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TRANSITIONS IN THE ELDER: CHANGES WHEN ENTERING A LONG-TERM CARE SETTING

A Masters Thesis presented to the Faculty of the
Graduate Program in Occupational Therapy
Ithaca College

In partial fulfillment of the requirements for the degree
Master of Science

by

Christine Slocombe

January/2012

Ithaca College

School of Health Sciences and Human Performance

Ithaca, New York

CERTIFICATE OF APPROVAL

This is to certify that the Thesis of

Christine Slocombe

Submitted in partial fulfillment of the requirements for the degree of
Master of Science in the Department of Occupational Therapy, School of Health Sciences
and Human Performance at Ithaca College has been approved.

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Date: January 31, 2012

Abstract

The transition to a long-term care facility may be traumatic for elders and result in decreased quality of life as well as a multitude of other changes including role and routine changes. Occupational therapy for residents in long-term care (LTC) facilities is typically focused on rehabilitation, because insurance companies will not reimburse occupational therapy for assistance with adjustments. The objective of this study was to deter-mine the relationships between quality of life and roles and routines during the transition to LTC.

The researcher qualitatively and quantitatively analyzed the results of a Hyland rating scale of Global Quality of Life as well as the Occupational Circumstances Assessment Interview and Rating Scale (OCAIRS). The study was inclusive of 12 elders aged 60 or over who had entered one of two skilled nursing facilities within the past year and who were judged by the referring staff member to have the cognitive ability to remember life prior to their transition to LTC. Participants reported a statistically significant change in mean quality of life based on two administrations of the Global Quality of Life scale, one for prior to entering the facility and one for current quality of life. The researcher analyzed this using a Wilcoxon signed rank test with a Z score of -2.034. A Spearman's rho correlation revealed significant correlations between current quality of life and the OCAIRS sections of "habits" ($r = 0.608$) and "skills" ($r = 0.661$). Other variables had relationships with current quality of life that were not statistically significant given the small sample size. Other areas considered in more detail include social environment, roles, goals, and interpretation of past experiences. Participants lost an average of 1.2 roles through the transition. Considerable additional research is needed to further address the relationship between quality of life and roles and routines and to assist occupational therapists in understanding how to best advocate for and serve clients during the transition into LTC.

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Dedication

I would like to dedicate this thesis to my grandmother

Helen Kolar Van Order

whose experiences and quiet wisdom inspired me to ask the questions of this work and whose strong will and peaceful strength will forever lead the women of her matronage to advocate for those whose voices may be harder to hear.

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Transitions in the Elder: Changes When Entering a Long-Term Care Setting

Chapter 1: Introduction

Background

Deciding where an elder should live is often complicated and emotional for the entire family. As families discuss the possibilities, weighing heavily on their minds is how the elder will like his or her new home. How will that individual settle in? Will it serve that person's needs and make the person happy? Finding the right place for an older family member can be a challenge, and even once the individual is there it is not always a positive experience. As the world reaches a time when the baby boomer generation is becoming the elder population, the demands on places that house and serve elders are increasingly higher. By the year 2030, there will be a predicted 55 million persons aged 65 and older (Winston, 1981, p. 635). More than ever it is essential that elder care facilities continue to examine all that they do in an effort to improve their services and create the best possible experience for the clients they serve.

Many things change when elders enter a nursing home, regardless of where they were living previously. Transitions are always challenging, but the switch to a nursing home typically means a loss of independence for the elder. As an elder moves in and familiarizes with a new place, their space is often smaller and there is often less freedom to arrange the room and entertain guests. Many elders may lose one or more roles that they used to fill, such as that of a host or hostess. The elder who was once able to invite people into her home and offer refreshments may now feel rude when dinner comes and she is eating in front of her guest, for example. The loss of control over the environment and the consequential frustration of changing and/or losing roles are likely to affect the life satisfaction of the person in the long-term care facility.

Similar to the loss of control elders experience in their roles is their loss of power over their routines. In their homes or assisted living facilities, elders chose what time to get up in the morning, what order to do things in, when to go to bed, what to wear, and often what time to eat during the day. In the nursing home these events are often scheduled around the times that work for the staff, and may be at different times than what the elder is accustomed to. These changes in routine may have an effect on the elder's quality of life.

This literature review will examine the existing literature on quality of life of elders, particularly as they transition between different living spaces. It will explore research that shows the ways in which roles and routines may affect quality of life and also what research says about elder roles and routines. Finally, it will identify the lack of research looking at the connection between quality of life and roles and routines in elders transitioning between living spaces.

Problem

Occupational therapists treating elders are encouraged by the processes of insurance reimbursement to focus on activity and self-care occupations (Brown, 1999). Despite theories that emphasize the importance of routines and roles, there is not enough research to highlight the importance or to suggest a means of intervening into the routines and roles of elders in a way that will benefit them. Though many studies have explored differences in quality of life and life satisfaction connected with living environment, no studies have looked at how routines and roles differ based on living environment. One study looked at the correlation between role maintenance and life satisfaction in elders; however, no one has connected the relationship with living environment or transitions between residences. There is an ongoing search to discover the determinants of quality of life, yet this search has seldom been connected with roles and routines, factors which may often become increasingly important in times of transition.

Rationale/Significance

If routines and roles change with living environment in a way that negatively correlates with quality of life, occupational therapists can begin to incorporate this into their therapy. Occupational therapists can assist elders in maintaining as many of their roles and routines as possible by helping elders to advocate for themselves within the institutional setting. They can also assist in coping mechanisms in the event of roles and routines that cannot be carried over between living environments. One group of researchers even proposed more specifically that occupational therapists could assist elders in using "selection, optimization, and compensation strategies" to help elders to find a way to maintain their involvement in important roles (McKenna, Broome, & Liddle, 2007, p. 282). On a more institutional level, occupational therapists can help advocate for changes in institutional routines in order to make transitions into these settings as routine continuous as possible for elders. Occupational therapists can therefore play an important role in increasing the quality of life, and hence the entire well-being, of elders transitioning into nursing home settings.

Definition of Terms

Elder: One with the "historical, *being*-rich (as opposed to *doing*-rich) responsibilities of making peace, giving wisdom, and creating a legacy" (Thomas, p. 226)

Quality of Life: "Individuals' 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 (World Health Organization, 1997, p. 1).

Roles: "Incorporation of a socially and/or personally defined status and a related cluster of attitudes and behaviors" (Kielhofner, 2008, p. 19)

Routine: a structure through which occupation is organized (Clark, 2000, p. 127S)

Habits of Routine: "help us locate effectively within the stream of time…they create the overall pattern by which we go about our various occupations" (Kielhofner, 2008, p.56).

Purpose

The purpose of the study is to determine if elders transitioning into a nursing home living environment will experience a decreased quality of life, and to determine if this decreased quality of life is correlated with changes in roles and/or routines.

Chapter 2: Review of Literature

A Brief History of Geriatrics in Occupational Therapy

With the aging of the baby boomer generation, the first of whom turned 65 in 2011, interest in geriatrics is on the rise. In 1961, when geriatrics was a hot topic, the American Journal of Occupational Therapy produced one issue (4) with a multitude of articles on geriatric occupational therapy. With the start of activity programs in nursing homes, interest in involvement for occupational therapists was peaking, and the world was beginning to see the profession within nursing homes and activity programs in senior centers (Bengson, 1961). In 1981 the profession was still struggling to move into nursing homes and long term care facilities, and created a Gerontology Special Interest Group as part of the American Occupational Therapy Association (Rogers, 1981). Despite these efforts to bring attention and funding to occupational therapy in geriatric populations, there is still a lack of occupational therapy presence and funding in long term care facilities. According to the Centers for Disease Control and Prevention (CDC), in their 2004 survey only 68.7% of nursing homes reported that they have "therapy services" (Jones, Dwyer, Bercovitz, & Strahan, 2009, Table 2). Though their survey did not measure occupational therapy services individually, it indicates a similarity between contemporary nursing homes and those in 1981, when "only the most advanced programs have turned to the professional competencies of the occupational therapist" (Winston, 1981, p. 637). In an environment where Medicare is most often responsible for reimbursement, many therapists must heed Medicare legislation when providing therapeutic intervention. This means that for those nursing homes that do have occupational therapists, therapy must be primarily rehabilitative rather than focused on improving quality of life and ensuring healthy and meaningful transitions because Medicare will not reimburse treatment that is not "medically necessary" (Brown, 1999).

Quality of Life

Over the years, numerous researchers have explored various aspects of quality of life and life satisfaction in order to gain an understanding of how to facilitate the highest quality of life for all people, and for elders more specifically. This research is made ever more confusing by the inconsistencies in the concepts of quality of life and life satisfaction utilized by the researchers themselves.

Quality of life alone is conceptualized by researchers both globally, as the present measure suggests, and also in more subject-specific measures, looking at, for example, "health-related quality of life" (Giles, Hawthorne, & Crotty, 2009). Many measures in themselves define the contributing factors of quality of life, among them the WHOQOL, the measure developed by the World Health Organization (WHO) itself. This measure includes six categories that together make up quality of life: physical health, psychological, level of independence, social relationships, environment, and spirituality/religion/personal beliefs (World Health Organization, 1997, p. 4).

The confusion over separating the concepts of quality of life and life satisfaction is also compounded by research articles that claim to measure one by their title but the other by the title of the measurement instrument utilized. Still other studies use one term in their definition of the other. Take as two examples an article titled "Subjective Life Satisfaction and Objective Living Conditions of Patients with Schizophrenia in Nigeria" that utilized the WHOQOL, and another titled "Clinical Validation of the Quality of Life Inventory: A measure of life satisfaction for use in treatment planning and outcome assessment" (Adewuya & Makanjuola, 2010; Frisch, Cornell, Villanueva, & Retzlaff, 1992). When quality of life and life satisfaction are used thus, both broadly and interchangeably by researchers themselves, it is easy to see how the concepts may

become confused. It is best then to settle on one definition for the purposes of this review. The World Health Organization (WHO) states that quality of life is "a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment," a definition clearly linked with its quality of life measure (1997, p. 1).

Despite the difficulty of understanding quality of life, a host of research has attempted to find correlates in the older adult population in order to understand what might create greater quality of life for elders. Factors that continually appear in research include physical environment, social environment, occupations or activities, and transitions.

The theme of physical environment manifests in varying vocabulary, beginning with the explicit term itself. A study using the WHOQOL-BREF and the WHOQOL-OLD to study cognitively intact Canadians and Norwegians aged 60 and over found it to be the most unquestionably clear contributing factor to quality of life (Low, Molzahn, & Kalfoss, 2008, p. 468). Two other studies considered quality of life differences dependent on housing. One found lower quality of life, according to a collection of 10 visual analog scales, for individuals with higher levels of mobility and cognition living in nursing homes as compared to their community-dwelling counterparts (Karayaka, Bilgin, Ekici, Köse, & Otman, 2009, p. 33). Similarly, a second found lower quality of life in nursing home residents compared to those in "personal dwellings" and "specialized housing," according to the Flanagan Quality of Life Scale (Crist, 1999, Table 2). When asked in an open-ended format what contributed to their quality of life, nursing home residents in a study by McKinley and Adler identified a "homelike environment" specifically, as well as "privacy," among other factors (2005, p. 44). When describing this theme in the responses, researchers cited aspects of control over the environment and/or the routine, as

one participant who described the home setting, "[You] 'go to bed when you feel like it. It's important'" as contrasting with the institution where, as another resident stated, "'pretty much we're told—you do what they tell you'" (McKinley & Adler, 2005, p. 44). Thus the physical environment is unmistakably a contributing factor to quality of life, labeled as such or as housing, privacy, or homelike environment, and encompasses much beyond its label, even into the possible realm of routine.

The most important findings to justify the present study are studies that show the differences in life satisfaction and quality of life based on living environment. One such study found that in people independent in activities of daily living, "meaning of home" aspects of activity had a significant association with life satisfaction (Iwarsson, Horstmann, & Slaug, 2007, p. 9). This included aspects of the meaning of home including activity, cognitive/emotional, physical, and social factors, as measured by a Meaning of Home Questionnaire developed by the authors (p. 8). Though the population of the study dependent in personal as well as instrumental activities of daily living was small, it showed a much higher impact of living environment on life satisfaction. A Japanese study echoes these findings, reporting that the morale of elders with self-care dependence was lower than that of elders who did not require assistance with self-care, and that their morale was even lower if they also lived in a nursing home rather than with family (Kudo, et al., 2007, p. 16). The former study also mentions that most recent gerontological studies have focused on personal characteristics of elders rather than characteristics of the environments in which they live, leaving a gap in research surrounding this area (Iwarsson, et al., p. 9). Finally, a study comparing life satisfaction and mood in nursing home residents and community-dwelling elders found that community-dwelling elders had significantly higher life satisfaction and scored higher on the Vigor-Activity subscale (Gueldner, et al., 2001, abstract).

In addition, "Nursing home residents scored higher on the Depression-Dejection, Tension-Anxiety, and Confusion-Bewilderment subscales of the Profile of Mood States" (Gueldner, et al., 2001, abstract). Clearly differences exist in quality of life and life satisfaction between different living environments.

In considering the physical environment, the social environment inevitably becomes part of the conversation. Many of the aspects of the physical environment often influence the social environment, as "privacy" does; that is, though privacy is defined by the physical environment, its indications are social in nature. One nursing home resident interviewed in the McKinley and Adler study discussed above sites the example that, "[I] 'dropped out of two clubs because I didn't have room to entertain'" (2005, p. 45). Feeling that one has a physical place in which to invite social interaction is an essential precursor to the interaction itself and thus in turn to an increased quality of life. The ability to entertain such interaction also allows a person to take on a role of host or hostess, which hints at the possibility of role fulfillment as an important contributor to quality of life. This same study also describes themes of generativity and spiritual well-being as contributors to quality of life, both of which may be related to roles that are important to individuals.

Relationships with family and friends are undoubtedly part of the social environment, and a part that Crist identified, in the study outlined above, as being important in determining quality of life. In fact, "individuals living in nursing homes rate family relationships as the most important factor affecting their quality of life" (Crist, 1999, p. 112). Another study used these relationships directly to inspect subjective quality of life in 303 "participants of senior centers" and 299 "residents of planned housing for older people," through the three categories of "Family Quality," "Friends Quality," and "Time Quality" (Lawton, Winter, Kleban, & Ruckdeschel,

1999, p. 177). Not surprisingly, family contact was correlated with the overall rating of family quality, indicating higher levels of family quality for individuals with more family contact, and similarly friend contact was correlated with the overall ratings for friends quality and time quality (Lawton et al., 1999, Table 2). These family and friend aspects of the social environment are similarly indicative of the importance of the roles to quality of life, though none of these studies considered roles.

