

THESIS

FUNCTIONAL COMPETENCE AND EMOTIONAL WELL-BEING FOR  
LONG TERM CARE RESIDENTS WITH DEMENTIA:  
CONFIRMING A CONCEPTUAL PRACTICE MODEL THROUGH ACTION RESEARCH

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## ABSTRACT

### FUNCTIONAL COMPETENCE AND EMOTIONAL WELL-BEING FOR LONG TERM CARE RESIDENTS WITH DEMENTIA: CONFIRMING A CONCEPTUAL MODEL

Long term care facilities often lack support for residents' quality of life. The Lived Environment and Life Quality Model (LELQ) is an empirically derived conceptual model on the effects of the lived environment on three quality of life indicators: daily time use, functional competence and emotional well-being, for long term care residents' with Alzheimer's disease and related dementias. This study's purpose was to further the LELQ Model by engaging in a theory building process. To do so, the study sought to understand how expert occupational therapists' conceptualizations of their work align with the LELQ concepts: functional competence and emotional well-being. Six expert practitioners engaged in two individual interviews, and three focus groups. Through qualitative data analysis, we found that in general, expert practitioners' conceptualizations aligned and confirmed the LELQ Model domains functional competence and emotional well-being, and the connections they have to other concepts described in the model. In addition to confirmation, the participants elaborated on aspects of the model and identified potential gaps for implementation of the model in practice. Several ideas were highlighted as a result of this study including: the importance of social environment support for use of retained capacities and emotional well-being, the addition of optimal health and personhood to the model and reimbursement as a barrier to application of the model in practice. The LELQ Model has been shown to be relevant and useful for practitioners however, further research is needed in order to revise and implement the model in practice.

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## CHAPTER 1: INTRODUCTION TO THE STUDY

This thesis is situated within a larger study that aims to refine, for operationalization in practice, the Lived Environment and Life Quality (LELQ) Model: a dementia specific conceptual practice model designed to guide the services of occupational therapy practitioners in long term care (LTC) settings on behalf of residents with Alzheimer's disease and related dementias (ADRD). Guided by the theory building process described Lynham (2002), the primary purpose of my thesis was to begin to bridge the gap between theory and practice specifically related to the LELQ Model domains of functional competence and emotional well-being, in LTC residents with ADRD.

### **The Limits of Long Term Care Facilities**

LTC facilities often focus mainly on the physical health and safety of residents, placing their overall quality of life as a low priority (Kane, 2001; Warchol, 2004). A common belief is that if the residents are clean, dry, fed and injury-free, then all their needs have been met (Warchol, 2004). LTC facilities, such as nursing homes, assisted living facilities and other extended care placements, are often based on a traditional medical model of care. A traditional medical model predominantly focuses on safety, physical health, rigid routines and operating practices, and duration of residents' survival; overlooking resident preferences, needs and freedom. Care that is limited to a focus on safety and physical health may limit opportunities for engagement in meaningful activities, which, in turn, could undermine residents' functional competence and emotional well-being.

The care environment is particularly important for residents with ADRD, as they are more vulnerable to the effects of their surroundings as competency decreases (Lawton, 1989). Therefore, the environment can play a pivotal role in the amount of skill or lack of skill a person

with ADRD exhibits in his or her daily life (Rogers et al., 1999), and can contribute to the development of excess disability. *Excess disability* is a reversible deficit that may result from problematic caregiving practices or environments rather than the disease itself (Wells & Dawson, 2000, 2002). People with ADRD often experience excess disability because of a pessimistic or unsupportive care environment that hastens the decline of their functional capacities and undermines their emotional well-being. In other words, a pessimistic culture of care in LTC assumes residents with ADRD are “gone,” or can no longer engage in activities; this can lead LTC staff to underestimate residents’ abilities and perform tasks for them while residents still retain the capacity to contribute (Kitwood, 1997; Wells, Dawson, Sidani, Craig, & Pringle, 2000). In such a pessimistic culture of care, residents’ personhood—meaning their individual identity, and their attempts at communication and action are often ignored (Kitwood, 1997). Ignoring these attempts leads to failure to support functional competence and emotional well-being (Wood, Womack, & Hooper, 2009), therefore reducing quality of life.

While the LTC industry is striving to better support quality of life for residents, one challenge is defining quality of life (Kane, 2001). *Quality of life* is a subjective and multidimensional concept that is expressed uniquely by each individual (Kane, 2001; Lawton, 1997). As noted by Kane and colleagues (Kane, 2001; Kane et al., 1997), quality of life for LTC residents encompasses not only safety and physical comfort, but also positive aspects of daily living including meaningful activity and relationships, functional competence, and multiple dimensions of emotional well-being such as joy, dignity, spiritual well-being, autonomy and choice. It is the premise of my thesis that the expertise of occupational therapy practitioners in environmental interventions that maximize performance of daily activities can help to enhance the quality of life of LTC residents with ADRD (Padilla, 2011a).

Yet while occupational therapists can and do contribute to holistic approaches for LTC residents' quality of life, they are limited by a lack of consensus on how best to promote meaningful activity, functional competence and emotional well-being (Padilla, 2011b). A careful review of a special issue of the American Journal of Occupational Therapy (AJOT) on occupational therapy services for people with ADRD found no widely shared rationale or approach to occupational therapy for this population (Padilla, 2011b). Of the 156 studies reviewed (excluding reviewed systematic reviews), 62 focused on people with ADRD residing in a facility. From these, only 15 studies involved occupational therapists directly (Baillon et al., 2005; Baker et al., 2001; Baker, Dowling, Wareing, Dawson, & Assey, 1997; Brooker & Duce, 2000; Chard, Liu, & Mulholland, 2009; Christofolletti et al., 2008; J. Cohen-Mansfield, 2001; Hope, 1998; Jarrott, Gozali, & Gigliotti, 2008; Lai, Chi, & Kayser-Jones, 2004; Lee, Camp, & Malone, 2007; Passini, Pigot, Rainville, & Tetreault, 2000; Robichaud, Hebert, & Desrosiers, 1994; Staal et al., 2007; van Diepen et al., 2002). Furthermore, among these 15 studies, there was wide variation in how the studies conceptualized best assessment and intervention approaches and outcomes measures. This variation appeared attributable, on the one hand, to reliance on widely different theoretical approaches and, on the other hand, to the lack of an apparent guiding conceptual practice model.

Occupational therapists must address this challenge as the rapidly increasing prevalence of ADRD, as documented by the Alzheimer's Association's Facts and Figures (2012), is placing increasing demands on LTC to support this influx. With this rise it is important to move away from the standard rehabilitation model of remediating impairments, and instead promote participation in everyday activities, use of remaining skills and abilities and emotional well-being in people with ADRD residing in LTC. To enable this shift, a conceptual model is needed

to provide guidance on understanding the degree of a person's excess disability and quality of life as well as possible supporting environmental interventions. The LELQ Model is a dementia-specific conceptual model directed at guiding occupational therapy practice in LTC through environmental modifications.

### **The Lived Environment and Life Quality Model**

The Lived Environment and Life Quality (LELQ) Model (Figure 1) is conceptually derived from a wide body of empirical research concerning environmental influences on dementia-specific elements of quality of life, specifically related to residents in LTC facilities (Wood, 2011). This thesis is dedicated to further develop this model and, as described later, move it beyond the conceptual phase of theory building. Doing so, will allow the model to be used to guide occupational therapy assessments, clinical reasoning, interventions, and outcome measures through understanding of how the environment can influence the three quality of life domains specific to people with ADRD in LTC: daily time use, functional competence and emotional well-being. The LELQ Model depicts the dynamic and active processes occurring throughout residents' time in LTC; more specifically, it embraces two temporal perspectives: the immediate situation including specific times of the day, and also the accumulation of these moments to influence quality of life over time. In the following presentation of the model, I will make these two perspectives as explicit as possible in each of the LELQ domains.

#### **The Lived Environment**

In both temporal dimensions, the LELQ Model proposes that the *lived environment's* two major domains, caregiving microsystems and person with dementia, together influence the quality of life domains through an emergent environmental press (Figure 1).



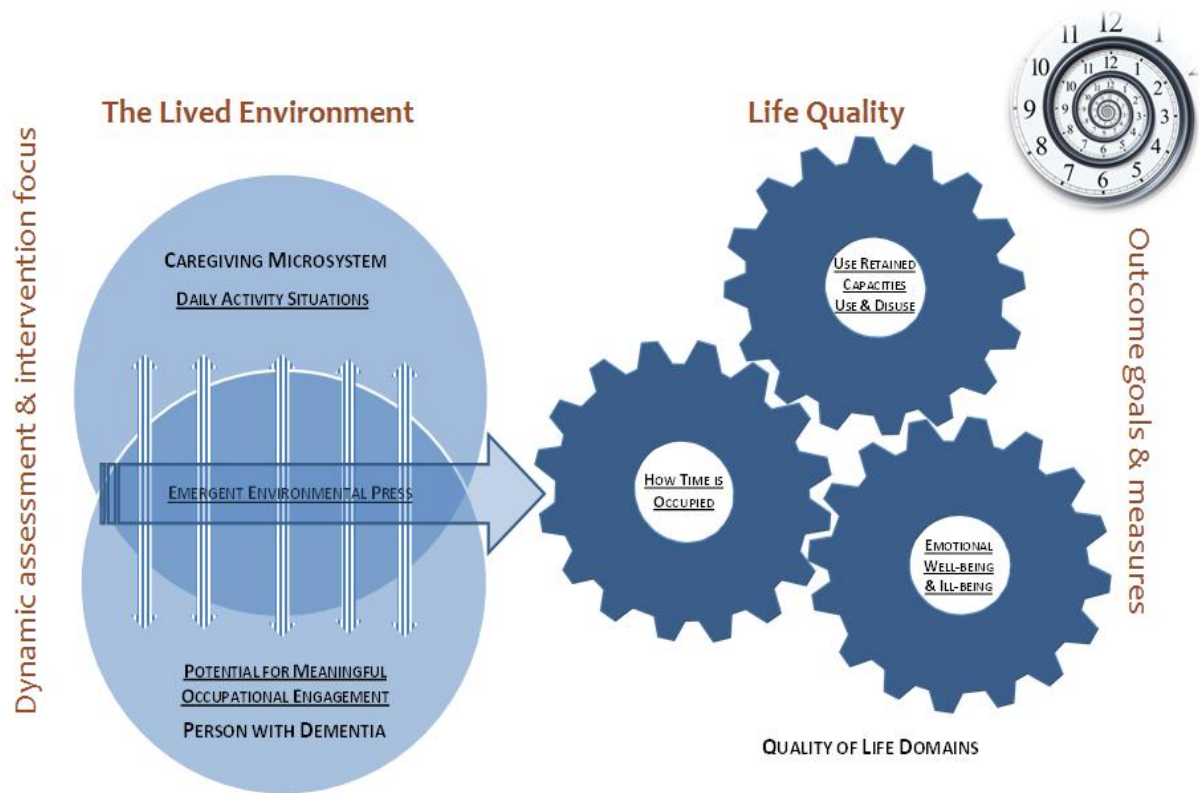


Figure 1: The Lived Environment and Life Quality Model

**The caregiving microsystem.**

The concept of *caregiving microsystems*, illustrated in the top circle, is derived from Bronfenbrenner (1977), who defined ecological microsystems as a person’s immediate surroundings including the physical features, social factors, the activities and roles a resident engages in, and time spent. Specifically, the LELQ Model is concerned with *daily activity situations*, which are defined as the routinely occurring situations that take place from the time a person rises in the morning to the time they go to bed. Examples include meal times, activity or music groups, television time, or downtime. The concept of activity situations is concerned with what a resident is actually doing during a block of time, rather than the defined purpose of the activity. For example, during meal time a resident may not actually be eating, but instead sleeping at the table.

What a resident is doing in an activity situation may be influenced by a number of physical and social environmental supports and barriers in the caregiving microsystem. Examples of physical environment supports include an enclosed outdoor area or nearby activity room, while barriers may involve gathering areas that are far away or unmovable furniture in residents' rooms. Social environment supports may include verbal reminders from staff about activities and staff knowledge on activities a resident can still do. While social environment barriers involve uncaring and inpatient caregivers, or limited support for social engagement.

An assumption of my thesis is that types of activity situations, and environmental supports and barriers manifest an optimistic or pessimistic culture of care as defined by Kitwood (1997) and Wells and Dawson (2000). A *pessimistic culture of care*, as described earlier, corresponds with little opportunity to engage in daily activities (Kitwood, 1997), while a more *optimistic culture of care* corresponds with opportunities for engagement in these activities and use of the skills and abilities a person retains (Wells & Dawson, 2000; Wells et al., 2000). Therefore, for an activity situation to have a positive effect on the person with ADRD, it must be responsive to the needs, history, preferences and retained skills of that individual.

### **The person with dementia.**

In the LELQ Model, a resident's potential and motivation to engage in meaningful occupation is influenced by a number of personal factors. These include, his or her occupational history, current preferences and needs, and retained capacities, as portrayed in the lower circle in Figure 1. *Occupational history*, or residents' life stories, involves knowledge of their past interests, roles and routines. *Preferences and needs* refers to a resident's current interests, preferences in routines and activities, and habits. Finally, *retained capacities* gets at what skills the resident still has, including cognitive, perceptual, sensory, physical, communicative, social

and emotional skills. Together these characteristics will contribute to a person's likelihood of engaging in a certain activity situation and the degree to which he or she is able to participate in the available activities. Understanding each resident with ADRD as a unique individual will play a role in matching the environment to the person.

