THESIS

OCCUPATIONAL THERAPY AND TIME USE OF PEOPLE WITH DEMENTIA IN LONG TERM CARE FACILITES: CONFIRMING A CONCEPTUAL PRACTICE MODEL

Submitted by

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In partial fulfillment of the requirements

For the Degree of Master of Science

Colorado State University

Fort Collins, Colorado

Summer 2013

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ABSTRACT

OCCUPATIONAL THERAPY AND TIME USE OF PEOPLE WITH DEMENTIA IN LONG TERM CARE FACILITES: CONFIRMING A CONCEPTUAL PRACTICE MODEL THROUGH ACTION RESEARCH

This study aimed to further develop a dementia-specific, occupational therapy conceptual model, the *Lived Environment Life Quality (LELQ) Model*, by asking: how do expert occupational therapists understand and promote positive time use patterns of residents with dementia in long term care facilities? Although occupational therapists are well-situated to promote such patterns for residents with dementia, time use has not been a focus of practice. Using an action research approach, six occupational therapists were chosen through selective sampling of extreme cases. Data were collected via twelve 90-minute interviews and six focus groups. Data analysis included coding, peer review, matrix and thematic analysis, and reflexive journaling. Overall, participants confirmed time use as represented by the LELQ Model as valid. While time use patterns were implicit in their practices, they viewed every moment as a possible moment of engagement and residents as if wearing a quilt with colorful squares symbolizing potential for meaningful daily time use. Participants also recognized that workers in dementia care can sometimes view residents with dementia through a pessimistic lens akin to a gray and stifling quilt, one symbolizing lack of potential for positive time use and leading to staff alienation and negative spiraling of residents' quality of life. Conclusions are that the LELQ Model is a valid conceptual practice model tool for promoting a focus on time use patterns as a vital quality of life indicator. Further, focusing on occupational engagement across the day can be seen as the core of occupational therapy philosophy, a means to avoid occupational deprivation, and a moral obligation of occupational therapists.

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CHAPTER ONE: INTRODUCTION TO THE STUDY

One spring afternoon, music resounded from the lobby of Sunny Acres, a dementia care unit within a nursing home. Two performers were singing and playing instruments, one on the keyboard and another on the guitar. This was "Music Hour" at Sunny Acres, an event that occurred every Thursday at two o'clock. Three residents were present for the event, although present in different ways. One resident, Susan, was sitting on the couch in front of the performers, closing her eyes, smiling, and tapping her hand on her knee along with the beat. Most nurses at Sunny Acres believed this event to be the highlight of Susan's week, as she worked for many years as a choir teacher. Another resident, David, was lying on his side on another couch, gazing off into space. He had happened to be doing the exact same thing before the performers even arrived. The nurses wondered why the music did not energize him in the least. The last resident in attendance, Herb, had been sleeping in his room while the performers were setting up. A nurse had invited him to attend and helped him sit on a chair in the corner of the room. That same nurse had a tambourine, and she was playing along with the beat and encouraging Herb to do the same. He laughed as he made up his own beat with the tambourine.

Music Hour at Sunny Acres seemed to invoke a wide variety of responses from different residents. Although Music Hour was a period of time characterized by an activity and therefore can be labeled an *activity situation,* not everyone was necessarily doing an activity that would be easily associated with it. The manner in which the residents were actually spending their time, regardless of the activity situation, is titled *time use*, and is the focus of this thesis.

The major concern of this study pertains to understanding time use as it relates to the everyday quality of life of people with dementia in long term care facilities (referred to also as "residents" within this paper). This concern is reflected in the problem that my study addresses, its need and purpose, and its conceptual framework. I discuss each of these elements of my thesis as background to the study after which I present the study's methodology and results. Lastly, I thoroughly discuss the study's results and explain what I believe to be its major conclusions. Overall, my motivations for completing this thesis are to connect theory and practice in the hopes of increasing quality of life for people with dementia, advocate for the role of occupational therapy in dementia care, and show my mastery of the topic in nomination for a Master of Science in Occupational Therapy degree from Colorado State University.

Overview and Study Aims

Dementia is an epidemic, and its effect on a large population of human beings, especially those living in long term care, must be addressed. Dementia, more specifically Alzheimer's disease and related dementias, is a type of neurodegenerative disease that occurs when nerve cells in the brain die or malfunction, adversely affecting a person's memory, behavior, and ability to think clearly (Alzheimer's Association, 2012). Eventually, the person's functional ability declines and death can result. As of 2012, 5.4 million Americans have been diagnosed with Alzheimer's disease. Although an estimated 60 –70% of people with dementia live in the community, a growing number are admitted to long term care centers, such as nursing homes, to allow for specialized care.

People with dementia living in long term care facilities experience a unique and difficult lifestyle. Not only do they have challenges that come with the disease, they also are vulnerable to the culture of the care center they are admitted to. The culture of care, which can be optimistic or pessimistic, functions as the lens through which care providers "see" and understand residents with dementia. The malignant social psychology of care centers reflecting a pessimistic culture, as described by Kitwood (1997), does not necessarily imply evil intent of caregivers, but nevertheless is composed of damaging characteristics that can include the following: treachery, meaning the use of deception to distract or manipulate a person; disempowerment, meaning failure to help someone complete an action he or she has initiated; and infantalization, meaning treating an adult as a child. When a pessimistic culture of care thus dismisses the personhood of the resident with dementia, the resident can easily become an object in the eyes of the caregiver. The care is then limited to concerns of physical health and safety. Although this emphasis can sustain physical health and safety of the resident, it may be ignoring major necessities of the full and comprehensive quality of life of the resident.

There is also evidence to suggest that various experiences of people with dementia living in a long term care facility fundamentally influence their day-to-day quality of life. Advocates for long term culture change have argued that the *medical model*, in this case the sole focus on physical health and safety, is not sufficient to maximize quality of life for residents with dementia (Kane, 2001). This thesis is grounded in research that supports the view that people with dementia can best be cared for when they continue to live with meaning and purpose. Supporting meaningful daily time use aids in maximizing mental, emotional, and physical health for people with dementia. Such time use may be inhibited by constantly focusing on keeping a resident clean and safe, thereby degrading his or her quality of life as the disease progresses. Post (2000) also spoke to the problems with this type of care when he said, “Like people with retardation, people with dementia can also receive oppressive care, a kind of care that protects from all risks while ignoring capacities to make choices and live actively, so they are to a degree made to be more demented than they are” (p. 14).

In light of the above premises, I aim in this thesis to: (1) explore the concept of daily time use with expert occupational therapy practitioners who specialize in dementia care, (2) understand these practitioners' perceptions on how daily time use is incorporated into their practice, and (3) identify modifications to the concept of daily time use within the study's guiding conceptual practice model and ideas for its application. My thesis consequently highlights the drastically important idea of time use and its relation to quality of life for the individual with dementia in long term care.

Time Use and Residents with Dementia

Time use can formally be defined as "what [long term care] residents with dementia actually do when in the immediate proximity of an activity situation regardless of its ostensible purpose" (Wood, Womack, & Hooper, 2009, p. 338). As in the introductory example, the purpose of Music Hour at Sunny Acres was to entertain residents and possibly include them in playing music; however, the actual time use of the residents varied. Herb was playing the tambourine, Susan was quietly listening, and David was lying on the couch, appearing disengaged. Perhaps two of those activities actually fell in line with the purpose of the activity situation. Additionally, two of the residents could be considered occupationally engaged and one occupationally disengaged.

Occupational engagement and disengagement of long term care residents are terms used in the *Activity in Context and Time* (Wood, 2005), an occupational science measure of patterns of time use and emotional well-being in context of specific activity situations. Wood defined *occupational engagement* in four observable levels: 1) *engaged gaze*, a very basic form of environmental interaction 2) *functional mobility*, demonstrating health and fitness 3) *participation in conversation*, which shows some engagement in a relationship and 4) *participation in activity*, showing full occupational engagement. Each of these manifestations of time use is somewhat hierarchical, meaning that latter levels can include former levels. On the other hand, behavior void of social and environmental interaction is considered *occupational disengagement*. More specific signs include withdrawn and passive behavior, eyes closed or null behavior, excessive dozing, or showing aggressive and agitated behavior.

Occupational Engagement is Necessary for Quality of Life

Overall, daily time use predominantly characterized by occupational engagement is conducive to a higher quality of life for every human, including the long term care resident with dementia. Occupational engagement is an inherent biological need for all people (Dickie, 2009). Occupations offer a way to form an identity, feel satisfaction and competence in life roles, and participate in life with purpose (Hocking, 2009). The inherent need for occupational engagement and its associated well-being do not change with the onset of dementia or its progression (Chung, 2004).

Accordingly, occupational engagement, including considerations of meaningful activity, functional mobility, social interaction, and ability to interact with the environment, are recognized as important gauges of quality of life as indicated by numerous scholars (Brod, Stewart, & Sands, 2000; Kitwood, 1997; Zgola, 1999). Conversely, time use marked by significant occupational disengagement adversely impacts quality of life. For example, Kuhn, Edelman, and Fulton (2005) found increased daytime sleeping in long term care residents with dementia negatively correlated with quality of life and positive affect.

Environmental press, vulnerability, and channeling for residents with dementia.

Although the person with dementia has symptoms that progressively complicate his or her ability to actively engage in occupation (Sclan & Reisberg, 1992), the living environs, including the social, physical, and cultural features thereof, can support the person to continue to do so. Therefore, the environment of the care facility can either support or hinder a meaningful daily time-use pattern for the resident with dementia.

As described by Lawton and Nahemow (1973)*,* an *environmental press* refers to the phenomenon in which conditions or characteristics of the environment inherently inhibit some behaviors while encouraging other behaviors. For example, during Music Hour at Sunny Acres described in the introduction, Herb was playing the tambourine along with the performers due to the environmental press provided by music being played, an available tambourine, and a caregiver who was sitting nearby assisting and encouraging him to play it. Nobody during Music Hour was watching television because the seats were circled around the performers and the television was in the opposite corner of the room, turned off. Therefore, the environment was pressing Herb to play the tambourine instead of watching television.

Lawton (1974) poses that people with dementia, due to their lowered cognitive capacity, are left in a state of vulnerability, otherwise known as *environmental vulnerability.* Therefore, an environment's particular press has a greater impact on residents with dementia than the average person because they have less capability to act upon their environment and are thereby more likely influenced by it. In sum, the environment has a large influence on time use for the individual with dementia because the environment can press him or her towards a state of occupational engagement or disengagement.

Ultimately, people with dementia living in long term care are at risk for *excess disability*. Excess disability is defined as "a reversible deficit that is more disabling than the primary disability" (Dawson, Kline, Wiancko, & Wells, 1986, p. 298). Factors like physical illness and social problems can cause excess disability and create greater functional decline than what can be attributed to dementia. In addition, an environmental press toward occupational disengagement means that existing skills are not put to use, which can invite excess disability. For example, David, the man lying on his side during Music Hour, was not engaged or using his remaining skills, which could possibly lead to a decrease in strength and endurance.

Over time, the environment can influence daily time use patterns of a long term care resident with dementia in such a way that exacerbates excess disability, thereby hastening the decline of his or her functional abilities, health, and quality of life. This phenomenon, capturing the compounding effects over time, is called *environmental channeling.* Environmental channeling, as described by Rushen, Lawrence, and Terlouw (1993) in reference to animals in captivity, is a channeling effect causing complex behaviors to become increasingly more simplified and stereotypic when animals are subjected to an unvarying captive environment. For people with dementia living in an unvarying long term care facility with a consistent environmental press in one direction, they may develop stereotypic behaviors that reflect that press. In the case of David described in the introduction, after a year of being disengaged during groups held in the lobby that did not spark his interest or skills, perhaps he no longer maintained the endurance to partake in his hobby of strolling through the courtyard after lunch. In effect, his environment channeled his previously wider range of capacities into a predominantly narrow habit of lying isolated on the couch.

Residents with dementia are often occupationally disengaged.

In fact, research shows that environmental channeling may well occur in long term care facilities resulting in time use patterns of occupational disengagement by residents with dementia. In a study by Chung (2004), the daily time-use patterns of 43 participants with dementia living in two different nursing homes were observed. Over a period of six hours, the participants spent 51% of their time during the day in passive (e.g. sleeping) or negative activities (e.g. self-stimulation). Wood, Harris, Snider, and Patchel (2005) observed seven residents with dementia in a special care unit over four days. The researchers found residents to be asocial for 10.5 hours and non-interactive with the environment for 8.5 hours out of a twelve hour day. In addition, Wood, Womack, and Hooper (2009) described one man with dementia in a nursing home who, although having functional ability for many occupations, spent 7.5 hours per twelve hour day sleeping or disengaged. In an ethnographic study by Holthe, Thorsen, and Josephsson (2007), residents were not encouraged to participate in activities on their own and ended up passively sitting through most of every day, feeling like a guest in their own home. Therefore, through environmental channeling, the behaviors of the residents appeared to have devolved into time use marked mainly by passivity (mostly sleeping and eating).

Ultimately, the daily time use pattern of occupational disengagement can be truly felt by the resident with dementia. The continued need for the person to engage in occupation is often not satisfied, leading to feelings of purposelessness, increased excess disability, and an overall lower quality of life. This outcome is vividly portrayed in an article titled "Dying of Boredom" (Wood, et al., 2009) in which a man with dementia approaches the principal investigator claiming that having nothing to do is causing his demise.

Occupational Therapists Can Support Occupational Engagement: A Need

Daily time use, especially promotion of occupational engagement for residents with dementia, should be addressed by occupational therapists working in long term care facilities. According to the *Occupational Therapy Practice Framework: Domain and Practice* (Roley, DeLany, Barrows, Brownrigg, Honaker, & Sava, et al., 2008), occupational therapy is a profession focused on assisting people to engage in daily life activities that they find meaningful and purposeful. Occupational therapists use occupation as a means and an end to help the client participate in these activities, which they believe are part of a person's identity and competence. By participating in occupations throughout the day, occupational therapists believe that health is supported and maintained.

Lack of Current Occupational Therapy Research to Guide Practice

To date, however, there is a paucity of research explicitly connecting time use and current occupational therapy practice for people with dementia in long term care facilities. Six recent systematic reviews in a special issue of the *American Journal of Occupational Therapy* on the effectiveness of occupational therapy for people with dementia (Padilla, 2011) did not include obvious references to a concern with daily time use patterns. While one study recorded the activity of a person every five minutes across a six hour period using Dementia Care Mapping and associated well-being scores, the study only emphasized the well-being scores and did not emphasize the connection between what the person was doing and well-being (Brooker & Duce, 2000). In fact, out of 141 studies cited in these reviews, only 15 studies directly involved occupational therapists in a long-term care setting, thus demonstrating the need for research in this important realm.

Overall, in these systematic reviews, identified assessments, interventions, and outcome measures did not appear to directly address the experiences of people with dementia living in long term care throughout the day and the long term effects of their typical time use patterns. The assessments and outcome measures consisted of heart rate measurements, agitation scales, functional success in activities of daily life, and mental status (Jensen & Padilla, 2011; Letts, Edwards, et al., 2011; Letts, Minezes, et al., 2011; Padilla, 2011a, 2011b; Thinnes & Padilla, 2011). Interventions often consisted of forty minute sessions of therapeutic activity per week, such as multisensory stimulation or reminiscence therapy sessions (Baillon, van Dapien, Prettyman, Rooke, Redman, & Campbell, 2005; Baker, Bell, Baker, Gibson, Holloway, Pearce, et al., 2001). Even occupation-based interventions, such as assisting people with a daily activity through verbal cueing, did not appear to foreground a concern with the person's pattern of daily time use (Chard, Liu, & Mulholland, 2009). Without disregarding the benefits of the research and the methods of practice used throughout, a simple sentence in one of the studies captures my concern. In regards to the residents with dementia who had just completed a sensory integration session, Robichaud, Herbert, and Desrosiers (1994) said, "At the end of the session, they were conducted to their rooms and thanked for their participation" (p. 356). The concern is for how the resident spent his or her time the rest of the day, in which he or she did not receive the direct support of the researcher.