Another way to conceptualize roles is related to the activities or meaningful occupations with which one fills his or her time. This is another area that has been linked, through research, to quality of life. The study described above by Lawton, et al., found a correlation between activity participation and both the categories of friends quality and time quality (1999, Table 2). This would indicate a relationship between friend quality and time quality with the way an individual spends his or her time, specifically the level of "activity participation;" a conclusion that, in turn, would suggest a relationship between activity participation and overall quality of life. Another study seeking to prove the benefits of occupational therapy, commonly known as the Well Elderly Study, provided meaningful occupation for independent-living older adults in a randomized controlled trial (Clark et al., 1997). As compared with peers in control groups receiving no treatment or participating in a social group, the participants in the occupational therapy group had higher levels of life satisfaction, as measured by the Life Satisfaction Index-Z (p. 1324). The treatment for these participants consisted of two hours of an occupational therapy group per week and nine hours of individual treatment in total over the nine-month treatment period, all centered on the theme of "health through occupation" (p. 1322). It seems clear, therefore, that activity and occupation positively contribute to quality of life in elders.

Despite the research suggesting the relationship of physical and social environment as well as occupation to quality of life, one area as yet considered little in research is the transitions of elders. The researcher found one study alone that reported on transition as it relates to quality of life, looking at the WHOQOL-BREF and WHOQOL-OLD in cognitively intact elders living in a variety of settings in Canada (202 participants) and Norway (490 participants) (Low, Molzahn, & Kalfoss, 2008). Using the Iowa model for gerontological nursing, this study found that both cognitive developmental transitions and social support transitions were contributing factors to overall quality of life. Alone, this research is incapable of proving any conclusion about transitions as they relate to quality of life, and indicates a need for further research.

As evidenced above, research on quality of life in elders is too broad and disorganized to condense into a true understanding of the contributors. Through the research above, it is possible to conclude with some level of certainty that physical environment, social environment, and occupation relate to quality of life.

Routine

The concept of routine is far more concrete and thus more easily researched than that of quality of life. Despite this fact, most of the research conducted thus far has related to the theoretical construct of routine and barely begins to scratch the surface of understanding routine fully. Florence A. Clark defines routine as "a structure through which occupation is organized," where occupations "can be thought of as the building blocks of one kind of routine, daily routines" (2000, p. 127S). Though this definition captures the broad scope of routine, Ludwig's explanation is perhaps more concrete: "the orchestration of specific consistent occupations into a fixed sequence in linear time, such as getting up at 7a.m., toileting, brushing one's teeth, and dressing" (1997). In either case, one can conceptualize that routines are so embedded in

everyday life that they are simple to overlook but important to consider, particularly when continuity is considered. Atchley explored this concept through "continuity theory," suggesting that people will look for continuity by engaging in routines or, "occupational patterns" that are familiar, or in other words, "consistent with their life experience" (1989, as cited in Ludwig, 1997, p. 218).

Though Atchley considered the continuity that routines implicate, it was Gary Kielhofner who helped routines assume their permanent place in occupational therapy and occupational science when he first published his Model of Human Occupation (MOHO) in 1980. This theory suggests that all human beings operate through a systems model of input, throughput, output, and feedback (Kielhofner, 2008). Within the throughput category, which occurs within the person, are three subsystems: volition or occupational choice, habituation, and performance. Literature and discussion have connected habituation with routine. Kielhofner suggests that developing habits and routines is adaptive and makes people more efficient in their everyday lives by allowing them to go about their occupations somewhat unconsciously. When one climbs into the shower each morning, one does not think of each individual action within the shower. Though there can be some variation, the basic habits give people the opportunity to think about other things as they go through their daily routines (Clark, 2000). Aside from the role of routine in motor learning and the cognitive attention required for completing occupations, others have explored routine as it relates to neurological processing and personality.

Dunn suggests that given changes in "biobehavioral status, environmental changes, and schedule changes" as well as the familiarity of a situation, a person's neural threshold will change (2000, p. 9S). That is, the more different a situation is, the lower the threshold is likely to be, indicating a higher level of sensitization and a lower level of habituation. The tolerance for

this lowered threshold can be measured by routinization factors, so termed by Reich and Zautra (1991), which describe the individuals' threshold for variability in a habit, routine, or activity. It was Kastenbaum who first theorized about "habituation" in such a way that it connected with the nervous system. He suggested that novel experiences or experiences with novel components would cause anxiety and therefore be rejected (Reich & Zautra, p. 162).

Reich and Zautra suggest that such rejections are indicated by character traits: an affinity for having daily order and routine (Factor I) and disliking disruption (Factor II). In their study, researchers conducted interviews once a month for ten months with older adults 60 to 80 years of age who had recently experienced bereavement or physical disability. They then provided "personal control/mastery treatment" intervention to one of three groups (the experimental group). They compared this to a placebo group that met with those providing the intervention but did not receive intervention, and a control group, made up of older adults who had not recently experienced such events as physical disability and bereavement, that simply continued with monthly interviews (p. 165). The study found similar scores on the characteristics of "Having Daily Order and Routine" and "Disliking Disruption," which implicates these characteristics as more stable "personality traits" (p. 172). The study also found that providing the aforementioned intervention for personal mastery increased distress and decreased well-being in those with high levels of disliking disruption. This suggests that for these individuals, trying to change their habits and routines was detrimental to their psychological health. In another study of 72 older adults, both participants with low levels of perceived health and those with higher levels of restriction to their activities of daily living (ADLs) adapted better if they had high levels of routinization (Williams, 2000, Figure 1a). For individuals with high levels of these routinization characteristics, or who have low levels of perceived health and more ADL

restrictions, it would therefore be best for their well-being to maintain routine and order, particularly in circumstances of change, such as a changing living environment.

Dunn discusses this very discomfort with novel experiences relative to the nervous system, using the concepts of "sensitivity to stimuli" and "sensory avoidance." Individuals with increased "sensitivity to stimuli" have "lower neurological thresholds," meaning that they take in more information than others and react more strongly to it because their neurological system cannot adjust to process the high volume of information (2000, p. 14S). By contrast, sensory avoiders have "variable neurological thresholds" (p. 16S). Because of their active response to these varied thresholds, "sensation avoiders" need "predictability" (continuity of habits and routines) in order not to overwhelm their nervous systems (p. 16S).

Both sensory avoiders and individuals with sensitivity to stimuli need habits and routines to be consistent in order to keep from overwhelming their neurological systems. For sensory avoiders, their active responses to variability in neurological threshold levels leads them to avoid novel experiences because in so doing they are avoiding new input that might cause firing of the thresholds (2000, p. 16S). Individuals with sensitivity to stimuli, by contrast, are avoiding novel experiences in order to prevent a need for their neurological systems to take in the increased input that their low thresholds are encouraging. In other words, if they do not take in new information, their nervous systems can continue to function even with their low thresholds for novel stimuli. Moving to a new living environment provides a multitude of novel stimuli that may be traumatic to the nervous systems of the individuals undergoing this experience. This suggests the possibility that intervention is necessary for sensory avoiders and individuals with sensitivity to stimuli at any time that they experience the potentially traumatic event of routine change, particularly in the case of moving or relocating.

Aside from the research available surrounding routine as a construct, two studies specifically looked at the continuity of routines for residents in nursing homes. One study found that care assistants did not "adhere" to bedtime rituals from before residents moved to the nursing home (Warner, 1997, p. 36). They did however incorporate "pre-sleep rituals followed by the residents" that were pre-existing. In this same study, nursing home residents indicated that they felt they did not always have control over their bedtime, but rationalized the change, stating, "I'm used to it now" (p. 37).

The second study found a "45% overall concordance between previous and current self-care practices" (Jensen & Cohen-Mansfield, 2006, p. 246). Researchers drew this conclusion through use of the Self-maintenance Habits and Preferences in Elderly (SHAPE) questionnaire with certified nursing assistants (CNAs), residents, and their spouses. Perhaps most striking is the 99% of CNAs who, when asked about eating, dressing, and hygiene routines of residents prior to entering nursing home care, stated, "I don't know," along with the similarly appalling 98% relative to sleeping routines (Table 4, p. 249). As the study identified, continuity of these important routines is "largely constrained by nursing home schedules, which are often inflexible with regard to resident wishes or past practices" (p. 249).

The dichotomy between the theoretical importance of routines and the respect for routines in nursing home settings indicates a need for further research. The research supporting the meaning of routines extends beyond occupational patterns in time and is easily interwoven with the concept of roles. Clark suggests that "routine and habit may play an important role in the construction of the self," a statement that echoes the implications behind Atchley's continuity theory and emphasizes the connection between routines and roles (Clark, 2000, p. 132-133S). The concepts of routine and role are perhaps linked best by their sheer proximity in the words of

Arnold Beissner on his experience with polio: "...More important...[than the physical impairment] was being separated from so many of the elemental routines that occupy people...I felt no longer connected with the familiar roles I had known in family, work, sports. My place in the culture was gone" (1988, pp. 166-167, as cited in Clark, 2000, p. 124S).

Roles

Just as Clark and Beissner connected routines and roles theoretically, when Gary Kielhofner introduced his Model of Human Occupation (MOHO), it not only encompassed routine but also considered roles as a primary factor in human occupation. Kielhofner identifies roles as part of habituation, which he defines as "an internalized readiness to exhibit consistent patterns of behavior guided by our habits and roles and fitted to the characteristics of routine temporal, physical, and social environments" (Kielhofner, 2008, p. 18). Habits, he maintains, eventually become automatic, after repeated action. MOHO further explains that this is, in fact, the purpose of habits, and thus of roles and routines (p.16). MOHO also suggests that environment has a fundamental "influence" on "any aspect of a person" (p. 12). This would then imply that environment has an important relationship with roles, one that thus far has been studied minimally.

One study has looked at roles and life satisfaction, but not in any relation to environment. A study completed in Australia found that participants, who were 65 and older, had an average of six roles (McKenna, Broome, & Liddle, 2007, p. 279). This reflected a change in roles, in this case two roles fewer than the participants previously had. The study emphasized the importance of roles, finding that 80% of roles are "very valuable." Greater role loss was correlated with lower life satisfaction, particularly with increasing age. Though the researchers clearly established a correlation, it is necessary now to take the research a step further and attempt to

understand the cause of the role loss and how to address the negative psychosocial consequences of that loss.

The limited research considering roles has found that nursing home residents tend to take on a "sick" or "residential" role and to lose social roles. In a study comparing semi-structured interviews of individuals living in their own homes with those living in residential homes in the United Kingdom, residents in residential homes, "appeared to have adopted a dependent sick role and passively conformed to a residential identity" (Hearle, Prince, & Rees, 2005, p. 29). In addition, these individuals made more "negative, self-deprecating comments" than their home-dwelling counterparts (p.28). They talked more about what they could not do relative to "health status," and thus took on identities and cultural mores of dependence. More specifically, the identities of the individuals in the residential home were "subsumed by the culture of the home, whereas older adults living at home adopted active and varied roles that were self-directed and expressed their individual identities" (Hearle, Prince, & Rees, 2005, p. 29). This research merely scratches the surface of the research needed to understand roles and role loss specific to the nursing home population.

Surprisingly, some research surrounding this population includes roles but fails to label them as such. One study on transitions, conducted by two registered nurses, followed 10 residents from within one week of admission for three months. Each was instructed to "tell me a story about what it is like for you to come here and live" (Heliker, & Scholler-Jaquish, 2006, p. 36). Phenomenological analysis of the data found three themes: becoming homeless, getting settled and learning the ropes, and creating a place (Heliker, & Scholler-Jaquish, 2006). Becoming homeless included "losing a sense of self," which represents significant role loss. One resident stated of her peers and staff, "'They don't know the meaning of me!'" (Heliker, &

Scholler-Jaquish, 2006, p. 38). This implies the discomfort behind a discontinuity in roles, wherein those surrounding a person do not know his or her roles in order to encourage engagement in past roles. Another resident stated, "'You don't know what it's like...you lose your identity for being able to do what you want to do when you want to do it'" (Heliker, & Scholler-Jaquish, 2006, p. 38). It seems feasible that this loss of control may in some ways represent a loss of the role of being an independent adult. Within the realm of "getting settled and learning the ropes" is "becoming known and knowing others," a label that in itself indicates a discontinuity in social roles. One resident whose husband was living in another unit of the same facility expressed her loss of her role as a spouse thusly: "'The hardest thing is the nights...I expect my husband to walk through that door...it's like being a widow'" (p. 39). While she still feels responsible for the role of a spouse, she has no control over this role because she can only visit under the direct supervision of a nursing aide. Similarly, transdisciplinary research emphasizes the changes in social and family relationships in nursing home care, indicative of, though not labeled as, social role losses (Crist, 1999; Shippee, 2009). One wonders if, given the interpretation of a trained occupational therapist with an eye to the construct of roles, these studies could draw more conclusions relative to roles and routines, given the expertise that occupational therapy programs cultivate in these areas.

The only study found by this author that looked at the effect of related occupational therapy intervention was not specific to individuals in long term care but rather looked at independent living elders aged 60 and over. The Well Elderly Study, as mentioned above, found significantly better results in an OT treatment group as compared with a control group in a multitude of areas including life satisfaction (based on Life Satisfaction Index-Z), role limitations attributable to health problems, and role limitations attributable to emotional

problems (Clark, et al., 1997, p. 1324). Treatment was focused on the idea of "health through occupation." The research available surrounding role changes during the aging process or during transitions into nursing home care is sparse, with small sample sizes and few if any repeatable studies. Occupational therapy interventions in the realm of role loss are non-existent or undocumented, despite the apparent need for increased assessment and intervention.

Environmental Transition

Transition in living environment may be the missing link to understanding some of the role loss that occurs in the aging population. Transition in general is neither well understood nor researched. In fact, most of the literature surrounding transition is purely theoretical, largely published within the field of nursing. Two theories, the Ecological Theory of Aging (specifically the Person-Environment Fit Model) and the Transition Theory, are used in nursing to consider different living environments. The Person-Environment Fit Model, developed by Lawton, considers both personal competence of an individual, and also environmental press (Young, Sikma, Trippett, Shannon, & Blachly, 2006). It suggests that adaptation occurs when the demands from the environment match the levels of functioning that the individual holds. The transition theory, by contrast, focuses on the transition that occurs in situations where one must change behavior patterns to better adapt to the situation (Young, et al.). Although restructuring routines is seen as part of this transition, the theory also claims to reflect values of continuity, which demonstrates an underestimation of the importance of routine stability.

