Congruence between nursing home resident and staff caregiver perceptions of residents' self-perceived autonomy

Paul E. Urbanski
*University at Albany, State University of New York*, purbanski@albany.edu
CONGRUENCE BETWEEN NURSING HOME RESIDENT AND
STAFF CAREGIVER PERCEPTIONS OF
RESIDENTS’ SELF-PERCEIVED AUTONOMY

by

Paul E. Urbanski

A Dissertation
Submitted to the University at Albany, State University of New York
in Partial Fulfillment of
the Requirements for the Degree of
Doctor of Philosophy

School of Social Welfare
2013
Congruence between nursing home resident and staff caregiver perceptions of residents’ self-perceived autonomy

by

Paul E. Urbanski

© 2013
### Table of Contents

Abstract .......................................................................................................................... viii  
Acknowledgements ....................................................................................................... ix  
List of Figures .................................................................................................................. x  
List of Tables ................................................................................................................... xi  
Introduction .................................................................................................................... 1  
CHAPTER 1 – Literature Review ................................................................................. 2  
Who is Affected ............................................................................................................. 3  
Frailty ............................................................................................................................... 5  
Definitions ...................................................................................................................... 5  
Autonomy ....................................................................................................................... 8  
Definitions and Dynamics ............................................................................................ 8  
Autonomy and Decision Making ................................................................................... 8  
Quality of Life among Nursing Homes Residents ...................................................... 10  
Autonomy and Quality of Life in Nursing Homes ....................................................... 11  
Autonomy and Institutional Influences ........................................................................ 12  
Autonomy and Protecting Residents .......................................................................... 13  
Autonomy and Quality of Care ..................................................................................... 14  
Autonomy and Culture ................................................................................................. 15  
Objective and Subjective Autonomy .......................................................................... 16  
Autonomy Measures ..................................................................................................... 17  
Autonomy as a Quality of Life Measure ....................................................................... 20  
Autonomy as Related to Frailty .................................................................................... 22  
Challenges in Determining Autonomy ......................................................................... 24  
Summary ....................................................................................................................... 25  
CHAPTER 2 – Theoretical Models ............................................................................. 26  
Salutogenic Model of Subjective Well-Being .............................................................. 27  
Modified Labeling Theory .......................................................................................... 28  
CHAPTER 3 – Research Design ................................................................................. 32  
Introduction .................................................................................................................... 32  
Research Rationale ....................................................................................................... 32  
Research Questions ...................................................................................................... 33
How do nursing home staff members perceive resident autonomy? ...............135
How do nursing home staff perceptions of resident autonomy change as residents becomes frailer? .................................................................137
How do nursing home staff perceptions of resident autonomy influence/affect the nursing home residents’ self-perceived autonomy? ..................138
How do residents’ self-perceived autonomy and staff perceptions of resident autonomy compare over time? .........................................................140
Autonomy .........................................................................................140
Phenomenology and Autonomy .........................................................143
CNA Turnover ..................................................................................145
Potential Benefits .............................................................................146
Policy Implications ...........................................................................148
Implications for Social Work ..............................................................149
Intersection of Social Work and Nursing ............................................150
Areas for Further Research .................................................................154
Conclusion .......................................................................................155
References ........................................................................................156
Appendix A – Geriatric Depression Scale ..............................................176
Appendix C – MDS 3.0, Section F .........................................................178
Appendix D – Timeline Consent ............................................................180
Appendix E – Study Introduction Script .................................................182
Appendix F – Invitation/Resident ..........................................................183
Appendix G – Invitation/Staff Caregiver ................................................184
Appendix H – Consent to Contact Resident/Staff Caregiver ..................185
Appendix I – Resident Consent Form ....................................................186
Appendix K – Interview Script/Resident ...............................................190
Appendix L – Caregiver Interview Script ..............................................192
Appendix M – Demographic Form .......................................................194
Appendix N – Data Analysis Sequence ................................................195
Appendix O – Contact Form/Resident ..................................................196
Appendix P – Caregiver Contact Form ................................................197
Appendix Q – HIPPA Form ................................................................198
Appendix R – Emotional Distress Protocol .........................................200
Appendix S – MDS 3.0 ......................................................................201
Abstract

This qualitative cross-sectional study examines autonomy among long-term care residents and how certified nurse aides (CNAs) understand resident autonomy as expressed through residents’ preferences. The study took place at one long-term care facility with N = 12 (7 residents and 5 CNAs). A phenomenological perspective is utilized in order to describe the meaning residents ascribe to personal preferences and the influence frailty has on those preferences. In addition, certified nurse aides, self-described as competent to report on a participating resident’s preferences were interviewed separately. Open-ended interviews were conducted and the data obtained was examined for congruence between the resident’s and CNA’s perception of resident autonomy. Congruence and incongruence was examined as well within the individual resident interviews and within dyads.

Findings indicate that resident autonomy as expressed in resident preferences is subjective, complex, durable, fluid, and in some instances, a rigid phenomenon. Long-standing preferences can endure and new preferences can evolve. Resident frailty can influence resident preferences to change and in some instances, reinforce a preference. Resident preferences can evolve from care giving interactions between the resident and CNA. Findings also indicate that CNA perception or understanding of resident autonomy often involves an intuitive process and is subjective in nature. Implications for social work are discussed including interdisciplinary opportunities in long-term care for social work and the nursing profession.
Acknowledgements

I would like to express my deep appreciation to my doctoral dissertation chair Dr. Ricky Fortune and committee members Drs. Phillip McCallion and Julie Novkov whose insights and guidance have been invaluable throughout this dissertation process.

I would also like to express my deep gratitude to the long-term care residents and caregiver support staff who participated in this study.

I would also like to express my gratitude to the following individuals and families for their generosity, encouragement and support. Kim Swire, Margy Westley, Linda, Paul and Christopher Mertz-Partridge, Yi-Yi Chen, Yao and Julie Shih, Anna Zendell, David and Richard Urbanski, Paul and Dan Weissman, and to my fellow doctoral students who helped me stay grounded and maintain a healthy sense of humor.

수진, 윤형, 효지에게 사랑과 감사의 마음을 전합니다.
List of Figures

Figure 1.1. Berlin Aging Study: Discrepancy between Subjective and Object Health ......6
Figure 1.2. Difference in perception of resident autonomy by resident and staff ..........11
Figure 2. Modified Labeling Theory Adapted for Nursing Homes..........................31
Figure 4.1. Congruence Diagram ........................................................................66
Figure 4.2. Transcended Construct Diagram .........................................................69
List of Tables

Table 1. Autonomy Scale..........................................................................................................20
Table 2. Components of Stigma as Related to Older Adults ..................................................30
Table 3. Eligibility for the Study...............................................................................................43
Table 4.1. Resident and Caregiver Analysis .............................................................................63
Table 4.2. Age & Gender Distribution of Sample .....................................................................74
Table 4.3. Race/Ethnicity of Sample ..........................................................................................74
Introduction

The benefit of placing the nursing home resident at the center of the decision-making process is an improvement in the resident’s sense of autonomy, which is an important aspect of resident quality of life (Andersen, Runge, Hoff, & Puggaard, 2009; Andresen & Puggaard, 2008; Boisaubin, Chu, & Catalano, 2007; Hwang, Lin, Tung, & Wu, 2006; Ackerman & Oswald, 2006; Hwang & Lin, 2004; Polivka & Salmon, 2003; Lidz, Fischer, & Arnold, 1992; Clark, 1988; Collopy, 1988; Langer & Rodin, 1976). Differences may exist in how residents experience autonomy and how nursing home staff view residents as autonomous individuals (Farquhar, 1995; Jang G., 1992; Lidz et al., 1992). Concerns regarding differences or disparities in patient/nurse assessment of patient symptoms (To, Ong, Rawlings, Greene, & Currow, 2012), life sustaining treatment preferences (Downey, Au, Curtis, & Engelberg, 2012) reflect broader concerns for understanding the impact of these differences and the importance of patient-centered care in improving patient outcomes and quality of care (Ruland, 1998).

Understanding the meaning resident ascribes to self-perceived autonomy, the changes for preferences that may take place due to resident frailty, and the congruence of staff perceptions of resident preferences with the actual preferences of those residents will be a helpful step to service providers wishing to support resident autonomy and quality of life. Providing a better description of residents' experience of autonomy and the meaning associated with these experiences, can lead to important insights into how institutional structures deliver critical needs to older, at risk adults. Understanding of how nursing homes are experienced by older adult residents is a useful step in achieving this goal.
CHAPTER 1 – Literature Review

Providing older adults who reside in nursing homes with the best possible quality of life has been an ongoing concern for policy makers, administrators, practitioners, and researchers. Many of those concerned have advocated for a culture change that supports a resident-centered approach in care provision, as a means of improving nursing home residents’ quality of life (Noelker & Harel, 2000; Rabig, Thomas, Kane, Cutler, & McAlilly, 2006; Weiner & Ronch, 2003). A resident-centered approach places the resident as the central authority regarding care plans, lifestyle choices, as well as expression of personal and spiritual beliefs. One benefit to placing the resident at the center of the decision-making process is an improvement in the resident’s sense of autonomy, an important aspect of quality of life (Polivka & Salmon, 2003). Jang (1992) however, found that significant differences can exist between resident and staff perceptions of autonomy, differences which may become more significant as residents’ health declines and they become more dependent on staff for support. These differences can be of particular importance when nursing home medical goals do not coincide with resident non-medical goals (Lidz et al., 1992). Currently, it is not clear how these interactions and influences affect residents' sense of autonomy or if the meaning of autonomy changes for residents’ as they become frailer.

Since nursing home residents often experience declining health and may even be in the end-stages of life, residents' perception of their autonomy may change as well. For example, even though a resident may experience increasing physical limitations due to declining health, their desire and need to exercise control over certain aspects of her or his life may remain (e.g. a resident may no longer be physically able to pick out clothing
and dress independently but the process and pleasure of deciding what to wear may still be present). Since these changes in a resident’s limitations may occur over time, it can be argued that staff perceptions of the resident’s ability to act autonomously may also change over time.

Previous efforts to measure autonomy as a distinct phenomenon among older adults have produced instruments such as the Autonomy Preference Index (Ende, Kazis, Ash, & Moskowitz, 1989) and the Perceived Enactment of Autonomy Instrument (Hertz, 1996; Hwang, Lin, Tung, & Wu, 2006). Yet these instruments are not specifically designed for older adults in nursing homes. Because older adults rarely choose to reside in a nursing home, understanding autonomy in an institutional setting may require a different approach. In an effort to expand the psychosocial assessment of nursing home resident autonomy has been addressed in a subsection of the Minimum Data Set (Kane et al., 2003) and as part of federal guidelines for nursing homes where autonomy is referred to as self-determination (Allen, 2006). While these instruments and guidelines have been important steps in addressing concerns about autonomy as a component of quality of life, they may have limited sensitivity to the influences residents and staffs have on each other in supporting or challenging residents’ autonomy. It is also unclear how effective these instruments are at detecting changes in how residents – as they become frailer – define autonomy and whether this definition changes over time.

Who is Affected

The Stanford Medical Center and the U. S. Veterans Administration have estimated that 80% of older adults died in an institutional setting, with 20% of those dying in a nursing home (60% in hospitals). According to 2004 CDC statistics, one third
of people 75 years of age and older and 42% of those 85 and older died in nursing homes (CDC/NCHS, Mortality Statistics, 2004 as cited in Bern-Klug, 2009). A Belgian study revealed that - independent of gender and age - older adults were 41% less likely to die in a hospital when a nursing home existed in the community (Ahmad & O’Mahony, 2005). Stone (citing Spillman & Lubitz in Binstock, Kerr, Cutler, Hendricks, & Schulz, 2005) showed that adults age 65 and older, in the year 2000, had a 44% likelihood of using a nursing home at some point in their later-life. What often fuels the need for nursing home placement is the likelihood that as older adults’ age, they become increasingly at risk of heightened frailty leading to disability.

According to a recent General Accounting Office report (Allen, 2005), there will be a doubling of disabled older adults between 2000 and 2040, an increase that may place significant demands on long-term care service providers and in particular nursing homes. Even though efforts have been made to find alternatives to nursing homes (assisted living, community support for aging at home) others argue that older adults are becoming increasingly dependent on nursing homes and other long-term care settings (Kane & West, 2005). What often leads to dependency on nursing homes among older adults is a sudden illness or growing frailty, combined with inadequate financial or personal resources needed to support the older adult’s independence. Illness and increasing frailty can often lead to vulnerability and dependency on nursing home staff for help with daily living. The loss of independence and a growing need for social support make nursing home staff and the services they provide critical influences on residents’ sense of autonomy. As previously mentioned, although efforts have been made to reduce the use of nursing homes, by providing supportive services within the community or through
intermediate forms of supportive housing, nursing homes remain an “essential” healthcare option for older adults (Vourlekis & Simons as cited in Berkman & D’Ambruoso, 2006, p. 601).

Frailty

Definitions

Frailty, while difficult to define, is a term common to the discussion of older adults and the gradual disability experienced as illness or end of life physical decline impacts their lives. Lack of a consensus on a definition impacts researchers’ ability to operationalize the concept and in turn create parameters within which the concept can be measured (Rockwood, 2005). In an effort to find a consensus on the definition of frailty, researchers demonstrated a clustering of physiological components around “mobility, balance, muscle strength, motor processing, cognition, nutrition (often operationalized as nutritional status or weight change), endurance (including feelings of fatigue and exhaustion) and physical activity” (Ferrucci, Guralnik, Studenski, Cutler, & Walston, 2004, pp. 625–626) that contribute to disability. Conroy (2009, p. 389) indicates that current research efforts are focusing on “mobility limitations and falls” as “clinically useful markers of frailty”. Yet others argue that frailty may have a psychosocial component as well. Expanding the concept of frailty, Rockwood (2005) points out that just as physiological components are frequently identified as key components in the construction of a clinical frailty measure, the individual’s social context and functional capacity, in some instances, become necessary considerations as well.

Addressing the psychological aspects of frailty, Fillit and Butler (2009, p. 348) propose that as older adults become frail, they develop a “frailty identity crisis”. The
phrase describes the psychological adjustment older adults make in their physical decline. The authors argue that an older adult’s ability to resolve the adjustment successfully may lead to improved health outcomes, a potential reverse of frailty and improved quality of life, or provide relief in the transition to death. While one would expect physical decline or an increase in frailty to affect an older adult’s subjective perception of health, the Berlin Aging Study showed that older adults below the age of 85 possess a significant ability to reshape their reality (Baltes & Mayer, 2001). The ability to reshape their reality reflected in the discrepancies between subjective overall health and health, when compared to that of others, as well as objective illness or objective functional health (Fig. 1).

**Figure 1.1. Berlin Aging Study: Discrepancy between Subjective and Object Health**

Older adults below the age of 85 felt that their subjective overall health and health compared to others was significantly better than their objective illness or objective functional health actually was. Those over the age of 85 may experience a “level of
biocultural incompleteness, vulnerability, and unpredictability” (Baltes & Smith, 2003, p. 2) greater than their younger counterparts. While there appear to be distinct differences between what have been termed the “young-old” (65 to 85 years of age) and the “old-old” (85 and older), the difference between objective and subjective health for the older group is less clear.

The differences seen between older adults' subjective health and objective health may offer insights into how autonomy is perceived. A nursing home resident’s ability to hold a subjective sense of overall health, which is better than an objective assessment of their functional health, indicates a possible coping mechanism. If a resident does not subjectively see her or him self suffering as severe an illness as an objective observer might, is it possible that their desire for self-perceived autonomy may hold to the subjective perception of health, rather than the objective view? Is it also possible that as nursing home staff focus on an objective view of the resident’s illness and functional health, they may not pick up on the resident’s subjective perception, suggesting an incongruence between a resident’s perception and staff perceptions. Older adults may maintain a sense of autonomy, or continued autonomy, even though physical decline may preclude control over many aspects of their life. In addition, it is possible that nursing home staff may perceive an older adult's physical decline as indicating a loss of control, or autonomy, without understanding or identifying the psychological aspects of autonomy.
Autonomy

Definitions and Dynamics

The word autonomy is derived from the Greek words *auto* = self, and *nomos* = rule or governance. The concept of self-rule or governance suggests that individuals experiencing autonomy exercise control over their choices (Andresen & Puggaard, 2008). Yet in a new environment, such as a nursing home, residents may be vulnerable to the influence of health care professionals. This influence poses a potential challenge to resident autonomy, with regards to how choices are made and whose values (resident or health care professional) will dominate those choices. Miller (1981, p. 22) argues that a shift in long-term care has taken place, from a utilitarian view (where a person's self-governance is vulnerable to forceful persuasion, “manipulation and undue influence”) to a person-centered perspective (where individual choices are not based on the values of others (professional or otherwise) but rather on the individuals “plans and conception of self”). The Federal Nursing Home Reform Act of 1986 mandates that those facilities receiving Medicare and Medicaid funding provide services that ensure each resident “attain and maintain her highest practicable physical, mental and psychosocial well-being” (OBRA, 1987). If resident autonomy is to be supported, how are its parameters defined and how are residents rights balanced within the nursing homes’ mandate to promote resident quality of life?

Autonomy and Decision Making

Much of past and current literature indicates personal choice and the decision-making process as an elemental aspect of autonomy (Andersen et al., 2009; Andresen & Puggaard, 2008; Barkay & Tabak, 2002; Clark, 1988; Collopy, 1988; Dreyer, Forde, &
Nortvedt, 2009; Dworkin, 1988; Lidz et al., 1992; Moody, 1996; Tobin, 1991). Research has indicated that retaining a sense of independence in long-term care settings and preserving personal choice is important to older adult residents (Boisaubin et al., 2007). In Langer and Rodin’s (1976) study on the effects of choice and enhanced personal responsibility, the authors found that when older adults in institutional settings (where decisions were made by staff), were given greater responsibility and freedom to make choices, they showed improved social participation, alertness, and happiness. As a side note, 20% of the residents participating in the study did not understand what the researchers meant by “control”. Autonomy, as measured by Kane, et al. (2003) shows a similar focus on the decision-making process or the ability to make choices.

Autonomy Items:

1. Can you go to bed at the time you want?
2. Can you get up in the morning when you want to?
3. Can you decide what clothes to wear?
4. Have you been successful in making changes at your nursing home?

The first three items represent choices or decision-making items (go to bed at the time you want, get up in the morning when you want, decide what clothes to wear), while the fourth question is a more complex expression of choice that may reflect a personal sense of power, an important aspect of autonomy. As will be discussed later in this paper, challenges may exist in whether these questions are able to reflect the impact of increased frailty on the resident’s self-perceived autonomy and how residents’ self-perceived autonomy is defined as changes in health take place.
Quality of Life among Nursing Homes Residents

Since the Omnibus Budget Reconciliation Act (OBRA, 1987) and its provision for the Federal Nursing Home Reform Act (FNHRA), there has been a shift in focus of health care evaluation, from that of physical structures and institutional practices to “clinical outcomes, patient satisfaction and quality of life” (Lowe, Lucas, Castle, Robinson, & Crystal, 2003, p. 883). The FNHRA mandates that those facilities receiving Medicare and Medicaid funding provide services that ensure each resident “attain and maintain her highest practicable physical, mental and psychosocial well-being” (OBRA, 1987). Well-being, (also referred to as quality of life) has been determined to be a critical measure for evaluating nursing home residents (Mittal et al., 2007). The definition of quality of life, as well as the domains under which it is expressed, have brought about significant debate over the years (Farquhar, 1995). A predominant example is the World Health Organization's definition of quality of life among community-dwelling older adults which reads; “…an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (Peel, Bartlett, & Marshall, 2007). This definition reflects a shift from health-related quality of life to a subjective perception of quality of life. Others argue that quality of life can take on unique features when older adults are in “constricted circumstances,” such as residing in a nursing home (Frytak as cited in Kane & Kane, 2000, p. 203).
Autonomy and Quality of Life in Nursing Homes

According to the Nursing Home Federal Requirements, *self-determination and participation* are required considerations when determining the quality of life among older adult residents (Allen, 2006). Self-determination, according to Tobin (1991) is synonymous with autonomy or self-rule. Kane, et al. (1999) are more explicit, requiring autonomy within quality of life measures of residents, indicating that older adults must maintain the ability to act on their own behalf and make choices regarding day-to-day life, as well as the care they receive. Nursing homes provide a unique environment for understanding quality of life, since they act both as a long-term residence and as an acute-care facility (Noelker & Harel, 2000). Researchers have incorporated health and perceived health as domains, or subcategories of quality of life (Peel et al., 2007). Yet it can be argued that the importance of objective health may recede in a nursing home residents’ self-perceived quality of life, especially as she or he grows more frail and dependent. While the resident’s concern about health recedes, nursing home staff may remain focused on her or his health (Fig. 2).

![Figure 1.2. Difference in perception of resident autonomy by resident and staff](image_url)
**Autonomy and Institutional Influences**

When older adults experience a decline in health and are placed in a long-term care facility (by prescription or because family members or other resources are unable to support the older adult in the community), the autonomy of the new resident is immediately challenged. It is not the choice of the new resident to be a resident in the first place; it is instead a medical or care-giving necessity. The environment can further challenge resident as is indicated by research on self-determination theory postulating that an environment and how it functions individuals psychological needs, allowing “one to experience feelings of competence, autonomy, and relatedness” (Vallerand, Pelletier, & Koestner, 2008, p. 257). For example, some stroke patients who are placed in nursing homes for rehabilitation can have significant dependencies on staff caregivers. Dependency may range from requiring help with ambulating, using the toilet and eating to understanding complex treatment options and making decisions regarding attendant health risks. If the resident “fails to thrive” (a medical phrase that describes an individual’s declining independence) following rehabilitation efforts at the nursing home, staff may unintentionally create impediments to the assessment and management of a resident (Sarkisian & Lachs, 1996), including developing perceptions of the residents’ ability to be autonomous that may be contrary to the resident’s self-perceived ability to be autonomous.

Recent research argues that autonomy can vary from individual to individual and that assessment of a person’s desire for autonomy should therefore be assessed on a case-by-case basis, over time (Cullati, Courvoisier, Charvet-Bérard, & Perneger, 2010). The need for continued assessment is particularly important, since a resident’s comfort with
and understanding of her or his health care decisions may improve over time. Tuckett (2006) states that much of the research on autonomy, within the medical community, has centered on the information provided to patients and their health-care decision-making. The ethical relationship that medical practitioners see between themselves and their patients may challenge resident autonomy. The medical community may see an over-assertion of resident autonomy as a direct challenge to acting in the best interest of, not causing harm to, and providing care for the patient (Schermer, 2002). As older adults grow more dependent on those around them, is there a point where they may relinquish their autonomy? Residents may recognize that they are at risk of self-injury unless some aspects of control are given to the caregivers they depend on.

**Autonomy and Protecting Residents**

From a philosophical viewpoint, residents may accept limitations to their ability to act freely because those limitations are generally seen as being reasonable and just (Rawls as cited in Dworkin, 1988). Caregivers may see a nursing home resident as being at risk for a fall or other injury. Administrators may consider this risk a liability for the nursing home. The need for concern is reflected in a past study on insurance premium increases, which showed a 130 percent increase between 2000 and 2001, followed by a 143 percent increase between 2001 and 2002 (Wright, 2003). Some of these increases have been attributed to a greater number of liability lawsuits, including the costs of defending against claims and a rise in compensations. Increased financial risk may cause staff and administrators to err on the side of caution when protecting older adults in nursing homes. But does limiting a resident in his or her ability to move about freely unjustly restrict the resident’s autonomy?
Supporting autonomy while at the same time protecting residents from harm can create difficult choices. To what degree should nursing homes be allowed to restrict residents’ movements, if they are disruptive to resident autonomy but protect their residents from the risk of falls? A recent court ruling in Germany has addressed the autonomy versus risk and in one case, found in favor of resident autonomy even when the potential risk of a fall existed (Sammet, 2007). A German nursing home resident fractured her neck and femur in a fall. The court found that “reasonable financial and personal efforts” were the limited obligation of the nursing home and that “permanent control or even restraining measures to reduce risk would deny the patient fully of her autonomy” (Sammet, 2007, p. 534). Decisions by staff and administrators to protect residents from potential health risks, and nursing homes from liability risks, may impact residents’ personal sense of autonomy, resulting in potential challenges for nursing home staff that wish to support resident autonomy while trying to preserve the quality of care each resident receives.

**Autonomy and Quality of Care**

Noelker and Harel (2000, p. 6) indicate the need for a broader view of quality of life, since long-term-care settings provide the opportunity for “ongoing experiences of life”. These ongoing experiences of life may remain important, even among those residents experiencing declining health. How these experiences are understood and integrated by residents may color their perspective of the nursing home and staff in particular. In addition, resident experiences may differ from the nursing home staff’s perception of the resident’s experience. The difference in perception may influence how residents and staff interact and in turn influence the care received. For example, gaps in
perception of the resident’s quality of life between those of nursing home caregivers and residents have been shown to correlate with job satisfaction (Mittal et al., 2007). A negative impact on job satisfaction for a caregiver and quality of life for the resident may occur if gaps exist between the staff's and resident’s perception of the resident’s increasing frailty (staff see a resident’s frailty as increasing whereas the resident may not) or the resident’s desire for autonomy (staff see the resident as being less capable of autonomy where the resident may not). It is possible that a resident’s perception of frailty and autonomy are mutually exclusive. That is to say that a resident may see her or his autonomy as a distinct factor, separate from an increasing level of frailty. On the other hand, staff may consider frailty and autonomy to be inextricably tied together, indicating a significant gap between staff perceptions and resident perceptions.

In their attempt to develop a conceptual model for care, Pieper and Vaarana (2007) examined past research on health-related and subjective quality of life. In institutions such as nursing homes, emotional and relational aspects of care are most frequently cited as significant factors in determining subjective quality of life. The authors further report that the role of care as an influence on quality of life is more often revealed in qualitative analysis, rather than quantitative analysis. One possible explanation is that emotional or relational aspects of the resident’s life are more substantively expressed through the meaning each resident makes from her or his lived experience of the nursing home through interactions with staff.

**Autonomy and Culture**

Blackhall (1995) found that, with regard to the decision-making process, there is a cultural aspect to autonomy. In a study of older adults, when asked whether they should
be told they have a terminal illness, European-American and African-American older adults indicated they would prefer that physicians explained all aspects of the terminal diagnosis and allow them the ability to make decisions regarding care (thus favoring autonomy). For older Korean-Americans and Mexican-Americans, the indication was that they would prefer that the diagnosis to be shared with family members so a joint decision could be made.

Decision-making that is focused around a major event (for example, a diagnosis of cancer) in the older adult’s life may be seen as an indication of future decisions related to autonomy. An older adult of Korean-American or Mexican-American background with a family focus on decision making may see being in a nursing home as the result of a family decision. The resident may see choices through the lens of, “my personal autonomy is subject to my needs, as well as my family’s needs or beliefs” raising an interesting question: if in some cultures older adults see entering a nursing home as a family decision, would residing in the nursing home mean that choices would continue to be shared with the family? Would the resident be acting on behalf of the family and therefore be more likely to place personal autonomy to the side?

**Objective and Subjective Autonomy**

Choice as an expression of autonomy may contain distinct components. For example, some may wish to have the ability to choose what type of food they eat and when to eat it. But the food and the timing of the eating may also hold meaning, or a meaningfulness, which is a combination of food, timing, and meaning. This meaningfulness attached to the choice, making it a richer and more complex expression than simply having a choice. For example, a resident may truly enjoy having peanut
butter and crackers at 2 am, when he or she would typically wake up and be unable get back to sleep. The autonomy she or he expresses in having the choice to eat, as well as the choices of what to eat and when to eat it are all objective aspects of autonomy. From a subjective view point it could also be argued that choosing to have peanut butter and crackers at 2 am expresses the meaningfulness of the choice as well. Tobin (1991) argues that both objective and subjective aspects to autonomy exist. Most often, concerns regarding autonomy in nursing homes are centered on objective aspects (e.g. residents choosing what clothes to wear or deciding what time to eat). It is not always clear that the meaning of choices are recognized or understood. The meaning may represent the subjective expression of autonomy as experienced by the resident.

**Autonomy Measures**

The Federal Nursing Home Reform Act (part of the Omnibus Budget Reconciliation Act and known as the FNRHA) mandates that those facilities receiving Medicare and Medicaid funding provide services that ensure each resident “attain and maintain her highest practicable physical, mental and psychosocial well-being” (OBRA, 1987). Part of the FNHRA mandates included the development of The National Resident Assessment Instrument (RAI), which contains the Minimum Data Set (past version 2.0, a new instrument version 3.0 went into effect in October, 2010). Primarily a clinical tool, the RAI reflects the minimum assessment of residents on admission to the nursing home and periodically afterwards (Hawes et al., 1997). It provides staff and administrators with a tool for determining quality of care within the nursing home, both as a whole and among individual residents (Hutchinson et al., 2010). The current version (MDS 3.0) includes a psychosocial section (see Appendix A), which triggers further evaluation when
a resident exhibits symptoms or behaviors that indicate potential health or psychosocial problems (Hartz & Splain, 1997). Upon examining the RAI for questions related to resident autonomy, five were found within the two categories of customary lifestyle and environmental factors.

Each item in the RAI requires the nursing home staff to assess the resident either through observation or documenting claims made by the resident, family members or clinical records. In each section is an area for submitting supporting documentation, explaining the reason for checking an item (which includes location, date and source of the information). Under “Environmental factors that may inhibit social involvement,” there is a question regarding the “Use of physical restraints” which logically refers to resident autonomy. Since it would be a nursing home's decision to apply restraints, rather than a resident’s, it does not offer a sense of the resident’s perception of its impact on the resident’s autonomy. Next, the nursing home staff is asked to determine if there has been a “Change in residence leading to a loss of autonomy and reduced self-esteem”. This is taken to mean a change in where the individual is residing in the nursing home, which has led to a loss of autonomy and reduced self-esteem. The item does not provide a description of autonomy or self-esteem, making it unclear how the item is to be selected or interpreted. The second area of interest falls under the heading of “Customary lifestyle” with the following questions: Was lifestyle more satisfactory to the resident prior to admission to the nursing home? Are current psychosocial/relationship problems consistent with resident’s long-standing lifestyle or is this relatively new for the resident? Has facility care plan to date been as consistent as possible with resident’s prior lifestyle, preferences, and routines? Each of these questions references aspects of autonomy
(choice, preferences) yet the selection offered does not express why or how these items are relevant to the resident. A lack of resident-specific relevance highlights challenges found in past research on the reliability and validity of the MDS 2.0. The process of selecting a particular item as true gives little in the way of context other than why the nursing staff selected the item for a certain resident (Hutchinson et al., 2010). Researchers found the reliability and validity of these measures questionable, especially since items were scored as either yes or no, making it possible to under-report or over-report indicators. The instrument recently went through an upgrade to version 3.0, which was implemented in October 2010.