### **Environmental Press.**

The overlap of the two circles in the LELQ Model illustrates the degree of fit between the person with ADRD and the caregiving microsystem. The degree of overlap of specific activity situations gives rise to a distinctive environmental press. As defined by Lawton and Nahemow (1973), *environmental presses* are forces produced by environmental stimuli that elicit specific behaviors or responses by all people. For example, a room set up with chairs facing each other elicits conversation between people in the room, while a room with chairs facing towards a stage presses towards listening to a single speaker. In a study of LTC residents with ADRD, Wood, Womack and Hooper (2009) found that lack of social interactions and overwhelming physical stimuli, such as turning the television on, likely elicits withdrawal, disengagement, sleep and lack of interest. In comparison, a music group likely elicits singing and dancing. In the scenario of watching television, there was little overlap of the circles. The model describes this as an *occupationally deadening* environmental press, meaning an environment supporting negative behaviors, in this case withdrawal. Conversely, significant overlap of the two circles, or a match between the person and environment, as in the music group example is regarded as an *occupationally enlivening* environmental press because it elicits and supports increased participation and engagement in daily activities. In the immediate temporal dimension, too demanding of an environment or too little expected from the resident can press towards withdrawal, confusion or negative behaviors, while an occupationally enlivening environment

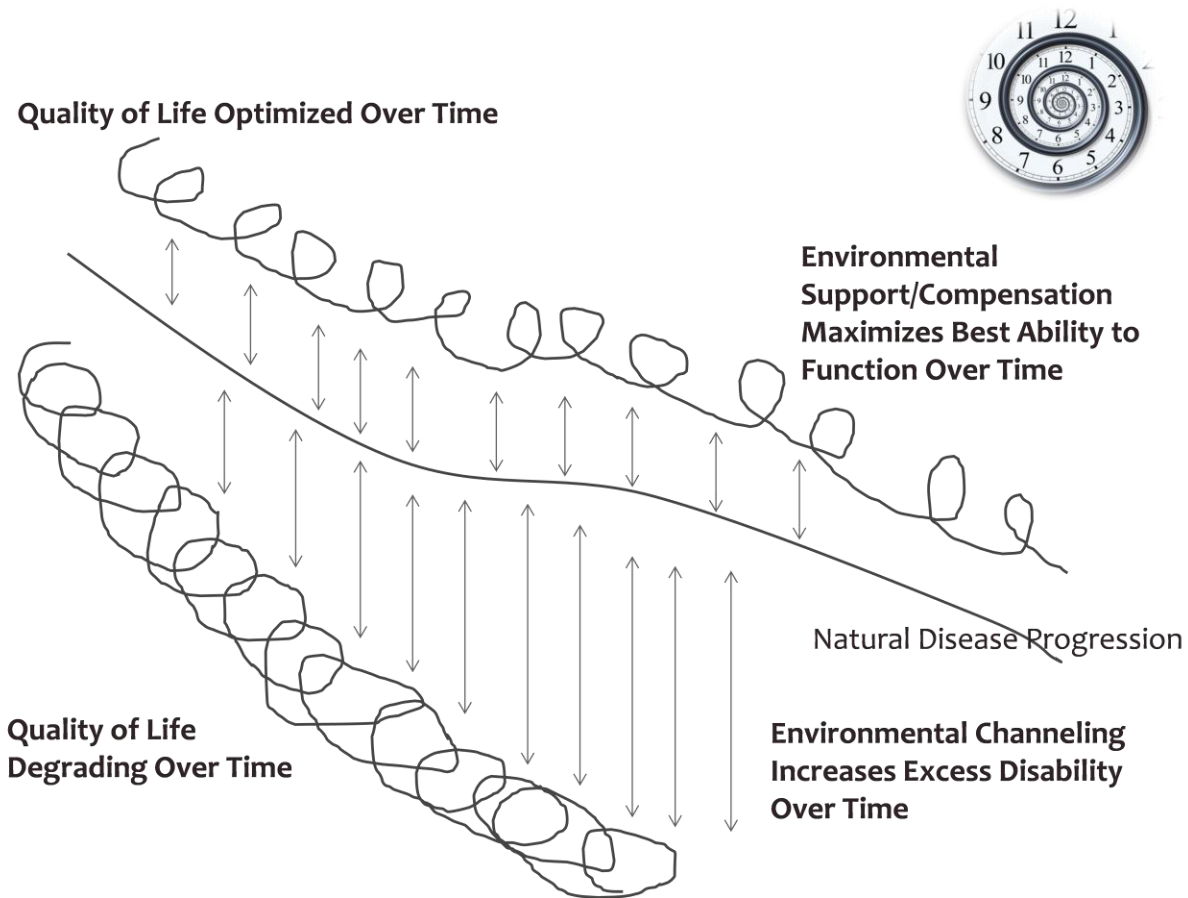
will press towards positive affect, occupational engagement and functional competence.

Overtime, inappropriate matches between the resident and the environment can result in learned helplessness, emotional ill-being and excess disability (Warchol, 2004).

### **Quality of Life Domains**

As the LELQ Model depicts, the congruence of the lived environment influences all the three quality of life domains: time use, functional competence and emotional well-being (Figure 1). These three domains work like cogwheels, each influencing the other two in a constantly varying manner. Quality of life can fluctuate as a result of day-to-day activities, however, the accumulation of these events affects overall quality of life. The culmination of activity situations overtime results in environmental channeling or awakening as depicted in Figure 2.

*Environmental channeling* occurs when the lived environment is consistently lacking in occupational engagement over an extended period of time (Wood, Towers, & Malchow, 2000) and is described as a negative spiral in health and function that often results in poor quality of life owing to the accumulation of excess disability and emotional ill-being over time. This is illustrated in Figure 2 as the lowest line declining at a rate quicker than natural disease progression. On the other hand, when the environment allows for opportunities to exercise skills in meaningful ways, a person is able to continue to participate in daily activities, and unnecessary regression of functional competence is avoided (Warchol, 2004), termed *environmental awakening*. While ADRD is progressive, environmental awakening refers to the best case scenario of progression in which a resident continues to engage in activities at the level



*Figure 2: Quality of Life Over Time*

they can and experience positive emotional well-being because of it, shown in Figure 2 as the line above natural disease progression. Based on the belief that LTC residents with ADRD can experience environmental awakening, the LELQ Model highlights the importance of engagement in occupation across the day, avoidance of excess disability, promotion of retained skills, and significance of positive emotional well-being in LTC residents with ADRD.

**Daily time use.**

Daily time use, the first quality of life cog wheel (Figure 1) is defined by Wood et al. (2009) as the ways in which people spend their time on a daily basis and, as the LELQ Model posits, is influenced by the lived environment. Reisberg et al. (2002) found that even in later

stages of ADRD, people seek to influence their environment, socially engage and engage in physical movement. However, some research suggests that LTC residents with ADRD spend much of their time disengaged from activities (Wood et al., 2009).

The degree to which a resident with ADRD engages throughout the day is an indicator of their quality of life. As the LELQ Model presents, the ability to do things or *occupational engagement*, manifests as engaged or communicative behaviors; the most basic of these being engaged gaze. Conversely, lack of engagement or *occupational disengagement*, manifests withdrawal: meaning disengagement while still awake, and behaviors such as agitation or aggression. A resident's occupational engagement is in part determined by the opportunities offered in a resident's lived environment. In the moment, a resident's engagement may vary. He or she may spend time dancing in the hallway or sleeping during music group. These moments of engagement or disengagement typically result in time use patterns, in which the person is predominately engaged or disengaged throughout the day. The accumulation of these engaged or disengaged moments often results in either environmental channeling including emotional ill-being and excess disability or environmental awakening including emotional well-being and use of retained capacities.

### **Functional competence.**

While ADRD is progressive, with symptoms typically beginning with memory loss and confusion, and advancing until the ability to complete activities of daily living is lost, even in moderate to severe forms of ADRD some skills and abilities are retained (Wells et al., 2000). The LELQ Model describes the culmination of these retained capacities as *functional competence* or a resident's ability to engage in daily activities. *Retained capacities*, as described earlier, are those abilities a resident may still have including cognitive, physical, perceptual,

sensory, communicative, social and emotional skills. Wells and Dawson (2000) identified a gap in the literature demonstrating the lack of understanding for which of these specific abilities people with ADRD retain. They found that most assessments of people with ADRD focus on function, for example the ability to perform specific activities such as bathing or dressing, failing to pinpoint the underlying capacities retained such as humor or mobility skills. Functional competence is focused not only on understanding what capacities remain but also how those skills and abilities are being used during daily activities. Understanding what abilities a resident has retained is of great importance in order to promote an individual's specific retained capacities, because people with ADRD can differ greatly in the skills and abilities they have (Wells & Dawson, 2000).

The promotion of a more optimistic form of care including encouraging engagement in meaningful occupations and, thereby use of retained capacities, is important for improving quality of life (Raber, Teitelman, Watts, & Kielhofner, 2010). This type of "enabling" care concentrates on individualizing care by assisting and promoting the use of a person's functional competence (Wells et al., 2000). The key is to enable or facilitate participation based on retained capacities, rather than just provide physical care for a person (Warchol, 2004; Wells & Dawson, 2002; Wells et al., 2000). Doing so in the moment could help people with ADRD not only maintain use of their skills in their day-to-day activities but can also reduce negative long term effects such as excess disability, slow deterioration of skills and promote a resident's emotional well-being.

### **Emotional well-being.**

The final quality of life domain, *emotional well-being*, is concerned with residents' *apparent affect* described as feeling states, emotional responses and experiences in context of

specific activity situations. Negative apparent affect can include anger, hostility, sadness, depression, anxiety and fear, while positive can entail interest, and pleasure (Lawton, 1983). Wells and Dawson (2000) found that while people with ADRD may have difficulty recognizing facial affect of others, a higher percentage retained subjective feeling states. These feeling states can range from boredom and despair to contentment and happiness, among others. In addition, Reisberg et al. (2002) identified basic human needs, even for people with moderate to severe dementia, to include maintenance of a sense of dignity and self-worth, avoidance of humiliation or trauma, and need for praise, acceptance, love, choice and happiness. This statement underscores the importance of emotional well-being as a concept to consider for institutionalized people with ADRD. Currently in LTC, if the person with ADRD has difficulty communicating their affective state emotional well-being is often neglected (Lawton, 1994, 1997)

While the systematic reviews presented by Padilla (2011b) used emotional well-being or apparent affect as an outcome measure, most focused on reduction of negative behaviors such as agitation rather than improving positive affect and well-being. While reduction of negative behaviors is important, Lawton (1994) found that negative affect and positive affect are actually only related rather than opposites, with each contributing to quality of life independently. Negative affect is linked primarily to physical health and passive involvement in events, while positive affect is associated with behaviors directed at influencing the environment or events that are self-initiated. For this reason a person with ADRD can experience both negative and positive affect concurrently (Lawton, 1994). Therefore, the LELQ Model emphasizes establishing positive affect in addition to lack of negative affect as an important consideration of quality of life for LTC residents with ADRD. Overtime, the accumulation of negative day-to-day emotional responses may hinder residents' ability to occupationally engage, exercise their retained



capacities and promote emotional well-being. Providing environmental interventions focused on matching available activity situations with the personal preferences, skills and needs of the person with ADRD promotes positive emotional well-being and overall quality of life.

While the LELQ Model is empirically and conceptually supported and has the potential to provide occupational therapy practitioners with a conceptual framework to promote quality of life in LTC residents with ADRD, it has not yet been tested in practice. The larger study, in which this thesis is situated, is focused on furthering the LELQ Model for implementation into practice. To do this, we engaged in the process of theory building.

### **Building Theory in a Practice Profession**

Bridging the gap between theories based in empirical research and practice is important when working in applied fields (Lynham, 2000), such as occupational therapy. The goal of theory building is to provide useful classification, explanation, understanding and description of specific phenomena, and ideally offer ways to influence those phenomena.

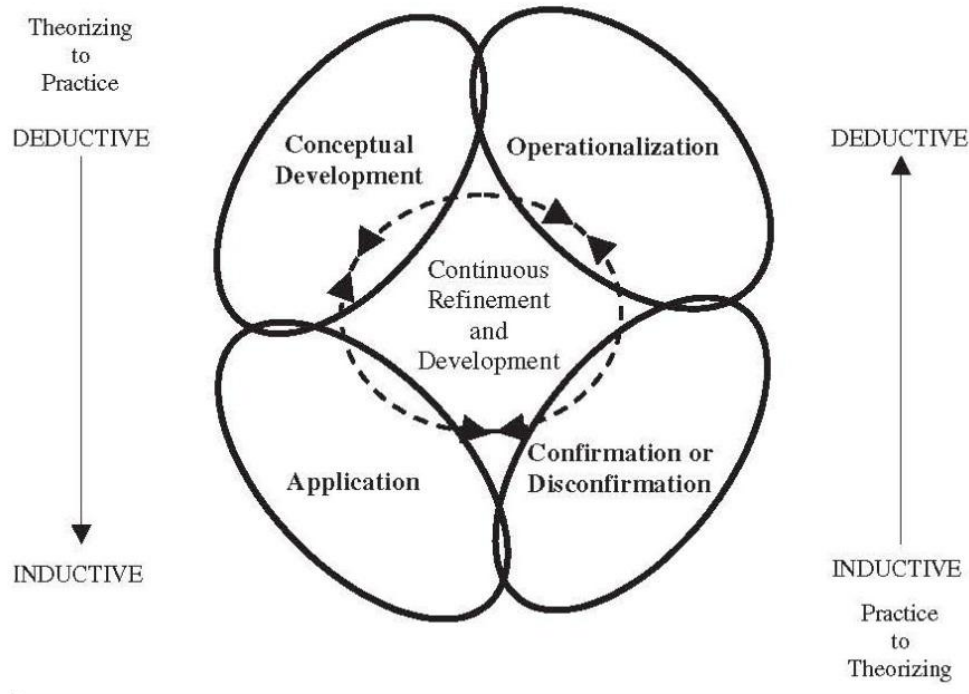
Theory building is “the process or recurring cycle by which coherent descriptions, explanations, and representations of observed or experienced phenomena are generated, verified, and refined” (Lynham, 2000, p. 161). As described by Lynham, there are three crucial factors of theory building that include: a theory developed based on a system of rigorous systematic collection of knowledge and explanation, research through disciplined scholarly inquiry, and application of this knowledge to inform and improve practice. A critical element of theory building is the combination of empirical knowledge with clinical experience in order to promote informed theoretical-based and research-informed practice. So far, the LELQ Model has been developed through extensive and systematic research and represents the theoretical basis of

quality of life in LTC residents with ADRD. The next step is to infuse the model with knowledge from clinical practice in order to promote the marriage between theory and practice.