A host of other models and frameworks suggest phases through which individuals move during transitions. These include the Senses Framework, a Conceptual Model for Understanding Life Crises and Transitions, the Life Event Model, and a Process Model. The senses framework uses the concept of "relationship centered care," wherein care is centered around balancing the

needs of all involved in the care, including the client, the health care team, and the family (Nolan, Davies, & Brown, 2006). It then outlines six senses essential to providing "high quality care:" security, continuity, belonging, purpose, fulfillment, and significance (p. 9). The framework also takes into account the resources necessary to provide the aforementioned senses.

The Conceptual Model for Understanding Life Crises and Transitions considers "general determinants of outcome" that interact to create a "resolution phase," which results in an "ultimate outcome" wherein the individual either transitions to the nursing home successfully or experiences a "crisis" (Moos & Schaefer, 1986, as cited in Brandburg, 2007). The Life Event Model similarly identifies three dimensions: "characteristics of the particular transition, characteristics of the individual, and characteristics of the pretransition and posttransition environments" (Schlossberg, 1981, as cited in Brandburg, 2007). Finally, the Process Model conceptualizes the transition as "three phases: endings, the neutral zone, and new beginnings" (Bridges, 1980, as cited in Brandburg, 2007).

Nicolson (1990) by contrast suggests four stages of transition that exist in a cycle: preparation, encounter, adjustment, and stabilization (Figure 2, as cited in Blair, 2000). Adams, Hayes, and Hopson (1976) suggest seven steps: immobilization, minimization, depression, acceptance of reality and letting go, testing, search for meaning, and internalization (Figure 1, as cited in Blair, 2000). All the above are general transition theories, but Brooke (1989) suggests four "phases of adaptation" specifically for individuals entering a nursing home: disorganization, reorganization, relationship building, and stabilization (as cited in Mikhail, 1992). Despite their many theories, researchers and theoreticians cannot seem to reach a consensus.

Research itself tells little of transitions, and no ideas have undergone sufficient research to state facts. The limited research available suggests that a person's control over the situation is

important in determining the success of his or her transition. This control relates to a number of decisions, beginning with the decision to enter the nursing home. One study found that the more individuals wanted to move the more involved they were in nursing home activities and the higher their satisfaction with services (Reinardy, 1995, Table 1). Control also includes power over the actual transition, i.e. when to move, where to move to, how to set up in the new environment. According to a study by Magilvy and Congdon (2000), "unanticipated" transitions are more traumatic (p. 339). Finally, the more decisions the person can make in the new environment, the higher his or her life satisfaction will be (Schulz, 1987, as cited in Rehfeldt, Steele, & Dixon, 2001).

One thing people can control is their own social networks. A study by Rehfeldt, Steele, and Dixon (2001) found a positive correlation between life satisfaction and social networks. The significance of such a correlation is highlighted by the 70% of participants who reported a "decrease in the number of close ties they felt they had with others following their relocation" to a nursing home (Rehfeldt, Steele, & Dixon, 2001, p. 29). In addition to a sense of control affecting social decline, the research suggests that many individuals enter nursing home care with undiagnosed psychological issues or develop psychological conditions following the move to the nursing home (Rehfeldt, Steele, & Dixon, 2001). This indicates a profound need for additional research and intervention development in this area.

Some research surrounding transitions has attempted to categorize aspects that affect the transition, such as motivational styles of the individuals involved, as well as adjustment styles and influences. Curtiss, Hayslip, & Dolan (2007) used the Elderly Motivation Scale to determine the motivational styles of 75 older adults living in a nursing home residence. Each individual was then classified as either "amotivational," "non-self-determined extrinsically

motivated," "self-determined extrinsically motivated," or "intrinsically motivated" (p. 18). They found that individuals with more self-determined motivational styles adjusted better to nursing home life (p. 26). Similarly Porter, Clinton, and Munhall classified 11 "adjustment approaches" and 4 "adjustment influences" identified in elders adjusting to nursing home life (1992). The adjustment approaches include: reframing, getting used to it, going along, confronting change, extending, fitting in, fitting in by not fitting in, doing one's best, renaming, keeping quiet, and obeying (p. 469-472). These adjustment approaches emphasize the many different ways of dealing with transitions that are still being explored. The four adjustment influences are factors that cause or "influence" the individual's approach to adaptation to the nursing home life. These include: "transfer circumstances, life history, person-environmental mesh, and belief in the only option" (p. 472). One must consider the possibility that these motivation and adjustment styles are closely connected with the changes experienced throughout the life of the individual and his or her response to those changes.

A third study identifies important "relocation transition styles" (Rossen & Knafl, 2003). A study of older women in residential relocation situations, it found that women moving to institutional facilities are "at risk for negative outcomes such as poorer health, decreased self-esteem, increased sense of social isolation and loneliness, loss of social support, and depression," according to their relocation transition style (Rossen & Knafl, 2003, abstract). What could prevent these negative outcomes? Maintaining independence and control, as well as perceived choice, the study suggests. The study also showed "emergent life pattern" to be an important predictor of life satisfaction following relocation. "Launching and continuing" patterns were associated with the style of "full integration," which resulted in the most satisfaction, while "restructuring, sorting out, and marking time" patterns were associated with "minimal

integration," leading to lower levels of life satisfaction (Rossen & Knafl, 2003, Table 3). This indicates an importance in the beginning of the transition to help initiate a "full integration" style, which therapeutic intervention could assist with.

Living environment usually offers a place for habituation to occur, creating habits and routines that can occur only in that location. The unfortunate challenge is that circumstances often make it impossible to remain in the familiar living environment that might best suit the habituation of the individual. Rowles therefore suggests that relative to control and change, "the trick is to reconcile the two by preserving, or creating and sustaining, habitual modes of being in place that maximize well-being and quality of life without limiting the autonomy and freedom of the individual" (Rowles, 2000, p. 60S). Put another way, Rowles suggests carryover of as many roles and routines as possible, with assistance to create healthy new roles and routines as necessary given what is pragmatic. Given the many factors at work during a transition, one might question which professionals should be involved in assisting an individual through transition into a nursing home. If the individual is coming from the hospital or another facility, discharge planning will likely be included in the process. If however the individual is coming from home, a transition more dramatic than any other, there is typically no discharge planning as the individual is not discharging from any location (Magilvy & Congdon, 2000, p. 341). It is therefore the responsibility of those receiving the patient in the nursing home setting to ensure a healthy transition.

Chapter 3: Methods and Procedures

The following will outline the researcher's methods in conducting the research and analyzing the results. This includes the procedures of recruiting and interviewing participants, in addition to the measurement instruments used and the data analysis techniques utilized. The researcher began with the research questions outlined below.

Research Questions

1. Does transition in living environment affect life satisfaction in elders moving into nursing homes?
2. Do elders maintain roles when transitioning between living environments?
3. Do elders maintain routines when transitioning between living environments?
4. Do changes in roles correlate with changes in life satisfaction in this population?
5. Do changes in routines correlate with changes in life satisfaction in this population?

The researcher developed additional research questions throughout the process of collecting and analyzing data:

1. How does personal causation relate to quality of life?
2. How do the values of participants relate to quality of life?
3. Is there a relationship between the affect of interests on occupational performance and quality of life?
4. Is there a relationship between skills and quality of life?
5. How does an individual's readiness for change affect his or her quality of life through the transition of entering long-term care?
6. What is the relationship between the physical environment and quality of life?
7. What suggestions do participants have to improve their experiences of the facilities in

which they live?

8. Is there a correlation between the number of roles and quality of life?
9. Is there a correlation between individuals who spend time alone and quality of life?
10. Is there a correlation between social support and quality of life?
11. Does the formation of goals relate to quality of life?
12. Is there a relationship between being able to choose the important things in life and quality of life?

Hypothesis

The researcher hypothesized that elders transitioning into a nursing home living environment would experience decreased quality of life, correlated with changes in roles and routines.

Participants

Prior to initiating contact with participants, the researcher submitted a proposal and received approval from the Occupational Therapy Department at Ithaca College on September 9, 2010. Following this approval, the All-College Review Board for Human Subjects Research (HSR) at Ithaca College also read and approved the study with stipulations on September 23, 2010 and in full on October 14, 2010. The original proposal included solely Beechtree Care Center. When it became clear to the researcher that she would not have ample participants from Beechtree Care Center alone, the researcher submitted revisions to the Review Board to broaden the study to additional locations. This addendum was approved November 18, 2010.

Participants in this study were elders who had recently transitioned into a nursing home setting. "Recently" was defined as within one year. Each individual was at least 60 years old and identified as someone who was cognitively aware enough to remember life prior to entering

long-term care. Additionally, each individual was residing in the skilled nursing facility in a long-term capacity, as identified by the referring staff member at the long-term care facility.

Exclusionary Criteria

Nursing home residents who were residing temporarily in the nursing home for rehabilitative purposes were excluded from participation in the study. This exclusion was made to narrow the population being studied and to focus on those who will remain in the nursing home more long term, as those individuals may be more permanently affected by a decrease in quality of life and may not have similar occupations as those participating in the rehabilitative process.

Nursing home residents who are not able to communicate either verbally or through written communication were excluded from participation in the study. Due to the interview-style administration of the study and the complex nature of the questions, analyzing other forms of communication would be outside the scope of this study.

Nursing home residents whose memory rendered them incapable of comparing between living environments were also excluded from the study. The main purpose of the study was to determine differences between living environments, which was only possible if participants were able to remember prior living experiences. The determining factor for this exclusion was the referral of participants by a staff member. At Beechtree Care Center, this staff member was the individual in charge of admissions in conjunction with the Activities Director. At Cayuga Ridge Health and Residential Community, this was the Activities Director.

Finally, individuals under the age of 60 were excluded from the study based on the definition of elders that has been used in most research surrounding this population. Using another operational definition of the "elder" or "older adult" group would prevent the application

of research on a 60+ "older adult" population.

Recruitment

Following approval by the All-College Review Board for Human Subjects Research (HSR) at Ithaca College, the researcher approached each of two facilities for permission to approach residents at that facility. Selected staff members referred participants to the researcher based on the criteria for inclusion outlined above. After administrators at Beechtree Care Center and Cayuga Ridge Health and Residential Community approved the study, the Activities Directors at both facilities identified for the researcher all appropriate candidates. At Beechtree Care Center the Admissions Coordinator and Director of Development & Community Relations assisted the Activities Director in referring appropriate individuals. The researcher then approached each individual privately to inquire about his or her willingness to participate in the study.

Measurement Instruments

The researcher utilized two different measurement instruments for this study: a Global Quality of Life measure and the Occupational Circumstances Assessment Interview and Rating Scale (OCAIRS), both of which are outlined below. The researcher administered the Hyland rating scale of Global Quality of Life twice following the demographic survey; during the first administration, the participant was asked to rate his or her quality of life prior to entering the long-term care facility. He or she was then asked to rate current quality of life. Following this, the researcher administered the OCAIRS.

Global quality of life scale.

For the purpose of quickly identifying the self-rated quality of life of each participant, the researcher administered the Hyland rating scale of Global Quality of Life. This rating scale asks each participant to very simply "Write any number between 0 and 100 that describes your quality

of life _____" (Hyland & Sodergren, 1996, p. 480). It also provides a visual scale of 0 to 100 in increments of five, corresponding to quantifying statements spanning from "Might as well be dead" to "Perfect quality of life."

This measurement scale was developed and tested by 197 participants. Participants were asked to place the eight quantifiers along the scale next to the number that "best described the quantifier" (Hyland & Sodergren, 1996, p. 470). The researchers then chose the position of each quantifier based on the mean position. A second portion of the same study tested 12 global quality of life scales, including four category rating scales, four visual analog scales, and four Hyland scales, including the one utilized for the present research study (Hyland & Sodergren, 1996, p. 471). A Hyland scale is defined by the researchers as: "a global QOL scale with labeled end points and eight additional quantifiers placed at defined points along the scale" (Hyland & Sodergren, 1996, p. 471). A group of 19 elderly residents of a residential home participated in the study and rated this scale the "most accurate representation" of their quality of life and tied with one other scale for the "easiest to use" scale (Hyland & Sodergren, 1996, Table 4).

The researcher chose this global quality of life scale due to both its brevity and the evidence-based validity with the elder population.

Occupational Circumstances Assessment Interview and Rating Scale.

The Occupational Circumstances Assessment Interview and Rating Scale (OCAIRS), Version 4.0, uses Gary Kielhofner's Model of Human Occupation (MOHO) (Forsyth et al., 2006, p. 3). It is a semi-structured interview measuring occupational adaptation through the use of 12 sections listed below:

1.Roles
2.Habits
3.Personal Causation
4.Values

5.Interests
6.Skills
7.Short-term Goals
8.Long-term Goals
9.Interpretation of past experiences
10.Physical Environment
11.Social Environment
12.Readiness for change

For each section, the researcher assigns a rating based on a four-point scale, where a four indicates that the area "facilitates participation in occupation," a three indicates that it "allows participation in occupation," a two that it "inhibits participation in occupation," and a one that it "restricts participation in occupation" (Forsyth et al., 2006, p. 11). The interview requires 20-30 minutes for a practiced interviewer or with some clients requires 35-40 minutes, with an additional 5-20 minutes necessary for scoring (Forsyth et al., 2006, p. 4).

The OCAIRS asks qualitative questions about routine, roles, and meaning in occupations and assesses the need for occupational therapy services to assist an individual with occupational adaptation. Its semi-structured format allows the interviewer the freedom to ask additional questions as necessary to grasp the client's perspective more fully.

Reliability.

This study is appropriate for use with a geriatric population (Forsyth et al., 2006, p.3). Inter-rater reliability was measured with an Intraclass Correlation Coefficient (ICC) of 0.88 to 0.96, which shows good reliability (Law, Baum, & Dunn, 2005, p. 87).

Validity.

The discriminant construct validity was measured in relation to Global Assessment Scale with an appropriately different construct (Law, Baum, & Dunn, 2005, p. 87). The criterion-referenced validity was measured in relation to the Assessment of Occupational Functioning, and found to be appropriately similar (Law, Baum, & Dunn, 2005, p. 87). Other measures of validity

were performed on the previous version of the OCAIRS and measured concurrent validity at an r value of 0.86 (Watts, Brollier, Bauer, & Schmidt, 1989, p. 13). This previous version also found that the OCAIRS validly measures the constructs of occupational identity and occupational competence (Lai, Haglund, & Kielhofner, 1999, p. 272).

Analysis and Interpretation of Data

Analysis of the data was both quantitative and qualitative in nature. The researcher analyzed all quantitative data using PASW Statistics 18 using descriptive and frequency statistics, bivariate correlations of Spearman's rho, and a Wilcoxon signed ranks test. The non-parametric Spearman's rho was utilized with all correlations because there was not enough data to create a linear relationship between x and y, and ordinal data analyzed did not contain enough categories. The researcher looked for a significant change in quality of life between measures of the global quality of life scale used in addition to correlations between low quality of life ratings and low scores on the routine and roles subsections of the OCAIRS.