The MDS 3.0 has included a new section (Section F), which has the potential for collecting more nuanced responses from residents regarding autonomy. The section is titled: “Preferences for Customary Routine and Activities” (see Appendix A), from which residents are asked; how important is it to you to...choose what clothes to wear, have snacks available between meals, choose your own bedtime, etc. Responses are measured using a Likert scale (very important, somewhat important, not very important, not important at all, important, but can’t do or no choice, and no response or non-responsive). These questions provide insight into the resident’s life prior to moving to the nursing home and a scale with which to understand their current importance. How frequently residents are given the RAI is not clear. Certain responses by residents may trigger further assessment. Nursing home administration and staff may view the measure as a means for analyzing the quality of care the nursing home provides. There is potential to observe changes in self-perceived autonomy, utilizing pre-test and post-test analysis of the scale, yet as stated earlier, this limits assessment to changes in those items provided
by the measure, but not potential shifts in how residents view or express autonomy when frailty makes a particular view or expression difficult or impossible. If changes that take place in self-perceived autonomy are identified as residents become frailer, the scales do not provide the opportunity to understand the meaning residents may give to these changes. The same problem occurs if alternative expressions replace those that are no longer applicable.

**Autonomy as a Quality of Life Measure**

In 2003, the Centers for Medicare and Medicaid Services contracted with researchers at the University of Minnesota’s School of Public Health to develop a quality of life measure, intended to help improve quality of life in nursing homes. The focus of these measures would be the psychosocial well-being of residents 65 years of age and older (including those with cognitive impairment). Autonomy is expressed when “residents take initiative and make choices for their lives and care” (Kane, et al., 2003, p. 2). Within the measures, the focus is on the decision-making process, or aspects of control within the nursing home (Table 1).

**Table 1**

*Autonomy Scale:*

Read: The next questions are about the choice and control that you have.

<table>
<thead>
<tr>
<th>Question</th>
<th>Often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
<th>Mostly Yes</th>
<th>Mostly No</th>
<th>DK</th>
<th>NR/REF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you go to bed at the time you want?</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>3.8</td>
<td>1.5</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Can you get up in the morning when you want?</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>3.8</td>
<td>1.5</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Can you decide what clothes to wear?</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>3.8</td>
<td>1.5</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Have you been successful in making changes in things that you do not like?</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>3.8</td>
<td>1.5</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

(3 out of the 4 questions must be answered in the first 6 columns to construct the scale. 1 DK/NR)
Response may be imputed to domain score average. Score Range: 16-4. A higher score is more positive.

The first three items represent choices or decision making items, (go to bed at time you want, get up in the morning when you want, can decide what clothes to wear), with a more complex expression of choice that may reflect a personal sense of power, an important aspect of autonomy, as the fourth question. While each item provides a range of responses indicating the importance of each item to the resident, there still appear to be challenges as to whether these items are able to reflect the changes in self-perceived autonomy caused by increased frailty, and how that autonomy is defined as these health changes take place. For example, the question; Have you been successful in making changes in things that you do not like? offers the resident the opportunity to express their ability or inability (and level of ability) to have control over aspects of the nursing home that are not pleasant to the resident. Yet it is possible that as the resident becomes frailer, this question may change in meaning to the resident. Initially the question may be viewed as “having success in making changes in things the resident does not like’ and could center around issues of room comfort, roommates, food services, etc. As the resident becomes frailer, she or he may wish to be someplace else (home, with a family member, etc.). Nursing staff may see the resident’s increased frailty as negating any possible changes and therefore also see the need to promote the resident's acceptance of remaining in the nursing home, indicating a potential incongruence between the resident's perception of autonomy and that of the nursing home staff.
Autonomy as Related to Frailty

Distinguishing how residents and nursing home staff may respond differently to a resident’s growing frailty is an important step in teasing out the influences nursing home staff may have on residents’ subjective quality of life. It will be helpful to understand how a residents’ medical condition or health influences the care she or he receives. Coronary artery disease is a “major cause of heart problems and death among older adults” (Lesnoff-Caravaglia, 1999, p. 72). Those with coronary artery disease experience a range of disability, across a spectrum of symptom severity and disability, depending on the severity of the condition. For example, heart attacks can result from restricted blood flow, caused by plaque formations along artery walls. An individual with similar restricted blood flow may suffer from angina pectoris, or sporadic chest pain, as a result of coronary artery disease. These two examples within a particular illness indicate a spectrum of disability, requiring each resident – from a healthcare perspective – to be treated (potentially) quite differently by nursing home staff. Coronary artery disease may also indicate a continuing decline in health, requiring nursing home staff to play a greater role in the medical treatment and support for activities of daily living. As each of these conditions lead to greater frailty, they impact the ability of residents with either condition to act independently and cause the development of a greater dependency on staff. Since nursing homes are medical facilities the staff may focus on those aspects of the illness and the dependencies resulting from the illness - and less so on a resident’s desire or potential to be an autonomous person.

Farquhar (1995) suggests that for some older adults, quality of life may be less connected to an individual's health and instead be connected to social needs, a
perspective which may place greater importance on the resident’s interaction with social characteristics of nursing homes. Residents in the afore-mentioned situation may see their illness become the primary aspect of their relationship with staff. These interactions may begin to define the older adult as frail, which may be contrary to the resident’s subjective sense of her or him self and their desire to maintain a sense of autonomy. It is also possible that as older adults become frailer, aspects or definitions of self-perceived autonomy may become more dependent on relationships between the resident and the nursing home staff. An incongruity could exist between staff perceptions of the resident and the resident’s own perception of self-perceived autonomy. Tobin (1991) presents an illustration, which expresses this incongruity (illustrated as a distortion between a past and present sense of self) between a nursing home resident’s self-perception and its congruence with her present environment.

An example of distortion is illustrated by the woman in a nursing home who also chooses the statement “I enjoy being in charge of things,” but the example she gave was “Sure. Here, I decide who is the boss.” Although both the statement and the example contain the dimension of control, her example is not congruent with the statement’s meaning of her being in control. Apparently, she is unable to use the institutional environment to provide an example congruent with the statement. Yet, knowing herself to be an “in-charge” person, she selected this item as characteristic of herself (p. 5).
Challenges in Determining Autonomy

As stated earlier, past efforts in defining quality of life have included assessing health-related quality of life (physical domains such as mobility, pain, discomfort, etc.) and subjective quality of life (social domains such as personal relationships, emotional state, etc.). Tobin suggests that two perspectives have guided the assessment; 1) the belief that residents are the best judges of their quality of life and 2) that certain conditions which can be witnessed by observers detract from or bolster quality of life (1991). It seems possible that nursing home residents are capable of a positive quality of life based on social and emotional aspects of their lives, even though they may suffer from poor or worsening physical health. Recognizing a resident’s social and emotional needs increases the importance of understanding the resident’s perception of quality of life and the influence interactions with staff have on quality of life and in particular, the autonomy and dignity experienced.

Determining how to measure quality of life has in recent years taken one of two perspectives, 1) objective/subjective and 2) subjective (Frytak, 2000). Where objective approaches may require a consensus on domains and the relevance of those domains, the measure must also be in concert with residents' perceptions of their worlds. On the other hand, subjective measures may be influenced by biases related to memory and the impact of momentary incidents in close proximity to administration of those measures. Objective measures which incorporate a subjective perspective must take a “normative stance,” where those taking only a subjective perspective reflect a “non-normative experiential stance” (George as cited in Binstock et al., 2005, p. 231). Viewing the influence of
nursing home characteristics on residents over time may be one approach by which to address these challenges.

**Summary**

The benefit of placing the nursing home resident at the center of the decision-making process is an improvement in the resident’s sense of autonomy, an important aspect of quality of life (Polivka & Salmon, 2003). As demonstrated in past research, differences may exist in how residents experience autonomy and nursing home staffs view it in residents (Farquhar, 1995; Jang G., 1992; Lidz et al., 1992). Older adults may maintain a sense of autonomy, or continued autonomy, even though physical decline may preclude control over many aspects of their lives. In addition, it is possible that nursing home staff may perceive an older adult's physical decline as indicating a loss of control (and therefore a loss of autonomy) without understanding or identifying/recognizing the resident’s desire to remain autonomous or adjust to changes in how the resident perceives autonomy or maintains a sense of being autonomous.

In order to address concern for resident quality of life and specifically autonomy instruments such as the Minimum Data Set have been developed to determine when residents exhibit symptoms or behaviors that indicate potential health or psychosocial problems (Hartz & Splain, 1997). Yet when residents become frailer such instrument may lack the sensitivity to recognize these changes. Also, if changes take place in how residents perceive their autonomy as they become frailer, the scales do not provide the opportunity to understand the meaning residents may give to these changes, or whether previously held views of autonomy may change.
CHAPTER 2 – Theoretical Models

Two theoretical models offer potential as heuristic devices for understanding how residents perceive themselves as autonomous individuals and how frailty and/or caregivers perceptions of residents can influence resident preferences and wellbeing. The salutogenic model of subjective well-being argues that even in the midst of declining health, older adults' subjective well-being remains constant (Antonovsky, 1996; Schneider, Driesch, Kruse, Nehen, & Heuft, 2006). Modified labeling theory offers a context within which to understand residents’ experiential response to their environment, or “how” residents are affected by characteristics of the nursing home (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989a). The models, as applied to older adults, offer a perspective of individual resilience (salutogenic model) or potential challenges to individual well-being (modified labeling). While both theoretical models have been examined within quantitative studies, qualitative studies have emerged in recent years, focusing particularly on the salutogenic model and older adults overcoming adversity (van Kessel, 2013). Modified labeling theory has been applied in qualitative, though not as frequently and not with older adults.

Autonomy for nursing home residents has been defined as supporting a resident’s self-direction in making choices that directly affect her or his life (Lidz et al., 1992). For nursing home staff, this includes insuring nursing home facility policies and practices support the resident’s sense of autonomy (Kane et al., 2003). In contrast, past and recent researchers have argued that institutional staffs are often seen as authorities in the lives of institutional residents (Dobbs et al., 2008; Foucault, 2003; Goffman, 1963). This authority is demonstrated by the staff’s ability to make decisions as to when or how
services, such as meals, bathing and other activities, are to take place. Nursing homes adopting a resident-centered perspective may provide residents with more control over such activities and, as a result, those residents may experience greater autonomy than residents in more traditional nursing home settings. Yet even within these resident-centered efforts, both residents and staff may struggle with negative social perceptions of frail older adults, challenging efforts to promote a positive quality of life.

**Salutogenic Model of Subjective Well-Being**

Schneider et al. (2006), utilizing a salutogenic model of subjective well-being, argues that even in the midst of declining health, an older adults' subjective well-being remains constant. The model's foundation is defined by the older adult's “sense of coherence” (page 851) predicted by the following conditions:

- The individual’s world is comprehensible, meaning her/his internal and external world is structured, predictable and explicable.
- The individual possesses the resources to manage external and internal demands.
- The individual finds value in engaging and managing these demands.

Applying the salutogenic model to older adult nursing home residents suggests that following a sudden illness or gradual decline in health, older adults may seek to maintain a self-perceived quality of life comparable to the quality of life they perceived prior to declining health. It is the author’s argument that nursing home residents are capable of maintaining a positive level of a self-perceived quality of life in the face of declining health. The argument requires clarifying and delineating subjective and objective perspectives on the quality of life.
Modified Labeling Theory

Examining the modified-labeling theory and resident quality of life measure, there is an overlap between subcategories of the two: *dignity/relationships* and *autonomy* in quality of life (R. A. Kane, 2003) and *devaluation*, as well as *loss of power* within the modified-labeling theory (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989b). These areas suggest complimentary lines of inquiry, but with potential differences in perspective. The modified-labeling theory reflects emotional responses to relationships with others within an environment. The emotional response to others in the nursing home appears to be missing in the quality of life measure. For example, an older version of one of the questions related to relationships in the quality of life measure asks: *Is it easy for you to make friends at this nursing home?*. While the question indicates a potentially positive attribute of the nursing home, it does not provide insight into what it is about other residents, the staff, or simply being in the nursing home that makes it easy to make friends.

Reviewing the Minimum Data Set (3.0), “choice and personal control over daily life activities assistance with activities of daily living and the interpersonal quality of the assistance” are important aspects of nursing home care according to residents and families (Degenholtz, Kane, & Kivnick, 1997; Gustafson & Gustafson, 1996; Kane et al., 1997; Spalding & Frank, 1985; as cited in Saliba & Buchanan, 2008, p. 111). Examining the MDS 3.0 for evaluation items (Appendix C: Section F: Preferences for Customary Routine and Activities), there is a series of questions regarding choice in clothing, bedtime, meals, bathing, having family members or friends involved in care, etc. (Centers for Medicare & Medicaid Services, n.d.). Each question allows for a Likert response of
“very important” to “important but can do or no choice.” The measures available for resident choice are limited in utility for expressing whether “importance” of choice translates into control over choice or realization of choice. Therefore it will be necessary to examine the modified labeling theory as it relates to open-ended interview responses of residents and CNAs.

Stigma has been defined as the connection between an attribute (a mark) and stereotype (negative social view) (Goffman, 1963; Jones et al., 1984) that leads to devaluation and discrimination (Link & Phelan, 2001). A reworking of Scheff’s (1975) labeling theory, modified labeling theory posits that there is an expectation by those in marked groups to be rejected. The expectation causes those stigmatized to isolate from social engagement (Link et al., 1989b). Prior research on labeling and modified labeling theory has focused on mental illness, yet other authors have argued that prejudicial attitudes towards older adults exist and manifest in the form of “ageism” which, “…often without malice, perpetuate(s) stereotypic beliefs about the elderly, reduce(s) their opportunities for a satisfactory life and undermine their personal dignity” (Butler, 1980). According to Link and Phelan’s (2001) modified labeling theory is the expectation by those marked groups to be rejected, and in turn isolate from social engagement (Link et al., 1989b) leading to greater stress, lower quality of life and loss of self-esteem.
Table 2
Components of stigma as related to older adults (Link & Phelan, 2001)

<table>
<thead>
<tr>
<th>Components of Stigma</th>
<th>Application to Older Adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>Labeling:</td>
<td>Being “old” – while descriptive of age – also becomes a label with social meaning.</td>
</tr>
<tr>
<td>Stereotyping:</td>
<td>The qualities attached to the label such as grumpy, senile, infirm, etc.</td>
</tr>
<tr>
<td>Separating:</td>
<td>Labels and stereotypes place older adults as separate from others that are younger.</td>
</tr>
<tr>
<td>Emotional Reaction:</td>
<td>The emotional response to being different and not a part of the whole (anger, anxiety).</td>
</tr>
<tr>
<td>Devalued/Loss of Status:</td>
<td>The sense of being different than those younger and as a result not valued by society.</td>
</tr>
<tr>
<td>Power:</td>
<td>Loss of political, economic, and/or social power (there may also be a reverse form of power where older adults maintain significant economic, political and social power and are resented by younger generations).</td>
</tr>
</tbody>
</table>

The modified labeling theory offers a context within which to understand the residents’ experiential response to her/his environment, or “how” the resident is affected by characteristics of the nursing home. In contrast, the current quality of life measure for a nursing home resident focuses on more normative outcomes and not on “how” they come about. For example, a question from the autonomy section of the measure asks; *Can you decide what clothes to wear?* suggesting a normative belief that choosing one's own clothing is an important aspect of autonomous behavior among most nursing home residents. It is possible that as a resident's health declines, deciding what clothes to wear may become less important to the resident. It is also possible that the resident enjoys having others choose clothes for her or him; that makes modified labeling theory an interesting framework from which to understand how residents experience autonomy in
the nursing home and whether the experience of autonomy is tied to the influence of residents on staff and staff on residents.

Figure 2. Modified Labeling Theory Adapted for Nursing Homes

Link, et al. (1989a) defined a linkage of events (fig. 3) that lead from the labeling of an individual to a consequential “vulnerability” (in the case of mental illness) to a new disorder or repeat of an existing disorder (p. 402). The application of the theory to being an older adult and frail suggests societal conceptions of aging and frailty become relevant to the resident. Internalizing negative societal conceptions about being old and frail leads to secrecy, and withdrawal, which could be expressed by an older adult remaining silent about preferences or withdrawing from exerting her/his control over preferences. A loss of self-esteem and inevitable vulnerability to anger, anxiety and stress is the outcome. The alternative course is that the individual is not labeled or societal conceptions are irrelevant to self. In that instance there are no consequences to the labeling and any negative psychosocial expressions are unrelated to the labeling.
CHAPTER 3 – Research Design

Introduction

As discussed earlier in this dissertation, past research has demonstrated that differences may exist between how nursing home residents experience their personal autonomy and how nursing home staff view residents as autonomous individuals (Farquhar, 1995; Jang, 1992; Lidz, Fischer, & Arnold, 1992). For example, older adults may maintain a self-perceived autonomy that is a continuation of the sense of autonomy they experienced prior to institutionalization, even though physical decline may preclude personal control over many aspects of their lives. Nursing home staff, in particular certified nurse aides, may perceive an older adult’s physical decline as an indication of an inability to maintain personal control (autonomy), without understanding that resident’s desire to remain autonomous, nor identifying the changes that are taking place in the meaning the resident ascribes to his or her personal autonomy.

Research Rationale

Determining the best fit between the research question and research methodology is critical to developing a cohesive research study. Research questions emerged from a critical examination of past literature on autonomy, frailty and potential consequences associated with institutional living. In addition, the “scarcity” of research focused on older adults living in long-term care facilities and how they may experience the phenomena of autonomy suggests a significant gap in our knowledge-base (Andresen & Puggaard, 2008, p. 7). The study establishes groundwork for inquiry on the following questions, which will provide nursing home staff, administrators, and policy makers with a clearer understanding of the meaning residents attribute to autonomy:
**Research Questions**

1. How do nursing home residents perceive/define autonomy?

2. How does the meaning residents assign to self-perceived autonomy change as residents’ become frailer?

3. How do nursing home staff perceive resident autonomy?

4. How do nursing home staff perceptions of resident autonomy change as residents becomes frailer?

5. How do nursing home staff perceptions of resident autonomy influence/affect the nursing home residents’ self-perceived autonomy?

6. How do residents’ self-perceived autonomy and staff perceptions of resident autonomy compare over time?

A clearer understanding of how residents experiences critical aspects of autonomy will provide nursing home staff with guidance in the assessment of older adult residents, so as to better provide for the development of supportive services that respect and support the autonomy as residents become frailer. The research questions indicate the need for a research methodology capable of capturing the meaning residents ascribe to self-perceived autonomy and caregivers’ perceptions of resident autonomy. Because autonomy may comprise subjective and objective attributes the research design should accommodate and increase the likelihood of capturing a broad range of preferences, the meaning residents ascribe to those preferences and the potential nuances associated with those preferences.

Fortune and Reid (1999) indicate that qualitative research - and in particular – research that intends to examine phenomena as a starting point, often takes an inductive approach. The examination incorporates moving from the “concrete and specific to the broader concepts and theories” (Fortune & Reid, 1999, p. 92). The definition fits well
with the study's broad research question (*How do nursing home residents experience autonomy and what meaning do they ascribe to their preferences?*). The concrete aspects are the specific preferences a resident may have (a certain bed time, shower versus a bath, etc.) and the meaning those preferences hold for the resident, while the broad concept captures the autonomy. There are a number of qualitative perspectives that could be applied to the research questions but each carries a particular scope and range of inclusion that helps clarify which would be the better fit. For example, an ethnographic approach would require a broad inclusion of various aspects of the long-term care facility (administrative staff, food service, social services, etc.) that may provide a more comprehensive view of the environment the resident inhabits but also take the focus away from the resident, which is a critical focus of the research questions posed. An empirical phenomenological perspective seeks to understand the meaning of the research subjects' lived experience and from there, extrapolate more general meanings related to the experience (*Miller & Salkind, 2002; Moustakas, 1994*).

A phenomenological perspective is appealing because it focuses on the experience of the individual, placing the researcher’s role as one of reflection and interpretation of the research participant’s experience. Examining the nursing home from the residents’ perspective also places that person in the position of being an authority on her or his world and provides an opportunity for the researcher to understand the residents' world from the resident’s perspective. The desire to understand nursing home residents’ perceptions of their world supports the argument for recognizing the meaning residents give to their experiences in nursing homes and the process involved in generating the meaning attached to their experience (*Schatz, 2009*).
Phenomenology as a Qualitative Method

Philosophically and epistemologically, phenomenology as a research perspective guides the description and understanding of the conscious experience of a “given” whether it is a person, object or “complex state of affairs” from the perspective of the person experiencing the “given” (Giorgi, 2009, p. 4). Founded by Edmund Husserl, a phenomenological approach to understanding a “given” requires viewing it as it presents itself to the viewer (Giorgi, 2009). Therefore, a phenomenological perspective is at its core an epistemological perspective, and that knowledge of the “given” requires the conscious expression of the individual experiencing the “given.” All other experiences, understandings or normative expressions of this “given” are placed to the side so that only the individual’s experience of the phenomena is described. As a result, a phenomenological perspective provides a clear goodness of fit with the research questions being addressed in this dissertation. A phenomenological approach provides a method for describing older adults self-perceived autonomy, as well as caregivers’ perception of resident autonomy.

Terms Used

In New York State the term “certified nurse aide” is used by the staff participating in this study. In other states and in the literature they are often referred to as certified nursing assistants, nurse aides, or nursing assistants. These terms are synonymous.

Research Design

The research design is a cross-sectional naturalistic, descriptive study utilizing qualitative data. Utilizing a convenience sample, a phenomenological perspective was utilized to determine the research questions, applied through open-ended interviews
intended to understand the meaning residents attribute to autonomy. The design also included certified nurse aides’ perception of resident autonomy and, more specifically, the caregiver’s perception in relation to a resident’s frailty. In addition, the study examined the congruence between residents' and CNA’s perceptions of resident autonomy. Methods for determining congruence included the researcher administering the MDS 3.0, Section F (See Fig. 1).

Minimum Data Set 3.0

The Minimum Data Set 2.0 (MDS) was developed by federal mandate to provide a “clinical assessment of all residents in Medicare and Medicaid certified nursing homes” (American Association of Homes & Services for the Aging, 2010). In addition, the MDS 2.0 was used to help nursing home staff interpret when residents express concerns or exhibit symptoms that indicate potential health or psychosocial problems (Hartz & Splain, 1997). In an attempt to address concerns regarding the MDS 2.0’s reliability, validity and relevance, as well as include residents in the assessment process, the Center for Medicare and Medicaid Services developed the MDS 3.0. The MDS 3.0 features a series of questions aimed at determining nursing home residents’ personal preferences (Appendix C). Yet as residents become frailer, their perceptions of autonomy may change.

If growing frailty causes a change in how the resident perceives their autonomy, it would suggest the need for repeated assessment with the MDS. These repeated assessments would allow for a better understanding of the meaning residents may give to these changes, or how previously held views of autonomy have changed. It has been stated that a benefit of placing a nursing home resident at the center of the decision-
making process can lead to an improvement in the resident’s sense of autonomy, which is an important aspect of resident quality of life (Andersen, Runge, Hoff, & Puggaard, 2009; Andresen & Puggaard, 2008; Boisaubin, Chu, & Catalano, 2007; Hwang, Lin, Tung, & Wu, 2006; Ackerman & Oswald, 2006; Hwang & Lin, 2004; Polivka & Salmon, 2003; Lidz, Fischer, & Arnold, 1992; Clark, 1988; Collopy, 1988; Langer & Rodin, 1976).

**Mixed-Method Research**

While utilizing open-ended interviews as well as the MDS 3.0 in the data collection process might suggest a mixed methods approach, it is this researcher’s belief that the personal understanding of autonomy and the congruence of interpretation between residents’ and staff opinions are the research question and therefore focus the data collected. The data gathered from the use of MDS 3.0 was not collected for the purpose of providing aggregate data from which to draw a parallel analysis with the qualitative data; instead, it was intended to be an additional qualitative component to the research.

Quantitative data collected from the MDS 3.0 supplemented the qualitative data, allowing for an estimate of the utility of the MDS 3.0. The data gathered from the MDS 3.0 (by this researcher) was not being collected for the purpose of providing aggregate data from which to draw a parallel analysis with the qualitative data; instead, it is intended to bring an additional qualitative component to the research. Utilizing what Tashakkori and Teddlie (1998, p. 126) call the “qualitizing technique” transforms quantitative data into qualitative data and will be discussed in more detail in the analysis section. It is important to note that the MDS 3.0 is not administered by certified nurse
aides at the research site but by the social services staff. Since social service staff are not participating in this study, MDS 3.0 data collected, as part of resident assessment will not be used.

Sample

Sample Nursing Home Residents

The sampling frame for this study included the nursing home residents currently residing at the Lorraine Nursing Home (pseudonym) located in the northeastern part of the United States, who met specific criteria. The study utilized a purposive sampling procedure in recruiting a convenience sample. The sample was purposive as the research design required participants be “typical” of the study’s focus (Fortune & Reid, 1999, p. 213). For example, end-of-life researchers have sought out patients’ physicians, nurse practitioners, nurses and other service providers to determine the patient’s appropriateness for the study (Steinhauser et al., 2006). Since frailty is a factor of interest in this study, it was seen as a potential component in determining which residents met the inclusion criteria. Prior to a long-term care placement an evaluation utilizing the Patient Review Instrument is performed to determine that an individual’s functional status and appropriateness for long-term care placement make them eligible for placement (“New York State Department of Health Frequently Asked Questions,” 2010). Therefore, placement at Lorraine indicates the resident is eligible for this study due to functional impairment as described by New York State guidelines for placement eligibility. This would also include individuals diagnosed with dementia and Alzheimer’s disease and do not meet the eligibility criteria for the study.

A past study of Maryland LTC facilities showed a higher rate of dementia among facilities with less than 50 beds (65.5%) and facilities with more than 200 beds (39.6%) (Magaziner et al., 2000). Averaging the two gives us approximately 52.55% of residents. According to the New York State Department of Health, the Lorraine (a residential health care facility) is a for-profit facility with 120 Medicare/Medicaid certified beds, based on self-reports (“Facility Characteristics: Lorraine A Residential Health Care Facility,” n.d.). Assuming the 120 beds at Lorraine are occupied and using the statistics from the Maryland study, this researcher predicted that approximately 57 residents are eligible for the study (assuming 52.55% of residents have some form of dementia at the research site).

**Certified Nurse Aide**

According to Title 42 of the U. S. Code, a nurse aide is defined as “any individual providing nursing or nursing-related services to residents in a skilled nursing facility” (not including “licensed health professionals, registered dieticians, or volunteers who provide such services without monetary compensation”) (ODISP SSA, n.d.). The State of New York defines a certified nurse aide as one who “helps care for ill, injured or disabled and/or infirm individuals in LTC facilities. “CNA’s answer patient “call bells” (a mechanical device a resident uses to alert caregivers they have an urgent need), deliver messages, serve meals, make beds, and help patients eat, dress and bathe” under the supervision of nursing and medical staff (“Certified Nurse Aide - New York State Department of Labor,” n.d.). NYS Department of Labor identifies additional tasks to include “observing patients’ mental, physical and emotional conditions and report changes to the nursing medical staff.” CNA’s “may provide skin care to patients, take
temperatures, pulse and respiration, help patients walk and get in and out of bed.” The tasks previously described indicate CNA’s provide a high-level of intimate care both in terms of hands-on contact (getting in and out of bed, bathing, dressing, eating, etc.) as well as interpersonal assessments (observing and reporting emotional and physical conditions). These tasks match assessment measures regarding resident preferences of daily activities incorporated in the Minimum Data Set (MDS) 3.0 (which will be described later in this dissertation) and guide resident care.

Certified nurse aides (CNAs) are the primary caregivers in LTC facilities (Johnson & Grant, 1985). According to the NNCNA (“National Network of Career Nursing Assistants,” n.d.), CNA’s provided as much as 80 to 90% of the direct care received by residents and clients in long-term care (http://cna-network.org/career-nursing-assistance). A positive relationship has been shown between an increase in nursing assistants hours allocated to assisting with residents’ activities of daily living and job satisfaction (Bishop, Squillace, Meagher, Anderson, & Wiener, 2009). In this national study, researchers found that an “increase in nursing assistant hours per resident day of 0.5 hr per resident day (an 18% increase at the mean) was associated with a decrease of .015 in the probability that a nursing assistant would be extremely or somewhat dissatisfied, an 8.5% decrease” (Bishop et al., 2009, p. 618).

Recent research suggests the care giving role certified nurse aides play in LTC facilities may place them in competing relationships between supervisors and the resident’s needs (Homberg et al., 2013). Job satisfaction among certified nurse aides has been linked to being respected and valued by supervisors (Bishop et al., 2009), which may create competing demands. While CNA/administrative staff relationships are not a
focus of this study, CNAs may face competing demands executing the resident’s care plan when care plan adherence is challenged by her or his preference, making difficult to support a resident’s preference. These preferences may be further challenged by time restrictions CNAs face in meeting competing needs of other residents potentially perpetuating barriers to resident quality of life. That stated, there are federally mandated measures for assessing quality of life and personal preferences that exist to support LTC staff to understand and support resident preferences. For the purposes of this study, caregivers are those certified nurse aides who self-describe as having knowledge of the residents preferences.

Sample Size

Determining a sample size for qualitative research requires a sufficient number of cases to provide an in-depth analysis of the phenomena of interest and that give a “richly textured understanding” of the respondent’s experience (Sandelowski, 1995, p. 179). It is difficult to know in advance the precise number of research participants required to satisfy such an in-depth analysis, since it is possible the phenomenon may vary considerably among study participants. On the other hand, with similar elements (residence in a LTC facility, autonomy and frailty) among the sample, it can be argued that representing a homogeneous population requires a smaller sample (Fortune & Reid, 1999). In addressing adequacy of data, Morrow (2005) argues that sufficiency is more critical than quantity. Further, Erickson (as cited in Morrow, 2005, p. 255) elaborates on five examples of adequacy (in evidence): adequate amounts, adequate variety (in kinds of evidence), adequate interpretive status of evidence, adequate disconfirming evidence, and adequate discrepant case analysis. Recommended sample sizes for qualitative studies
vary significantly. Pollio, Henley and Thompson (2006) argue for a range of three to five “interview transcripts” and Morrow identifies a “magic number of 12” when predicting sample size prior to data collection (2005, p. 255). During the proposal stage of this study the anticipated sample size was \( N = 30 \).

Samples sizes in qualitative research are subject to an iterative process and as a result “are not static or shaped by the original conceptualization in the research design (as cited in Higginbottom, 2004, p. 13). Each qualitative method (ethnographic, grounded-theory, narrative, phenomenology) has its own epistemological and philosophical underpinning and a blanket sample rationale is difficult. Typically, phenomenological studies employ a small sample size due to the in-depth nature of the interviews (Higginbottom, 2004, p. 12).