A Possible Solution: Linking Theory with Practice through a Conceptual Model

Connecting time use and quality of life for people with dementia living in long term care facilities to occupational therapy practice could provide a solution to the need for occupational therapists to address these concepts. Theory is beneficial to practice in the following ways: a means for which research data can be interpreted and coded, a means for responding to problems for which solutions have yet to be identified, providing a guide for determining which parts of the phenomena are important, a way to guide and inform research, and a means for members of this discipline to have a common language and frame of reference for further development (Torraco, 1997).

A conceptual model can be the link that connects theory to practice, especially by helping occupational therapists understand theories associated with daily time-use of people with dementia and providing a framework from which to develop ideas incorporating daily occupational engagement for the person with dementia. Occupational therapy practice is often guided by conceptual models, which are ways of viewing components of complex systems and understanding the relationships between the components (Brandt & Pope, 1997). Conceptual models connect occupational therapy assessments, interventions, and outcome measures with theory and can be useful in this case to give occupational therapists a lens in which to view occupational engagement and quality of life of people with dementia.

The Lived Environment Life Quality Model: A Conceptual Framework

The conceptual model used in this thesis is titled the *Lived Environment Life Quality (LELQ) Model* and is under development by Wood, myself, and my fellow thesis students: Christina Alvord and Amy Metcalfe. The model has been formed after years of research by Wood (2011) in understanding environmental channeling and environmental press in non-human primates and her mixed method studies on the environmental effect and time-use of adults with dementia in long-term care settings. Wood has tied together this research with scholars in a variety of fields and created a model that describes the effects of the environment upon the quality of life of the person with dementia in two different temporal dimensions: in the moment and over time. Figure 1 depicts the LELQ Model in the “now” temporal dimension.

The LELQ Model consists of two sections: the lived environment and life quality. The lived environment contains the caregiving microsystem and the person with dementia, which are represented as circles that overlap to some extent. Out of the overlapping area emerges an arrow, which represents environmental press and aims towards three cogwheels within the life quality section. The cogwheels represent the following: (1) how time is occupied (2) use of retained capacities, and (3) emotional well- and ill-being.

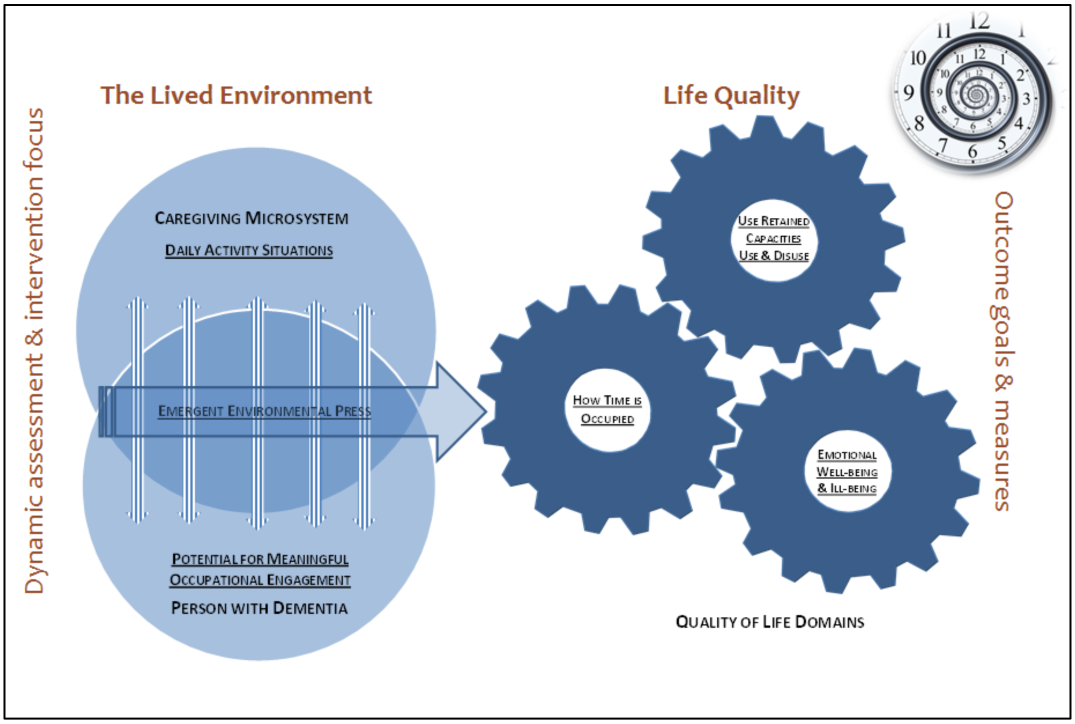


Figure 1. The Lived Environment and Life Quality Model: The Now Temporal Dimension. Adapted from PowerPoint presentations given in all three focus groups.

Ultimately, the nature of the domains within the lived environment causes them to fluctuate in the amount they overlap. The *caregiving microsystem* is the immediate physical and social surroundings of the person in the long term care center and includes the daily activity situations of the facility. The caregiving microsystem also includes the culture of care, whether the culture is optimistic, in which the personhood of the resident is valued, or pessimistic, in which the resident might be seen as the "walking dead." The *person with dementia* contains his or her life history, interests, skills, personality, and other features that may influence the person's potential for meaningful engagement. At any given moment in time, the aspects of the person and the aspects of the environment blend with one another at some points and oppose one another at others, giving rise to an environmental press and the resulting time use of the person.

Differences in the amount of overlap between the two lived environment domains influence an environmental press, which directly impacts how an individual does or does not occupy time. If there is little overlap between the caregiving microsystem and the person with dementia, the environment is considered *occupationally deadening* and presses the person towards the time use pattern of occupational disengagement. An occupationally deadening environment can be characterized by physical environs offering few opportunities for action and a lack of social interactions and support for the person with dementia to engage in occupation or by providing occupations that are too challenging for the resident. For example, at Sunny Acres, David does not have a history of playing instruments and, as his family would say, is not musically inclined. Therefore, Music Hour does not overlap with his interests and talents and shows him to be disengaged during the activity. On the other hand, a large amount of overlap between the caregiving microsystem and the person with dementia is determined as *occupationally enlivening* and presses the person towards a time use pattern of occupational engagement. Therefore, an occupationally enlivening environment would be characterized by physical environs with diverse opportunities for action and the social interactions and support needed by the individual with dementia to exploit those opportunities.

Time use is part of the life quality section along with *retained capacities* and *emotional well-being*. Retained capacities are the skills and abilities that are still pertinent to the person with dementia. For example, Herb playing the tambourine during Music Hour has the retained capacities of hearing the music (auditory skills), holding the tambourine (functional grasp), and hand-eye coordination. Emotional well-being includes the apparent affect of the person with dementia. Is the person smiling, concerned, agitated, peaceful, or showing some other type of emotion? Of course, apparent affect can represent either emotional well- or ill-being. An assumption of the model, as seen by the life quality domains represented as cogwheels, is that meaningful time use involves use of the person’s retained capacities and indicators of emotional well-being. Therefore, occupationally enlivening environments lead to optimized quality of life domains.

All of the interactions thus described are taking place in a moment of time; however, the LELQ Model has another temporal dimension showing long term effects of the interplay between the lived environment and life quality of the person with dementia depicted in Figure 2.

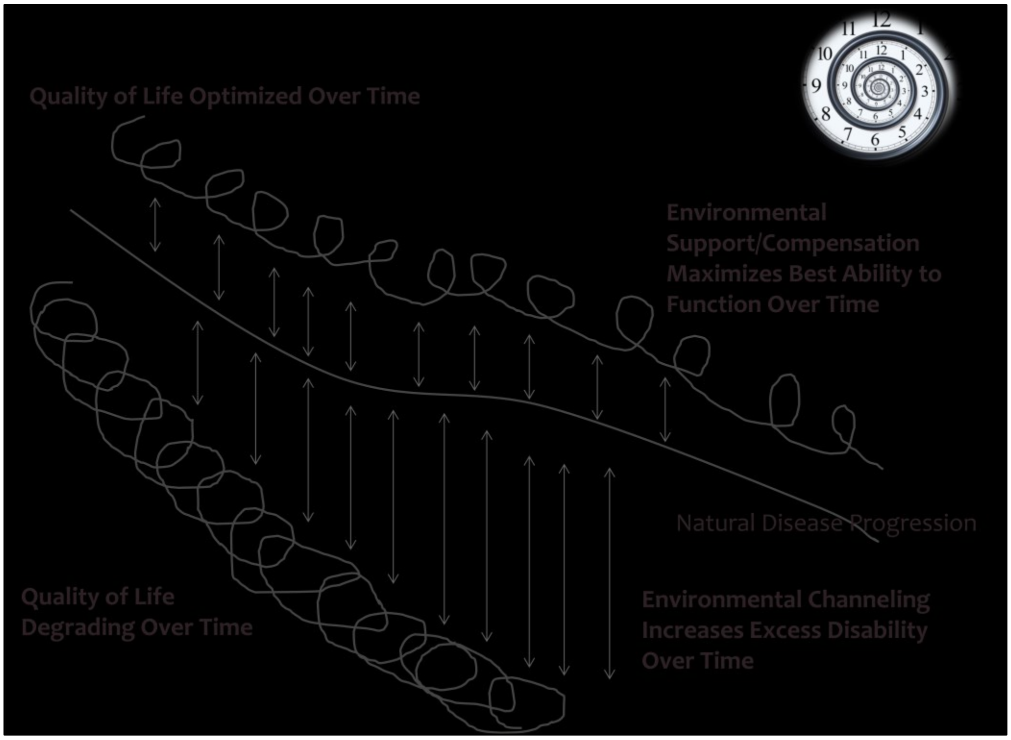


Figure 2. The Lived Environment and Life Quality Model: The Extended Temporal Dimension. Adapted from PowerPoint presentations in all focus groups.

The solid, center line shows an assumed natural disease progression of a resident, with quality of life decreasing over time. The degenerative nature of the disease continues to inhibit the person's ability to partake in life no matter the level of care. Above the line is a spiral that shows quality of life optimized over time. When environmental support maximizes best ability to function over time, the resident's health and quality of life is optimized throughout the course of the disease and follows the natural progression, with excess disability minimized. However, if environmental channeling increases excess disability over time, quality of life degrades at a greater level than the natural disease progression and can have a detrimental effect on health and well-being.

The LELQ Model can be used to help occupational therapists understand the effects of the environment on the time use of a long term care resident with dementia and provide a framework for interventions that may maximize the resident's quality of life. This model also can provide a way to organize assessments, interventions, and outcome measures within practice.

Research Questions

My research questions are based on the aims of the study in exploring the concept of daily time use in current occupational therapy practice and how practitioners understand daily time use in the LELQ Model and ideas practitioners have on future application of daily time use. The guiding questions of inquiry are as follows:

1. How do occupational therapists identified as experts working with people with dementia understand daily time use for people with dementia in long term care facilities?
2. How do these occupational therapists understand the concept of daily time use within the LELQ Model, and how do these understandings relate to other concepts in the model?
    a. In what ways do the practitioners' perspectives confirm or disconfirm the LELQ Model's proposed relationship between the caregiving microsystem and long term

   care residents with dementia, including the impact of the emergent environmental press on their daily time use?

   b. In what ways do the practitioners’ perspectives confirm or disconfirm the LELQ Model’s proposed relationships between time use, emotional well-being and retained capacities?

3. How do these occupational therapists apply daily time use in their practice, and what are the implications for practice based on these occupational therapists’ understandings of time use and its place in the LELQ Model?

CHAPTER TWO: METHODOLOGY

The LELQ Model has the potential to connect the concept of time use and its relation to quality of life to research and practice for occupational therapists working with people with dementia in long term care facilities. Accordingly, the methodology adopted in the present study was designed to further the development of the model through collaboration with occupational therapists while at the same time empowering them to achieve a higher level of practice and incorporation of time use by giving them the concepts and frame of thought the model provides. To achieve both collaboration and empowerment, an action research approach was used. Next, action research is introduced, followed by an explanation of its compatibility with both how theory is built in a practice profession and a participatory inquiry paradigm.

An Action Research Approach

This thesis employed an action research approach. According to Meyer (2000), there are three important elements of action research: participatory character, democratic impulse, and social change. *Participatory character* of action research means that participants, in this case the expert occupational therapy practitioners, agree change is needed within the subject of study and are involved past the point of being "studied" to become co-researchers. Therefore, this study involved all researchers (the practitioner-researcher team) collaborating together on the methodology and development of the concepts and visual representation of the LELQ Model. Thus the occupational therapy practitioners are referenced as "participants" in the remainder of this paper in the truest sense of the word. The next element of action research, *democratic impulse*, ties in well with the participatory nature in that participants are included in both data collection and evaluation of the results (Meyer). Accordingly, this study involved consistent reflective questioning with the participants to determine appropriate understanding and evaluation of the results, modifying the LELQ Model based on their feedback, exchanging vocabulary, and providing input on the methodology. In this sense, the study created a democratic pulse to reverberate throughout the practitioner-researcher team. Finally, the last element of action research, *social change*, was included in the study's mission of empowering occupational therapists with the knowledge and ability to increase quality of life of people with dementia living in long term care facilities and included the very people able to bring about change. Overall, the collaboration of the practitioner-researcher team was centered on a powerful action research process, which "emerges when all participants become researchers in their own right, gaining the skills and insights that enable them to systematically investigate issues in their own lives" (Stringer & Genat, 2004, p.10). In this way, use of an action research approach was employed in order to help bridge a gap between theory and practice.

Theory-Building in a Practice Profession

As described by Lynham (2000), theory-building in a practice profession involves a "process or recurring cycle by which coherent descriptions, explanations, and representations of observed or experienced phenomena are generated, verified, and refined" (p. 161). This cycle of identifying and refining concepts of a phenomenon leads to knowledge that is judged by its usefulness to practice and its rigor and relevance. Therefore, theory-building creates a valid theory through cyclical verification and a usable theory by making understanding of phenomena explicit and transferable (Lynham, 2002). Lynham further proposed that building such an applied theory requires two different forms of expertise: knowledge and experience. In this study, the participants and academic researchers had both types of knowledge. Yet the pairing of practitioners currently working in the field and academic researchers currently devoting time to scholarly work was believed to be beneficial in informing the process through different perspectives.

A model showcasing the five main theory-building phases, some of which were utilized within this study is depicted in Figure 3.

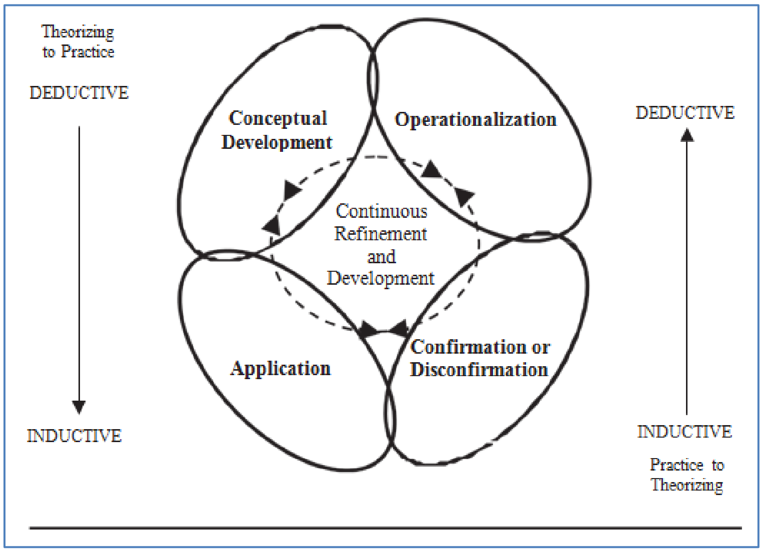


Figure 3: A model showing the iterative steps of the theory-building process. Retrieved from "The General Method of Theory-Building Research in Applied Disciplines," by S. A. Lynham, 2002, *Advances in Developing Human Resources, 4*, p.231.