The interview data was also transcribed and analyzed using a phenomenological research method. This research strategy required horizonalization of the data in order to ensure appropriately equal value to each statement made by the interviewee (Moustakas, 1994, p. 123), as well as clustering and textural description to identify and describe themes between participants (p. 97). Because much of the data was the result of questions asked directly by the researcher, answers were categorized and percentages were used to represent common responses. The researcher then performed post-hoc analysis for questions that seemed particularly pointed toward relationships with quality of life by coding and entering additional data into the statistics program and analyzing it with additional Spearman's rho bivariate correlations.

Chapter 4: Results

This chapter describes the demographics of the participants and the quantitative and qualitative results of the study.

Demographics

The researcher collected demographic data in order to understand the likelihood that data would generalize to participants outside of the present study. She also sought to link quality of life changes with other possible contributing factors supported by previous quality of life research. Participants in this study were 12 long-term care residents between the ages of 61 and 93 years of age, with an average age of 80.92 years. When the researcher initiated the interview process, participants were reported by the facility to have been in residence between 9 and 309 days, with an average of 172.42 days since admission. The average participant was male, with a 58 %: 42 % male to female ratio.

All surveyed participants reported involvement in Roman Catholic (25%) or Christian (approximately 42%) religions, or no involvement in any religion (25%), with one individual reporting spirituality not affiliated with an organized religion. Fifty percent (6 individuals) of all participants were widowed, two were married, two separated, one divorced, and one in a long-term relationship without marriage.

Work-related demographic statistics provide information about the typical relationship of participants to their work or previous work. Seventy-five percent of all participants were retired. In addition, one participant responded in each of: not retired, spontaneous involvement in an area of employment, and one participant was a housewife until entering the long-term care facility. Most individuals who were retired had long been retired; 16.67% had retired between six and ten years ago, while another 16.67% retired between eleven and thirty years prior, and another

8.33% retired over thirty years before entering long-term care. By contrast, one individual (8.33%) retired within the past year and one (8.33%) within the past two years.

The researcher categorized vocational information based on the job zones and vocational categories provided by O*NET OnLine, an initiative of the United States Department of Labor (DOL). Fifty percent of participants at one time in their lives occupied vocational positions that required "some preparation" (Zone 2). One individual had no specified job zone (a housewife), while 25% needed "medium" preparation (Zone 3) and approximately 17% needed "considerable preparation" (Zone 4) (National Center for O*NET Development). Participants represented six vocational categories specified by O*NET OnLine, represented in the figure below (Figure 1).

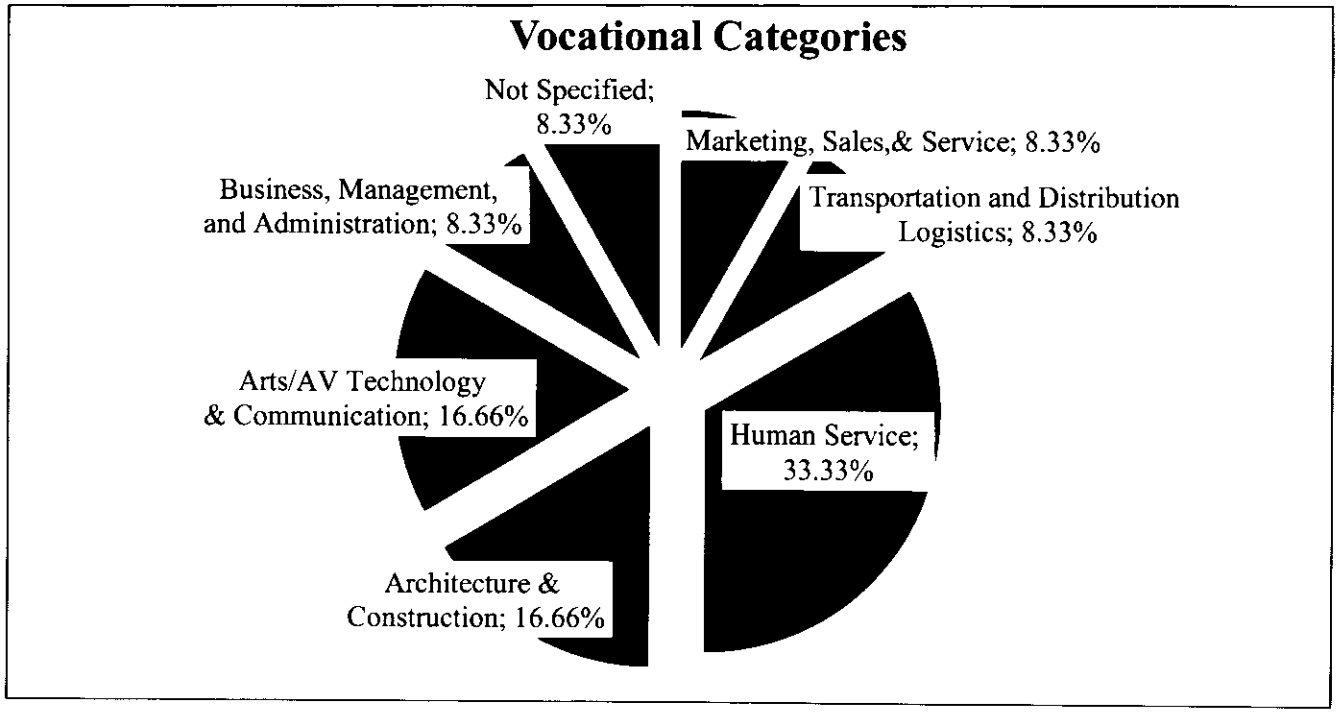


Figure 1. Vocational categories of participants according to O*NET OnLine (National Center for O*NET Development).

The researcher also examined the past and present living environments of each participant as well as average number of visiting hours. Prior to entering the long term care facility, 50% of

all participants report living independently, 33% report living with others, and 17% report that they were residing in an independent living facility. Currently, 83.34% live in a double room with a roommate they did not know previously, and 16.67% live in a single room. 16.67% of these residents reside apart from a living spouse. On average, participants reported visiting with friends and family 7.96 hours in a typical week, though the tallies were greatly variable for residents, ranging from 0 to 50 hours. The visiting hours are therefore represented below in a graph.

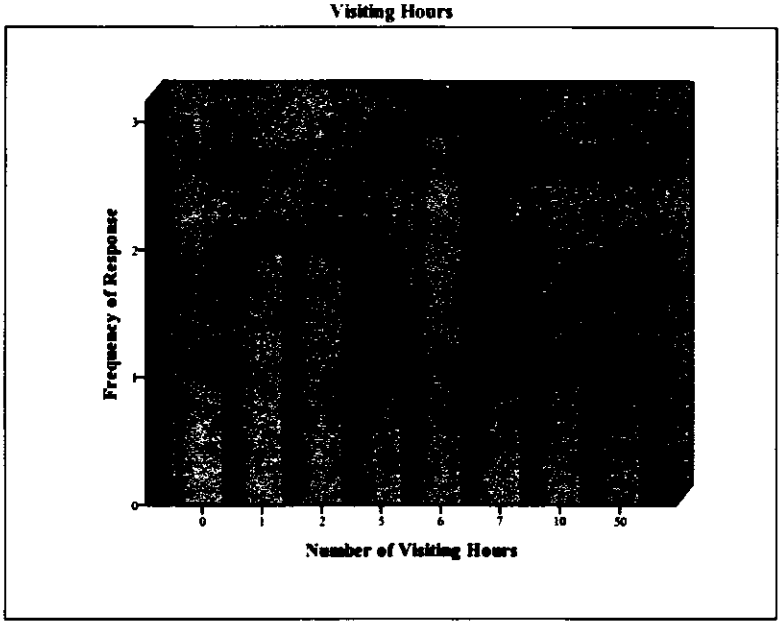


Figure 2. Frequency of reported visiting hours.

Also found below are visual representations of self-reported health and financial statuses. In each case, participants were asked to mark along the continuous line provided to represent their perception of their financial or health status (see Appendix D, p. 78). Most participants rated themselves in the middle of the scales, indicating that most "have enough money" and are "generally" healthy people.

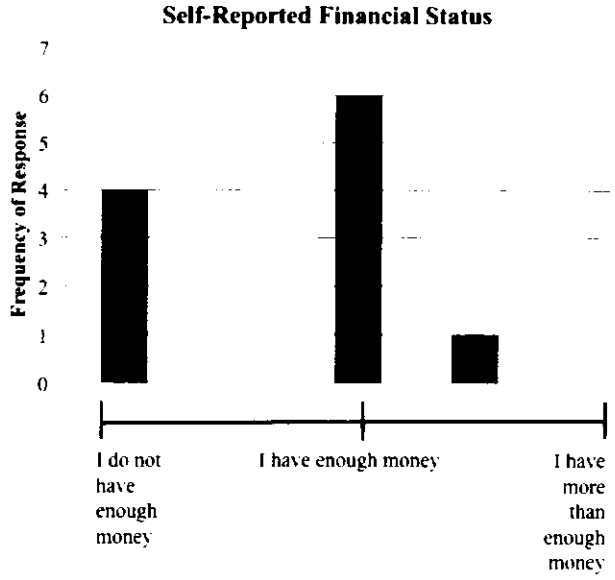


Figure 3. Self-rated financial status along a continuum (with one individual abstaining).

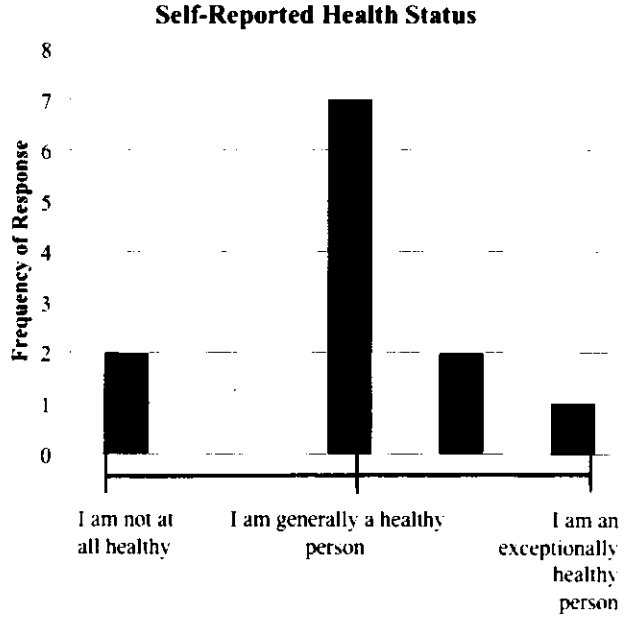


Figure 4. Self-rated health status along a continuum.

Quality of Life

The mean quality of life was 75.42 prior to entering long term care, by report of the participants, with a range of 65-90. This mean corresponds most closely to the descriptor, "Good quality of life," which the Hyland rating scale of Global Quality of Life charts at 70. This mean score is between this "Good quality of life" descriptor and the "Very good quality of life"

descriptor, at 85 on the scale. By report of the residents interviewed, their current quality of life at the time of the interview while living in the long term care facility was on average 62.92, with a range of 40-85. This mean corresponds to the descriptor "Moderately good quality of life," between the numbers 55 and 60 on the scale, and also to the descriptor "Good quality of life" at 70. This change in mean quality of life is significant, as measured by the Wilcoxon signed rank test, at a signficance level of 0.041 and with a Z score of -2.034. It should be noted that for two individuals, their reported quality of life increased following their move to a long term care setting.

In a bivariate Spearman correlation between current quality of life measures and all measures of the OCAIRS, there were significant positive correlations with scores in the categories of habits, and skills. The correlation coefficient for habits was 0.608, with a two-tailed significance of 0.036. Similarly, the correlation coefficient for the relationship between current quality of life and skills is 0.661, with a two-tailed significance of 0.019. These results are demonstrated in the figure below.

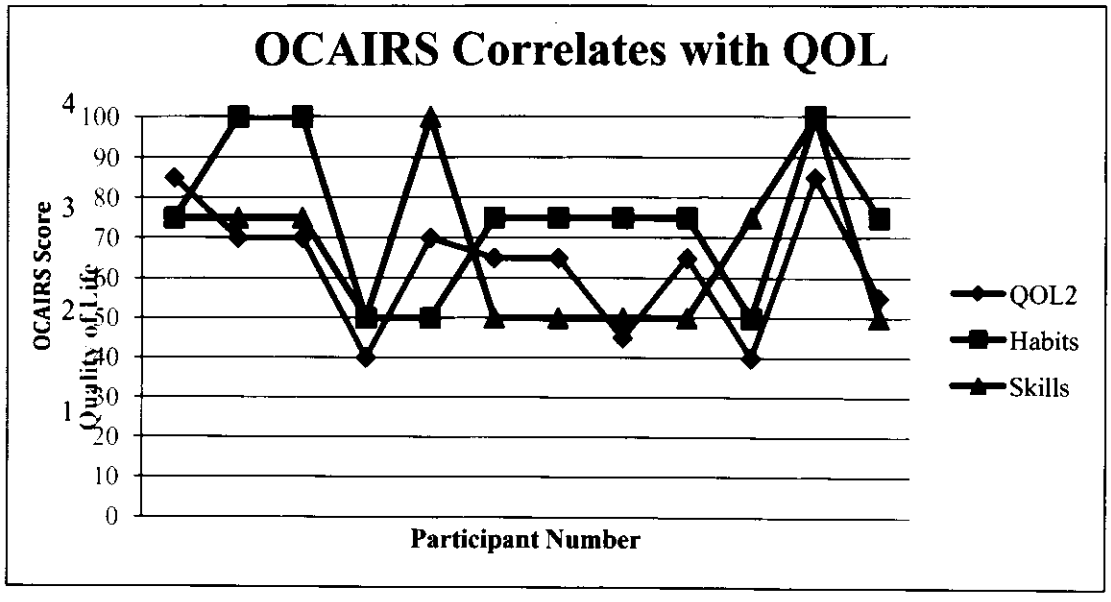


Figure 5. The correlation between quality of life and the OCAIRS groups of "habits" and "skills."