In this thesis, the LELQ Model was applied to the non-linear five phase theory building process as described by Lynham (2002). These phases, depicted in Figure 3, include conceptual development, operationalization, confirmation or disconfirmation, application and ongoing refinement and development. *Conceptual development* is described as the creation of an initial, informed conceptual framework depicting a current understanding of the issue or phenomenon in context. To bridge the gap between the conceptual phase and practice, the theory will engage in operationalization. *Operationalization* will begin to make the connection between concept and practice explicit by testing it in a real-world context. For operationalization to occur, the theory must be transformed into confirmable elements. In a practice-oriented context, the theory can be confirmed or disconfirmed. For the theory to be *confirmed or disconfirmed* it must be examined and evaluated for use to inform practice. *Application* of the theory to the issue or phenomenon will consist of implementing the theory to practice, in order to further evaluate its relevance and value. Finally, *continuous refinement and development* occurs during all stages of this process to further reinforce the value and relevance of the theory to practice. While the phases are described here in a linear manner, the process is in fact flexible and recursive. Phases may be repeated or occur in a different order depending on the theory. The overarching outcome of this theory building process is to explicate the understandings and explanations of a specific issue or phenomenon in the context of practice. Clear explication allows the theory to naturally inform understanding for ease in real-world application to practice.

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*The environment in which we live, observe and experience the world.*



*Figure 3: The General Method of Theory Building Research in Applied Disciplines (from Lynham, 2002)*

Lynham (2002) stated that good theory building should result in two kinds of knowledge. *Outcome knowledge*, usually in the form of description, and *process knowledge*, which describes how something works and what it means. This research aims to understand both these types of knowledge; what is occurring in practice as well as how practice is being carried out particularly related to functional competence and emotional well-being. Mapping how occupational therapy practitioners are conceptualizing and carrying out practice with LTC residents with ADRD on to the LELQ Model will allow the model to begin to bridge the gap between theory and practice.

## **Purpose and Research Questions**

With Lynham's (2002) theory building process in mind, the purpose of my thesis was to identify how expert occupational therapy practitioners' conceptualize functional competence and emotional well-being in their work with LTC residents with ADRD. Additionally, I aim to understand how those conceptualizations confirm or disconfirm the LELQ Model. To achieve this purpose, I asked four research questions, as follows:

1. In what ways do expert occupational therapists in dementia care conceptualize functional competence and emotional well-being as related to LTC residents with ADRD?;
2. In what ways do these expert occupational therapists' conceptualizations generally confirm or disconfirm the LELQ Model's descriptions of functional competence and emotional well-being?;
3. In what ways do expert occupational therapists in dementia care confirm or disconfirm the linkages between functional competence and emotional well-being and the other LELQ domains?; and
4. In what ways do expert occupational therapists in dementia care relate the concepts of functional competence and emotional well-being to the two time dimensions posed in the LELQ Model: in the moment and overtime?

## CHAPTER 2: METHODOLOGY

### Research Approach

#### A Participatory Paradigm of Inquiry

While Lynham (2000) stated that the theory building process can be approached through several different research paradigms, the action research approach of my thesis aligns best with a participatory inquiry paradigm described by Heron and Reason (1997) and Lincoln, Lynham, and Guba (2011). Working from a participatory paradigm offers a basic set of assumptions about reality and how it is constructed. The participatory inquiry paradigm describes the nature of reality to be both subjective and objective (Heron & Reason, 1997). In other words, to experience reality is also to participate in it. A participative worldview, therefore, is made up of an interaction between what reality is and the way in which it is engaged. Reality is experienced through mutually shared language, values, norms and beliefs and that through participation with reality there is a mutual knowing and understanding. Each encounter in knowing is transactional and interactive. This belief aligns well with the democratic nature of action research. By acting as equals and collaborating with the research team, participants not only shape the research process but also were shaped by it.

Through the lens of a participatory inquiry worldview, knowing occurs in four ways: experiential, presentational, propositional, and practical knowing (Heron & Reason, 1997). *Experiential knowing* involves direct contact with reality; knowing through participative interaction with a person, place or process. *Presentational knowing* is described as knowing through metaphors, symbols and imagery. This can be through graphic, plastic, musical, vocal and verbal art forms. *Propositional knowing* is knowledge expressed by statements and description. It involves knowing in conceptual terms after mastery of the theories. The final way

of knowing is *practical knowing*, or demonstration of knowing through a skill or competence. Practical knowing brings the three previous ways of knowing to practice. Altogether, experiential, presentational and propositional knowing inform practical knowing and how that knowing is manifested in action. Due to the subjective and objective nature of these ways of knowing and presentation of knowing through practice, participatory inquiry methodology is best performed through dialogue with persons who work closely with the phenomenon.

Participatory inquiry methodology parallels many features of action research. As described by Heron and Reason (1997), participatory inquiry methodology involves participants working collaboratively with researchers to engage in exploring reality. Thus meaning the outcome should be grounded in participants' experiential knowledge and that they are asked to participate fully in the research design and the gathering of knowledge. In this sense research is *with* the participants rather than *on* them, similar to what Meyer (2000a, 2000b) describes as the participatory approach in action research.

## **Action Research**

I employed an action research approach in order to answer my four research questions. Due to three essential qualities of action research—its participatory approach, democratic nature and contribution to change (Meyer, 2000a, 2000b)—it is particularly well suited to meeting the needs of theory building and the participatory paradigm. In action research, *participatory approach* demands that participants believe change is needed and are willing to play an active role in this change (Meyer, 2000a). The *democratic nature* requires that these participants are seen as equals and consulted throughout the research process for validation of findings and to inform the next stages of research. Finally, *contribution to change* refers to the purpose of the study to better understand and improve practice. Action research is particularly aligned for

contribution to change, as it is argued that practitioners who work close to the phenomenon find greater meaning in change.

Because action research relies on participants to take an active role in all aspects of the research, it lends itself to building collaborations, which Lynham (2000) viewed as necessary to ensuring applicable and useful theories in applied fields. Likewise, because action research relies on a democratic process to work out any conflicts that arise (Meyer, 2000a, 2000b), a level of collaboration is established that allows for the gap between theory and practice to be bridged by establishing a direct connection to current practice; promoting the use of theory. Accordingly, action research can effectively and simultaneously facilitate research informing practice as well as practice informing research (Meyer, 2000a, 2000b). Due to the emphasis on dialogue in both the participatory inquiry paradigm and action research, this study focused on democratic dialogue with expert occupational therapy practitioners.

### **Participants**

Extreme case sampling was used in order to “learn from highly unusual manifestations of the phenomenon or interest” (Creswell, 2007, p. 127); specifically, this study aimed to learn from occupational therapists who were experts in, and recognized leaders because of their work with, institutionalized people with ADRD. For the purposes of the study, *experts* were defined as individuals who had authored credible publications, were involved in presentations or continuing education events, or were otherwise recognized as leaders or had been recommended by established leaders in this field. Inclusion criteria consisted of current certification or licensure as an occupational therapist in the United States, Canada or the United Kingdom, a minimum of 10 years of practice experience with institutionalized people with ADRD, recognition of being an expert as defined above, and willingness to participate in the research study. Reasons for

exclusion included no access to the technology necessary to participate in the study and those who don't speak English.

Participants were identified through a review of occupational therapy publications, magazines, conference events and available continuing education events. To gain a diverse perspective, participants were selected from across the United States. In addition, chain sampling as defined by Creswell (2007) was used wherein participants identified other potential candidates for the study. Ultimately, six female registered occupational therapists from across the United States were selected to participate in the study (Table 1). Each of these participants signed informed consent forms that had been approved by the Internal Review Board of Colorado State University. While no compensation was provided, participants were invited to contribute towards authorship of a publication of the findings. For the purposes of staying true to action research, the academic research team is made up of three thesis students and a thesis advisor, while the expert practitioners in the study were referred to as the participant research team.

### **Data Collection**

Each of the expert practitioners agreed to participate in two individual interviews and three focus groups. The purpose of multiple data collection sessions was to use a cyclical and recursive process of data collection and analysis to gain a holistic understanding of the participant's practice and its alignment with the LELQ Model. Each data collection session was tape recorded and transcribed verbatim by a member of the academic research team. Analysis of the interviews and focus groups occurred during the collection process in order to use member checking, and integrate discussion points and questions in the subsequent data collection sessions.



Table 1:

*Participant Attributes*

	Place	Date of Cert.	Highest Degree	Current Role	Experience with Dementia
1	Colorado	1984	BS	1 to 1 Consult	12 years
2	Minnesota	1996	BS	Business Mentor Consult Program Development	15+ years
3	North Carolina	1977	BS	1 to 1 Mentor	29 years
4	North Carolina	1989	BS	Business Consult Program Development Physical Design	18+ years
5	Alabama	1996	BS	Mentor Consult	16 years
6	North Carolina	2003	MS	1 to 1 Consult	10 years

Table 2 highlights the purpose and associated theory building steps described by Lynham (2002) for each of the five interactions. The process began with individual interviews in which participants were questioned on current perceptions of practice with people with ADRD and how they carried out their practices. In addition, participants were asked to present two stories of personal experiences when working with people with ADRD. The first story highlighted a good time in which everything worked out, while the next story described a time in which things didn't work out. Appendix A offers sample interview questions from the first interview. Open-ended questions were used to reduce interviewer bias.

Next, three small focus groups were held using conference calling and an online meeting program. Each focus group consisted of the academic research team and three participants. Participants were selected for each focus group based on availability of meeting, therefore

grouping of participants changed for each subsequent focus group. Mixtures of the groups was promoted by the academic research team to ensure participants had an opportunity to communicate with the other five participants and made certain that all voices and ideas were heard by the entire research team. While each focus group had a particular focus (Appendix A), all groups aimed to encourage collaboration and trust between the entire research team.

Table 2:

*Data Collection and Analysis Process*

Data Collection	Purpose	Associated Theory Building Steps*
Opening Individual Interview	Explicate current practice techniques	CD, C/D, Op
Focus Group 1	Presentation of the model	Op, C/D, R/D
Focus Group 2	Analysis and modification of the model	Op, C/D, R/D
Focus Group 3	Discuss practice implementation	Op, C/D, App, R/D
Closing Individual Interview	Member checking and application of the model to specific practice context	App, C/D, R/D
* CD- conceptual development, Op-Operationalization, App-Application, C/D-Confirmation or Disconfirmation, R/D-Continuous Refinement and Development		

The *first focus group* involved a presentation of the LELQ Model by the academic researcher team followed by open discussion. The first focus group’s goal was to begin to introduce the model to the participants and clarify major points of discussion. In addition, participants provided input on how the next forum should be designed.

The *second focus group* involved analysis and critique of the LELQ Model; per request of the participants, this analysis was done through application to two case studies. The discussion helped to highlight gaps in the model, suggestions for modification, and areas for improvement as well as enhancement. The research team began to discuss potential difficulties integrating the model into practice, however then decided that would be the focus of the third focus group.

In the *third focus group*, participants discussed the model's usefulness in practice while identifying potential complications and suggestions for best implementation of the model in the final focus group. In addition, participants identified ways in which they assess, intervene and measure outcomes related to the LELQ domains. The final interaction with the participants was an individual interview that focused on application and continued refinement of the model.

The final interview was used to validate research findings and offer time for the participant to reflect on the research process. The goal was to understand the how each expert practitioner and her work has been influenced by the model, and her perceptions on how the model may influence other practitioners. This provided a better understanding of applicability of the model to different practice sites, and the knowledge the participants gained during the research process.

### **Data Analysis**

Prior to analyzing data from the interviews and focus groups, the academic research team developed and defined apriori codes based on the LELQ domains including “retained capacities,” “emotional well-being” and “environmental channeling.” These codes and definitions were entered in the qualitative data software, *NVivo*. Qualitative data analysis software was used in order to maintain validity, auditability and a unified record of analysis between team members.

In order to establish consistency and reliability in use of these deductive codes as well as in inductive codes that we identified, the academic research team openly coded the first two individual interviews as a group. Open coding refers to a process in which data are organized into a small number of categories (Creswell, 2007). For the purposes of my thesis, I used both

*parent codes*; which are larger category codes, and more specific codes within the parent codes, called *child codes*. Open codes related to my thesis included parent codes such as “emotional well-being,” “emotional ill-being,” and “retained capacities practitioner perspectives” and children codes such as “excess disability” and “optimal functioning” among others. Appendix B provides a complete list of open codes and definitions. These codes organized the data into the domains of the LELQ, allowing for better understanding of how participants were conceptualizing and confirming or disconfirming elements of the model.

When consistency in coding as a group was reached, the next interviews were coded individually by three members of the team. Using the coding comparison function of NVivo, use of codes was compared across the individually coded interviews. This feature provided percent agreement, percent disagreement and the kappa coefficient for each code. Percent agreement and disagreement, as calculated by NVivo, was displayed as the percentage of the transcripts’ contents where the two researchers agreed or disagreed on the same codes (NVivo, 2012). Kappa coefficient is a statistical measure used to identify inter-rater reliability based on the percentage agreement in coding and taking into account the agreement that may have been caused by chance, and is displayed as a number between 0 and 1. Using both percent agreement and the kappa coefficient for each node, areas of discrepancies were identified and discussed until code definitions were agreed upon. After four of the initial interviews had been coded, the academic research team held a retreat. Activities of the retreat included eliminating other coding disagreements, eliminating overlapping or repetitive codes, and removing unused or unnecessary parent and child codes. The percent agreement and kappa coefficients were revisited during this time and used to further identify areas of discrepancy. Upon conclusion of the retreat, the

majority of kappa coefficients of .75 or greater and percent agreements of 98% or higher were reached, establishing intercoder reliability between the three coders.