The phases are not linear, yet are all necessary for a valid outcome. The phase of *conceptual development* is formation of a framework that gives initial understanding and explanation of the nature and dynamics of the phenomenon at hand. The *operationalization* phase is the connection of the conceptual framework to real life practice; the study's work in this phase is especially evident in the first research question in which my research team sought to understand how the participants understood and used their ideas about daily time use within their respective practices to further inform the model. The phase of *confirmation or disconfirmation* serves to strengthen the operationalized conceptual framework by supporting and further shaping the parts of the model that are seen as relevant and valid and removing the parts that do not meet that criteria. Throughout this study, the occupational therapists participated in this phase through their feedback and ideas on the model's development. The *application* phase puts the conceptual framework to the test by actually implementing it in practice. Overall, the methodology of the study fit in the operationalization and confirmation and disconfirmation phases within the theory-building process and started the application phase in that some discussion was devoted to implementation of the LELQ Model.

Participatory Inquiry Paradigm

Ultimately, the methodology, including the influences of action research and theory-building, strongly aligned with a participatory inquiry paradigm. Within this paradigm, reality consists of both objective and subjective states; each experience a person has is composed of something objective that a person is experiencing, perceiving, and relating with and also is composed of his or her feelings and reaction to the experience (Heron & Reason, 1997). The methodology of this study embodied this idea of reality in attempting to understand the experiences of practitioners working with people with dementia in long term care, recognizing both the description of the actual events and the thoughts and emotions of the participant.

Also within the participatory inquiry paradigm are different ways of knowing. There is an experiential way of knowing, a presentational way of knowing that involves symbolic expressions, a propositional way of knowing involving diagrams and theories, and a practical way of knowing that involves taking action (Heron & Reason, 1997). All four of these ways of knowing are included in the study by recognizing the experiential knowledge base of the participants, demonstrating experiences and processes through the LELQ Model and the symbols therein, discussing the theories behind the model, and encouraging the model to be implemented into practice and influence the actual work of the practitioners.

Finally, the participatory inquiry paradigm aims towards human flourishing (Heron & Reason, 1997). The methodology must aim towards benefiting humankind and go above and beyond simple research to promote action towards that end. Accordingly, action research and theory-building allowed the participants and the researchers in this study to collaborate to increase the effectiveness of the results and application to practice. Overall, the underlying and unwavering motivation of the practitioner-researcher team throughout the entire study was to optimize quality of life for people with dementia living in long term care facilities.

Participants

Due to the important and inclusive role the participants played in this study, they were chosen through selective sampling of extreme cases. Extreme cases are those people "that are highly unusual manifestations of the phenomenon of interest" (Creswell, 2007, p. 127). The methodology begged for "expert" practitioners that were not only knowledgeable and experienced in the field of dementia care but also showed a level of leadership and active engagement in discovering and promoting best practice. Through research of practitioners that were contributing scholarly articles and recommendations provided by selected participants, six expert occupational therapists were identified and agreed to participate in the study. The inclusion criteria included at least one of the following: authorship of publications related to the care of people with dementia, leading continuing education on the topic, demonstration of leadership roles in caring for residents with dementia, or recommended by established leaders in occupational therapy for people with dementia. The exclusion criterion was less than five years of direct clinical experience with people with dementia. All participants were provided the IRB approval form and consented to the project.

This method of sampling led to a collection of well-qualified, experienced, caring, active and engaged occupational therapists from around the country. Table 1 shows the demographics of the participants with numbers instead of names for anonymity purposes.

Table 1

Participant Demographics

Participant Number	State	Highest Degree in Occupational Therapy	Year of Certification	Current Role	Experience with People with Dementia (Years)
1	CO	BS	1984	One to One Consult	12
2	MN	BS	1996	Business Mentor Consult Program Developer	15+
3	NC	BS	1977	One to One Mentor	29
4	NC	BS	1989	Business Consult Program Developer Environment Design	18+
5	AL	BS	1996	Mentor Consult	16
6	NC	MS	2003	One to One Consult	10

Data Collection

Overall, data were collected through semi-structured interviews and focus groups. Semi-structured interviews were chosen to keep interviews focused on the topic at hand while still allowing for freedom in answering questions and developing thoughts. Focus groups have a wide range of benefits that include encouraging participants to generate and explore their own understandings of the topic, identifying group norms and values, and illuminating perspectives through group debate (Kitzinger, 1995). Focus groups work best when designed to be small enough to give everyone a chance to provide input in the discussion but still large enough to offer a variety of perceptions about the topic (Krueger & Casey, 2009). Therefore, three sets of focus groups were divided into two groups each with three participants in a group and completed by conference calling and shared computer desktops. Each focus group transcription was analyzed to inform the next focus group on pressing topics and areas of interest. Participants were also asked for ideas about structuring the methodology at each point, and their suggestions were implemented. For example, one participant requested looking at a case study through the lens of the model. Therefore, we incorporated a case study to promote further discussion of the model in the second set of focus groups. The methodological map of data collection and analysis is shown in Figure 4.

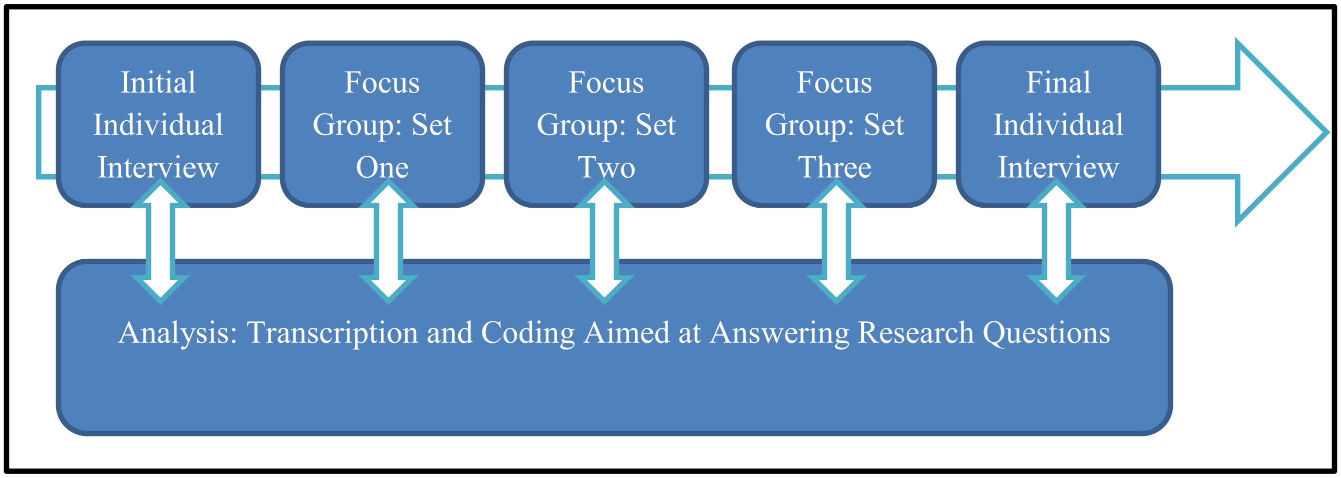


Figure 4. Map of Data Collection and Analysis

Initial Interviews

The study began with individual phone interviews to become familiar with the personality and background of the participant and personally welcome them as co-researchers. The interview was categorized into three major parts: participant background, nature of work, and stories. The participant background section served to collect demographic data. The nature of work section focused on what the participant was actually doing throughout the day in her current role and setting, including evaluations, interventions, and outcome measures the participant often used and valued in practice. The last part of the interview, the stories, focused on the participants' versions of a story in their practice "where it all came together" and a story "where it just didn't work out." The request to share stories was open to participants' interpretations and most offered one-to-one experiences with an individual with dementia. Some participants offered experiences with an authoritative figure or a group of individuals over a period of time. A sample interview guide is attached in Appendix A.

Focus Groups

The first two sets of focus groups were structured to address operationalization, confirmation and disconfirmation of the model, and ideas for its application. The agenda of the first set of focus groups was introducing the LELQ Model, educating participants on the language and concepts within the model, and identifying initial perspectives and questions. In the second set of focus groups, discussion was centered on further confirmation and disconfirmation of the model, as well as its application. As suggested by a participant, a discussion of a case study was included to further frame the model in a real-life event. The case study chosen was from the aforementioned article titled "Dying of Boredom: An Exploratory Case Study of Time Use, Apparent Affect, and Routine Activity Situations on Two Alzheimer's

Special Care Units" (Wood, et al., 2009). This article described the settings of two long term care centers and a vignette of an individual with dementia that lived in each one. These stories were used to further explain the concepts of the model and organize participant discussion.

The third set of focus groups included three parts: the big picture view, the detailed discussion, and supports and barriers to implementation. The big picture view involved a brief review of the model and the thoughts of the participants on the benefits of implementing the model as well as the strategies to do so. The detailed discussion involved separation of the model into assessment, interventions, and outcome measures related to their associated parts of the model. Participants were encouraged to give specific ideas for each area of the occupational therapy process. The section on supports and barriers was limited due to time constraints but aimed to identify further support and barriers to implementation of the model as perceived by the participants. The outline of every focus group and the final interview is included in Appendix B.

Final Individual Interviews

The final interviews consisted of member-checking and ensuring that no information was missed from the participants. The confirmation and disconfirmation that were provided throughout the transcripts were gone over with each participant to ensure proper understanding. Then each academic researcher presented results thus far to allow the participant to change or elaborate on any given area and enhance the end result. The participant was asked for further reflections on how the model had changed her practice, how she saw other occupational therapists using the model (supports and challenges), and asked for thoughts on further engagement in the research process.

Data Analysis

The process of analyzing the data was iterative, dynamic, and multimodal. Analysis was completed during interviews and focus groups through noting and journaling. Analysis was also completed directly after an interview or focus group through academic-researcher discussion and digestion of the participants' words. Analysis was conducted through long periods of time reading and coding interviews, developing relationships and sub-codes, examining matrices, and writing draft upon draft of the results. Most of the coding, matrices, and methods of analysis were completed on the qualitative software NVivo to aid in organization and efficiency in analysis. To understand the context and process of data for "analyzing my analysis," I have explained my processing in a somewhat narrative form as follows.

Before any data were collected, the two other academic researchers and I were educated on the LELQ Model by Wood and conducted an in-depth literature review on its concepts to prepare to develop the research proposal and provide a framework for analyzing data. The knowledge resulting from the literature review and the specific research questions developed by each researcher guided the formation of *a priori codes*, which are codes defined before examination of data (Gibson & Brown, 2009). These a priori codes were directly related to the model's concepts in an effort to view the data through the model's lens and thereby guide the operationalization, confirmation, and disconfirmation of the model's theories. Some examples of the a priori codes that were developed include "Lived Environment - Social" and "Quality of Life – Time Use – Outcome Measures" with the hyphen designating a code within a code. The process of creating such "sub-codes" within "parent codes" allowed further investigation into the nuances within a given code structure (Gibson & Brown); most sub-codes were created later in the process.

During the individual interviews and focus groups, I took notes on a blank copy of the interview or focus group outline, allowing me to write down questions to ask the participant, points of discussion for the group after the interview was over, and my personal reflections on the interview for future analysis. After each interview or focus group, the academic researchers and I discussed the parts that stood out to each of us, questions for further investigation, and implications of the discussion on each of our research questions. This allowed us to collaborate on the initial meaning taken from the interview or focus group before too much time had passed and we forgot our original thoughts and was a way to incorporate peer checking.

After completing the first interviews, the academic research team met as a group to conduct line-by-line coding of two interviews. This time-consuming process proved to be beneficial in allowing us to develop a set of *empirical codes*, which are codes that are given to the data upon examination (Gibson & Brown, 2009). This extended our list of codes much further than the original list of a priori codes. This first set of open coding with a priori codes included and their definitions can be found in Appendix C. By completing this process as a group, we were able to collaborate together on common definitions of each code and work through any discrepancies in our view of how the code should be applied. For example, a new code, “Practice Influences,” was developed to identify thoughts, events, and theories that worked to form the practitioner’s practice and professional identity.

After completing this process of group collaboration, the academic researchers split up to individually code two other interviews using the empirical codes created as a group. Any other codes developed by each researcher at that time were recorded for further discussion with the group. The researchers then met to check reliability by comparing codes given to each line. Through group process, the researchers again worked through any discrepancies to establish higher reliability in the coding process. The researchers then individually coded the remaining interviews by splitting up the codes and assigning them to each researcher according to the focus of her thesis. Therefore, I focused on codes associated with time use and coded the remaining interviews as well as checking the use of those codes on the previously coded interviews. The group met together again to spend a day "cleaning up" the codes to ensure that codes were mutually exclusive and to discuss new codes and sub-codes added.

Once we started the process of conducting focus groups, I coded each focus group according to time use. I had originally coded time use within the categories of assessments, interventions, and outcome measures; however, I felt like I was forcing these categories upon the transcriptions. Therefore, I created four main categories based on how the idea of time use was presented in the data: "time use explicit", "time use implicit – occupational engagement", "time use implicit – occupational disengagement", and "time use other". The reason for this change also came from my realization that time use seemed to be missing in the discussions of the participants, but when I reviewed the transcripts on a deeper level, it became obvious that the ideas behind the concept of time use were embedded in many of the stories and examples the participants gave. Therefore, the implicit and somewhat hidden discussion of time use could not be ignored. The "other" category was used as a catch-all for any codes that did not fit within the other categories, especially codes that could be considered *negative cases*. Negative cases are data that run counter to emerging propositions and used for refining those propositions (Pope, Ziebland, & Mays, 2000) and were essential to ensuring that any disconfirmation of the model was not missed. Further sub-codes within the "time use – explicit category" were also added to group similar ideas for examination of their relationship to other codes; these are included in Appendix D.

When the initial interviews and focus groups had been completed, extensively reviewed, and coded, I conducted multiple modes of analysis. First, I reviewed all of the quotes under each code and sub-code to start forming relationships between the codes. Then, I completed matrices comparing time use codes to other codes to further explore relationships and ensure I was not ignoring any strong ones. Matrices, according to this study, were essentially tables comparing frequencies of codes in relationship to one another. I first ran a matrix comparing time use codes to all other codes (see Appendix E) and then used the results to run more specific matrices. After completing these matrices and exploring the relationships they presented, always memoing along the way, I started to write the results. The process of writing, having to actually connect relationships and logically define the data, is a part of analysis in itself (Gibson & Brown, 2009). During the writing process, I was continuously drawn back to the transcriptions, the matrices, my notes during the data collection sessions, and my journaling to thoroughly capture the analysis. The findings of these explorations are discussed in the results section below and were judged using action research evaluation criteria.

Evaluation of the Research

Although there are differing views amongst scholars on how to properly ensure the trustworthiness and effectiveness of the data collection, analysis, and portrayal of results (Lincoln & Guba, 2004; Morse, Barrett, Mayan, Olson, & Spiers, 2002), one thing is clear: verification of the results and analysis should take place during the entire research process rather than only at the end (Morse, Barrett, et al.). As analysis was completed throughout the entire process of the study, as well as instances of establishing trustworthiness and effectiveness. To emphasize these instances and aid in evaluation of this study, information is presented in the four categories provided by Meyer (2000) on evaluations specific to action research: generalization, trustworthiness, ethical code of practice, and judging success.

Generalization.

Within action research, generalizability of the research depends on the study being “reported in rich contextual detail and written in accessible language” (Meyer, 2000, p. 9). To make an effort of understanding and capturing the context of this study for inclusion in this paper, we collected demographic information of the participants, including amount of time working with people who have dementia and current work setting, and we held an in-depth discussion on understanding their practices. Inclusion of this information along with detailed descriptions of the LELQ Model and the methodology aim to provide insight into the contextual influences of the data; therefore, readers can better understand the process and results to judge the relevance of the presentation and discussion of the results to their own situation.