Table 1

OCAIRS Categories Correlated with Quality of Life

	OCAIRS Category		Current QOL
Spearman's rho	Roles	Correlation Coefficient	.225
		Sig. (2-tailed)	.482
		N	12
	Habits	Correlation Coefficient	.608*
		Sig. (2-tailed)	.036
		N	12
	Personal Causation	Correlation Coefficient	.261
		Sig. (2-tailed)	.413
		N	12
	Values	Correlation Coefficient	.078
		Sig. (2-tailed)	.810
		N	12
	Interests	Correlation Coefficient	.363
		Sig. (2-tailed)	.247
		N	12
	Skills	Correlation Coefficient	.661*
		Sig. (2-tailed)	.019
		N	12
	Short-term goals	Correlation Coefficient	.063
		Sig. (2-tailed)	.846
		N	12
Spearman's rho	Long-term goals	Correlation Coefficient	.354
		Sig. (2-tailed)	.258
		N	12
	Interpretation of Past Experiences	Correlation Coefficient	.271
		Sig. (2-tailed)	.394
		N	12
	Physical Environment	Correlation Coefficient	.431
		Sig. (2-tailed)	.161
		N	12
	Social Environment	Correlation Coefficient	.454
		Sig. (2-tailed)	.138
		N	12
	Readiness for Change	Correlation Coefficient	-.075
		Sig. (2-tailed)	.816
		N	12
	TOTAL	Correlation Coefficient	.396
		Sig. (2-tailed)	.202
		N	12

*. Correlation is significant at the 0.05 level (2-tailed).
**. Correlation is significant at the 0.01 level (2-tailed).

In addition to quantitative analysis of the data, the researcher utilized phenomenological research methods in order to analyze the OCAIRS interviews qualitatively, as described in the Methodology section.

Roles

There was no significance to the Spearman correlation calculated between the OCAIRS category of roles and quality of life. Participants identified a number of roles that they fulfilled,

including self-care roles, family roles, pet caretaker roles, friend roles, the "sick" role, and work roles including building, carpentry, and musician roles. Residents also identified several responsibilities, including: crossword puzzles, reading, writing letters, relaying messages, helping others, walking, paying bills, and rehabilitation. In addition to roles and responsibilities, 58.33% of participants identified one or more groups to which they belong: religious groups, a cooperative extension group, senior citizen groups, college alumni groups, architectural historian groups, and coin collecting groups.

Family roles were most common, and many participants identified that they had lost part or all of some of these roles. The researcher has therefore compiled these role losses in the figure below. Please note that step-parent and step-grandparent roles were included in this data with their most similar categories.

Table 2

Presence and Loss of Identified Family Roles

Role	**Complete role loss**	**Some role loss**	**No role loss**
Daughter/Son	1	0	1 (despite deceased parents)
Sibling	1	0	0
Spouse/Partner	0	1	1
Parent	1	0	5
Grandparent	0	1	3
Great-Grandparent	0	1	0

In addition to quantifying family roles, the researcher also noted the number of roles participants identified and compared them with the number of roles participants were currently active in. Please note that caution is important when conceptualizing roles numerically, given

that not all roles are of equal importance. This information is presented in the figure below, in addition to the number of group roles identified and explanatory notes regarding role loss. In the numerical values below, the researcher used 0.5 to represent a partial role loss. Participants lost an average of 1.2 roles. The researcher then investigated the numerical values of roles identified, active roles, and roles lost in Spearman correlations with current quality of life ratings, with no significant results. These results are presented in Table 4.

Table 3

Numerical Representations of Roles for Each Participant

Participant #	# of Roles Identified	# Active roles	# roles lost	# Groups	Notes
1	5	3	2	2	STATED loss of control over 2 family roles, leaving 1 true role
2	8	4.5	3.5	3	
3	2	2	0	0	"I'm doing my best."
4	3	2	1	1	Loss of control over 2 family roles not included (would leave 0)
5	2	2	0	0	
7	7	3.5	3.5	2	Denial, yielding fewer role losses identified
8	5	4.5	0.5	1	Previous loss of spouse, not included
9	5	3.5	1.5	2	Non-stated parent role not counted
11	2	1.5	0.5	1	Actively searching to fill religious role
12	1	0	1	0	Loss of control in ability to fulfill family roles (not explicitly stated)
13	3	3	0	0	Parents deceased, but still identifies daughter role
14	5	4	1	0	Partial loss of both partner and musician roles = 1 role lost

Qualitative analysis of the "Roles" section of the OCAIRS found that self-care was identified as the primary role for 8 out of 12 individuals (66.67%). Participants identified this with phrases like, "getting myself up, maintaining myself," or, "survival." One participant stated that he wished to "get myself back into life—involved in life." All these quotes reinforce the theme of self-care as a primary role among the participants.

Table 4

Post-hoc Analysis of Role Values Correlated with Quality of Life

			Current QOL
Spearman's rho	Roles	Correlation Coefficient	.225
		Sig. (2-tailed)	.482
		N	12
	Total number of roles identified	Correlation Coefficient	.148
		Sig. (2-tailed)	.646
		N	12
	Number of active roles	Correlation Coefficient	.166
		Sig. (2-tailed)	.607
		N	12
	Number of roles lost	Correlation Coefficient	-.221
		Sig. (2-tailed)	.490
		N	12

Another theme was role change, which one participant stated specifically. "My roles have completely changed from the stroke, obviously," he stated. In addition to the theme of role change, six participants (50%) made limiting statements. These included participants describing their roles followed by phrases like, "that's it!" or preceded by "just..." One resident interviewed stated, "I'm nothin' now."

Routines

When analyzing the "Habits" section of the OCAIRS, the researcher used the question posed to participants, "Has your daily routine changed (since coming here)?" In response to this

question, 75% of participants responded "yes." 16.67% responded "no," while 8.33% (one person) responded "I don't remember." The results of this question were compared with current quality of life in a Spearman correlation, with no significant results (significance level 0.064). Despite the fact that the results were not significant to the 0.05 level required for significance, there was a positive trend with a correlation coefficient of 0.551. When asked, "Are you satisfied with your current daily routine?" 66.67% of participants responded "yes." 25% responded "no," while one person, representing 8.33%, responded "I don't care." In response to the question, "Does your daily schedule let you do the things you need and want to do?" 50% of participants responded "yes." 33.33% responded "no," while 8.33% responded that their needs were met but not their wants.

Qualitative analysis also revealed several themes related to routines. The first was the theme of losing choice and control of habits, described by 50% of the participants. One participant stated, "I mean...mostly...I would go out and...do it. When my wife was still alive, we used to...just come and go, wherever we wanted to." He contrasted this with his current situation. Another stated, "Don't do much here, no. Not like home. It doesn't allow me." Finally, one resident said, "When I wake up early now, I have to wait. Because they're busy! And so I run more patience than I have!" All these participants collectively conveyed the theme of losing choice and control over habits and routines.

Another similar theme was that habits are more structured and regulated in the long term care facility, which 25% of participants described. One participant stated, "It's kind-of...regulated. I get up at a certain time and get myself dressed, and wheel myself to meals, and wheel myself to anything I want to attend, wheel out to the TV room and watch the news." Other participants mentioned the same theme by way of describing things they were not

"supposed" to do or that staff did not like; for example, "I get up early. But I'm not supposed to." Another resident stated, "If it's a nice day I'll go outside sometimes and sit outside here. They don't like me doin' that neither. They watch me like a hawk. When I go out there, they figure I'm gonna take off." All these are part of the theme of regulated habits.

In addition to these themes, there were themes in the pre-existing and current routines of the participants interviewed. Of the eight participants who provided detailed descriptions of their routines prior to entering the facility, 50% typically woke around 8-9am and 50% were early risers. By comparison, in the long term care facility, participants in the former group wake at 5:30am for medication and many then sleep until breakfast at 8am. Others who were early risers prior to entering the facility wake early as they previously did and then wait for breakfast or wait for assistance with dressing and grooming.

Personal Causation

Kielhofner describes personal causation in "two dimensions:" "sense of personal capacity" and "self-efficacy" (2008, p. 35). The section of the OCAIRS examining personal causation explores the way participants feel about their capabilities and control over their own lives. Participants were able to identify several categories of things they were "proud of." These included people skills, skills related to being part of a family, coping skills, work roles, helping skills, leisure skills, and also pride for "existing." The most common source of pride in this sample (50%) was pride for the family, often expressed as pride for the success of the children. This was followed closely by the theme of work roles (41.67%), both in the past and continuing work roles. Approximately 33.33% of the participants expressed pride over people skills, such as listening and making people happy. Another 33.33% expressed pride over helping others. This included activities of carpentry work, writing recommendations, providing financial

assistance, and bringing happiness to others through music. Coping with various aspects of life was a source of pride for 25% of all subjects. These include coping with being a senior citizen, with New York state weather, with the adjustment to living at the nursing home, and with "moment to moment" challenges during each day. In addition, one individual identified leisure activities of walking and doing crossword puzzles as a source of pride, and another expressed pride for "existing." A few individuals (33.33%) were unable initially or entirely to identify anything that they were proud of.

Participants were also able to identify a number of things that had been difficult. The majority (58.33%) identified keeping involved and active as being difficult. This included keeping moving and continuing with routine personal responsibilities, as well as keeping the mind active and motivated and maintaining health. Approximately 33.33% of the individuals interviewed cited adjusting to loss of control as difficult. This included feeling "confined to place," a loss of driving ability, and "having to do something at a certain time and I'm not used to that," indicating a frustration with routine change. Some individuals (25%) identified a frustration with not being able to help their children, the staff, or other residents of the facility. A couple (16.67%) of participants were unable or unwilling to identify anything that had been difficult. One individual identified a difficulty with machinery or anything mechanical, and another identified that wishing she had children to live with is difficult. Each individual identified his or her biggest challenge, most of which were unique. Despite the individuality of each answer, 58.33% cited issues related to mental or physical health or life overall, for example "keeping my...life together." One resident enhanced her answer of frustration with her health with the statement "there are very few atheists in nursing homes!" Two individuals (16.67%) identified "getting out of here" as their biggest challenge, despite the fact that one immediately

stated it was "unrealistic" and gave another answer. One individual stated that his biggest challenge was "nothin'," while another cited avoiding boredom and a third was frustrated by "having to do things their way, at a certain time."

When asked how they handled these challenges, participants identified a variety of coping mechanisms. Twenty-five percent chose to take control of their own occupations and keep themselves busy and their minds active. Another 25% chose to deal with their frustrations by "sucking it up," using strategies like "keep my mouth shut" or have a "pity party." A third 25% identified contact with friends and family as a strategy. Other strategies included finding someone else to fix a difficulty, negotiating, giving advice, remembering how little she really needed, and fighting back by communicating frustrations to staff.

Despite their frustrations, 50% projected that over the next six months they would be partially better or have accomplished something. For some this included specific timelines, for others it involved leaving the facility or fulfilling specific goals. Some (16.67%) stated that they expected or desired death within the next six months. The rest fell somewhere in the middle or had specific concerns. Two (16.67%) felt that they would be about the same, and an additional 16.67% similarly anticipated being moderately successful. The rest were unable to identify how successful they expected to be, but stated hopes, concerns, or coping mechanisms. One stated that she would "go with the flow," while another stated that she hoped she would not "get a stroke or heart attack or anything." Still another expressed a need to return to work and come out of retirement in order to support his medical needs.

Values

When asked what they valued most, 75% of the participants identified family. Others (16.67%) identified their health, and the last identified his friends. Other valuable ideals, though

not supreme, included: honesty, political rights and freedoms, heirlooms, "my house," kindness toward others, leading by example, conservation, health, animals, personal freedom, and the leisure pursuit of reading. The majority of participants (58.33%) stated that they are able to live life in ways that fit with their values. Another 16.67% reported that more or less they are able to live life to fit with their values. Only one (8.33%) stated that he is not able to live life in ways that fit with his values. One was not quite able to live according to her values, and another was similarly able to live according to some values but not others. Despite the fact that most are able to live in ways consistent with their values, when asked, "what about your life reflects these values?" many responded with more theoretical answers. Only 25% cited specific actions that aligned with their values, such as one participant who described her financial and voting support for "people who support the things I support." Another 25% explained that they were doing what they could to live by their values but did not give any specific examples. Some individuals (16.67%) described their values as what got them through challenges. One described his life post-stroke: "I lost my career, I lost my music, I lost my home. I have nothing to go home for. It's gone! And—had I not had, or kept…the values that I believe in in my heart, I would have nothin'. And I actually don't need anything! I need those values." One individual stated that not much of his life reflected his values.

Consistent with their previous answers, 58.33% stated that there was nothing about their lives that went against their values. A few (33.33%) described aspects of their lives that did go against their values, including two individuals who expressed frustration over an inability to provide for their families. One of these individuals described that sometimes her health did not allow her to live by her values. Finally one individual stated that there were "probably" aspects of her life that went against her values, but she could not think of any at the time.

Interests

Participants identified various major occupational roles that they hold. The most common major occupational role was caring for one's own health (33.33%). Equally as many participants were unable to identify a major occupational role or identified it as "nothing." Twenty-five percent described being as their major occupational role. Other identified roles were getting well, healing others through music, and being a listener. Most did not identify whether or not they enjoyed their major occupational role. Participants were then asked what it was about their major occupational role that interested or satisfied them. The only individuals who answered (25%) mentioned aspects of life in which they felt unsuccessful or unable to have what they desired, with the exception of one individual who answered, "just the matter of getting through the day in some way."

In addition to their major occupational roles, participants identified a myriad of common interests. The most popular activities (each with 33.33% responding) were reading, physical activities such as sports, and social visits with friends. Twenty-five percent reported that they enjoy going out in the community. Other common occupations include word games and puzzles, crafts, exploring the place of residence, group activities, collecting coins and antiques, musical programs, watching television, family activities, assisting with fixing things or helping people, and driving.

Skills

Cognitive, physical, and social skills allow or prevent participation in the aforementioned interests. When asked if they are able to do the things they want or need to do, half of the residents answered in the affirmative and half in the negative. Those that reported not having the physical ability to accomplish their needs and wants total 41.67%, while 50% do have the ability

and one other individual gave an inconclusive answer of "within the means I can." Of the participants 83.33% report that they are able to "concentrate, problem-solve, and make decisions to get things done." The remaining 16.67% did not report significant difficulties with cognitive skills either but did not respond affirmatively to the question. Fifty percent of the participants reported that they are able to overcome any limitations or barriers. One individual was unable to identify anything that she needed to "struggle against."

Despite their insistence that they were not limited, residents identified a number of factors that limited them. The most common limiting factor was mobility, a limitation identified by 33.33% of the participants. Twenty-five percent of the participants cited their thoughts and cognition as limiting factors. Fatigue (16.67%), the mores and rules of the facility (16.67%), lack of money (8.33%), and the inability to drive (16.67%) were also described as limitations.

In examining social skills, participants were asked whether they preferred to work alone or with others. Participants were split almost exactly in half, with 50% reporting they prefer to work alone, 41.67% preferring to work with others, and 8.33% with no preference. When asked how well they worked with others, 33.33% felt that they got along with others very well. Another 33.33% got along with others "pretty well" or "better than average," and 16.67% got along with others to a degree described as "okay." One individual stated simply, "I always try to adapt if it's necessary," while the final individual (representing 8.33%) described herself as not working "very well" with others because she becomes distracted easily.

