THESIS

DEVELOPMENT OF A PROCESS MODEL WITH DEMENTIA SPECIFIC STRATEGIES TO

OPTIMIZE QUALITY OF LIFE FOR LONG TERM CARE RESIDENTS

Submitted by

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ABSTRACT

DEVELOPMENT OF A PROCESS MODEL WITH DEMENTIA SPECIFIC STRATEGIES TO

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With a thorough review of 156 studies encapsulated in a special issue of the *American Journal of Occupational Therapy* (AJOT) on occupational therapy services for people with Alzheimer's disease and related dementias (ADRD) (Padilla, 2011), there was no commonly shared rationale or approach for occupational therapists working with this population. This study's purpose was to further the Lived Environment Life Quality (LELQ) Model and complement it with the creation of a process 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 three occupational therapy process domains of assessment, intervention, and outcomes. Several key themes that emerged from this qualitative research process include functioning of the facility, being an occupational therapy detective and problem solver, education, prevention, occupational engagement, occupational performance, and personal factors. Results also indicated that the expert occupational therapists' conceptualizations aligned with concepts embedded in the LELQ Model as well as with the three occupational therapy process domains. The themes and the alignment with the LELQ Model facilitated the development of the process model. Overall, findings suggested that there is a shared rationale for the occupational therapy process in long term care (LTC) facilities when working with persons with dementia. Furthermore, these findings guide the clinical reasoning of occupational therapists as they plan the specific actions or approaches that they take from initiation through

termination of services. However, further research is needed in order to confirm, revise, and

implement the process model in practice.

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CHAPTER ONE: INTRODUCTION TO THE STUDY

April, my friend Andy's grandmother, was a very active, outgoing woman who was an amazing artist. Unfortunately, she was diagnosed with Alzheimer's disease in her early 70s. Due to the progression of the dementia disease, April was admitted to a long term care (LTC) facility in her hometown. Andy helped her move to the facility with all of her art supplies and would visit as often as possible. In the early stage of the dementia disease, April still had great potential to do the things that brought her joy and satisfaction in her life; she could direct her own activities and most importantly engage in her artwork. However, as the disease progressed and her cognitive capacities dwindled, she found herself having less motivation and lost her interest in art altogether. As time continued, Andy began to notice that April was not performing anything that used to inspire her or bring her joy. Instead, she would just lie in bed, watch television, and wait for Andy to come visit. I rarely observed April's caregivers encourage her to pursue past or new occupations. Being active everyday was important to April, but with the progression of her disease and little help from her caregivers she would tire more quickly, and this made it difficult for her to maintain her daily routines. Eventually, April would only leave her room for food and sometimes even this was a challenge. After a year in the facility, she fell asleep one night and never woke up. I once heard Andy speaking to one of the nurses at the facility shortly after April died, saying the last year of her life was not one April wanted to live.

April's story emphasizes the impact and toll not only of the progression of a degenerative dementia such as Alzheimer's disease, but also of how a person's living environment can contribute to decline. People with dementia can be directed into lower quality of life pathways for various reasons. In April's case, she would have loved to maintain her passion of art until her

dying day, but with the constant negative transactions of environmental and disease barriers, she lived the last year of her life in a way she would have never previously imagined nor desired.

The need to optimize the quality of life of residents with dementia in LTC facilities is crucial if stories such as April's are to cease. Occupational therapists are integral members of health care teams whose specific skills and expertise can foster people's performance capacities and participation in everyday contexts across the lifespan. Related specifically to dementia, therefore, Hasselkus (2011) proposed that "in progressive illnesses such as dementia, we, as occupational therapists, try to help people hold onto some semblance of their occupational definition of themselves and their days as they journey more and more into the disability and their bodies" (p. 136). However, with a thorough review of 156 studies encapsulated in a special issue of the *American Journal of Occupational Therapy* (AJOT) on occupational therapy related services for people with Alzheimer's disease and related dementias (ADRD) (Padilla, 2011), there was no commonly shared rationale or approach for occupational therapists working with this population. Given this gap, a fundamental premise of my thesis is as follows: if occupational therapists are to help optimize the quality of life of LTC residents with dementia by helping them hold onto their occupational definition of themselves as the disease progresses, then they need both a conceptual practice model and a related process model to guide their practice.

Thus, the purpose of my thesis is to develop a process model that accompanies the Lived Environment Life Quality (LELQ) Model, a conceptual practice model. The LELQ Model was designed to help occupational therapists optimize the quality of life of LTC residents with dementia. In this chapter, I first define conceptual practice and process models. I next describe

the LELQ Model and the theory building process and how that associates with my research, and then I present my study's research question.

Conceptual Practice Models and Process Models

Conceptual practice models help professionals understand the complexity of occupational engagement and structure their critical thinking processes in order to provide clients with the highest quality interventions possible. More specifically, conceptual practice models address the "what" a practitioner is to attend to. Along these lines, Kielhofner (2009) described a conceptual model as a representation of a complex phenomenon or process, designed to establish order among abstract concepts and provide a simplified framework for thinking about and describing the phenomena of interest. Conceptual models are significant in their capacities to describe the organization among parts of some empirical phenomena and to identify abstract features and associations that apply to a whole class of phenomena. Krefting (1985) stated that conceptual practice models include a philosophical base, key concepts and their transactions, and an application for clinical practice. Furthermore, utilization of a conceptual model in practice is intended to improve client care and guide treatment; models may also support communication of complex ideas and promote professionalism and unity across a diversity of practice settings. Examples in the occupational therapy literature of conceptual models include the Canadian Model of Occupational Performance (Law, Baptiste, McColl, Opzoomer, Polatajko, & Pollock, 1990), the Person-Environment-Occupation Model (Law, Cooper, Strong, Stewart, Rigby, & Letts, 1996) and the Model of Human Occupation (Kielhofner, 2002). Conceptual models are very valuable because they highlight the key considerations (the environment, the person with dementia, or quality of life) to which a practitioner must attend. In contrast, the guiding decisions for occupational therapy practice are outlined within a process model.

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Process models in occupational therapy have been used to guide the clinical reasoning of practitioners as they plan the specific actions or approaches that they take from initiation through termination of services. More specifically, process models tells practitioners the "how or how to". One process model within the occupational therapy literature is embedded within the "Occupational Therapy Practice Framework: Domain and Process" (OTPF) (American Occupational Therapy Association, 2008). That model is the Framework Collaborative Process Model, which illustrates the client-practitioner interactive relationship and interactive nature of the service delivery process. Within this model there are three broad sections that describe occupational service delivery: evaluation, intervention, and outcomes. Another example of a prevalent process model within the occupational therapy literature is the Occupational Performance Process Model (OPPM) (Craik, 2003). This process model is broken up into seven distinct stages that focus on providing a structured process of assessment, intervention, and evaluation. In addition, the OPPM recognizes the importance of collaborative, client-centered relationships and the importance of identifying theoretical perspectives to inform practice.

To make the distinction of a conceptual model and process model clearer, I will use a metaphor. I like to use metaphors for clarification because it helps me make a comparison between two different things that have an important characteristic in common. In regards to conceptual models and process models, I am relating them to maps. For example, there are overarching maps such as a map of the United States, which serve to show many locations. Then there are specific maps with given directions to a desired location. The overarching, broader map is like a conceptual model used in practice and the more specific with designated directions, such as a MapQuest search, is the process model. The Domain aspect of the OTPF is therefore, an overarching map because it serves as the key *concepts* an occupational therapist must consider

given a situation with a client. The process, previously described above, is like the results of a MapQuest search because it provides the associated *guiding steps* for the occupational therapist to employ with a given client.

The Lived Environment and Life Quality Model

The LELQ Model (Figure 1) was derived from and based upon a wide body of research pertaining to environmental influences on dementia-specific elements of quality of life. My comprehension and perception of the model has been influenced by research in occupational therapy and occupational science (Hasselkus, 2011; Wood, Womack, & Hooper, 2009), rehabilitation science (Brandt & Pope, 1997), and an ecological model of aging and classic works (Bronfenbrenner, 1977; Lawton, 1989; Lawton & Nahemow, 1973). Altogether, these influences highlight the significance of an environmental viewpoint for understanding the occupational lives of people affected by ADRD.

 The LELQ Model was designed to describe environmental influences of the overall life quality of LTC residents with dementia. As next described, there are two primary domains of this model: one, the lived environment, which is composed of the subdomains of the caregiving microsystem, the person with dementia, and an emergent environmental press; and two, quality of life, which includes subdomains related to time use, functional competence, and relative well-being. The model also approaches these domains and subdomains from two temporal perspectives; the here and now and progression over time.
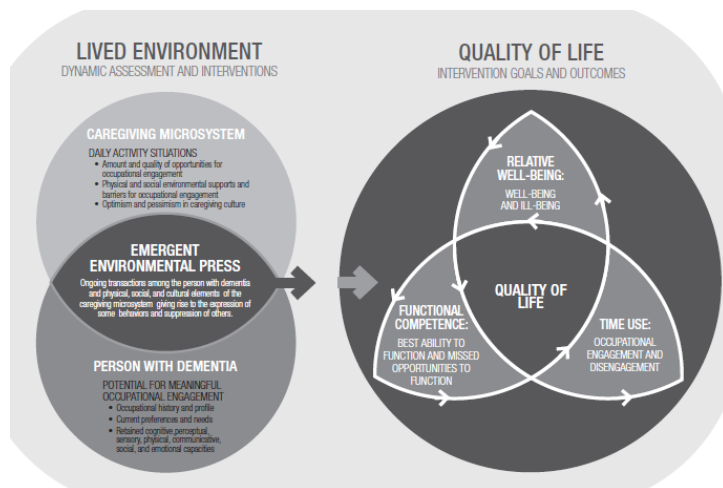
Figure 1: The LELQ Conceptual Model (from, Wood 2013)

Lived Environment

As shown in Figure 1, the lived environment addresses transactions among the systems of care experienced by LTC residents with dementia (the upper circle) and who those residents are as occupational beings (the bottom circle). The degree of overlap of these circles influences the fit with the person with dementia and his or her participation within the environment. For instance, substantial overlap of the circles conveys congruence between the environment that is supporting the person with dementia. Little overlap of the circles conveys a lack of customization or individualization to that individual. As posed in the LELQ Model, when these circles are overlapped to a greater extent, then the environmental press of a particular activity situation is better accustomed to a particular individual. Therefore, this strong overlap demonstrates that the person with ADRD has some meanginful activity and participation in the present moment.

Referring back to April, the LTC facility in which she resided did not allow her or Andy to create an optimal combination of personal, social, and physical characteristics to help decrease her undesired behaviors; specifically, agitation. Instead, April's new home appeared very static

and dull as she often sat alone in her room and did not participate in any of the activity situations as none appealed to her. Accordingly, April's experience revealed little overlap of the lived environment circles, as she experienced a lack of individualization in her care.

Caregiving microsystem. Bronfenbrenner (1977) defined an environmental microsystem as "the face-to-face setting in which certain physical, social, and symbolic features interact both to invite and to inhibit which interactions or activities are likely to occur" (p.15). Bronfenbrenner's definition of the microsystem fosters a linkage to the LELQ Model as the caregiving microsystem is portrayed. That is, in the LELQ Model the caregiving microsystem is understood to consist of the amount and quality of opportunities for occupational engagement that are provided to LTC residents with dementia, physical and social environmental supports of their engagement in those opportunities, and optimism and pessimism within the caregiving culture of the LTC facility.

The amount and quality of opportunities for occupational engagement offered to persons with ADRD in LTC facilities are both subjective and objective. Subjective can be illustrated when the caregiving environment takes the person's own view and feelings into consideration for the planning of the person's care. Unfortunately with April, subjective care was not apparent as she did not participate in any activities, as they were inadequate and did not offer quality experiences for her. The objective aspect can be specified relative to context. For instance, "an objective aspect of quality of life might be indicated when an in-service training program at a LTC facility emphasized sensitivity and individual care" (Lawton, Van Haitsma, Perkinson, & Ruckdeschel, 2000, p. 96). Using the information acquired through the in-service (the objective component), a staff member now has the knowledge to better serve a client and truly individualize their care. Referring back to April, by building the rapport with her, a staff member

such as a nurse, could have learned by asking April, or observing her behavior patterns, to discover that she was not a morning person and preferred to have breakfast later on. By simply making this change in her morning routine, April's agitated behaviors could have decreased, making her more willing to participate in other activity situations in the latter part of the day. The physical and social environment can support the person with dementia's engagement in opportunities. The social environment refers to the interactions of the people present within the LTC facility. An illustration of a supportive social environment may be when two residents who both fought in the Vietnam War are encouraged to go in a common room and chat with one another about their shared experiences. The built environment and the physical objects and their qualities refer to the LTC facility in general. In the previous Vietnam War example where the residents were able to share their experiences with one another, the access to a common room is an illustration of the built environment. However, it is not to be forgotten that many facilities may not have built, physical environments that are supportive for the residents and their needs.

The person with dementia can experience optimism and/or pessimism within the caregiving culture of the LTC facility. For instance Wells and Dawson (2000) highlight the idea of an optimistic and pessimistic caregiving culture; "If there is a professional belief that persons with dementia will have a progressive loss of human abilities, cognitive and functional, based on the general description of dementia, patterns of caregiving may follow accordingly" (p. 164). Thus, professionals may perform activities for, instead of with, the person with dementia, therefore increasing risk of a compromised quality of life. However, if certain abilities and chosen occupations are encouraged within the caregiving culture, persons with dementia may maintain a desired quality of life. To further describe the necessary caregiving culture, Kitwood (1997) emphasized 13 requirements (Table 1) of caregivers when working with persons with

dementia to reach the substantial overlap of the previously discussed circles, in the LELQ Model,

which then conveys congruence between the environment that supports the person with

dementia.