Trustworthiness.

Trustworthiness, as Meyer (2000) described, involves triangulation, member checks, and reflexivity to acknowledge subjectivity. Trustworthiness of the data was strengthened in various ways. First of all, the study aimed for methodological coherence among all parts of the study including its research questions, methodology, findings and interpretation of findings (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Also, the process of data collection and analysis was iterative: each step of collection was informed and directed by analysis of previous transcripts, and modifications were made to the LELQ Model during the study based on the requests by participants. This ensured that the researchers did not force the data to flow with a pre-made, step-by-step collection process, but rather opened the researchers to exploring the data as a whole.

Trustworthiness was also strengthened through the interaction among members of the entire research team. The extensive contact made with the participants through the interviews and focus groups allowed the academic researchers to go over questions they had about something a participant had previously said to ensure correct understanding. In this way, the researchers conducted a simple form of member checking. The academic researchers met once a week to discuss developing codes and themes, correct any missteps in understanding the data, and bring new ideas to the table from each individual's review. This review amongst researchers and the inclusion of both individual interviews and focus groups in data collection reflected *investigator* and *methodological triangulation*, as described by Guion, Diehl and McDonald (2011) because multiple researchers brought different perspectives to the data and we used different sources to generate data (interviews and focus groups); it also reflected thorough and ongoing peer checking. All in all, the review amongst researchers allowed each to discuss ideas, gain feedback from the group, and develop an original view of the data each one had spent so many hours looking over. In addition, the mix of interviews and focus groups allowed for both an individualized, personal account from each participant and rich discussion and debate through group processing.

Another part of trustworthiness was exposing my own bias and perspectives on the research, or my *reflexivity* within the research. Reflexivity means understanding one's own place in the research and level of influence upon the research (Mauthner & Doucet, 2003). In this context, bias is not considered a limitation, but rather bias is considered a stance that offers insight to the development of the study. Situating oneself socially and emotionally in relation to the participants is an important element of reflexivity. Accordingly, I have included a section on my own stance in beginning this study in Chapter 5 on my reflections. Also, understanding my perceptions of my place in the researcher-practitioner team was important in gaining insight on what I brought to the discussion and the results. Overall, because of our choice in recruiting "expert" practitioners, I felt like an extremely novice, not-quite-yet practicing occupational therapy student. The participants had a wealth of knowledge and many years of experience in this field of study. Therefore, I often felt like a sponge, passively soaking up as much information as I could. My influence on the study's results came when I was responsible for hosting an interview, leading parts of a focus group, and presenting my results to the participants. These opportunities made me feel more included in the *team* of researchers and understanding this allowed me to find my place in the study. Finally, reflecting on ontological and epistemological perspectives is another essential element of reflexivity (Mauthner & Doucet), and those according to this study were explained in the paradigm underlying our methodology in the previous chapter. As Mautner and Doucet emphasize, there may be limits to my reflexivity in this process, but I have established some "degree" of reflexivity.

Ethical code of practice.

An ethical code of practice defined by Meyer (2000) is respecting the confidentiality and autonomy of researchers by working with their values and beliefs and differing agendas in a sensitive way. Therefore, developing an ethical code of practice was first addressed via an IRB consent form for each of the participants before the study began and the explanation that the methodology was fluid. In fact, participants were invited to assist in directing data collection, aid in analysis, and continue the study to publication. Participants were informed that their personal information would be confidential to everyone but the researchers, which included the participants themselves. Eventually, the participants showed interest in receiving names and emails to keep in touch due to similar passions for their work. Participants were reminded of their consent and their right to not give an answer or leave the study at the beginning of each collection phase. Overall, there were no notable power differences and variations on sensitive topics that might have stifled the results, and none of the participants left the study.

Judging success.

Judging success in action research is defined not by the demonstrable change but more by "what was learnt from the experience of trying to change practice" (Meyer, 2000, p. 9). Each participant showed passion for the cause of engaging people with dementia in long term care, comfort with sharing personal experiences, and gave a resounding, "Yes!" to the LELQ Model. The general feeling gleaned from data collection was that the model represented their understandings and motivations and was needed in long term care to give language and further understanding for the phenomenon at hand. The academic researchers modified the model based on explicit and implicit input from the participants, learned more about the system dynamics of occupational therapy in long term care, and identified a movement for change to a positive culture of care that still pushes forward. Although modifications to the model were not necessarily made regarding time use, suggested modifications regarding time use are included in the results. Overall, much was learned from this study as presented in Chapters Three, Four and Five.

CHAPTER THREE: RESULTS

A common language describing time use was not prevalent in the data, yet the concepts of time use, especially occupational engagement, were consistently discussed by the participants even before introduction of the LELQ Model. Through the data analysis process explained above, I was able to synthesize the data in regards to the three research questions of this study. The major points are spelled out according to each research question below. For possible references, quotes are labeled by interview or focus group and participant. Quotes have also been slightly modified without compromising the meaning for ease of reading.

Research Question One: Understandings of Time Use

Research question one asked, "How do occupational therapists, identified as experts in working with people with dementia, understand daily time use for people with dementia in long term care facilities?" Both the explicit and implicit discussion of time use in all interviews and focus groups were examined to answer this question. Time use was most talked about in subtle ways: embedded in the stories and examples of one-on-one experiences of the participants in working with a long term care resident with dementia. Overall, ways in which the participants understood time use are presented according to four themes: (1) occupational engagement and disengagement in the moment, (2) occupational engagement and disengagement over time, (3) importance of occupational engagement, and (4) occupational therapy in a nutshell.

Occupational Engagement and Disengagement in the Moment: Snapshots of Time

The participants in this study were alert to the time use of the long term care resident with dementia in the moment, and this time use was presented in story form often including indicators of use or disuse of retained capacities and emotional state. Each participant seemed to be taking snapshots in time of the resident. The very nature of these snapshots depict time use in the moment, whether that of occupational engagement or disengagement.

Each positive example of time use in the moment was distilled from the participants' snapshots by using the indicators of occupational engagement presented by Wood (2005) as a guideline, which again are engaged gaze, functional mobility, participation in communication, and participation in activity. I have listed these examples of occupational engagement and their frequency in the transcripts in Table 2.

Table 2

Examples of Occupational Engagement in Order of Descending Frequency

Example of Occupational Engagement	Frequency
Not sleeping	3
Speaking to a neighbor	2
Alert and engaged	2
Doing puzzles	2
Dancing	1
Sorting cards	1
Peeling an Orange	1
Eating	1
Playing golf	1
Demonstrating tasks for students	1
Sweeping and watering	1
Telling stories	1
Taking pictures	1
Discussing selected topics	1
A degree of recognition	1
Eyes open and squeezing hand	1
Picking turnip greens	1
Feeding oneself	1
Transferring	1
Serving and volunteering	1
Picking up objects	1
Typing on a typewriter	1
Singing opera	1
Pulling slot machine handle	1
Making cards	1

As the table suggests, a wide variety of occupations in the "now" temporal dimension were observed. Although most examples were in the category of participating in an activity, all indicators of occupational engagement were represented, showing possible levels of engagement across all stages of dementia. The reason "not sleeping" was included as an indicator of occupational engagement in the moment is that the participant emphasized the fact that the resident in question was clearly engaged at some level.

Despite the varying levels of engagement, these instances are not specific to the population. Examples such as "playing golf," "telling stories," and "taking pictures" could be activities of many a type of person, not activities telling of a disease and residence in a long term care facility. In fact, the apparent joy and excitement of the participants while sharing an example of occupational engagement implied that the participant celebrated when the resident partook in such an essential part of being human. For example, one participant showed excitement and interest in a moment where multiple residents with dementia were engaged:

> One of the things the activity director brought in I just thought was brilliant. I couldn't believe how many wheelchairs and people with walkers were trying to get up to the table. You guys may not be familiar with it, but they brought in turnip greens. They brought them roots and all. So that means [residents] had to do what they had done in the garden, which was pick them off from the root. These [residents] were so into it (Intvw 1, Ptcpt 5).

As this quote suggests, participants demonstrated pleasure when they observed a resident with dementia occupationally engaged. In this quote specifically, the participant demonstrated excitement because so many residents were eager to participate and there was a connection between the present activity and the past of picking turnip greens in the garden.

Although the instances of occupational engagement fit into Wood's (2005) four levels, the instances also speak to three of four categories Hammell (2004) describes as human dimensions of meaning: being, belonging, and doing. According to Hammell, *being* means reflection, introspection, meditation, and engaging in a contemplative manner. Thus, instances described by the participants such as "a degree of recognition" and "not sleeping" speak to this category and are important in that they show someone can be engaged in occupation by simply existing. *Belonging* means inclusion and social support (Hammell) and includes instances described by the participants as "demonstrating tasks for students" and "speaking to a neighbor." And finally, *doing* means purposeful, goal-directed activity (Hammell) which encompasses all of the other, somewhat more active moments of time.

Although these instances could be included in such positive categories, snapshots in time also included examples of occupational disengagement. Using Wood's (2005) categories for occupational disengagement, again withdrawal, null behavior, dozing, and agitation/aggression, I created a list of the key words and phrases used to describe someone showing a negative moment of time use. This list is included in Table 3 with the frequency of each example mentioned. Overall, the examples seem to speak more to two overall categories of occupational disengagement rather than four: isolating behavior and catastrophic reactions.

Isolating behavior includes the examples of disengagement such as "not talking" and "not getting out of bed." These phrases speak to a sort of passive existence that isolated the person in the moment not only from staff but also from interacting with his or her environment in general.

Table 3

Examples of Occupational Disengagement in Order of Descending Frequency

Example of Occupational Disengagement	Frequency
Sitting in a line	2
Sleeping more than necessary	2
Not talking	1
Trying to get out of the facility	1
Not getting dressed	1
Closing eyes while being fed	1
Wandering	1
Yelling and screaming	1
Not getting out of bed	1
Calling staff names	1
Crying	1
Trying to break a window	1
Not walking	1
Stopped eating	1
Zoning out	1
Roaming	1

Catastrophic reactions, on the other hand, can be identified by such phrases as "yelling and screaming" and "calling staff names." One participant introduced us to the term catastrophic reaction, which seemed to describe this behavior best. When asked to give examples of what she meant, she said,

> Crying, yelling…I had a lady one evening that knew she had to get out to her kids, so she picked up her quad-cane and was trying to break the window out of the back door. I call that kind of thing [a catastrophic reaction] (Intvw 1, Ptcpt 5).

In total, these examples of occupational disengagement in the moment were also not necessarily indicative of long term care residents with dementia, as one participant pointed out; however, the examples seemed to be descriptive of people who were unwell, maybe very bored or unhappy. Overall, the participants were able to create a picture in their minds of the residents and the facility by the snapshots they took.

Occupational Engagement and Disengagement over Time

Although an important dimension of time use includes what is going on in the moment, and was expressed in both tables of occupational engagement and disengagement, I needed to understand how the participants understood the idea of time use *patterns,* or time use over longer durations of time. Patterns of daily time use were again implicit in the stories participants provided yet were explicit in the way many participants talked about each day being filled with opportunities for the long term care resident with dementia to be engaged.

One example of the way in which a participant incorporated negative and positive patterns of time use into the discussion was when she was asked to describe a positive, "where-it-all-came-together," story. In this story, the participant described being called in to see a woman, given the pseudonym of Mary, who had recently been put on hospice care. The purpose of the participant's visit was to determine if Mary would be appropriate for a new memory care facility where the participant worked. The participant described her first encounter with Mary in this way:

> And there she was, sitting in the corner of an activity room by herself, hunched over in her chair, and she looked like she was dying. So, we were able to look at her medical charts, and we learned a lot of things. We learned she was on a lot of medications, especially a lot for behavior. She had stopped eating and all kinds of things that might be indicative of end of life (Intvw 1, Ptcpt 4).

Yet, within the first visit, the participant was able both to determine Mary's interests based on information from the Mary's daughter and to identify Mary's remaining abilities based on skilled observations. After thirty minutes, the participant decided that Mary would be a great candidate for the memory care facility. The participant then implicitly noted a change in the way Mary spent her time across the day. Once Mary's interests were supported by the facility at a level she was capable of, Mary started engaging in activities across the day, such as assisting in self-care and lying on the couch, singing opera. Within weeks, Mary went from dependency on hospice care to functioning at the ability level of someone in mild stages of dementia.

In presenting the story, the participant implicitly tied in points that indicate a woman who had not been engaged for a good chunk of time; in other words, Mary's daily time use pattern consisted of occupational disengagement. For example, the participant said Mary had stopped eating, did not participate in grooming any longer, and was usually just "sat in a corner" during the day. Then the participant implicitly noted a change to a positive pattern of time use and the amazing results of that change.

This powerful story showed the implicit nature of patterns of time use in relation to the ultimate quality of life outcomes of the resident with dementia. The participant had not described an instance in time in a therapy session but rather how the woman was engaged throughout the day. As suggested by this example and others, time use patterns *were* on the participants' minds.

In a more explicit and general fashion, participants in this study discussed the view that "each moment can be a moment of engagement" for the long term care resident with dementia. Participants had an optimistic outlook on the potential of the resident to engage at any given moment and were willing to go out of their way to ensure that other staff realized this potential and could assist in engaging the resident throughout the day. One participant described sharing her perceptions with front line staff:

> As [people go from our skilled nursing side to our long term care side] we have [their] therapist follow them and make sure that they continue to do the things that they are capable of doing and try to stretch them to the things that might be challenging for them so that they can have that sense of competence. Then we

> expand that into the areas of their life where they can engage in activities that are meaningful to them and that they enjoy (Fcs Grp 1, Ptcpt 1).

Another participant described how making each moment a moment of engagement had to be a systems level change and cautioned against ignoring the person's potential: "People look sad and they are sitting at the nurses' station and [long term care staff] aren't realizing their potential to do more and make [the residents'] entire day meaningful" (Fcs Grp 3, Ptcpt 5). As suggested by this quote, this particular facility's ignorance of the potential for the residents' engagement led to residents' isolating behavior and emotional ill-being.

Importance of Occupational Engagement

The effort participants in this study put forth in sharing the potential of the long term care resident to be engaged throughout the day possibly stemmed from the immense value the participants placed on the quality of life of the long term care resident with dementia and its connection with occupational engagement in the moment and over time. Even before the LELQ Model was introduced, occupational engagement was seen as highly important. Occupational engagement was described both as an indicator of and a precursor to health, well-being, and overall quality of life. One participant in particular stated that occupational engagement indeed enabled all three. When she was asked how occupational engagement enabled health, she responded,

> I've just seen many individuals that through occupational engagement were more active. So, if you want to really compartmentalize it, they were able to be mobile longer, they were able to have more coherent, verbal, enjoyable conversations for longer periods of time, have better nourishment, laugh more, smile more, have more opportunities for healthy engagement with people, their family and their friends, and many of them live longer. So, if you talk about it being from the standpoint of mortality, those who are engaged live longer (Intvw 1, Ptcpt 6).

Another participant, after identifying quality of life as the goal of her work, was asked to define quality of life:

> Being able to do as much for yourself as you can, and being able to engage with people that are important to you or the activities that are important to you. Just being able to do that or being given the opportunity to be able to do that at the level you are capable of (Intvw 1, Ptcpt 1).

As these quotes suggest, occupational engagement was seen as an ends and a means for achieving overall quality of life. In other words, occupational engagement was included in the residents' quality of life that the participants worked for and also was a way in which participants helped residents achieve quality of life. Whether occupational engagement was the explicit end or a means to an end varied by participant and by situation.

Occupational Therapy in a Nutshell

Many participants described occupational engagement as a means and an ends the defining work of the profession of occupational therapy. During one focus group, Wood read the sound bite a participant had given as a summary of her work: "Know your resident well enough to exceed in some task so that they can engage in something meaningful." The participant responded,

> There ya go, thank you. That's it in a nutshell. What I try and do and teach is exactly that. What occupation, what skill can we have the resident engage in, however big or however small, and to have them be able to do that in a meaningful way (Fcs Grp 1, Ptcpt 3)?