Readiness for Change

Questions about "big changes" and daily routine changes assist in understanding how prepared each individual is for change in his or her life, such as the change of moving to a new place. When asked to discuss a "big change," 33.33% of participants discussed moving to the

facility, which was often secondary to a change in health status. Other popular changes include deaths or relationship changes such as divorce or marriage, each 25%. The remaining 16.67% cited career changes, including retirement or job transitions.

When dealing with routine changes, 41.67% report that they "go with the flow." An additional 16.67% similarly "take 'em in stride" or "just let things pass." Some participants (50%) indicated a lack of choice and expressed that they did whatever was needed through statements like, "you know I don't like being here, but I'm here, so I might as well make the best of it...ain't nothin' else I can do." Some individuals utilized both strategies. Only 25% reported that they did not handle routine change well, 8.33% of whom stated that adjustment took approximately one week. One resilient resident stated that handling changes in his daily routine taught him patience.

Given feedback or a request to change behavior, 41.67% report that they feel angry, to the point that one individual states "sometimes I get almost...choke the person!" Twenty-five percent make the requested change, whereas 16.67% make a partial change. Some (33.33%) described a process of listening and contemplating before deciding whether or not to change. One individual stated that she thinks to herself, "I better listen to that person better." Two individuals (16.67%) stated that negative feedback does not happen in their lives. One individual stated that he would feel depressed and possibly express that to the individual critiquing him, while another stated that she would "try to justify my behavior."

Physical Environment

The physical environment is an important part in the holistic view of the individual. The majority (66.67%) of residents stated that they did find it relatively easy to "get around" and "get things done" in their place of residence, while 33.33% did not. Most (66.67%) found there were

things to do and places to go in their area of residence that interested them while 16.67% were not interested. One individual stated that she was not particularly interested in being involved, while the last answered, "probably, if I looked."

Most of the participants (66.67%) reported that they did not go anywhere on a regular basis other than the bathroom or BINGO. One participant even stated, "I wouldn't attempt to go outside by myself." Only 25% of the participants reported any regular visits in the community. One reported attending monthly meetings of a local group as well as monthly luncheons out, though she had not participated in these since arriving at the nursing home. Another went to the library and bookstore in town using his wheelchair. One other individual stated that he occasionally goes into town for concerts, but that this was not a regular occurrence.

Despite the aforementioned report that most participants felt it was relatively easy to navigate their environment, only half reported that there were no physical barriers preventing them from "getting things done." Of the remaining, 41.67% reported physical barriers and one individual (representing 8.33%) did not feel the question applied to her. Physical barriers described include: decreased independence during ambulation secondary to dependence on supplemental oxygen, difficulty with navigating stairs, curbs, and sidewalks, lack of access to a vehicle, and dependence on others for vehicular transportation in the community. Some individuals who said that physical barriers did not prevent them provided strategies they use, which included calling a local transportation agency and planning ahead for the use and navigation of a wheelchair.

Certain factors did prevent individuals from participating in activities by their reports. The most common factor is physical ability, which prevented 41.67%. Transportation prevented 25%, and each of supplemental oxygen, rules of the facility, and money each prevented 8.33%.

In addition, one individual stated indicated that were her desire strong enough, she was confident she could follow through. Though one person stated he could not think of any resources that would be available to overcoming these barriers, 33.33% actively stated that there were not resources to their knowledge. Twenty-five percent were able to identify resources, though the remaining participants were not comfortable answering affirmatively or negatively. The resources suggested were a local bus line, the local transportation company mentioned above, and counseling and social work services at the local independence center.

Social Environment

If physical environment is important, social environment is certainly equally as important if not more. When asked who they spent the majority of their time with, 83.33% mentioned that they spent a significant amount of time alone, despite only one individual who reported that she preferred this. Given the high volume of similar responses to this question, the researcher ran a post-hoc Spearman correlation relating current quality of life with those who identify they spend most of their time alone versus those who do not. This correlation was not significant (significance level 0.058), but the correlation coefficient of -0.560 did show a negative trend. The two most common answers, each 33.33%, were with their children, or with people who live at the facility. This does not include the 16.67% who reported spending time with their roommates. An additional and overlapping 16.67% reported spending time with their best friends. One individual reported spending time with her cats and with an aide who had assisted her in her previous dwelling. One other individual mentioned his spouse.

These answers were similar to the answers to the question "who are the most important people in your life right now?" The most common answer was again children, this time at 83.33%. One individual even stated that he talks to his children every day. Most of the other

people who rated important were also family members, including grandchildren (33.33%), spouses (16.67%), great grandchildren (8.33%), and family in general (33.33%). In addition, 33.33% of participants described one or more close friends, and one individual cited her doctor and the staff of the facility because, as she put it, "I'm in their hands!"

Half of all surveyed reported that what the important people in their lives expected from them matched what they would like to do, more or less. One was unsure, and 25% did not believe that expectations always matched up. Of these, one resident expressed frustration at not being able to provide financial assistance for his daughter. Despite the variety of these answers, 66.67% described their setting as supportive when asked. "I'm well fed, and comfortable...there are activities that they provide that I enjoy," stated one. "Everybody's very pleasant and very helpful" stated a second. One individual's description of help was more one of learned helplessness: "It would be so easy to have somebody help me do just about everything. And I have to remind myself that I'm supposed to do just about everything. And sometimes the aides don't even understand it—they come in and they see that the bed needs to be made and they start making it, and I say, 'no, no, no, mustn't touch that.'" An additional 16.67% made comments that described the setting as supportive because "it has to be and it is." One individual stated that her family was supportive but her community was not. The last cited the setting as "mostly" supportive.

When asked if the people or situations in their lives place limits on them, 66.67% reported that they did not, while 25% said they did and 8.33% was "borderline." Those who answered affirmatively cited not being able to leave the building alone, family members not giving all the information because they did not think she could handle it, and situations that brought dependence due to difficulty with transfers and transportation.

Seventy-five percent of all participants stated that they could count on family, while 25% could not. When asked the same of friends, 58.33% could count on them while 25% could not. Anticipating community support seemed slightly more challenging, with 41.67% stating yes, 25% no, 16.67% "sort-of," and the final 16.67% "probably" and "if I asked for it." The researcher used a Spearman correlation to compare the presence or absence of these support networks with current quality of life. Though none of the correlations were statistically significant to the required level (significance levels were 0.279, 0.159, and 0.074 respectively), the correlation coefficients all suggested a negative trend: social support of family with -0.341, friends -0.433, and community -0.534.

Goals

Researchers asked participants to identify short and long-term goals and explain strategies they use for accomplishing these goals. Most participants (75%) stated that they do set goals, while 16.67% report that they do not. The last participant, representing the remaining 8.33%, said that he used to make plans for the future, but now, "How the hell am I gonna get a goal in this place? I don't even know when I'm getting out of here. I know I'm supposed to be getting out of here. That's all I know." Overall 58.33% of participants stated that they either had no long term goals or that their goal was "nothing." Negative responses to similar inquiries for weekly goals (16.67%) and monthly goals (33.33%) suggest that short-term goals were easier to conceptualize than long term goals. The researcher investigated the relationship of these different types of goals through a Spearman correlation with quality of life, which revealed no significant relationships. The results are presented in the table below. There was a positive trend with a significance level of 0.102 with those who set weekly goals, with a correlation coefficient of 0.495. Participants identified goals that fit into six categories, with three additional goals that

did not fit into any of these groups.

The most common goal (41.67%) was the goal of being or getting through. For example, one participant stated that he wished, "to be able to do the things that I want to do, when I want to do them." Strategies for accomplishing these goals included letting things "fall naturally," being "very careful when I walk so I don't fall," and trying "a little bit harder to do what I want to do." One final participant stated, "it's just a matter of...just going along with...what happens." These strategies seem loosely to support the idea of either accepting things as they go along, or being careful to prevent negative outcomes by using extra care and effort.

Table 6

Correlations Between Different Types of Goals and Quality of Life

			Current QOL
Spearman's rho	Weekly Goals	Correlation Coefficient	.495
		Sig. (2-tailed)	.102
		N	12
	Monthly Goals	Correlation Coefficient	-.052
		Sig. (2-tailed)	.872
		N	12
	Long-term Goals	Correlation Coefficient	-.075
		Sig. (2-tailed)	.817
		N	12

Rehabilitation was an identified goal for 33.33% of the participants. Most of these goals surrounded walking or managing transfers, though one individual identified a desire to learn how to effectively use a piece of adaptive equipment for donning stockings. All these participants identified practice as their strategy for accomplishing their rehabilitation goals. One emphasized, "being very careful when I use the walker." An additional 16.67% of participants mentioned more general goals of staying healthy, such as "keep all moving parts moving and my mind alert." One participant identified walking in his walker with aides as often as possible and

peddling his wheelchair, while another identified completing crossword puzzles as a strategy.

Twenty-five percent of the participants stated or implied that going "home" was a goal. Aside from thinking and planning stated by one individual, another suggested that his strategy was "trying to get stuff done so I can get somebody here to get me out." By contrast, 16.67% identified landmarks that they were working toward, specifically the birthday of a daughter, voting, and Christmas. The strategy for each of these goals is unique to the landmark itself, and equally as diverse. The goal of celebrating Christmas was abandoned as unrealistic, while the goal of voting was relegated to staff of the facility. The only goal that the individual took responsibility for was her daughter's birthday, for which she planned to stay "in contact."

Two participants, representing 16.67% of participants, identified goals related to leisure or vocation. These included goals relating to golfing, riding his bike, and recording and re-mastering original songs. While the first participant stated that he would not accomplish his goal, he did state that his son would assist him in attempting, and he would use a toy golf set at his place of residence. The second individual stated that he was receiving assistance at the facility to accomplish his goals, through physical therapy and the assistance of another staff member at the facility.

The remainder of the goals are relatively individualized: getting things in order at home and prepared to get her cat back, having her nails done, and visiting a son who lived far away. The participant dismissed the latter goal, as she did not think she was well enough. None of these goals had particular strategies associated. Approximately 33.33% of the participants stated or implied that they have stopped setting goals. Aside from the aforementioned reason described at the beginning of this section, participants cited three other reasons. One stated she was too old, another stated that he ceased making goals when his wife died and because "that way I don't

get disappointed," and the last stated, "they never work out. I used to, years ago, when I was about 18, 19, I did. I wanted to be an architect—you know, a house designer? I didn't make it, so I just—after that, I just forget it, you know."

Interpretation of Past Experience

Understanding how each individual interprets his or her past experiences assists in understanding roles that each has taken on throughout life. This section of the OCAIRS first asks participants how the "ups and downs" in their lives compare with what is "typical." A slight majority (33.33%) felt that their lives are better, though one of these specified that his was "harder but better." Twenty-five percent felt that their lives were typical, while 8.33% identified as worse. An additional twenty-five percent were unable to specify, for various reasons. One individual expressed that her life was on an "even keel," another stated he had "no idea," and a third stated that she had "more calamities," and that "it probably isn't a typical life. But I'm satisfied with it, in retrospect." Four individuals, representing 33.33% of the sample, rated their current lives rather than their lives overall. These individuals expressed a diverse range of feelings: that their current lives were "boring," "worse than it was," "leveled out," and "better now."

Participants then identified the best and worst periods of their lives. Twenty-five percent of the participants cited raising children and their participation in their families as the best periods of their lives. One of these participants specifically mentioned having "the big family, running around the house" during family occasions. Similarly, an additional 25% cited loving their spouse as the best period, for example, when one woman and her husband were deciding how to spend money when building their own home. Another 25% identified travelling or other youthful experiences, such as dating "frantically" during the freshman year of college. Two

other participants (16.67% of the total participants) mentioned their jobs as part of the best period of their lives, though it did not seem to be the most important aspect; one stated that while working he was in good "physical health" because he did not need to take pills, and the other mentioned working as a nurse while raising her family. The final participant cited his involvement in several groups in the first year after retirement as the best period of his life.

Goodbyes were the self-reported worst period in the lives of 33.33% of the participants. This included the deaths of spouses and parents, miscarriages, as well as divorce and separation from military husbands. Illness such as stroke or a ruptured appendix made the "worst period" for 16.67% of the residents. Another 16.67% gave nondescript answers such as, "I've begun to remember a lot of things that I've done that I shouldn't have...I pretty much always did what I wanted to do...the way I wanted to do it!" Two participants (16.67%) cited the time that preceded the pivotal landmarks of having children and a marriage dissolving, respectively. One participant cited the current period of time: "right here," while the last cited seeing war.

When asked how their lives were "affected by these ups and downs," 33.33% of participants gave a neutral response. Of these few, half expressed control over the situations, such as "I'm comfortable in dealing with it." Another 33.33% had a negative response. "It makes me turn more inward," said one, "'cause I don't care." One of these participants stated that her strategy was to rely on her older daughter, while another tried to continue, pretending nothing was wrong. "I just can't do what I wanna do, you know?" stated another. Twenty-five percent had a positive response, with 16.67% saying that they learned from their experiences and one participant (8.33%) stating "we had a very nice marriage" and continuing by speaking about how wonderful her husband was.

Participants were split fairly evenly on the question of if they had been able to "choose the

important things in life." While 33.33% responded affirmatively, 25% responded negatively. One participant even identified several things she would change. Another 33.33% indicated that they have sometimes been able to choose, as one stated "to a certain degree." These responses were compared post-hoc with quality of life to investigate a possible relationship through the use of a Spearman correlation. This correlation was not significant (significance level 0.547) and suggested no relationship ($r = 0.193$). Some participants seemed stuck in the idea of the current time, and one said, "the only thing I know is right now I want out!"

Chapter 5: Discussion

Quality of Life

The participants in this study reported on average a lower quality of life after admission to the nursing home as compared with before, according to the Global Quality of Life scale. These results are consistent with the literature in this area that suggests that those in nursing home care have a lower quality of life as compared with their community-dwelling counterparts. The existing research measured this disparity using visual analog scales in individuals with higher levels of mobility and cognition living in nursing homes (Karayaka, Bilgin, Ekici, Köse, & Otman, 2009, p. 33), as well as using the Flanagan Quality of Life Scale (Crist, 1999). Similarly, Kudo et al. found lower morale in elders who lived in a nursing home (2007, p.16), and Gueldner et al. found lower life satisfaction in elders in nursing home care as compared with their community dwelling counterparts (2001). The researcher hypothesized that the decrease in quality of life was due to changes in roles and routines that occur following a move to long-term care.