For determining the sample size, Grinnel and Unrau (2004, p. 450) suggest a small sample size of “30 or fewer,” which for this study would include approximately one-third of the eligible LTC residents. While it was the intent of the researcher to meet this requirement, 7 residents were recruited, each with a matching certified nurse aide to complete the dyad. All eligible residents at Lorraine were offered the opportunity to participate in the study. An effort was made to expand recruitment of participants from two other LTC facilities in the same area as the Lorraine. Engaging LTC facilities in the research process is a time consuming and unpredictable process. In both instances agreements were reached to conduct the study at each of the sites but one facility withdrew and the researcher was unable to maintain engagement of the second facility in the recruitment process.
Sampling LTC Resident

Table 3

*Eligibility for the study is determined by the following measure outcomes.*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Accepted</th>
<th>Rejected</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Geriatric Depression Scale: scoring ≤ 9</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>1. Geriatric Depression Scale: scoring ≥ 10</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>2. Mini-Mental Status Exam: scoring &lt; 26</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>2. Mini-Mental Status Exam: scoring &gt; 25</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>3. Residing in the LTC facility: ≥ 4 weeks</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>3. Residing in the LTC facility: ≤ 4 weeks</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

1. Residents eligible for the study will have scored ≤ 9 on the Geriatric Depression Scale (GDS)(Yesavage et al., 1983). The GDS will only be used for screening participants.

2. Residents whose Mini-Mental Status Exam (MMSE) scores are 26 points and lower (the range for mild to severe dementia symptoms) will not be included in the study (Hartmaier et al., 1995). The MMSE will only be used for screening participants.

**Influence of the Residents' Adaptation to the Long-Term Care Facility**

Past research suggests that older adults adapt to LTC facilities overtime and that this adaptation may include downplaying the negative characteristics of the LTC facility while acknowledging the lack of choices due to health restrictions and alternative housing options (Kahn, 1999). This adaptation may influence some residents’ responses to questions regarding autonomy. For example, if an increasingly frail resident’s desire to
move about the LTC facility freely is restricted by the availability of staff to assist with ambulation, the resident may downplay the desire to move about freely, as well as the availability of staff for assisting her/him. The resident may recognize the time limitations staff experience and her/his ability to be available to the resident when the resident wants staff assistance. While this influence is a concern, it did not preclude a resident from participating in the study. It was the interviewer’s responsibility to be mindful of this influence when interviewing residents. If such an influence became apparent over the course of an interview, the interviewer responded with appropriate probes that aimed to determine the resident’s meaning of autonomy, as it is distinguished from what the resident perceives as the meaning of autonomy within the limitations of the nursing home.

Sample LTC Facility Staff

The sampling frame for staff included all certified nurse aides (CNAs) who were employed at Lorraine during the period the study was conducted. Since CNAs are assigned specific residents to work with, it was not necessary to match staff to the residents in the sampling process. It was, however, necessary to determine staff perceptions of residents' autonomy preferences, so one criterion was to determine the CNA’s familiarity with a given residents preference. Determining CNA familiarity required the assistance of the administrative representative at Lorraine who supervised nursing staff and was the researcher’s main contact at the site. Once eligible residents were identified, those CNAs familiar with these residents were given consent to contact forms as an initial stage of recruitment. When the researcher received consent to contact forms from CNAs interested in the study, each CNA was asked if she/he thought she or
he understood the preferences of a given resident, if the CNA responded yes, the consent process (to participate in the study) was begun.

Limitations of the Sample

Because this study takes a phenomenological perspective in guiding the research process, findings are not meant to be generalizable but rather, descriptive of the experiences and beliefs of the participating residents and certified nurse aides. The data collected for this study is from a small sample of residents and certified nurse aides and is not intended to be representative of the broader population. The sample reflects the “idiographic and emic” nature of qualitative research, concentrating on individuals and “finding categories of meaning from the individuals studied” (Morrow, 2005, p. 252).

The data collected for this study is relevant only to the individuals who provided the data; the meaning ascribed to those portions of the data selected is the result of a descriptive process employed by the researcher. While efforts have been made to corroborate descriptions drawn from the interviews, only the researcher performed the process of collecting data. Therefore, all initiating questions and probes were the researcher’s response to the interviewee, consistent with the design of the research project and potentially introducing any biases the researcher may have had at the time of the interview.

While the initial intent of the study was to interview residents who were new to the facility, all of the residents participating in the study have lived at Lorraine for two years or more. The purpose for interviewing new residents was the belief that residents would not have had the opportunity to develop relationships with various individuals at the long-term care facility and their responses would not be seen as being protective or
supportive of the staff each resident interacts with. While follow-up questions were asked to determine whether the preferences described were long-standing or established prior to entering Lorraine, it is also possible that preferences described may be the result of resident interaction with various aspects of the institutional setting.

Morrow (2005) cites adequacy and interpretation of data as two key areas specific to quality and trustworthiness of qualitative research. Patton further argues that adequacy of data is less about sample size (though having a sufficient number specific to the context of the study to identify thematic patterns is important) than about the “information-richness” present in the individual cases and the researchers observational and analytical abilities (as cited in Morrow, 2005, p. 255). Since this is a phenomenological study with the intent of understanding resident autonomy and the meaning ascribed to preferences the focus is on each participant as an individual. The study is therefore not intended to describe or define autonomy in long-term care but rather the experiences of the individual resident participants. Since the Lorraine draws residents from a local geographic area, the demographics of residents (age, gender, race, ethnicity, education, income) at the LTC facility may not represent demographics that are typical of the county, state or country as a whole.

Regarding the issue of residents' time in residence; it would be preferable to administer the MDS 3.0 and begin qualitative interviews immediately following admission to the LTC facility. If there is incongruence between resident self-perceived autonomy and staff perception of autonomy over time, early interviews might make it possible to identify staff influences on residents' opinions that may result from this incongruence. For example, a staff member may continue to respect a specific preference
a resident has regarding what meal to have at lunch. As the resident comes frailer, that preference may change and the meaning previously associated with the meal may change. If the staff member is unable to recognize changes in meaning and preference, it may lead to a conflict between the resident and staff member (even though the staff member is doing everything possible to respect what is believed to be the resident’s preference). While and effort was made to select only newly admitted residents the restriction proved unrealistic in meeting the sample size requirement. Therefore there was no limit set regarding the participants' time in residence.

Attrition

In past research, attrition, or loss of research participants during the course of a study, has played a significant role in longitudinal studies examining end-of-life care (Steinhauser et al., 2006) and aging adults (Powell, Furchtgott, Henderson, Prescott, & et al., 1990). In these instances, attrition led to missing data and a potential bias in findings when determining the influence that the independent variables may have on the dependent variable over time. Since older adult residents in LTC facilities often are experiencing declining health and may die or become too ill to continue participating in the study at any given moment during their stay, it is important to determine prior to beginning the study what influence attrition may have on the data. This study was cross-sectional and attrition was relevant when follow-up questions or a second interview was needed. In the case of this study, no participants died or were unable to participate in a follow-up interview.

Staff turnover is a potential challenge to timely or complete data collection, particularly if follow-up interviews become necessary. Though turnover of certified
nurse aides has been considered common in long-term care (Fitzpatrick, 2002), those recruited for this study have been with the Lorraine for a number of years indicating the facility has a stable workforce of care providers.

**Conceptual Framework for Guiding Interview Questions**

Collopy (1988) suggests that autonomy, as it relates to older adults in long-term care facilities, can be conceptualized as a group of polarities (see Appendix D). Each of these six polarities (*decisional/executional, direct/delegated, competent/incapacitated, authentic/inauthentic, immediate/long-range, negative/positive*) indicates an aspect of autonomy and risks, which may adjoin these aspects as a challenge to an individual enacting a preference. The *decisional* component references the decision making process. Collopy (1988) argues that older adults acting autonomously are able to make decisions based on preferences, yet challenges arise when these same older adults lack the ability to execute those decisions. It also provides a delineation of those ways in which autonomy can be limited in definition and the risks inherent in such limited definitions. For example, if autonomy simply means the ability to make decisions, we can lose sight of the fact that changes in the perceptions, or the meaning, of autonomy may accompany changes in physical health. A decision by a LTC resident to grant a health care proxy to a family member may indicate an autonomous decision by the older adult that may preclude that same resident from autonomous decisions regarding health care at a later date.

**Previous Research**

Past research with LTC residents has often been cross-sectional in design (Degenholtz, Rosen, Castle, Mittal, & Liu, 2008), limiting the researcher's ability to
understand effects over time. In addition, residents are often experiencing physical symptoms (pain, poor eyesight, difficulty hearing, fatigue, depressive symptoms, etc.) which can challenge recruitment, participation, collection of data and the quality of analysis (Uman and Urman as cited in Hall, Longhurst, & Higginson, 2009). Studies examining resident satisfaction, which is different from, but connected to quality of life, have been conducted, providing an important voice for LTC residents (Lowe et al., 2003; Peak & Sinclair, 2002; Robinson, Lucas, Castle, Lowe, & Crystal, 2004). Yet these measures are unable to provide an understanding of how services interact with and affect resident quality of life or, specifically, resident perceived autonomy over time. As a result, relatively little is known about how older adults experience LTC facilities (Hall et al., 2009).

In an effort to better assess LTC residents and services provided, the Minimum Data Set (MDS) has been expanded to include psychosocial assessment of older adult residents (Centers for Medicare & Medicaid Services, n.d.). Significant changes were made to Section F, titled “Customary Routine and Activities,” to reflect growing concern for “principles of autonomy,” as well as provide residents with a voice in the assessment and planning of their care (Saliba & Buchanan, 2008, p. 101). Items used in this section were drawn from quality of life domains or conceptual areas identified by Kane et al. (2003). The MDS 3.0 began at selected sites in October 2010 (and in use at Lorraine in 2012, when data collection began). Pilot testing indicated that 80% of staff changed their view of residents’ preferences with respect to customary routines (Saliba & Buchanan, 2008). Developers state that retesting after 4 months indicated changes in residents’ preferences and a recommendation was made for additional assessments past baseline of
resident preferences. The items listed in the MDS 3.0 indicate objective preferences (preferred bedtime, methods of bathing, etc.) assuming normative items, preferences which this researcher argues embody meaning that may be complex and nuanced such that the item may be inadequate in conveying the preference. It is also possible that meaning is subject to change as the resident’s experience increased frailty. A phenomenological approach to understanding resident preferences offers the opportunity to describe the role meaning plays in resident preferences as well as the meaning caregivers (CNAs) perceive regarding resident’s preferences.

Use of Dyads

Dyads are described as the elementary measure of “interpersonal interaction and interpersonal relations” (Kenny, Kashy, & Cook, 2006, p. 2). These dyadic relationships require face-to-face, intimate relations that are constant over such a period of time that a “discernible pattern of interacting personalities” is established (Becker & Useem, 1942; as cited in Thompson & Walker, 1982, p. 2). Establishing a dyadic relationship requires that the relationship: 1) takes place over a considerable period of time and is durable; 2) exhibits an established pattern of “mutual action”; and 3) includes personal aspects of the participants. Dyads are typically seen as familial pairs (child/parent, husband/wife) reflecting the intimate and personal nature of these relationships formed over an extended period of time (Thompson & Walker, 1982). Previous studies have examined patient and informal caregiver dyads in heart failure care (Retrum, Nowels, & Bekelman, 2012), congruence of symptom intensity between hospice patient and family caregiver (McMillan & Moody, 2003) and brain tumor patient and caregiver symptom reports
(Armstrong et al., 2012). To the best of the researcher’s knowledge, no previous qualitative dyad studies have included non-familial caregivers.

In examining residents and skilled nursing and rehabilitation facility caregivers for this study the researcher asserts that residents and certified nurse aides fit Thompson’s and Walker’s (1982) definition of a dyad because the care giving/care receiving process includes intimate contact that is often part of care giving (washing, dressing, assistance with feeding ambulation, etc.). In addition, the intimate contact described has taken place over an extended period of time and that a pattern of mutual action is present in the relationship (care giving and care receiving). The notion of mutual action is further supported by past research identifying informal caregiver dyads engaging in negotiated behaviors (Coeling, Biordi, & Theis, 2003). As reflected in the study interviews, resident and certified nurse aides stated that a negotiating process exists regarding certain aspects of caregiving (bedtime, preferences around bathing, dressing, etc.).

Relationships of necessity rather than relationships of choice may be one aspect of caregiver/patient dyads that distinguish them from conventional familial relationship dyads. Long-term care residents are engaged in relationships with caregivers out of the necessity placed on them by the level of frailty or disability. Residents are assigned caregivers rather than having a choice in caregivers. This assignment implies a power dynamic that often has been described as paternal (either pejoratively or as a compliment) suggesting that even within a non-familial relationship, aspects of familial relationships may exist as well.

In this study skilled nursing and rehabilitation facility residents’ are describing their personal preferences and the nurse aides are describing their perceptions of their
residents’ preferences. In intimate partner dyads the interviewees are responding about each other from their own perspective. In the case of this study, the intimate aspect of the relationship might be seen only from the perspective of the nurse aide. The dynamic of (the caregiver) being needed for the provision of care rather than being the one in need of care may promote a sense of intimacy (for the caregiver) not experienced by the person in need of care. The resident may see the relationship as functioning within her/his care giving needs. In this context preferences may emerge out of happenstance that are unspoken but are much like the habits or patterns couples will establish and embrace. There are aspects of these patterns that are relational, i.e. the caregiver may see a particular preference that the resident has that is directly related to the caregiver.

**Validation of the Screening Instruments**

In designing the study it was predetermined that resident would be screened using the Mini Mental Status Exam and the Geriatric Depression Scale (short form). The GDS has been used extensively and has shown excellent internal consistency (alpha= .94), stability and split-half reliability (.94). Concurrent validity has been established with both the Hamilton Rating Scale for Depression (alpha = .84) and Zung’s Self-rating Depressions Scale alpha = .83) and has been shown to distinguish non-depressed adults from mild to severely depressed adults (Fischer & Corcoran, 2006). It has also demonstrated validity in its ability to distinguish mild depression in participants in a known group. Aikman and Oehlert (2001) tested the short version against the long version and found the short predicted the long version 100% of the time, whereas the long predicted the short 94% of the time.
The researcher initially intended to use the Mini Mental Status Exam (MMSE) for screening residents with dementia as ineligible to participate in the study. Respondents scoring 26 points or lower on the MMSE would be excluded from the study. A cut-off score of 26 has been shown to be the most accurate diagnostic point for researchers and less so for clinicians (Roper, Bieliauskas, & Peterson, 1996). The MMSE is an 11-item module that has shown test-retest reliability between .45 and .50 over a 1-year interval, .38 over a two year interval, when tested with community-residing older adults between the ages of 57 and 85 years of age (Mitrushina & Satz, 2006). It is important to note that challenges have been established when MMSE scores alone are used for assessing decision-making capacity. Fitten, Lusky and Hamann (1990) found the MMSE to be 53% to 65% sensitive in determining decision-making capability among LTC residents when asked about their understanding of three “increasingly complex” health conditions.

The Minimum Data Set 2.0 (MDS) and the GDS have been compared in LTC settings. In the past, researchers found that the “MDS 2.0 showed greater depression among those with cognitive impairment while the GDS indicated more severe depression among those with better cognitive functioning” (Koehler et al., 2005, p. 1). The authors further state that the MDS and GDS may measure differing aspects of depression and, as a result, the measures are neither “exchangeable nor equivalent” (2005, p. 5). The GDS has been chosen because it is a self-report instrument, or direct interview, with the resident. The MDS 2.0 and 3.0, on the other hand, include a semi-structured interview with the resident, a review of the resident’s chart, interviews with caregivers, family members and others in developing a final report (Koehler et al., 2005). The GDS does
exhibit “higher internal consistency and reliability” than the MDS 2.0 and as a result has been selected as the preliminary depression scale for determining the sample.

In the researchers discussions with the Lorraine’s Director of Nursing it was determined that the MDS 3.0 screening instruments (for dementia and depression) as used by Lorraine staff sufficiently identified those residents meeting the study requirements.

**Human Subject Considerations**

A protocol for this study was reviewed by the University at Albany’s institutional review board and approved. Consent to contact (Appendix G) and consent to participate protocols were followed with residents (Appendix I) and certified nurse aides (Appendix H).

**Data Collection**

Interviews were digitally recorded and later transcribed. As data from interviews was gathered it became clear that resident experiences varied. As a result of these variations, the interview questions changed in response. This researcher followed Yin’s (2008) argument that interview questions be open ended enough to prevent leading the respondent or creating a bias in the question that indicates a desired response.

**Data Monitoring and Storage**

An “audit trail” was created from the beginning of the study, in order to provide a clear description of how the study was executed. This was accomplished by generating a “transparent record” of how the researcher’s choices are linked to the data generated, as well as the resulting inferences (Yanow & Schwartz-Shea, 2006, p. 105). The goal of the audit trail is to demonstrate “dependability (reliability) and confirmability (objectivity)”
in the research process (Lincoln & Guba, 1985, as cited in Yanow & Schwartz-Shea, 2006, p. 98). The audit took the form of a reflexive journal, kept by the researcher during the course of the study, and included decisions made regarding interviews, interactions with staff and residents at the LTC facility, and personal reflections on interviews that may color interpretations of the research, participants and reflections on the inductive process used in ongoing data analysis.

All recorded data contained on flash drives were kept in a locked cabinet at a secure location, at the University at Albany's School of Social Welfare. Data were monitored by the principal investigator to ensure confidentiality of the participant was maintained. The data was only accessible to members of the research team. Following the transcription of the interviews, all transcriptions were saved in the form of a Microsoft Word document on a password protected data storage site provided by the University at Albany. Once the interviews were transcribed, the digital voice recordings on the flash drive were erased.

Schatz (2009), argues that multiple interpretations are present in the data collection and assessment process, with the first being the research participants’ interpretation and expression of the given phenomena. The researcher is interpreting the data as collected and in the analysis as well. In the case of this study, each LTC resident is interpreting situations that she or he has participated in making. For example, while in the midst of an interaction with LTC staff, a resident will be actively interpreting the interaction and its meaning. Post-interaction, the same resident may re-interpret both the interaction and the meaning drawn during the interaction, in formulating a response to the interviewer. Therefore, a well-defined method of analysis is required.
Data Analysis-Methodology

As guidelines, Miller and Slakind (Moustakas, 1994, as cited 2002, pp. 153–154) identify five steps for analyzing data generated in a phenomenological study.

1. From the complete transcription of each resident interview:
   a. List every expression relevant to the experience.
   b. Assess expressions for the following conditions:
      i. Is there a “moment of the experience” that provides a needed component for understanding the experience?
      ii. Can it be labeled as an abstract expression of the experience?

2. Condense these expressions to “units or themes” of meaning.

3. “Analyze the context” in which the individuals experienced the units or themes of meaning.

4. The researcher reflects “on own personal experiences relevant to the phenomena”.

5. A written analysis is generated on the “essence” of how the phenomenon is experienced by the participants.

In analyzing the interviews, the researcher will seek to understand words and phrases within the context of the overall interview. As Soss states (as cited in Yanow & Schwartz-Shea, 2006, p. 129):

…the parts and the wholes (of the interviews), as I gradually came to understand them, could be used as a kind of commentary on one another. Small, seemingly isolated statements hinted at broader conceptions; their patterns of convergence and discord offered a way to develop, assess, and revise an emerging account of latent understandings.
Soss’ approach to analysis acknowledges the potential for misleading results when a thematic analysis approach is used, where similar expressions or words within different interviewees’ responses are treated as equivalent. This will require an descriptive approach that is question focused. “Question focus” refers to the primary research questions dictating the means by which the interviews will be interpreted. As stated earlier, how each interview progresses depends solely on how the resident responds to the questions. For example, one resident participant may be at the LTC facility for rehabilitation (though failing to thrive), while another participant may have a terminal illness and be cared for through the late stages of the disease. In these two scenarios, each resident may attribute different meanings to self-perceived autonomy over time. Staff perceptions of these changes may be quite different from those of the residents, as they view these residents becoming more dependent on assistance with treatments and ADL’s.

Analysis as Evolving Process

It was anticipated that 30 residents and 15 certified nurse aides would be interviewed for the study. The numbers were based on the research being conducted at a long-term care facility that capable of providing such a sample. As stated previously, due to unexpected circumstances the study was conducted at an alternative site where a much smaller sample was feasible. As a result, the number of participants totaled 7 residents and 5 CNA’s. The size of the sample made it possible to do the analysis “by hand” using techniques similar to those available in the qualitative software packages. Themes were identified. Congruence and incongruence were examined within resident and CNA dyads utilizing a chart system; dialogue from the interviews was copy and pasted into categories...
identifying themes, descriptive text, resident ability to execute a given preference and the meaning ascribed to the preference. Similar columns were created to categorize established for the CNA responses. This system allowed for a continuous review of content from the interviews and supported an evolving evaluation of the data.

**Reflexivity Concerns**

There is a potential for conflicts of a personal nature, as well as inter- and intra-personal influences that may color interactions with the participants, the data collected, and responses to data collected. Between 2005 and 2007, the researcher played a significant role in the care of both of his parents. Towards the end of each of their lives, they were placed in LTC facilities. The researcher had multiple interactions with doctors, nursing staff, administrators, certified nurse aides, and other caregiver providers regarding the care that each parent received. This intimate knowledge of the mechanics of LTC facilities (process of delivering care) and the challenges faced when ensuring appropriate care for loved ones is, in part, the reason for the researcher's interest in this study; it can be a tremendously challenging environment to work in. Individual LTC facility staff members and care-giving teams played an important role in delivering rehabilitative and eventually palliative and end-of-life care to the researcher's parents. He also became aware of the challenges LTC staff faced in balancing the needs of patients with disabilities that ranged across a spectrum of illnesses. These challenges made it difficult for staff to respond to patient needs, contributing to a sense of powerlessness. As a result, the researcher has a deep sense of gratitude towards, and respect for, the professionals that work in LTC facilities. It is the researcher's belief that by adopting a firm, theoretical perspective to ground the study and a critical, evaluative process to the
design of the study, safeguards will exist for addressing bias in how data is collected and analyzed.

Providing a description of and understanding the phenomena of autonomy as expressed through resident preferences requires the researcher to understand the preference from the conscious experience of the resident. One challenge to understanding resident autonomy is the researcher’s preconceptions of the phenomena as well as the inter- and intra-personal dynamics that can influence understanding of the phenomena. By applying the concept of epoch and “bracketing” the researcher’s conscious experience of the preference is identified, reflected on, then placed to the side so that the resident’s experiential understanding of the preference can be understood and described (Bednall, 2006). Patton (1990) refers to epoch as a continuing part of analysis whereby the researcher remains mindful of her/his prior understanding of or emotional responses to the study participant and phenomenon being study (as cited in Bednall, 2006). Bracketing is when those moments of prior understanding or response are held next to the related content in the participant’s responses.

**Interview Process**

Autonomy and preferences related to autonomy could be expressed through innumerable variations. Preferences may be tied to getting up in the morning, going to sleep at night, napping, bathing, entertainment, privacy, interactions with others, etc. and the subcategories within these preferences (a morning preference may include what time the resident wakes-up, if someone wakes them or the resident awakes on their own, etc.) which may vary in meaning from resident to resident. The variation of meaning suggests that autonomy (as expressed through preferences) is a complex phenomenon. Following a
phenomenological approach preferences are viewed from the experiential perspective of the respondent; hence, the researcher asked each respondent the same structured question that provided a unified starting point for residents and caregivers, but remained flexible in that the question allowed each respondent to determine and guide the interview from her or his own perspective.

Within each dyad or paired resident and caregiver, the respondents were asked the following questions:

**Residents:** I’d like to talk with you about your preferences or the things you enjoy doing or a particular way that you like things to be. It might be picking out what clothes you’d like to wear, having time in the morning to yourself, or maybe eating or going to sleep when you feel like it. Can you tell me about something you did recently that you enjoy doing either daily or once in a while, that is important to you?

**Caregivers:** I’d like to talk with you about (resident’s code name) preferences. By preferences, I mean those things that she/he enjoys doing or a particular way that she/he likes things to be. It might be picking out what clothes she/he would like to wear, having alone time in the morning, or maybe eating or going to sleep when she/he feels like it. Can you give me an example of something she/he likes to do?

Following the initial question the respondent (resident or caregiver) guided the interview.

To support the respondent, the researcher employed an “active listening” approach to the interviews. This consisted of engaging the respondent prior to and during the interview,
listening empathically and providing reflective responses to indicate understanding and follow-up probes to clarify or to gain a deeper understanding of the response.

Asking the same question of each respondent did not ensure that the resident and caregiver dyad would mirror each other’s responses or that their answers would be congruent with each other. As will be discussed in the following sections, overlap or congruence was found in certain instances and this overlap served as the primary focus of the analysis. As well, incongruence or differences between responses were equally important in providing a rich understanding of the complex nature of resident preferences and caregivers understanding of those preferences. An unanticipated outcome of this process is similar to what Eisikovits and Koren (2010, p. 1642) describe as a “dyadic version that is more than the sum of the two individual versions.” An outcome of the dyad it is not quite a dyadic version, but rather a composite construct focused on the resident that transcends the dyad. The process may be similar to what Greenberg and Pascual-Leone (2001) describes as a dialectical constructivist process. The process is elaborated on as requiring “…two major sources of experience, a conscious, deliberate, reflexive conceptual process (thinking) and an automatic, direct, schematic emotional process (feeling), and the constructive, dialectical relationship between them” (as cited in Greenberg, Rice, & Elliott, 1996, p. 55).
CHAPTER 4 – Research Findings

Introduction
As stated previously, analysis was an evolving process and as a result, findings will be presented in a manner that reflects this evolving process. Initial analysis was part of the transcription process. Two people were involved in transcribing the interviews; the researcher and one research assistant (IRB approved “additional personnel”) transcribed all interviews gathered for the study. The researcher randomly selected and reviewed research assistant transcriptions against the audio recording of the interview for accuracy and the research assistant did the same with the researcher’s transcriptions. This review process also provided the researcher the opportunity to discuss initial impressions from the interviews and clarify, if necessary, any portions of the interviews that were unclear (due to poor audio) or to double-check the intent of a statement or portion of the interview (e.g. double negatives, using of the word “you” instead of “I” as in “…you get tired of the same thing day after day and you just give up.”)

Preparation of Data
After the initial analysis of the interview the researcher generated a table identifying themes extracted from the resident and caregiver’s interviews (Table 1). A grid was created with three major columns from left to right, which were labeled – theme of resident, resident content and caregiver content. Sub columns were created beneath the resident and caregivers heading with columns providing space for transcription supporting the theme (“descriptive text”), ability of the resident to enact the preference (“ability to execute preference”), and the “meaning” inferred from the transcript regarding the particular theme (“meaning of preference”) of preference. Rows indicate
themes extracted from the interview. Congruence was indicated by dyadic overlap within the various themes.

Table 4.1

*Resident and Caregiver Analysis*

<table>
<thead>
<tr>
<th>Theme</th>
<th>S-0X Descriptive text</th>
<th>Ability to execute preference</th>
<th>Meaning of preference</th>
<th>S-0X-10X Descriptive text</th>
<th>Ability to execute preference</th>
<th>Meaning of preference</th>
</tr>
</thead>
</table>

**Themes Identified**

Themes identified were divided into two general categories: “practical” preferences and “experiential” preferences. “Practical” preferences refer to those things which the resident enjoys doing such as reading, listening to music, or going for a walk. Practical preferences also refer to the foods a resident prefers, the time s/he likes to go to bed or get up in the morning, etc. These preferences are finite in the sense that they describe an activity or choice that the resident is of executing independently or with the help of an assistant (CNA). For example, a wheelchair-bound resident may wish to go outside for fresh air and possesses adequate upper body strength to complete the task independently. Another resident may require an aide to perform the same task. It is important within this concept of preferences to acknowledge that important subtleties and variation in meaning can exist within these preferences. A preference for eggs at breakfast may include certain preparation requirements (sunny side up rather than over easy), which may also be a lifelong preference.

“Experiential” preferences are broad expressions such as resident’s preference for being independent, active, social, etc. These preferences may at times find embodiment in
practical preferences, generating a deeper understanding of the meaning practical preferences may hold. For example, a resident may express a desire to be independent while living in a typically dependent environment. That independence may be expressed through practical preferences such as self-bathing or unaided ambulation while requiring the use of a wheelchair. The inter-relatedness of preferences indicates a need for constant data review, monitoring for relationships and congruence or incongruence within the resident data, as well as between resident and CNA data. Congruence and incongruence will be discussed following a description of “analysis of dyads.”

Analysis of Dyads

Analysis of the dyads took place in multiple stages. Early stages determined themes emerging from the transcripts of individual resident and caregiver respondents. For example, within a given response, a caregiver may describe his/her perception of a resident’s preference but this description may also include information about how the caregiver perceives the resident in general and the meaning that the caregiver infers from interactions with the resident regarding the preference. These perceptions could include caregiver interpretation of resident preference, caregiver perception of resident ability, caregiver’s personal assigned meaning of the preference, and how she thinks the resident assigns meaning to the same. In later stages, the researcher moves between a preference-specific analysis and a more global analysis of the interview to search for supporting or negating content within the interviews.

Congruence

Quantitatively, congruence in organizational research is determined by “similarity, fit and agreement” (Cheung, 2008, p. 63). Congruence as it relates to this
study utilizes similarities in resident and caregiver responses, how well the fit is between similar responses and whether the responses are in agreement in those areas where the individual resident and caregiver interviews have similar descriptive content. Since open-ended questions were used and respondents guided the interviews, it was possible that only limited overlapping of themes would take place. The initial focus was to only examine where dyad “themes” overlapped and the content of these overlaps (Fig. 1); however, the overlapping of particular themes (preferences about bedtime, hygiene, etc.) does necessarily reflect complete congruence between resident and caregiver “theme content.” Therefore, “within theme” congruence was examined in order to better describe resident and caregiver meaning associated with the preference described. For the purposes of this study, congruence and incongruence will be defined as:

**Congruence** - those preferences and/or themes emerging within a particular dyad, which have been identified by both the resident and caregiver.

**Incongruence** - those preferences and/or themes emerging within a particular dyad as identified by either the resident or caregiver but not by both.

The researcher identified multiple aspects of congruence within dyads, which prompted re-examination of how congruence was expressed in the dyad. Did the overlap or agreement between the resident and caregiver accounts of a particular resident preference provide rich content from which a meaning could be ascribed to the preference (from both the resident and caregivers perspective)? Was the meaning ascribed to the preference by the resident, similar to that described by the caregiver? Following these steps, transcriptions were examined for any meaning that might emerge from those descriptions that were not congruent. For example, does a resident’s
preference appear differently to the resident than to the caregiver? Did the caregiver ascribe meaning to a preference when the resident did not? What inferences can be made from these incongruities?

**Figure 4.1. Congruence Diagram**

The initial reason for examining congruence and incongruence was the belief that a caregiver’s understanding of the resident’s preference(s) (autonomy) was an aspect of supporting resident autonomy. For example, if a caregiver understood that music was an important resident’s preference and the meaning that preference held for the resident, she/he would likely to support the resident’s preference. As the study evolved, congruence and incongruence became a methodological tool for understanding how
preferences are expressed by residents and in turn reflect resident autonomy, including what the resident and caregiver described around a particular preference (e.g. both discuss the resident’s fondness for music). If the resident and caregiver both spoke of the meaningfulness of the resident’s fondness for music, a deeper or more specific congruence was present. Because there is congruence does not always indicate that congruence is meaningful in itself. For example, both the resident and caregiver may understand the practical and experiential aspects of the preference, but this understanding did not indicate that the caregiver would be involved in supporting the preference. It may be that the preference did not require support because the resident was capable of acting on and enjoying preference without the aid of the caregiver.