After intercoder reliability was established, each coder was assigned codes specific to her thesis focus. While each coder focused on her topic area, connections to other codes were still identified. If new codes were developed, these were discussed and defined with the academic research team to ensure reliable use.

After saturation in open coding was reached, meaning that no new information or understanding was found that merited further elaboration through coding, we began axial coding for our individual foci. Axial coding involves looking at groups of open codes and identifying categories in order to further organize the data (Creswell, 2007). For example, among the open codes related to emotional well-being, I identified two axial codes: personhood and observable affect.

### **Individual Data Analysis**

To begin my individual data analysis process, I engaged in content analysis by repetitively reading transcripts and reorganizing the information presented in order to determine concepts, meanings and relationships within each code. In addition, I used context analysis to identify where in the transcripts of the individual interviews and focus groups the codes appeared most and where codes were absent. Finally, the matrix analysis feature of NVivo, allowed me to compared amount of overlap in quotations of codes. This provided me with information on relationships between codes and allowed for identification of the strongest and weakest connections and confirmation or disconfirmation within the model (matrices used can be found in Appendix C.) From here I investigated further areas with the largest and least amount of

overlap in order to identify the weakest and strongest connections between domains. After repetitive analysis, multiple approaches to inquiry, and continued scrutiny of bias and negative case analysis, I felt I had exhausted the data in regards to my research focus.

During the entire analysis process, I kept a research journal on potential routes for inquiry, surprises in the data, further questions and my reflections of the process. This journal provided me with an audit trail that can track how I came to certain conclusions or assumptions in the results. In addition, I engaged in weekly peer debriefing with Dr. Wood and the other two researchers. This allowed us to maintain intercoder reliability and project cohesiveness across the academic researchers, as well as allowed opportunity for feedback and critiques on my analysis process. Furthermore, feedback on my analysis was gained from the participant research team through extensive member checking during subsequent data collection sessions. Particularly, the final interview offered time for presentation of our results and feedback from the participants. Finally, triangulation of researchers, or having multiple analyzers, increased use of peer checking was used to add credibility and thus trustworthiness to our study. This process allowed inductive codes to be added to capture all concepts, deleted if unnecessary and redefined as needed.

## CHAPTER 3: RESULTS

To best represent the six participants' conceptualizations of functional competence and emotional well-being and the ways in which those perceptions confirmed, disconfirmed, elaborated upon and added to the LELQ Model, key findings are presented in relationship to each of the study's four research questions.

### **Research Question 1**

The first research question asked: In what ways do expert occupational therapists in dementia care conceptualize functional competence and emotional well-being as related to LTC residents with ADRD? Overall, findings suggested that participants' conceptualizations of functional competence and emotional well-being greatly aligned with the LELQ Model. However, participants also expanded and elaborated upon the model in several areas. To begin conceptualizations of functional competence are presented including the confirmation and elaboration found within and then confirmation and elaboration of the domain emotional well-being are presented.

#### **Conceptualizations of Functional Competence**

Concern for functional competence was unmistakable when the participants described their work, specifically whether residents had opportunities to use their retained capacities. Without exception, participants believed that the emphasis should be upon a person's remaining abilities, rather than only upon his or her limitations and disabilities. They described the role of occupational therapists as understanding the skills a person has and providing opportunities in which those skills could be used. For example, one participant stated:

I think we are trying to see what skills they [residents] are lacking in, so we are giving the assistance and supervision that they need, but also seeing what remaining abilities they

have so that we know how to tap into what they still can do. (1.31.2013-3FocusGroup-MVS)

Many participants also described occupational therapy's role in educating staff about remaining abilities:

It's best for OT to look at helping staff realize they [residents] still do have skills because at that point, staff may assume they can't do anything and can't help. They think 'I just need to come in and quick get them dressed and get them out to breakfast.' Well, maybe they [residents] can still brush their teeth on their own if set up properly. (9.28.2012-1Interview-MH)

Particularly, participants discussed the misunderstanding of residents' remaining abilities, agreeing that frontline caregiving staff often do not recognize residents' skills. One stated "typically a caregiver, unfortunately, has not been taught to see the retained capacities or abilities. So they usually jump to the conclusion that someone with dementia is very disabled (10.12.2012-1Interview-KW)." This participant also highlighted the misunderstanding of behaviors:

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. (10.12.2012-1Interview-KW)

The participant then described that disruptive behaviors such as rummaging, wandering, or exit seeking are often misinterpreted. She provided an improved way to view these behaviors:

So, I would observe, how does that caregiver define that person with dementia and how do they respond to that. When in fact, that person with dementia can walk and can pick up objects and desires to interact. So, I look at how does that caregiver perceive 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?" (10.12.2012-1Interview-KW)

This change in view was described by several participants as "intent to function." In other words participants recognized these behaviors as residents' efforts to engage in an activity even if their efforts were misdirected. Participants furthermore believed that the idea of intent to function was



an important concept for caregivers to consider in order to promote residents' use of their retained capacities.

Once knowing residents' abilities, participants suggest that setting up the environment to support a resident's retained capacities and redirect the residents' intent to function could make staff's job easier. For example, one stated:

Somewhere there is place where everything did come together but it's trying to help the care partner understand it and it is worth the time to set up the tray and the wheelchair by the bed and use just the one cue. It's worth it, because then you're not fighting with [the resident]... you're not going to have to find someone else to help you try and get this man out of bed. (10.10.2012-1Interview-SH)

Participants described the support or opportunity for use of retained capacities as resulting in several different outcomes including optimal functioning, optimal health and excess disability.

### **Excess Disability**

All six participants addressed the issue of excess disability in LTC residents with ADRD relative to disuse of retained skills. Excess disability was often described in relation to limited social interaction or social isolation, catastrophic reactions, and limited engagement often due to an unsupportive environment. It was repeatedly discussed that as a person declines in function, more environmental support is needed to ensure that the resident is able to engage in activities and with other people. One participant stated in regards to one of her clients, "She was not thriving in her assisted living apartment. She was isolated in the apartment all day and slept all day because they [staff] were not in a position to provide the level of support that she needed (10.04.2012-1Interview-AC)." This quote describes the participant's concern when a lack of environmental support leads to limited functional competence.

## **Optimal Health and Functioning**

Conversely, from the perspectives of the six participants, use of retained capacities by LTC residents with ADRD resulted in advantageous outcomes including optimal health and functioning. Optimal health was described by participants as prevention of negative physical conditions including pressure sores, falls, dehydrations and poor nutrition, while optimal functioning referred to maximizing residents' skills for use in their daily activities. These two outcomes were very much intertwined when participants described the benefits of promoting functional competence.

Many of the participants described optimizing physical health as a positive outcome of using residents' retained capacities. When describing the benefits of using residents' retained capacities for physical health one participant stated:

Their sleep schedule is better, they're awake more, they're alert more, and they're moving more. If they're up and moving, they're not sitting and developing, for example a pressure sore or ulcer. They're engaged during the dining experiences, so they want to eat so they're more nutritionally healthy, and the skin integrity is better. (10.04.2012-1Interview-AC)

Another participant said "by promoting function, by promoting movement, by promoting emotional health, we should be preventing medical conditions from occurring like falls and weight loss and that kind of thing (10.12.2012-1Interview-KW)." These statements emphasized that by promoting functional competence through use of retained capacities, residents' physical health may be improved.

Additionally, participants often talked about optimal functioning as a potential outcome of use of retained abilities. One participant stated "Mentally and emotionally when they're engaged I think that they maintain a higher level of cognition (10.04.2012-1Interview-AC)." suggesting the importance of using retained capacities to support optimal cognitive functioning.

Participants also suggested that with activities that are meaningful to the client, structured to meet the client's abilities, and supported by knowledgeable caregivers, optimal functioning is achieved in people with ADRD. One participant stated, "...at every stage a person with dementia has abilities to offer and engage at every level (09.28.2012-1Interview-MH)." When defining quality of life for LTC residents with ADRD another participant highlighted the importance of optimal functioning:

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. (10.11.2012-1Interview-MM)

Simply stated "You do as much as you can, for as long as you can, as best as you can" (10.11.2012-1Interview-MM). The number and emphasis of quotes related to the using retained capacities to promote optimal health and functioning highlighted the importance the expert practitioners' placed on this topic and its relation to quality of life in LTC residents with ADRD.

### **Conceptualizations of Emotional Well-being**

Like functional competence the concept of emotional well-being was highly evident in the work of the participants; particularly they emphasized emotional well-being when discussing outcomes of treatment strategies. For example, one participant stated:

Throughout the day, you see somebody brighten up when a family member walks in the room. Or you see someone just breathe better; be more comfortable because they are in an environment where they are surrounded by things that are meaningful to them and that helps them feel comfortable. Or we turn on music... their favorite composer or favorite singer, you see them typically look more relaxed. (10.04.2012-1Interview-AC)

While emotional well-being was highly prevalent in the participants' work, it differed from functional competence in that emotional well-being resulted from an intervention but typically

was not the planned outcome. For example, one participant described her treatment with a resident unexpectedly resulting in positive emotional well-being like this:

But now after three weeks, she was staying awake, turning her hands over, catching and tossing it [a ball] back; that was still working to try and get trunk rotation. This time she waved me over and she turned my hands over. And I thought "Oh, she's like 'okay, I get it, you know. Let's do it to you.'" What she did was turn my hands over, she took one of them, and she kissed it, and put it on her cheek. And when I knew that she was in there, and it was literally was like a kick in the stomach to me. (10.10.2012-1Interview-SH)

In their stories and description of their work, participants described emotional well-being in two distinct ways: observable affect and expression of personhood. Concern for both affect and personhood were prevalent throughout the interviews by all six of the participants.

### **Observable affect.**

When discussing observable affect, participants described both positive and negative expressions including smiling, happy, laughter, anxiety and depression. For example, one participant stated:

You have to be able to observe this person's responses. Is this person demonstrating feelings of comfort or anxiety? Is this person expressing happiness or fear? Emotional wellbeing to me is a state of contentment, whatever that person's level of contentment was pre-morbidly is what I'm trying to achieve now. (10.12.2012-1Interview-KW)

Most often, affect was discussed as the expression or countenance residents showed during or after an activity as observed by a staff or family member. For example, participants used affect as an indicator of a resident's well-being and therefore often used affect to describe secondary results of an intervention: for example "you see a smile on someone's face or someone laughing or you see somebody stay awake a little bit longer when they usually just fall asleep." Additionally, participants attended to aspects of personhood in the residents with whom they worked.

## **Personhood.**

The second way emotional well-being was presented was through expression of personhood, or characteristics representative of being human and of having individuality. A participant talked, for instance, about her commitment to opening the eyes of LTC staff so that they could see the whole person and understand that personhood was an important element of quality of life. LTC residents with ADRD were, in her view, “just as entitled to as the next person” (01.18.2013-3FocusGroup). Many of the stories were lined with elements of personhood and often described neglect of residents’ personhood by staff.

I think people don't get touched enough. It's the medical system, where you're here just to help residents with self-care and forget that we're each human beings and people like a hug or a handshake, those kinds of feelings, love. I think if that can be incorporated more into the care it would make it feel more like home. (09.28.2012-1Interview-MH)

Concerns for loss of personhood encompassed experiences of isolation and loss of control. One participant described a resident’s experience of losing his sense of personhood like this:

I had a gentleman who had been a Vice President of a major corporation in the U.S., and I feel like I know his behaviors were a result of the fact that I'm not in control anymore and I used to control a heck of a lot. (10.10.2012-1Interview-SH)

Participants identified a wide range of personhood dimensions, which included feeling a sense of confidence, competence, pride, autonomy, contentment, control, and success, as well as feeling loved, respected and treated with dignity. Related to competence and confidence, for instance, one participant noted:

There is an inherent, innate desire to take care of ourselves, take care of our personal care and those very familiar things, like brushing our teeth and combing our hair. I think that when somebody has dementia, it is a good place to start. That it is, to start to have that feeling of competence and confidence and ‘I'm okay and I can do this much’ and build on skills from there. (10.11.2012-1Interview-MM)

In that situation, the participant used aspects of personhood as a place to begin intervention. Many of the other participants described focusing their efforts on restoration of personhood traits. In one participant's words:

People with Alzheimer's at all stages have the capacity to thrive. They have the ability to feel like a whole being, who still has purpose and meaning, who can still contribute to life, who can still love and be loved. (10.12.2012-1Interview-KW)

This statement of treating residents as whole people with thoughts and feelings was highly present in all of the participants' stories and descriptions of their work.

## **Research Question 2**

Question two asked, in what ways do these expert occupational therapists' conceptualizations generally confirm or disconfirm the descriptions of functional competence and emotional well-being in the LELQ Model? As presented in the previous question, the participants' conceptualizations were rich and expansive. Generally, the conceptualizations confirmed the LELQ Model domains. We found no disconfirmation: however, participants' descriptions and perceptions elaborated specific areas of the model and identified potential gaps in the model related to implementation.

Participants' conceptualizations of their work with LTC residents with ADRD strongly confirmed the domains of functional competence and emotional well-being in the LELQ Model. As noted above, even before being introduced to the model, participants' descriptions of their work confirmed that they believed it vital to know residents' specific skills in order best to provide opportunities for occupational engagement at a level that residents could achieve. Often in describing what they were hoping to achieve with residents, participants likewise confirmed the model's focus on emotional well-being, including avoidance of negative affect and promotion of positive affect.