The participant seemed to suggest that enabling the resident to engage in a meaningful way was the most reducible definition of her work: in other words, occupational therapy in a nutshell.

Another participant described how focusing on the continued occupational engagement of a person with dementia was inherent in the philosophy of occupational therapy when asked what she meant by quality of life:

> Meaning that they feel they have a purpose, that they have lot of opportunities where they are engaged or they are singing or they're having a give-and- take with a caregiver or another resident, they are smiling, they have a moment where someone connects with them or they connect with an object and they do something successful. So, having moments [like that] even though they may forget a half hour later, even 10 minutes or 5 minutes later. Some of the family members say, 'Why should I even go to this activity or why should I bring them dinner because they don't remember it?' I'd say that feeling that they had at that moment when they were having a good time or a good feeling or a feeling of familiarity of people around them or loved ones, that moment lasts with them even though they can't verbalize and they can't remember what exactly they did. They are going to have a better few hours after that than if they had some bad experience. The negatives last; they're going to stick in there too. That feeling can carry over even if they can't remember it. So creating those moments throughout the day can just make the day go smoother and is more angled toward [occupational therapy] philosophy: that we're occupational beings and each human being is (Intvw 1, Ptcpt 2).

These quotes suggest that occupational engagement in the moment and over time had a clear and indivisible connection with the work of occupational therapy.

To summarize, both implicit and explicit discussions of time use showed that the participants viewed occupational engagement in the moment as important to the resident's health and well-being. Participants spoke to the potential of engaging the person throughout the day in meaningful activities and involving the rest of the facility in promoting positive patterns of time use. Therefore, the participants desired a positive outlook of the entire staff, one in which every moment could be seen as a moment for occupational engagement and isolating behaviors and catastrophic reactions were prevented and redirected. No matter the stage of dementia, the participant saw the resident to have potential and to be an occupational being. In summarizing her work, one participant said this very point:

> At every stage [of dementia], a person with dementia has the ability to offer and have engagement at every level. So, it may be someone who cannot communicate anymore and can't respond to an activity because they don't know that a ball is coming at them and they are supposed to catch it; they can, at that level, respond to music. So, at the lower levels [of dementia] they can still respond to music and touch. Knowing that can [help someone] create that moment of connection and that moment of joy. The person is never really locked out or completely unaware of everything that's around them. There are always glimmers of ways to engage the person even if it is 20 second eye contact or a 5 second smile in those later stages. There are abilities or ways to engage them and then teaching people around them to recognize that and to draw that out of them: to use those abilities that remain (Intvw 1, Ptcpt 2).

This quote sums up the positive outlook that the participants had for residents with dementia regardless of the stage of the disease and a somewhat underlying mission to help other staff recognize this potential.

Research Question Two: Confirmation and Disconfirmation of Time Use in the LELQ Model

Research question two asked, "How do occupational therapists understand the concept of daily time use within the LELQ Model, and how do their understandings compare with the relation of time use to other concepts in the model?" The sub questions were, "In what ways do the practitioners' perspectives confirm or disconfirm the LELQ Model's proposed relationship between the caregiving microsystem and long term care residents with dementia, including the impact of the emergent environmental press on their daily time use?" and "In what ways do the practitioners' perspectives confirm or disconfirm the LELQ Model's proposed relationships between time use, emotional well-being and retained capacities?"

The participants confirmed both the ideas and language of time use as represented by the LELQ Model, especially the relationship of time use to activity situations. As described previously, time use can best be understood when placed in the context of an activity situation, meaning how the resident is actually spending his or her time regardless of the activity situation's purpose. The participants expressed support for this concept in statements such as this:

> I really loved the categorization of activity situations and how we work with individuals to optimize their meaningful engagement within those activity situations, and also how we work with caregivers to understand how activity situations can be molded to best suit the individual rather than to suit the flow of the day for the institution (Fcs Grp 1, Ptcpt 6).

Confirmation for time use was not only found in explicit discussion but also implicitly embedded in every transcript. Upon review of a matrix comparing time use to other major domains of the model (Appendix E), the most common comparisons were between the following: time use and an alive environmental press, time use and optimal functioning (a sub-code under outcomes of retained capacities), and time use and emotional well-being. Other notable comparisons were occupational disengagement and excess disability, occupational disengagement and environmental channeling, and occupational engagement and environmental awakening. These relationships coincide with how each concept is displayed and connected in the model and are further discussed next.

Time Use and Environmental Press

All in all, the participants recognized activity situations as having distinct environmental presses, whether or not they had the language for environmental press, and connected the press of an activity situation to how long term care residents with dementia occupied time. One participant described the press of a somewhat negative environment and said,

> I've seen [impoverished and facilitative environments] and have tried to work with [residents] in both types of environments to have as enriching an experience as possible. I've seen the negatives of individuals sitting in a stark hallway, not engaged (Intvw 1, Ptcpt 6).

Furthermore, participants took it upon themselves to ensure that physical and social environmental elements were supportive of occupational engagement throughout the day. As a result, the participants emphasized observing staff-resident interactions, even more so in many cases than observing residents individually.

Although the participants seemed to agree that a supportive physical environment was beneficial for occupational engagement of a resident with dementia, the social environment was emphasized as more imperative. Almost every time an example of occupational engagement was mentioned, the meaningful activity was initiated by another person and participated in with others. For example, the previously noted moment of "telling stories" involved staff prompting the residents and facilitating discussion. "Playing golf" involved occupational therapy interns asking and encouraging residents to show the students how to use the equipment, and "picking turnip greens" involved a recreational therapist bringing turnip greens into the facility and assisting the residents in preparing the greens. Therefore, ensuring occupational engagement throughout the day meant ensuring a positive environmental press through staff who understood the potential of the person with dementia and provided support. One participant went further to describe her role in ensuring the readiness of a caregiver to offer support for residents with dementia:

> If you saw a person with dementia walking down the hall, picking objects up from a nursing station, and trying to ask everybody, 'How do I get home?' some

> caregivers may call that person a wanderer or a rummager or confused. So, I would observe how that caregiver defines that person with dementia and how they respond to that [behavior]. When in fact, that person with dementia can walk and can pick up objects and desires to interact. So, I look at how that caregiver perceives the person with dementia. Do they see the abilities or do they label it negatively? And, what is their response to that? Do they try to foster that ability through their intervention, or do they try to discourage it and take it away (Intvw 1, Ptcpt 4)?

Overall, participants further confirmed the connection between environmental press and daily time use patterns. The focus of creating a "just-right fit" between the environment and the person with dementia was seen as essential, especially in regards to the social environment.

Time Use and Retained Capacities

Coinciding with the LELQ Model, the data showed examples of time use intertwined with use or disuse of retained capacities. Moments of occupational engagement were accompanied by the engaged resident using and preserving remaining skills and abilities. To the participants, engagement had inherent connections with retained capacities because truly being engaged meant a person was doing as much as he or she could, thereby maintaining a higher level of cognition, maintaining strength, and sustaining attention. The participant that gave the previous example of Mary coming out of hospice care and thriving in a memory care unit also described the ability to optimize Mary's remaining capacities through occupational engagement:

> One of the things her daughter told us is she loved gambling. So, we didn't have her try to stand up in a walker and move cones back and forth or do any silly therapy activity. We actually happened to have a little area of our clinic that we created called Function Junction. And we had a section of it that had a slot machine. So, we pulled the slot machine handle and it made all this noise, and that got [the resident's] attention and encouraged her to stand up and pull the handle. That was the best therapeutic exercise to help her regain her strength and standing balance than anything I'd ever seen (Intvw 1, Ptcpt 4).

Maintaining and preserving remaining skills seemed to be best accomplished in the context of a meaningful activity.

Occupational disengagement, in contrast, was often seen as a missed opportunity for preservation of skills. The discussion of occupational disengagement was often accompanied by a description of demise in the resident's health and functioning. One participant linked the catastrophic reactions of a resident with dementia to the participant's inability to tailor activities for the resident. Another participant also expressed the decline of one resident and the participant's feelings of sadness in not being able to figure out an occupation that preserved her abilities:

> Once [residents] start zoning out, they look down at their laps. They really don't track any auditory stimuli anymore, and it's a really sad process to watch. [One] woman wasn't here very long. She was still mobile. She was still ambulatory but sat in an isolated way. [I] couldn't get a hold of any family, and it was a very sad thing because I really wanted to know what she was all about just to touch something within her, some familiarity (Intvw 1, Ptcpt 3).

As suggested by the LELQ Model, occupational engagement is associated with use of retained capacities and occupational disengagement with missed opportunities for preserving skills; this was confirmed by the participants. One point of elaboration, however, is that the participants noted at times, occupational disengagement, especially catastrophic reactions, could still be a moment of using and expressing retained capacities. The defining part of whether or not the moment in time was an indicator of quality of life was not if abilities and skills were used, but whether or not the activity was meaningful and demonstrated some form of emotional well-being. Although elaboration should be made on the complex connection between time use and retained capacities, the inclusion of all three quality of life indicators in the quality of life domain is supported.

The participants in this study were motivated and able to see remaining abilities a resident presented in a catastrophic reaction and redirect the resident to a meaningful activity that still allowed those abilities to be expressed. The participants stressed that occupational therapists and other staff could participate in this redirection. Therefore, wandering and roaming, activities that could be very disruptive could also be viewed as showing the remaining endurance, strength, and initiation of the resident; truly helping the resident meant going beyond stopping the catastrophic reaction. One participant emphasized this view as seeing "functional intent" of the resident with dementia:

> We might look at [the behavior] and go, 'Well, that's odd. That's weird. That's not appropriate.' But it is part of what someone is doing and it's part of their intention and they feel like they are doing something that's right and important to them (Fcs Grp 2, Ptcpt 6).

As suggested by this quote, the participant's positive outlook of the resident with dementia, seeing him or her as an occupational being, allowed the participant to go beyond simply preventing a catastrophic reaction and seeing the functional intent behind the behavior. In conclusion, while both occupational engagement and disengagement may demonstrate retained capacities, occupational engagement works more to optimize and preserve them while simultaneously promoting emotional well-being.

Time Use and Emotional Well-being

Discussion of time use was also highly intertwined with the other quality of life domain: emotional well-being. In fact, participants often described instances of occupational disengagement with language that conveyed emotional ill-being of the resident with dementia, such as depression, anxiety, fear, yelling and screaming, and crying. There was little difference between descriptions of catastrophic reactions and emotional ill-being, making the act of separating time use from emotional state almost impossible. In fact, catastrophic reactions were seen as the language by which some residents communicated that they were in distress: an expression of their emotional state. One participant described this phenomenon of catastrophic reactions being a language and the negative spiraling or environmental channeling that resulted:

> Negative behavior is [the residents'] language. They can't tell us what's wrong, but they're speaking very loudly because something is terribly wrong. My conclusion is the environment is really not fitting them. And we have to figure that out. We need to say, 'They're talking to us. What is it?' We need to ask the question, "Why?" Why are they having these negative behaviors? Again the onus is on us to evaluate and assess why they're having these negative behaviors. What I've seen over the years, which is very, very sad to see, is that [negative behavior] doesn't attract professionals; it doesn't allow professionals to respond appropriately because they end up ignoring the patient. These behaviors get ignored. Therefore they just become louder because we just don't know how to respond to them. So it can only create a negative spiral of further negative behaviors (Intvw 1, Ptcpt 3).

As suggested by this participant, the resident enters a negative spiral when he or she exhibits a catastrophic reaction that alienates staff and others who do not understand what the resident is trying to communicate and eventually leads to less social support and more catastrophic reactions.

On the other hand, and consistent with the LELQ Model, participants' descriptions of instances of occupational engagement were linked with positive emotions, not only of apparent affect but also deeper feelings. For example, descriptors of positive emotions related to occupational engagement included smiling, laughing, alertness, joy, interest, brightening up, relaxing, and breathing better.

Time Use and Long Term Effects

As already discussed, time use patterns leading to long term effects were identified implicitly by the participants. For example, the negative spiral of further catastrophic reactions falls within the idea of environmental channeling, which was defined previously as the negative effects of health and quality of life over time resulting from an unsupportive environment and the accumulation of excess disability. The participants strongly endorsed the LELQ Model's proposition that occupational disengagement could lead to isolating or negative behaviors, which then leads to a negative spiral of degrading quality of life and failing health. The participants also resonated with the part of the LELQ Model that diagrammed these long term effects. One participant described a downward spiral of isolation and failing health in a resident who had fractured a hip and moved into a memory care unit:

> [The resident] was getting weaker because she was doing little more in the assisted living than just walking to meals, and she wasn't eating well because there wasn't that kind of the support to help prompt her and encourage her and to be around other people who were also eating well. She just wasn't getting that consistent social engagement that made her feel important and wanted and included (Intvw 1, Ptcpt 6).

Both the negative behaviors and isolating behaviors were represented by the participants as a result of an environment that was unsupportive of the residents' progressive disease, leading to lower quality of life than caused by the disease alone.

In a different light, time use patterns of occupational engagement led to environmental awakening, reaching the optimal quality of life given the disease. The emotional well-being and preservation of retained capacities led to optimal health and well-being of the person with dementia and radiated out to caregivers and family of the resident. An example of this phenomenon understood by one participant was in an interaction with a resident that was so functionally impaired the resident was being spoon-fed with her eyes closed. The participant described her interaction and success in engaging the resident as "literally waking this woman up."

In a way, environmental awakening represented the optimal understanding of time use in the LELQ Model. The occupational therapist and other staff saw the need for occupational engagement the resident had, maintained an optimistic outlook on the resident's potential to have a positive pattern of time use, and supported each moment to be a moment of engagement. Thus, the positive pattern of time use continued despite progression of the disease, exercised the resident's retained capacities, and provided the resident a majority of moments of emotional well-being. Finally, this environmental awakening led to the resident's optimal quality of life.