It is not clear from the data that congruence or incongruence separately is meaningful, other than as categorizing or organizing tools. One resident did state that he was uncertain how aware caregivers were of his preferences and the extent of those preferences. “Sometimes I feel they (caregivers) don’t understand it…the extent of my preferences.” In the previously given instance the resident described a specific situation where a caregiver was helping him with something but the caregiver needed to leave to take care of another resident, leaving the resident waiting. The preference became the caregiver returning and helping the resident complete the preference. The emergence of the preference from the caregiver leaving and not returning suggests for this resident that caregiver knowledge of the resident’s preferences and in particular the extent of those preferences is important. There is also an indication with this particular resident that congruence is perhaps not as critical as the caregiver knowing or acknowledging that
preferences come in a variety of forms and that being aware and responsive to the variety of forms, in some instances, may be more important.

Transcended Construct Emerging from Dyad

As previously described in the dyad section of this paper, an unanticipated outcome of the analytical process is similar to what Eisikovits and Koren (Eisikovits & Koren, 2010, p. 1642) described as a “dyadic version that is more than the sum of the two individual versions.” In other words, an outcome of the dyad it is not quite a dyadic version, but rather a composite construct focused on the resident that transcended descriptions presented in the dyad (Fig. 2), and is thus termed a “transcended construct.” For example, a resident describes himself as independent and not requiring assistance from the caregivers except in occasional circumstances. The resident exhibits defiance and pride in his ability to be independent. The caregiver confirms the preference for independence acknowledging the resident can be aggressive or express frustration if the caregivers attempt to provide help. The caregiver adds the detail that when the resident moves around the facility, she (the caregiver) is greeted by this man as if she were his friend or a neighbor and not a caregiver. The caregiver’s sense of being seen in a role other than caregiver to a resident suggests a transcended construct whereby the resident sees himself not as a patient needing the assistance of caregivers, but rather that his presence is unique. The resident reinforces the construct by describing himself as the only resident who can leave the grounds of the LTC facility on his own. In the case of the described resident and caregiver dyad the construct becomes more than the sum of its parts.
Triangulation

Triangulation is a technique for assessing, validating or challenging a particular piece of data from more than one perspective. It has also been argued that the method can facilitate deeper and broader understanding of particular phenomena (Olsen, 2004). For this study triangulation, is possible through use of resident and caregiver comparisons of overlapping content. Triangulation also allowed for what the researcher identifies as a transcendent meaning to emerge from overlapping content. The emergence of a transcended meaning suggests that triangulation provides a broader understanding of the
sum of resident and caregiver overlapping content and, in some cases, non-overlapping content.

**Analysis**

Beginning from Husserl’s view of phenomenology as a descriptive process the researcher first examined the transcripts for content that provided a description of the phenomena of interest (autonomy as expressed through resident preferences). The content describes a preference (theme) – “I love to read” with *reading* being the theme and “I love…” a description of the meaning of the theme. The description may also express a preference over which the resident states she or he has little control (e.g. “I love to read but am unable to turn pages”) which describes the resident’s inability to execute the preference.

Data analysis process: 1) After the transcriptions of the recorded interviews and reflection on general qualities of the overall interviews (including examination of field notes and second readings of the transcriptions) was completed, two dyads that offered contrasting narratives were selected. In one instance the resident expressed, at numerous times during the interview, both a strong sense of personal preferences and comfort as a self-advocate as well as an advocate for other residents. In the second dyad, another resident expressed a cooperative relationship with caregivers. 2) Printed copies of the interviews were made and given to a fellow doctoral student with experience coding qualitative content. The only direction given was that the phenomenon of interest was autonomy (as expressed by preferences) of each individual resident. 3) The principal investigator performed a content analysis of the same transcriptions, identifying themes
within the interviews. 4) After the analysis was completed a meeting was held to discuss the themes emerging from the interviews.

In order to avoid accidental influence from the principal investigator, the volunteer doctoral student presented insights regarding the interview and themes identified first in these meetings. Afterwards the principal investigator would describe their response to the same content. Through these two assessments the two discussed their understanding of the themes and any discrepancies or alternative explanations present in the analysis. Common understandings were noted and alternative evaluations were discussed to better understand whether these alternatives were mutually exclusive or alternate explanations that could potentially coexist.

This researcher also discussed the analysis process with committee members. These discussions acted as a touch-stone during the analysis process. The intent of these discussions was to maximize rigor and to identify any issues or concerns discovered in the analysis process, as well as in the researcher’s interpretation of the interviews.

**Concerns and Efforts to Address Validity**

Polkinghorne (2007) identifies “differences” in the meaning individuals ascribe to experiences and the narratives they provide regarding differences in meaning, as well as the “connections between storied texts and the interpretations of those texts” (p. 1) as potential threats to validity. Interpretive process qualitative research depends on the ability and effort of the researcher” (Patton, 2001, as cited in Golafshani, 2003, p. 600). Therefore, qualitative research is scrutinized for its credibility, transferability and trustworthiness. Polkinghorne (2007) further argues that the reader determines the
reliability of the research based on the argument made from the data and the methods used in generating that argument.

**Presentation of Data about Residents**

Generally, data will be presented in the following form; 1) a demographic description of the interviewee including age, gender, educational background, additional content regarding the researcher’s impressions of the interviewee, environmental features where the interview took place, interruptions or interactions with others, any difficulties or concerns experienced during the interview, etc.; 2) themes emerging from the interview; 3) a specific example (with quotations) from the interview that provides a descriptive example of autonomy expressed through either a particular preference, or how the interviewee describes herself or himself as an autonomous individual; 4) additional quotations that substantiate, contradict or otherwise provide a richer description of the resident’s experience of autonomy through preferences; 5) a summation of the analysis.

**Presentation of Data about Caregivers**

Since the focus of the study is congruence between residents’ autonomy and certified nurse aides’ perceptions of the meaning that each resident ascribes to her/his preferences, it is necessary to intertwine caregiver and resident data for each dyad. The intertwining is intended to provide a format for showing congruence (and incongruence) as well as provide consistent flow to the descriptive nature of the data. The data will be presented first from the individual resident’s interview data and then the CNA’s (congruent/incongruent with resident) interview data. There are also instances where there is incongruence within the resident’s interview data itself, in which case those instances will be provided as well.
General Comment Regarding Data Presentation

Because these were in depth interviews it was necessary to select those instances within the interviews where the resident gave a rich description of the phenomenon in question (autonomy). For example, a resident may have discussed a number of preferences over the course of an interview but only in certain instances was a preference discussed in such a rich descriptive way that the text (examined within the context of the interview as a whole) provided a sense of the meaning the preference held for the resident. The presence of a sense of meaning turned out to be truer for certain themes than others. The selection process was determined by the following criteria; 1) the theme presented a rich description of the phenomenon, 2) the theme contained content that displayed characteristics unique to that resident, 3) the theme or content of the theme was distinct from other residents’ or indicated a transcendental construct.

General Characteristics of the Sample

The interviews took place between April 11\textsuperscript{th} 2012 and June 22\textsuperscript{nd} 2012. Since the sample size for this study is small it is possible to make only general statements regarding the representativeness of the sample. Gender and age demographics of the resident sample indicates that more men than women participated in the study (Male n = 4, Female n = 3) and the age range was 74 to 98-years-of-age. The CNA sample was all female, ranging in age from 27 to 52-years-of-age.
Table 4.2

Age & Gender Distribution of Sample

<table>
<thead>
<tr>
<th>Age Range</th>
<th>0 – 21</th>
<th>22 – 30</th>
<th>31 – 64</th>
<th>65 – 74</th>
<th>75 – 84</th>
<th>85 – 95</th>
<th>95+</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Residents</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>Female</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>CNAs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Female</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>12</td>
</tr>
</tbody>
</table>

The race/ethnicity breakdown of the resident sample for this study was White = [n = 6] and Hispanic/Latino = [n = 1].

Table 4.3

Race/Ethnicity of Sample

<table>
<thead>
<tr>
<th>White/Non-Hispanic</th>
<th>African American</th>
<th>Hispanic/Latino</th>
<th>Asian/Pacific Islander</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Residents</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Female</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>CNAs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Female</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>12</td>
</tr>
</tbody>
</table>

Income (for five of the residents) ranged from $15,000 to $65,000 with two residents deciding not to report income. CNA’s reported income ranging from $20,000 to $50,000 but an error was found on the questionnaire where the increment changed from $4,999 per item to $14,999 or $35,000 to $49,000. Therefore, the CNA income range may not be accurate. The range for resident time staying at the LTC facility was from 1 ½ years to 12 years with (1) = 1 ½ years; (2) = 2 years; (2) = 4 years; (1) = 6 years and (1) =
12 years. CNAs reported length of time working at the LTC facility as follows: (1) = 1 year and 1 month; (1) = 3 years and 2 months; (1) = 4 years; (1) = 5 years; (1) = 12 years.

**Dyad 1**

The resident is a 74-year-old Caucasian male, divorced with some post-high school education. His room is private, which the resident states he pays for out of his personal savings. The resident describes having a son who was involved in his care at one point, but no longer is involved. He also states that he has lived in this skilled nursing and rehabilitative facility for approximately four years and that it is the second one he has lived in. The trait I noticed on first meeting the resident was his stature. Even though he is in a wheelchair there is still the sense that he is a tall and substantially-built person. His voice has a slightly gravel quality and when he speaks there is a force and clarity that carries a good distance. He appears comfortable being interviewed, and talks and laughs easily.

The certified nurse aide who works with him is a 42-year-old Caucasian woman, married with some children, and has worked at the skilled nursing and rehabilitative facility for three years and two months [the CNA states that she was working at the skilled nursing and rehabilitative facility when the resident first arrived, indicating a discrepancy between the resident and caregiver]. She states that she had worked in medical care field for approximately 19 years as a medical assistant in intensive care units. The CNA is also has a family member living in a LTC facility and would occasionally talk about the practical and emotional difficulties she has faced dealing with a sub-standard (by the CNA’s definition) facility.
The following are areas where the resident and caregivers interviews overlapped, titled “Congruent Themes” followed by those areas where the interviews did not overlap titled “Incongruent” themes:

**Congruent Resident and Caregiver Themes** – Experiential: resident’s desire for independence, advocating on his own behalf and on behalf of other residents, trust or distrust of staff, physical limitations due to frailty, aspects of the LTC facility and/or staff that impact the resident, difficulties with family relationships, making his preferences know to staff. Practical: managing personal belongings, CNAs and the resident’s personal hygiene, food served by the facility, gardening.

**Incongruent Resident Themes** – Experiential: expectations of privacy, religiosity and spiritual providers associated with the LTC facility, Practical: reading, polka and country music.

**Incongruent Caregiver Themes** – Experiential: developing resident and caregiver relationship, how the resident changed over time (when first admitted versus current disposition), resident’s keeping or losing control, personal benefits of care giving, resident rejecting medical care. Practical: resident wanting coffee.

The theme of independence came up early in the interview along with the resident’s willingness to advocate on his own behalf.

They all know me…they all…no matter where I go [in the skilled nursing and rehabilitative facility] …“trouble” they say, cause I’m not afraid to speak up, and I’ll argue when I’m right.
Examining the resident’s dialogue for subthemes to independence, key words emerge. “Fear” or not being “afraid to speak up” suggests awareness of a power dynamic and the belief that in some instances other resident’s may be afraid to speak up. (Advocating on behalf of other residents’ is a theme that emerges in both resident and caregiver interviews.) That being “right” about something, contrary to staff opinions, has led to vindication and an apology from the staff, particularly “staff that run the place” suggesting administrative-level staff. The resident seems to enjoy notoriety among the general staff as well. His expression “they all know me…” suggests some pleasure in this belief. Independence, defiance, and self-sufficiency are reoccurring themes throughout the resident’s interview, and are congruent with the following caregiver comments that the resident is “…very independent. He makes his needs known and it is on his schedule and his schedule alone.”

Following the caregiver’s comment on the resident’s independence and being on “his schedule and his schedule alone” a discussion of bedtime came up and that seemed to identify a combination of congruence and incongruence within both the resident’s and certified nurse aide’s interview. The resident had stated that choosing his bedtime was “very important” to him.

The caregiver suggests a time for the resident to go to bed which from the CNA’s perspective helps her plan his transfer (from wheelchair to bed) and other residents’ transfers as well. Competing demands highlight one of the key challenges to caregivers wishing to support resident preferences. Managing competing demands of residents’ particularly in the morning and evening care giving can compromise the CNA’s ability to manage other residents efficiently. But with respect to this resident’s preferences, that
difference may challenge the resident’s autonomy if the option of going to bed when the resident wants to (his schedule) is contrary to the suggestion of the caregiver. For this resident, the meaning associated with going to bed may be about maintaining control. From the resident’s perspective, bedtime is when the resident is ready to go to bed, not a prearranged time at which he will go to bed. When asked if waiting to be helped with going to bed while other residents needs are met was something he was willing to do, he replied, “Well, you almost gotta…there ain’t much you can do about it.”

**Summation**

The resident describes himself as being able to advocate on his own behalf as well as for others. The resident’s description is congruent with the caregiver’s perception of the resident. There appear to be incongruities’ within his perception of self-advocacy, however, that suggest the resident’s self-perception does not always match caregiver statements or resident observations by the researcher. For example, at one point during the interview a caregiver entered the resident’s room while knocking, which is incongruent to a later statement by the resident (“Right, they just knock on the door and walk in. I said, ‘no, no, don’t just walk in, knock on the door and I’ll tell you to come in.”). Incongruence between statements by the CNA and the resident also appeared with regards to the resident’s choice of bedtime. The caregiver stated that the resident goes to bed when the resident wants to, rarely when the caregiver wants him to (“…you can suggest a (bed) time, but most likely it’s not going to happen. It’s gonna be on his (the resident’s) schedule.”). Yet the resident indicates he is accommodating to the caregiver’s by going to bed when they are free to assist him (in those instances when his bedtime is preempted by the needs of another resident). The resident’s self-perception of being
independent is supported by the caregiver’s perception of the resident but that independence is not consistently present when examining overall content of the interviews. A resident’s preference can be in direct conflict with caregivers’ ability to support the preference while attempting to satisfy the competing demands of other residents. Another potential result of negotiating a preference is where the outcome is a combination of the resident’s preference and the caregiver’s ability to support the preference. The resulting negotiated outcome may leave both the resident and caregiver satisfied that their preference has been met while keeping intact the resident’s self-perception of independence and the caregiver’s sense of control over care-giving obligations. In contrast, both may be dissatisfied with the outcome and simply accept the inability of this resident to satisfy a particular preference or the CNA’s inability to satisfy the resident’s preference as one reality of living or working in an institutional setting.

The incongruences in this dyad suggest the difficulties in identifying or describing autonomy for this resident. While his statements indicate a self-described autonomy, which includes the desire and ability to self-advocate and the ability to advocate for others, it is undercut by institutional characteristics that subjugate the resident’s preferences as being second to the caregiver’s ability to support a particular preference. There is also the suggestion that the resident maintains the belief that he is an autonomous actor even when this belief is challenged by evidence. Much like the Berlin studies finding that older adults’ self-perceived health can be more positive than objective measures of their health (Borchelt et al., 1999), self-perceived autonomy may be resilient even when faced with contradictory experiences. Compromising a preference to accommodate the caregiver can be described as a negotiated autonomy where the
resident’s acquiesced preference (accepting a later or earlier bedtime than the preferred bedtime due to caregiver availability to support the resident’s preference) replaces the autonomous preference.

Moody (1988) argues similarly that “negotiated consent” is perhaps a more reasonable standard when attempting to ensure resident informed consent in nursing homes (p. 64). He argues for a negotiated response as a means of reframing the conflict between resident autonomy and perceived institutional paternalism. While this interview suggests that even when a resident sees himself and is perceived by a caregiver as a strong self-advocate, preferences can still be compromised. So while supporting resident autonomy has been the goal of recent quality of life efforts in nursing homes, a negotiated autonomy may be the outcome. The question is whether a negotiated autonomy is still autonomy.

The resident describes surviving a medical crisis as the result of his son circumventing his wishes (not to have extreme measures taken to keep him [the resident] alive). As a result, the resident describes being in constant pain and regretting having survived the crisis. He is able to move about the facility in a wheelchair though has difficulties washing certain parts of his body and requires help with numerous activities of daily living. Still the resident is able to stay active and has maintained a physical therapy regimen that helps him maintain his current level of activity. In one instance the resident describes a CNA (not identified as the CNA in this dyad) as having not properly cleaned him after a bowel movement.
So they’ll say, “Yeah, here’s the rag, all clean.” The next girl comes in to wash you up for the night and (says) “Who did that?” I said, “Hey, the aide there that took care of me.”

The description “yeah, here’s the rag, all clean” indicates the CNA is displaying a soiled rag meaning the resident was cleaned after the bowel movement. Since the resident is unable to clean himself after the bowel movement, his preference to be cleaned is not supported by the caregiver, and the resident is unable to negotiate being adequately cleaned until the evening caregiver arrives. While it can be assumed that a person wishing to be cleaned following a bowel movement is expressing a preference (health considerations/personal comfort), the resident’s inability to perform the task compromises his ability to act autonomously. The interview did not clarify why the resident was unable to get the CNA clean him properly or enlist another CNA who might be willing to help. The resident may be unaware that he was not cleaned properly or completely and only realized (as suggested by the interview content) that he had not been cleaned properly when he was being washed at the end of that same day. Being dependent on the CNA to execute the resident’s preference makes it no less a preference, but the inability to get help from the CNA to execute the preference erodes resident autonomy. Frailty, which stops a resident from executing a preference, places them in a vulnerable position of needing the help of the CNA to realize the preference.

**Dyad 2**

The resident is a 78-year-old Hispanic male, married with a professional doctorate degree. He states that he pays for his room. He has a number of adult children living in the area that are, along with his wife, involved in his care. He estimates that he has lived
in the skilled nursing and rehabilitative facility for approximately two years and this is the only skilled nursing and rehabilitative facility he has lived in. The resident was warm and gracious when we first met to discuss his participating in the study. Classical music played softly in the background on each of my visits. His voice was quite soft which made it difficult to understand his speech at times. Since English was not the resident’s native language and the researcher does not speak Spanish, there were additional challenges for the researcher in transcribing.

The certified nurse assistant is a 52-year-old Caucasian woman, divorced and living with a partner. She has worked at the skilled nursing and rehabilitative facility for five years and two months. She has a high school degree and described beginning an undergraduate program but did not complete her studies because she went from being an amateur to professional athlete, which overlapped with (and contributed to) the end of her academic career. The CNA appeared eager to participate in the study and was very forthcoming during the interview.

**Congruent Resident and Caregiver Themes** – Experiential: resident’s gratitude for being in a good LTC facility, importance of the resident’s marital relationship, socializing with other residents, importance of religious practices, prior knowledge of skilled nursing and rehabilitative facilities. Practical: hygiene (shaving), dressing routine, music, sports (hockey in particular).

**Incongruent Resident Themes** – Experiential: the importance of time alone.

Practical: resident’s past travels, reading.

**Incongruent Caregiver Themes** – Experiential: how to determine resident preferences (including MDS 3.0), the CNA having known the resident socially
prior to his being placed in the facility, preferences or routines the resident
developed with a previous caregiver, the resident realizing he will not be “going
home.” Practical: hygiene (in particular, cleaning around genitals).

Generally the resident describes himself as very fortunate to be able to afford a
private room in good nursing facility and that he is not a burden to his wife. The theme of
being “fortunate” emerged over the course of initial and the follow-up interview in a
number of contexts (skilled nursing and rehabilitative facility, marriage and family,
career, trips taken abroad prior to becoming ill). “I know that there are many places that
are horrible, and considering everything else, I’ve been very fortunate to be in here.”

While it can be inferred from this statement that the resident’s preference is
residing in a generally good skilled nursing and rehabilitative facility rather than a
“horrible” one, his sense that he is fortunate and the consistent way this expression
appears throughout the interview suggests a lens through which the meaning of his
preferences might be viewed. For example, the assumption of the right to a preference as
expressed by the resident in dyad 1, reflects an expectation that his preference is
reasonable and therefore within his rights to demand. On the other hand, this resident’s
often repeated sense of being fortunate or lucky suggests that, while he may have
preferences, it is not expected that those preferences will always be supported or
necessarily take place when the resident chooses. The inability of the resident to rely on a
caregiver is also present in a portion of the interview regarding the resident’s preference
for reading.
The resident physically has difficulty holding a book and turning pages. It is necessary to have help from a certified nurse aide (CNA). The difficulty the resident appears to have has to do with the predictability of who will be available to help when he wishes to read; different shifts (mornings, afternoon or evening) have different CNAs who have what the resident describes as “…pretty much their own routine.” When asked if CNA availability also requires he adjust to the various CNAs the resident states that he has “…no choice.” When asked about whether caregivers are aware of (or understand) his preferences the resident responded that “…the majority of the persons assigned to my case…know my routine” and “…they are pretty good that way.” So the resident acknowledges that CNAs in general understand his routines; yet the resident also perceives the CNAs as having routines of their own to which he must be accommodating. The accommodating of a CNA’s routine can also evolve into a resident preference.

According to the CNA, the resident prefers to be shaved in bed. Yet in discussing his shaving routine, he only states that being shaved in bed is “…easier that way.” When asked why it was easier his answer is vague and does not sound like a preference (“well, with the electric shaver they go…turn the head to one side, then they do the opposite side, and it works fine”). The CNA describes his shaving routine as one established by a previous CNA who found it easier to shave the resident while he was in bed. The current CNA also states, “…he prefers to be shaved in bed, rather than after you get him up into his wheelchair…it didn’t used to be that way” and she states that the resident regularly tells her (the CNA) “…that it’s easier if I do it when he’s in bed…it’s something he’s firm about.” The routine of shaving and the order of events in the resident’s morning routine may help the resident feel a sense of predictability and familiarity. There may
also be a meaning associated with being shaved in bed that is appealing to the resident. It could be described as a more intimate way of being shaved.

The CNA of the dyad identified the resident’s willingness to accommodate caregivers stating, “…he’ll voice preferences, but he’ll always ask rather than demand or state.” The distinction of asking rather than demanding in voicing preferences is clarified further by the CNA stating the resident will preface his request for preferences with, “couldn’t we do thus [sic] and such?” or “I’d like to go to the activity if I may.” The CNA also indicates that the resident is willing to postpone a preferred activity and that if she is busy with another resident, she will indicate she will be right back and he will often reply with “Okay, take your time.” This description suggests congruence between the residents and CNAs descriptions of the resident’s behavior when needing assistance with preferences, though it is not clear whether there is congruence regarding the meaning, or perceived meaning, of the resident’s perspective. The resident’s description has a tone of resignation, whereas the CNA interpreted the resident as accommodating. These two perspectives, while not contrary or conflicting, reflect the challenge of supporting resident preferences against competing demands, and the descriptions used by the resident and CNA to frame the perspective. [Note: As stated previously, the resident described himself as very fortunate to be at the facility and was inclined not to complain.]

Both the resident and the caregiver identified music as an important preference, with a significant meaning to the resident (classical music was playing in the resident’s room during both interview visits). The resident describes the music as “…very soothing.” In addition he describes music as having been an important part of his life that produces a “very peaceful” effect on the resident. The CNA provides a congruent


... description, providing insight into the resident’s preference and the meaning the music has for him. She states that the resident has described to her how the music “…gets into [his] body and it makes [him] calm.”

The resident’s preference for music is a clear example of congruence between the resident’s preference and the meaning of the preference as well as the caregiver’s recognition and understanding of the meaning the preference has for the resident. Examining the other dyads, there are similar instances where there is congruence between resident and caregiver when identifying preferences but not always on the meaning of the preference. The resident is able to satisfy his preference for classical music and does not require the caregiver to play a role in supporting the preference. So does it matter if the caregiver recognizes or understands the meaning of the preference? Perhaps if the resident loses the ability to turn on his stereo, having a CNA that understands the importance of this preference and assist him in maintaining the preference would be helpful to the resident.

Reading when the resident requires help turning pages may be a more difficult preference for CNAs to manage. Setting aside a block of time to spend with a resident as he reads may be beyond the facility’s ability to accommodate. The data indicates that supporting the resident’s preference requires him to negotiate scheduling with the caregiver. It also indicates that in this particular skilled nursing and rehabilitative facility, CNAs schedules are always changing, which may require the resident to negotiate with a number of caregivers over time. Negotiating with various CNAs may be particularly difficult if strong emotions are related to the need for caregiver help.
The CNA described an occasional exchange with the resident that comes up while she is washing him in the morning, “he’ll say to me …this is just so embarrassing.” The caregiver describes an ongoing perception that the resident feels embarrassment for being dependent on others. The dependency may be more critical when care giving involves contact with the resident’s genitalia or clean up following bowel movements. There may also be a feeling of embarrassment in being unable to read a book independently or depending on others to complete simple tasks such as shaving or eating. The resident does not discuss feeling embarrassed about needing help and is vague when discussing the times he needs caregiver assistance (“All of the helpers I have here, they’re pretty good. They have a routine and they know my routine.”). A feeling of embarrassment may, in part, reflect the resident’s desire to be seen by the researcher as competent or capable even though he is unable to manage basic tasks. He may also have unguarded moments with this CNA (dyad) and share personal feelings or thoughts that he is less comfortable sharing with the interviewer.

**Summation**

Examining dyad 2 as a whole suggests that preferences may serve a purpose that is connected with but distinct from the preference (e.g. shaving). It can be part of an inventory of the day the resident may use to feel some sense of control over his life in an environment that is not of his choosing or design. It can also be expressed as part of a shared experience with the caregiver. As the resident accommodates the caregiver a shared preference is expressed (as in the shaving in bed example) and eventually becomes the resident’s preference when that particular caregiver is no longer caring for him. In this instance the preference of shaving while in bed, which was established
between the resident and a previous caregiver, is durable and does not change even with the introduction of a new caregiver.

Two unexpected insights emerged from the interviews. The resident often spoke of feeling lucky to be at this particular skilled nursing and rehabilitative facility. He also expressed feelings of being lucky with regards to his marriage, family and career. The resident was reluctant to complain or appear to be complaining. Since the expression of being lucky was a comparatively unique theme among the residents interviewed, and because the resident is Latino, the researcher consulted with an expert on aging and Latino culture who, after examining the transcription of the interview, stated that Latino men are more inclined to be grateful or express gratitude than complain or focus on their own wants.

Lastly, two interviews were completed with this resident. In both sessions the responses and details of the responses were highly consistent. For example, when asked why classical music was important to him he replied in each interview that the music was “soothing.” The consistency held true in a number of other areas and in some ways presented a problem for the researcher. Because his responses were so consistent and succinct it was difficult to probe for a deeper understanding. More so than the resident’s succinct responses, was the sense that the interview was touching on a sensitive topic. When discussing the resident’s religious practices it became clear to the researcher that probing into the resident’s beliefs was making the resident uncomfortable. Responding to a question regarding why practicing his faith was important, he replied, “It’s hard for me to (unintelligible) with you.” I replied, “It’s deeply personal?” and he responded “yes.” There was a change in the tone of his voice (previously he had been engaged and
somewhat open) to a reserved or hesitant quality. It also felt as though he was becoming disengaged from the interview. The exchange was moving because it felt deeply personal and gave a brief glimpse of a very private part of the resident’s life in a long-term care facility where even in the resident’s private room there is still a sense of being in a public space.

**Dyad 3**

The resident is a 75-year-old Caucasian male, divorced with an undergraduate degree. He states that he has lived in the skilled nursing and rehabilitative facility for approximately 12 years. On first meeting the researcher, he answered my first interview question with what appeared to be a pre-prepared response. That is not to say that the resident knew what was going to be asked and prepared an answer in advance, but rather that he had a general sense of what the interview was about and had prepared a response that stated what was important to him. The resident stated that he does not “…depend on anybody.” He did acknowledge that an “aide” helped with his shower once a week, but that was all the help he needed. Considering the length of time the resident has been living at the facility, such a strong statement of independence was clearly purposeful on his part.

The certified nurse aide is a 28-year-old divorced Caucasian woman with a high school degree, who has worked at the long-term care facility for 13 months and has previously worked at two other long-term care facilities. Our interview was somewhat awkward and tense. She may have had concerns about being interviewed, particularly being interviewed about caring for residents; as a result the CNA was guarded in her
responses. Questions were reanalyzed before asking, in order to minimize the impression that part of the study was to uncover mistakes or poor care giving.

**Congruent Resident and Caregiver Themes** – Experiential: the resident’s desire for being independent, impact of physical limitations, family relationships (especially his daughters). Practical: hygiene, food at the LTC facility, gardening, personal scooter.

**Incongruent Resident Themes** – Experiential: caregivers with shared interests (smoking and tattoos), the resident’s past and present roommates (and not getting emotionally involved with them), resident’s life-long enjoyment of outdoor activities. Practical: gardening, television programs he watches.

**Incongruent Caregiver Themes** – Experiential: the resident’s physical limitation and how he wants to remain active, learning how to serve the resident. Practical: resident not feeling well, resident being protective of personal belongings, the resident being touched by the CNA, the resident’s care-plans.

At the onset of the first interview the resident states that he does not “depend” on anybody and proceeds to list a number of self-care activities (“I dress myself, I feed myself, wash myself…”), suggesting that being independent is important and meaningful to him. The resident appears to the researcher to be able to take care of the mentioned ADL’s though the resident stated he did have physical limitations (stating loss of the use of one arm and one leg). The resident indicates that he needs help with showering and will typically have the aide (CNA) help. Independence is further asserted during an exchange regarding the resident’s desire to lose weight.
The resident describes frustration (‘‘…it gets to be crazy here’’) with one aspect of his care: control over his ability to diet. He describes an incident where he lost 5 pounds in one week that raised concerns among the nursing staff. The resident states that he was on a diet and ‘‘…lost 5 pounds because I’m too heavy.’’ While it seems appropriate, the nursing staff were concerned about the sudden weight loss and the resident appears to feel staff are ignoring his right and ability to make decisions regarding his weight. There also appears to be a frustration that he is viewed as someone to be observed rather than respected for having insights into his personal health when he states, ‘‘they ask the aide, tell what he weighed, head nurse wants the weight…the head nurse…the dietician…why don’t they ask me.’’ Control over changes in his life appear later in the interview as well. ‘‘I’ll make changes…I make my own changes. But they don’t agree with that (laughs). ‘‘Your [nurses/dietician] make the changes’’…no, I make the changes.’’ The overall tone of the resident’s comments suggests a desire by the resident to appear the rational person in comparison to the staff. Rational in the sense that he is capable of making decisions and changes to those choices he has some control over, such as dieting. Since he is capable of making these decisions and states he should be viewed as the authority (‘‘why don’t they ask me?’’), the healthcare staff are irrational for thinking they have any authority over his diet or weight. There is a tone of incredulity in his voice The theme of independence surfaces in the CNA interview when asked how she came to understand that independence was important to the resident:

…he’ll blatantly, you know, just from the way he does things, he’ll let you know that that’s how he likes it. He doesn’t really like you fondling [sic] to much with his belongings…it’s his stuff…it’s his personal stuff…when I first started
working here, and...cause he’s on my assignment...when I first started working here I was helping transfer into...from his regular wheelchair to his powered wheelchair. He would pull himself up on the railing and I would try to help...I was trying to help him by putting the gate on him and he said “...no, no don’t touch me.”