Table 1

Caregiving Requirements

Term	Definition
Being present	Be psychologically available, be present in the situation
Recognition	Bring an open and unprejudiced attitude
Negotiation	Set aside all ready-made assumptions; dare to ask, consult, and listen
Collaboration	Allow space for the person with dementia to fully contribute to the action
Play	Access a free, creative way of being
Timalation	Be at ease with your own sensuality, as the person with dementia receives pleasure through the direct avenue of the senses
Celebration	Be open to joy, and thankful for the gift of life
Relaxation	Be able to freely stop active work, for a while, and to even stop planning; slow down and allow both mind and body a respite
Validation	Go beyond your own frame of reference in order to have an empathetic understanding of the person with dementia
Holding	Remain fully present, whatever the stress the situation may have,
Facilitation	Share in the creation of meaning and enable action to occur with the person with dementia
Creation	The creative action initiated by the person with dementia is seen and acknowledged , with a response
Giving	Accept whatever gift of kindness or support a person with dementia presents

Daily activity situations. The LELQ Model's focus with on caregiving microsystems

draws particular attention to the idea of daily activity situations. Wood, Harris, Snider, and

Patchel (2005) defined activity situations as "comprised of bouts of time that are readily

recognizable because they routinely happen at designated times of a day in specific facilities" (p.

123). Staff and administrators of the facilities determine the timeframes, the purpose, and the

form of these daily activity situations. Examples of daily activity situations in LTC facilities may

include meal or snack times in large dining rooms, television time, and music groups.

Furthermore, the caregiving requirements that Kitwood previously described illuminate what is needed to create an optimal caregiving microsystem, in which persons with dementia experience certain daily activity situations.

Person with dementia. Another subdomain within the lived environment of the LELQ Model is the person with dementia. In particular, the LELQ Model highlights the importance of the individual's occupational history and profile, current preferences and needs, and takes into consideration what the person with dementia still can do relating to their physical, cognitive, sensory, perceptual, and social capacities. Referring back to the Wells and Dawson quote in the previous section, it is evident that the capacities of an individual are integral for a person's quality of life outcome. Moreover, Wells and Dawson offered the idea that a caregiving approach focused on abilities will promote an individual's use of retained physical, cognitive, sensory, perceptual, and social capacities. Another aspect occupational therapists try to understand are people's occupational histories and profiles. That is, they take into consideration the persons education, vocations, interests, family and other valued relationships, values, beliefs, and spirituality: all characteristics that can influence motivations to engage in some occupations over others and that can give life meaning (American Occupational Therapy Association (AOTA), 2008). The LELQ Model highlights the importance of these characteristics of the person with dementia in order to facilitate optimal outcomes. Taking consideration of persons with dementia even further, Lawton, Van Haitsma, and Perkinson (2000) emphasized the need to understand that residents in LTC facilities are still people with a past, a present, and a future.

In April's circumstances, she was not given the opportunity to engage in what she had always loved and had a passion for, her artwork. Consequently, her needs, wants, and desires out of life diminished not only with the progressive disease but also with the scarcity of chances for

involvement. An essential contribution of an optimal quality of life is the connection of the previously mentioned characteristics of the person and emphasizing that time is utilized in an occupationally meaningful way (Wood, Womack, & Hooper, 2009).

Environmental press. In any context, physical, social, and interpersonal environmental stimuli interact to generate an environmental press (Lawton & Nahemow, 1973), which "serves to elicit or press toward the expression of some behaviors and suppression of others" (Wood, Womack, & Hooper 2009, p. 338). Indeed, Wood, Womack and Hooper (2009) found that activity situations in two Alzheimer's special care units had distinctive environmental presses; some supported the expression of positive behaviors among residents whereas others undermined expression of positive behaviors. Care practices that do not support or sustain the person's existing skills or provide activity opportunities that tap into the person's full range of skills and capacities suppresses that person's expression of positive behaviors. Again, the subjective and objective pieces need to be taken into account to help individualize care, thus supporting and sustaining a person's skills. Clarifying the environmental press concept even further, April would often be taken for television time right after lunch, and would then just doze off for several hours. However, referring back to the LELQ circles, if the television had been playing one of April's favorite past time shows, she may have maintained eye contact, demonstrating at least some level of engagement with the show and thus presenting a greater overlap of the circles. Both of these instances demonstrate how the environmental press can elicit more positive behaviors for persons with dementia or suppress them.

Furthermore, Lawton (1974) described the environmental press concept as fluctuating with time, as the environment is constantly shifting as well as an individual's need and competence. In relation to Lawton's idea with fluctuating time to the LELQ Model, we can see

how not only the person's behaviors can shift with time but also how the environment has an effect on those behaviors. To demonstrate this environmental shift and its impact on the individual, I refer back to April. April was taken to television time, and positive behaviors were suppressed as she was isolated in the room. However, let's say that a new staff member was hired and decided to take her to craft group instead on a regular basis after lunch. April's expression of positive behaviors could have increased both in the moment and possibly over time as well assuming she continued frequently to participate in crafts. This example illustrates the idea of environmental press again, but most importantly, highlights how the environment, the new staff member taking her to the craft room, can alter momentarily, the staff member's quick judgment to take her to the craft room, thus resulting in a positive impact of the temporal dimensions for the persons with dementia. The hiring of a new staff member in April's scenario may have proven to be influential in April's well-being over time.

In summary, the first portion of the model, the lived environment, can be enlivening for an individual over a period of time, thereby positively affecting his or her quality of life. If people with dementia are living in an environment that understands and is responsive to their needs, wants, and desires, then they will undoubtedly use their time more effectively by maintaining engagement in desired occupations. People with dementia will also use their retained capacities within those occupations, and have an overall positive emotional experience within the given LTC unit environment. However, we learned that this is not always the case. People with dementia that are admitted into unreceptive environments in which caregivers do not value their preferences or needs or existing capacities, may experience, in the language of the LELQ Model, an occupationally deadening environmental press over time.

Quality of Life

The life quality portion of the LELQ Model is influenced by the lived environment that is made up of the caregiving microsystem, the environmental press, and the person with dementia. The transaction of the three elements of the lived environment generates the life quality portion, which is composed of people's time use, their functional competence, as well as their relative well-being.

Time use. According to Wood, Womack, and Hooper (2009), it is crucial that LTC residents with dementia be able to occupy time in meaningful and purposeful occupations throughout the day. Christiansen (2010) further described meaning in occupations as related to time by stating, "People understand the meaning of their lives by considering their occupations as part of their life story, and these occupations gain meaning over time by becoming part of an individual's unfolding autobiography or personal narrative" (p. 13). In order to fully understand a person's time use and the meaning and purpose of a situation, it is important to take the time to learn about a person's life history. As Hasselkus posed, afterall, "Out of a person's stories about the past comes the meaning of the present" (p. 10). April loved artwork type activities, which I learned about from her past by talking with Andy and looking at the artwork displayed in her room. By incorporating art back into her life, meaning would have once again emerged. I constantly think to myself how easy it would have been to bring in an art magazine or book for her to look at the pictures to rekindle her art desire.

Therefore, the use of time refers to a person's engagement or disengagement during his or her day and night. How the person with dementia is occupying his or her time is assessed within this element of the model. Is the person occupationally engaged or disengaged within activities that use his or her time? Wood (2005) used the Activity in Context and Time (an

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occupational science measure of patterns of time use and emotional well-being in context of specific activity situations) to describe occupational engagement and disengagement of LTC residents. Occupational engagement was defined by Wood and classified into four observable units: 1) engaged gaze, a very basic form of environmental interaction 2) functional mobility, demonstrating health and fitness 3) participation in conversation, which shows some engagement in a relationship and 4) participation in activity, showing full occupational engagement. Furthermore, occupational engagement may refer to "people doing occupations in a manner that fully involves their effort, drive, and attention" (Christiansen, 2010, p. 8). However, the opposite behavior can occur as well with the person with dementia. Wood described this opposing behavior as occupational disengagement, where the person with dementia is withdrawn of social and environmental interactions. For example, the person with dementia may display agitated, aggressive, or null like symptoms towards their caregivers when they are occupationally disengaged.

In April's scenario, she spent the majority of her time in her bedroom, rarely coming out to occupy her time in a meaningful way, such as doing her artwork. Instead, she often sat in the corner of her room with the television on and her head down in her lap. In order to occupy the person with dementia's time, especially as the disease progresses and symptoms worsen, the need to provide opportunities in order to prevent degradation in the disease progression is critical!

Functional competence.   This subdomain assesses whether a person is able to elicit a desired functional expression. Elicited expressions can be described as a person putting his or her capacities to use, which increases the likelihood of preservation over time. For example, imagine that a LTC resident is very organized and structured, as evident in his bedroom. Yet this same

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resident dislikes participating in activities offered throughout the day. To allow that person to participate in an activity they enjoy, while preserving certain capacities such as process skills, a therapist may have that person clean up and organize materials after certain activities. However, missed opportunities to preserve capacities through meaningful participation can occur and are described as *environmental channeling*. To be more specific, environmental channeling occurs when over time, the environment influences daily time use patterns of a LTC resident with dementia in such a way that exacerbates excess disability, thereby hastening the decline of his or her functional abilities, health, and quality of life. Furthermore, Wood, Towers, and Malchow (2000) state that two requirements are necessary for environmental channeling to be going on; "a relatively static environment that offers few opportunities for action coupled with duration of time in that environment" (p.13). For example, if some of the only activities that are offered in LTC facilities are big social groups and the person with dementia is an introverted person, then that individual may end up feeling uninvolved in his or her own life. April often sat in her room alone, as she did not like large group activities. If she had been given an opportunity to be in a private room with her art supplies, perhaps she and her granddaughter, Andy, would not have felt as if she had these missed opportunities that led to a degradation or environmental channeling in her quality of life over time.

My observations of April demonstrated the absence of using her abilities in everyday tasks. Often times, the caregivers would just come in the morning to get her ready for the day, not encouraging her to do things herself, or even assess what her abilities were capable of at that stage in the dementia disease. Wells and Dawson (2000) depict this example as a pessimistic care approach such as, "If professionals believe that there will be a progressive loss of human abilities based on general descriptions of dementia, patterns of caregiving may follow accordingly" (p.

164). Furthermore, by using this more pessimistic care approach, we then place the residents in a more vulnerable route for a compromised quality of life. However, if abilities are promoted, persons with dementia could function to capacity, which is an integral component of their quality of life as supported by Lawton (1994) and the LELQ Model.

Taking it even further, Wells, et al. (2000), stated, "Focusing on a person's abilities may prevent the emergence of excess disability" (p. 448). *Excess disability* is any capacity beyond that which can be accounted for by the dementia disease such as irreversible cognitive, physical, and affective impairments (Kahn, 1965). Thus to avoid excess disability and instead, enhance the abilities of people with dementia, it is necessary that care providers acquire knowledge of their remaining or retained capacities (Wells & Dawson, 2000). Therefore, the LELQ Model serves to provide a structure for critical thinking to occur by having a visual to guide the elements you should consider in caring for persons with ADRD. In favor of, high quality interventions may be developed and carried out for persons with dementia.

Relative well-being. This final quality of life domain refers to the spectrum of positive and negative affect experienced by the person with dementia residing in LTC facilities. Personhood is one factor that can impact a positive or negative affect. There are four separate characteristics of personhood that are embedded in the LELQ Model: *experiences of competence, autonomy, relatedness, and contentment* (Ryan & Deci, 2000; Kasser & Ryan, 1999). An experience of competence refers to a sense of success and confidence in daily activities. Autonomy involves the resident's ability to assert their control and will to influence their surroundings. Relatedness refers to the resident's sense of connection to others. This connection may involve the family, staff, or other residents and emphasizes love, belonging, and respect within the LTC environment. Lastly, contentment refers to the emotional responses as well as the

residents feeling states, and will be further described with apparent affect. These personhood characteristics are ultimately perceptions of the individual residents, but are generally observable behavior and can be influenced by environmental supports or barriers.

One of the desired outcomes of the LELQ Model is to create positive emotional experiences for the person with dementia ensuing in well-being. Hasselkus (2011) described the importance of a person's ability to engage in life's daily activities in order to achieve the state of emotional well-being. Furthermore, a person's apparent affect in the moment which can be positive, neutral, or negative, can come and go depending on internal and external situations (Lawton, Van Haitsma, and Perkinson, 2000). Drawing from Lawton et al's work, the LELQ Model characterizes positive emotional well-being of a person as involving experiences of interest, happiness, satisfaction and content, as well as appreciation for the moment and perhaps life in general. For instance, being able to be doing the doing you choose and continue that doing for as long as possible ensures these more positive emotional experiences.

Unfortunately, however, many people with dementia predominantly experience a sense of ill-being. With ill-being, a person often has more negative feelings of anxiousness, fear, hostility, depression, and boredom with any given situation (Kitwood, 1997). Referring back to April, emotional well-being could have been recognized and promoted. For example, an occupational therapist could have discovered during an intervention and family interaction that she loved to paint. The occupational therapist then could have taken April to a room setup with paint supplies after lunch instead of placing her in front of a television; as a result, the desired outcome of April exhibiting and experiencing positive affect may have occurred. As Hasselkus observed, "It is not so much what you create as what happens to you while you create it. It is the spirit of the experience of the occupation that moves one along in life's journey" (p. 94). Thus with April,

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pursuing her artwork throughout the dementia disease may have helped decrease negative

symptoms and increase her quality of life pathway.