Though the average participant's quality of life decreased, there were four individuals, representing 33.33%, who reported that their quality of life remained consistent or even increased from pre-admission to the time of the interview. Three of these four individuals maintained or gained a routine schedule. Two of these individuals were transitioning from assisted living facilities. The third expressed that he did not have much of a routine while living with his son, prior to entering long-term care. The final participant was struggling from depression following the loss of his wife. Since entering the long term care facility, a psychologist has been actively addressing his depression. The transition to long-term care had a positive impact on the quality of life of these four individuals, possibly for the reasons outlined

above. The following is an exploration of why this transition conversely led to a decrease in quality of life in the majority of participants.

Roles

The researcher hypothesized that participating in roles is important to motivation in occupational participation because individuals consider their success in the fulfillment of roles when evaluating their own value. Successful fulfillment of roles results in a sense of competence and contribution that results in a sense of "ego integrity," as Erickson labeled it. Following the transition to long-term care, the researcher theorized that many individuals lose control over their ability to fulfill their roles, which may lead to Erickson's alternative of "despair," causing a decrease in quality of life. The present results demonstrate that the majority of participants did experience some role loss during the transition. This supports the original hypothesis that elders do not maintain all roles when transitioning between living environments. This role loss likely occurs because of the well-documented loss of control that elders experience when they enter long-term care facilities. Elders lose control over their environment, in addition to the functional losses that are often the impetus for the relocation to long-term care. Schulz tied decision-making to life satisfaction (1987, as cited in Rehfeldt, Steele, & Dixon, 2001). Two other studies touched on the same point less directly (Heliker & Scholler-Jaquish, 2006, & McKinley & Adler, 2005). This explains the weak negative correlation between number of roles lost and current quality of life, even though it was not statistically significant. Given a larger population and a more accurate way to quantify roles, the strength and significance of this correlation may increase. When asked about their major occupational roles (in the Interests subsection of the OCAIRS), some individuals expressed that they feel unsuccessful. In addition, many were unable to identify a major occupational role. Both these results reinforce the loss of control and

loss of roles in the transition to long-term care.

There is no significant relationship between the number of roles and quality of life, which would suggest that changes in roles do not correlate with changes in quality of life in this population. This rationale is bound by the concept that the value of roles can be conceptualized numerically, that each role is equal in importance to the others; however, a concept that is illogical. Roles cannot be so easily quantified, despite the researcher's quantification for the purposes of the study. In addition, this conclusion would contradict the limited existing literature on the subject, which suggests that role loss is correlated with decreasing life satisfaction (McKenna, Broome, & Liddle, 2007). In an atmosphere of long-term care, where declining physical and cognitive abilities result in increasing dependence for occupational performance, the ability to fulfill roles becomes increasingly important. In particular, social roles become fundamentally essential because they are inherently less affected or affected last by physical and cognitive limitations. Providing more effective intervention to assist in the maintenance of roles during transition would therefore assist in maintaining quality of life.

Routines

The vast majority of participants identified that their routines had changed since entering the long-term care facility. This indicates that, as hypothesized, elders do not maintain routines when transitioning between living environments. This reflects prior research that found that care assistants in nursing homes did not maintain rituals for bedtime (Warner, 1997), and were unaware of eating, dressing, and hygiene routines that residents were accustomed to following prior to entering the nursing home (Jensen & Cohen-Mansfield, 2006). As this literature suggests, many staff are simply unaware and/or unconcerned with maintaining routines from the home environment. Routines in the nursing home are therefore guided by what is most efficient

for the staff and what is most cost effective to the insurance company, rather than what the individual is accustomed to.

There was no statistically significant correlation between routine change and quality of life, but there is a positive trend that demonstrates the possibility of a "moderate to good" relationship (Portney & Watkins, 2009, Box 23.1). Given a larger sample size, the researcher hypothesizes that a statistically significant correlation would arise. Existing research does not address this correlation precisely, but it does suggest that a disruption in routine can be difficult to handle. Dunn's explanation of the sensitive neurological system (2000) as well as the characteristic of routinization that Reich and Zautra present (1991) indicates that the impact of routine change on quality of life is far from simple. Their work suggests that routine change would positively impact the quality of life of some, while negatively impacting the lives of others. Atchley's continuity theory (1989, as cited in Ludwig, 1997) and Clark in her writing even suggest that routine is an important part of self-identity (2000). Kielhofner in his Model of Human Occupation theorizes that habits and routines assist with occupational performance by creating more automated performance patterns, requiring less effort (2008). Routine changes cause a break in the automated nature of the performance, requiring the individual's more concentrated effort. The person must then rely more on their motor and cognitive skills. Those with more limitations to their cognitive skills—a common trait in this population, are now less able to independently fulfill their own wants and needs. This explains the "moderate to good" correlation in this sample between quality of life and the "skills" factor measured by the OCAIRS (Portney & Watkins, 2009, Box 23.1). The more the skills impact occupational performance, the lower the quality of life. Since the data did not measure the amount of routine change but rather whether or not any routine change occurred, the measure was not sensitive

enough to provide a statistically significant correlation. The meaning participants assigned consciously to their routine change may be different from the impact it has actually had indirectly on the quality of life of each. This also explains why the majority of participants stated that they were satisfied with their routines.

There was a significant correlation that demonstrates a "moderate to good relationship" between the habits subsection of the OCAIRS and quality of life (Portney & Watkins, 2009, Box 23.1). This makes sense because it indicates that the more routines affect occupational performance, the more quality of life may also change, though the data cannot suggest a causal relationship.

Additional OCAIRS Areas

The researcher hypothesized that the various areas of the OCAIRS: roles, habits, personal causation, values, interests, skills, readiness for change, physical environment, social environment, goals, and interpretation of past experience, were related to quality of life, given the related research about contributors to quality of life. Of these, only habits and skills are significantly correlated with quality of life, and have been discussed in the previous section. The literature nonetheless supports the relationships between the topics of the other categories and quality of life.

The WHOQOL assessment tool identifies and measures the following categories as contributors to quality of life: physical health, psychological, level of independence, social relationships, environment, and spirituality/religion/personal beliefs (World Health Organization, 1997). Each of these can be linked with an OCAIRS section. Physical health, psychological, and level of independence are all indicative of a connection between skills and quality of life. Social relationships emphasize the importance of the social environment, in addition to

"environment," which clearly includes both the physical and social environment. Finally, spirituality/religion/personal beliefs seems relatively similar to the OCAIRS category of values.

In addition to the associations discussed in the WHOQOL, two studies tie physical environment with quality of life (Low, Molzahn, & Kalfoss, 2008; Karayaka, Bilgin, Ekici, Köse, & Otman, 2009). Others add to the body of literature about the importance of family relationships (Crist, 1999), social networks (Rehfeldt, Steele, & Dixon, 2001), and other aspects of social environment (Lawton et al., 1999). Though time spent alone and the social support of family, friends, and community did not correlate significantly with quality of life, there were negative trends. The correlations with time spent alone and social support of the community both showed a "moderate to good" trend, while the social support of family and friends both showed a "fair" trend. The former two in particular suggest that a larger sample size may find statistically significant relationships. It is the social support of community over family and friends that proves most surprising. This could be a reflection of the need of elders to achieve the value of those around them. Additionally, residents may be considering the staff to be the "community," or may be defining the support of the community as their opportunities for involvement in occupations provided or not provided by the facility or larger community.

Other OCAIRS areas are more loosely attached to the literature. One study looked at adjustment as it relates to motivational style, which is distantly comparable to personal causation (Curtiss, Hayslip, & Dolan, 2007). Others link activity participation and meaningful occupations with quality of life (Lawton, et al., 1999; Clark, et al., 1997). Literature considering different adjustment styles and relocation transition styles suggests that the literature also considers how readiness for change affects the individual (Porter, Clinton, & Munhall, 1992; Rossen & Knafl, 2003).

The significant correlations with quality of life found, and the relationship with roles, were discussed in the sections above. Despite the literature that suggests a possible relationship between quality of life and many of these areas, the results of this study do not show a significant relationship between quality of life and the OCAIRS categories of personal causation, values, interests, readiness for change, physical environment, social environment, goals, and interpretation of past experience. This is hardly surprising given that each of these categories is scored based on its impact on occupational performance. That is to say that a correlation would indicate that, for example, interpretation of past experiences restricts occupational performance, which is correlated with a change in quality of life. This relationship would imply that occupational performance is correlated with quality of life. Perhaps the viewpoint more rooted in occupational science would suggest that it is not the outcome but the process, the occupational participation, that is important to quality of life. While the interpretation of past experiences might restrict occupational performance, it might more importantly restrict occupational participation altogether. It is presumably this lack of occupational participation, then, that would correlate with decreasing quality of life, rather than the actual performance. Despite the relationship each of these aspects may have with quality of life, this study does not measure that. Data collected in these categories was collected primarily for the associated qualitative data. Given the close connection between occupational participation and occupational performance, however, the researcher thought it worthwhile to analyze the correlations quantitatively in order to gather as much information on the subject as possible. The results in this case neither confirmed nor contradicted the existing literature, because the correlations measured were not reflective of associations found in previous research.

The researcher did perform limited post-hoc analysis in response to hypotheses formed

during the analysis process relative to sub-questions asked on the OCAIRS. Despite the complete lack of any literature connecting goals to quality of life, the researcher did find a positive trend, though not statistically significant, between setting weekly goals and current quality of life. This relationship was "fair," according to Portney and Watkins, though there was no relationship between monthly and long-term goals and quality of life (2009, Box 23.1). This suggests that those who set short-term goals are perhaps the same who have higher quality of life, though the direction of the relationship is not clear. It seems equally possible that those with a high quality of life would be more likely to set goals, as it does that individuals with weekly goals would have a high quality of life owing to their sense of control in setting said goals.

Participant Suggestions for the Facility

A few participants did have complaints or suggestions regarding the facility where they live. One described staff members who came off as angry despite attempting to be welcoming: "There are a couple of women…who are trying…to be…very welcoming. But they're not…succeeding…Both of these women appear to be…angry…They appear to be angry at…everything." Another also expressed frustration with meeting people, stating that "I can certainly think of things I'd like to change here…the first day, seventeen people by…count, came in, introduced themselves to me, told me what they did." Other individuals were frustrated with the way things were organized. Specifically, the fact that one person decides who goes home: "I found that out. They have one woman that does it, lettin' 'em go…SO, good let me go!" Another struggled to adjust to "having to do things their way, at a certain time."

Three expressed their frustration at the plight of others and their helplessness to do anything about it. One man said of a staff member's broken down car, "She didn't have enough money to fix it, so I give her 50 dollars. Somehow they got a hold of it and they give it back to

me and give me hell for it. For givin' her money—I'm not supposed to give anybody money. I'm not supposed to help anybody." Another stated "I've rung the bell a couple of times for other people, when I just couldn't stand—it seemed to me that there were nurses around, and that they could do something." A third participant reported that he follows another resident around while he walks to ensure his safety: "We have one guy that walks with one crazy foot. He's got one foot turned like that. And he'll slide that right. And I followed him. That's what I do! Follow him in case he's in trouble! I ain't supposed to, but I do it anyway. They don't say nothing to me, because they need help in that way."

Limitations

Despite the information this study provides, there are a number of limitations that prevented the results from being more significant and meaningful. Primarily, the use of the OCAIRS as a measure was a significant limitation for multiple reasons. Although the OCAIRS examines the areas of importance to the researcher, participants often expressed confusion with the questions asked to glean information. The measurement tool was cognitively challenging for many members of the population, and many grew frustrated or answered questions in a way other than the question intended. In addition, the questions did not allow the researcher enough specific information to analyze specific routines or the importance of various roles. The OCAIRS and the Global Quality of Life scale are both self-report measures, creating an inherent bias. Participants were also asked to rate their quality of life retrospectively to achieve a rating for quality of life prior to entering long-term care. This measure would have been more reliable if the study were longitudinal in nature, able to measure prior to entry in real time rather than asking the individual to remember. A longitudinal study was not possible given the circumstances of the research project and the added difficulty of gathering participants prior to

entry.

The researcher had hoped for a larger sample size but was unable to recruit enough individuals. The small sample size of 12 limited the researcher's ability to categorize and to find significance in the data. In addition, it limits the ability to generalize the data to a larger community. The recruitment strategy of using staff to recommend individuals for the study was ineffective. Despite the researcher's presentation of the importance of providing all eligible participants, staff appeared to avoid mentioning individuals they felt would not agree to participate. Though the researcher emphasized the need for competent individuals who would be able to remember the past, some individuals recommended were not able to remember or struggled to attend in order to complete their participation. Finally, the population sampled did not represent a typical 60+ population, given the high number of male participants. According to the 2010 United States Census, the overall sex ratio is 96.7 males to every 100 females, and the ratio becomes smaller with age (Howden & Meyer, 2011, p. 4). By this logic, there should be more females than males in the population in order for it to be a representative sample, which there are not. Analyzing these limitations provides insight into how to improve the study for future use.

Implications for Future Research

There remains a need for more research examining roles, routines, and transitions in this elder population. Future research needs to utilize a different, more simple but more specific measure for roles and routines, or a narrative interview analyzed by the therapist. A more visual measure, rather than one relying entirely upon auditory processing and response, could assist in making the measure more accessible. The measure used should also require less sustained attention by being shorter. In order to enrich the data collected for more applied analysis, the

researcher should ask how the decision for the transition to long-term care occurred and what if any occupational therapy services the participant receives or has received since entering the facility. Recruitment for future research should use a cognitive evaluation or screening tool to rule out individuals who will be inappropriate or unable cognitively to attend for the duration of the interview. If possible, future research should use a longitudinal research design to look at individuals in a variety of settings, such as assisted living and independent living, prior to their entry into long-term care. Using this type of research design would nonetheless run the risk of affecting the transition by the researcher's communication with the participant throughout the transition, a constant that could positively or negatively impact the mental health of the participant.

Clinical Implications

The qualitative data in conjunction with the limited significant quantitative data suggests a need for adjustments in the way staff treat elders in long-term care facilities. Occupational therapists need to be involved in the continuity of transitions in elders, both in receiving new participants into the long-term care facility and in discharging them from other locations. They need to advocate for client-driven environments with role continuations to assist in this transition. Regardless of the therapy services that an individual qualifies for, it is important for the occupational therapist to be involved in occupation-based activities with elders in long-term care. Finally, occupational therapists need to work more effectively with nursing staff to address the mental health needs of elders in long-term care. All of these changes must be documented and added to the data available for research analysis. This will assist the field of occupational therapy in supporting the importance of its role with elders in long-term care, particularly those who might not, under the current stipulations, qualify for therapy services.

Chapter 6: Conclusion

This study was intended to investigate the relationship between quality of life and roles and routines during the transition into long-term care. It also aimed to explore other correlates with quality of life in order to better understand how to provide assistance during the adjustment period. The study confirmed previous literature, which suggested that a decrease in quality of life follows transition to a skilled nursing facility.