The description that the caregiver gives shows an understanding of the resident’s preference for independence and awareness of the significance independence has for the resident. This theme of independence is further demonstrated by the resident stating he does not request help from the CNA. For example, the CNA states that the resident “...doesn’t ask for much,” telling the interviewer she changes his bedding and makes his bed. The CNA equates the resident’s desire for independence to being “stubborn.” She determines this meaning based on her interactions with the resident. She states, “I just...can just tell just by the way the interaction...the little bit of interaction that it is with him.” It is an implied meaning either by the resident’s behavior or statements. She explains, “…he’ll blatantly, you know, just from the way he does things, he’ll let you know that that’s how he likes it.” The CNA continued to struggle with describing how she is able to determine the resident’s preferences. Later in the interview she clarifies how she understands the residents she works with (particularly when the resident is not feeling well) stating, “I can go into the room and just talk to them and just by the tone or the way they’re speaking back to me, I can almost tell they are having a bad day.” Having the ability to intuit what the preferences of the individual are is a distinct theme in the caregiver’s interview. It indicates the ability of this CNA to imagine the response of a
resident to a particular procedure or a particular type of help without knowing the resident verbally expressing the preference.

The resident’s resistance to receiving help from his caregiver suggests a complication to supporting resident autonomy for the caregiver. It is the CNA’s role to provide care or to help the resident. A resident who does not wish that help, possibly because of the meaning being helped or needing help implies, may appear difficult, resistant or in this case “stubborn”. When asked what his independence means to him she states:

“It means everything to him. He doesn’t want to be here. Umm…he doesn’t think he needs to be here, but in a sense he does need…you know what I mean? He needs that little bit of assistance every once in a while.”

The congruence of independence in this dyad indicates the resident may view himself as someone who does not require the services the facility provides. How he interacts with the CNA separates him from the other residents, indicating he is someone other than a patient. The CNA provides the following description of her general interaction with the resident:

“…he conversates [sic] with us like we’re just like his friends or a family member, not like we’re…not like we’re here to help him.”

The statement suggests that the resident in some fundamental way views the CNA as not being his help aide. The resident converses with the caregiver as if she is a “friend or family member...” One implication from this comment is that the caregiver must view the resident as someone who is not under her care, a person who in some ways is not really a resident in the skilled nursing and rehabilitative facility. Put another way, the resident
lives in the facility but is not a patient. In a sense, this neutralizes the care-giving role of this particular CNA.

**Transcended Construct**

This dyad in particular presents what the researcher has described as a transcended construct (see fig. 2, page 69). The theme of independence utilizes the transcended construct diagram, identified in the “overall theme congruence.” Following this analysis, “within theme congruence” is identified as both the resident and the caregiver’s descriptive content being both congruent and incongruent. For example, both describe the resident’s independence as one in which he needs no help or little help (Resident: “I don’t need help from nobody.” CNA: “For the most part he does everything himself.”). In the incongruent portions of the interviews where independence is being discussed the resident indicates he makes decisions for himself and does not require the staff (nurses/dietician in one particular instance regarding his diet) to participate stating; “I make the changes.” The comment is particularly meaningful because the resident is stating that he knows what is best for himself and is, therefore, the logical person to make certain decisions. The resident’s comment highlights how resident independence within the institutional setting may be challenged when the caregiver’s opinions differ from those of the resident’s. Differences of opinion between the resident and caregiver may be of particular concern around health care decisions (using the resident’s diet as an example) where the resident is unaware of health implications linked to his choices, though it was not evident in this interview.

The caregiver further supports this transcendent construct by acknowledging a particular quality to her interactions with the resident. For example, she states that:
“…he [converses] with us like we’re just like his friends or a family member, not like we’re…not like we’re here to help him.”

The CNA describes these conversations as if they are between “friends or a family member.” There is congruence with the resident’s previous statement that he “…don’t depend on nobody.” There seems to be clear effort on the resident’s part to acknowledge little need for the CNAs in their capacity as health aides, which is confirmed by the caregiver. This negation of a “need” is congruent with the caregiver’s sense that the resident does not see the CNAs as being there “to help him” or more specifically, the resident does not see himself as needing the CNAs’ help. Extending the meaning, it can be inferred that the resident views himself as someone who lives at the skilled nursing and rehabilitative facility, but does not require certain services of the facility provides, suggesting a meaning central to the resident’s preference of independence in what is an environment often defined by dependency.

**Summation**

Dyad 3 suggests a unique perspective on how a particular resident may utilize the facility and take on behaviors that limit the role caregivers can play in his daily life. The caregiver reinforces this perception of the resident and, per her description, has adjusted her interactions with the resident in a way that supports (or does not challenge) the resident’s preference for autonomy within the facility.

**Dyad 4**

The resident is a Caucasian male, age 88, divorced with a graduate education and has lived at the facility for 4 years. This is the first time he has lived in a long-term care facility. He has a private room. On entering his room, the resident was seated in a
wheelchair and appeared to be watching a television program. During this initial conversation with the resident, adjustments needed to be made to the interviewing style to accommodate his speech patterns: he always took a few moments to consider questions before answering. Sometimes these moments could turn into long pauses, leading the interviewer to be uncertain as to whether the question had been heard. It may be that talking was not easy for him (though he did not state as much). His responses were often short bursts though and his voice was thin, sometimes strained. He was direct and succinct in his answers, which made asking follow-up questions difficult, because the interview never became conversational, a phenomenon which had been the case with other residents’ interviews.

The certified nurse aide is a Caucasian female, age 46. She has worked at the facility for 12 years and has training as a vocational nurse. She was very comfortable with being interviewed and was candid in her responses. Her responses were detailed and seemed genuine and frank. She was unique in that she had worked in the kitchen of the facility for a number of years before deciding to train as a CNA. She pointed out two interesting points during the interview that were descriptive of how she views the residents and the residents view her. She first states, in response to a question regarding her ability to intuit resident preferences; “…it’s just a feeling. It’s gonna sound weird but just like a mother’s intuition with a kid. …and I think I only say that cause I have kids and it seems like the same thing.” Later in the interview, referring to the residents again, she states, “I mean, they’re like all my parents and my grandparents almost…the resident’s and stuff, that’s how I feel, when they…most of them say that about us aides. That they feel like we’re their kids and grandkids.” The CNA’s comments describe
generational positions that also indicate roles and relationships associated with roles, acknowledging dynamics between the CNA and the resident that reflect relationships of dependency (mother and child or father and child) and nurturing affection (child and parent or grandparent).

After reviewing the emerging themes, congruence between resident- and caregiver-identified themes were present in a number of areas. On examining “within theme congruence” there appeared to be little congruence between the resident and caregiver’s description of the preference. The content of the interviews were examined to determine if there was an overall descriptive pattern to preferences in general that might be a starting point for the analysis. From this perspective the researcher identified the following:

**Congruent Resident and Caregiver Themes** – Experiential: the variety of preferences the resident has, preferences that change when the resident is not feeling well, the resident’s desire for independence while being dependent, interactions with certified nurse aides, family members’ roles in supporting the resident’s preferences. Practical: clothing, television (sports and the news), wake-up routine, meals at the facility.

**Incongruent Resident Themes** – Experiential: adapting to being in a facility. Practical: personal hygiene, going outdoors, reading, bedtime.

**Incongruent Caregiver Themes** – Experiential: the resident’s privacy, the resident staying active, teasing the resident about competing sports teams. Practical: back rubs following his shower, activities outside and within the facility, coffee.
After a review of the themes, there was some congruence found between descriptive themes. At the same time there was very little congruence in the discussions regarding each theme. For example, while the both the resident and caregiver talked about the resident’s morning wake-up routine, the resident describes waking up one hour before the CNA comes in to wake him up because this is his “…natural waking time.” The CNA states that when she enters his room she greets him and he responds, “…so I’m assuming he’s pretty much awake.” The resident says that he enjoys staying in bed for the hour before the CNA enters to wake him up. When asked if he is in any hurry to get out of bed and get dressed and he replied “No.” Each describes a similar event, but the CNA does not describe or is not aware of the resident’s preference for time to himself when he wakes. This scenario is an example of where there is congruence between resident and CNA descriptions of the early morning routine even though the CNA is unaware of the meaning of one aspect of the routine (the resident’s preference to have time in the morning to himself). That the CNA is unaware of this morning preference is perhaps irrelevant since her interaction with the resident support the preference.

The resident identifies his inability to perform certain preferences without help, as well as the impact caregiver availability has on facilitating those preferences. He also suggested that CNAs lack understanding of the “extent of [my] preferences” or, more specifically, his need to do as many things on his own stating, “…if I didn’t do it on my own, I think other people would miss what I was really interested in.” While it is possible he does not let the CNAs know about the extent of his preferences, the preference may evolve out of a particular and unexpected situation or instance. He provides an example of such an instance:
“Sometimes I have an aide, which will be, uh, taking care of me, in some specific instances, and they’ll say that they have to leave me for a minute. Then they don’t show up for quite a while, they just disappear.”

The resident’s inability to perform certain preferences without help is impacted by a caregiver’s availability. The issue of caregiver availability reinforces the resident’s earlier comment that there are certain things that are important for the resident to be able to do on his own, in part because he feels he may not be able to depend on the caregiver to help him. Paradoxically, when asked about how the resident’s level of frailty impacts his ability to enjoy certain preferences the caregiver describes the resident in the following way:

“…he goes and does things, you know. He’s not one to sit around. He goes on the trips [social outings], the racetrack, he goes to casino, he goes out for lunches.”

While this content indicates that the resident has been involved in certain types of activities, those activities are more event-like and would require a certain level of support for the resident (attending a wedding, going on social outings) as well as a certain level of preparation. The resident, in pointing out concerns about CNAs understanding the extent of his preference, may be discussing less involved preferences (preferences that do not require a great deal of support). It could also be that he would like to have a particular care activity completed in such a way that he can go on to another activity without interruption.

There was a unique story told by the CNA in which she describes how the resident developed a preference where “…he always asks me to rub his back with a dry
The key to making morning routines suit the resident’s preference was making the bed between drying the resident’s back and rubbing his back with the dry towel. The interaction between the resident and the CNA was not confirmed with the resident, so it is not clear if this is the caregiver’s perception of a preference that the resident does not share. Yet accepting the story as accurate, it suggests that the resident and CNA have established a unique and specific preference - a preference enacted by the resident and supported by the caregiver and with a sequential aspect that is clearly defined. Separating drying off the resident after a shower/bath with making the bed may be part of the way the task has been done since first initiated. It is also possible that the resident is unaware of the need for time between being dried and having the towel rubbed on his back.
Having his specific preference supported required the resident request the back rub from the new caregiver, but according to the CNA that did not happen or was never communicated clearly. The CNA states, “he probably just thought she was still drying him” indicating that the preference may have an unconscious aspect for the resident. What the story does suggest is that preferences between caregiver and resident can evolve with specific elements and timings that are key to supporting the preference. The evolution of a preference may take place without the resident or the CNA being aware that a preference is being established. The same phenomena appeared in other dyads suggesting that preferences established in the patterned interactions between resident and caregiver is common.

**Summation**

This dyad was somewhat rare in that similar themes emerged; yet the content of the themes were quite different. It seemed as if these two individuals were interacting around the resident’s needs but little of the meaning of the preferences held by the resident were being communicated. When the caregiver discussed the resident’s preference for having his back rubbed with a dry towel, she indicated that she had never given it much thought before. Only because another CNA had difficulty with the timing of the back rub did it register that a preference had been established. It appears from this particular instance that preferences can evolve out of resident and caregiver interactions and that preferences can be unconscious, accidental, and the result of arbitrary actions.

**Dyad 5**

The resident is a 98-year-old Caucasian female who is widowed and has graduate school training. She states that she has been residing in the long-term care facility for
approximately 2 years. This is her first LTC facility stay. The resident expressed a strong personality that was immediately felt by the interviewer during the first meeting. She directed the researcher from her personal room, which she shares with a roommate to a common room, where she could discuss the study. She gave the impression of being glad for the company and that the interview would be focused on her preferences. Initially, the discussion did not stay focused on her preferences; yet the change of focus turned out to be her way of focusing on a much broader preference. After reviewing the interview in the transcription and analysis processes it became evident that the topics discussed were those things that were important to her, but had little to do with the facility (preferences that did not required assistance or support from a CNA). Further congruence in the theme was provided by the CNA, regarding how important maintaining her life outside the facility is: “Like today, it was not a good day, she took a pain pill, she’s still gone. She still went out with the son.”

The certified nurse assistant is a 42-year-old Caucasian woman, married with some children and has worked at the skilled nursing and rehabilitative facility for three years and two months [the CNA states that the resident has been at the facility “almost the whole time” the CNA has worked at the facility, indicating a time slight discrepancy between the resident and caregiver]. She states that she had worked in the medical care field for approximately 19 years as a medical assistant in intensive care units. Following a move to the East Coast to care for a family member, she trained to become a CNA after being unable to transfer her medical assistant license.
The following are areas where the resident and caregivers interviews overlapped titled “congruent themes,” followed by those areas where the interviews did not overlap titled “incongruent themes.”

**Congruent Resident and Caregiver Themes** – Experiential: resident’s desire to remain active, continuing efforts by the resident to remain independent, physical challenges to autonomy, importance of family relationships, emotional impact of physical illness on the resident, Practical: meals at the facility, the resident’s roommate, getting dressed.

**Incongruent Resident Themes** – Experiential: caregiver preference for alone time (napping). Practical: fishing, music, newspapers, libraries, gardening, bedtime preferences.

**Incongruent Caregiver Themes** – Experiential: personal privacy of the resident. Practical: resident’s wake-up routine.

The resident repeatedly returned to a theme of adjustment and acceptance in describing her transition to living at the skilled nursing and rehabilitative facility.

“My attitude…I would blame it all on myself. It wasn’t that bad [being at this skilled nursing and rehabilitative facility] but it was an inside adjustment. I had to sell my home. I couldn’t get back to doing anything. I couldn’t stand, I couldn’t walk [interrupted by intercom] jeez [unintelligible]…and things that I had done all my life, even though I’m old…I mean I still did it…I went fishing with my son, with his family. That was a big part of our whole spring, and summer and fall…fishing and boating. When I couldn’t get into the boat anymore…to me that
was a sad day. Since I’ve done it all my life. So it was things like that were happening to me…I can’t say they had anything to do with the home, because I…umm I have to know I’m getting old…I shouldn’t do this…so uh…I’ve finally given up the fight.”

There is significant loss being described in this passage including a transition experienced in moving into the skilled nursing and rehabilitative facility. She states, “…the things that [she] had done all [her] life” were still things she had been able to do prior to her transition to the skilled nursing and rehabilitative facility. Even though she was “old” she had still maintained these activities as part of her life. Yet she goes on to describe the difficult process of accepting physical limitations, acknowledging she “…couldn’t be on [her] own.” She states that she “can’t stand, can’t walk,” and that she could not “do it on [her] own anymore.”

The resident indicates a sense of loss that accompanied losing the ability to perform aspects of her preferred activities (getting into a boat to go fishing, for example). The loss and her decision to have “finally given up the fight” suggest a reconciliation between the fact that aspects of preferences are lost, though the desire and ability to engage in those activities remains; she recognizes accommodations, or altering the method of engaging in the preference can reconnect the person to the preference. For example, fishing has been an enjoyable activity for the resident much of her life. A fishing trip was scheduled at Lorraine and the residents participated. She describes having a “…casting rod. But the flies were hard. You have to flip it out [cast the fly]. But I’ll admit, my son flipped it out. But I pulled it in. I hooked it and pulled it in.”
The aspects of fishing that the resident is unable to perform are managed by her son and her choice of the phrase “but I’ll admit, my son flipped it out [cast], I can’t” indicates a resignation that can be referenced back to her earlier comments regarding her life prior to being in the skilled nursing and rehabilitative facility.

The adjustment coincides with an ongoing effort to maintain a connection with those activities she enjoyed prior to being in the skilled nursing and rehabilitative facility though she is unable to walk. She states the “…outdoors have always been part of my life. I’m happy that I can still do the things here that I did before.”

Content from the caregiver interview reflects congruence with the resident’s desire to remain active:

“…9 times out of 10 she’s not here, or if she is here, she’s either doing her own thing, like genealogy, or reading a book, watching TV programs, they have specific ball games. So she really keeps herself busy, doesn’t dwell on, ‘oh my God I’m in the skilled nursing and rehabilitative facility’. She really makes the best of it.”

From the perspective of the caregiver, there is an additional aspect to the importance the resident places on her desire to remain active. The desire is such that according to the CNA, the resident:

“…doesn’t like to take any medications at all. She doesn’t even like to take Tylenol. “…it knocks her out sometimes and she just doesn’t like that. Cuz she’s missing out. So she deals with the pain.”

The CNA’s assessment of resident’s approach to pain medication is contrary to the CNA’s belief regarding appropriate care (taking pain medication when the resident is in
pain) and she sees the resident’s behavior as “…a big part of her problem,” suggesting that the resident’s willingness to forego pain medication in order to stay active aggravates her arthritis. While the content regarding medications is not corroborated by the resident’s interview, it is reasonable to assume due to her active role in caring for the resident, that the CNA would have accurate information regarding the resident’s medication preferences. That the medication sometimes “knocks her out” and might lead to the resident “missing out” on activities, and as a result, the resident knowingly “deals with the pain” indicates a strong congruence between the resident’s preference and the caregiver’s understanding of how important it is for the resident to remain active. It also suggests that the resident’s desire to remain active trumps treatments that might alleviate pain but interfere with her ability to participate in her preferences.

Summation

The presence of a desire to maintain pre-nursing and rehabilitative service facility preferences while reconciling changes the resident is experiencing in her ability to perform those preferences is a unique feature of this dyad, though possibly present and expressed less clearly in the previous dyads. The resident appears to be juggling two competing realities: a resignation of her life prior to becoming a resident, and her need to maintain some form of connection to those same preferences - even in modified form. For example, the resident describes her inability to “get into the boat anymore…” as a “sad day.” She describes it as something she has done “all [her] life,” even though she was “old.” Yet when the opportunity arose to go fishing with a group of residents she was able to manage her limitations with the help of her son (“But I’ll admit, my son flipped it out [casting], I can’t.”). She also indicates that she was still able to execute a part of the
experience (“I hooked it and pulled it in.”), which reinforces the inference that a meaningful connection with her preference for fishing is still possible, though she acknowledges a resignation and perhaps acceptance that important aspects of her prior abilities tied to the experience of fishing have been lost.

The resident’s desire to remain connected to meaningful activities of her life prior to becoming a resident are further amplified by the caregiver’s statement regarding medications. The physical activity needed to participate in these activities can be hampered by pain medications that sometimes “knock her out.” As stated previously, the resident did not corroborate the information regarding medications, though it is possible to infer that the caregiver’s comments are congruent with the resident’s self-described desire to remain active.

**Dyad 6**

The resident is a 98-year-old widowed female and has resided at this long-term care facility for approximately four years. She states she has a high school diploma. This is the first time she has stayed in a long-term care facility and at the time of the interview shared her room. An attempt was made to schedule the interview but was not completely accomplished, given the resident’s inability to remember appointments. The researcher was advised by caregiver staff that dropping in during a time of day when the resident was typically free would be a more effective strategy. On the day of the scheduled interview, the researcher found the resident seated in a common area where residents watch TV. The resident only vaguely remembered meeting the researcher, but was accommodating after being reminded of a previous meeting and discussion of the research project.
When asked if the resident had a preference for where to go over the consent process, she chose an area that was away from the TV area but still a public space. Listening to the interview afterwards, the resident’s very soft voice made it difficult at times to distinguish her voice from other nearby sounds.

The researcher’s impression of the resident’s overall demeanor was that she was pleasant and appeared somewhat frail. It was late in the morning when we began the interview (approximately 9 am) and the resident stated that she was waiting for her shower and to get dressed. She indicated that this was later than normal for her, but when asked whether the interview was further interrupting her morning, indicated she was not concerned that the interview would further disrupt her morning schedule.

The caregiver paired with the resident is a 27-year-old African-American woman with an undergraduate degree and has worked at this long-term care facility for approximately four years; this is not her first job working in a long-term care facility. She is a highly regarded certified nurse assistant and is often utilized by the facility’s nursing staff to train new certified nurse assistants. She states that a key aspect of her care giving is that she asks residents how they like things done and that she does it for them that way from then on. She also states “[she] only need[s] to be told once” (with regards to what the residents’ preferences are).

The following are areas where the resident and caregivers interviews overlapped titled “Congruent Themes” followed by those areas where the interviews did not overlap titled “Incongruent Themes.”
**Congruent Resident and Caregiver Themes** – Experiential: the resident’s desire to stay active, contact with family, socializing with other residents. Practical: bathing, morning routine.

**Incongruent Resident Themes** – Experiential: spirituality and the resident’s desire to practice her faith, resident’s enjoyment of outings. Practical: playing cards or board games, newspapers, dressing, meals, personal belongings, reading, shopping, bedtime, bird watching, music.

**Incongruent Caregiver Themes** – Experiential: a general discussion on why residents want to maintain personal control, the resident’s helpfulness with other residents, Practical: helping the resident walk.

While resident themes emerged that were congruent with the CNA’s perception of the resident’s preferences, they were congruent only in that the respondents discussed those themes, but the content or description within those congruent themes varied considerably. As a result, the researcher decided to examine the resident’s preferences for areas where substantive content was present.

The first substantive theme where there was congruence between the resident and CNA was an overall belief regarding the resident’s preference for staying active. The resident states that it is important to her to “…keep doing things that keep [her] busy.” She keeps busy by participating in games scheduled by the facility that also support her desire to be in “…contact with other people…you, things to do with them.” She further explains that she “…cannot sit still like some people here, I’d go nuts,” reflecting her self-described long-standing desire to be active. Staying busy also includes being involved in outings the facility provides and finding new activities like bowling. She
states, “oh, bowling, I like bowling. I just got into that last year, I think.” [NOTE: On rare occasions the resident had difficulties recalling past events. While the researcher found consistency in many of her comments (comparing various portions of the interview on similar topics) throughout the interviews (initial and follow-up), concern for possible early-onset dementia was necessary in analyzing the data.]

Congruent with the resident’s preference to remain active, the CNA provided a more specific description of the resident’s desire to walk.

She likes walking, because not everyone (other CNAs) walks her…um, so she enjoys it when I do get a few minutes and we can take a walk around the unit or whatever, because she doesn’t, you know, there’s so…everybody is so busy…I try and do it at least every day so…she enjoys that.

The CNA’s comments exhibit congruence with the resident’s desire to remain active by participating in outdoor activities as well. Also, the CNA recognizes that the resident “enjoys” the activity. While confirming the resident participates in outings scheduled by the facility, she points out the challenge to supporting the resident’s desire to walk.

…she’s also gone at activities… if I had more time I might not meet up with her…cuz she’s gone and she’s able to go on the outings and stuff so sometimes she’ll go out and to the restaurant with the activities, so it’s not…we don’t always line up. I try and do it like at the end of the day when I got time and I know she’s maybe just getting up from a nap.

But she acknowledges that scheduling walks is difficult since “…there’s forty other residents, so…” There is a desire and willingness by the CNA to support the resident’s preferences but the CNA’s ability to support the preference can be challenged by the
competing demands the caregiver faces. Recognizing these competing demands may be a source of the resident’s perception that she fit into a schedule determined by the CNA.

In another segment of the interview, this perception of competing demands is not expressed regarding outings or walking, but instead with respect to bathing options. The resident when asked whether she had a choice regarding when she receives a shower stated, “No…they…[inaudible] well, you’re going to get your shower today.” When asked how important it was to her to have a choice she stated, “I would like having a choice.” Just prior to making the previous statement she explained: “Well, I don’t have a choice. I just do what they have for me.” The CNA indicates the resident needs help bathing and when asked if she has preferences around bathing states, “Nope, she’s not too picky.”

During a follow-up interview, the caregiver provided more detail to her perception of why this resident’s preferences (and other residents’ preferences) were important or had meaning for the resident.

“This think it’s important cause to an extent it helps them maintain their independence and their, um, I don’t know, like, I don’t wanna say power, but it makes them feel like their in control. So, by me doing what they like after they’ve told me that’s what they like - I think... they feel some sort of control. That they have control over their life a little bit, cause, you know, you come in a place like this and you’re eating sleeping, going to the bathroom on somebody else’s terms.”

In the context of this statement and previous content regarding the resident’s preference, there appears to be an underlying sense that the desire or willingness to support the
resident’s preferences is subject to competing demands or the capacity of CNA to manage the responsibilities that can interfere with supporting resident preferences.

**Summation**

This dyad provides a familiar theme compared with the other dyads, but does so in a more clear and compelling way. The resident has clear preferences that she is able to act on (participating in outside or inside the facility activities), and maintains a long-standing desire to remain active. The meaning the resident ascribes to remaining active is that she would “…go nuts,” if she had to sit still all day, that she “…cannot sit still like some people here.” Yet in terms of specific preferences or choices around bathing she states that she “…does not have a choice.” This aspect of choice appears to be tied more to timing than on type of bathing suggesting an influence of the facility’s structure rather than the CNA’s desire or willingness to support the resident’s preference.

Another aspect unique to this dyad is the willingness of the resident to accept (from the researcher’s perspective) the schedule of the CNA over her own personal preference. The resident, described by the CNA as “…not too picky,” was waiting for a shower when the researcher first approached her about participating in the study. She was dismissive about the wait and would joke about it, but it was clear that this was not her preference. Still in her nightgown and waiting meant she would be unable to participate in resident activities. Whether a resident is demanding of her/his preferences or willing to accommodate the CNA’s other demands in lieu of her/his preferences indicates the resident’s disposition may play a role in whether or not the resident receives timely support of her/his preferences. For example, if a resident is demanding, the CNA may be more inclined to satisfy the resident’s preference because the resident’s demand, unmet,
may negatively affect the CNA’s other obligations. A resident willing to accommodate the CNA’s other demands may provide the CNA with the needed time to manage other obligations without the distraction of satisfying the accommodating resident’s preference.

Dyad 7

The resident, a Caucasian female, is 85-years-old and has a high school diploma with additional training as a dental assistant. She shares a room and has been residing at the long-term care facility for one year and six months. The resident has been in a long-term care facility before. The resident has a resonant voice and is direct and clear during the initial meeting for this study. She spoke with confidence and authority and was accommodating in her busy schedule to make time for these interviews.

The certified nurse assistant is a 42-year-old Caucasian female who is married and has had some undergraduate schooling. She has been working at this particular long-term care facility for three years and two months. While this is her first experience working in a long-term care facility, she has also had 19 years of experience working in intensive care units as a medical assistant.

The following are areas where the resident and caregiver’s interviews overlapped, titled “congruent themes” followed by those areas where the interviews did not overlap titled “incongruent themes.”

Congruent Resident and Caregiver Themes – Experiential: describes herself and is described by the caregiver as independent, limitations and challenges the resident experiences a result of physical illness, comments regarding resident’s perceptions of staff and the facility, resident’s
relationship with other caregiver, issues and concerns with roommates.

Practical: N/A

**Incongruent Resident Themes** – Experiential: resident views on spirituality. Practical: outings, dressing and maintaining clothes (washing and ironing), meals, reading, medical needs.

**Incongruent Caregiver Themes** – Experiential: general comments on contact with intimate relationships, personal experience as a person with a family member in a long-term care facility. Practical: personal hygiene.

After a review of the emerging themes, a particularly present theme for the resident was independence. While the CNA acknowledges the resident as being independent, it did not stand out as a congruent theme since the CNA focused more on the resident’s personality rather than the meaningfulness of the resident’s desire to remain independent. The resident describes herself as “…what they call independent. (CNAs) don’t really have to do a lot for me. She expands on her independence by stating that the caregivers describe her as …a breath of fresh air.” She clearly identifies what her independence means to her and in particular, her remaining independence in the following quote:

“I’ve given up a lot of my independence and what little bit I got left, I’ll be goddamned, I’m not going to give it up. I’m going to continue to do it till I can’t do it.”

The resident provides a context for her acclimation to the site. She acknowledges the significant loss of independence she has experienced, though uses the phrase “given up a
lot of independence.” The phrase suggests a relinquishing of independence, not that she has lost the ability to be independent. It is possible, however, that her sense of independence is more about place than ability to act independently. As previously noted, she describes the various independent tasks she is still capable of performing such as folding her clothes, being able to go to the dining room without help, doing her own hair, etc. Autonomy in this instance appears to be expressed less in a preference, but in the absence of a preference. She sees herself as still is able to act independently in the facility and refers to her independence as “what little bit [of independence] I got left.” Her diminished independence indicates, for this resident, that independence is more than the ability to do things; it is also the context or place in which the independence is experienced or expressed.

Staying independent has required the resident to make adjustments, particularly with respect to how much she exerts herself. She indicates that she would push herself in the beginning but found this had serious ramifications with respect to her health. She states: “I do not push myself anymore. I come back from dialysis…there’s sometimes I can partake of the activities that they’re gonna have and there’s other times I don’t, but they know if I say ‘nope,’ they don’t bother me.” She indicates a desire to maintain the same level of activity after dialysis, as she was capable of before dialysis. The preference may still be to participate in activities, but she is no longer willing to “push” herself, and indicates that the staff understands not to “bother” her to participate. She maintains independence by deciding not to participate in activities at the facility.

The CNA describes changes in the resident’s health (especially those associated with dialysis) as having a “very big impact” on the resident. The impact is particularly
evident in the resident’s food preferences since, “…she can’t eat solids, …maybe soup or a cup of tea, …sometimes not even that.” She further describes the impact:

“…she’s very independent, you do nothing for her. Except for when she’s sick. …you might have to give her ice, or make her bed.”

The resident also describes additional challenges resulting from the adverse effects of dialysis treatments, particularly stomach cramps: “when I got ‘em, forget it. … and you feel sick… So when I come back if I don’t feel real good I just plain get undressed and crawl right into bed. …and sleep it off. …sometimes it runs 3 or 4 hours, sometimes it can be two days. You never know.” The CNA’s content is congruent with the resident’s:

“…when she comes back in [after dialysis], it’s really affected her. She gets the stomach cramps, or she starts with the dry vomiting. Then you can see how frail she is.”

The resident’s physical response to dialysis and physical limitations already present are expressions of frailty which fit prior definitions of frailty from the literature (p. 13-15) and in particular the clustering of physiological components that are present with this resident (Ferrucci et al., 2004). The aftermath of dialysis treatment further challenges this resident’s ability to maintain her previous level of activity and independence. For this resident, increased frailty has a significant impact on the ability of the resident to maintain desired preferences and a desired level of autonomy.