It is important to remember that each individual is unique and thus will perform

differently from others as the dementia disease progresses. For instance, someone who has been

flexible and adaptive in life may compensate in ways that support occupational function, whereas

another person who was previously prone to anxiety or has fewer coping skills might have more

significant functional losses (Atchison and Dirette, 2012). According to Wood (2005), "The

environment also influences how extensively people with dementia use and maintain their

functional capacities in everyday activities. Hence, everyday behaviors and functional skills

influence quality of life, or how people experience and evaluate their life as gauged by a greater

balance of positive versus negative emotional experiences" (p. 123).

Progression Over Time

The temporal dimension of the LELQ model further elaborates on how the lived

environment influences the overall quality of life for persons with ADRD in LTC facilities

(Figure 2). This figure illustrates quality of life optimized, the natural disease progression,

quality of life degraded, and the impact of an effective environmental intervention. When the

circles of the shape displayed on the left side of the figure shows substantial overlap, then the

lived environment domain of the LELQ Model is providing an optimal fit between the

environment and the person with dementia, therefore, a positive environmental press is elicited.

Subsequently, the life quality portion of the LELQ Model is represented as an occupationally

enlivening experience for the person with dementia as their quality of life is optimized.

Contrary, when there is little overlap of the circles (shown on the bottom of the figure) then there

is conflict with the person with dementia and his or her environment, which then presses an

occupationally deadening experience onto the person with dementia. If these situations continue to occur with the progression of time, quality of life is ultimately degraded. However, with an effective environmental intervention put in place, this deadening progression can be altered to a more optimal position of an enlivening experience, thus impacting their quality of life more positively. To make this figure more explicit, I will highlight both an enlivening experience and a deadening experience for April.

When April was admitted into the LTC facility, the occupational therapist gathered information from Andy about April's daily routines and habits. With this information, the occupational therapist learned that April preferred to have breakfast at a later time, as she was not a morning person. The occupational therapist then forwarded this information onto the care staff so they would know to check in with April in the late morning for breakfast. When allowed to sleep in later, April was much more awake during the day and able to participate in activities that she enjoyed and found meaningful throughout her entire day. This situation is best represented by substantial overlap of the quality of life circles represented in figure 2.

Conversely, she was taken to the large dining hall in the morning for breakfast at 7 am, as staff had their own routines they followed. Being woken up so early agitated April to the point where she would yell at people whom she was a friend with at the table over breakfast. This example had a problematic impact on her behaviors, which ultimately began so early in the morning for not only April but the staff as well. As a result, there was little overlap of the circles for April's experience and therefore, the progression over time for April can be described as a detrimental impact on her quality of life, as no environmental intervention was put into place.
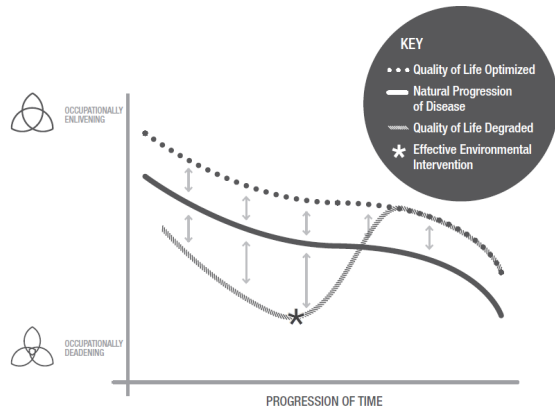
Figure 2: Progression over Time (from Wood, 2013)

In summary, the lived environment part of the LELQ Model is made up of the caregiving microsystem, the person with dementia, and the environmental press. The life quality portion of the model is made up of time use, functional competence, and relative well-being. The lived environment elements all transact with one another to either create an enlivening or deadening experience for the person with dementia's life quality that is best represented with the progression over time.

Utilization of Theory Building

As defined by Lynham (2000), "theory building is the ongoing process of producing, confirming, applying, and adapting theory;" additionally theory building is described as "the purposeful process or recurring cycle by which coherent descriptions, explanations, and representations of observed or experiences phenomena are generated, verified, and refined" (p. 223). Linking action research and theory building together, our research employed an action research approach and used theory building as an informative organizer and guide to the research team. For example, the LELQ model research was subjected into the 5 distinct phases of theory building (see figure 3): conceptual development, operationalization, application, confirmation or disconfirmation, and continuous refinement and development.
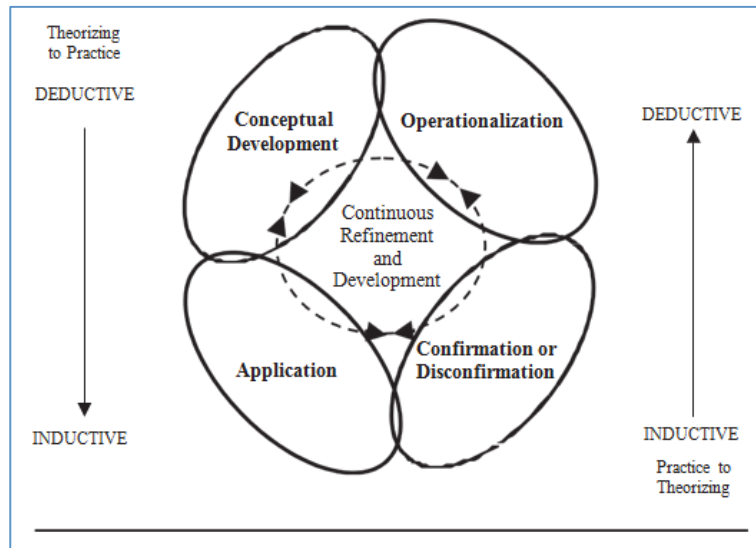
Figure 3: General Method of Theory-Building (from Lynham, 2002)

The conceptual development phase consists of an informed conceptual framework that provides an explanation of the dynamics of the phenomenon that is the focus of the theory. The operationalization phase creates the explicit connection between the conceptualization phase and practice. The confirmation or disconfirmation phase involves the planning and evaluation of the research agenda to either confirm or disconfirm the theoretical framework. The application of the theory enables further study, inquiry, and understanding of the theory in action. Lastly, the ongoing refinement and development phase ensures that theory in action is kept current and relevant, thus provides utility in the practical world (Lynham, 2002). Accordingly, with these five theory building phases defined, the LELQ model research agenda is apparent.

Purpose and Research Questions

In relationship to the theory building stages, my study emphasized the conceptualization and operationalization phases, as my purpose was to develop a process model for occupational therapists to use in LTC facilities with persons with dementia as guided by the LELQ Model. In addition, my study aimed to prepare both models for the application phase. Lynham (2002)

further describes the purpose of the application phase as such; "To enable the theorist to use the experience and learning from the real-world application of the theory to further inform, develop, and refine theory" (p. 233). This quote inspired me to use the experiences shared within the LELQ study to support my research during the creation of a more structured guide for occupational therapists to use in their practice when working with persons with dementia. Three questions were asked to better understand the dynamic interactions of occupational therapy practice:

- What implications do the practices of expert occupational therapists have for development of the assessment dimension of a process model?
- What implications do the practices of expert occupational therapists have for development of the intervention dimension of a process model?
- What implications do the practices of expert occupational therapists have for development of the dimension of outcomes for a process model?

My research was part of a larger in-depth collaborative action research study that generated findings critical for understanding theoretical and practical application for occupational therapists in LTC units where many of the residents are affected by dementia. As a future occupational therapist hoping to work in a LTC unit, the need to improve quality of life and care for persons with dementia is crucial. This need is also obligatory as an increase in the number of persons with dementia living in LTC facilities is anticipated as the baby boomers age (Alzheimer's Association, 2012).

CHAPTER TWO: METHODS

Research Approach

An action research approach was employed in the larger study upon which my master's thesis was based. One purpose of research is to provide people with knowledge and understanding that make a difference in their lives. As future health professionals and co-researchers in the LELQ Model study, the research team (described below) aimed to provide a transformational understanding of how to optimize quality of life in LTC facilities. Our hope was to provide people with new concepts, ideas, explanations, or interpretations that enable other health care professionals, in particular occupational therapists, to see the world in a new way when working in LTC facilities with persons with dementia and adjust their actions, if necessary, to better bring about quality of life outcomes. According to Meyer (2000b), "Action research is a process of systematic inquiry and its purpose is to provide health practitioners with new knowledge and understanding enabling them to improve professional practices or resolve significant problems in clinical and/or community settings" (p. 15). The defining elements of an action research approach are an orientation to change, reflection, participation, and a focus on understanding. Furthermore, Meyer (2000b) described change as "improving practices and behaviors by changing them;" reflection as "people thinking, reflecting, and/or theorizing about their own practices, behaviors, and situations;" participation as "people changing their own practices and behaviors, not those of others;" and lastly, understanding as "achieving clarity of understanding of the different perspectives and experiences of all involved within the study" (p. 8). Action research was ideal for the LELQ Model study as a major objective for the research was to be participatory in nature in order to effect change in LTC practices through a highly

reflective research process. Also, the study involved coherent reflective questioning with the participants to determine appropriate understanding of the phenomenon under study.

Participatory Inquiry Paradigm

Both the influence of action research and theory building strongly align with a participatory inquiry paradigm. This paradigm consists of both objective and subjective states. Each experience a person has is composed of something objective that a person is experiencing, perceiving, and relating with and also is composed of his or her feelings and reaction to the experience (Heron & Reason, 1997). The larger LELQ study exemplified this paradigm, as the overall aim was to understand the experiences of occupational therapists that work with persons with dementia in LTC facilities.

Additionally, this paradigm offers different ways of knowing; an experiential way of knowing, a presentational way of knowing, a propositional way of knowing, and a practical way of knowing (Heron & Reason, 1997). These four ways of knowing are found in the study by distinguishing the experiential knowledge base of the therapists, demonstrating experiences and processes through the LELQ Model, discussing theories behind the model, and encouraging the model to be implemented into practice in order to influence actual work.

Lastly, the aim of human flourishing is prominent with the participatory inquiry paradigm. Here, the methods must focus on benefiting humankind and enhance simple research to promote action (Heron & Reason, 1997). Both action research and theory building enabled the participants and the research team to collaborate in order to augment the effectiveness of the results and future application to practice.

Participants

Our study used extreme case sampling in order to learn from exceptional occurrences of the phenomena being examined. Snowball or chain case sampling method was also employed to help derive our participants for the research study. Creswell (2007) described this process of finding participants by identifying "cases of interest from people who know people who know what cases are information-rich" (p. 158). In other words, we identified occupational therapists that fit established sampling criteria to aid our search for other participants for their involvement in the study as they provided recommendations for other therapists that had met the sampling criteria. This snowball or chain approach was used until six expert occupational therapists were selected. These occupational therapists were recognized experts in the area of occupational therapy services for people with ADRD in LTC institutional settings. Inclusion criteria for these expert occupational therapists within the study were as follows: he or she authored credible publications on the topic of occupational therapy for people with ADRD in LTC facilities; or, were known through juried presentations and credible continuing education events; or, were subsequently recommended by well-known or established leaders in occupational therapy for people with ADRD. Exclusion criteria were that occupational therapists had less than five years of clinical experience working with ADRD. The occupational therapists in our study, all female registered occupational therapists, were dedicated to answering research questions aimed to evaluate, confirm or disconfirm, and improve the LELQ Model relating to their occupational therapy practice, Table 2 describes participant characteristics.

Table 2

Participant Characteristics

Participant	Place	Date of Cert.	Highest Degree	Current Role	Experience with Dementia
MM	Colorado	1984	BS	1 to 1 Consult	12 years
MH	Minnesota	1996	BS	Business Mentor Consult Program Development	15+ years
MVS	North Carolina	1977	BS	1 to 1 Mentor	29 years
KW	North Carolina	1989	BS	Business Consult Program Development Physical Design	18+ years
SH	Alabama	1996	BS	Mentor Consult	16 years
AC	North Carolina	2003	MS	1 to 1 Consult	10 years

Data Collection

My thesis was based on the primary LELQ action research data collected one year previously. This collection period enabled me to develop a process model to be utilized in LTC facilities by answering my focused research questions.

Data collection consisted of two individual semi-structured phone interviews and three focus groups, each group consisting of a mixture of the research participants (see Table 3, for phase one: purpose of interviews and focus groups). The research team consisted of the principal investigator (PI), three second year M.S. occupational therapy thesis students, and myself a first year occupational therapy (at the time of the collection) M.S. thesis student. Throughout the

entire research process involving the individual phone interviews or focus groups the research team consisting of the PI and the second year M.S. students were present; I was able to participate in the focus groups. All phone interviews and focus groups lasted 90 minutes, were audiotaped, and then individually transcribed by the research team for further analysis.