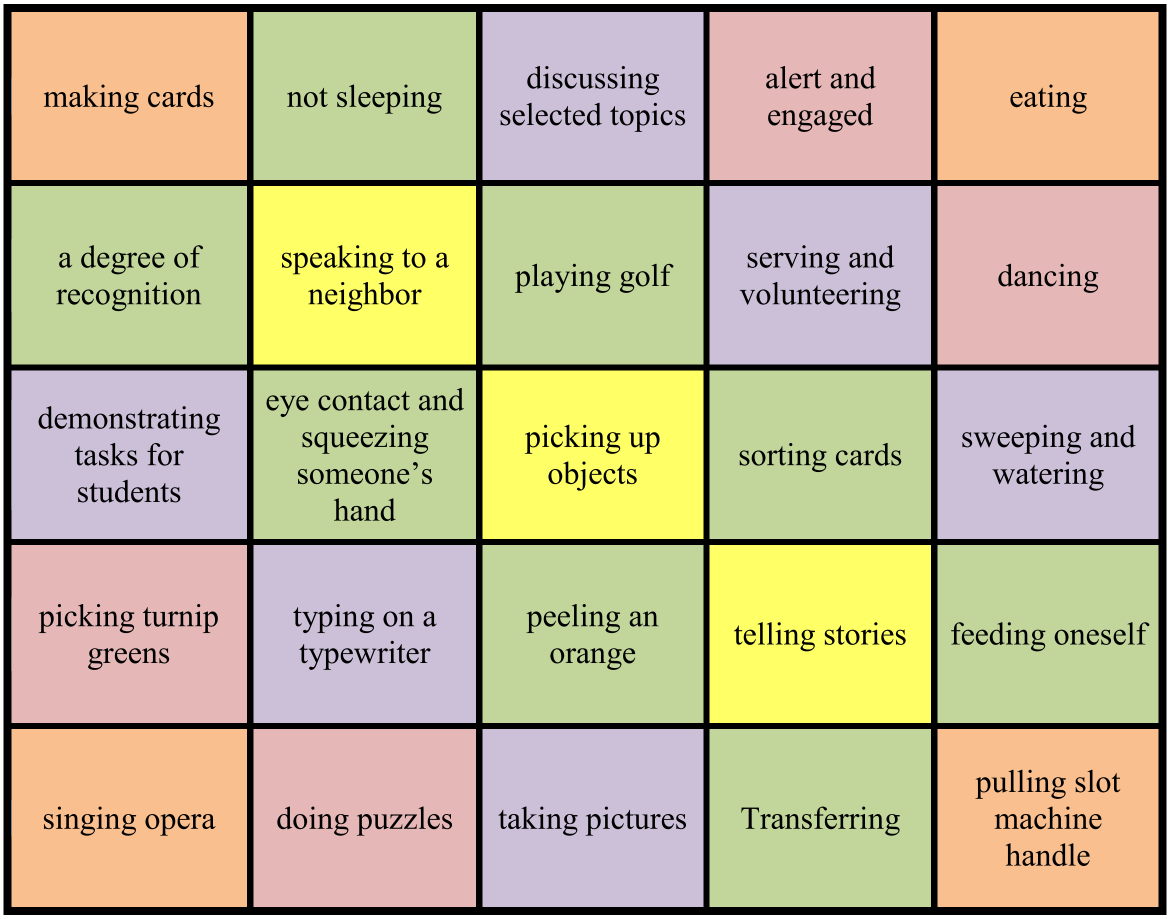
Research Question Three: Implications for Practice

Research question three was, "What are the implications for practice based on these occupational therapists' understandings of time use and its place in the LELQ Model?" Although application of time use was not often discussed in an explicit, specific way, the participants' understandings of time use and the general references to applying the LELQ Model as a whole led to many implications for practice. As already somewhat explored in the sections above, the results suggest that applying the concepts of daily time use to practice involve maintaining a positive view of the long term care resident with dementia in order to see the resident's potential and then move forward in shaping a supportive environmental press.

The participants in this study, all expert occupational therapists in dementia care, had this rich, optimistic view of long term care residents with dementia. They saw the residents as people who still had the inherent need to engage in meaningful activity; catastrophic behavior was viewed as the residents' language in saying something was wrong. This positive outlook led to an image of the potential lifestyle of the resident with dementia, one where every moment could be a moment of engagement. Therefore, the participants intervened with this image in mind, with the underlying, almost inexplicable motive of promoting positive time use patterns. The participants did not necessarily use the language of time use patterns, environmental awakening, and environmental channeling, yet they understood, as shown by their stories, the implications of a resident with dementia in a consistent state of occupational disengagement.

The snapshots the participants took of the long term care residents with dementia and the excitement and pleasure the participants demonstrated when the snapshot was occupational engagement was a way in which the positive view of the resident stood out. To showcase the variety of occupations a resident with dementia was observed to be engaging in, I created a figure (Figure 5) based on the previous table showing the examples of occupational engagement in the moment. This figure is how the participants saw the residents still engaging in life. Although not all described regarding the same resident, together these momentary examples make a positive pattern of time use: a "quilt" pattern of occupational engagement. The positive outlook the participants in this study had for long term care residents with dementia was as though they saw each resident clothed in such a colorful, beautiful quilt.

The quilt symbolizes more than just a play on the word "pattern." A quilt represents active doing, creative expression, personalized design, and a link between the present and the past through tradition. Quilts often provide warmth, are put together in love, and are welcoming. In this way, the idea of a quilt works well with the value and meaning behind occupational engagement. Although the quilt of occupational engagement represents moments of multiple residents with dementia, each resident has a quilt of his or her own. Each resident's quilt is made up of different squares and colors stitched together throughout the day to create a personalized pattern of time use.



making cards	not sleeping	discussing selected topics	alert and engaged	eating
a degree of recognition	speaking to a neighbor	playing golf	serving and volunteering	dancing
demonstrating tasks for students	eye contact and squeezing someone's hand	picking up objects	sorting cards	sweeping and watering
picking turnip greens	typing on a typewriter	peeling an orange	telling stories	feeding oneself
singing opera	doing puzzles	taking pictures	Transferring	pulling slot machine handle

Figure 5. Quilt Pattern of Occupational Engagement. Depicts examples of occupational engagement in a pattern resembling a quilt. Colors represent variety and livelihood in examples.

When the participant saw the long term care resident cloaked in such a quilt, she was able to work towards removing the barriers of the resident's potential and create a supportive environmental press; however, the data suggested that a positive pattern of time use, or the realization of such a wonderful quilt, could not be promoted by a single therapist throughout the entire day due to the huge impact of the social environment on the time use pattern. The long term care resident with dementia was at the mercy of other staff as well: other occupational therapists, doctors, frontline caregivers, nurses, activity directors, and so on. Participants described some staff who shared their positive outlook; however, some staff were described as having a negative outlook of long term care residents with dementia, a sort of stigma.

The negative outlook of long term care residents with dementia is also demonstrated as a quilt in Figure 6 because the participants described some staff as only seeing the isolating behaviors and catastrophic reactions of the resident. Therefore, the staff seemed to see the resident wearing multiple snapshots of occupational disengagement stitched together in its own pattern. As implied by the participants, such a quilt masked the potential of the person wearing it to engage and thrive in life. Indeed, quilts can sometimes be heavy, restricting, and stifling.

sitting in a line	sleeping	not talking	trying to get out of facility
not getting dressed	closing eyes while being fed	wandering	yelling and screaming
not getting out of bed	calling staff names	crying	trying to break a window
not walking	stopped eating	zoning out	roaming

Figure 6. Quilt Pattern of Occupational Disengagement. Depicts examples of occupational disengagement in a pattern resembling a quilt. Shades of gray symbolize lack of variety and livelihood.

This quilt of occupational disengagement is heavy not easy to take off: the participants perceived that isolating behavior obviously worked to isolate the resident and catastrophic reactions caused staff to label and avoid the resident. This negative outlook caused less and less social support and more and more gray quilt squares in the actual time use pattern of the resident.

Ultimately, the importance of seeing the resident with dementia clothed in a quilt of occupational engagement is that the image energized the participant to look to barriers and supports within the environment to enable the resident to achieve engagement throughout the day and an optimized quality of life. In other words, the participants in this study pushed the boundaries of some facilities in showing that despite the stage of dementia, the resident was still cloaked in a beautiful quilt of potential to engage throughout the day.

Summary of Results

Overall, the participants' understandings confirmed that the concept of time use as represented by the LELQ Model was valid. As discussed previously in Chapter One, theory-building, a theoretical underpinning of this study's methodology, works to refine a theory to increase its validity and usability for practice. Thus, Table 4 depicts the major points of the results according to each research question and how they can be used to further refine the LELQ Model.

Table 4

General Refinements of the Lived Environment Life Quality Model Based on Theory-Building Results

Research Question	Major Findings	LELQ Model Refinements
How do occupational therapists, identified as experts in working with people with dementia, understand daily time use for people with dementia in long term care facilities?	• Occupational engagement in the moment can be categorized into being, belonging, becoming. • Occupational disengagement in the moment can be categorized into isolating behaviors and catastrophic reactions. • Time use patterns were implicitly observed. • The transformation from a negative pattern of time use to a positive pattern of time use can drastically increase quality of life. • Each moment can be a moment of engagement for the person with dementia. • Occupational engagement was seen as important for health, well-being, and quality of life. • Use of occupational engagement as both a means to health, well-being, and quality of life as well as an end in itself was seen as occupational therapy in a nutshell.	• Distinction can be made between occupational engagement and disengagement in the moment with categories clearly explicated. • Time use patterns (more than simply time us in the moment) can be emphasized as an important concept that must be measured and focused on in occupational therapy practice due to its large influence on the resident's quality of life. • Time use can be emphasized and described in a language that better connects the idea to core occupational therapy philosophy and practice.

How do occupational therapists understand the concept of daily time use within the LELQ Model, and how do their understandings compare with the relation of time use to other concepts in the model?	• Concept and language of time use was confirmed as valid and understandable. • The social environment was emphasized as extremely important and led participants to observe staff-resident interactions. • Occupational engagement was synonymous with using retained capacities and occupational disengagement was missed opportunity for using them. • Catastrophic reactions were seen as the language some residents use to express emotional ill-being. • Emotional well-being was the gauge for meaningfulness of an activity. • Negative spiraling results from catastrophic reactions leading to staff alienation leading to less social support leading to more catastrophic reactions.	• Social environment can be emphasized over physical environment. • Catastrophic reactions can be explicated as the language of the residents and showing the possibility of redirection to a meaningful activity. • Occupational disengagement can still be a way to use retained capacities but is considered disengagement when not associated with emotional well-being and is indicative of an overall decreased quality of life. • Environmental channeling can reflect the language given by the participants in describing the "negative spiraling" of behaviors.
What are the implications for practice based on these occupational therapists' understandings of time use and its place in the LELQ Model?	• Staff who see the resident wearing a quilt pattern of occupational engagement can remove barriers in the environment to make a positive pattern of time use a reality. • Staff who see the resident wearing a quilt pattern of occupational disengagement are blind to the potential of the resident and instead support the reality of a negative pattern of time use.	• The tremendous influence staff perceptions have on time use patterns and resulting quality of life of the resident must be explicated and emphasized possibly using the quilt concepts as educational tools.

CHAPTER FOUR: DISCUSSION

Both the aims of this study and the motivations for completing this study led to further interpretation of the results. The aims of this study included exploration of daily time use concepts in current occupational therapy practice and understanding how daily time use can be better modified in the LELQ Model and incorporated into practice. The motivations for this study included connecting theory and practice in the hopes of increasing quality of life for people with dementia and advocating for the role of occupational therapy in dementia care. Three major points synthesize the data in light of these aims and motivations. One, the way in which the participants in this study viewed long term care residents with dementia, an almost idyllic image, is tied to the core philosophy of occupational therapy and literature on lifestyle balance. Two, recent research on occupational deprivation further explicates the plight of the long term care resident with dementia and highlights the moral obligation of the occupational therapist working in this setting. Three, the goal of lifestyle balance, the moral obligation of the occupational therapist, and the previous discussion of implication for practice based on the participants' understandings of time use lead to specific, practical ideas for practice that are important to mention. Each of these points is further developed in the following sections.

The Core of Occupational Therapy and Lifestyle Balance

Results from this study strongly affirmed that occupational engagement is not simply a luxury reserved for those with cognitive abilities intact but rather a need of every human, including long term care residents with dementia. This outlook on residents with dementia and the role of occupational therapists in supporting occupational engagement embodies Yerxa's (1998) belief that occupational therapists are "search engines for potential." More exactly, Yerxa proposed, "Occupational therapists discover a person's resources and emphasize what that person can or might be able to do instead of the person's incapacities; what's right instead of what's wrong" (p. 413). This quote seems to match wonderfully with how the participants described their own work. Furthermore, the participants' work in establishing time use patterns of occupational engagement is also supported by a longstanding philosophy of occupational therapy. In his classic work on this philosophy, Adolph Meyer (1922) explained the importance of living life with a rhythm, especially rhythm between work, play, rest, and sleep. To achieve balance in these one has to actually *do* them:

> Our body is not merely so many pounds of flesh and bone figuring as a machine, with an abstract mind or soul added to it. It is throughout a live organism pulsating with its rhythm of rest, and activity, beating time (as we might say) in ever so many ways, most readily intelligible and in the full bloom of its nature when it feels itself as one of those great self-guiding *energy-transformers* which constitute the real world of living beings. Our conception of man is that of an organism that maintains and balances itself in the world of reality and actuality by being in active life and active use, i.e., using and living and acting its *time* in harmony with its own nature and the nature about it. It is the *use* that we make of ourselves that gives the ultimate stamp to our every organ. (p.5)

The participants in this study seemed to work with this idea that active life could still be possible for those with dementia.

Therefore, the core philosophy of occupational therapy is upheld in the quilt of occupational engagement that the participants seemed to see long term care residents with dementia cloaked in. This quilt is somewhat an idyllic image because each person's quilt would realistically be a mixture of colorful and gray squares. A person's life is made up of moments of both occupational engagement and disengagement. Yet, the quilt of occupational engagement represents an achieved *lifestyle balance.* As proposed by Matuska and Christiansen (2008), lifestyle balance consists of occupational patterns that meet psychological needs rather than an equal distribution of different types of occupation: "a satisfying pattern of daily occupation that is healthful, meaningful, and sustainable to an individual within the context of his or her current life circumstances" (p.11). The psychological needs occupational patterns must meet are biological health and physical safety, rewarding and self-affirming relationships, feeling engaged, challenged, and competent, and creating meaning and a positive identity. Kitwood (1997) similarly defined psychological needs specific to a person with dementia: attachment, comfort, inclusion, identity, occupation, and, ultimately, love. Ideally, a positive pattern of time use would meet all psychological needs through occupational engagement and create lifestyle balance.

The participants described the possibility that long term care residents with dementia could achieve more in life than just biological health and physical safety as long as residents had proper social support. Through their discussions, participants seemed to suggest that occupational therapists working to create an occupationally enlivening environment can promote rewarding relationships, opportunities to be challenged and feel competent, create meaning, and enable maintenance of personal goals. In this way, the participants in this study were inspirational; they set the bar high for other occupational therapists working in long term care facilities where residents have dementia. The goal for these residents must no longer be stagnant in safety and physical health; the overarching goal can be lifestyle balance through occupational engagement. Although this view seems lofty, the participants suggest an occupational therapy practice that simply lives up to the core of their profession.

Occupational Deprivation and the Occupational Therapist's Moral Obligation

The reality of the quilt of occupational disengagement, or the negative view of the long term care resident with dementia, and the implications of this view for the resident's quality of life show how important the occupational therapist's work really is. Each square in the quilt of occupational disengagement showed an instance of *occupational imbalance*, which comes from being over-occupied or under-occupied (Backman, 2010). A consistent pattern of occupational imbalance can lead to occupational deprivation. *Occupational deprivation* can be defined as “a state in which a person or group of people are unable to do what is necessary and meaningful in their lives due to external restrictions” (Whiteford, 2000, p. 200). Whiteford (2010) presented concepts of occupational deprivation according to people who live in geographic isolation, are unemployed, are incarcerated, are refugees, and experience stigma due to a disability. There are so many striking similarities of long term care residents with dementia and people in these situations that exploring them shows the vast importance of the occupational therapist in sharing his or her positive outlook.

First of all, Whiteford (2010) described living in geographic isolation as living with diminished opportunities for social interaction, lack of resources, and lack of opportunities for occupational engagement in general. Although people with dementia in a long term care facility may not be geographically isolated in the literal sense, perhaps even living in the heart of a large city, the caregiving microsystem of the facility may take on the characteristics of a geographically isolated place. Drawing upon the work of Erving Goffman (1961), a long term care facility has features of a *total institution*, which means a place of residence and work where similar-situated people, cut off from the rest of society, lead life within a culture of their own. The setting for the residents involves the same place, time, physical features, activities, participants, and roles almost every day. When this unchanging setting is an “impoverished environment,” a phrase by a participant implying that there were little physical affordances for action, the resident with dementia could have difficulty developing relationships and feel challenged and competent. A locked down facility with few visitors, a stark hallway with little resemblance of a home, and staff, including occupational therapists, that only interact with the resident for medical reasons could lead to occupational deprivation as experienced by those living in geographic isolation.

Secondly, Whiteford (2010) described the experience of occupational deprivation of those who are unemployed. She stated, “For most people in Western countries, paid employment is the occupation that most significantly influences social acceptance and social status” (p. 308). People with dementia living in a long term care facility no longer participate in such a valued occupation and thereby experience a loss in the areas of social acceptance and status. The loss of certain roles people experience simply by having dementia can be compounded by a facility that does not identify the resident’s remaining roles and enable the resident to maintain them. Essentially, the person with dementia can then become a resident only. The lack of resources to be engaged in a meaningful way and in meaningful roles could lead to occupational deprivation as experienced by those who are unemployed.