However, though conveying fundamental concerns with helping residents use retained capacities to minimize excess disability, and also with optimizing residents' emotional well-being, participants typically did not use the language of the model prior to learning about it. For example, as apparent in several of the participants' stories, they often described excess disability as loss of functioning due to lack of environmental support for the resident; yet only one participant actually used the term 'excess disability.' Importantly, however, upon introduction to the LELQ Model, participants expressed comfort with its language. After presentation of the model, participants more easily articulated the concepts they had suggested during the first interviews related to functional competence and emotional well-being. Moreover, comfort with the model and its description allowed the model to grow into a source of unifying language.

Beyond their strong confirmations of the model and increasing comfort with its language, participants importantly elaborated on the model, suggesting expansions to its domains. Particularly, they elaborated on the emotional well-being domain to include concern for personhood and the functional competence domain by suggesting addition of optimal physical health through use of retained capacities, and identification of often misunderstood retained skills.

Personhood, an element not previously identified in the LELQ Model, elaborated on the domain of emotional well-being by suggesting that current practice often overlooks human needs including sense of control, success and dignity in residents with ADRD. The participants by and large concurred that identifying a lost sense of personhood and adjusting to allow for personhood could help to improve residents' emotional well-being.

In terms of functional competence, participants expanded on the limited used of retained capacities by describing staff's assumption that residents with ADRD do not have any abilities

left and focus on residents' disabilities rather than abilities. Participants described this stigmatization as often cause for residents' withdrawal and failure to use their skills.

Finally, participants identified a third outcome of retained capacities that was not previously explicated in the LELQ Model. Currently the LELQ Model described outcomes that focus on functioning. Instead, as described in the previous section, participants expanded on this to include optimizing health. They suggested this was done through the prevention of negative physical health such as pressure sores, injurious falls, poor nutrition and dehydration with use of retained capacities and maintenance of residents' functional competence.

While the participants expanded on the LELQ domains, disconfirmation of the model never appeared in the form of disagreement. Instead, there were identified gaps in the model specifically related to its applicability in practice. Reimbursement was the topic most often discussed as a barrier for application of the LELQ Model. Particularly, participants were concerned with reimbursement for emotional well-being. While all participants spoke of attending to a person's emotional responses, behaviors and apparent affect during their initial interviews, it was not until after introduction of the model that they began to discuss the difficulties of measuring emotional well-being and gaining reimbursement for it. The participants suggested that reimbursement issues may cause major difficulties when attempting to address well-being, as laid out in the LELQ model, in practice with this population.

Several participants offered suggestions on ways that practitioners could gain reimbursement for outcomes related to emotional well-being. The alternative routes to reimbursement they discussed included measuring emotional ill-being or the reduction of negative behaviors instead of well-being or accepting emotional well-being as non-reimbursable by-product of other goals. Others, too, mentioned the possibility of gaining reimbursement with



the identification of the appropriate language within the current Medicare policy. However, while many ways strategies to achieve reimbursement of the LELQ Model were offered, all participants identified it as a barrier that would need to be addressed to support the model's application to practice.

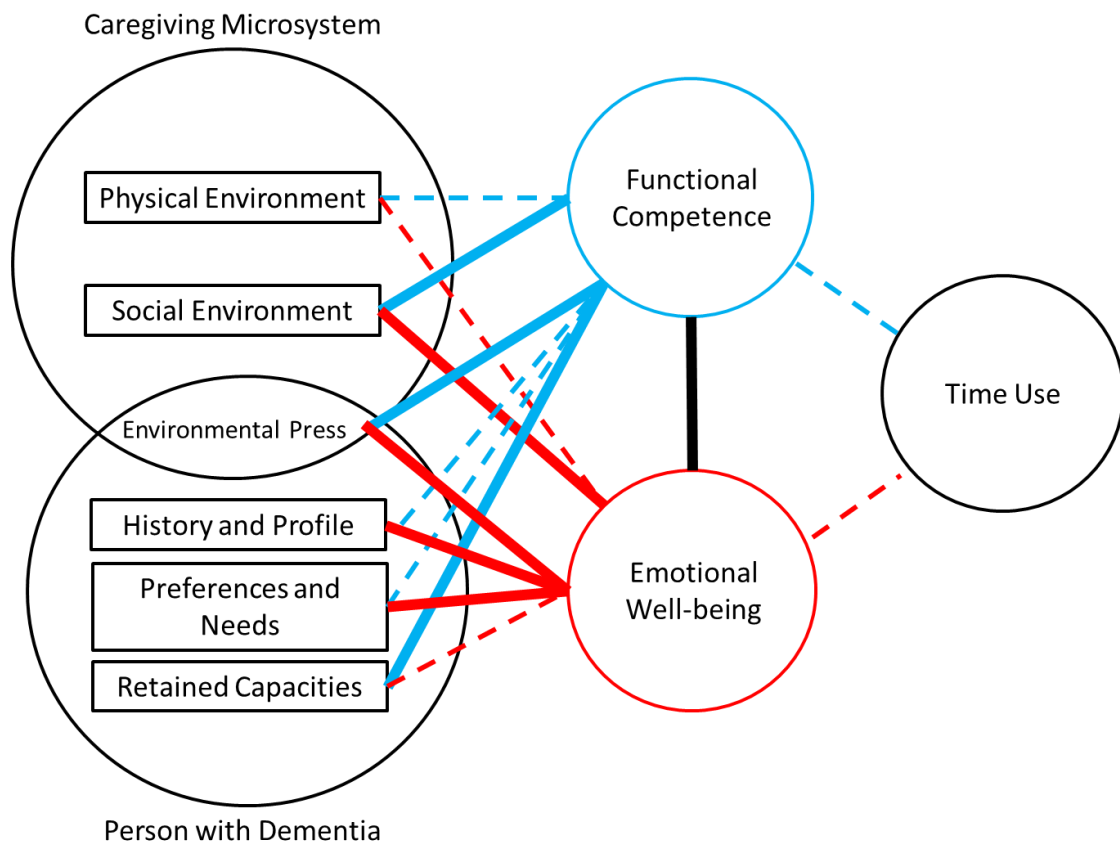
### **Research Question 3**

Overall, the participants' conceptualizations of functional competence and emotional well-being aligned well with the LELQ Model. Similarly, the results of research question three—In what ways do expert occupational therapists in dementia care confirm or disconfirm the linkage between functional competence and emotional well-being and the other LELQ domains?— were largely confirmed. However, the strength of connections described by participants varied. Figure 4 provides a visual illustration of the strength of connections described in the subsequent paragraphs. Due to the qualitative nature of these connections, the lines in the figure do not represent specific numbers of overlapping quotes. Instead they represent the degree of emphasis placed on each connection in corresponding quotations of overlap, as described in each of the following sections: quality of life connections, connections between functional competence and the lived environment, and connections between emotional well-being and the lived environment.

#### **Quality of Life Connections**

Of the quality of life domains, emotional well-being and functional competence had the strongest confirmation of a link to each other as evidenced by matrix analysis and overlapping quotations, as shown in Figure 4 as the solid black line. These concepts were often discussed in parallel when describing favorable outcomes to interventions. The link arose out of creating moments of well-being through use of retained capacities. For example, in reference to residents

with lower levels of functioning one participant described “They can still respond to music and touch. You can create that moment of connection and that moment of joy (09.28.2012-1Interview-MH).” This phrase shows a concern for what a resident is able to do and the emotion they gain from participating. The connection between emotional well-being and functional competence was most evident when participants described stories about residents with whom they have worked. For instance, one participant described shifting her approach in order to get a man out of bed in the morning. Typically, this man would scream in pain and require a two-person transfer. When she changed her approach to fit his cognitive capacity, for example, by



*Figure 4: LELQ Domain Connections.* This figure offers an illustration of the strength of connections between the domains. Thicker solid lines represent strong connections between concepts, while the dotted lines represent connections that are less strong. The blue lines represent connections related to functional competence and red lines represent connections made to the emotional well-being domain.

using one word cues, he was able to transfer himself and needed minimal assistance to get ready for the day. With this approach, this resident was able to use the skills he retained to reduce the typical pain and anger he experienced prior. Another participant summed the connection between functional competence and emotional well-being up by stating: “Let them [residents] have an opportunity to complete the other pieces of the skills themselves and you come back and they're doing it and they feel really good about it (12.07.2012-2FocusGroup).” This example, among many others, confirm the link in the LELQ Model of functional competence influencing emotional well-being, however the reverse is true.

Many of the participants also identified emotional well-being as an influence on use of retained capacities. For instance one participant believed that one benefit of knowing residents was being able to recognize when their countenance or temperament was off and using that recognition to looking for a cause, such as inability to complete a step in a task. Additionally, several participants described how ignoring residents’ human rights such as dignity and choice may lead to learned helplessness or withdrawal. Through their stories and examples, participants confirmed the reciprocal relationship between functional competence and emotional well-being in the LELQ Model. One person clearly described the relationship as symbiotic:

I think it’s kind of symbiotic, you give a person an opportunity to do something and then they're able to do it. They feel a sense of competence and then they have confidence to try a harder level of that activity or to generalize that feeling of confidence to the next activity they try, so I think it’s a symbiotic relationship. (12.07.2012-2FocusGroup)

Matrix analysis and supporting quotations revealed that the link between functional competence and emotional well-being to the third quality of life domain, time use, was confirmed. This link, however, did not have as strong of a connection as that between the other two quality of life domains (Figure 4). Upon review of quotations, functional competence and

emotional well-being were more connected with occupational engagement than with time use patterns. Connections of time use were often implicit in practitioners' descriptions of stories. The example below shows an implicit concern for patterns of time use.

On the other side, I would say that people are doing what they wish to and they are doing it well and they feel confident and competent and...they have a social life. They can go to the dining room and feel comfortable chatting with others, they can go on outing and really enjoy it and not think about those basic things that they literally had to work on just to feel like they were human. (10.11.2012-1Interview-MM)

This participant spoke of residents having the abilities and feeling competent enough to engage in activities across the day as they would like. However, the majority of overlapping quotations were in regards to occupational engagement in specific activity situations. For example, one participant described a woman who previously had limited occupational engagement and was therefore experiencing excess disability and emotional ill-being. By engaging in a meaningful way, the resident was able to use her retained capacities.

We pulled the slot machine handle and it made all this noise, and that got Mary's attention and that 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. (10.12.2012-1Interview-KW)

Another participant described the benefits of using the skills a person has in order for the resident to return to meaningful activities.

She's independent, back in her wheelchair and she's supervised on her four wheel walker. She is engaged in and serves on the residential council and she volunteers in the library... She goes on outings. She is able to go out with her family and engages in good conversations with her family and staff. The things that were important to her that she could do here, she has been able to become participatory again. She is engaged in her activities again and that makes her happy (10.11.2012-1Interview-MM).

This quote exemplifies how a balance of using retained capacities can encourage occupational engagement, which ultimately improves emotional well-being.

More specifically, matrix analysis showed occupational engagement was most connected with the retained capacity outcome of optimal functioning and the emotional well-being outcome of positive affect, suggesting that positive occupational engagement seems to result in optimal functioning and positive affect. One participant describes:

We had residents who would come out and say, 'I think this place needs to be cleaned up. I'd like a broom.' And then you'd see them kind of sweeping and then another one came out, 'We need to take care of this flower bed; the flowers are dry,' and holding a watering can with the hose... and it was a great moral to the staff to say, 'listen these are people who have done this in the past and can still do it to this degree...(10.04.2012-1Interview-AC)

This quote implicitly shows her concern for use of the skills a person does have and ways they can use these skills across the day, confirming the link between all three quality of life domains. Another participant stated "she's back doing just about everything that she was doing before and really happy about it (10.11.2012-1Interview-MM)," showing confirmation of the connection to daily time use and emotional well-being.

Overall the concept of the three quality of life domains acting like cog wheels was confirmed, in that the participants described each domain: time-use, functional competence, and emotional well-being, as effecting each other and being effected by the others. In addition, to the links between the quality of life domains, the LELQ Model suggests that the lived environment, including the caregiving microsystem and person with dementia, impact functional competence and emotional well-being. As next described, the connections among the lived environment and functional competence and emotional well-being were confirmed; however, like the quality of life domains, certain links were stronger than others.

## **Connections between Functional Competence and Lived Environment**

The connection between functional competence and caregiving microsystems was confirmed; however matrix analysis and supporting quotations showed the link with the social environment appeared stronger than that of the physical environment (Figure 4). The role of the social environment was apparent throughout the interviews in regards to both positive outcomes and negative outcomes. One participant described a story of a person with dementia experiencing excess disability because his caregiver was burnt out and no longer required him to do daily activities such as get dressed. When this person moved into the facility, the caregiver continued to believe the resident did not have the capability to complete any tasks, which continued to suppress his abilities and make it difficult for the staff to intervene. This example shows how even in a more supportive physical environment, because of the people around him, this resident was unable to maximize his abilities.

Conversely, participants identified the social environment as critical to gaining optimal functioning. Often times, participants described changing the social environment to involve educating family or staff on the capabilities that the resident still had, and taking the time to provide adequate supports to allow the resident to exercise his or her skills. For example, this story exemplified using education in order to create the optimal social environment for individuals to use their remaining functional competence.

Educating the caregivers and family, so whoever is primarily involved...we want to keep them abreast of here's their [residents'] functional level and here's what I am seeing. We would coordinate together so that if I had some thoughts about of how they might best respond or maybe they need some more verbal cues than somebody else we could incorporate that when they are doing activities (09.28.2012-1Interview-MH).

This statement exemplified the importance of building up social supports as the person declines in functioning:

You have been concerned with are they [the resident] too isolated. As they [residents] lose their abilities, they are just more home-bound; they're not going to come out, they can't handle a calendar, and can't initiate phone calls to do an activity. They likely just don't go out with friends or may not even come out of their assistive living anymore. There may be lots of activities going on, but if they can't follow their calendar they are not able to initiate it themselves. OTs help with educating families on the need of an escort to an activity because, otherwise, the resident is not going to know when it is or how to get to where it is (09.28.2012-1Interview-MH).