The first individual interviews served as a way to gather information about best practice strategies for working with people with dementia in LTC facilities in order to inform our understanding of what expert occupational therapists are using and how they are making decisions in their practice. To keep interviews focused on the topic at hand while allowing for freedom in answering questions and developing thoughts, a semi-structured interview guide was chosen by the research team. After these first interviews, the focus groups were conducted. The focus groups provided a means for discussing findings to date and collaborating to improve the LELQ Model to better its application to practice. Focus groups have an array of benefits for research in action including that they encourage the participants to generate and discover their own understandings of the topic at hand, identify group norms and values, and highlight viewpoints through group debate (Kitzinger, 1995). Krueger and Casey (2009) state that, "Focus groups work best when designed to be small enough to give everyone a chance to provide input in the discussion but still large enough to offer a variety of perceptions about the topic" (p. 300). Thus, the research team divided the participants into two groups each consisting of three participants in a group. These focus groups were completed by conference calling and shared computer desktops. Lastly, six final individual phone interviews were conducted to confirm findings that are portrayed within the LELQ Model.

All data were transcribed verbatim and uploaded into a qualitative software program, NVivo, to be analyzed by the PI and previous M.S. thesis students. This software program helps

you easily organize and analyze unstructured information so that you can ultimately make better

decisions for your research. Benefits of using NVivo as a research team can include working

systematically so you do not miss anything offered in the data, managing all the material in one

project so you can effortlessly share your work with other research members and justifying your

findings with evidence (Edhlund, 2012). With little training with the NVivo software program, I

rented books on the program and watched several tutorials via YouTube before beginning my

analysis to better prepare myself for my study.

Table 3

 Purpose of Interviews and Focus Groups

Interview or Focus Group	Purpose
Initial Individual Interviews (6 total)	Nature of practice and stories that highlighted practice strategies as well as desolate practice stories
Focus Group One (2 total)	LELQ model presentation from PI with emphasis on stimulating discussion within the entire research team surrounding the model and its various components, as well as potential applications to practice.
Focus Group Two (2 total)	Research team discussion on further evaluation and critique of the LELQ model, with emphasis on needed further revisions.
Focus Group Three (2 total)	Presentation of data analysis and presentation of modified LELQ model with an emphasis on identifying strategies for implementation of the model into occupational therapy practice.
Final Individual Interviews (6 total)	Understanding of LELQ model and whether application of model bears a new perspective on best practice strategies in working with persons with ADRD.

Data Analysis

Referring back to Lynham's (2002) work, analysis was primarily focused on

understanding the future application of the LELQ Model for practice. Therefore, I wanted my

study to emphasize the application phase of theory development, as my purpose was to develop a process model for occupational therapists to use in LTC facilities with persons with dementia as guided by the LELQ Model. In order to best understand the process model development, I describe two phases of analysis. Analysis of data in both phases occurred during and after the collection process in order to take advantage of the member checking and integrate discussions and questions that had occurred through that process.

Phase One

I extensively reviewed all data from phone interviews and focus groups. The process of transcribing the three final individual phone interviews further enhanced my understanding of the larger in depth action study. The three prior master students (previously referenced) had already conducted extensive qualitative analysis of all data collected. I thus took my data analysis even further by closely reviewing all of their prior analyses, including all levels of coding (see Appendix A, for LELQ Model codes).

During this review of the data, I created memos. "Memoing is a research technique that helps clarify thinking on a research topic, provides a mechanism for the articulation of assumptions and subjective perspectives about the area of research, and facilitates the development of the study design" (Birks, 2008, p. 69). In my case, through the use of memos, I immersed myself in the data, explored meanings that the data held related to my research questions, maintained consistency with study procedures, and sustained momentum in the conduct of research.

During phase one, I also explored published ADRD literature in order to gain a firm grasp on current evidenced-based practice (e.g., Gitlin 2005 & 2010 and Rader, 1995). Furthermore, I was able to frame my research interests in relation to my "existing knowledge,

opinion and forms of work, and to develop concepts and theoretical spaces that are in turn, used to conceptualize, organize and manipulate data" (Gibson & Brown, 2009, p. 206). For example, the literature served as a foundation that enabled my critical thinking to best apprehend findings from the study as well as implications for ADRD practice, in particular occupational therapy. This broad analysis then allowed a thorough understanding of practice strategies employed by these expert occupational therapists when working with persons with LTC residents with ADRD. With this comprehensive understanding of phase one data, I then began my journey of developing a process model with phase two.

Phase Two

　　After reading the prior analyses and my memos, the P.I. and I developed and defined sub codes based on the LELQ parent codes and my established research questions with specificity for a process model such as "process-lived environment-caregiving microsystem-assessment" and "process-lived environment-environmental press-intervention." Furthermore, these sub codes were treated as subsidiary features of the existing parent codes. As such, these new codes represented, as advocated by Gibson and Brown (2009), relational branches specifying the linkages between the codes. These newer codes and definitions were then entered into the qualitative software NVivo (see Appendix B, for Process Model codes).

　　Once these codes were entered into the software program, I reread the previously established LELQ action research study parent codes and categorized them into the newly created process model sub codes. For example, the LELQ action study parent code "LE-CM-Assessments" became the sub code of "Process-LE-CM-Assessments" with a specific focus on the actions or therapist doing in relation to assessing the person with dementia, the task at hand, and the environment. With this, I then looked at the frequency among coders at each process

model sub code, as represented by coding stripes in NVivo. Coding stripes illustrate a visual representation of frequency, with darker areas displaying the most coding between the research team. For example, under "process-lived environment-caregiving microsystem-assessment" code, I was able to see that from the previous research team, all three students had coded that data as an assessment piece of information.

By looking at the frequency of the codes among all coders through the coding stripes in Nvivo, I was able to detect patterns and regularities that helped me formulate tentative themes. I plotted out each of my tentative themes onto a large piece of paper using large post-it notes labeled as the subdomains from the LELQ Model. This visual representation enabled me to create a system of classification and/or a list of mutually exclusive categories that best related to the LELQ Model. In addition, I found supporting quotes for each category in order to increase my study's reliability. I then reflected on elements, through the use of memos, of the data that did not support or appeared to contradict the themes that emerged from the data analysis. One example that did not support the theme of *defining the resident as an occupational being* was commonly held dementia stereotypes in LTC facilities. Here, it was apparent that staff can have low levels of understanding about dementia and hold the notion that nothing can be done to help the person. However, this perception was not central in understanding what the person with dementia embraces. Instead this view fit under the caregiving microsystem level and focus of assessment, as the impact of systems is of emphasis. An example of one supporting idea for the theme *defining the resident as an occupational being* was the importance of uncovering the person's life story, focusing on not just the present but the past and future needs, wants, and desires. Saturation was reached with careful review of each process model sub code in NVivo in relation to thematic data support found when mapped onto the visual representation.

In addition to the above analyses, I engaged in weekly to bi-weekly peer debriefings with Dr. Wood (the P.I.) and kept a code log. This code log was used to index all coding decisions made during the entire analytic process. In particular, my code log helped me keep track of when codes were created, altered, merged, or deleted, and therefore, was useful for reflecting on the development of my analysis process. These debriefings and logging methods allowed me to maintain reliability and project cohesiveness. In addition, I was availed of opportunities for feedback on and critiques of my developing analyses during both phases. After repetitive analysis employing multiple approaches to inquiry, I felt I had exhausted the data in regards to my research focus and reached final results that were significant for the development of the process model.

CHAPTER THREE: RESULTS

Key findings that are embedded within the process model are presented in relationship to the three research questions below. For each section, I first present key ideas or conceptualizations of relevance to a process model that were suggested by the practices of the expert occupational therapists in this study. I then conclude each section with implications for a process model.

Research Question 1

The first research question asked: What implications do the practices of expert occupational therapists have for development of the assessment dimension of a process model? Overall, findings suggested that participants' approaches to the assessment dimension greatly aligned with one another's practices and the domains of the LELQ Model. The following four conceptualizations were found to have particularly salient implications for the assessment dimension of a process model: functioning of the facility, being a good detective, understanding the transactional nature of the resident in his or her environment, and gauging occupations and their inherent use. Findings pertaining to each of these ideas are elaborated upon below.

Key Conceptualization: Functioning of the Facility

Participants in this study strongly believed that occupational therapists must understand the overall *functioning of the facility* in which the person with dementia resided. Understanding how a given facility functioned required, in the view of participants, knowledge of its characteristic physical, social and cultural environmental elements. That is, without exception, participants emphasized the importance of exploring the physical layout of the facility, understanding the facility's prevailing values and beliefs, getting to know the facility administration, and knowing the level of training of staff members who interact with residents

with dementia on a daily basis. A related important action was seeking to understand the LTC's

facility's overall culture of care. For example, one participant stated:

> When I'm in a nursing home setting, I think: What is this team [member] going to be
> willing to engage him [the resident] in, to change this person's daily life? So, am I going
> to be able to change the dynamics of rolling everybody up to sit in front of the nurse's
> desk so they can be quote unquote "supervised?" Am I going to be able to change the
> practice of turning on the TV, or the radio so we're more alert every time a CNA comes
> into the room? Those are the things I look at. How do I get buy-in, and how do I help?
> You got to learn what your circle of influence is. (10.10.12-1Interview-SH)

The participants spoke of the importance of assessing both physical and social

environmental elements as thoroughly as possible in order to become familiar with all

components of the function of the facility. At the *social environment level*, the participants

shared four areas to assess to gain a complete understanding of where a practitioner is working

and what resources he or she has to work with: staffing patterns, structure of the day, and staff

support and education. In addition, elements in the social environment were often discussed

between the participants in the focus groups of the study. Here, they shared significance of

family support and education, relationships with the residents, communication and language

skills, and staff attitudes. Lastly, at *the physical environment level*, the participants spoke about

the importance of observing noise levels, lighting, floor surface types, seating, and furniture.

These elements of the physical environment were almost always associated with residents'

overall safety.

Lastly, the participants discussed the elements of the *functioning of the facility* as

important for the occupational therapist to explore when looking for causes of resident behavior

as well as serving as a way to engage the administration in examining possible system level

problems and changes that need to occur. In doing so, problems and solutions could be addressed

as administrators would be challenged to look more closely at the *functioning of the facility's*

daily operations, with emphasis on overall philosophy and policies that may be impacting

residents' quality of life. According to the participants, both the social and physical

environments are significant in that they foster a sense of positivity within the LTC facility and

thus, greatly impact the overall facility.

Key Conceptualization: Being a Good Detective

When describing occupational therapy, many of the participants alluded to the idea of a

detective role. That is, being a *good detective* throughout the assessment part of the occupational

therapy process involves:

> It's about getting as much information as I can from the family. I do try to get history
> information from the person, but I also like to verify because depending on the person's
> dementia stage, I want to make sure the report I am getting is accurate. I always go
> through, if I don't have access to family… the social services section of the chart. It will
> give me level of educations, occupation; was there a spouse; were there children? The
> activities department can give you good information on things they enjoy doing,
> gardening, cooking that sort of thing. (10.4.12-1Interview-MH)

In addition, the participants frequently explained the importance of getting to know the

resident to the best of their ability in order to optimize the resident's quality of life. "A

connection to [the resident's] life story is important so that the person is still being and doing

what they've always loved…how do I say this, it's a catalyst for the person to thrive in their

environment" (10.10.12-1Interview-SH). Likewise, another participant explained, "When we

focus on the fundamentals of the person, we are enabling he/she to live in a pleasurable and

meaningful way on a daily basis" (10.17.12-1Interview-MVS). By taking on a detective role, the

participants described the importance of uncovering clues in order to identify residents' unmet

needs. Furthermore, they shared these actions needed to be taken to ascertain the clues: ask

questions and lots of them, follow intuition, review resident's medical history and become

familiar with medications and their assumed side effects and reactions. These strategies were

described as being of upmost importance in collaborating with caregivers about appropriate

medias and methods to be utilized. Accordingly, the participants stressed that once unmet needs

have been recognized, it was essential to select appropriate solutions that were evidenced based.

Key Conceptualization: Transactional Nature of LTC Residents and their Environments

Furthermore, participants highlighted the importance of understanding the *transactional*

nature of the resident and his or her environment through observation to better equip the

occupational therapist for treatment planning. For instance, one participant stated:

> I am simultaneously concerned with understanding who this person is, what their
> interests are, what their daily habits and routines are so that how the day is structured for
> them in a dementia care unit or other part of the facility matches what they have become
> accustomed to and preferred prior to admission. Your perspective is to be tuned into their
> habits, their routines, their preferences but also to do that… by observing the balance of
> their activity engagement over the day. (10.4.12-IInterview-AC)

As posed by Lawton (1982) and reinforced by the participants, persons with dementia are

not simply controlled by their environment, but they also act to influence the environment. Here,

it is apparent there is a transactional nature between the resident and his or her doing and the

surrounding environment. One action that the participants shared in order to best comprehend the

impact of both the resident and the environment is observation. They further explained that

through observation, barriers and enablers move from the background to the foreground in the

occupational therapy lens, thus, making it easier to determine what currently is impacting

performance and participation during the residents' structured days. Having an occupational

therapy lens on while assessing the transactional nature was significant to the participants, as

they believed it allowed best service delivery that stayed true to the foundation upon which

occupational therapy is based.

Key Conceptualization: Meaningful Occupation

Finally, all participants expounded upon the importance of determining what role

occupational therapists play and how they can best use *meaningful occupation-based* activities.