At one point in the interview the resident describes family and acquaintances that have stayed or are currently at the facility. The resident’s sister was at the same facility at the same time as the resident, and she also describes a man she has known since childhood becoming a resident. The CNA’s comments regarding the resident’s view of
the facility is congruent with her sense of community, of having familiar aspects of her small-town background. The CNA acknowledges that the resident “…came from a very small town where everybody knew everybody.” She points out the resident’s preference for gossiping and placing herself in the center of the social environment at the LTC facility.

“She likes to gossip and be in the midst of everything. And she doesn’t miss a trick. She literally will only sleep a certain amount of time, and at night, she is up, like up, busy bodying. Like talking to the staff. If they have a party, she’s part of it. Like… but she was always like that on the outside.”

The content suggests that the CNA has personal insight into the resident’s past and that the active nature of the resident’s engagement with the staff is a continuation of previous aspects of her life. In addition, the pejorative terms “gossip” and “busy bodying” suggest a critical view of the resident’s behavior. While the resident’s perceived behavior can be viewed as reflecting the meaningfulness in how the resident views her surroundings and her engagement with staff and residents it is not clear that the meaningfulness reflects a continuation of her previous home life. The resident is inclined to engage socially with staff as she reveals in the following interview quote:

“…one of the girls that works here [at the LTC facility], her daughter … they had a contest [in ballroom dancing], [and the daughter] made it to the finals so she said, ‘…would you like to go?’ I said, ‘I would love it.’”

While it is possible that the resident sees her involvement with staff at the LTC facility as a continuation of her prior life, it may not be in the same context that the CNA describes. There is content from the resident’s interview that suggests that the continuation of her
prior life is supported by her desire and willingness to remain engaged with the world around her. She describes her childhood, the feeling of having had a wonderful childhood and marriage and she feels fortunate that she is still able to remember much of that time. Her sense of no longer being able to remain at home is part of the adjustment she has gone through. It is also clear that, on reflection, her sense of her life was that it was a good one and that it is impossible to expect that to continue at the LTC facility.

**Summation**

While the resident in this dyad indicates a strong desire to maintain her independence, congruent with the CNA’s perception of the resident, there is an acknowledgement that it is what remains of her independence, rather than a continuation of her prior independence. This adjustment of perspective suggests that autonomy for this resident lies in what she still has control over. For example, she makes her own bed, a task typically performed by the CNA, suggesting that the act is meaningful and perhaps symbolic of her prior independence. When the resident experiences physical setbacks (e.g. reactions to dialysis) she adjusts again and puts aside her desire to remain active.
CHAPTER 5 – Theoretical Models

Introduction
The use of a phenomenological perspective (a field of philosophy and theoretical viewpoint) in this study indicates an open-ended descriptive process rather than a theory-driven process (though phenomenology is theoretical). As a result, discussion of theoretical models and how they relate to the concept of autonomy as described by the data collected is an ex-post application. This distinction is important because the starting point of this study was not to test a theory or theories but rather to understand and provide a description of the phenomenon of autonomy as experienced by long-term care facility residents.

Salutogenic Model of Subjective Well-Being

As stated in section on theoretical models, Schneider et al. (2006), used a salutogenic model of subjective well-being (Antonovsky, 1996) to argue that even in the midst of declining health, older adults’ subjective well-being remains constant. The model's foundation is defined by an older adult’s “sense of coherence” (page 851), predicted by the following conditions:

- The individual’s world is comprehensible, meaning her/his internal and external world is structured, predictable, and explicable.
- The individual possesses the resources to manage external and internal demands.
- The individual finds value in engaging and managing these demands.

Data collected for this study supports the condition that “the individual’s [resident’s] world is comprehensible.” Each resident interviewed understands the
structure of Lorraine; the structure imparts a level of predictability, so they are able to explain these aspects of the facility. For example, one resident includes humoring the CNA who enjoys mixing and matching the resident’s jewelry and clothes to find a pleasing combination, in her morning ritual of getting dressed. Although this process is unnecessary to the resident, she understands it as an extension of her dependency “…I’m like a baby, which is all right.” Like this particular resident, other residents’ internal and external worlds appear manageable though these (internal/external) worlds may at times be at odds.

Incongruence between the resident’s internal and external world is one area where data suggests a challenge to well-being, while also highlighting the challenges of balancing maintenance of internal preferences with external realities. One resident indicates that choosing his bedtime is “very important” and the resident’s matched-CNA reinforces his resolve in having things “…on his schedule and his schedule alone.” At the same time, conflicts between the resident’s bedtime preference and the needs of other residents challenge his ability to have the bedtime he prefers. He recognizes that his preference can be compromised by his dependency on the staff and the competing demands for staff assistance.

Even when there seems to be a discrepancy between the resident’s internal world (e.g. the resident believes that a caregiver must knock and be acknowledged before being allowed to enter the his or her room) and external world (a caregiver was observed entering without knocking or being acknowledged by the same resident), the incongruity appears to be manageable or acceptable. Entering the room without knocking or waiting for acknowledgement may be a predictable feature of how caregivers behave in the
facility. The preference for the predictability of the caregiver’s behavior may replace the resident’s preference for a different behavior from the caregiver. Data also indicates the necessity of a predictable external world to many of the resident participants.

The importance of predictability with regards to resident preferences emerged from the data as well. The sequencing of morning routines according to the preference of the resident was displayed in a number of dyads, for example; what pieces of clothing (socks, shirt, pants, etc.) went on a particular resident first, the physical location where shaving took place in one resident’s morning routine, and the sequence of events that played a critical role in one resident’s back rub.

Incongruence between the resident’s internal and external world is one area where data suggests a challenge to well-being but also highlights the challenges of balancing maintenance of internal preferences with external realities. One resident indicates that choosing his bedtime is “very important” and the resident’s matched-CNA reinforces his resolve in having things “…on his schedule and his schedule alone.” At the same time, conflicts between the resident’s bedtime preference and other residents’ needs challenge his ability to have the bedtime he prefers. The preference can be compromised by the resident’s dependency on the staff and the competing demands of the staff.

Each resident expressed finding value in managing internal and external demands. One resident describes his frustration with how staff clean and straighten his room. For this resident, it is important that the things he uses in his room have a place and are accessible to him. Regarding the belongings, he describes his conversation with the CNA as follows: “Wherever they are now, that’s where I want to see ‘em.” He describes the CNA’s response as, “I thought it would look better [there].” His perception of the ability
to act autonomously with respect to his belonging is for them to be “…where it’s easier for [him] to get at.” Control over his belongings follows Andresen and Puggaard’s (2008) concept of autonomy as the older adults’ control over their choices. The resident’s preference finds value in his belongings being in a consistent and predictable place that allows him access. He describes his willingness to engage his CNA to ensure his preference is maintained.

Health Promotion and Long-Term Care

Antonovsky (1996, p. 12) argues that health promotion should be viewed with respect to “…value rather than in market-oriented terms.” The terms that consistently influence research and practice are: cost-effectiveness, cost-neutral practices and cost/benefit ratios. Limited health care dollars stretched to cover growing health care costs put an even finer point on these research and practice concerns related LTC. Yet taking a resident-centered view of long-term care, focused on autonomy and its influence on subjective quality of life, requires a shift from concerns related to cost of care to concern for value of care. While such a shift should not ignore the importance of costs related to supporting resident autonomy, it does suggest that the outcome of supporting resident autonomy is related to valuing the experiences of the resident. The result of a focus on value of care for the LTC resident may include outcomes similar to Langer and Rodin’s (1976) findings of improved social participation, alertness and happiness.

Modified Labeling Theory

Upon comparing the modified-labeling theory and resident quality of life measure, there was an overlap found between dignity, relationships, and autonomy from quality of life (Kane, 2003), and devaluation, and loss of power within the modified-
labeling theory (Link et al., 1989a). Examining the data collected for this study in relationship to these subcategories (dignity, relationships, autonomy, devaluation, and loss of power), it is possible to see how the resident and certified nurse aide experiences challenge or support the modified-labeling theory model.

Review of the interviews recorded for this research raised challenges to dignity, relationships, and autonomy being taken as key components of resident quality of life in long-term care settings. Kane (2003) states that dignity reflects a domain of quality of life among residents that connotes worth and respect, something which is challenged when residents “feel belittled, devalued or humiliated” (p. 2). Devaluation, as defined by modified labeling theory is the first step in a process of societal conceptions regarding what it means to have a certain label (such as “LTC facility resident”) and how these conceptions become relevant to self (step 2). Labeling can lead to secrecy, withdrawal, or positive efforts such as education (step 3). It is possible that it could also (skipping step 3 and going right to step 4) lead to negative consequences for self-esteem or social network ties leading finally to (step 5) “vulnerability to a new disorder” (stress, depression, anxiety, etc.). Alternatively, the process could result in “not being labeled,” and therefore no impact (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989c, p. 402).

On reviewing the data, there did not appear to be an overt expression among the residents of feeling labeled, or experiencing the perception of being viewed as different, or having been devalued. In contrast, there seems to be an effort by a majority of the residents (to lesser and greater degrees) to assert themselves as autonomous individuals. In one instance a resident gently patronizes the certified nurse aide helping her pick out clothes for the day:
“…she [the CNA] enjoys me ‘cause…I’m like a baby, which is all right (laughs). She enjoys picking out the clothes and the jewelry. She loves to get into jewelry and holds it up like this (demonstrates holding up different jewelry) you know, you got brown and green, tan…she likes to pick out the colors. Sometimes it takes a little while but I let her do it anyhow.”

The long process of picking out clothes and jewelry is perhaps more than the resident wishes to be involved in or is more than she would have invested if able to do it on her own. That the CNA “…enjoys picking out the clothes and the jewelry” also reinforces the sense that the process is as much to benefit the caregiver as it is for the resident. The resident states that she is, “…like a baby” and appears accepting of her situation.

Another resident purposefully maintains little interaction with the certified nurse aides by washing and dressing himself (though he does require some assistance with showering) stating, “I don’t depend on anybody.” The CNA describes the resident/CNA interactions as, “he (talks) with us like were just like his friends or a family member, not like we’re…not like we’re here to help him.” This description suggests the resident challenges the care giving role of the CNA (as it relates to the resident) downplaying or neutralizing the caregiver role of the CNA. Neutralizing the caregiver’s role may suggest that the resident views aspects of the LTC facility as potentially having a negative impact on him. As a result, this may be the resident’s way of avoiding the label of “patient” or someone requiring care and therefore, not susceptible to the devaluing outcome associated with the label.
Theory Summation

Of the two theoretical models, the salutogenic model of subjective well-being provides the best fit, when applied to the data collected. Resident interviews revealed a number of instances where conditions of the model were supported by data. One aspect implied by the model and pertinent to LTC residents is that the individual is successful in managing the conditions of the model. Successful management may not always be the case for each resident across a myriad of personal preferences. A given resident might be successful overall in managing preferences where support from a CNA is required yet unsuccessful in other areas (e.g. caregiver knocking before entering the resident’s room). These preferences may also carry varying values to the resident suggesting the resident’s inability to manage aspects of her/his external world might be seen as minor disappointments or major loses.

While there were instances suggesting self-labeling, there does not appear to be clear support for the theory among the interviews collected. In both instances the resident implies the sense of being perceived as different from how she/he actually is (like a baby, or a person who does not need help). The response, in both cases, is a form of active engagement that does not suggest devaluation or suggests resistance to the label.
CHAPTER 6 – Discussion

Limitations

Pringle, Drummond, McLafferty & Hendry (2011) suggest that interpretive phenomenological data analysis presents important limitations. While allowing the individual’s voice to emerge, the small sample sizes that are typical of a phenomenological research method indicate findings that are only applicable to those participating in the study. The resulting limitation precludes any generalization to other individuals or groups. This descriptive study includes all residents that met the inclusion requirements for the study and agreed to participate. Other residents within the same long-term care facility may have very different experiences regarding preferences and the meaning each ascribes to those preferences. In addition, caregivers who were not interviewed but may have significant interpersonal interaction with various resident participants may have different impressions of a participating resident’s preferences and the meaning associated with those preferences. In other words, two caregivers working with the same resident may have different understandings of the resident’s preferences and the meaning the resident ascribes to those preferences. The difference in understanding suggest another CNA not interviewed for this study might describe with greater congruence the resident’s preferences and the meaning associated with those preference resulting in a different dyad analysis then presented here.

Because the study was conducted in a single long-term care facility, the data collected is only descriptive of residents within that facility. It is possible that residents at other long-term care facilities may recount different preferences and meanings ascribed to those preferences. That said, it is the researcher’s contention that a single-site study of
autonomy is actually preferable since the inclusion of multiple sites might indicate the need for comparison of facilities, suggesting an ethnographic or grounded theory approach. In addition, a number of the residents interviewed were private-pay, indicating those residents had financial resources available to cover the cost of staying at the facility that may also carry expectations that their preferences will be met. One CNA provided the following description of one resident interviewed who is described as private-pay:

“…and they pay a lot of money to live here. So some people with that perception, they feel like, okay, you’re their maid, you’re…this is a hotel… ‘cause I’m paying privately…chop chop, snap snap…what I want is what I’m gonna get’.”

While the resident paying for her/his own private room cannot be assumed to influence preferences and the meaning these residents ascribe to those preferences, it may play a role in resident assessment of the reasonableness or validity of a preference.

The study was originally intended to be longitudinal, which would have provided important insights into how the resident manages preferences over time. The research question (particularly questions 2, 4, 5 & 6) presented in this study reflect this initial research design. These questions imply time change or causality. Resident and CNA interviews did contain references to time changes and suggested causality and efforts have been made to describe those portions of the interviews but the design of the study precludes demonstrating change/causality directly.

From a positivist perspective, establishing researcher credibility is fundamental. This credibility is attached to and challenged by the intuitive nature of the researcher’s relationship to data collection and analysis. Throughout the analysis process the researcher has utilized expert feedback, and transparency in data presentation (especially
in documenting the analysis process), etc., in order to provide ample evidence of the process along with a clear linkage of research design and execution to the data analysis and findings. It should be stated that previous efforts to operationalize phenomenological methods into prescribed stages eventually acknowledged the need for flexibility in all aspects of those studies (Giorgi & Giorgi, 2008; Smith, et al., 2009 as cited in Pringle et al., 2011). This flexibility is a critical component because it allows the method to be true to the research questions; it provides the ability to examine “convergence and divergence” in data collected, rather than focusing on “commonalities” (Pringle et al., 2011, p. 22). The convergence and divergence of data within individual participants’ own account as well as between participant and caregiver dyad responses is, in the end, a strength of the method. This (the flexibility of the researcher in analyzing data) can be described as a limitation, but also a strength, in that it provides flexibility in allowing the researcher to be guided by the data collected.

**Research Challenges regarding Autonomy**

Utilizing a phenomenological perspective for this study was the most logical choice for understanding autonomy as a lived experience among older adult long-term care facility residents. Yet phenomenology provides a singular philosophical perspective that has evolved into two distinct research approaches. Husserl argues that phenomenological inquiry is in the service of a *descriptive* process while Heidegger asserts an *interpretive* approach (Reiners, 2012). It could be argued that the two are not mutually exclusive though recent arguments suggest they are (Reiners, 2012). This exclusivity is prefaced on Husserl’s argument that the researchers preconceived notions or biases can influence the collection and descriptive analysis of data (Reiners, 2012).
Heidegger, however, proposes that these preconceived notions and biases are a natural, necessary part of the process of collecting data and that interpretation of said data requires utilizing one’s prior experience and knowledge.

**Research Questions**

**How do nursing home residents perceive/define autonomy?**

Reviewing the data, resident autonomy (as expressed by preferences) appears to be a complex, subjective, durable, transitory, and at times rigid phenomenon. A resident may have a clear sense of preferences (and, therefore, autonomy) which are no longer manageable (e.g. bathing, eating, reading, moving about independently, food preferences, etc.) or are no longer relevant (e.g. making one’s bed, ironing, cooking, etc.). In some instances, a resident may still practice certain behaviors (e.g. making the bed) even though CNAs are available to do this for them. The meaning of making the bed may be complex in that it gives the resident a purposeful opportunity to remain active, or there may be a particular way the resident prefers the bed to be made, so that it allows her or him to get into bed on her/his own, or the sheets are arranged, in such a way that provides additional comfort. The preference (in these instances) is purposeful.

The incongruities within the observed dyads provide important data for describing autonomy for some residents. While a resident may describe her or him self as independent, this self-perceived independence can be undercut by institutional characteristics that treat the resident’s preferences as being second to the CNA’s ability to support a particular preference. There is also the suggestion (as seen in dyad 1) that a resident may maintain the belief that she/he is an autonomous person, even when this belief is challenged by contrary evidence. The finding parallels the Berlin study’s finding
that older adults’ self-perceived health can be more positive than objective measures of their health might indicate (Borchelt, Gilberg, Horgas, & Geiselmann, 1999). As a result, self-perceived autonomy may be resilient, even when faced with contradictory experiences. These findings can also be described as a negotiated autonomy, where the resident’s acquiesced preference (accepting a bedtime other than the preferred time due to caregiver availability) replaces the resident’s actual preference.

It is important to note that “choice” is a term employed in literature as an expression of autonomy (Andersen et al., 2009; Andresen & Puggaard, 2008; Barkay & Tabak, 2002; Clark, 1988; Collopy, 1988; Dreyer et al., 2009; Dworkin, 1988; Lidz et al., 1992; Moody, 1996; Tobin, 1991). The word connotes an anticipated or implemented action, since a person may wish one outcome over another, or make a choice and, in implementing that decision, be autonomous. Yet, according to data collected for this study, choices may be limited or there may be no choice options at all. If a resident has a preference for a specific bedtime, for example, but the only choice for bedtime is the window when the CNA is able to help the resident to bed, is this bedtime decision completely autonomous? The resident going to bed at a time decided by (or agreed upon with) the CNA and not determined solely by the resident still indicates a choice, but not necessarily a choice associated with resident autonomy. Choice and the power to act on a choice either on one’s own or with assistance, appear to be a more accurate description of autonomy, particularly in long-term care. The term “choice” constitutes a partial expression of autonomy (“choice,” n.d.). The word choice is synonymous with preference, defined by Merriam-Webster as the “power or opportunity of choosing” (“preference,” n.d.).
Examining Collopy’s argument regarding polarities associated with autonomy, “decisional versus executational,” autonomy indicates that a resident may be able to make decisions regarding preferences, regardless of the ability to “implement them or carry them out” (1988, p. 11). The author further argues that autonomy is nullified when the ability to execute a preference is “diminished or lost” (Collopy, 1988, p. 11). Yet the data from this study suggests an alternative perspective; while there is an increased risk of a resident not realizing a preference due to her/his inability to execute that preference, the preference may be altered or shaped to accommodate the limitations the resident is experiencing. For example, the resident in dyad 5 describes a preference of her life prior to being placed in LTC stating, “I miss the outdoors tremendously… Fishing, boating, all outdoor activities.” Later in the interview the resident provides a further explanation:

“…and things that I had done all my life, even though I’m old…I mean I still did it…I went fishing with my son, with his family. That was a big part of our whole spring, and summer and fall…fishing and boating. When I couldn’t get into the boat anymore…to me that was a sad day.”

A preference (being outdoors) or an aspect of a preference (fishing as part of being outdoors) that is a longstanding preference of the resident’s life can continue, though the turning point for the resident appears to be her ability to “get into the boat.” Not being able to get into the boat indicates a potential end to the preference and the sense of lost autonomy. That one aspect of the set of preferences (to be outside, in a boat, fishing) is no longer possible does not preclude that other aspects of the preference are still possible. This resident describes a recent fishing trip hosted by the facility. So, even though the resident has lost the physical ability to participate in an important aspect of her
preference, her autonomy does not appear to be “nullified” as Collopy (1988, p. 11) argues; instead options become available that allow the resident to adjust to limitations and retain aspects of the preference.

Another example of how autonomy is defined by residents interacting with CNAs came in a situation related by the resident in dyad 1. The resident has difficulties (or is unable in certain instances) washing certain parts of his body. In this episode, the resident describes a CNA (not identified as the CNA in this same dyad) as having not properly cleaned him after a bowel movement.

“So they’ll say, ‘Yeah, here’s the rag, all clean.’ The next girl comes in to wash you up for the night and [says] ‘Who did that?’ I said, ‘Hey, the aide there that took care of me.’”

The description “yeah, here’s the rag, all clean” indicates the CNA is displaying a soiled rag, which means the resident was cleaned after the bowel movement. There are two aspects of autonomy related to frailty present in this description. First, the resident is unable to clean himself after a bowel movement. His preference to be cleaned is not supported by the caregiver, and (in the second instance of frailty-related autonomy) the resident is unable to negotiate being adequately cleaned until the evening caregiver arrives. While it can be assumed that a person wishing to be cleaned following a bowel movement is expressing a preference (health considerations/personal comfort), the resident’s inability to perform the task compromises his ability to act autonomously.

Being dependent on the CNA to execute the resident’s preference makes it no less a preference, but the inability to get help from the CNA to execute the preference erodes resident autonomy. Frailty, which stops a resident from executing a preference, places
the resident in a vulnerable position of needing the help of the CNA to realize certain preference.

**How does the meaning residents assign to self-perceived autonomy change as residents’ become frailer?**

Some residents acknowledged that their preferences change when they are not feeling well, while others push themselves to continue maintaining preferences. Pushing themselves may include forgoing medication that would relieve pain (because of the incapacitating impact of the medicine), in order to maintain a preferred level of activity. The data suggests that for some residents, preferences are quite durable and it was the expression of autonomy that became fluid and subject to change. In another example, the meaning that the same resident ascribed to autonomy appears to have changed (e.g. what the resident could do before being placed in LTC and what the resident can physically do after placement). Therefore, it may be more accurate to state that a resident’s ability to perform or act on preferences, rather than the preferences themselves, is tied to the meaning the resident ascribes to self-perceived autonomy.

In determining this meaning there also appears to be incongruence between what the resident believes to be an expression of her/his autonomy and how that autonomy appears to be realized. One resident described having clearly informed CNAs that they must knock and be invited before entering his room, which represented a preference for privacy. During the interview with this resident a staff person entered his room while knocking, contrary to the resident’s preference, suggesting that the perception of autonomy or how the resident sees himself as autonomous is fluid. This internal sense of autonomy appears contrary to the external expression of autonomy or how the preference is actually enacted or acted upon. Autonomy can also appear as compartmentalizing
preference, where a person may no longer be able to enact the full preference and accepts
a partial expression of the preference.

In some instances, a resident might attempt to balance her/his desire to remain
autonomous or to act on preferences even though she/he may have lost the ability to act
due to increased frailty. In one instance a resident describes a longstanding enjoyment of
polka music:

“...I used to like to go dancing and, uh, polka dancing especially. But [I] can’t do
that anymore, or any type of dancing, unless you could find a way to learn it in a
wheelchair. …there’s two polka shows on [the radio]. I call in and make requests
for the different people [other residents]. Well you oughta see how they enjoy that
there. They come by my door, and start clapping and kicking their feet up and
down.”

Efforts to maintain aspects of longstanding preferences may take on new meanings or
expressions that satisfy new preferences. The resident sees his polka music as a way to
“help out the residents here.” Data also suggests that changes in their ability to do a
certain thing (or do it at the level they are accustomed to) may lead them to moderate
their behavior.

Lastly, subtle changes in preferences may emerge as the resident experiences
increased frailty. For example, one resident describes the beginning of his morning
routine in the following way: “...sometimes they just come in, in the morning and, uh,
immediately, they’ll take the covers off ya, and, uh, then I’ll get real cold, and they just
leave the covers off. I would prefer that they would do it more slowly.” The resident
goes on to explain that when he is not feeling well the sensation of being exposed to the
cold is even more uncomfortable. Increased frailty at times may cause this resident to be particularly sensitive to his environment. When asked if he is able to talk with the CNA and request they go slower, he stated that he did tell them his preference and they complied with his wish.

**How do nursing home staff members perceive resident autonomy?**

As Schermer (2002) points out, those in the medical community may see an ethical conflict between the resident asserting her/his autonomy (especially a preference that is a direct challenge to the provision of care) and care giving staff not causing harm. In addition, staff perceptions of the resident as autonomous individuals may create unintentional impediments to the assessment and management of residents (Sarkisian & Lachs, 1996). Combined, these arguments indicate that care giving staff may need to acknowledge potential conflicts that can place pursuing resident care over resident autonomy or stress resident compliance as a priority over resident autonomy.

How a CNA views resident autonomy may be constrained by the CNA’s mandate to provide care to that resident. The mandate may also be perceived as (or could actually be) direct opposition by the resident to the CNA’s efforts to provide care. One such resistant resident was described in dyad 1:

“He was verbally abusive at times to the staff, …but working with him over the past…I think he’s been here for two years …he’s turned into a cupcake, as I call him now. So he’s more compliant with things…and he realizes that we are here to help him, and when I make suggestions, usually it’s because it’s for the best. Like if he’s sick, or, you know, ‘…well maybe you need to go to bed and take a nap or
maybe you should try some soup or have some tea.’…and…he’s more compliant with it than before, where it was just “no, no, no, no, no, no, no.”

This resident had entered the facility following a major health event. He described his wish not to have extreme measure taken to save his life but states that his son (serving as his health care proxy) agreed with the physician’s wish to provide life-saving treatment which has left the resident in a great deal of pain and discomfort.

A resident asserting autonomy as a direct challenge to care is also apparent in dyad 3. The resident describes himself as someone who does not “depend on anyone” in the facility. While the assertion does not appear to lead to a confrontation of the resident by staff, requiring the resident to accept care, it clearly changes the CNA’s sense of her role with the resident. The CNA even goes so far as to say her conversations with this resident are more akin to those between “friends and family members” than a CNA and resident. The CNA appears to have accepted a non-caregiver view of her relationship with the resident and indicates that she understands that the resident “does not want to be here.”

One afternoon, the same research participant from dyad 3 was seen outside on the sidewalk, in a wheelchair, his head tilted back and to the side, apparently sleeping. It might at first seem odd and sad to see an older adult, outdoors, unattended and asleep in a wheelchair, as if the resident had been pushed outside and once asleep, left on his own, one did not know how much he enjoyed being outdoors, particularly in the sun. In the interview he stated, for example, “…summertime I go out. I’m outside every day, that’s why I got tan.” Taking various aspects of this resident’s self-described preferences, this scene should no longer seem sad and strange, as it depicts the resident acting
autonomously on a preference. Yet my initial reaction was a feeling of sadness and that I was seeing something odd. Recognizing a resident’s preference may cause discomfort in a caregiver and suggests, reflexively, the subjective nature of assessing resident autonomy and the importance of the resident’s voice in the assessment process.

**How do nursing home staff perceptions of resident autonomy change as residents become frailer?**

Considering the likelihood of a nursing home resident experiencing periods of greater frailty or impairment, the resident participants for this study were quite active, especially since they all required a wheelchair to move about the facility. The CNAs generally described active and engaged residents who may occasionally feel under the weather, but are still able to remain active. The resident who underwent regular dialysis treatments was prone to the most dramatic shifts or periods of increased frailty; her CNA describes her as “…a very sick lady.” But in describing the resident during these periods the CNA acknowledges:

“…she’s very independent, you do nothing for her. Except for when she’s sick. Then you need to get her – you might have to give her ice, or make her bed. Generally, she makes her own bed.”

The CNA describes giving minimal care to the resident (give her ice, make the bed) or care that would be expected rather than unusual.

In one resident’s life preferences and frailty intersected with regards to memory and one CNA’s perception of the role a preference plays in his treatment, she describes the resident’s preference for being shaved in bed. It is the CNA’s sense that the preference began with a previous caregiver. “I think it was easier for her in bed [shaving him]. She got him into that habit, so now he just thinks that it’s easier for everybody
[other CNAs as well], and he’s very sweet, and tries to make things easiest for us.” It is the CNA’s perception that the resident maintains the preference because it is a routine. The value of the routine is related to the resident’s memory and the role routine plays in reinforcing memory. “…sometimes, …they can’t quite remember what did or didn’t get done today. So they like to keep the same routine…in order to keep track of everything and make sure it’s all done.” The resident (from the CNA’s perspective) relies on the routine as a touchstone.

“…he’s at a point where he still knows when something has not been done and he’ll keep reminding, ‘are you going to shave me? Are you going to give me my glasses? Are you gonna…’ On the occasion when I go out of order, he’ll keep going back to that and making sure that I remember.”

**How do nursing home staff perceptions of resident autonomy influence/affect the nursing home residents’ self-perceived autonomy?**

The point of this question is to determine whether or not a CNA’s perception of the resident as autonomous or (non-autonomous) influenced how the resident saw her/his own autonomy. It was clear from the interviews that CNAs have a perception of residents’ desire to be in control, though the ability of a particular resident to be autonomous is sometimes challenged. For example, in one instance the CNA saw the resident’s behavior in a negative light, even though the resident was exercising her preference not to take a pain medication.

“…that’s a choice that she makes, whether to be in pain, function, or do something about it. Sometimes it’s just a simple as getting rubbed down with that Icy-Hot, and she’ll be stubborn and, ‘no, I’m gonna do without it today.’ Because
maybe someone on another shift said, ‘oh, you don’t need that every day.’ Well, yes, she does."

There were a number of instances where the CNA states what appears to be an objective observation (often generalized to the resident population) of a resident’s preference, which is actually subjective.

“He was non-compliant…so when you put those dynamics into nursing homes and things…there’s just, not good sometimes. You know, he shut people out…he would always be like…” get out…I don’t need your help... I can do this myself” and he knew he couldn’t, but it was just…I think, you know, working with them…the more difficult they are the more you do have to build trust…it’s very important to build trust with them.”

The caregiver describes an objective term (non-compliance) reflected in the resident’s behavior towards the CNA (“get out, I don’t need your help”) and the caregiver’s observation of the resident’s ability (“he knew he couldn’t”). Hughes (2008, p. 445 citing Haynes, 1979), defines compliance as the “extent to which a person’s behavior coincides with medical or health advice.” While the CNA describes the resident’s behavior in rejecting help, it is not clear (in-part due to lack of data) that the task was contrary to medical or health related advice. The CNA does link the resident’s behavior to his ability to trust the caregiver, a subjective perception of the resident’s view of the CNA. Regardless of the task or objective (help with activities of daily living) there is a subjective perspective in how this CNA interacts with each resident.
“…I mean every person is very different I find. I don’t think you find one resident the same, ever. …you may be a priest, a mother, a father, whatever you have to be for that moment to make ‘em happy is what you have to do.”

How do residents’ self-perceived autonomy and staff perceptions of resident autonomy compare over time?

[this question is a holdover from when the original study design which was longitudinal]

Autonomy

The decision making process and ability to make choices has been utilized to guide the development of nursing home measures to aide residents in maintaining autonomy (Kane, 2003). Tied to these efforts is a broader shift from viewing quality of life from an objective, health-related perspective to a subjectively perceived phenomenon (Peel, Bartlett, & Marshall, 2007). An argument has also been made that autonomy can vary from individual to individual and that assessment should therefore be done on a case-by-case basis over time (Cullati, Courvoisier, Charvet-Bérard, & Perneger, 2010). In total, the literature suggests that personal choice and control over choices supports resident autonomy and subjective quality of life.