The results of this particular research demonstrate that most elders experience changes in their routines when entering a long-term care facility. The data indicates a change specifically in morning routines to fit the structured schedule of the institution. These adjustments interfere with the individual's ability to complete the morning routine, which may cause additional stress. The influence of these habit changes on occupational performance, as measured by the OCAIRS, correlates moderately well with quality of life. The effect of physical, cognitive and social skills on occupational performance also correlates moderately with quality of life. The higher incidence of physical skill decline in this population may explain the significance of the relationship between routines and quality of life. Given the decreases, particularly in physical skills, upon entering the facility, the researcher postulates that participants may need to rely more on previous habits for improving occupational performance.

Participants in this study also reported role loss following entry into the skilled nursing facility (1.2 roles on average). Due to the small sample size and limitations of the measure used, the OCAIRS, the researcher was unable to prove or disprove a relationship between roles and quality of life. Future research should explore the use of a different measure to better capture and quantify the importance of role changes during the transition to long-term care. In addition, the multitude of factors presenting correlative yet statistically insignificant relationships with

quality of life indicates a need for a larger sample population.

The field of occupational therapy needs more research into the transition to long-term care in order to effectively address the decrease in quality of life and to create a case for insurance reimbursement for this service. Occupational therapists working in long-term care facilities can assist the treatment team in better understanding the difficulties of transition, particularly in relation to changes in routine. They can discuss familiar routines with their clients and report back to the nursing staff in order to ensure a smooth transition with similar routines upon entering the facility. Occupational therapists can also assist staff in understanding the importance of maintaining routines in order to best use skills that are limited by changes in health. In addition, their expertise can aid in overcoming barriers to maintenance of social roles and networks through assistance with transportation plans, finding community activities of interest, and acting as a social advocate for the individual's voice within the community.

Appendix A: Human Subjects Review Board Approval

October 14, 2010

Christine Slocombe, Graduate Student
Department of Occupational Therapy
School of Health Sciences and Human Performance

Re: How Changes in Roles and Routines Affect Quality of Life in Elders Moving to Long Term Care

Thank you for responding to the stipulations made by the All-College Review Board for Human Subjects Research (HSR) on September 23, 2010. You are authorized to begin your project at any time. This approval will remain in effect for a period of one year from the date of authorization.

After you have finished the project, please complete the enclosed Notice-of-Completion Form and return it to my office for our files.

Best wishes for a successful study.

Sincerely,

Carol G. Henderson, Associate Provost for Academic Policies & Administration
All-College Review Board for Human Subjects Research

/mat

Cc: Melinda Cozzolino, Associate Professor

Ref: HSR 0910-10

Appendix B: Human Subjects Review Board Revisions Approval

November 18, 2010

Christine Slocombe, Graduate Student
Department of Occupational Therapy
School of Health Sciences and Human Performance

Re: How Changes in Roles and Routines Affect Quality of Life in Elders Moving to Long Term Care-Revisions

The All-College Review Board for Human Subjects Research (HSR) has received your request for review of revisions to the above named proposal. The proposal has been reviewed and the Board authorizes you to revise the study. This approval will remain in effect for a period of one year from the date of authorization.

After you have finished the project, please complete the enclosed Notice-of-Completion Form and return it to my office for our files.

Best wishes for a successful study.

Sincerely,

Carol G. Henderson, Associate Provost for Academic Policies & Administration
All-College Review Board for Human Subjects Research

/mat

Cc: Melinda Cozzolino, Associate Professor

Ref: HSR 0910-10

Appendix C

ALL-COLLEGE REVIEW BOARD
FOR
HUMAN SUBJECTS RESEARCH

COVER PAGE

Investigators: Christine Slocombe, OTS & Dr. Melinda Cozzolino, OTD, OTR/L, MS, CRC
Department: Health Science and Human Performance, Occupational Therapy
Telephone: Christine Slocombe (413) 687-8004, Dr. Melinda Cozzolino (607)-274-3618
Project Title: How Changes in Roles and Routines Affect Quality of Life in Elders Moving to Long Term Care

Abstract:

Despite theories that bring out the importance of habits, roles, and routines, there is not enough research to emphasize its significance or suggest a means of intervening into the routines and roles of elders in a way that will benefit them. Though many studies have explored differences in quality of life connected with living environment, no studies have looked at how routine differs based on living environment.

This study aims to use semi-structured interview and quality of life measures with elders to determine changes occurring during the transition to a long term care setting. Exploring the routine and role changes that occur throughout this adjustment will assist occupational therapists in establishing a role to assist in transitions between different care settings within this population. Administering the Occupational Circumstances Assessment Interview Rating Scale (OCAIRS) and the Global Quality of Life Scale to 25 residents of Beechtree Care Center, in addition to a demographic questionnaire, will allow researchers to evaluate the growing need for further research in the realm of routines and roles in elders experiencing environmental transitions.

If routines and roles do change with living environment in a way that affects quality of life, occupational therapists can begin to incorporate this into therapeutic practice. Not only can they help elders to cope with changes in routines and roles, but they can also act as advocates for modifications in the routines of institutions in order to make moving into institutional settings as routine and role continuous as possible for elders, which may improve quality of life.

Proposed Dates of Implementation: Ithaca College Fall 2010 semester

Print Name of Principal Investigator	Print Name of Faculty Advisor
Signature of Principal Investigator	Signature of Faculty Advisor

ALL-COLLEGE REVIEW BOARD
FOR
HUMAN SUBJECTS RESEARCH
CHECKLIST

Project Title:
How Changes in Roles and Routines Affect Quality of Life in Elders Moving to Long Term Care

Investigator(s):
Dr. Melinda Cozzolino, OTD, OTR/L, MS, CRC
Christine Slocombe, OTS

Investigator Use	HSR Use Only	Items for Checklist
X		1. General information
X		2. Related experience of investigator(s)
X		3. Benefits of the study
X		4. Description of subjects
X		5. Description of subject participation
X		6. Description of ethical issues/risks of participation
X		7. Description of recruitment of subjects
X		8. Description of how anonymity/confidentiality will be maintained.
X		9. Debriefing statement
X		10. Compensatory follow-up
X		11. Appendix A - Recruitment Statement
X		12. Appendix B - Informed Consent Form
N/A		13. Appendix C - Debriefing Statement
X		14. Appendix D - Survey Instruments
N/A		15. Appendix E - Glossary to questionnaires, etc.
X		17. Appendix F - Letter of Support

Human Subjects Review Board

1. General Information:

A. Funding

A digital recorder (approximately $60.00) will assist in the recording of interviews and allow for review of results by other therapists/therapy students to reduce bias and increase evidence of inter-rater reliability. Additionally, approximately $40.00 will be utilized to purchase gardening supplies for use as incentives for participation. All costs will be covered by the Occupational Therapy Department.

B. Location

Interviews will take place at Beechtree Care Center, 318 South Albany Street in Ithaca, NY 14850 in the location of preference for each individual resident. Residents will be encouraged to choose a location that allows for privacy given the nature of the interview questions and emotions they may elicit.

C. Time Period

The researchers will be conducting interviews during the Ithaca College Fall 2010 semester. Each interview will last for approximately one hour.

D. Expected Outcomes

Elders transitioning into a long term care living environment will experience a decrease in life satisfaction, correlated with changes in roles and routines. The results of the study will allow further understanding of ways in which occupational therapists can expect to assist elders and will provide insight into the needs of elders in a long-term care setting that can be used to improve client-centeredness of long-term care facilities as well. If roles and routines are important to life satisfaction in elders, research will be implicated to understand how to best address these needs. Completion of the study will fulfill the primary research required for the Master of Science degree. Results of the study will be presented during an occupational therapy research symposium, regional or national conference, and possible manuscript publication.

2. Related Experience of Researchers:

Christine Slocombe is a graduate Occupational Therapy student at Ithaca College. During pursuit of her Bachelor of Science degree in Occupational Science, she took courses in research methods and biostatistics. She has done an extensive literature review regarding roles and routines. She also completed a minor in Aging Studies and has significant personal experience interacting with elders.

Dr. Melinda Cozzolino has earned a post professional doctorate in occupational therapy and is an associate professor and chair of the graduate program in the occupational therapy department at Ithaca College. Dr. Cozzolino has been faculty advisor for numerous thesis and group research projects and is also a member of the Human Subjects Review Board.

3. Benefits of the study

There are no inherent benefits to participants. Results of the study will be provided to Beechtree Care Center with any applicable suggestions. More globally, these researchers believe that the study will benefit elders in environmental transitions by implicating and further clarifying the role of occupational therapy with this population.

4. Description of the participants.

a. The number of participants will depend on how many residents at Beechtree Care Center fit the parameters of the study. Data collection aims to collect data from 25 participants.

b. Participants will be residents at Beechtree Care Center who have entered the facility within the past year. All participants will be capable of recalling events one year prior to the interview, as identified by the activities director with assistance of the medical records of each resident.

5. Description of Participation.

Patients who agree to participate in the study will be asked to complete an Informed Consent Form (Appendix B). Participants will complete a demographic questionnaire and a Global Quality of Life scale. The Global Quality of Life scale will be administered twice, once to indicate quality of life prior to entering the facility (as a retrospective review) and once for current quality of life. The researcher will then administer the Occupational Circumstances Assessment Interview Rating Scale (OCAIRS), a semi-structured interview that requires approximately 40 minutes. Total participation will not exceed 60 minutes. All interviews will be audiotaped for later review.

6. Ethical Issues.

a. There are no risks for participation in this study; however, participation questions may elicit emotions based on the memory of past events or differences identified from past to current abilities.

b. All of the participants will be informed about the project through the Informed Consent Form (see Appendix B).

7. Recruitment Procedures.

a. Participants will be recruited through personal conversation with each resident by the researchers and/or the activities director at Beechtree Care Center (see Appendix A).

b. There is no inducement for participation in this study; however, residents will receive a small plant to keep in their room as a token of appreciation for their participation in the study.

8. Confidentiality/Anonymity.

All assessments and audiotapes will be stored in a locked cabinet to be accessible only to researchers and committee members. All identifying names will be changed to a number or pseudonym of the participant's choice.

9. Debriefing.

There is no deception involved in this study. Participants will be provided with contact information located on their copies of the Informed Consent forms if they choose to inquire about the study during and/or after the study. No debriefing will be necessary as the interaction will occur only once with no follow-up action.

10. Compensatory follow up.

If emotional or physical concerns arise after and/or during participation in this study, researchers will inform a staff member and recommend follow-up.

Recruitment Statement

To be read by the researcher:

"I am a graduate student at Ithaca College in the occupational therapy department. I am researching quality of life in elders. I would like to interview you about your experience entering Beechtree Care Center. The interview will take approximately one hour. If you are interested, could we set up an appointment?"

To be read by Activities Director Beth Coveney:

"I have been in contact with a graduate student at Ithaca College in the occupational therapy department. She is researching quality of life in elders. She would like to interview you about your experience entering Beechtree Care Center. The interview will take approximately one hour. If you are interested, could we set up an appointment?"

INFORMED CONSENT FORM
How Changes in Roles and Routines Affect Quality of Life in Elders Moving to Long Term Care

1. Purpose of the Study
This is an evaluation of the affect of role and routine changes in quality of life for elders entering a long term care setting. The purpose of the study is to decide whether or not there is a need in this area that implicates occupational therapy treatment.

2. Benefits of the Study
Participation in this study will allow you to contribute to creation of a strong body of evidence for occupational therapy in the treatment of elders, which may improve the care that you and your peers will receive.

3. What You Will Be Asked to Do
You will be filling out a questionnaire about your life and how you feel today, as well as how you felt before you began living here. Then the researcher will be asking you questions about your recent transition into long term care. This should take approximately one hour.

4. Risks
There are no risks to this study; however, participation in the quality of life measure and the interview could cause you emotional stress by nature of some of the questions asked. Please speak to a staff member if at any time you have concerns about your participation in, or response to, this study.

5. If You Would Like More Information About the Study

Christine Slocombe, OTS Department of Occupational Therapy Ithaca College 953 Danby Rd Ithaca, NY 14850 cslocom1@ithaca.edu	Dr. Melinda Cozzolino, OTD, OTR/L, MS, CRC School of Health Science and Human Performance Department of Occupational Therapy 607-274-3618 mcozzoli@ithaca.edu

6. Withdraw from the Study
You have the opportunity to terminate the interview or your participation at any point during the study.

7. How the Data will be Maintained in Confidence
Any identifiable information will be blacked out, and assigned a pseudonym along with a unique identification number to protect your privacy. If you wish to choose what your pseudonym is, please notify the researchers.

8. I have read the above and I understand its contents. I agree to participate in the study.

_____
Print Name

_____ _____
Signature Date

I give my permission to be audiotaped.

_____ _____
Signature Date

Appendix D: Demographic Questionnaire

Participant Demographic Sheet

Date of Admission:_____ Date of Assessment:_____

Age:____ Sex:____ Marital Status: _____

Religious/Spiritual Involvement: _____

_____

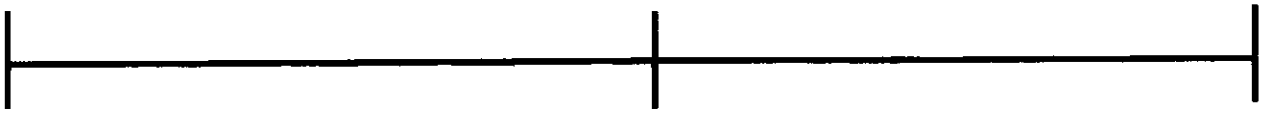
Vocation(s):_____

Expected Retirement Date:_____

Please explain your current work status:_____

_____

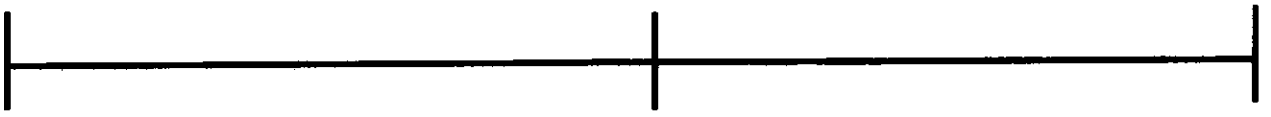
Please rate your **financial status** on the scale below, marking at the appropriate point on the continuous line:



I do not have enough money	I have enough money	I have more than enough money

How many hours do you visit with family and friends in a typical week? _____

Please rate your **health** on the scale below, marking at the appropriate point on the continuous line:



I am not at all healthy

I am generally a healthy person

I am an exceptionally healthy person

Please briefly explain your current living environment, including where you live and with whom:_____

_____

_____

_____

Please list any activities that you enjoy participating in:_____

_____

_____

Thank you so much for your participation in this study! The results will be available by request to cslocom1@ithaca.edu.

References

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