As one participant expressed:

> We have so much to offer even if it's a little piece to offer in dementia care. But we are
> offering so much more, people just don't know where to find it. They [caregivers] don't
> know what to do; they don't know how to communicate with someone. They don't know
> how to understand, there is just so much we can offer with our unique focus being
> occupation-based therapy. (10.17.12-1Interview-MVS)

The emphasis on occupation was described by all participants in both individual

interviews and focus groups. Here, the participants associated using occupations with an

enhanced quality of life, indicating the power of occupations as a therapeutic agent. Several

occupation-based assessment methods that were frequently discussed included performance and

task analysis. Furthermore, the participants stressed the importance of allowing the residents to

do something with associated meaning to the resident. To illustrate, if the resident had a favorite

outfit, then the occupational therapist should have them dress with those particular garments to

best analyze the quality of the person's occupational performance as well as person factors, body

functions, and environment factors that may be impacting occupational performance. As a result,

the participants described this occupation-based assessment method as a means to allow

occupational performance to unfold as the complex transactional nature of all elements was

brought forth through use of meaningful occupation.

Implications for a Process Model

What do these results indicate for the development of a process model? First and

foremost, there were several key implications discussed for occupational therapists to utilize in

the assessment domain of the occupational therapy process. Emphasis was placed on getting to

know the functioning of the facility inside and out, as there were different levels of functioning such as physical and social components. More specifically, understand how days are structured, how things are communicated, what training is available to both staff and family, and what overarching policies and procedures will govern the treatment planning for the residents with dementia. Emphasis was also placed on the occupational therapist becoming a detective so to speak. In more detail, the participants shared the importance of asking questions and following intuition in regards to identifying the unmet needs of the residents. Also, the unique skill of assessing the transactional nature of the resident in his or her environment was highlighted. Here, the participants discussed the importance of being a good observer, more specifically, paying attention to all the supports and barriers that are impacting the resident's performance and participation on a day to day basis. Lastly, utilizing occupations and thus, maintaining the premise of the occupational therapy foundation, was commonly suggested as a best assessment tool. These four results are all significant pieces to the construction of a comprehensive, thorough process model.

Research Question 2

The second research question asked: What implications do the practices of expert occupational therapists have for development of the intervention dimension of a process model? Overall, findings suggested that participant's conceptualizations of the intervention dimension greatly aligned with one another's practices. The following four conceptualizations were found to have particularly salient implications for the intervention dimension of a process model: education, maintenance, modification and/or adaptation, and prevention. Findings pertaining to each of these ideas are elaborated upon below.

Key Conceptualization: Education

Like the assessment aspect of the occupational therapy process, the intervention domain

was evident through the work of the participants; particularly they highlighted specific

approaches commonly used within their daily practice in LTC facilities. To start, the approach of

education was of great importance, signifying the need to train staff and other caregivers about

dementia strategies. For example, one participant stated:

> CNAs… their training is a task oriented checklist where they need to make sure the
> laundry's done and everyone's clean and everyone's had their meals and their medicines.
> Knowing that it's okay to stop and do something fun with somebody, something that
> they've enjoyed doing, and recognizing that as a staff that they might share some of the
> same interests needs to be addressed. (10.4.12-1Interview-AC)

In addition to describing the education approach, the participants identified questions and

considerations for effective treatment planning: What educational opportunities are available and

provided for families and staff members? How have the resident's support system been

encouraged to be involved in the care? Do staff members at all caregiving levels feel a sense of

competency? (11.09.12-1Focus Group). More so, the participants inherently spoke of the

organizational environment and philosophy of the facility being the catalyst of how all

caregiving levels are educated and supported both in a positive and negative manner, therefore,

further supporting the need for the occupational therapist to understand how the facility actually

functions. For instance, a participant commented:

> I had to do some kind of education with the staff once a month, what they did was they
> did it on payday so basically they held their paychecks captive so they had to come to this
> education piece, and then they could get their checks. So as part of that she [supervisor]
> gave me 15 minutes and we [therapist team] would do a little snip-it, our whole team, on
> dementia and what it looked like and I cannot tell you the ripple that it started to have.
> We started having, literally administrative people come, secretaries come, the
> housekeepers even started to come. It was a big deal because people were starting to
> understand the dementia disease. (10.11.12-1Interview-MM)

Steps in regards to an educational approach that were supported by the participants included these: establish what is to be taught, select appropriate teaching techniques, provide practice opportunities, use proper feedback, and assess carryover of learned tasks. These five steps were deemed imperative for the teaching-learning process to occur. Moreover, by undertaking them, they could help to expand on problem-solving initiated in assessment to fully allow changes in the environment and resident to transpire.

Key Conceptualization: Maintenance

Another important intervention piece that was apparent in the findings was the concept of *maintenance*. Here, participants specifically referred to the need to preserve capacities by providing meaningful opportunities for the residents. Many of the participants discussed the creation of a maintenance plan for staff to follow as being an important part of their job. One participant stated:

> One COTA took over all the treatment on that day and actually said, I [COTA] can't get him [the resident] to do anything for me and he keeps yelling at me. I [occupational therapist] said go to my maintenance plan in the chart (I wanted to see if it would work), and read it, try that, and call me back if it doesn't help. I eventually forgot about it because I didn't see her again until lunch, and she said yeah, it worked great! (10.10.12-1Interview-SH)

To describe the idea of maintenance even further, this same participant stated, "The maintenance plan is a strategy. It is used especially for a person with dementia; it is what Medicare is asking us, as therapists, to do; to provide quality service to our patients" (10.10.12-1Interview-SH). More so, "We try to keep them [residents] doing what they can for as long as they can, within their realm of capability and then if there is a change in status then we can move that program, change it if we need to, and revise if we need to, or go in and see if there is a problem" (9.28.12-1Interview-MH). One key principle of a maintenance program, as supported by the participants, is sharing of training and knowledge to enhance the resident's function,

safety, and well-being. Emphasized by all participants and reinforced by the OTPF (AOTA, 2002) was the general purpose of the idea of maintenance. Here, the participants described selecting this occupational therapy approach in order to provide the supports that will allow the resident to preserve any performance capacity, those ranging from body function to person factors. It was assumed by the participants that choosing not to select this approach would lead to occupational decline and thus, an overall poorer quality of life.

Key Conceptualization: Modification and/or Adaptation

The idea of *modification and/or adaptation* was also found to be essential. All of the participants discussed the need to grade the physical and social environment to allow for the just right challenge for the resident's level of function. For example, one participant said:

> I always try to figure out the way that the person [resident] has done it before or some way they would feel most comfortable doing it, and then try to help staff understand how to adapt and adjust to the person's desires and routines. (10.11.12-1Interview-MM)

To illustrate the impact of a modification to the environment, one participant in the focus group provided this statement:

> When you have the just right challenge between the person, the environment, and what they are doing, then you have a great instigator of positive change. (11.09.12-Focus Group)

Participants resonated with one another on commonly used principles and methods in relation to adaptation and modification. For instance, frequently utilized methods included: providing social supports, changing the complexity of the task at hand, introducing physical environment modifications, and providing specialized adaptive equipment. In general, the participants associated the main purpose of employing an adaptation and modification approach in order to best enable the resident to compensate for ineffective actions.

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Key Conceptualization: Prevention

Lastly, in the domain of intervention, the concept of *prevention* was constructed from the

data. Many of the participants discussed the importance of decreasing excess disability and

avoiding adverse secondary health complications. One specific story reveals the need for

occupational therapy intervention:

> One evening I was going home and thought I am going to go by and say goodbye to Ruth
> before I head home. I went in and I was appalled because they [staff] 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. The second thing that upset me was that she was so thin and frail
> and was between the mattress and the bed rail. She was trapped and she was struggling
> against this bed rail, and no one was around. I alerted nursing, ran back down, and got her
> settled, but the thing that hit me was the lack of dignity. Their [staff] thing was it's better
> for their [resident] skin if they don't have anything on from the waist down in bed. So
> here we are telling this women who has been a lady her whole life that because of her
> sundowning, the solution was to trap her in a bed that was a hazard for her that she
> couldn't get out of. Nursing really blew me off on that one, as oh we thought something
> was really wrong. This is just Ruth and what she does in the evening kind of thing. At
> that time, I didn't have the language I needed or the knowledge I needed to help come up
> with a better solution. That was definitely a failure, I think. (10.10.12-1Interview-SH)

Several aspects of the story indicate the absence of a prevention focus from the staff. For

instance, many of the participants spoke to the idea that physical restraints (bedrails in the story),

could have many negative consequences and as far as efficacy went, did not avoid the reasons

for restraint use in the first place, such as falling, or agitated and aggressive behaviors.

Specifically with this story, it was clear that staff used the bedrails and undressed the resident

because that was the "norm" carried out on a day to day basis when a resident was perceived to

be "sundowning," meaning symptoms of confusion and agitation begin to worsen for the resident

in the late afternoon and evening, or as the sun goes down. Furthermore, personal factors such as

autonomy and freedom were not taken into consideration for the resident to the extent that safety

in regards to body function and structure was. Consequently, the prevention approach was not

utilized, and instead, secondary health problems to dementia could have occurred for this

resident such as bed sores, depression, and contractures. The participant that shared this story

discussed how this experience motivated her to be an assertive occupational therapist when

implementing a preventive approach. She accordingly believed that occupational therapists could

research, train, and then provide these practical preventative solutions that are a best fit for the

person and enhance quality of life.

In the quotation below, a participant alluded to the significance of having heart and

passion in practice. By embracing these qualities, she believed that occupational therapists could

be empowered to go that extra mile for residents in order to best support their daily functioning.

> I think it goes back to that heart and that passion and that love. People know, there is
> something in us that knows, we are not providing the best care that we can. I think when
> we see that person [resident], when I saw Ms. B kiss my hand, put it on her cheek, and
> interact, that that's all it takes for me to say it's worth it. Money is not what truly drives a
> therapist, it's the changes that I think we can help and facilitate for that person. Taking
> someone from being pretty much in bed all the time, or asleep all day falling out of a
> chair, and enabling them to interact a little bit in activities and being awake, being alert,
> being engaged is great. I mean to me, it is that heart where you want to see people thrive
> and you are willing to go that extra mile" (10.11.12-1Inerview-MM).

This quote highlights the role occupational therapists can have in prevention, as it was apparent

that this participant strived to facilitate the resident to be alert, engaged, and thriving within her

environment.

All the participants established the notion that as occupational therapists, the need to

provide prevention-focused services to persons with dementia is imperative to cease destructive

health conditions from occurring and for optimal well-being to occur. The general consensus

from the participants in utilizing a prevention focus was to cease the occurrence or advancement

of barriers to the resident's performance in his or her context. Therefore, focus of preventative

interventions may be at the level of the resident, activity, and/or the environment.

Implications for a Process Model

My findings suggested four key conceptualizations and related intervention strategies that occupational therapists could employ to direct treatment planning when working with persons with dementia in LTC: education, maintenance, modification and adaptation, and prevention. The realm of education focused on collaborating with frontline caregivers in order to better dementia care practices. Maintenance highlighted the need to preserve the resident's performance capacities being that dementia is a progressive disease. The terms modification and adaptation were discussed and the participants frequently associated those terms as being a compensatory mechanism to be used in practice. Lastly, prevention was emphasized, as the need to reduce or prevent secondary health consequences is clear if an enhanced quality of life is to be experienced by the person with dementia. These collective ideas explicit in the data are fundamental components in the intervention domain of the developed process model.

Research Question 3

My last research question asked: What implications do the practices of expert occupational therapists have for development of the outcome dimension of a process model? Overall, findings once again suggested that participant's conceptualizations of the outcome dimension greatly aligned with one another's practices. The following five conceptualizations were found to have particularly salient implications for the outcome dimension of a process model: health, engagement, performance, social participation, and personal factors. Findings pertaining to each of these ideas are elaborated upon below.

Key Conceptualization: Health

All of the participants discussed health as a significant aspect of treatment outcomes. Health was described differently by each participant but overall, there were similarities. For

instance, many of the participants associated health with physical factors experienced by persons

with dementia. Several physical factors commonly discussed included: weight, vision, and

surgical related impairments. One participant described health as:

> I think health could be everything from Miss Smith who has a cognitive impairment but also has a knee replacement. So health wise, I'm looking at, making sure she doesn't damage those repairs (knee replacement) in the healing process. (10.11.12-1Inerview-MM)

Here, it is clear that the participant focused on not only addressing cognition but physical factors

due to the surgery to optimize the healing process for that particular resident. Another

participant's description of health further supports the focus on physical factors of the resident:

> Health basically means our enabling this person to remain healthy within whatever diagnosis they have. So, for example, we [staff] don't want to create excess disability or functional dependence that leads to weakness that leads to fall. We want to promote movement and engagement in activity to promote strength that hopefully reduces falls. We want to promote self-feeding, so that this person [the resident] swallows more safely and eats more food- that they don't have aspiration pneumonia, or weight loss that leads to health deterioration. So, those are some examples that 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. (10.10.12-1Interview-SH)

This quote in particular emphasizes the transactional nature of intervention pieces previously

discussed. For instance, it is apparent that the participant had numerous strategies for treatment

planning that served to reverse excess disability. Within the quote the participant suggests

promoting self-feeding, promoting activity, and promoting movement. These strategies,

therefore, serve a purpose of preventing other physical complications such as falls from

happening.