Control over personal choices can (in some instances) be perceived negatively by caregivers. Over-assertion of resident autonomy can be seen as a direct challenge to medical caregivers who are ethically motivated to act in the best interest of the resident, particularly when personal choices are perceived as contrary to medical care (Schermer, 2002). While permanent control or restraining measures to reduce risk would deny a patient full autonomy (Sammet, 2007), residents may accept limitations to their ability to act autonomously because those limitations are generally seen as reasonable and just (Rawls as cited in Dworkin, 1988). Within this mix is the recognition that, for an older
adult nearing the end of her or his life, ongoing life experiences remain important (Steinhauser et al., 2006).

Autonomy is seen as having objective and subjective aspects (Tobin, 1991). The author refers to “objective” aspects as relating to efforts “to enhance self-determination through removal of manifest barriers and the subjective aspect referring to the latent, more personal experience of self-determination, of being in control” (p. 82). These definitions reflect what the author describes as an “assumption” regarding contemporary views of autonomy whereby self-determination and self-control require the resident participating in the decision making process (p. 81). These definitions may be applicable at the macro-level when seeking to define policy, but on a micro-level, the concept of objective and subjective aspects of preferences (as expressions of autonomy) appear to have different meanings.

The Oxford Dictionary defines objective as meaning that which is represented or considered without the influence of personal feeling (“objective,” n.d.), and subjective as that “based on or influenced by personal feelings, tastes, or opinions” (“subjective,” n.d.). Molyneux (2007) suggests that objectivists inevitably must acknowledge the “centrality of a subjective component to wellbeing” though combined theories (subjective and objective components) still indicate a subjective position. I argue that objective wellbeing requires neither a positive or negative perception. In others word, “objectively” my wellbeing would not be dependent on my attitude, yet a subjective sense of wellbeing requires “our attitudes of favor or disfavor” (p.568).

For the purpose of this study the researcher has identified aspects of autonomy indicating practical preferences and experiential preferences. Linking aspects of
autonomy to descriptors of wellbeing requires examining where these expression overlap. Practical aspects of autonomy appear objective in that they refer to those things which the resident enjoys doing such as reading, listening to music, going for a walk. Practical preferences also refer to the foods a resident prefers, the time she/he likes to go to bed or get up in the morning, etc. These practical preferences are finite in that they describe an activity or choice of a thing or behavior which the resident is capable of executing either independently or with the help of an assistant (CNA). Additionally, practical preferences are often linked to personal criteria. For example, a preference for reading the news is not limited to reading any newspaper or website, the resident may have a preference for a particular newspaper that provides a certain range of news and may represent a level of quality that is meaningful. The resident may also prefer local news over national or international news, suggesting that practical preferences can have subjective dimensions as well.

“Experiential” preferences are broad expressions such as resident preferences for being independent, active, social, etc. These preferences may at times embody practical preferences and as a result can inform a deeper understanding of the meaning practical preferences may hold. For example, independence, or the preference an individual may have for being independent may find this preference expressed through a practical preference such as being able to obtain a newspaper on her or his own or through a means of her or his choosing.

An example of the linkage between objective/subjective and practical/experiential preferences is provided by one resident who saw every aspect of his life discussed as some expression of independence and any limitation set by the institution as an
infringement on his independence. He describes his longstanding preference for “eggs over easy” and his consistent frustration with the facilities version he describes as “hard as a rock.” He acknowledges and dismisses the states/facilities argument that eggs cannot be served to residents undercooked, but argues that he can go out to a restaurant and order eggs the way he likes them.

“I’ve been eating the same things (unintelligible) eggs, all my life…75 years. I’m living, but they tell me I’m wrong.”

While eggs could be argued an objective or a practical preference, there is a subjective experiential aspect that is deeply rooted and defined by the meaning associated with how the eggs are prepared. Unique features of institutional living, for this resident, are contrary to his life prior to being placed in the facility. “Immediate Jeopardy” is a term used by the Center for Medicare and Medicaid indicating a crisis situation in which the health and safety of individual(s) (residing in a nursing home) are at risk (“State Operations Manual: Appendix Q - Guidelines for Determining Immediate Jeopardy,” 2004). A recent court decision in Texas overturned an Immediate Jeopardy citation of undercooked eggs which had included a $5,000.00 fine and suspension of the Medicare provider agreement (Mullaney, 2013).

**Phenomenology and Autonomy**

Two schools of thought guide phenomenological study: those based on Husserl’s epistemological perspective and on Heidegger’s ontological view. Central to Husserl is the concept of the “intentionality of consciousness” (Ricoeur, 1967). Intentionality is the mind directed toward an object or events (Reiners, 2012) resulting in thoughts, ideas, and emotions about these objects or events. Husserl later extended this mental process to
include the body as well. Giorgi (2009) states, “we can use the term subjectivity to encompass the body and the mind as the basic source of intentionality” (p. 184). Husserl believed that we cannot understand or describe a given phenomenon unless we examine the phenomenon from the perspective of the individual experiencing the phenomenon. This understanding is brought about by a descriptive process where any preconceptions or experiences the research may have of the phenomenon are placed to the side or bracketed, allowing the phenomenon to be revealed. By contrast, Heidegger argues that placing our experiences to the side is impossible and unnecessary and espouses an interpretive approach.

Central to Heidegger is the concept of existence or “being” where Husserl is focused on consciousness (Reiners, 2012). Heidegger espouses an interpretive approach that acknowledges the researchers experience and seeks to understand the meaning of the experience through patterns that embody the gestalt of the phenomenon (Dahlberg, Drew & Nystrom, 2008, as cited in Reiners, 2012). The choice of philosophical perspectives is dependent on the aim of research. For this study the researcher has chosen Husserl’s view since the purpose is to describe the residents’ experience of autonomy (as experienced through preferences) within the nursing home. It is not the intent of the study to understand how the residents’ interpret the experiences.

Following Heidegger requires the resident to interpret what the experience of autonomy or a given preference means to her or him. This presents a potentially difficult burden on the resident to examine a given preference for meaning within the context of the nursing home. For example, a preference may be getting up at a certain time of the morning but for the resident, interpreting meaning from that preference may be quite
difficult. In addition, the CNA may have little to go on in providing an interpretation of the resident’s preference, if an interpretation of meaning is the intent. Husserl’s descriptive approach provided a potentially clearer route to understanding autonomy. A descriptive process allows for the resident to discuss everyday preferences (morning routines, eating habits, bathing requirements, etc.). These descriptions can illuminate a resident’s control over ability to execute the preference, control over whether or not to participate in a preference and how this control is negotiated within the nursing home.

It is important to note that while a descriptive approach was used, residents did discuss the meaning of certain preferences or interpreted how aspects of the nursing home impacted a given preference. This happened naturally since the interviews were open-ended and residents’ guided the interview through their responses. This data was considered valuable and included in the analysis process.

**CNA Turnover**

A possible influence on caregiver understanding of resident preferences is caregiver turnover. The turnover rate for nursing home staff has been reported to be “as high as 71%” (American Health Care Association, 2003; U.S. General Accounting Office, 2001, as cited in Bishop et al., 2009, p. 611). Regional turnover rates provided by Center for Disease Control (“NNHS - Nursing Assistant Tables - Estimates,” n.d.) report a 40.9% turnover rate in a catchment area including the state where this study was conducted. Job dissatisfaction has been shown to be associated with staff who are considering leaving their job (Castle, Engberg, Anderson, & Men, 2007). A high rate of staff turnover may create an unstable environment for residents. Residents may pick up on CNA job dissatisfaction, and this may act as a barrier to fulfilling residents’ preferences. A CNA
not satisfied with her/his job may see the work with residents as burdensome. Residents may wish to avoid being a burden to the CNA and repress preferences or voicing demands for preferences.

The CNAs at Lorraine did not follow this national pattern. They expressed greater stability and satisfaction. The certified nurse assistants, at the time the study was conducted, had been employed at the nursing home from just over 1 year to 5 years with one CNA stating she has worked at the site for 12 years in various capacities before training to be a CNA. Each respondent described enjoying her job working with the residents, and in many cases CNAs saw the work as a calling or what they were meant to do. The following statement was typical of the CNAs interviewed.

“I get to interact with the residents and I’m a people person so…I’m not a…it’s not a good day for me unless I can make somebody smile and help somebody out. So, me coming in to work just feel like it’s something that I was meant to do everyday.”

It is possible that job dissatisfaction is related to dissatisfaction with administrative features of the institution and not working relationships with residents (it is important to note that none of the participating CNAs acknowledged dissatisfaction with their job). This may be a valuable area for further study. Does CNA interaction with administrative or institutional aspects influence interactions with residents?

**Potential Benefits**

As stated previously, one benefit to placing the resident at the center of the decision-making process is an improvement in the resident’s sense of autonomy, an important aspect of quality of life (Polivka & Salmon, 2003). Jang (1992) however,
found that significant differences can exist between resident and staff perceptions of autonomy, differences which may become more significant as a resident’s health declines and she or he becomes more dependent on staff for support. Increased frailty may, in some cases, reinforce a resident’s desire to remain autonomous. It may also have a significant impact on the resident’s perception of her or him self as autonomous an individual, particularly where increased frailty includes a functional loss that negatively impacts the ability to perform certain preferred tasks that are important to that individual. A caregiver’s perception of this change in frailty can also lead to changes in the caregiver’s interaction with the resident. The caregiver may respond to the resident’s physical limitations brought about by the increase in frailty while the resident may continue to see themselves as autonomous and able individuals.

While one might expect physical decline or an increase in frailty to affect an older adult's subjective perception of health, past research indicates that older adults (below the age of 85) possess a significant ability to reshape their reality (Baltes & Mayer, 2001). Reflecting on the data gathered as part of this study, reshaping of reality may be an outsider’s perception (that of the researchers) of the resident maintaining a self-perceived health that is a continuation of a pre-frail state. It is important to note that older adults in long-term care facilities were not the subjects of the Berlin study and a different subjective perception health may be present among older adults in institutional settings. It is also as possible that subjective perception of health is persistent and durable regardless of setting. Moreover, it is the interaction between a caregiver’s perceptions of the resident and the resident’s perception of her or him self that is at the heart of supporting older adult autonomy in long-term care facilities.
Policy Implications

Assuming the primacy of resident autonomy in long-term care and resident authority in determining personal autonomy and understanding the influences that support or challenge resident autonomy are critical steps to informing the goals of policies that impact resident autonomy. Of particular importance is when nursing home medical goals do not coincide with resident non-medical goals (Lidz et al., 1992). One finding of this study is the importance of resident and certified nurse aide interaction in supporting, challenging and in some instances defining aspects of resident autonomy. While it is the intent of current policy to provide caregivers a better sense of resident preferences (implementation of the MDS 3.0) it is not clear what the impact of this policy change has been.

Data suggests that there are limitations to the utility of the MDS 3.0 in identifying and providing guidance on how certified nurse aides should respond to resident preferences. At Lorraine access to the MDS 3.0 is limited to nursing and activities staff, and certified nurse aides do not have access. According to the certified nurse aides participating in this study, an informal process is practiced whereby certified nurse aides ask and interact with residents in determining resident preferences:

“Well, we tend to ask the residents initially. So the first week or two that they’re with us their routine, in the morning and evening, because you have a routine right through the day… But their general routine takes a little longer, because we’re still learning about each other. And they have to get to where they trust us to do things the way they want them done.”
The process may also include reviewing accessible patient documents (e.g. care plan) but even with this additional information there still appears to be a process that relies as much on the initiative of the certified nurse aide:

“I kinda read the care plan, ask a little bit, and then, I go down to the room at a time, (I try to do it at a time) when I’m not in a huge rush because of all the work that’s hanging over me so that I have time to talk a little bit and introduce myself and explain what’s going on…and you know, that sort of thing, just to, you know, just to sort of get a little familiarity before I jump in and start washing their bottom.”

Among participating certified nurse aides, length of employment at Lorraine ranged from 2 to 12 years. These CNAs seemed to enjoy the work and their interactions with residents, which is consistent with recent research (Homberg et al., 2013) stating the respect CNAs voiced for residents (p. 1).

**Implications for Social Work**

Gonyea (as cited in Berkman & D’Ambruoso, 2006, p. 565) argues that person-in-environment - a fundamental perspective in social work theory – provides a means for understanding “the importance of a place” in older adults' lives. A nursing home is an important place in the life of any nursing home resident, and providing an understanding of how nursing home staff’s influence residents’ lives is a task uniquely suited to social work. The distinct skills social workers possess as clinicians, program designers and policy advocates make them well-suited for assessing needs, providing social services, advocating on behalf of nursing home residents and providing solutions that address older adults’ experiences of nursing homes.
Understanding how older adult residents experience characteristics of nursing homes may also provide insight into how resident quality of life is influenced. Providing a better description of residents' experiences and the meaning older adults associate with these experiences can lead to important insights into how nursing homes can promote the quality of life older adults experience in nursing homes. It may also provide a deeper understanding of how current efforts to place residents at the center of the decision-making process in nursing homes are succeeding and where efforts and resources can be shifted to ensure better quality of life for older adult residents. The potential also exists for informing on how nursing homes and the policies that determine their shape, size and functions might be addressed to reduce older adults’ risk of stress and anxiety that can accompany a loss of personal autonomy and feelings of being devalued. A CNA can play a significant role in supporting a resident who is experiencing loss of personal autonomy. Supporting resident autonomy may require the CNA display empathy towards the resident’s desire to maintain autonomy and actively listen to the preferences of the resident. Empathy and active listening are skills embraced by the social work profession suggesting an interdisciplinary opportunity between social work and nursing.

**Intersection of Social Work and Nursing**

In 1911, an argument was made for the potential cost effectiveness of combining nursing and social work practices into what might be termed a “social nurse” (La Motte, 2012). Others pointed to the expanding responsibilities of hospitals requiring an expanding outlook for nurses and social workers “…on how they can adequately serve each other in the furthering of their common task of service to the patient” (Slater, 1930, p. 598). One aspect of the nurse/social worker relationship is the overlap LaMotte
identifies, viewed as shared roles that were not complimentary but rather redundant. Slater’s view suggests a mutual need between nurses and social workers; that one should serve the other. From a nursing standpoint social work can be seen as a valued contributor to patient care.

The social work profession plays an important role in nursing home care. The 1987 Nursing Home Reform Act implemented regulations ensuring facilities with over 120 beds employ a social worker (ORDP SSA, n.d.). Center for Disease Control statistics indicate fewer than 50% of nursing homes have more than 99 beds (“FASTSTATS - Nursing Home Care,” n.d.), suggesting social workers have a limited presence in nursing homes. Further compounding the issue, a nationally representative study of social service directors found that most nursing homes employ one social service staff member with half of those directors having degrees in social work (Bern-Klug et al., 2009). While the presence of the profession has been a critical step in providing important social services to residents their families and other nursing home staff, it is less clear what role social workers play in supporting resident autonomy.

Certified nurse aides are engaged in the process of supporting resident preferences but may struggle with competing demands in doing so. For example, if a resident prefers to go to bed at a specific time and requires help getting into bed, the CNA (if wanting to support the resident’s preference) must negotiate that resident’s preference with the preferences of competing resident bedtimes. It is also possible that the resident’s preference will not be met. In the dyads examined for this study, each CNA indicated benefiting from supporting resident preferences, suggesting CNAs’ capacity to meet resident demands may need to be examined.
The data from this study suggests that CNAs play a key role in supporting resident preferences. The process CNAs employ in understanding and responding to resident preferences is unclear. It appears that informal mentoring (peer mentoring by a senior CNA) is one aspect of training related to this process. CNAs who were interviewed often referred to an intuitive process playing an important role in understanding their residents and that this understanding is a critical component of supporting residents. One CNA stated, “well, when the residents are happier, it makes our life easier as well as the residents.”

A recent research page by the Social Work Policy Institute, a branch of the National Association of Social Workers, states, “…social work contributes to quality psychosocial care in nursing homes” (NASW, 2010). The website continues by describing the valuable skills social workers bring to nursing homes resident, staff and family members as “key to promoting improvement in quality of life domains” and resident autonomy as one such domain. The process by which social work can accomplish this includes:

“…building on their person-in-environment perspective; implementing environmental interventions; … and being involved in continuous quality improvement efforts (NASW, 2010).”

The data gathered for this study supports social work efforts in the three areas cited; yet it is not clear how social workers interact and support resident autonomy. The facility where the research was conducted employs one social worker for 120 beds. As of May 1st 2013 the facility had a 95.8% occupancy rate (approximately 145 beds occupied). Considering the complex and subjective nature of autonomy among residents it would be
difficult for one social worker to ensure the autonomous preferences of each resident. It is possible for social workers to play currently undefined role in supporting resident autonomy as part of an interdisciplinary training team with CNAs.

Based on CNA interviews, the process of understanding residents’ preferences is often an informal and intuitive one. One CNA describes the importance of her facial expressions or projection of negative mood as influencing interactions with residents and challenging the CNA’s ability to successfully interact with the resident. A patient-centered intervention between caregivers and stroke patients is currently being tested with the purpose of improving communication with patients experiencing speech difficulties (McGilton et al., 2012). Previous research examining the process by which nurse aides communicate with residents, indicates that “personal conversation, addressing the resident, checking in and emotional support and praise” contribute to affective (or “rapport building”) communication during mealtime assistance (Carpiac-Claver & Levy-Storms, 2007, p. 59). Building on this positive note, literature identifies challenges present in CNA communication (baby talk, elderspeak) with residents that is responsive to intervention (Williams, Kemper, & Hummert, 2003). Continued efforts should be encouraged to expand on the informal skills being utilized by CNAs aimed at understanding residents’ preferences and supporting resident autonomy.

Strategies for improving nursing home quality of life (and in particular, strengthening consumer advocacy and the caregiver workforce) often lead to substantial resource requirements including increased costs (Wiener, 2003). Efforts aimed at improving caregiver resident interactions have focused on managing behaviorally disturbed residents (Burgio et al., 2002) and empowering CNAs towards the goal of a
patient-centered care (Yeatts & Cready, 2007). While there are indications that these interventions can be helpful it is not clear to what degree these efforts have been implemented. Prior research on training CNAs who work with residents with dementia illustrates the role social work can play in designing and implementing training intervention (McCallion, Toseland, Lacey, & Banks, 1999).

**Areas for Further Research**

As stated previously, this is a set of studies reflecting a small number of long-term care residents. In addition, the facility states its philosophy on its webpage as one that “…enhances quality of life and accommodates a remarkable degree of individual preferences.” A facility with a policy or mission supporting resident preferences would suggest a positive bias in the sample (a greater likelihood that resident preferences are a focus of care) indicating the study should be expanded to determine if similar expressions of autonomy or resident preference descriptions are typical of other settings (e.g. for-profit versus not-for-profit). A meta-analysis of nursing homes showed not-for-profit facilities provided higher quality of care than for profit facilities.

While it was not the intent of this study to determine the influence of the environment on resident autonomy, resident perceptions of the facility may play a role in perceptions of support. Further research should be conducted on the role various long-term care settings play in supporting or challenging resident autonomy. In addition, how do structural features influence caregiver interaction and understanding of resident preferences?
Conclusion

Autonomy for older adults in long-term care, as reflected in the enactment of preferences, appears to be a complex and subjective phenomenon. Many of the residents interviewed for this study expressed a strong desire to maintain a particular level of activity and independence even though challenged by significant physical limitations. New preferences can evolve through ongoing resident and caregiver interactions, indicating the important role a caregiver can play in supporting such preferences. The new Minimum Data Set 3.0, Section F, Preferences for Customary Routines and Activities is an important step forward in supporting resident autonomy in long-term care facilities. The complex nature of preferences and the intuitive process that caregivers utilize to understand and support resident preferences suggests Section F is a starting point for understanding preferences. It is not clear how CNAs are trained in this intuitive process. Further research is needed to understand this interaction between resident and CNA, suggesting an important role for social work.

According to the National Association of Social Workers, Social Policy Institute (NASW, 2010), the profession has an important role in “promoting improvement in quality of life” among LTC residents through resident-centered care. Supporting resident autonomy requires addressing what Reinardy (1999) describes as the “tension between rights, decision making, and autonomy, on one hand, and the efficiencies and demands of institutional life” (p. 76). The fact that social workers and certified nurse assistants share an imperative to support resident autonomy within the demands associated with institutional life suggests the importance of an interdisciplinary approach. Efforts to encourage and nurture such an approach will ultimately benefit long-term care residents.
References


Allen, K. (2005). Long-term care financing: growing demand and cost of services are straining federal and state budgets (No. GAO-05-564T) (pp. 1–24). House of Representatives: Government Accountability Office. Retrieved from http://docs.google.com/viewer?a=v&q=cache:h5nqQcE9-p4J:www.gao.gov/new.items/d05564t.pdf+GAO+predictions+on+disability+among+elderly+2005&hl=en&gl=us&pid=bl&srcid=ADGEESgIcNc-_dqNQvPkjIthrcvmOTCj0Ub09JMo1xBMVWg3gYGXs0BqFhyLILp2fU0f3Ok3r5AxdaSw9B_fLaYMZPBZR4p1pLJhbHXhzgM_AroA0jj9BYzE0iRFsQrixQ8_FXMjjjt_F&sig=AHIEtbTIV_bDa9u4j0-3IfxH6XvnalwZcA


doi:10.1037/0022-0167.52.2.250


Reiners, G. M. (2012). Understanding the differences between Husserl’s (descriptive) and Heidegger’s (interpretive) phenomenological research. *Journal of Nursing & Care, 1*(56), 1–3. doi:10.4172/2167-1168.1000119


Appendix A – Geriatric Depression Scale

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Are you basically satisfied with your life?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Have you dropped many of your activities and interests?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Do you feel that your life is empty?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Do you often get bored?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Are you in good spirits most of the time?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Are you afraid that something bad is going to happen to you?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Do you feel happy most of the time?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Do you often feel helpless?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Do you prefer to stay at home, rather than going out and doing new things?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Do you feel you have more problems with memory than most?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Do you think it is wonderful to be alive now?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Do you feel pretty worthless the way you are now?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Do you feel full of energy?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Do you feel that your situation is hopeless?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Do you think that most people are better off than you are?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Answers in **bold** indicate depression. Although differing sensitivities and specificities have been obtained across studies, for clinical purposes a score >5 **bold** answers is suggestive of depression and should warrant a follow-up interview.

This instrument, and other versions of the GDS in multiple translations, are in the public domain and can be found at: www.stanford.edu/~yesavage/GDS.html.

Appendix B – The Mini-Mental State Exam

The Mini-Mental State Exam

<table>
<thead>
<tr>
<th>Maximum</th>
<th>Score</th>
<th>Orientation</th>
<th>Registration</th>
<th>Attention and Calculation</th>
<th>Recall</th>
<th>Language</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>( )</td>
<td>What is the (year) (season) (date) (day) (month)?</td>
<td>Name 3 objects: 1 second to say each. Then ask the patient all 3 after you have said them. Give 1 point for each correct answer. Then repeat them until he/she learns all 3. Count trials and record. Trials ________</td>
<td>Serial 7's. 1 point for each correct answer. Stop after 5 answers. Alternatively spell “world” backward.</td>
<td>Ask for the 3 objects repeated above. Give 1 point for each correct answer.</td>
<td>2 ( ) Name a pencil and watch.</td>
</tr>
<tr>
<td>5</td>
<td>( )</td>
<td>Where are we (state) (country) (town) (hospital) (floor)?</td>
<td></td>
<td></td>
<td></td>
<td>1 ( ) Repeat the following “No ifs, ands, or buts”</td>
</tr>
<tr>
<td>3</td>
<td>( )</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3 ( ) Follow a 3-stage command: “Take a paper in your hand, fold it in half, and put it on the floor.”</td>
</tr>
<tr>
<td>1</td>
<td>( )</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1 ( ) Read and obey the following: CLOSE YOUR EYES</td>
</tr>
<tr>
<td>1</td>
<td>( )</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1 ( ) Write a sentence.</td>
</tr>
<tr>
<td>1</td>
<td>( )</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1 ( ) Copy the design shown.</td>
</tr>
</tbody>
</table>

______

Total Score

ASSESS level of consciousness along a continuum
Alert Drowsy Stupor Coma

Appendix C – MDS 3.0, Section F

Preferences for Customary Routine and Activities

<table>
<thead>
<tr>
<th>F0300. Should interview for Daily and Activity Preferences be Conducted?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enter Code</td>
</tr>
<tr>
<td>0. No (resident is rarely/never understood and family/significant other not available) → Skip to and complete F0800, Staff Assessment of Daily and Activity Preferences</td>
</tr>
<tr>
<td>1. Yes → Continue to F0400, Interview for Daily Preferences</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>F0400. Interview for Daily Preferences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Show resident the response options and say: “While you are in this facility…”</td>
</tr>
<tr>
<td>Coding:</td>
</tr>
<tr>
<td>1. Very important</td>
</tr>
<tr>
<td>2. Somewhat important</td>
</tr>
<tr>
<td>3. Not very important</td>
</tr>
<tr>
<td>4. Not important at all</td>
</tr>
<tr>
<td>5. Important, but can’t do or no choice</td>
</tr>
<tr>
<td>9. No response or non-responsive</td>
</tr>
<tr>
<td>□ Enter Codes in Boxes</td>
</tr>
<tr>
<td>A. how important is it to you to choose what clothes to wear?</td>
</tr>
<tr>
<td>B. how important is it to you to take care of your personal belongings or things?</td>
</tr>
<tr>
<td>C. how important is it to you to choose between a tub bath, shower, bed bath, or sponge bath?</td>
</tr>
<tr>
<td>D. how important is it to you to have snacks available between meals?</td>
</tr>
<tr>
<td>E. how important is it to you to choose your own bedtime?</td>
</tr>
<tr>
<td>F. how important is it to you to have your family or a close friend involved in discussions about your care?</td>
</tr>
<tr>
<td>G. how important is it to you to be able to use the phone in private?</td>
</tr>
<tr>
<td>H. how important is it to you to have a place to lock your things to keep them safe?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>F0500. Interview for Activity Preferences</th>
</tr>
</thead>
<tbody>
<tr>
<td>CA</td>
</tr>
<tr>
<td>Show resident the response options and say: “While you are in this facility…”</td>
</tr>
<tr>
<td>Coding:</td>
</tr>
<tr>
<td>1. Very important</td>
</tr>
<tr>
<td>2. Somewhat important</td>
</tr>
<tr>
<td>3. Not very important</td>
</tr>
<tr>
<td>4. Not important at all</td>
</tr>
<tr>
<td>5. Important, but can’t do or no choice</td>
</tr>
<tr>
<td>9. No response or non-responsive</td>
</tr>
<tr>
<td>□ Enter Codes in Boxes</td>
</tr>
<tr>
<td>A. how important is it to you to have books, newspapers, and magazines to read? 4 or 5 = 7, 10</td>
</tr>
<tr>
<td>B. how important is it to you to listen to music you like? 4 or 5 = 7, 10</td>
</tr>
<tr>
<td>C. how important is it to you to be around animals such as pets? 4 or 5 = 7, 10</td>
</tr>
<tr>
<td>D. how important is it to you to keep up with the news? 4 or 5 = 7, 10</td>
</tr>
<tr>
<td>E. how important is it to you to do things with groups of people? 4 or 5 = 7, 10</td>
</tr>
<tr>
<td>F. how important is it to you to do your favorite activities? 4, 5, 6 = 7, 10</td>
</tr>
<tr>
<td>G. how important is it to you to go outside to get fresh air when the weather is good? 4 or 5 = 7, 10</td>
</tr>
<tr>
<td>H. how important is it to you to participate in religious services or practices? 4 or 5 = 7, 10</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>F0600. Daily and Activity Preferences Primary Respondent</th>
</tr>
</thead>
<tbody>
<tr>
<td>CA</td>
</tr>
<tr>
<td>Indicate primary respondent for Daily and Activity Preferences (F0400 and F0500)</td>
</tr>
<tr>
<td>1. Resident</td>
</tr>
<tr>
<td>2. Family or significant other (close friend or other representative)</td>
</tr>
<tr>
<td>9. Interview could not be completed by resident or family/significant other (&quot;No response&quot; to 3 or more items)</td>
</tr>
</tbody>
</table>
## Appendix C (continued)

### Section F: Preferences for Customary Routine and Activities

#### F0700. Should the Staff Assessment of Daily and Activity Preferences be Conducted?

<table>
<thead>
<tr>
<th>Enter Code</th>
<th>0. No (because Interview for Daily and Activity Preferences (F0400 and F0500) was completed by resident or family/significant other) → Skip to and complete G0110, Activities of Daily Living (ADL) Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. Yes (because 3 or more items in Interview for Daily and Activity Preferences (F0400 and F0500) were not completed by resident or family/significant other) → Continue to F0800, Staff Assessment of Daily and Activity Preferences</td>
</tr>
</tbody>
</table>

#### F0800. Staff Assessment of Daily and Activity Preferences (CAA)

Do not conduct if Interview for Daily and Activity Preferences (F0400 - F0500) was completed

<table>
<thead>
<tr>
<th>Resident Prefers:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>□</td>
<td>A. Choosing clothes to wear</td>
</tr>
<tr>
<td>□</td>
<td>B. Caring for personal belongings</td>
</tr>
<tr>
<td>□</td>
<td>C. Receiving tub bath</td>
</tr>
<tr>
<td>□</td>
<td>D. Receiving shower</td>
</tr>
<tr>
<td>□</td>
<td>E. Receiving bed bath</td>
</tr>
<tr>
<td>□</td>
<td>F. Receiving sponge bath</td>
</tr>
<tr>
<td>□</td>
<td>G. Snacks between meals</td>
</tr>
<tr>
<td>□</td>
<td>H. Staying up past 8:00 p.m.</td>
</tr>
<tr>
<td>□</td>
<td>I. Family or significant other involvement in care discussions</td>
</tr>
<tr>
<td>□</td>
<td>J. Use of phone in private</td>
</tr>
<tr>
<td>□</td>
<td>K. Place to lock personal belongings</td>
</tr>
<tr>
<td>□</td>
<td>L. Reading books, newspapers, or magazines not ✓ = 10</td>
</tr>
<tr>
<td>□</td>
<td>M. Listening to music not ✓ = 10</td>
</tr>
<tr>
<td>□</td>
<td>N. Being around animals such as pets not ✓ = 10</td>
</tr>
<tr>
<td>□</td>
<td>O. Keeping up with the news not ✓ = 10</td>
</tr>
<tr>
<td>□</td>
<td>P. Doing things with groups of people not ✓ = 10</td>
</tr>
<tr>
<td>□</td>
<td>Q. Participating in favorite activities not ✓ = 10</td>
</tr>
<tr>
<td>□</td>
<td>R. Spending time away from the nursing home not ✓ = 10</td>
</tr>
<tr>
<td>□</td>
<td>S. Spending time outdoors not ✓ = 10</td>
</tr>
<tr>
<td>□</td>
<td>T. Participating in religious activities or practices not ✓ = 10</td>
</tr>
<tr>
<td>□</td>
<td>Z. None of the above</td>
</tr>
</tbody>
</table>
A. If nursing staff consider the resident eligible for the study and resident has had a recent evaluation:

**Initial Contact**
Based on nursing staff assessment, the resident meets study requirements. Read introduction script.

1. Consent process
2. Administer MDS 3.0 Section F
3. Complete interview

**Follow-up interview**

Resident does not indicate interest in participating, no further contact by researcher.