In addition to social supports, physical environmental supports were more briefly mentioned in regards to adapting the physical environment to fit residents' abilities. These included putting contrasting tape to identify grab bars in a bathroom, setting up meal trays, and identifying food that can be carried. Both the physical and social supports mentioned were very individualized and meant to support each resident's specific needs.

The aspect of the person with dementia that participants most strongly confirmed when discussing residents' functional competence was by far residents' current retained capacities (Figure 4), as shown in the matrix analysis (Appendix C). They often discussed the need to know the specific skills each individual still had in order to better support them. For example, one person described needing to look beyond the published literature and instead look directly at the individual. "I know there are a lot of different scales of determining whether or not, mild dementia, or moderate dementia. But what I like to do, and what I train therapists to do, is to see what skills are present (10.17.2012-1Interview-MVS)." She went on to say: "Language is something that diminishes with the progression of the disease. So if you're using language that they [residents] can't understand, that could really get in your way of being successful with your treatment." These quotes show the emphasis the participants place on knowing the individual skills residents' retain.

Participants also spoke of referencing a person's needs and preferences, and occupational history when promoting use of retained capacities. Specifically, participants referenced things residents are interested in or used to do to encourage them to get involved now such as doing word searches or puzzle that had been adapted. One participant in particular exemplified the importance of understanding residents' preferences by describing how activities need to be changed to fit their unique abilities, preferences and history. An example she gave was offering the choice for a bath or shower and how such a choice could reduce negative behaviors and allow the resident to be more involved in the process. She also stated that staff must be, "Okay if someone wanders out and then wanders back in a few minutes later and starts engaging again and understanding that maybe everyone doesn't like bingo (10.10.2012-1Interview-SH)." The resident's wandering may not be a negative behavior but instead just a lack of interest in the activity.

### **Connections between Emotional Well-being and Lived Environment**

Similar to functional competence, the link between emotional well-being and the lived environment was confirmed; and like functional competence, emotional well-being was more strongly linked to social aspects of the caregiving microsystem than physical aspects (Figure 4). One physical feature of the environment that was described to influence emotional well-being involved the abundance of clutter, which could cause the residents to feel overwhelmed. In addition, another participant described how the physical feature of a bed (i.e. bed rails) was used to restrain a resident from getting up at night and the negative impacts of this restraint on her dignity. In this same story the participant described the impact of the social environment on this resident. The staff's limited attention and consideration of this resident's personhood including her dignity, control and sense of respect, negatively impacted her emotional well-being.



The lack of attention or respect for the residents' feelings or personhood was of utmost concern for participants. One participant, when describing feelings of success, even suggested a simple change in language by staff to promote emotional well-being:

And, that comes from how we as therapists and other health care professionals interact with the person. Say that a healthcare profession tells this person, "You're doing a good job," and promotes independence, then that person will have a good sense of self. But if we are saying, "No, you did that wrong," or we're over challenging them and having them fail in our treatment sessions, or we're not encouraging them to do anything anymore and we're having them feel like an inanimate, helpless object, then we'll get a bad result. (10.12.2012-1Interview-KW)

This confirmation for emotional well-being within the lived environment continued into the domain of person with dementia. Matrix analysis revealed emotional well-being appeared most strongly associated with occupational history and profile, and personal preferences and needs (Figure 4; Appendix C). One participant described the importance of using residents' life stories to promote well-being.

I think a connection to our life story is important. So, that person still being and doing what they've always loved is ...it's a catalyst for this person thriving. I think also is that feeling of success, that, 'I'm not disabled. I actually have the ability to still do something and do it well (10.12.2012-1Interview-KW).'

Occupational history and life story also appeared very strongly linked to emotional ill-being. Many of the participants described feelings of sadness, depression and anxiety when residents could not engage in activities they used to do. Participants described some catastrophic responses that were seemingly provoked by lost sense of self including a woman trying to break a window out in order to pick up her children or a woman yelling because she was not being dressed as dignified as she did in her early life.

Participants additionally described how providing residents with a sense of autonomy, purpose, control and respect in their daily life could improve their overall well-being. For

instance, one participant acknowledged that it really bothered her “to see individuals not being able to live as they would like to.” (10.04.2012-1Interview-AC).” Adding:

I think that occupation is just the foundation for where we build our day, our experiences, our context, our memory. It’s really tough with an individual with dementia, when they can’t entirely speak for themselves about the accuracy of their history, things that they’ve done and they’ve enjoyed.

This participant then described several stories of fieldwork students integrating residents’ preferences, needs, and life histories to promote a thriving and happy community, ultimately highlighting the connection between the LELQ domains: emotional well-being and person with dementia, even more.

#### **Research Question 4**

The final research question asked: In what ways do expert occupational therapists in dementia care relate the concepts of functional competence and emotional well-being to the two time dimensions posed in the LELQ Model: in the moment and overtime? Both time dimensions, that is, in the moment and over time, were confirmed in regards to functional competence and emotional well-being. However, the participants elaborated on these concepts to include two long-term outcomes: permanent loss of functioning and reversible effects.

#### **In the Moment**

Without exception, participants confirmed that occupationally enlivening environmental presses could support the emotional well-being and functional competence of LTC residents with ADRD, specifically positive affect, personhood and optimal functioning. These connections showed a concern for both emotional well-being and functional competence as an immediate outcome of intervention. The example below shows the press towards optimal functioning and improved emotional well-being created by moving into a residential facility.

The smaller setting and the more staff around and some of the set up was just exactly what she needed to alleviate her fears. She was at the point where she couldn't remember what she was doing. She had a little bit of insight but the supports were enough to give her confidence, she still had some questions, she is just that way, it's probably just her nature, but much less and she seemed more relaxed and engaged because she had more social opportunities than before. She was more happy and you could see it in her face, and she felt like part of the group. (09.28.2012-1Interview-MH)

Conversely, excess disability, ignorance of personhood, and emotional ill-being were related to occupationally deadening environmental presses. One participant described how the staff had set up a resident's environment in order to keep the resident "safe," and the negative impact that had on her immediate well-being and functional competence.

One evening I was going home and thought I am going to go and say goodbye to Ruth (pseudonym) before I head home. I went in and was appalled because they had put her to bed and pulled the rails up and she was nude from the waist down. That was the number one thing that had upset me, and the second thing that upset me was she was so thin and frail that she was between the mattress and the bed rail and she was trapped and she was struggling against this bed rail, and no one was around. (10.10.2012-1Interview-SH)

The participant showed concern for the resident's distress, which seemed to have resulted from her personhood being ignored. The participant also identified the misconception of restraining the resident because she has the skills to get up at night: "our solution to her sundowning was to trap her in a bed that was a hazard for her; that she couldn't get out of..." This quote shows the participants concern for the resident's intent to function, and her concern for how the residents' actions should be supported and not discouraged or blocked. This story and others suggest that influences of the environment, in this case caregiver's perceptions of safety, have an immediate effect on resident's quality of life. Particularly, negative experiences promote withdrawal and distress among residents in the moment. Additionally, participants' stories suggested that an accumulation of these moments had long term effects on the residents.

## **Overtime**

The linkages of functional competence and emotional well-being were confirmed most often through participants' stories of long term effects of positive or negative environmental presses. The cumulative negative effects that limited use of residents skills and resulted in depressed and anxious affect on residents was a common theme throughout the interviews and focus groups. Environmental channeling was referred to when discussing the accumulation of residents' loss of abilities and limited environmental support resulting in isolation and poor quality of life. One participant described that without the proper supports, residents would no longer initiate phone calls or know when activities occur, therefore resulting in a negative cycle of more and more social isolation. This concern for environmental channeling was echoed among all practitioners. Another stated, "That's something that we kind of preach, that when people are not engaged, they deteriorate or the progression of the disease speeds up (12.07.2012-2FocusGroup)." Several of the participants shared stories about residents that have grown into dependency roles because it is easier for the caregivers to do the task for them than it is to provide support for the resident to do it. One participant described an important piece of training staff as educating them on the importance of residents' involvement in their self-care "so they don't lose all those skills (09.28.2012-1Interview-MH)."

The descriptions and stories the participants shared reflected two types of negative outcomes over time: permanent and reversible. The following story describes a case in which a resident was experiencing environmental channeling but, with the participant's intervention, the effects of channeling were reversed. The participant described meeting a woman in an assistive living that had recently been put on hospice.

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. 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 was stopping eating, you know, all kinds of things that might be indicative of end of life. . . . We watched her caregivers comb her hair, sit her in a corner, and that was Mary's life. (10.12.2012-1Interview-KW)

The participant then described the reversal of environmental channeling upon moving the resident into a more supportive environment.

Within two weeks, Mary was not only off of hospice, but she actually had the cognitive ability of somebody in early stage dementia. She was assisting with her own ADLs, she was lying on the couch in the living room at our facility singing opera, and she lived there for a good three years, which is the last I checked on her, in health and wellbeing. So, what was happening to Mary is much like your professor's paper [Wood, Womack, Hooper, 2009]; she was dying of boredom. She wasn't dying for any medical reason.

In contrast to this example, many participants offered stories in which the effects of environmental channeling were non-reversible; in which the residents were "too far gone." For example, one participant described a person with ADRD moving in to the LTC facility after experiencing environmental channeling at home. In this story, the home caregiver was so burnt out, she chose to no longer support the individual with dementia in daily activities such as showering and dressing, often leaving the individual in his pajamas throughout the day. This led to the even more disengagement, loss of skills, and emotional ill-being for the individual. The accumulation of these negative experiences transferred over even when moving to a more supportive care environment.

The individual [with dementia] had deteriorated and developed quite a degree of depression and the caregiver was depressed and burnt out. There wasn't a great type of engagement or relationship between the two [resident and caregiver] anymore. And by the time we were able to work with this individual I could see great potential for things the person had done in the past, and things that I hoped the person could do...but things just didn't turn out as well as I thought they could have. (10.04.2012-1Interview-AC)

This participant's story displayed the permanent effects of environmental channeling; in that even when placed in a more supportive environment, the resident was unable to improve in quality of life due to his complete withdrawal and lack of motivation to engage in daily activities and potentially accelerated deterioration of skills and abilities.

In addition to describing negative results over time, the participants described the influence of functional competence and emotional well-being in a positive trajectory over time.

One participant described:

But it's [dementia] got a progressive component to it, it's like fighting up stream but there is no reason you shouldn't feel like you shouldn't have some quality of life just because of that. You do as much as you can, for as long as you can, as best as you can, and you ask people around you to help you do that. (10.11.2012-1Interview-MM)

Another person described the influence a supportive environment can have in saying, "I guess the just right challenge and the just right fit between the person and the environment and the occupations then you have a great instigator of positive change (10.04.2012-1Interview-AC)."

Overall, the participants described residents as being mobile longer, having more verbal conversations, better nourishment, laughing and smiling more, and overall healthier engagement when more involved in daily activities; potentially even living longer. They also concurred that a person's quality of life could be good even though significant disability may exist. "Health and quality of life doesn't always mean living longer but living better (10.04.2012-1Interview-AC)."

These perceptions suggest a positive trajectory despite the progressive decline of ADRD.

## CHAPTER 4: DISCUSSION

Results from this study suggest that the perspectives of six expert occupational therapy practitioners strongly converged with the concepts of functional competence and emotional well-being in the LELQ Model indicating high face validity of the LELQ model to the practitioners involved. In addition, the connection between functional competence and emotional well-being and the concepts in the rest of the model were confirmed. Participants' confirmations and elaborations have several implications for both the LELQ Model and future best practice for LTC residents with ADRD; Table 3 offers a brief summary of the results of each research question and corresponding implications for the model.

### **Functional Competence**

The major emphasis on functional competence suggested that use of retained capacities represents an important piece of best practice for occupational therapists at a one-to-one intervention level. Through understanding residents' specific abilities and deficits, practitioners can find the most effective treatment strategies for that individual. This concept goes back to occupational therapy's professional roots in which treatments should be individualized and match the clients' needs and abilities (Friedland, 2011). As participants suggested, this perspective should not change for LTC residents' with ADRD; in fact, more attention may need to be given to gathering information on residents' skills and abilities due to communicative and cognitive deficits, and the expert practitioners in this study strongly suggested that efforts in these regards were well worth the time and energy that they took.