Key Conceptualization: Engagement

Another key conceptualization that the participants resonated with was the notion of

promoting engagement. One participant highlighted engagement as an ultimate outcome stating:

Your [occupational therapist] ultimate outcome, or where you know things are really going well has to do with a sense of that they [resident] are interested and engaged in their environment, that they are having pleasurable experiences, and you could measure this experience through observation tools. (10.4.12-1Interview-AC)

Furthermore, engagement as an outcome was suggested by another participant:

I've just seen many individuals that, through occupational engagement were more active, so if you [occupational therapist] want to really compartmentalize it, they [residents] were able to be mobile longer, they [residents] were able to have more enjoyable conversations for longer periods of time, to have better nourishment, to laugh more, to smile more, to have more opportunities for healthy engagement with people, their family and their friends, and many of them live longer. So if you talk about it being from the standpoint of mortality, those who are engaged live longer...I've seen them live longer than the individuals who are not occupationally engaged…(10.10.12-1Interview-SH)

This participant specifically linked engagement to an enhanced quality of life through the use of daily occupations and suggested that numerous factors can confirm that engagement is occurring. For instance, this participant along with others, referred to observing whether or not laughter, smiling, conversation, and gestures are occurring for residents on a daily basis, and if not, then engagement as an outcome needed to be revisited through revisions in treatment plans.

Key Conceptualization: Performance

The concept of performance was implicit throughout all individual interviews and focus groups. Performance was described as whether or not the resident was able to carry out an action, with the emphasis being the action of the task. For instance, one participant recounted this episode:

One of the residents was a repetitive-caller-outer, she was constantly asking when the meal times were. I was able to have her, with the compensatory strategy of using a cue card to recall the meal times, look at her own watch and anticipate when the next meal would come, so therefore her calling out lessoned greatly. (10.11.12-1Inerview-MM)

This example highlighted an action that the resident desired: being able to know when meal times were to occur. As the participant described, through the use of a compensatory strategy, the resident was able to use the cue card to notify her to look at her watch and figure out when the

next meal was on her own, demonstrating performance implicitly. As a result, this enhanced

ability to perform went hand in hand with lessening the negative and distressed behavior of

yelling.

All of the participants also suggested that an increase in performance in daily activities

aligned with an overall enhanced quality of life. That is, they reported that if residents were

given opportunities or activities to do throughout the day, then their functional competence

increased. To best describe an increase in functional competence one participant shared a

compelling story:

> Mary was sitting in the corner of an activity room by herself, hunched over in her chair,
> and she looked like she was dying. So, we [occupational therapists] 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, and all kinds of
> things that might be indicative of end of life. So, we asked her daughter to tell us as
> much about her mom as she could possibly tell us. And she told us two things that I still
> remember to this day. One was that her mom was a secretary, and the other is that her
> mom loved to sing opera. So, we brought this lady into a quiet place in the other assisted
> living where she was living and we introduced ourselves and the lady opened her eyes
> and she looked. And we got down on her level and we held her hand and we started
> reminiscing about some of those things important to her. And in this community they
> happened to have an old typewriter, so I put her in front of that typewriter and I asked if
> she could type her name. She then sat up real straight and her fingers started moving
> across the typewriter keys. (10.4.12-1Interview-MH)

Here, it is clear that a performance outcome was achieved, as Mary had the capacities to carry

out a task that was once an everyday activity for her.

Key Conceptualization: Social Participation

Social participation was discussed and elaborated on by all participants as a desired

outcome for residents. For instance, one participant shared:

> I would say to them [caregivers], "Listen, this lady yearns to have social contact, but she
> also has terrible vision. So, potentially she wouldn't recognize you walking in the hallway
> towards her. But I further said, whenever you think about it, if you can just take 10-15
> seconds to say, hey how are you doing, boy you look marvelous, touch her on the
> shoulder, and keep going. This increases her [resident] social ability, social contact

during the day, and it added to the treatment plan, if you will, to have her needs fulfilled of having social contact, as she was a very social person. (10.4.12-1Interview-MH)

However, achieving this end was not always an easy pathway to take as a therapist, as caregivers could question whether or not the means a therapist decided to take would reach an optimal end for the resident. For example:

> I advocated for a particular individual several weeks ago to move to a more social environment and someone [in that environment] said, 'Well you know, how's that going to help her. I see her as being quiet. What is she going to contribute to this environment, and I don't see that she is very socially engaged.' And actually that's not true if she has the right degree of support and someone to help her initiate conversation. Once you initiate, she actually is very socially active and very socially engaged and enjoys that, and she doesn't sleep all day when somebody helps her engage in activities. (10.10.12-1Interview-SH)

Once again, it is clear that, through social participation, the resident was able to achieve other outcomes as well such as engaging in activities and being functionally active. Expanding on participants' conceptualizations, social participation serves as a key outcome that indicates overall quality of life.

Also, this quote was connected back to the importance of education, one of the discussed intervention areas. That is, the participant spoke on the idea of educating the caregiver about the resident's personal factors in order to promote acceptance and support among the caregiver for the move to occur. This interaction would have then elicited a positive social participation type outcome to have occurred for the participant and caregiver. Therefore, the quote highlights that both the person with dementia and the caregivers can experience social participation as an outcome.

Key Conceptualization: Personal Factors

Findings suggested that participants described their practices with a primary focus on personal factors, meaning characteristics that comprise who the resident is. Participants

identified a wide range of personal dimensions, which included feeling a sense of confidence, competence, autonomy, control, and success, as well as feeling loved and respected. 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 personal factors as a place to begin intervention in order to reestablish the feeling of competence and confidence in daily activities. Many of the other participants described focusing their efforts on restoration of person factors. 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. Another participant captured what was important to the person and in turn ensued in a sense of competency:

> This one lady did a lot roaming in other people's rooms. She was a very large lady and had some visual problems as well, and would think nothing of ramming into another resident in their room, in like ramming into their wheel chair. But she was really looking for some familiarity, and our facility is like a rectangle, so she would roam and roam. This was going on for a long time, and it wasn't problematic until she started going into people's rooms. Because roaming is an occupation, I don't really want to stop that, because she got secondary gains from that. People would interact with her, or she would hear conversations, and she wouldn't interrupt that much verbally. So, I found out about her, and little bit more about her past, she was a New Yorker. And she was an avid, avid Yankees fan. So, I started placing Yankee, the symbols of the New York sign all around the unit to help find her room. (10.4.12-1Interview-AC)

With these rich descriptions from the participants, it is apparent that person factors are essential priorities for their LTC practice.

Implications for a Process Model

There were five comprehensive notions that are to be aimed at for outcomes when working with persons with dementia in LTC: health, engagement, performance, social participation, and personal factors. All five outcome descriptors were discussed in a transactional nature with other outcomes. That is, intervention strategies employed by the occupational therapists resulted in several outcomes. The health outcome was perceived to be significant in reversing secondary health issues. Engagement was discussed in regards to the resident being able to meet the demands of the occupation. A performance outcome focused on whether or not the resident was functional in his or her day to day activities. Social participation was described as enhancing the human connection, that being both verbal and nonverbal ways of communicating. Lastly, when a restoration of personal factors in daily activities occurred, so did the enhancement in the resident's level of competency. These collective ideas explicit within the participant's descriptions are fundamental components in the outcome domain of the developed process model.

CHAPTER FOUR: DISCUSSION

Results from this study suggest that the perspectives of six expert occupational therapists strongly aligned with one another's practices indicating key ideas to be incorporated into a process model that could be associated with the LELQ conceptual practice model. Guided by findings related to each research question, I created such a process model corresponding with three domains: assessment, intervention, and outcomes (see Appendix C, for Process Model). These domains will be described in detail and elaborated on with specific examples from the data. Finally, several implications for the process model and future best practice for LTC residents with ADRD will be discussed.

Assessment Domain

While creating this domain, it was apparent that the four key conceptualizations most supported in the data—functioning of the facility, being a good detective, observing the transaction between the resident and his or her environment, and the use of meaningful occupation—needed to be incorporated into the process model. Figure 5 depicts the resulting domain of assessment. Its main heading, *Level and Focus of Assessment,* represents the "what" of assessment by identifying four levels and foci of assessment that correspond with the lived environment domains of the larger LELQ Model: the caregiving microsystem, person with dementia, emerging environmental press, and the notion of data-based intervention planning. The main heading, *Process for Gathering and Integrating Data,* signifies the "doing" or better yet the "process of how to" of the assessment domain. Here, the occupational therapist is either represented as an OT detective or an OT problem solver. These titles were explicit within the data and are frequently used in other related dementia literature (Rader, 1995). The detective is where the occupational therapist seeks to answer the "what" questions posed under the level and

focus headings. To answer these questions, the detective follows intuition, uses expertise and professional knowledge for assessment, employs observation, and confronts staff, family, and most importantly the resident. The problem solver is where the occupational therapist identifies probable causes of the resident's unmet needs. Specifically, the occupational therapist remains occupation-focused using the gathered data during intervention planning and selects an appropriate role or roles to fill in order to carry out that intervention. Fisher (2012) described the term occupation-focused in great detail:

> To be focused is to bring something into focus and to concentrate one's attention on it, thus, when occupational therapists are occupation-focused, attention is focused on occupation. That is, immediate focus is on evaluating and/or changing a person's quality of occupational performance in the present moment (p. 166).

Many of the participant's implicitly spoke to being occupation-focused, just as Fisher described. Each of these main areas of the process model is next explained in more detail.

Assessment Domain

Level and Focus "The What"	Process for Gathering and Integrating Data "The How"
Caregiving Microsystem:	As an OT detective, gather data by:
• Where does the facility fall on an optimistic vs. pessimistic spectrum of its culture of care? • How are days predominantly structured and why?	• Exploring the facility's webpage, physical layout and dementia-related programming • Considering levels of staff training, the facility's values/beliefs, and communication styles and means • Observing routine activity situations and informally interviewing key stakeholders to determine structures and routines of days
Person with Dementia:	As an OT detective, gather data by:
• What defines the resident as an occupational being?	• Exploring who are key informants and how they can assist you • Reviewing resident's medical chart • Assessing physical, social, cognitive, and emotional capacities
Emerging Environmental Press:	As an OT detective, gather data by:
• How does the resident typically spend his or her time in predominant activity situations? • What barriers and enablers exist that are impacting performance and participation during activity situations?	• Observing fluidly various levels of interaction between the resident, the activity, other residents, and staff members • Monitoring behavioral changes
Data-based Intervention Planning:	As an OT problem solver, develop an intervention plan by:

• How will you optimize quality of life across the day through meaningful occupation?	• Integrating data to determine where, when, and how best to infuse occupation-based activities across the day in order to optimize the resident's quality of life
	• Determining which role(s) you will need to carry out (self-reflection):
	   o Collaborator
	   o Consultant
	   o Educator
	   o Advocate
	   o One-to-One Interventionist
	   o Paradigm Shifter
	   o Responsibility Taker
	• Taking into consideration the LELQ Model, your past experiences/expertise

Figure 5: Assessment Domain

Caregiving Microsystem

As shown in Figure 5, findings from this study suggest that two significant questions about the caregiving microsystem must be answered by occupational therapists in order to bring the function of a facility into focus: 1) Where does the facility fall on an optimistic vs. pessimistic spectrum of culture of care? and 2) How are days predominantly structured and why? To answer these questions, the occupational therapist assumes the detective role and performs these actions: explores the facility; considers training methods, communication styles, and values/beliefs; and lastly, observes routine activity situations that occur in the facility and interviews key stakeholders. Answering these two questions equips the occupational therapist with a place to start for the intervention domain.

Person with Dementia

From the findings one key question was developed for the resident level of the assessment domain: What defines the resident as an occupational being? Referring back to Hasselkus in order to better understand our responsibility as occupational therapists (2011), "in progressive illnesses such as dementia, we, as occupational therapists, try to help people hold onto some semblance of their occupational definition of themselves and their days as they journey more and more into the disability and their bodies" (p. 136). To answer this central question for the profession of occupational therapy, we need to gather data by exploring key informants such as family members, friends, close staff, etc., reviewing the resident's medical chart through an occupational lens, and assessing physical, social, cognitive, and emotional capacities through standardized and non-standardized tests as needed (see Appendix D, for Commonly Used Assessments).

Emerging Environmental Press

Relative to this section of the assessment domain, findings suggest that a process model associated with the LELQ Model must represent the transactional nature of LTC residents and their environments. Accordingly, the process model proposed herein asks two questions to guide the therapist's next actions: 1) What specific barriers and enablers are impacting performance and participation during activity situations?, and 2) How does the resident typically spend his or her time in predominant activity situations? With these questions in mind, the therapist as an OT detective looks for clues by observing various levels of interaction among the resident, staff, friends, and family and by closely monitoring behavioral changes during those interactions to best identify the resident's unmet needs (see Appendix E, for Behavioral Monitor Sheet).

Data-Based Intervention Planning

This section of the assessment domain is the part that makes the occupational therapy profession most distinct from others; occupation is infused into interventions. The findings suggest one question that needs to be asked in order to deliver best occupational therapy services that aligns with the profession's foundation of occupation: How will you optimize quality of life across the day through meaningful occupation? However, "New practitioners often struggle with how to select interventions, perhaps because they are overwhelmed with all the factors that must be considered. A good place to start is to attend carefully to the person's valued occupations" (Schell, Crepeau, & Cohn, 2003, p. 457). To assist in determining valued occupations, this process model suggests that occupational therapists need to integrate all data that has been gathered to aid in developing a meaningful, resident-centered, intervention plan. Moreover, and building on the work of Alvord, Lampe, Metcalfe and Wood (2014), the occupational therapist needs to determine which role or roles he or she will take on as part of this plan (see Appendix F,

for Roles and Definitions). In turn occupational therapists use self-reflection, their professional knowledge, and past experiences to help them select which role is to be filled and what approach is to be taken in intervention.