B. If nursing staff consider the resident eligible for the study but resident has not had a recent evaluation:

**Initial Contact**
Based on nursing staff assessment, the resident meets study requirements. Read introduction script.

1. Consent process
2. Administer MMSE and GDS

Resident scores on MMSE and GDS indicate resident is not eligible for the study. If resident wishes to proceed with interview researcher will accommodate so as not to upset resident. Nursing staff will be informed of scores.

1. Administer MDS 3.0 Section F
2. Complete interview

**Follow-up interview**

Legend:
- MMSE = Mini Mental Status Exam
- GDS = Geriatric Depression Scale
- MDS 3.0 = Minimum Data Set
Appendix D - Timeline Consent (continued)

C. If resident is eligible for the study and received a recent evaluation but, because of ill health, is unable to participate in study:

Initial Contact Follow procedures for either A or B.
Consult nursing staff to determine best time to contact resident.

Follow-up interview

Complete Interview

Consent process, 2. Administer MDS 3.0 Section F

Resident does not indicate interest in participating, no further contact by researcher.

Staff caregiver interview: An announcement for the study will be placed in a common area for where each Staff Caregiver

Staff caregiver completes consent to contact form, researcher arranges meeting

Study announcement is posted

Staff caregivers do not indicate interest in participating, no further contact by researcher.
Appendix E – Study Introduction Script

Resident/Staff Caregiver

Hi. My name is Paul Urbanski and I am completing a research study at the nursing home about resident preferences and choices in daily living and how staff caregivers understand the resident’s preferences and choices. As part of the study you will be asked to complete a questionnaire and participate in an interview that will take about 1 hour. I would like to invite you to participate in the study because of your experience (“living” for residents) (“working” for staff caregiver) at the nursing home and the valuable information you can provide.

Your participation in the study is completely voluntary and deciding to participate or not participate will not affect your status at the nursing home. If you do decide to participate you can choose to stop at any time. You may also choose not to answer any questions which make you feel uncomfortable.

I would like to give you this consent to contact form. Filling out and signing this form means you give me permission to talk with you in more depth about the study and answer any questions you might have. Accepting or signing this consent to contact form does not mean you wish to participate in the study. Would you like a copy of the consent to contact letter and form?

*If respondent answers “yes” the researcher will give the consent to contact material to the individual.*

There is contact information included in the invitation if you have any further questions.

Thank you.
Appendix F – Invitation/Resident

Resident Invitation to Participate in a Research Study

“Resident Preferences in Nursing Home Settings”

Dear Potential Participant,

You are invited to participate in a research study being conducted by Paul Urbanski, MSSW, under the supervision of Dr. Anne E. Fortune. Both Mr. Urbanski and Dr. Fortune are from the University at Albany School of Social Welfare.

The researcher is interested in better understanding nursing home resident preferences and choices in daily living activities. If you decide to participate in the study, you will be asked to fill out a personal history form and a questionnaire about what preferences you have in your day-to-day life at the nursing home. Then you will be interviewed and asked questions about what it means for you to have control over the things you enjoy doing or having in your day-to-day life and how the staff caregiver’s are able to help you with these choices. The interview is voice recorded and will take about 60 minutes and you will be able to schedule it at a time and place that where you are most comfortable.

Participation in the study is voluntary.

This study is separate from and not connected with the Lorraine Nursing Center.

If you wish to find out more about the study, please complete the attached “Consent to Contact” form and Mr. Urbanski will contact you to discuss the study in more detail.

Thank you.

Paul E. Urbanski, MSSW
University at Albany
School of Social Welfare
135 Western Avenue
Albany, NY 12210
(518) 442-5346
Appendix G – Invitation/Staff Caregiver

Staff Caregiver Invitation to Participate in a Research Study

“Resident Preferences in Nursing Home Settings”

Dear Potential Participant,

You are invited to participate in a research study being conducted by Paul Urbanski, MSSW, under the supervision of Dr. Anne E. Fortune. Both Mr. Urbanski and Dr. Fortune are from the University at Albany School of Social Welfare.

The researcher is interested in better understanding the nursing home resident’s preferences and choices in daily living activities. If you decide to participate in the study, you will be asked to fill out a personal history form and a questionnaire about what preferences you have in your day-to-day life at the nursing home. Then you will be interviewed and asked questions about what it means for you to have control over the things you enjoy doing or having in your day-to-day life and how the staff caregiver are able to help you with these choices. The interview is voice recorded and will take about 60 minutes and you will be able to schedule it at a time and place that where you are most comfortable.

Participation in the study is voluntary.

This study is separate from and not connected with the Lorraine Nursing Center.

If you wish to find out more about the study, please complete the attached “Consent to Contact” form and Mr. Urbanski will contact you to discuss the study in more detail.

Thank you.

Paul E. Urbanski, MSSW
University at Albany
School of Social Welfare
135 Western Avenue
Albany, NY 12210
(518) 442-5346
Appendix H – Consent to Contact Resident/Staff Caregiver

Consent to Contact - Resident/Staff Caregivers

A research study will be taking place at the Lorraine Nursing Center. A researcher will be asking questions about what it means for residents to have control over the things she/he enjoy doing or having in their day-to-day life and how staff caregivers understand and help with those preferences. The interview would last about 60 minutes, will be voice recorded and you would be able to schedule it at a time that works best for you.

By filling out and signing this form you give the researcher, Paul Urbanski, permission to get in touch with you and talk with you in more detail about the study. Signing this form does not mean you agree to be part of the study.

Name:___________________________ Signature:___________________________
Date:________

Indicate whether you are a resident or staff caregiver:

☐ Resident
☐ Staff caregiver

Method of Contact (please select at least one)

Email:_____________________________________

Phone:_____________________________________

Location or Other:___________________________
Appendix I – Resident Consent Form

CODED IDENTIFIER:_______________

Resident Preferences in a Nursing Home Setting
Resident Consent Form

I (Paul E. Urbanski) am conducting a research study examining nursing home residents’ thoughts and feelings about preferences they may have while living at the nursing home and how staff understand and support those preferences. You will be asked to complete a personal history form a questionnaire and an interview. The interviews will be scheduled at a time and place of your convenience and will take approximately 60 minutes.

Purpose of the Research Study: This study is part of a doctoral dissertation, and is intended to fulfill the requirements set by the University at Albany School of Social Welfare for the degree of Doctor of Philosophy in Social Welfare. The information you provide in this study is highly valuable in building the knowledge base on how nursing home residents are able to have control over preferences in their day-to-day life at the nursing home.

Participating: Your participation in this study is completely voluntary and your status at the nursing home will not change, whether or not you participate in this study. We do not anticipate any risk in your participation, other than the potential for you to become uncomfortable answering some of the questions. If you decide to participate in this study, you may decline to answer any question or you may decide not to participate at any time during the study, without penalty. All information is confidential and will be used for research purposes only. Results from the study will be written in the form of anonymous data only. While it may be necessary to use verbatim parts of your interview, your name will not be used.

Criteria for Participation: To qualify as a participant, it may be necessary to complete two psychological examinations and assessments. The results of these examinations and assessments will be provided by the researcher to the nursing home following completion of the interview.

Audio Recording: A voice recording will be made of the interview. By consenting to participate in this study you will also be agreeing to have your interview voice recorded. The recording will be stored at a secure location with
a coded identifier and your name will not be connected to the recording. The recordings will be transcribed to text and the recordings will be erased.

Benefits to Participating The benefits of participation in this study may include a better understanding of how residents’ at the nursing home see their day-to-day preferences and how staff caregivers understand and support them. Though all information is kept confidential, there may be a risk of identified due to the size of the nursing home and the fact that interviews will take place in the nursing home. As a result, it is possible that some of the nursing home staff could know your identity if you participate. If any publication results from this research, you will not be identified in any way.

If during the course of the interview you indicate that you have experienced or are experiencing abuse by another person, or that you are aware of abuse taking place at the nursing home, that information will be reported to the appropriate.

If you have any questions about the study, please contact either Paul Urbanski, by mail at: University at Albany School of Social Welfare, Richardson Hall 287, 135 Western Ave., Albany, NY 12222, by telephone at (518) 442-5327, by email at pu324612@albany.edu, or Mr. Urbanski’s doctoral committee chair, Dr. Anne E. Fortune, by mail at Richardson Hall 119, by telephone at 442-5322, by email at rfortune@albany.edu. If you have any questions concerning your rights as a research participant that have not been answered by the investigator, or if you wish to report any concerns about the study, you may contact the University at Albany’s Office of Regulatory Research Compliance at 518-442-9050 or, if outside the 518 area code, 1-800-365-9139 or orrc@uamail.albany.edu.

By signing this consent form, I acknowledge that I have read and understand the above information and I agree to participate in this study.

__________________________________________  Date:___________
Your name

__________________________________________
Your signature

__________________________________________  Date:___________
Name of legally responsible person

__________________________________________  Date:___________
Signature of person signing for the individual
Appendix J – Staff Caregiver Consent Form

CODED IDENTIFIER: ________________

Resident Preferences in a Nursing Home Setting
Staff Caregiver Consent Form

I (Paul E. Urbanski) am conducting a research study examining nursing home residents’ thoughts and feelings about preferences they may have while living at the nursing home and how staff understand and support those preferences. You are being asked to participate in an interview. The interview will take approximately 60 minutes.

Purpose of the Research Study: This study is part of a doctoral dissertation and is intended to fulfill the requirements established by the University at Albany School of Social Welfare for the degree of Doctor of Philosophy in Social Welfare. The information you provide in this study is highly valuable in building the knowledge base on how older adult residents are influenced by the interaction with nursing home staff during her or his stay.

Your participation in this study is completely voluntary, and your status at the nursing home will not change, whether or not you participate in this study. We do not anticipate any risk in your participation other than the potential for you to become uncomfortable answering some of the questions. If you decide to participate in this study, you may decline to answer any question or you may decline to participate at any time, without penalty. All information is confidential and will be used for research purposes only. Results from the study will be written in the form of anonymous data only. While it may be necessary to use verbatim parts of your interview, your name will not be used.

Audio Recording: A voice recording will be made of the interview. By consenting to participate in this study you will also be agreeing to have your interview voice recorded. The recording will be stored at a secure location with a coded identifier and your name will not be connected to the recording. The recordings will be transcribed to text and the recordings will be erased.

Benefits to Participating: Although you may not receive direct benefit from your participation, others may benefit from the knowledge obtained from this research. Benefits of participation in this study may include a better understanding of the how residents’ at the nursing home see their day-to-day preferences and how staff caregivers understand and support them. Though all information is kept confidential, there may be risk of identification due to the size of the nursing home and the fact that the interviews will take place in the nursing home. As a result, it is possible that some of the nursing home staff/residents could know your identity if you participate. If any publication results from this research, you will not be identified in any way.

If during the course of the interview you indicate that you have experienced or are experiencing abuse by another person, or that you are aware of abuse taking place at the
nursing home, that information will be reported to the Program Director of the nursing home.

If you have any questions about the study, please contact either Paul Urbanski, by mail at: University at Albany School of Social Welfare, Richardson Hall 287, 135 Western Ave., Albany, NY 12222 Richardson Hall 287, by telephone at 442-5327, by email at pu324612@albany.edu, or Mr. Urbanski’s doctoral committee chair Dr. Anne E. Fortune, by mail at Richardson Hall 119, by telephone at (518) 442-5322, by email at rfortune@albany.edu. If you have any questions concerning your rights as a research participant that have not been answered by the investigator or if you wish to report any concerns about the study, you may contact the University at Albany’s Office of Regulatory Research Compliance at 518-442-9050 or, if outside the 518 area code, 1-800-365-9139 or orrc@uamail.albany.edu.

By signing this consent form I acknowledge that I have read and understand the above information and I agree to participate in this study.

________________________________________________________________________________________
Your name

________________________________________________________________________________________ Date:__________________
Your signature
Appendix K – Interview Script/Resident

NOTE: Prior to recording the interview the resident will be asked if there is a particular staff caregiver that helps them with her or his preferences. If so, the resident will be asked to choose a code name for that caregiver in order to avoid using the staff caregivers or actual name during the interview. In the event the resident uses the actual name of the caregiver during the interview the recording device will be stopped and the interviewer will remind the resident to use the code name of the staff caregiver during the interview. The code name will only be used to help facilitate the interview and will not be used as part of the coding process for comparing resident and caregiver interviews. The PI will make the following request: Generally speaking this interview is about your personal feelings and perceptions so it is best to avoid using anyone else’s name as much as is possible.

Interviewer: I’d like to talk with you about your preferences or the things you enjoy doing or a particular way that you like things to be. It might be picking out what clothes you’d like to wear, having time in the morning to yourself, or maybe eating or going to sleep when you feel like it. Can you tell me about something you did recently that you enjoy doing either daily or once in a while, that is important to you?

(Resident response)
Interviewer: (Reframe the response to ensure the interviewer’s understanding of the response is in agreement with the interviewee’s response.) Why is important to you?

(Resident response)
Interviewer: Can you do this on your own or do you need help?

(No resident response)
Interviewer: If nothing comes to mind could you tell me what the beginning of your day is like?

(Resident response)
Interviewer: Would you say that one of those parts of your morning is important to you? If so, why?

(Resident response)
Interviewer: Can you do this on your own or do you need help?

(Resident “can do on own”)
Interviewer: (If able to do on their own.) Do you think it was important for you to do this on your own? If so, why? If not, why?

(Resident “cannot do on own”)
Interviewer: How did you go about getting help?
Interviewer: What does the staff caregiver think about what you like to do?

(Resident “understands”)

Interviewer: Is there something the caregiver does that helps them understand your preference?

(Resident “does not understand”)

Interviewer: Why do you think the staff caregiver does not understand your preference?

Interviewer: What if you are not feeling well?

(Resident response)

Interviewer: How are things different when you are not feeling well?

(Resident response)

NOTE: The questions regarding resident health may cause some distress or sadness. It is the researchers desire to end the interview on a more positive note.

Interviewer: Thank you for talking with me today. Before we end the interview I’m hoping you can tell me about something you have always enjoyed doing. It might be traveling or visiting with friends, playing a musical instrument, painting or reading. What is the one thing that you have always enjoyed doing?

(Resident response)

Interviewer: Thank you for taking the time to talk with me. Are there any questions you have before we end the interview?

(Resident response)

Interviewer: Thank you.
Appendix L – Caregiver Interview Script

Interview Script

NOTE: Prior to recording the interview the staff caregiver will be asked to choose a code name for the resident in order to avoid using the resident’s actual name during the interview. In the event the staff caregiver uses the actual name of the resident during the interview the recording device will be stopped and the interviewer will remind the staff caregiver to use the code name of the resident during the interview. The code name will only be used to help facilitate the interview and will not be used as part of the coding process for comparing resident interviews. The PI will make the following request: Generally speaking this interview is about your personal feelings and perceptions so it is best to avoid using anyone else’s name as much as is possible.

Interviewer: I’d like to talk with you about (resident’s code name) preferences. By preferences, I mean those things that she/he enjoys doing or a particular way that she/he likes things to be. It might be picking out what clothes they would like to wear, having alone time in the morning, or maybe eating or going to sleep when she/he feels like it. Can you give me an example of something she/he likes to do?

(No Caregiver response)

Interviewer: If nothing comes to mind could you tell me what the beginning of (resident’s code name) day is like?

(Caregiver response)

Interviewer: Would you say that one of those parts of her/his morning is important to her/him? If so, why?

(Caregiver response)

Interviewer: Is (resident’s code name) able to do this on their own or do they need help?

(Caregiver response is “can do on own”)

Interviewer: Do you think it was important for them to do on their own? If so, why? If not, why?

(Caregiver response is “cannot do on own”)

Interviewer: How did she/he go about getting help?
Interviewer: What if (resident’s code name) is not feeling well?

(Caregiver response)

Interviewer: What do you do if (resident’s code name) is not feeling well?

(Caregiver response)

NOTE: The questions regarding resident health may cause the caregiver some sadness. It is the researchers desire to end the interview on a more positive note.

Interviewer: Thank you for talking with me today. Before we end the interview, can tell me what it is that you enjoy about working with residents?

(Caregiver response)

Interviewer: Thank you for taking the time to talk with me. Are there any questions you have before we end the interview?

(Caregiver response)

Interviewer: Thank you.
Appendix M – Demographic Form

Nursing Home Autonomy Study
Demographic Form

1. Year of birth:    _______

2. Gender:            3. Marital Status:
    □ Female    □ Married       □ Widow
    □ Male      □ Single        □ Living w/ partner

4. Ethnicity:
    □ Caucasian
    □ African American
    □ Hispanic/Latino
    □ Asian/Pacific Islander
    □ Native American
    □ Other ______________________

5. Education:
    □ Graduate School
    □ Undergraduate School
    □ High school
    □ Junior High School
    □ No School

6. Income:
    □ 0 – 9,999          □ 25,000 – 29,999          □ 55,000 – 59,999
    □ 10,000 – 14,999   □ 30,000 – 34,999          □ 60,000 – 64,999
    □ 15,000 – 19,999   □ 35,000 – 49,999          □ 65,000 – 69,999
    □ 20,000 – 24,999   □ 50,000 – 54,999          □ 70,000 – or more

7. Is this the first time you have been stayed in a nursing home or long-term care facility?
   □ Yes
   □ No
Appendix N – Data Analysis Sequence

- Resident Interviews
  In-depth/open-ended
- MDS 3.0 Assessment
  Quantitative
- Staff Interviews
  In-depth/open-ended
  Qualitative

Qualitative and Quantitative response are analyzed

Congruence evaluated
Appendix O – Contact Form/Resident

CODED IDENTIFIER:______________

Name:_____________________________________________________________________

Location:_________________________________________________________________

Family member or caregiver/friend contact:

Name:_____________________________________________________________________

Address:_________________________________________________________________

City:__________________________State:_____________________

Phone:___________________________________________________________________
Appendix P – Caregiver Contact Form

CODED IDENTIFIER:_______________

Name:__________________________________________________

Location:_______________________________________________

Contact:

Address:________________________________________________

City:_________________________State:____________________

Phone:_________________________________________________
Appendix Q – HIPPA Form

Health Insurance Portability and Accountability Act (HIPAA) Authorization Form

Study title: Congruence between Nursing Home Resident and Staff Caregivers Perception of Resident’ Self-Perceived Autonomy

We are asking you to let us use and share your health information in a research study. Your medical care will not change in any way if you say no.

Why sign this document? The purpose for signing this document is to give permission to a researcher from the University at Albany’s School of Social Welfare to use and share your health information for this research study, please sign this document. We will give you a copy.

Why are you asking for my information? There are requirements for participating in this research study. The information being requested will help determine your eligibility.

What information will you use and share for the study? If you say yes, we will:

Use and share information from your Minimum Data Set 3.0 including;

1. Cognition examination (Section C: Cognitive Patterns)
2. Depression examination (Section D: Mood)
3. Preferences of daily living (Section F: Preferences for Customary Routine and Activities)

The information we are asking to use and share is called “Protected Health Information”. It is protected by a federal law called the Privacy Rule of the Health Insurance Portability and Accountability Act (HIPAA). In general, we cannot use or share your health information for research without your permission.

If you want, we can give you more information about the Privacy Rule. Also, if you have any questions about the Privacy Rule you can speak to our Privacy Officer at (phone number).

How will you use and share this information?

We will use your information only for the study described in this document.

We will do our best to make sure your information stays private. Only de-identified data not subject to the Privacy Rule will be shared outside the research team unless disclosure is required by law. Let us know if you have questions about this.
**What happens if I say no?** We will not use or share your information for this study. The care you get from your doctor will not change.

**What happens if I say yes, but change my mind?** At any time, you can tell us to stop using and sharing your health information that can be traced to you. We will stop, except in very limited cases if needed to comply with law, protect your safety, or make sure the research is done properly. If you have any questions about this, please ask.

If you want us to stop, you have to tell us in writing. Write or e-mail: Paul Urbanski at the University at Albany School of Social Welfare, 135 Western Avenue, Room 287, Albany, NY 12222. Or e-mail at: pu324613@albany.edu.

If you stop, the care you get from you doctor will not change.

**How long will my health information be used?** We expect our study to take at least 1 year. We will not use or share your information after the study is done.

**What if I have any questions?** If you have any questions about the study, call or write the Principal Investigator of the study Paul Urbanski at 1-518-442-5346 or by mail at 135 Western Avenue, Room 287, Albany, New York, 12222, or by email at pu324612@albany.edu.

___________________________________________________
Your name (please print)

___________________________________________________ ___________________
Your signature Date

___________________________________________________
Name of legally responsible person (please print)

___________________________________________________ ___________________
Signature of person signing for the individual Date

___________________________________________________
Relationship to you

___________________________________________________
Name of person conducting the consent discussion

___________________________________________________ ___________________
Signature of person conduction the consent discussion Date
Appendix R – Emotional Distress Protocol

Protocol for Identifying and Responding to Emotional Distress during Resident Interview

Coming up with a specific protocol for identifying and responding to distress in an interview situation can be very difficult as much of the response to signs is very dependent on the subject and how well you know the subject. The interventions clearly vary case by case and by practitioner. Below is a very generic list of signs we often use in identifying distress with our population and possible interventions that can be utilized. These lists are clearly not complete.

List of signs for identifying emotional distress in an interview:
- Elder requests you to stop or leave
- Elder gets up or exits on her/his own
- Crying or tear fullness
- They stop talking/silence
- Loss of eye contact
- Changing the subject (by the elder)
- Becomes angry/ shows anger
- Shows aggression in some way/becomes aggressive, physically pushing you away
- Waving you away
- Excessive joking or giddy behavior
- Excessive fidgeting (i.e. moving around a lot, changing positioning, biting nails, biting lips, wringing hands, picking at self, scratching, pulling at clothing)
- Changes in breathing, particularly exhibiting shortness of breath or breathing heavier
- Excessive complaints of a medical issue
- Complaints of being too hot or too cold
- Appearance of flushing in face or sweating
- Increased confusion that is different from the resident’s baseline or from start of interview
- Facial expression of fear or expressing fearfulness

Interventions or steps to take if distress is displayed:
- Stop the interview
- Thank elder for their time participating and talking with you
- Pause, and wait to proceed
- Offer reassurance
- Acknowledge the distress
- Restate
- Take a break and re-approach
- Non-verbal communication such as smiling, nodding, make eye contact
- Comforting touch (if appropriate, varies case by case)
- Notifying the nurse or house Shahbaz of issues during interview as they may affect the elder’s mood and behavior after you leave
- Depending on severity of reaction you may need to notify medical staff of upset or response to interview

Most important to note in our scope of practice is that we stop our interviews at most signs of anxiety or distress, especially if it is a first interview or someone we don't know very well. Our ability to move through the process increases as we get to know our elders.
Appendix S – MDS 3.0

Psychosocial Well-Being Care Area Assessment (CAA) of the MDS 3.0

Review of indicators of psychosocial well-being

<table>
<thead>
<tr>
<th>Modifiable factors/Relationship problems (from resident, family, staff interviews and clinical records)</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Resident says or indicates he or she feels lonely</td>
</tr>
<tr>
<td>☐ Recent decline in social involvement and associated loneliness can be sign of acute health complications and depression</td>
</tr>
<tr>
<td>☐ Resident indicates he or she feels distressed because of decline in social activities</td>
</tr>
<tr>
<td>☐ Over the past few years, resident has experienced absence of daily exchanges with relatives and friends</td>
</tr>
<tr>
<td>☐ Resident is uneasy dealing with others</td>
</tr>
<tr>
<td>☐ Resident has conflicts with family, friends, roommate, other residents or staff</td>
</tr>
<tr>
<td>☐ Resident appears preoccupied with family, friends, roommate, other residents, or staff</td>
</tr>
<tr>
<td>☐ Resident seems unable or reluctant to begin to establish a social role in the facility; may be grieving lost status or roles</td>
</tr>
<tr>
<td>☐ Recent change in family situation or social network, such as death of a close family member or friend</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Diseases and conditions that may impede ability to interact with others</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Delirium (C1600 = 1, Delirium CAA)</td>
</tr>
<tr>
<td>☐ Mental retardation (A1550)</td>
</tr>
<tr>
<td>☐ Alzheimer’s Disease (I4200)</td>
</tr>
<tr>
<td>☐ Cerebrovascular Accident (CVA)</td>
</tr>
<tr>
<td>☐ Aphasia (I4300)</td>
</tr>
<tr>
<td>☐ Other dementia (I5800)</td>
</tr>
<tr>
<td>☐ Depression (CVA)</td>
</tr>
<tr>
<td>☐ Speaks different language</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health status factors (that may inhibit social involvement)</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Decline in activities of daily living (G0110)</td>
</tr>
<tr>
<td>☐ New onset or worsening of pain</td>
</tr>
<tr>
<td>☐ Health problem, such as falls (J1700, J1800), pain (J0300, J0800), fatigue, etc.</td>
</tr>
<tr>
<td>☐ Trouble falling asleep or staying asleep (D0200C)</td>
</tr>
<tr>
<td>☐ Mood (I4300) or behavior (E0200) problem that impacts interpersonal relationships or that arises because of social isolation (See Mood State and Behavioral Symptoms CAAs)</td>
</tr>
<tr>
<td>☐ Change in communication (B0700, B0800, vision (B1000), hearing (B0200), cognition (C0100)</td>
</tr>
<tr>
<td>☐ Use of communication devices, interpreters, etc.</td>
</tr>
<tr>
<td>☐ Weight gain or loss</td>
</tr>
<tr>
<td>☐ Medications with side effects that interfere with social interactions, such as incontinence, diarrhea, delirium, or sleepiness</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Customary lifestyle (from resident, family, staff interviews and clinical records)</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Was lifestyle more satisfactory to the resident prior to admission to the nursing home</td>
</tr>
<tr>
<td>☐ Are current psychosocial/relationship problems consistent with resident’s long-standing lifestyle or is this relatively new for the resident?</td>
</tr>
<tr>
<td>☐ Has facility care plan to date been as consistent as possible with resident’s prior lifestyle, preferences, and routines?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Environmental factors (that may inhibit social involvement)</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Use of physical restraints</td>
</tr>
<tr>
<td>☐ Change in residence leading to a loss of autonomy and reduced self-esteem</td>
</tr>
<tr>
<td>☐ Change in room assignment or dining location or table mates</td>
</tr>
<tr>
<td>☐ Living situation limits informal social interaction, such as isolation precautions</td>
</tr>
<tr>
<td>☐ Living environment/situation prohibits close relationship/privacy with spouse/significant others and family</td>
</tr>
<tr>
<td>☐ Adapted the resident’s environment to his or her unique needs (photos, quilts, pillows, etc.)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Strengths to build upon (from resident, family, staff interviews and clinical record)</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Activities in which resident appears especially at ease interacting with others</td>
</tr>
<tr>
<td>☐ Certain situations appeal to resident more than others, such as small groups or 1:1 interactions rather than large groups</td>
</tr>
<tr>
<td>☐ Certain individuals who seem to bring out a more positive, optimistic side of the resident</td>
</tr>
<tr>
<td>☐ Positive traits that distinguished the resident as an individual prior to his or her illness</td>
</tr>
<tr>
<td>☐ What gave the resident a sense of satisfaction earlier in his or her life?</td>
</tr>
<tr>
<td>☐ Including family and friends in nursing home activities</td>
</tr>
</tbody>
</table>

201
Appendix T – Autonomy Polarities

<table>
<thead>
<tr>
<th>Polarity</th>
<th>Inherent Risks</th>
<th>Possible Correctives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decisional vs. Executorial (having preferences, making decisions vs. being able to implement them or carry them out)</td>
<td>Decisional autonomy too easily abrogated whenever autonomy of execution is diminished or lost.</td>
<td>Enabling the elderly to continue making decisions in activities (ADL, IADL) where they need assistance.</td>
</tr>
<tr>
<td>Direct vs. Delegated (deciding or acting on one’s own vs. giving authority to others to decide/act for one)</td>
<td>Only direct autonomy fully recognized and respected; delegation effectively reduced to surrender or forfeiture of autonomy.</td>
<td>Developing norms for delegation of decisions/activity to caregivers; developing explicit, mutually acceptable maps of what authority is retained by the elderly, what is delegated to caregivers</td>
</tr>
<tr>
<td>Competent vs. Incapacitated (reasonably and judgmentally coherent choice/activity vs. that which exhibits rational defect or judgmental incoherence)</td>
<td>Labeling of the elderly as incapacitated because of: (1) the sheer difficulty and complexity of competency assessment; (2) decisions made by the elderly which challenge institutional goals, and motivations in favor of caregivers’ value system.</td>
<td>Avoiding global and perfunctory judgments of incompetency; recognizing the often partial, context-specific nature of competency; respecting elderly individuals’ own norms for what constitutes reasonable, logical or coherent choice.</td>
</tr>
<tr>
<td>Authentic vs. Inauthentic (choices/actions which are consonant with character vs. those which are seriously out of character)</td>
<td>Defining autonomy solely in terms of rationality; ignoring or over-riding the elderly individual’s own personal values, moral career, goals, and motivations in favor of caregivers’ value system.</td>
<td>Developing an understanding of and protective response to the value histories of elderly clients; documenting a value inventory to aid caregivers in identifying authentic choices (particularly those which are highly idiosyncratic).</td>
</tr>
<tr>
<td>Immediate vs. Long Range (present or limited expressions of autonomy vs. future or wide-ranging expressions)</td>
<td>Defining autonomy only in terms of a rigid rights perspective which unquestioningly allows immediate freedom to work against long-range autonomy; conversely, defining autonomy only in terms of long-range considerations, thereby giving wide latitude to paternalistic intervention and interference.</td>
<td>Admitting the inherent tensions between immediate and long-range autonomy; considerations may often be secondary to immediate ones; developing a calculus of care that counter-balances present/limited with future/global autonomy.</td>
</tr>
</tbody>
</table>
Appendix T – Autonomy Polarities (continued)

<table>
<thead>
<tr>
<th>Polarity</th>
<th>Inherent Risks</th>
<th>Possible Correctives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative vs. Positive (choice/activity that claims a right only to non-interference vs. that which claims positive entitlement, support, capacitation)</td>
<td>Defining autonomy only in terms of non-interference, thereby encouraging a laissez-faire response to harmful choice and behavior; defining autonomy in positive terms that do not recognize scarcity of resources; defining enhancement as a license for intervening in spheres where the elderly themselves want only a non-interfering commitment to their autonomy.</td>
<td>Developing balanced interplay between positive and negative notions of autonomy; admitting and protecting primacy of the negative definition (non-interference); moving beyond this minimum to explore caregiver obligations to enhance autonomous choice and activity among the elderly.</td>
</tr>
</tbody>
</table>