Thirdly, Whiteford (2010) explored occupational deprivation of those who are incarcerated. I am not claiming that people with dementia living in long term care facilities are being held for crimes and are treated how prisoners are treated; however, certain aspects between the two groups are similar. Whiteford says, “[Imprisonment] represents a powerful reminder that the right to do what one chooses, when and where (within the confines of the law) is considered to be so central to our cultural understandings of what it is to be human, that to remove that freedom of choice and participation in occupations is considered the most severe punishment” (p.312). A social and physical environment depleted of affordances to do what is meaningful to the resident with dementia is removing his or her freedom and choice to do them. A resident who cannot even open certain doors of the facility when desired can feel imprisoned indeed.

Residents with dementia, as discussed previously, are environmentally vulnerable and because of this, the ability of the staff to recognize their responsibility of supplying choice and chance for participation is essential to the resident's occupational engagement. Ignorance of this responsibility could lead to long term care residents with dementia feeling occupationally deprived as though they are incarcerated.

Fourthly, refugeeism, Whiteford (2010) described, is an experience of someone who is forcibly removed from his or her environment to enter another environment that is completely new and sometimes unaccommodating. In a similar fashion, people with dementia do not always enter long term care facilities by choice and as some participants described, residents can be forced to follow the routines and activities of the unfamiliar facility versus the facility attempting to accommodate the routines and activities of the resident. The difficulties that come with dementia may be compounded by a facility that does not make any effort to support the resident with dementia to continue his or lifestyle and could lead to occupational deprivation as experienced by a refugee.

Lastly, Whiteford (2010) described occupational deprivation resulting from stigma of disability. Two points make this a reality for people with dementia living in long term care facilities and further summarize the negative outlook of some staff, characterized by participants in this study. One, occupational deprivation is "not inherent in limited physical, psychological, emotional, or cognitive abilities" (p. 319). Yet, isolating behaviors and catastrophic reactions are sometimes seen as inescapable results of dementia. Some residents are labeled as "wanderers" before staff realize the possibility that a boring or stressful environment could be pressing the resident to wander. Second, "The conceptualization and construction of the physical, nonhuman environment is important, but the social environment is what really enables or constrains the occupational opportunities for people with nonphysical impairments and disabilities" (p.321). This echoes what the participants said: the physical environment may be important but the social environment makes the difference for people with dementia. A social environment with people who see the resident with dementia covered in the quilt of occupational disengagement leads to occupational deprivation of that resident.

Because the social environment is so influential to the resident with dementia, and a negative outlook can literally be the tipping point for environmental channeling and occupational deprivation, the occupational therapist is morally obligated to work at a systems level. Post (2000) agreed that overcoming stigma is a moral challenge of Alzheimer's and said "that we overcome the stigma associated with dementia, principally by being with deeply forgetful persons in attentively caring ways that draw upon their remaining emotional, relational, and creative capacities" (p.3). According to the code of ethics for occupational therapy, occupational therapists must be true to the altruistic nature of their profession in promoting the common good and aid in social justice (American Occupational Therapy Association, 2010). Occupational deprivation exposes the power of the environment over a person's quality of life and can be seen as more powerful for the long term care resident with dementia. A negative view has the possibility of leading to a negative outcome: "Judgments of the quality of life can be self-fulfilling prophecies – that is, an inclination toward negative judgments can lead to a failure to invest the personal and social resources that will enhance quality for the affected individual" (p. 60). The occupational therapist in a situation where the negative view is prominent must work to change that view.

A negative view that remains has large implications for the resident with dementia living in that facility. Whiteford (2000) explained the impact of occupational deprivation on a group of inmates and suggests that other groups of people occupationally deprived for long periods of time may show similar results, including atrophied capacities, hopelessness from lack of opportunity to develop self-efficacy, loss of identity, and maladaptive responses, such as excessive sleeping. These characteristics seem to be the opposite of a lifestyle balance as described earlier and are similar to the isolating behaviors and catastrophic reactions the participants' discussed. Therefore, a negative outlook, one that can lead to promoting occupational deprivation in the resident with dementia rather than lifestyle balance must be transformed into a positive outlook if long term care residents with dementia are to maintain positive patterns of time use throughout progression of their disease.

Practical Examples of Occupational Therapy with Time Use in the Foreground

To support the resident's journey on a path to lifestyle balance rather than a path to occupational deprivation, an occupational therapist must work with time use in the foreground of his or her practice. The focus on occupational engagement in the moment is great, but a focus on engagement throughout the day is also important. An occupational therapist can support a positive pattern of time use by understanding how the resident would like to spend time, adapting the environment to match that desire, measuring time use across the course of the resident's disease, and sharing their positive outlook with all other staff. Essentially, the occupational therapist must find a way to take off the heavy quilt of occupational disengagement and clothe the resident in the quilt of occupational engagement.

Using the LELQ Model as a guide, an occupational therapist would first need to assess the caregiving microsystem and the person with dementia. When focusing on time use, the caregiving microsystem should be assessed by observing activity situations in the facility throughout the day and making a list of those situations. The occupational therapist must also assess the person with dementia, not only his or her retained capacities, but the habits, routines, and occupational roles the person has and used to have. Habits, routines, and automatic behaviors are building blocks of a lifestyle (Christiansen & Townsend, 2010) and should be assessed by the occupational therapist in order to develop a comprehensive goal and intervention aimed at enabling occupational balance for the resident with dementia. Many participants already described using “life story assessments” to promote such a practice and could be used in the formation of a more comprehensive assessment.

Next, the occupational therapist must determine what the resident is actually doing throughout the day and measure time use patterns. Although there are multiple time use assessments listed in the literature using tools such as calendars, smart phones, and other technological devices (Harvey & Pentland, 2010), most are inappropriate for use with a person who has dementia. The assessment must not rely on self-report and must be easy and quick enough for the occupational therapist to use efficiently. One measure, the Dementia Care Mapping tool would be useful in recording activity of the person observed matched with an indicator of well-being throughout the day (Bradford Dementia Group, 1997). This tool, however, has been used more for groups of people and not individuals, requires three days of training, and takes more than six hours to accurately measure and interpret results (Fossey, Lee, & Ballard, 2002)

A simpler measure, recommended by one of the participants, is titled the Activity Engagement Assessment and is included in Appendix F. This assessment is a one-page, fill-in-the-blank questionnaire that includes activity situation, adaptations and modifications to the activity, level of the person’s engagement in the activity, level of disengagement in the activity, positive or negative emotions expressed, and any negative behaviors. This amount of information, yet still formatted to provide efficiency in observation, allows the occupational therapist a wealth of knowledge about how the person with dementia is actually spending time and could even be completed multiple times throughout the day or weeks to establish an understanding of the person's time use patterns. The occupational therapist could then start to develop a picture of the resident's quilt: Is the quilt multi-colored with some gray squares, or is the quilt completely black?

By assessing time use, understanding the caregiving microsystem, and understanding the person with dementia, the occupational therapist can work to create environmental presses across multiple routine activity situations that press toward patterns of occupational engagement, overall lifestyle balance, and a good quality of life. In order to truly enable the participant to engage throughout the day instead of just during one-to-one occupational therapy intervention, the entire facility must be on board. The physical environment can be perfect, but unless the social environment is supportive, the person with dementia can still fall into time use patterns that lead to occupational deprivation. The work of the occupational therapist then involves changing stigma and helping others see residents with dementia as not wearing the quilt of occupational disengagement as a default of their disease but rather having the ability to wear the quilt of occupational engagement. One possible way of changing stigma is an activity that demonstrates the risk of residents with dementia to be occupationally deprived through comparing residents to the groups of people discussed above (e.g. those living in geographical isolation). By educating and collaborating with other staff on the abilities and interests the residents still have, and all people's inherent need to engage, perhaps any negative outlook can change. Once all staff have a common perspective on the differences between a positive and negative pattern of time use and how they can influence those patterns, the staff can work as a team to optimize quality of life in the residents they work for.

Because dementia is a progressive disease, the occupational therapist must never feel that enabling a person with dementia living in a long term care facility to achieve a time use pattern of occupational engagement is enough. Rather, the occupational therapist must be able to measure time use throughout the course of the disease and develop a working relationship with other staff in order to have any big changes in time use or function communicated to the therapist. In this way, the occupational therapist is truly fulfilling his or her duty in enabling occupational balance and an optimized quality of life.

Limitations of the Study

To establish credibility, the known limitations of this study must be discussed. First, due to the extensive research and familiarity with the LELQ Model before the study began, I had emotional and intellectual investment in the model. Although this investment proved beneficial in connecting my passion for the project with participants who had a similar passion and thereby contributed to the effectiveness of action research, I had to work hard to be fair to the data. While this investment could have led me to look for more confirmation of the model and less disconfirmation, three techniques were used to ensure that I was not blinded by my own perceptions of the model. One, initial interviews were completed allowing me the opportunity to hear about the participants' background, work, and values before they were given the model. Two, I searched for negative cases. An example of a negative case I found is that time use can show indicators of occupational disengagement yet still involve the use of retained capacities. This case does not disconfirm any part of the model but rather elaborates on the quality of life domains within the model and showcases the importance of emotional well-being in determining whether quality of life is good or bad. I did not find any major points of disconfirmation in my search for negative cases. Finally, extensive member checking was conducted throughout the entire process. Within interviews, the participants' words were often repeated back to them to ensure understanding and ask for clarification. Also, the final interview allowed me to share some of my results and ask for further elaboration or correction on my perceptions of the data.

A second possible limitation of the study was the limit to democracy in the methodology. Although participants were included in modifying the model and asked their input on how to frame each successive interview, the methodology was mostly determined by the academic-researchers for submission to the IRB and for preparation of the study in advance. That is to say, the participants were not included in shaping the format of the interview, three focus groups, and final interview sequence; however, the input we did receive on shaping the methodology was included to the best of our ability as shown by including participant recommendations of a case study in the second set of focus groups and holding discussions on reimbursement.

Conclusion

In conclusion, the ability of occupational therapists to see the potential and need of the long term care resident with dementia to be engaged across the day is vital to the resident's quality of life. Due to the large influence of the social environment on the resident's time use patterns, the facility's view of the resident can promote lifestyle balance or occupational deprivation. Occupational engagement in the moment is indicative of health and life quality, but the importance of a pattern of time use to environmental awakening and channeling cannot be ignored. Occupational therapists not only are in a prime position to modify the social environment to create an occupationally enlivening environment across multiple activity situations, they are morally obligated to do so.

This study takes a step into understanding the possible power of a unifying conceptual framework for occupational therapists working with long term care residents with dementia. More research is needed on applying the LELQ Model in practice and the development of a possible process model compatible with the main model. Specific to time use, occupational therapy practice would benefit from research contrasting and comparing occupational deprivation and environmental channeling, as well as assessments for easily measuring time use.

Ultimately, with this new knowledge and focus on time use, perhaps Music Hour at Sunny Acres would look a little different. An occupational therapist whose practice is informed by the LELQ Model may notice the response to the performers given by the three residents: Herb, Susan, and David. The therapist would smile and make note of how helpful the caregiver was to Herb, and also note that he enjoys playing the tambourine and has functional abilities remaining that can be used in other activities throughout the day. Then the therapist may observe Susan and look up Susan's file. Seeing Susan used to work as a choir director, the therapist would explain to a caregiver that perhaps Susan might like to sing and how to help her interact more with the performers. And finally, seeing David lying on the couch, the therapist may remember that David did not especially enjoy music and invite and assist him to join another resident in completing a small puzzle. All three of the residents would be supported in meaningful time use in the moment and across the day with their quality of life optimized.

CHAPTER FIVE: REFLECTIONS ON LESSONS LEARNED

I began this study after a year of completing an undergraduate project on a similar topic. Therefore, I was used to the LELQ Model and Wood's work. My undergraduate project involved observing time use in the context of activity situations within a new memory care facility to better understand how occupation can meet the other psychological needs of a person with dementia listed by Kitwood (1997). Being a Biological Sciences major at the time, I was not yet used to the field of occupational therapy or dementia care for that matter; however, I was inspired to complete such a project after talking with my grandma, a woman who has dementia and lives in a nursing home. Whenever I would visit her, I was struck by how nice everyone who worked in her facility was and how many nice events and activities they had planned for the residents. Therefore, my grandma's consistent, repetitive phrase seemed out of place. Somewhere in our phone conversations she would find somewhere to insert, "We eat, and we sleep. That's all we do here. It's like I'm living in a prison." How could my grandma feel this way in such a great nursing home? Was she really only just eating and sleeping? How did she *really* spend her time? This inspired me to have a focus on time use in long term care residents with dementia all along, and through this study, I learned a lot. In reflecting on this study and the thesis process in general, I have learned three important points: 1) action research can be a powerful form of methodology, 2) stigma around people with dementia still exists in a pessimistic culture of care, and 3) the LELQ Model presents an advanced model of occupational therapy practice that requires some form of culture change at a systems level.

First of all, action research can be a powerful form of methodology. The process of inviting participants to be a part of the research team and using their recommendations to modify the model and direct the research worked to benefit both parties. For me, I felt as though I was truly working with those who had a similar passion but whose knowledge and experience could broaden my views significantly. For the participants, the opportunity to work as a team provided them continued interest and power in the project. During the final interview, all participants excitedly gave their consent on including them in further development of the model and future publication. Although some participants said the model more summarized their work rather than "changed" their work, others said the model actually shifted the lens in which they viewed their work with people with dementia. I think this passion and empowerment came largely from the democratic nature of action research with its focus on human flourishing. I can see action research being very useful for future studies, especially any study that aims to connect theory to practice.

Second, I was surprised to hear that so many participants described the stigma of people with dementia in a pessimistic culture of care as a phenomenon that still exists. Kitwood's (1997) work first introduced me to a culture of stigma. Yet, his book is 15 years old! After reading studies from more optimistic cultures, I thought progress had been made for the better. Also, in the memory care facility I observed during my undergraduate project, I saw an amazing, supportive care environment that enabled the five psychological needs of people with dementia Kitwood (1997). There was love in that facility. In this study, however, many of the participants described facilities that still work under the weight of the medical model and see occupational therapy irrelevant to the diagnosis of dementia. This is surprising and scary to me. The fact that people with dementia can still be regarded as hopeless and without a future needs to be recognized by the community at large. Education and empathy must erase the myths surrounding dementia for people living with the disease to be truly cared for.

Lastly, participants described the LELQ Model as demonstrating an advanced level of practice. The reason for this is that the social environment has such a huge influence on the quality of life of the resident with dementia. The disease simply does not allow for a fantastic physical environment to have as much of an impact. After working with the model now for three years, it has been ingrained in my identity, values, and perceptions as an emerging occupational therapist. The participants seemed to challenge beginning occupational therapists such as me to spread a practice based on the model at the same time warning that this could be a difficult job, especially in facilities that remain under a strict medical model of care.

Overall, I have learned about the usefulness of action research, the stigma that may still be present, and the possible difficulty in overcoming that stigma with the LELQ Model. My new knowledge of time use and the emphasis I have made on bringing time use patterns to the forefront give me a mission. I should practice what I preach and share the positive, idyllic vision of residents with dementia with other staff if I ever work in a long term care facility. The possibility that residents with dementia in long term care facilities may only be supported an hour or so throughout the day would be hard to live with. I have more understanding in how my grandma can feel like she's in a prison, and now I have a new question to ask: How is she supported by the social environment in engaging in occupations throughout the day? With more research on the time use patterns of people with dementia, maybe feeling incarcerated in a nursing home will no longer be a reality.

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APPENDIX A: INITIAL INTERVIEW GUIDE

Introduction

Thank you!:

Thank you for agreeing to be a part of our study. We appreciate your time and look forward to your contribution. During this interview, if you have any questions or need clarification on anything, please do not hesitate to stop me and ask. Before I start the interview, there are just a few items I want to quickly go over.