Besides the typical outcomes of functional gains seen in the literature and LELQ Model, participants asserted that negative physical health, meaning conditions related to illness or injury such as falls and pressure sores, can be avoided through interventions focused on maintenance

Table 3:

Summary of Results and Implications for the LELQ Model

<p><b>Research Question 1: In what ways do expert occupational therapists in dementia care conceptualize functional competence and emotional well-being as related to LTC residents with ADRD?</b></p>	
<p><i>Findings:</i> The participants in the study conceptualized functional competence and emotional well-being in a way similar to the LELQ Model. Participants emphasized focusing on residents’ abilities rather than disabilities, attending to residents’ intent to function, and recognizing physical health as an outcome of use of skills. Additionally, participants recognized the need for residents to express personhood.</p>	<p><i>Implications for the Model:</i> These findings suggest that the model is applicable and useful to practice, however can be expanded to include aspects of personhood and outcomes of physical health.</p>
<p><b>Research Question 2: In what ways do these expert occupational therapists’ conceptualizations generally confirm or disconfirm the LELQ Model’s descriptions of functional competence and emotional well-being?</b></p>	
<p><i>Findings:</i> The participants generally confirmed the LELQ Model’s domains of functional competence and emotional well-being. Additionally, we did not find disconfirmation, only elaboration on the model.</p>	<p><i>Implications for the Model:</i> These finding confirmed the LELQ Model’s usefulness to practice, but suggested areas of further refinement of the model including the addition of personhood and physical health.</p>
<p><b>Research Question 3: In what ways do expert occupational therapists in dementia care confirm or disconfirm the linkages between functional competence and emotional well-being and the other LELQ domains?</b></p>	
<p><i>Findings:</i> All linkages were confirmed by the participants in this study, however the strength of the connections varied. Both functional competence and emotional well-being were strongly linked to each other and less strongly to time use. Additionally both had a strong connection to the social environment but differed in connections to the person with dementia domain.</p>	<p><i>Implications for the Model:</i> Again, these findings further support the LELQ Model’s usefulness in practice. Further application of the model is needed to explore these connections deeper. Specifically more research is needed on the influence of the social environment on quality of life and ways occupational therapists can intervene to promote residents' sense of personhood.</p>
<p><b>Research Question 4: In what ways do expert occupational therapists in dementia care relate the concepts of functional competence and emotional well-being to the two time dimensions posed in the LELQ Model: in the moment and overtime?</b></p>	
<p><i>Findings:</i> The expert occupational therapy practitioners confirmed the two time dimensions in the LELQ Model and suggested that residents may experience either permanent or reversible long term functional losses.</p>	<p><i>Implications for the Model:</i> These findings confirmed the LELQ Model time dimensions in regards to functional competence and emotional well-being. Further application of the model is needed to explore the permanency of environmental channeling and potential for reversing the effects to promote quality of life.</p>



and use of residents' functional competence for residents with ADRD. The literature surrounding use of retained capacities in people with ADRD focuses on how use of skills can promote slower decline and lack of use results in excess disability (Wells & Dawson, 2002; Wells et al., 2000), neglecting how physical health may be improved. For example, Wells et al. (2000) sought to understand how care that is directed to the resident's specific abilities affects behaviors and functioning. Their outcome measures addressed level of agitation, level of function, level of stress, and ease of caregiving; disregarding outcomes such as decreased fall, dehydration or hospitalization rates. Additionally, research on generalized physical activity for people with ADRD offers little indication of how physical health may be influenced by increased movement or mobility (Potter, Ellard, Rees, & Thorogood, 2011).

While research on use of retained capacities and promotion of functional competence in LTC residents with ADRD doesn't currently address outcomes related to health, the participants seemed very aware of the benefits. It is in my view, that future integration and empirical support of these physical health benefits, including reduced falls and hospitalizations, into the LELQ Model is important as it may reduce costs and burden of the facility as a whole; ultimately encouraging administration buy-in and support of the model.

### **Emotional Well-being**

Similar to the emphasis on functional competence, the appearance of concern for emotional well-being in the stories of participants showed the importance they placed on residents' subjective experiences living in LTC facilities. Participants went beyond what the LELQ Model describes as well-being and included elements of personhood such as sense of competence, confidence, choice and dignity. Kitwood and Bredin (1992) agree that good care for people with ADRD includes attention to personhood traits.

Kitwood and Bredin (1992) describe twelve indicators of well-being, many of which were discussed by participants and several that were not. Participants spoke passionately and often about concerns for personhood stressing the importance of attending to these traits for LTC residents with ADRD, however each had their own language and focus on specific aspects of personhood. For example, one participant often described a sense of competence and confidence, while another participant focused more on dignity and respect.

Drawing from participants' perspectives as well as Kitwood and Bredin's (1992) work, I suggest that four characteristics of personhood be included in the LELQ Model. These include experiences of competence, autonomy, relatedness, and contentment. *Experiences of competence* refers to a resident's sense of success and confidence in daily activities. *Autonomy* involves a residents' ability to assert their control and will to influence their surroundings. Similar to the definition by Kasser and Ryan (1999), *relatedness* denotes that residents' feel a sense of connection to others, may it be family, staff or other residents, and that residents' experience as sense of love, belonging and respect in their environment. Relatedness depends on respect for the residents, therefore involves treating residents with dignity and recognizing their personal worth. Finally, *contentment* is an expansion of the model's previous description of apparent affect, and refers to residents' emotional responses as well as their feeling states including sense of relaxation, or freedom from anxiety or worry. While these personhood characteristics are ultimately perceptions of the individual residents, the extent to which each trait is being experienced by the residents is generally observable behavior.

By integrating this view of personhood into the LELQ Model, practitioners will be equipped with a set of specific characteristics to be used in practice with LTC residents' with ADRD. Consequently integration of personhood in the model will involve a language change

related to the domain of emotional well-being. The term ‘emotional’ well-being seems to be insufficient in describing the broader perspective of well-being for LTC residents with ADRD.

To broaden the LELQ model to encompass elements of affect and personhood, the domain of emotional well-being should be renamed “relative well-being.” The term relative well-being, used by both Kitwood and Bredin (1992) and Hasselkus (1998, 2011), refers to experiencing positive health and consistency in one’s life despite health problems or other life imbalances (Hasselkus, 2011). For the purposes of the LELQ model, relative well-being refers to the spectrum of positive and negative affect and personhood experienced by LTC residents with ADRD despite losses in cognitive function or other deficits.

### **Social Environment**

In describing the importance of functional competence and emotional well-being for LTC residents’ with ADRD quality of life, participants asserted that the greatest reason residents are experiencing poor functional competence and emotional ill-being is the social environment, described for the purposes of this study as the thoughts, beliefs and actions of the people in a resident’s immediate surroundings.

Participants described the social environment as critical to residents’ well-being; particularly the negative effects of inattention to the residents’ personhood and misunderstanding of retained capacities. Kitwood and Bredin (1992) echoed this belief and described residential care to have an obvious separation between "us" and "them." With the residents with ADRD, or “them,” as the damage or problem, and no attention to problems staff, or “us”, may cause. They go on to suggest a different view of care in which "we" contribute to the problems and "they" are human beings living within our limitations and failures.

This separation is especially important, as personhood relies heavily on social sanctions (Kitwood & Bredin, 1992). Of the proposed personhood traits, relatedness is clearly dependent on the social environment. However less obviously, experiences of competence, autonomy, and contentment rely on staff and family to support these endeavors for LTC residents with ADRD. For example, activities that meet a residents' ability level must be offered in order for them to experience success or confidence in completing the activity, and choices must be made available for residents in order for them to be able to exert control.

The times participants described threats to residents' personhood involved disregard for residents' dignity or worth, adherence to staff schedules rather than residents' exertion of choice, or neglect of residents' need to feel competent. Additionally, participants described the negative effects of disregard to a resident's functional competence. Due to lack of knowledge on retained capacities, LTC residents' with ADRD are often marginalized causing emphasis to be placed on disabilities rather than abilities. This emphasis by staff threatens residents' opportunity to use their skills, ultimately endorsing loss of those skills and excess disability.

Due to the magnitude of social environment influence on functional competence and emotional well-being, it is important that all LTC staff recognize that residents have skills they can use and deserve the respect and opportunity to engage as any other person would. Hasselkus (1998) described the ideal connection between staff and people with ADRD as a "meeting of minds." By establishing a connection, caregivers are better able to elicit occupational engagement and therefore promote functional competence and emotional well-being. However, this "meeting of minds" requires strong interpersonal skills from staff members including persuasion, redirection, enablement, and identification of a key to opening the resident up. The story Hasselkus provided as an illustration of the "meeting of minds" parallels many described

by this study's participants. In each story, the staff or caregiver is responsible for encouraging the resident's engagement, thus highlighting the need to provide a supportive social environment.

In order to support residents' quality of life, strategies such as those Hasselkus (1998) described need to be used in practice. Occupational therapy may be align in a way that practitioners already know and use the skills described by Hasselkus, as in the case of the participants in this study. Yet, from the stories described, use of interpersonal skills by occupational therapists alone is not enough. Occupational therapists will need to expand services beyond a one-to-one intervention model to promote quality of life through the social environment at a systems level, similar to many of the participants' efforts. This part of occupational therapists role in LTC should involve a systems level intervention to educate staff and caregivers on strategies, such as those described by Hasselkus, to promote functional competence and emotional well-being.

### **Environmental Channeling**

Change in the social environment is especially important due to the two long term outcomes of environmental channeling that participants described: reversible and irreversible loss of functioning. As the model describes, environmental channeling is the process of accumulation of excess disability, occupational disengagement and emotional ill-being, resulting in a negative spiral and even more excess disability, occupational disengagement and emotional ill-being. What the model does not describe is the extent to which a person may be "pulled out" of this negative cycle.

There is limited research on the reversal of environmental channeling effects. Kitwood and Bredin (1992) described "rementia" or the reversal of functional losses with a more

supportive social environment. They state that even hopelessly demented people can experience improvements in functional conditions and describe the areas with most opportunity for positive change to include social skills, independence and continence (Kitwood & Bredin, 1992), however these proposed areas of improvement have not yet been empirically supported.

Research on the effects of more supportive care environments have shown promising but inconclusive results (Sixsmith, Stilwell, & Copeland, 1993). In a study by Sixsmith et al., residents with dementia were moved into one of three care homes depending on severity of symptoms and behaviors. Each care home was based on an individualized care approach in which caregivers had greater expectations of residents' functioning, choice and control and activity engagement. The care home with residents experiencing the most severe behaviors resulted in the best, although varied, outcomes. A general pattern was noted of improved functioning upon relocation, with the eventual decline to residents' previous status. The other two homes saw individual improvements but no generalized improvement across the residents overall.

The concept of rementia, or the improvement in functioning, in LTC residents with ADRD is compelling. Through their stories, participants of this study suggested that residents' can regain functioning with a more supportive environment even far into the negative spiral of environmental channeling, inferring that practitioners should be optimistic in what a resident may or may not be able to do despite their current functioning. The extent to which a person may be able to experience rementia is unknown, and the participants spoke of residents that did not improve in functioning. However, it should be argued that best practice includes attempts at reversing the environmental channeling process.

## **Reimbursement**

It is easy to advise practitioners to attend to ideas like quality of life and environmental channeling in practice, but realistically practitioners function within specific guidelines deeming what services will be paid for. Reimbursement was identified as one of the greatest barriers to implementation of this model by participants, particularly for emotional well-being as an outcome of intervention.

The suggestions the participants offered to evade this barrier included measuring reduction of ill-being and accepting emotional well-being as a non-reimbursable by-product of other outcomes. These suggestions represent the participants focus to work within the current medical and reimbursement system. However, because of the emphasis the participants and LELQ Model put on positive well-being it is important that language is identified to explicitly support this goal, rather than accept well-being as a secondary outcome. As several of the participants suggested, identifying appropriate reimbursable language within the current healthcare system is essential for application of the LELQ Model to practice.

Fortunately, current Medicare guidelines include language that aligns with the LELQ Models outcomes. Specifically, Chapter 15-220.2 Section B. Reasonable and Necessary states:

There must be an expectation that the patient's condition will improve significantly in a reasonable (and generally predictable) period of time, or the services must be necessary for the establishment of a safe and effective maintenance program required in connection with a specific disease state. In the case of a progressive degenerative disease, service may be intermittently necessary to determine the need for assistive equipment and/or establish a program to maximize function. (Medicare Benefit Policy, 2010, pp. 171-172)

This statement suggests that services occupational therapy practitioners can receive reimbursement related to maximizing function for LTC residents' with ADRD because these services are reasonable and necessary. As the expert practitioners and LELQ Model assert

maximizing function involves all three quality of life domains including functional competence and emotional well-being. Additionally, Chapter 15-220.2 Section C. Rehabilitative Services states

The fact that full or partial recovery is not possible does not necessarily mean that skilled therapy is not needed to improve the patient's condition. In the case of a progressive degenerative disease, for example, service may be intermittently necessary to determine the need for assistive equipment and establish a program to maximize function. (Medicare Benefit Policy, 2010, p. 172)

Again this statement supports occupational therapists work with LTC residents with ADRD by contending that reimbursement rehabilitative services do not require recovery of function or skill but instead need to demonstrate maximization of function.

As it seems, it is not only the health care system acting as a barrier to reimbursement but also the learning needs of health care professionals (Murray & Boyd, 2009). Several of the expert practitioners are aware of this language and use it to support their work with LTC residents with ADRD, however this is not the norm in practice. Instead, practitioners discussed the higher prevalence of uninformed practicing occupational therapists. Therefore, it seems that currently the largest barrier to reimbursement for the LELQ Model is not the health care system but rather the lack of education of professionals.

Guided by the LELQ Model, occupational therapy practitioners can begin to educate other health professionals on the potential LTC residents with ADRD have for maximizing function through reducing the effects of environmental channeling and how to gain reimbursement for it. In regards to intervening with the social environment, what participants deemed most important for this population, Medicare guidelines support the need to educate caregivers on treatment and care for residents (Medicare Benefit Policy, 2010). Chapter 15-220.2 Section C states covered rehabilitative services include "Patient and family training to augment



rehabilitative treatment or establish a maintenance program. Education of staff and family should be ongoing through treatment and instructions may have to be modified intermittently if the patient's status changes" (Medicare Benefit Policy, 2010, p. 172). This statement supports occupational therapists intervention at the social environment level to support the care of LTC residents with ADRD. However, where the potential hang up may be is with providing objective measurable outcomes of the LELQ domain emotional well-being or demonstrating how well-being supports the goal of maximizing function as stated in the Medicare guidelines.

Each of the personhood traits proposed earlier are observable and potentially measurable, however no standardized outcome measures specifically address the traits. Tools such as the Observed Emotion Rating Scale (Lawton, Van Haitsma, & Klapper, 1999), observational or informant rated measures of agitation (Jiska Cohen-Mansfield, 1996), or measures of choice and control such as the Duncan Choice Index (Duncan-Myers & Huebner, 2000), among many others could be used to measure specific aspects of a residents' well-being. However using several measures to understand the whole picture of residents' well-being is time consuming and unmanageable in practice. Instead, development of a quick stream-lined measure that practitioners could use to look at all four of the personhood characteristics would be highly advantageous for the LELQ Model's use in practice.