Intervention Domain

Intervention is where the occupational therapist selects and applies methods, meaning actions that must be used and fulfilled in order to help the resident with dementia achieve desired goals. Furthermore, intervention facilitates the occupational therapist's understandings of the resident's performance and participation in everyday activities. This added understanding then allows the occupational therapist and anyone involved in the therapy to collaborate with one another to develop a sound intervention plan. Reasoning and evidence undergirds the findings from the evaluation and assists in the appropriate selection of intervention approaches (Schell, Crepeau, & Cohn, 2003).

Figure 6 shows the resulting intervention domain for the process model. Once again, the farthest left column reflects the original domains of the LELQ Model, as the domains serve as catalysts for the therapist focus for addressing remaining columns. This thereby linking the LELQ conceptual practice model to the "doing aspects" of the associated process model reflected in all other columns.

Intervention Domain

Level "The What"	Approach "The How"	Purpose	Roles	Suggested Activity Strategy
Caregiving Microsystem	Education	To increase facility and frontline caregiver competence	• Educator • Consultant • Collaborator • Paradigm Shifter	Language: Common area of frustration; educate about the importance to listen to key words and understand nonverbal communication Functioning of Facility: Provide in service presentations on the impact of policy and procedures, staff support and education, staffing patterns, and structure of day for the resident
Person with Dementia	Maintenance	To preserve capacities through meaningful time use to support optimal emotional well-being	• One to One Interventionist • Advocate • Responsibility Taker	Physical Activity: Provide a planned walking routine or group exercise class Reminiscence Opportunities: Assist the person in rediscovering their history through the use of a memory box
Emerging Environmental Press	Modification	To enable the resident to compensate for ineffective actions	• One to One Interventionist • Collaborator • Educator • One to One Interventionist • Collaborator • Consultant	Context: Use a quiet location for small groups or one on one occupational tasks Cueing: Provide simple, 1 step directions
	Prevention	To reverse excess disability and prevent adverse secondary health conditions		

Figure 6: Intervention Domain

Approaches or "the how" are the specific plans selected to direct the process of intervention that are based on the client's desired outcome, evaluation data, and evidence (AOTA, 2008). The four primary approaches that are supported by findings include education, maintenance, modification, and prevention. Each of these four approaches are described below in detail, including their purpose and essence, as well as specific roles which best fit that approach.

Caregiving Microsystem: The Education Approach

Findings from the study suggest that educational approaches are best related to the caregiving microsystem domain within the LELQ Model. To recap, the caregiving microsystem domain in the LELQ model emphasizes the amount and quality of opportunities for occupational engagement, physical and social environmental supports and barriers for occupational engagement, and the optimism and pessimism in the caregiving culture. Likewise, with the process model originating from my findings, there was a focus on working with all systems levels to optimize quality of life for the resident with dementia through the use of collaborative partnerships with administration and caregivers throughout the facility coupled with understandings of how the facility functions. Therefore, the essence of this approach is resource and knowledge sharing at all system levels (facility organization, staff, coworkers, resident, family, friends, community), with a goal of increasing dementia care among the facility and frontline. To reach this goal, the development of a therapeutic relationship with all system levels is of critical importance (Hasselkus, 2011). Once again referring to Alvord et al's (2014) work, specific roles that correlated to this approach are educator, consultant, collaborator, and paradigm shifter (refer to Appendix F for Role Definitions).

Activity strategies. The focus of two repeated strategies suggested by findings that fell under the education approach included language and focus on administration level. *Language* is

just one environmental barrier that the person with dementia faces as the disease progresses and

shows to be a common area of frustration for not only the person with dementia but many

caregivers who attempt to interact with that person as well. It is imperative to listen to key words

and recognize the nonverbal communication that the resident is using to best understand what

their unmet needs and emotions are in that particular activity situation. Some important actions

to implement when working with persons with dementia in regards to communication include:

make eye contact every time you come into contact with the person, adopt a calm, unhurried

approach, try not to disagree about facts in order to validate the person's feelings and

experiences, and adopt a running commentary to whatever you do, that is, indicate what has

happened and what is about to happen to the person with dementia (Perrin & May, 2008).

The *functioning of the facility* is another area at which to intervene for the education

approach. That is, the process model recognizes that educational approaches can be appropriately

applied across multiple administrative levels, from individual frontline caregivers to family

groups and education of administrators themselves. To illustrate, the occupational therapist can

provide in service presentations for staff, family, and friends about the degenerative dementia

disease. Some other useful educational tools include providing resources such as respite care

and support groups, and model calming strategies to the caregiver that is to be used with the

person with dementia. Perrin and May (2008), suggest making a commitment to learning and

educating on dementia care, as the more understanding and knowledge there is in a facility, the

more a positive impact will occur for the resident.

Person with Dementia: The Maintenance Approach

The maintenance approach best relates to the person with dementia domain within the

LELQ model. This domain emphasizes residents' occupational history and profile, their current

preferences and needs, and their retained capacities. Similarly, the participants associated the need to focus on maintaining these aspects with the LELQ model in order to allow best ability to function and augment the resident's quality of life during the progressive dementia disease. Therefore, the essence of this approach is finding the match or best fit between the resident's existing capacities and who he or she is as an occupational being, with a specific purpose being to preserve capacities through meaningful time use that corresponds with emotional well-being. To illustrate the importance of the maintenance approach, Perrin and May (2008) suggested that occupational therapists should appreciate wellbeing over function for the focus of intervention, as restoring physical and cognitive capacities is impossible due to the progressive disease. The specific roles previously identified by Alvord et al (2014) that are correlated to this approach include one to one interventionist, advocate, and responsibility taker.

Activity strategies. Providing physical activity and reminiscence opportunities are two strategies that connect to the maintenance approach. Through these two activity strategies, the participants believed that residents with dementia could thrive. By providing physical activity, the resident can better maintain his or her strength, coordination, flexibility, and range of motion; all which can positively impact their daily participation and performance in daily routines. Several examples of physical activity strategies include planned walking routines, exercise groups, and activities of daily living. Reminiscence is when the resident recollects past experiences or events by sharing personal stories with others (Hasselkus, 2011). Several examples of reminiscence opportunities include: memory boxes, photo collages, and socialization groups. Furthermore, these strategies allow the resident opportunity to work on their memory, pacing, attention, and sequencing in order to help slow the progression of the disease.

Emerging Environmental Press: The Modification Approach

The modification approach best aligns with the environmental press domain of the LELQ model (Figure 6). Referring back to the work of Lawton and his colleagues (1986), an environmental press is best described where human behavior and function result from the competencies of the individual, the demands or "press" of the environment, and the interaction or adaptation of the person to the environment. Many of the descriptive examples the participants provided in relation to the modification approach discussed the transactional nature of the person, the activity, and the environment. That is, through modifying the activity or the environment, competency among the person with dementia was facilitated. Accordingly, the essence of this approach is as follows: alter the physical and social environments in activity situations and beyond. The overall purpose is to enable the resident to compensate for ineffective actions (Fisher, 2009). By altering the physical and social environments, occupational therapists can then produce opportunities to allow best ability to function and improve quality of life for the resident. Additionally, Braun and Lipson (1993) encourage occupational therapists to recognize the changes in thinking and doing that take place within a person's experience over the dementia course and be able to adapt occupational interventions accordingly. That is, create an optimal fit between the person and his or her environment given the progressive nature of the dementia disease. Roles that were a best match for this approach in the intervention domain include one to one interventionist, collaborator, and educator.

Activity strategies. In late stages of dementia, modification of the environment is imperative, in which focus is on safety. The occupational therapist can provide task simplification, where demands of activities of daily living and other tasks are reduced by increasing visual, verbal, or tactile cues. Also, it is important to keep the environments consistent

to decrease confusion for the person with dementia. Specific areas that can be modified in order to increase performance and participation in daily tasks include lighting, adaptive equipment (grab bars, door alarms), labeling objects, and creating a low stimulus atmosphere in which the resident spends most of his or her time (Meibeyer, 2013).

Emerging Environmental Press: The Prevention Approach

Again, findings suggested that prevention best aligns with the level of emerging environmental press. Many of the participants commented on the notion that in order to optimally impact quality of life for the resident with dementia, you need to intervene in a transactional nature. For example, April was losing a lot of weight and muscle mass as she was not participating in any activities. With a thorough assessment, an occupational therapist identified that she loved art. In order to help April gain weight back and reverse excess disability, the therapist set her and her meals up in an art gallery. During the meals, April was engaged with the art and was more willing to eat, and eventually began to gain weight and participate in more activities within the facility. This example highlights the essence of the prevention approach: to develop occupation based solutions to avoid future health complications and reverse excess disability. Common health concerns that the participants highlighted that can be prevented include pressure ulcers, contractures, weight concerns, and neuropsychological symptoms. More so, these health concerns can be better understood in relation to the course of dementia and its stages. For instance, Reisberg et al. (1982) recognized the decline of dementia as broadly analogous to childhood developmental processes in reverse (see Appendix G, for Example of Retrogenesis). These stages equip occupational therapists with common behavioral knowledge and enables the therapist to predict how the resident will present in the future and what supports he or she will need. Accordingly, occupational therapists are able to create treatment plans that

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illuminate a prevention approach. Occupational therapists utilizing the prevention approach are most likely fulfilling one or more roles: one to one interventionist, collaborator, and consultant.

Activity strategies.   Activities within this approach focus on preventing common complications secondary to the primary diagnosis. These complications can include contractures, skin breakdown, pain, loss of quality of life, weight loss, falls, and resistive behaviors. Strategies to combat these complications include using a functional approach for therapeutic exercise, incorporating sensory stimulation programs, self-feeding using finger foods, and using therapeutic use of self to gain trust and agreement to best respond to behavioral communications (Crisis Prevention Institute, 2014).

Outcome Domain

Targeted outcomes are identified that reflect the resident's unmet needs. In addition, outcomes consist of measurable goals with an identified time frame and predetermined objective method to measure progress (Chisholm & Schell, 2014). During the intervention domain, the occupational therapists considers targeted outcomes for the person with dementia and strives to align those outcomes with the ultimate goal of occupational therapy services, "to support health and participation in life through engagement in occupation" (AOTA, 2008). Also, it is important to note that outcomes can overlap. That is, multiple outcomes can occur for the person with dementia at any time, as a result of the selected intervention approach or approaches. Targeted outcomes are revisited during reevaluation to address progress. There is a primary question that needs to be answered during reevaluation; does the resident continue to need occupational therapy services? In trying to answer this question, the occupational therapist takes on the detective role again from the assessment domain in order to determine if services should be continued or discontinued.

Figure 7 shows the resulting outcome domain for the process model. Once again, the farthest left column reflects the original domains of the LELQ Model, thereby linking "the what" of the conceptual practice model to the "doing or how" of the associated process model reflected in all other columns. The findings suggested five types of outcomes and furthermore, these outcomes were supported in the OTPF. The outcomes include reversal of adverse health consequences, occupational engagement, occupational performance, social participation, and restoration of personal factors. Each of these outcomes are described below in detail, including their definitions and suggested outcome measures.

Outcome Domain

Level and Focus "The What"	Type of Outcomes	Definitions	Suggested Outcome Measures
Time Use, Functional Competence, & Relative Well-Being	Reversal of Adverse Health Complications	The promotion of a healthy, positive lifestyle at all system levels (resident, caregiver, facility)	Physical Assessments, Activity in Context and Time, and Observation Tool: Dementia Care Mapping
Time Use	Occupational Engagement	The ability to meet the demands of the occupation both physically and emotionally	Observation Tool: Dementia Care Mapping & Activity in Context and Time
Functional Competence	Occupational Performance	An enhancement in the ability to do meaningful daily life activities	Abilities Assessment Instrument
Time Use and Relative Well-Being	Social Participation	An enrichment in the human connection	Screens & Activity in Context and Time
Time Use, Functional Competence, & Relative Well-Being	Restorative Personal Factors	The ability to elicit prominent characteristics of the resident into daily life	Observation Tool: Dementia Care Mapping & Activity in Context and Time

Figure 7: Outcome Domain

Time Use, Functional Competence, & Relative Well-Being: Reversal of Adverse Health

Complications

Stories that discussed outcome examples were extracted from the data and combined with a key occupational therapy document, OTPF, in order to develop a sound outcome type definition for the process model. The reversal of adverse health complications outcome is defined as, the promotion of a healthy, positive lifestyle at all system levels. More so, the reversal of adverse health complications related to all quality of life domains within the LELQ Model. That is, elements of time use, functional competence, and relative well-being contribute to the promotion of a healthy, positive lifestyle for residents with dementia in LTC facilities. Further, these elements are expressed as outcomes experienced by the person with dementia rather than by the structural features or processes thought to be associated with outcomes. Each of these elements can be perceived by the person with dementia as positive or negative experience: it is the LTC facility that shapes these experiences. These facilities should be capable of engaging the person with dementia in daily activities, that is, there should be a transactional nature between all three quality of life domains in order to reverse adverse health complications if occurring (Kane, 2001).