Overview of Study:

In this first interview, we are interested in how your experience and expertise translates to your everyday practice.

We regard you and all other participants as co-researchers in our study. What we mean by co-researcher is that we are not researchers studying you, but rather we are working alongside you towards a shared goal of improving care and quality of life for individuals with dementia.

Thus, your role in this project is just as, if not more important, than our role. Accordingly, we invite you to participate in submitting a manuscript of the results as an author, if you are interested and willing. Do you have any questions so far about this study?

Logistics of Interview:

This interview should last approximately 90 minutes. Your answers will be confidential and will only be shared with other members of the research team, except for the 3 group forums where answers will be shared between participants who are co-researchers in the process.

You may end the interview at any point, and you are not required to answer any question you do not want to. I have a number of questions to ask you, so I may summarize your answer in order to clarify your point. Also, due to time constraints, we may need to move along in the interview in order to ensure that I address all questions. However, please feel free to let me know if you do not want to move on and have more to say because your answers are valuable to our study.

Overview of Interview Questions:

Before we begin, I want to explain the general structure of the interview. There are 3 main parts. First, I will ask questions your background as a practitioner. Then the questions will be based upon what kind of things you do as a practitioner, specifically in your particular work as an occupational therapist with people with dementia in long-term care. Then I will want you to tell stories, specifically one satisfying story in your experience where everything came together and also one that was not so gratifying. I will ask you clarifying questions throughout the interview. We'll conclude with two brief wrap-up questions.

Background Information

- When did you become certified as an occupational therapist?

- Can you share the areas of practice you have worked in since then?

- Where do you work now? How long have you worked in this capacity?

- What is your role in this work? That is, do you work in direct one-on-one interventions with clients, in program development, management, and/or in your own business?

- How many years of experience do you have working where your caseload or role is predominantly working with people with dementia in long-term care?

- How did you discover you wanted to work with people with dementia, or how did you come to working with people with dementia?

Nature of Work Questions

Thank you, the next session of the interview pertains to your perspectives on the practice of occupational therapy with people with dementia.

- What do you believe it is most important for occupational therapists to assess or evaluate when they are working with people with dementia?
    - Potential Probe: Do you typically focus on an individual or a group of people with dementia?
- What do you believe it is most important for occupational therapists to assess or evaluate related to the social and physical environments in which people with dementia live?
- Describe how you go about your work.

    System's Level Potential Probes:
    - Who do you typically work with? (Client, family, staff, rehab team etc.)?

    - How do you prioritize what you do?

    Individual Potential Probes:

    - In your experience, what are typical interventions you have found to be effective?

    - What is your thought process behind deciding which interventions are effective?

- What are you hoping to achieve on behalf of people with dementia?

    - Potential Probes:

        - What are positive outcomes of your practice? (short term and long term)

        - Tell us how you know you've achieved what you've wanted to in your particular role as an occupational therapist?

        - Do you use or recommend any specific outcome measures?

- What do you believe causes or brings about positive outcomes in your practice? Researchers often refer to this as “mechanisms of action.” In other words, what drives success in going from point A to point B in terms of positive outcomes? What is the vehicle of change that you find has the greatest influence?

    - Potential probe:
        - Of everything that you do, what has the greatest impact?
        - What do you believe most powerfully drives change?
        - Why do you think this has such an impact?

Story Questions

Okay, now we are moving into the story part of the interview.

Tell us a story about a time when, in your particular role, everything came together. In other words, things turned out as good as they possibly can.

- Potential probe: *ask clarifying questions about story, possibly related to each of our domains (i.e. “so it really seems like you focused on training caregivers in that situation; why did you find that important?”).*
    - Person-centered care
    - Activity situations – “just-right fit”
    - Environmental press – deadening or enlivening
    - Time-use – occupational engagement/disengagement
    - Retained capacities
    - Emotional well-being

Tell us a story about time where it didn’t come together.

- Potential probe: *ask clarifying questions about story, possibly related to each of our domains (i.e. “you mention the person you worked with was really distressed, can you expand on the reasons for that distress in your story?”).

Wrap-up

If you could give a 30 second sound bite on what you believe is absolutely most important in your work with people with dementia, what would it be?

Is there anything else we haven’t covered that you feel is important to tell us about your practice with people who have dementia?

Conclusion

Another Thank You!: Thank you again for taking the time to answer these questions.

Next steps:

This interview will be followed by three focus groups with all other participants and one final individual interview to be scheduled at a later time.

The next step of our study is scheduling a focus group with you and the rest of the participants of the study. What are a few of the best times during the week where you would be available for about an hour and a half to participate in a focus group? Will you have access to a computer at that time? We will send an email with times available for the focus group after we have conducted the remainder of our initial interviews. The email will also contain more information about the focus group session. Please contact us about any questions or concerns before then if needed."

APPENDIX B: FOCUS GROUP AND FINAL INTERVIEW OUTLINES

Focus Group 1 Guide

1) Are there ways in which your beliefs about best OT practice in long term care for residents with dementia are reflected in the LELQ Model?
    a. If so, what stands out to you as most compelling and/or congruent?
    b. If not, where are the greatest discrepancies or areas incongruence?
2) What do you see as the LELQ Model's strengths
3) What do you see as the LELQ Model's limitations and/or gaps?
4) Did you find the LELQ Model reasonably clear and easy to understand?
5) Do you think the LELQ Model might be useful to you or other occupational therapists in guiding practice?
    a. Why or why not?

Focus Group 2 Guide

1) Your further thoughts on the LELQ Model
2) Case presentation to further illustrate the model
3) Follow up discussion on areas of confirmation/disconfirmation
4) Ideas for final focus group focused on practice implications

Focus Group 3 Guide

1) Big picture discussion of the LELQ Model's implications for assessment, intervention and outcome measures
2) More detailed discussion based on review of the focus groups
    a. Assessment approaches & measures
    b. Interventions

    c. Outcome measures

3) Supports and barriers to implementation
4) Recommendations for final individual interviews

Final Interview

1) Areas of confirmation and elaboration of the LELQ Model
2) How these discussions may have influenced your practice
3) How you imagine the model might guide the practices of other occupational therapists
4) Your thoughts about future engagement in the project

APPENDIX C: OPEN CODES

**Note: key to abbreviations provided at the end of the table*

Code Name	Definition
QL-EW-Practitioner's Perspectives	Passage reflects practitioner's rationale, understanding of and/or concern and responsibility for emotional well-being. Can be implicit or explicit and is more general and abstract in nature
Setting Description	Description of the current setting
QL- Other	Other quality of life indicators not represented in the LELQ Model
AA-rationale	Rationale behind occupational therapy decision making and clinical reasoning related to the use of activity as an intervention
AA-Just Right Challenge	Providing a person with dementia with the just right challenge
AA-meaningful activity	An activity directed to be meaningful within the person's context
AA-personhood	Considering the dignity and respect of the person
LE-EP-Practitioner's Perspectives	Passage reflects practitioner's rationale, understanding of and/or concern related to considerations of environmental press. Can be implicit or explicit and is more general and abstract in nature.
LE-Transformation	An outcome that has transformed the culture of care including staff relationships with people with dementia
PI- OT role	Beliefs and values that occupational therapy makes a difference in people with dementia
PI- personal connections	Personal connections that influence current practice
PI- theory	Theories or frameworks influencing current practice
PI-T-Whole Person	Taking into account the whole person when deciding what to work on with a person with dementia
PI-Turning Point	An "ah ha moment" in the therapists' career

QL-Long Term- Environmental awakening	The composite experiences of occupationally enlivening moments over time
QL-Long Term - Environmental Channeling	The composite experience of occupationally deadening moments
QL-EW- Emotional Ill-being	Passage reflects concern for or appearance of negative affect and other emotional ill-being indicators
QL-EW-Emotional Well-being	Passage reflects concern for or appearance of positive affect in the person with dementia. Prevalence of apparent affect related to sense of purpose, confidence, competence, intent to perform
QL-RC-Intervention	Formal interventions related to retained capacities or informal encouragement of use of retained capacities
QL-RC-Outcomes	Outcomes related to retained capacities
ED	Excess Disability: a reversible deficit due to the environment rather than the disease itself
optimal health	Improved physical health is reached through the use of retained capacities and avoidance of excess disability
optimal functioning	Use of retained capacities within occupational engagement; passage reflects concern of functional capacities of person with dementia
QL-TU-Implicit Occupational Engagement	Parts of a story or example that signify the four areas listed under occupational engagement: engaged gaze/responsiveness, purposeful movement, communication, and/or participating in activity.
QL-TU-Implicit Occupational Disengagement	Parts of a story or example that signify at least one of the three categories under occupational disengagement: withdrawn/passive, eyes closed/dozing, and/or aggressive and agitated behavior.
QL-TU-other	Areas of time use that are outside of the scope of the LELQ model and may provide modifications to the model.

QL-TU-Explicit	Time-use is explicitly discussed and includes answers to questions such as, “What is the person doing throughout the day?" Items may often be dually coded under this section and LE-A-PC because habits and routines fall under both. I'm looking to see what occupational therapists are focusing on as far as time-use
PD-Hx	Participant practice setting
PD- OT Cert	Participant description, year certified as an occupational therapist
PD- current 1 to 1	Current one to one role
PD-Current Consult	Works in consultation role in current practice
PD-current Program Dev.	Works in current program development role
PD- current mentor	Acts as mentor to other care providers
PD- current business	Business description and approaches
PD-Physical Environment	Participant has contributed to the design of a physical environment for individuals with dementia at the facility and individual level.
LE-CM-Traditional	Environments that model a traditional long-term setting.
LE-CM-Social	Aspects of the caregiving microsystem in which characteristics, properties, or changes to the social environment lead to positive or negative outcomes for people with dementia. Social microsystems include interactions and qualities of the relationship between the patient, family, therapist, frontline caregivers, other residents, and the facility, or administrators in influencing outcomes of care
LE-CM-Physical	Aspects of the caregiving microsystem that relate to physical structures, changes to the physical environment, or how the physical environment contributed to positive or negative outcomes within a long-term care facility. Can relate to assessment, intervention, or outcome of the physical environment

LE-CM-staff training	Aspects of transcripts that specifically reference the involvement of staff training in influencing negative or positive aspects of care. Often coded with LE-CM-systems as changes or reference to staff training is a part of systems level caregiving microsystems.
LE-CM-systems	Aspects within caregiving microsystems that involve change to the system that impact outcomes of the person with dementia. Involves both positive and negative examples and characteristics of how changes to, or characteristics of the entire caregiving system from the administrators down to the patient, impacted care of the person.
LE-CM-Home	Caregiving microsystems in which the goal or purpose is to create an environment that resembles or is reminiscent of the person's home in order to illicit increased engagement in an activity or promote a sense of well-being by reminding the person of familiar objects so that they can feel safe and relaxed. Often discussed in terms of a desired outcome-to make a person's environment 'fit' the person by making it more home-like.
LE-PWD-Occupational history and profile	(self-explanatory)
LE-PWD-preferences-needs	(self-explanatory)
LE-PWD-RC-assessments	Assessments related to capacities a person with dementia still has
LE-PWD-transaction	Transaction between all elements of understanding who the person is in order to inform evaluation and treatment. The 'Gold Standard' of assessing people with dementia.
LE-EP-Alive	Lived environment, environmental press, occupationally enlivening, Refers to a short term temporal perspective or snap shot of time that is enlivening. Is more general and/or non-specific than just right fit.

LE-EP-Alive-just right fit	The optimal transactional relationship between the daily activity situation and the occupational history and profile of the person with dementia. Implies maximum overlap between the person with dementia and caregiving microsystem domains of the lived environment.
LE-EP-Dead	Lived Environment- environmental press, occupationally deadening. Refers to a short term temporal perspective or snap shot of time that is deadening
LE-EP-Dead-not right fit	Minimal to no overlap between the caregiving microsystem and person with dementia domains of the lived environment.

Key	
Abbreviation	Meaning
QL	Quality of life
EW	Emotional well-being
AA	Activity approach
EP	Environmental press
PI	Practice influences
OT	Occupational therapy
RC	Retained capacities
ED	Excess disability
TU	Time use
Hx	History
PD	Participant description
LE	Lived environment
CM	Caregiving microsystem
PWD	Person with dementia

APPENDIX D: SUB-CODES UNDER TIME USE EXPLICIT

Sub-code	*Definition*
OT in a nutshell	the occupational therapists describing time use in relation to best practice or a central part of occupational therapy work
Each moment can be a moment of engagement	the talk of time use emphasizes how it involves the therapist ensuring occupational engagement more than just a direct service or part of the therapist's intervention but as something done throughout the day
Activity situation time use disparity	understanding or identifying the disparity between activity situation and time use
Missing their potential	the identification of a need related to time use (i.e. need for assessing time use) and for staff to recognize how people with dementia can still be engaged
Importance	answers the question of "why is it important to be occupationally engaged?"
Measurement	an informal or formal way of measuring occupational engagement

APPENDIX E: MATRIX OF TIME USE AND OTHER LELQ MODEL CONCEPTS

**Note: for key of abbreviations, see key provided in Appendix C*

Other Codes	Time Use Codes			
	QL-TU-Explicit	QL-TU-Implicit Occupational Disengagement	QL-TU-Implicit Occupational Engagement	QL-TU-Other
LE-CM-Physical	1	2	3	1
LE-CM-Social	2	6	5	1
LE-CM-Traditional	1	5	1	0
LE-EP-Alive	6	3	14	0
LE-EP-Dead	2	8	2	1
LE-EP-Practitioner's Perspective	5	0	2	2
LE-PWD-Occupational history and profile	2	4	3	0
LE-PWD-preferences and needs	3	4	10	1
LE-PWD-RC-assessments	3	4	2	0
QL-EW-Emotional ill-being	2	7	0	1
QL-EW-Emotional well-being	3	0	12	0
QL-Long term-Environmental channeling	1	10	1	1
QL-Long term-Environmental awakening	2	1	11	0
QL-RC-Outcomes	1	1	2	0
ED	0	11	1	1
Optimal functioning	3	1	12	0
Optimal health	3	0	0	0

APPENDIX F: ACTIVITY ENGAGEMENT ASSESSMENT

Resident's Name: ______________________________ Date: ______________
Target Activity Assessed: ____

Has This Activity Been Modified for the Resident's Individual Preserved Abilities?
Yes ___ No ___
If This Activity was Previously Modified for this Individual,
When Were The Modifications Developed? ______________ (approximate date)
List Modifications: ____ N/A ___

1) Was the resident constructively taking part in the TARGET activity by:
- talking about it
- holding materials related to the target activity
- asking questions about the target activity

____ Not at all _____ Some of the time _____ Most of the time

2) Was the resident passively taking part in the TARGET activity by just watching and listening (INSTEAD of being Constructively Engaged?):
____ Not at all _____ Some of the time _____ Most of the time

3) Was the resident talking to other people, looking at things other than the target activity, self-stimulating (picking at their own clothes) or manipulating things not related to the TARGET activity (INSTEAD of being either Constructively Engaged OR Passively Engaged):
____ Not at all _____ Some of the time _____ Most of the time

4) Was the resident sleeping or staring blankly into space (NOT engaged):
____ Not at all _____ Some of the time _____ Most of the time

5) During the TARGET ACTIVITY, did the resident show positive emotions like laughing or smiling or making happy or positive comments :
____ Not at all _____ Some of the time _____ Most of the time

6) During the TARGET ACTIVITY, did the resident show negative emotions like crying, showing anxiety, nervousness, or making sad or anxious comments:
____ Not at all _____ Some of the time _____ Most of the time

7) During the TARGET ACTIVITY, did the resident show problematic behaviors such as verbal or physical aggression, saying negative things about another resident or staff member, or interrupting the activity repeatedly:
____ Not at all _____ Some of the time _____ Most of the time

Therapist's Signature: ____________________________ Date: ______________