless, because previous literature primarily posits that care providers for those with dementia may need to support one's need for autonomy, it is important to give voice to those who are living with this illness in order to understand more deeply what psychological needs are salient for them. Understanding the needs of those with dementia, along the entirety of the spectrum of this illness, assists us in understanding and serving their needs most optimally. By providing valuable insight into this population's needs as a whole, training and education necessary within healthcare services would become more tailored

in meeting the needs of those they serve. We would not only develop an important body of literature that may inform policy and practice, but we may be able to implement a more person-centered care approach in serving those with dementia.

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Appendices

Appendix A: Interview Questions/Prompts

Interview Prompts which allow room for clarification/probing and questions:

For first set of interviews to develop context:

- 1) Tell me about your day
- 2) Tell me about your morning routine.
- 3) What is your experience with food and eating?
- 4) What do you think about the staff here?
- 5) What is your experience with your family who visit?

For second set of interviews to establish meaning:

Modified from measuring autonomy in disabled people scale (Sibley et al., 2006) and used as prompts for second set of interviews.

- 1) What are the chances for getting washed and dressed the way you wish?
- 2) What are the chances of getting washed and dressed when I want to?
- 3) What are the chances of eating and drinking when I want to?

Modified from Self-Determination Theory-Autonomy:

Support Climate questionnaire

- 1) Do you feel your care team and family listen to how you would like to do things?
Can you tell me more about that?
- 2) Do you decide what to eat for breakfast?
- 3) Who decides what time you go to bed?
- 4) Did you get to pick out your clothes today?
- 5) How does it make you feel when your food is picked out for you?
- 6) How does it make you feel when your clothes are picked for you?

Modified from Self-Determination Theory -The Self-Determination scale questionnaire and from Self-Determination Theory- Basic Psychological Needs scale questionnaire

- 1) Are you able to dress yourself? Tell me how you do this? (competence)
- 2) Are you able to make your own meals? Tell me how you do this? (competence)
- 3) How do you feel when someone helps you get dressed? Tell me about this. (relatedness)
- 4) How do you feel about the person who helps you eat? (relatedness)

Appendix B:**Participant Summary**

		Psychological Needs		
Participants	Demographic and descriptive information from key informant	Primary Initial codes in order of prevalence	Focus Codes/Categories	Relevant Concepts
One - "Debbie"	-87 yr. old -female/ Caucasian -widowed -at facility, just over 1 year -five children/owned family farm/worked full time at large corporation in area -graduated High school -good sense humor -uses humor to cope with her memory issues - "misses home throughout day", per key informant	-choice -competence -insight into memory -having control -wanting to be left alone -restricted/denied -satisfaction -independence -inward -compliance/no complaining -compromise -can -being controlled/constrained -belong/acceptance/family -sense of self/identity -meeting needs -safety/security -routine/familiarity -humor	-choice/having control/ restricted/denied/ independence/ being controlled/ constrained/sense of self/identity -competence -insight into memory -wanting to be left alone/ inward -compliance/no complaining/ compromise/belong/acceptance/family/ satisfaction/humor -meeting needs/familiarity safety/security/ routine/continuity	-autonomy -competence -insight into memory issue/turn inward -related-ness -meeting needs/safety/continuity/security/routine

Two – “Marianna”	-86 yr. old -female/ Caucasian -widowed -at facility 1 ½ years - waiting to go to higher level of care -four children - worked various jobs -didn’t finish high school -has serious and somber disposition - tends to keep to herself -misses home when “Sun downs” at night. She doesn’t struggle with her memory issues or embarrassed by it but accepts it for what it is, per key informant	-choice -competence -insight into memory issues questionable -having control -compliance/no complaining -power -belonging/ acceptance -inward -worry -sense of self/identity -family -dignity -independence -meeting needs -routine/familiarity	-choice/having control/power/ independence/ sense of self/ identity -competence/ dignity -insight into memory issues not present/ inward/worry -belonging/ acceptance/ compliance/no complaining/family -meeting needs/routine/ familiarity/ continuity	-autonomy -competence -insight into memory issues not present/ inward -related-ness -meeting needs/ routine/ familiarity
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Three- “Venecia”	<ul style="list-style-type: none"> -87 yr. old -female/Caucasian -widowed -at facility, just over 1 year -three children one died -worked fulltime -finished High School -very “prim and proper” -initially missed home and put up fight, now adjusted and cooperative -considered more advanced in her dementia than others - “Likes routine and uses it to hide her deficits in memory”, per key informant 	<ul style="list-style-type: none"> -choice -competence -having control -routine/familiarity -satisfaction -safety/ security/ continuity -meeting needs -belong/acceptance -dignity -being controlled/ constrained -independent -pride -sense of self/identity -closeness -not struggling with memory issues but has some insight into the deficit 	<ul style="list-style-type: none"> -choice/having control/ being controlled/ constrained/ independent/sense of self/identity/ dignity/pride -competence -routine/familiarity/ meeting needs/ continuity -safety /security -hides memory deficit -satisfaction in being cared for -belong/acceptance/ closeness 	<ul style="list-style-type: none"> -autonomy -competence -meeting needs -safety/ security / uses routine to hide memory deficit/ familiarity -relatedness
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Four – “William”	<ul style="list-style-type: none"> -86 yr. old -male/Caucasian -widowed -at facility, just over 2 years -two children -worked fulltime -didn’t finish High school but went back for GED - “A gentleman” but “doesn’t like to be told what to do, very dignified” -has adjusted to his living situation 	<ul style="list-style-type: none"> -choice -having control -competence -pride -sense of self/identity -power -dignity -independent -worry about others getting too close -hides memory deficits -belonging/ acceptance 	<ul style="list-style-type: none"> -choice /having control/ sense of self/identity/power/ independent -competence/pride/ dignity/worry /hides memory deficit -belonging/acceptance 	<ul style="list-style-type: none"> -autonomy -competence -hides memory deficit -relatedness
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Five – “Marybeth”	<ul style="list-style-type: none"> -81 yr. old -female/Caucasian - one of seven children -widowed -at facility, just over 7 months -three children -worked fulltime -graduated High School -mostly in good spirits but “gets sad daily and states she wants to go home” also “angry at son for putting her here” - “Sun downs at night and struggles with her Memory and then gets angry” per key informant 	<ul style="list-style-type: none"> -choice -competence -sense of self/identity -dignity -satisfaction in care/likes routine and continuity -meeting needs -power -compliance/ no complaining/ compromise -family/ wants closeness -denies memory issues -doesn’t know why she’s there 	<ul style="list-style-type: none"> -choice/power/sense of self/identity -competence /dignity -meeting needs/satisfaction/ routine -compliance/no complaining/ family/closeness/ compromise -denies memory problems/insight varies according to sundowning 	<ul style="list-style-type: none"> -autonomy -competence -meeting needs/ routine/ continuity -relatedness/ compromise -denial of memory issues/ insight varies
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Appendix C: Central Themes

Relevant Concepts as a whole	Major Themes
<ul style="list-style-type: none"> -Choice -Competence/ability/action -Having control -Inability/reality -Restricted -Sense of Self /Identity /dignity - Compliance/no complaining/ compromise -Relatedness/connection -Familiarity/Routine/safety/ continuity/being cared for -Insight into memory-varies 	<ul style="list-style-type: none"> -Autonomy- control/choice/ Identity-sense of self/dignity -Competence-sense of having ability -Relatedness-no complaining/compliance/ compromise/connection -Familiarity/routine/safety/ comfort -Memory Issues- insight of deficit