### **Potential Constraints**

The purpose of this study was to understand expert occupational therapists views on best practice for LTC residents with ADRD and how their perceptions aligned with and thereby confirmed, or disconfirmed the LELQ Model. Even though these six practitioners confirmed the model, we cannot assume that most occupational therapists in LTC would resonate with this model to the extent that our participants did, particularly because they were identified as experts

in the field. Because of use of extreme case sampling and a small number of participants, the study's results may not be representative of all LTC occupational therapists. However, this study's goal was to learn from expertise of leaders in this field to further advance the LELQ Model, endorsing the restricted sample.

Additionally, the study could be perceived as being limited by the extent to which the study was democratic, a key aspect of action research. However, participants were asked for their input on discussion topics and meeting organization on each subsequent phase, while the design of the study including amount and format of data collection sessions was predetermined by the academic research team.

Finally, there was considerable emotional and intellectual investment by the academic research team in confirmation of the model. While this investment might be construed by some as a limitation, our knowledge, understanding of, and commitment to the LELQ Model were the very criteria and characteristics that made us well suited to conduct this study; they reflect the four kinds of knowledge Heron and Reason (1997) highlight as ontological to this participatory paradigm and selected action research methodology. However in order to optimize our open-mindedness to new constructions, understandings, descriptions and explanations, and simultaneously satisfying the important tenets of the participatory paradigm of inquiry, we wanted to understand the expert practitioners' perspective on practice prior to presenting the model, went out of our way to identify areas of discrepancies or disconfirmation and used extensive member and peer checking. Furthermore, because the participants knew the purpose of the study their perceptions may be construed as skewed by some, but once again their level of expertise is precisely what was needed to further confirm or disconfirm the model.

## **Conclusion**

This study aimed to begin to bridge the gap between theory and practice in regards to the Lived Environment and Life Quality Model. Through engagement with expert occupational therapy practitioners, the concepts of functional competence and emotional well-being, and the connections they have to the other domains in the LELQ Model, were largely confirmed.

What was not expected from this research was the profound respect and optimism the expert practitioners had for LTC residents with ADRD. Participants' stories and descriptions of their work were enclosed with utter respect for the residents as an individual and occupational being. The participants' stories showed their belief in the residents' abilities even when others did not. As a result of these positive beliefs, residents often experienced positive outcomes in health, functioning and well-being. By contrast, the participants' stories in which the resident experienced poor quality of life were often a result of staff's limited knowledge and pessimistic beliefs about residents' abilities, and lack of attention or concern for residents' personhood.

The LELQ Model began to act as a unifying language in which participants were able to better describe their work, including the importance of functional competence, well-being and the social environment. While these expert practitioners were already using many of the concepts from the LELQ Model and easily integrate the language of the model into their descriptions, the model's language may prove to be useful for explaining occupational therapy practice to other health professionals as well as for guiding new or less experienced occupational therapy practitioners' work with LTC residents with ADRD.

In order to guide occupational therapists working with LTC residents with ADRD, the LELQ model requires further refinement and application to practice. The domain of functional

competence needs to be further researched to identify effects on physical health. Doing so may promote use of the LELQ Model if it is shown to reduce medical costs due to physical health improvements resulting in decreased hospitalization. Additionally, the domain of emotional well-being, needs to be expanded to include features of personhood including: experiences of competence, autonomy, relatedness, and contentment. Explication of these personhood characteristics in the model will encourage balanced attention for all personhood traits relevant to persons with ADRD by occupational therapy practitioners working in LTC facilities, ultimately optimizing quality of life. Finally, more research is needed on the effects of environmental channeling and residents' potential for reversal of lost function to encourage and support occupational therapy interventions focused on the social environment. Further refinement and application of the LELQ Model can provide occupational therapy practitioners working in LTC with residents with ADRD a guide to understanding how the environment influences residents' quality of life, including residents functional competence and well-being, and ways to promote a positive environmental press for improved life quality.

## CHAPTER 5: SELF-REFLECTIONS

I would be mistaken to suggest that I engaged in this research with no predispositions. Instead it is through identification of these predispositions that trustworthiness of my interpretations of the research is reached (Mauthner & Doucet, 2003). As stated in the methodology section, data analysis was based on the theoretical assumptions of a participatory inquiry paradigm. This shaped the way in which data were analyzed and interpreted. Beyond this research paradigm, my own personal beliefs, values and assumptions have shaped the way in which I have engaged in this research and positioned me well to do this research.

My path of deciding to become an occupational therapist and arriving at Colorado State University seemed obvious. My love of puzzles and problem-solving matched with my love of working with people, particularly those in need, directed to me a career in which I served people by facilitating the solving of their individual puzzle or predicament. Occupational therapy was an obvious career choice based on the holistic and individualized approach used.

I can't say engaging in research was a goal of mine upon entering the occupational therapy program. However, in search of the richest experience in my two years at Colorado State University, I swallowed my fear of research and pursued this thesis work with Dr. Wendy Wood. I was particularly drawn to this research project as it seemed the LELQ model provided the answer to the puzzle of reaching quality of life for LTC residents with ADRD. Looking back, I was greatly optimistic about the simplicity of implementing the LELQ Model in practice. While I still remain optimistic, this project brought the reality of the problems in LTC back into focus, and has taught me a lot not only about the research process but has also shaped my beliefs and assumptions about the culture of LTC facilities and the effect this culture has on the quality of life in residents with ADRD.

Learning the research process was something I expected. I have become comfortable with the iterative process of qualitative data analysis including open and axial coding, and using exclusive codes. Action research feels familiar, and the benefits of it stand out in this type of research. Additionally, I expected to learn the concepts at hand. Language such as excess disability, retained capacities, emotional well-being and environmental stress just roll off my tongue. I find myself integrating these concepts into my broader occupational therapy studies and wanting to educate peers about the benefits. What I didn't expect from this process was the development of such a tight knit cohesive team and a growing personal passion for change in the long term care system.

The experience I have had would not be the same if it weren't for my fellow teammates. Through this process I have learned a lot about my own personal strengths and weaknesses, including my tendency to overstress and be less flexible with deadlines. My team supported these needs and often offered guidance and reinforcement. While each teammate functions in a unique way, we all have something to offer. By relying on each other for intellectual and emotional support, we established a high functioning supportive work group.

Through participating in this project I have grown passionate about the subject of quality of life in LTC residents' with ADRD. Prior to engaging with the participants, I associated negative quality of life with a combination of the unyielding physical environment, deterioration of the disease and strict guidelines staff were required to follow. What surprised me was that participants attributed negative quality of life not to the strict physical environment or guidelines given to staff, instead quality of life was influenced by the beliefs and assumptions held by staff, family or residents' themselves.

The amount of stigma that exists in not just moving to a residential facility but also with having dementia was surprising. I had not previously realized that the diagnosis of dementia led to such assumptions or stereotypes of functioning. I, too, had the belief that people with ADRD slowly lose abilities but not that a diagnosis of ADRD meant all hope was lost. The amount of marginalization and under-expectations that exist with this population is alarming. As an occupational therapy student and compassionate person, my goal is to optimize performance and participation in all populations; a concept easily applied to this population. However, I think even I had too low of expectations for not only the residents with ADRD, but also for the staff that works with them.

My previous assumption that staff are doing all that they can within such a strict healthcare system has changed. Through this research, I realized that much more can be done even through much smaller changes, such as promoting use of retained capacities and supporting residents' personhood. Staff should be expected to not only keep residents' safe, healthy and dry but also to treat them as respected individuals with the ability to engage at every level of functioning. With the right social support, these residents can experience well-being and engage in activities throughout the day using the skills they still have. Residents' diagnosis of ADRD is not the only reason they experience poor quality of life, it is also the lack of understanding and support in their environment.

Prior to this project, I agreed with much of society that nursing homes and other long term care facilities are a last resort; that people move there only when they are no longer safe at home. I came to the realization that long term care facilities do not have to be a negative transition, or sacrifice of control over one's life. Instead long term care facilities have the potential to provide people with dementia the support and opportunity to flourish, more so than

they would in their own homes. With additional research, education and support from the larger long term community, nursing homes and assisted living facilities could allow for the same or better sense of health and quality of life as a person experiences living in the community.

Unfortunately, I must realize that not all practitioners or health professions know or recognize this perspective. The LELQ Model and our research participants offer strategies indicative of best practice, not typical practice. What now seems obvious to me is not as obvious to occupational therapists that have been practicing with this population for a number of years. These changes won't happen overnight. I suspect, instead, they will be met with some resistance and obstinacy.

While I knew I would learn and grow from the experience, I never would have predicted the magnitude and breadth of what I would gain. I am nervous and excited about entering the field of long term care as a practitioner because there is a long, hard road of change ahead of us. However, I am grateful to have had this experience and knowledge to build from, and have gained the same sense of respect and optimism for people with ADRD as the participants displayed. I feel armed and ready to educate others and be part of the exciting change ahead.



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## APPENDIX A: INTERVIEW/FOCUS GROUP GUIDES

### Interview #1 Guide

#### **Purpose of Interview**

To gather information from expert practitioners of best-practice strategies for working with people with dementia in long-term care facilities in order to inform our understanding of what expert practitioners are using and how they are making decisions related to our research questions. Reminder: any missed details we can go back to during the final interview.

#### **Introduction (10 MIN MAX)**

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 (10 MIN MAX)**

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 (45 MIN MAX)**

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 (25 MIN MAX)**

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 wellbeing

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 (15 MIN MAX)**

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 (5 MIN MAX)**

- 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.”

- \*Send follow-up thank you email with information about next interview session and confirm availability.\*

### **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

Your thoughts about future engagement in the project

APPENDIX B: OPEN CODES AND DEFINITIONS

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-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-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.
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-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
QL- Other	Other quality of life indicators not represented in the LELQ Model
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-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
QL-Long Term - Environmental Channeling	The composite experience of occupationally deadening moments
QL-Long Term- Environmental awakening	The composite experiences of occupationally enlivening moments over time
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
QL-RC-Outcomes-optimal functioning	Use of retained capacities within occupational engagement; passage reflects concern of functional capacities of person with dementia
QL-RC-Outcomes-ED	Excess Disability: a reversible deficit due to the environment rather than the disease itself
QL-RC-Outcomes-optimal health	Improved physical health is reached through the use of retained capacities and avoidance of excess disability
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
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-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-other	Areas of time use that are outside of the scope of the LELQ model and may provide modifications to the model.

APPENDIX C: MATRICIES USED IN ANALYSIS

**Retained Capacities**

	A: QL-RC-Outcomes	B: ED	C: optimal functioning	D: optimal health	E: QL-RC-Practitioner Perspectives
1: LE-CM-Physical	0	2	4	0	1
2: LE-CM-Social	1	5	5	2	1
3: LE-PWD-Occupational history and profile	0	5	1	0	2
4: LE-PWD-preferences-needs	3	3	6	0	4
5: LE-PWD-RC-assessments	2	6	3	0	12
6: QL-EW- Emotional Ill-being	1	9	1	1	1
7: QL-EW-lack of personhood	0	2	0	0	0
8: QL-EW-negative affect	1	5	0	1	1
9: QL-EW-Emotional Well-being	1	1	6	2	3
10: QL-EW-Personhood	1	1	4	1	17
11: QL-EW-positive affect	2	0	6	2	3
12: QL-EW-Practitioner's Perspectives	2	0	8	0	14
13: QL-TU-Explicit	1	0	3	3	2
14: QL-TU-Implicit Occupational Disengagement	1	11	1	0	1
15: QL-TU-Implicit Occupational Engagement	2	1	12	0	7
16: QL-TU-other	0	1	0	0	1



### Emotional Well-being

	A: QL-EW- Emotional Ill-being	B: QL-EW- lack of personhood	C: QL- EW- negative affect	D: QL-EW- Emotional Well-being	E: QL-EW- Personhood	F: QL- EW- positive affect	G: QL-EW- Practitioner's Perspectives
1: LE-CM-Physical	0	1	2	0	3	0	5
2: LE-CM-Social	6	1	4	5	8	1	6
3: LE-PWD- Occupational history and profile	6	3	4	2	6	1	6
4: LE-PWD- preferences-needs	1	1	1	8	4	2	8
5: LE-PWD-RC- assessments	3	0	3	2	3	0	4
6: QL-RC-Outcomes	1	0	1	1	1	2	2
7: ED	9	2	5	1	1	0	0
8: optimal functioning	1	0	0	6	4	6	8
9: optimal health	1	0	1	2	1	2	0
10: QL-RC- Practitioner Perspectives	1	0	1	3	17	3	14
11: QL-TU-Explicit	2	0	5	3	4	5	7
12: QL-TU-Implicit Occupational Disengagement	7	1	3	0	0	0	0
13: QL-TU-Implicit Occupational Engagement	0	0	0	12	4	15	6
14: QL-TU-other	1	0	1	0	0	0	1

### Time Dimensions

	A: LE-EP-Alive	B: LE-EP-Alive-just right fit	C: LE-EP-Dead	D: LE-EP-Dead-not right fit	E: QL-Long Term - Environmental Channeling	F: QL-Long Term-Environmental awakening
1: QL-EW-Emotional Ill-being	0	3	7	7	10	1
2: QL-EW-lack of personhood	0	1	0	0	2	2
3: QL-EW-negative affect	3	0	3	2	5	2
4: QL-EW-Emotional Well-being	10	12	3	0	0	15
5: QL-EW-Personhood	11	16	6	4	4	11
6: QL-EW-positive affect	7	11	1	1	1	10
7: QL-EW-Practitioner's Perspectives	10	14	6	3	2	8
8: QL-RC-Outcomes	1	4	0	0	1	2
9: ED	2	3	8	13	16	3
10: optimal functioning	8	15	1	1	0	10
11: optimal health	2	0	0	0	0	2
12: QL-RC-Practitioner Perspectives	7	10	2	0	1	4