Time Use: Occupational Engagement

Occupational engagement is defined as the ability to meet the demands of the occupation physically, cognitively, and emotionally. This definition was also created by integrating the findings and occupational therapy documents. This outcome specifically aligned with the LELQ's domain of time use. That is, the physical components of the occupation influences how extensively people with ADRD use and maintain their functional capacities in daily living (Wood, 2005). More so, the time use domain pertains to positive and negative behaviors in order

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to capture whether or not optimal occupational experiences are occurring for the resident. Matuska and Christiansen (2008) also elaborated on the concept of engagement and connects engagement to the significance of personal factors, "engagement in occupation is fundamental to life because it is through the active transactions with people, places, and things in an environment that people develop a sense of competency and self-efficacy" (p. 13). Even further, when people have a sense of control over their environment, competency and self-efficacy fundamentally drives the elicited behaviors. For example, let's say April was engaged during craft time every day and disengaged during movie time. Here, she met the demands of the craft because the occupation intrigued her physically, cognitively, and emotionally, whereas, during movie time, April dozed off, as she was not able to choose the movie and thus was not in control of her environment.

Functional Competence: Occupational Performance

The outcome type of occupational performance best aligns with functional competence, as this outcome primarily focuses on one's ability to do occupations. Specifically, the definition of this outcome is an enhancement in the ability to do meaningful daily life activities. In relation to the OTPF, this outcome results if the person with dementia is using their remaining capacities to do what they desire or need to do. More so, Wells and Dawson (2000) suggested that if abilities are promoted, persons with dementia could function to capacity. Referring back to April, let's say she did not have the fine motor skills to pursue her artwork, therefore, she did not meet the targeted occupational performance outcome, as she did not have the ability to hold her paintbrush. However, had April been given a modified, larger paintbrush, she may have been able to hold the brush with her gross motor skills and pursue the meaningful activity, thus demonstrating an enhancement in her daily occupational performance. In regards to the outcome

domain, it is imperative to reevaluate whether or not abilities are being encouraged throughout the day.

Time Use and Relative Well-Being: Social Participation

Social participation is defined as an enrichment in the human connection. Basically, social participation is understood as whether or not the person is interacting with those surrounding them and then identifying how (Perrin & May, 2008). This outcome type aligns with the time use and relative well-being domains, as both domains are very influential on each other. For example, let's say April enjoyed participating in arts and crafts group with other women at the LTC facility. Because this activity was a passion, she was more engaged with the activity, using her time effectively, and subsequently, enjoyed conversing with the other women about their art. Therefore, April experienced enrichment in her daily life through making social connections with other residents. However, it is important to note that this outcome can also be negatively situated in that, if April had never participated in the arts and crafts group, the opportunity to interact with the other women would have been limited. With this example it is apparent that occupation was the catalyst that enhanced the connection between the women. Additionally, these connections led to the doing of meaningful occupation, and therefore enhanced April's well-being.

Time Use, Functional Competence, & Relative Well-Being: Restorative Personal Factors

Findings suggested strong emphasis on personal factors in LTC. This outcome focuses on whether or not personal factors were restored. In that the definition is the ability to elicit prominent characteristics of the resident into daily life. The *International Classification of Functioning, Disability, and Health* (IFC) listed gender, age, coping styles, social background, education, profession, past and current experiences, and behavior pattern as examples of personal

factors. Furthermore, Fisher (2009), posited that restoration for personal factors includes a person's habits, routines, and values. Due to the progressive nature of dementia, the focus on restoration does not aim to bring back lost capacities, as the term restoration is often regarded as, but is to reestablish those habits, routines, and values that were once a part of the person with dementia's everyday life (Fisher, 2009). This outcome type related to all quality of life domains presented in the LELQ Model. That is, Hasselkus (2011) associated the significance of personal factors to the quality of life domains with the work of Wood (1998), "the ubiquitous recognizable stream of transactions between humans and their worlds is organized around recognizable activities from which whole constellations of skills and routines, identities and lifetimes, radiate" (p. 321). It is through the integration of prominent personal factors into daily occupations that time use, functional competence, and relative well-being are enhanced.

Suggested Outcome Measures

Reevaluation is the process of critical analysis of the resident's response to intervention. Several outcome measures were suggested by the participants to be utilized in the reevaluation process. Specifically, screens, observation, and physical assessments. Screens and observation are "viewed as a hands off approaches where there is limited interaction between the client and the therapist, often taking the form of consulting with staff or reviewing intake information such as recent changes in the living environment, health status, and occupational performance" (Shotwell, 2014, p. 285). Physical assessments and document review are also reevaluation methods. Several common physical factors to test for this population include changes in range of motion, changes in nutrition, changes in vision, and changes in cognition. Document review on a continuous basis is also very important within LTC facilities. These records will contain the resident's history and profile, specialist consultation reports, progress notes, and results of

testing. All these elements involved in the resident's health record are possible causes for undesired outcomes.

With a thorough literature review completed during the study, several specific outcome measures were identified that have been suggested for reevaluation of outcomes in the process model. These include the Activity in Context and Time (ACT), Dementia Care Mapping (DCM), and the Abilities Assessment Instrument (AAI). The ACT was previously mentioned in the time use section of the LELQ background, but to review it, it is, "a direct observational measure that records environmental correlated of daily patterns of time use and apparent affect of people with moderate and severe AD living in LTC facilities" (Wood, 2005, p. 121). DCM is a clinical tool that has attracted interest as a potential observational measure of quality of life and well-being of LTC residents with dementia. DCM coding involves continuous observation over a 6 hour period, with observers recording a behavior category code and a well and ill being score at 5 minute intervals (Brooker, 2011). Lastly, the AAI assess the self-care, social, interactional and interpretive abilities of older people with cognitive impairment related to dementia (Dawson, Wells, Reid, & Sidani, 1998). All three tools are shown to be reliable and valid instruments that can be used to provide assessment data.

Implications for Future Best Practice

The primary goal of occupational therapy intervention for persons with dementia is to maximize quality of life. It is important to note that assessment and intervention must occur at intervals over time given the progressive nature of ADRD, therefore, goals and treatment planning change based on the evolving needs of the person at each stage of the disease. That is, the process of carrying out an activity is set in the here and now. The product of an activity belongs to the future, thus, the person's experience is set in the here and now and is of more

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therapeutic value. More so, it is central to employ a person-centered approach and recognize that the person's occupational identity may change over time. Ultimately, findings aligned with Perrin and May's (2008) suggestion that occupational therapists need to bring both a multifaceted and non-prescriptive approach to assessment and intervention in order for the resident to achieve optimal outcomes to enhance quality of life.

Study Limitations and Next Steps in the Theory Building Process

There were several study limitations. First, by employing extreme and chain case sampling to recruit participants, we cannot assume that participant's perceptions are representative of commonly held notions by LTC occupational therapists working with residents with ADRD, as other occupational therapy practitioners may not have as much experience and/or dedication to dementia care, thus, limiting this study's reliability.

Secondly, due to the extensive research and familiarity with the LELQ Model and related dementia literature before and during the study, it was clear that I had developed an emotional and intellectual investment in the development of a process model. This investment proved to be beneficial in connecting my passion for the process model with the P.I who has similar interests, which thereby contributed to the effectiveness of action research. However I had to work especially hard to be fair to the data throughout the study.

Lastly, the process model development represents only two of the five stages of theory building, specifically, the phases of conceptual development and operationalization. Although the primary aim of this study was the operationalization stage of the theory building process, it was our hope to undertake the confirmation and disconfirmation phase as well, which would stimulate a new study for the application phase. Initially the research team wanted to present the process model during a focus group to the expert occupational therapists, with the aim being to

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gain their perspectives on the overall components of the process mode and confirm its trustworthiness. However, this was not possible given time constraints.

Once the confirmation and disconfirmation phase has been completed, the application phase can occur. That is, further study, inquiry, and understanding of the theory in action is enabled, as "it is in the application of theory that practice gets to judge and inform the usefulness and relevance of the theory for improved action and problem solving" (Lynham, 2002, p. 233). Lastly, the transition from the application phase to the ongoing refinement and development phase comes into the foreground. This is where the practical world becomes an essential source of knowledge and experience for the ongoing development and refinement of the original theory. To illustrate, through implementing the process model into LTC facilities, occupational therapists will then be able to utilize the model within their practice and later self-reflect on whether or not the process model can be refined or developed in other ways than those presented, according to their knowledge and expertise in dementia care. The discussed limitations provide opportunities for future research. Researchers should build on the existing stages of theory building presented in order to contribute to best available evidence in occupational therapy.

Contrary to the study limitations, the development of this study's process model aligned with Lynham's (2002) description of good theory building. To achieve good theory building, two types of knowledge should result: *outcome and process knowledge. Outcome knowledge* is described as a form of explanative and predictive knowledge. In regards to this study, outcome knowledge was most present during phase one of analysis, as it was this phase that extracted significant elements within the data to best help me combine and explain important terms needed for a process model. Through that extraction, I then developed defined process model codes that transitioned my study into phase two of analysis. *Process knowledge* is described as a form of

increased understanding of how something works and what it means. Within the study, this knowledge type was most apparent during phase two of analysis, as I began to make clear connections between emerging findings through triangulation. Here, I integrated several sources of data including the LELQ Model, previous theses work, and other dementia related literature. These connections led to practical questions and strategies implemented in the process model.

Conclusion

This study was created for two reasons. First, referring back to my friend April, it was obvious that she had many passions and abilities that were just not recognized in her care. Being exposed to her care and watching her diminish every day, I wanted to learn how this experience could be avoided for others. Second, my literature review revealed that there was no commonly shared rationale or approach for occupational therapists working with the dementia population. However, findings suggest that there is a shared rationale for the occupational therapy process in LTC facilities when working with persons with dementia. The results from this qualitative research process yielded key themes that served as the essential backbone of the developed process model. This model assists occupational therapists by providing them with specific guiding steps that helps them recognize key considerations that ultimately impact quality of life. More specifically, this process model serves to assist in ceasing stories such as April's.

I was surprised by the findings, as there was great congruency of practice strategies among the participants in regards to all three process model dimensions: assessment, intervention, and outcomes. First, given the complexity of assessment, it was astonishing to hear from all participants that there were just four main themes to consider: emphasis on functioning of the facility, understanding who the person with dementia is as an occupational being, conceptualizing the transaction of the person and the activity situation, and then gathering all

these data in order to select an appropriate intervention. It was surprising how well each of these areas coordinated with the LELQ Model domains. That is, it is sufficient to say that the process model can be associated with the larger LELQ action study results. Furthermore, my findings suggest that occupational therapists need to first assess across all components involved in the care spectrum, that being, the person, the physical and social environment, the transactional nature of the two, and the meaningful occupation in which the person desires to do in order to move forward into the intervention domain of the process model.

Second, findings related to the intervention domain highlighted four key approaches: education, maintenance, modification, and prevention. The occupational therapists in this study shared a sense of knowledge in regards to this population and selecting appropriate interventions to best handle the person's unmet needs.

Lastly, a set group of outcomes for this population and setting were established with the findings and are supported with the OTPF. Results indicated that there were five outcomes congruent with the LELQ quality of life domains: reversal of adverse health complications, occupational engagement, occupational performance, social participation, and restoration of personal factors. The findings suggest that these outcomes are commonly documented in LTC facilities for persons with dementia. Furthermore, because these outcomes correspond with an increase in performance and participation in daily activities, they suggest a positive impact on persons' overall quality of life.

The developed process model serves as a means for the occupational therapy process. That is, the process model assists occupational therapists in the problem solving method in order to help persons with dementia improve their occupational lives. The profession of occupational therapy is a multi-theory profession. In other words, occupational therapists adhere to several

theories to explain their services. To generate a comprehensive process model, the process model proposed in this study was derived not only from the findings, but also from other exemplary dementia related works. Specifically, this model highlights key components in each domain (assessment, intervention, and outcome) and relates those components to actions to be completed by the occupational therapist when working with people with dementia in LTC facilities. Both the LELQ conceptual practice model and the associated process model provide a solid foundation for therapeutic reasoning with this specific population and setting. In addition, both models serve as an outline of the building blocks for thinking. It is with the process model that an explanation occurs for how occupational therapists move from one component to another and how to integrate information efficiently and effectively to make sound therapeutic decisions for their clients. Most importantly, both models contribute to transforming occupational therapy service delivery in dementia care by emphasizing methods that are top-down, resident-centered, and occupation-based.

CHAPTER FIVE: REFLECTIONS AND MY FUTURE BEST PRACTICE

Throughout the thesis process, I cannot say I engaged in the research with no biases. Contrary to biases, my identification of them only augments trustworthiness of understandings reached with the research (Mauthner & Doucet, 2003). As described in the methodology chapter, both phases of data analyses were based upon the participatory inquiry paradigm. Consequently, this shaped the way I analyzed and interpreted the data. Beyond this research paradigm, a key aspect of action-based research is employing reflexivity throughout the research process. Reflexivity expends the method of self-searching. Self-searching involves assessing the evolution of beliefs, assumptions, and implications to better understand how these may impact research decisions. Here, self-searching allowed me to understand how I was engaging in the research and through this deeper understanding I was positioned better to do the research. Employing the method of reflexivity, I will discuss assumptions, beliefs, and values I brought with me to occupational therapy school and throughout the thesis project, including considerable discussion allotted to the evolution of my beliefs and assumptions, and end with a final remark related to my future best practice.

To start, I want to share a brief background of my education that exposed me to research and the profession of occupational therapy. My passion for this health field developed while I was completing my B.S. in Rehabilitation Psychology and Kinesiology program at the University of Wisconsin-Madison. While studying at UW-Madison, I contributed to the development and assessment of a cooking program designed to assist young adults with disabilities to become self-reliant in the kitchen. During this experience I participated in collecting and quantitatively analyzing performance parameters set for the participants in the cooking program. This experience led me to explore the field of occupational therapy and

participate in many job shadowing opportunities in various practice settings during my undergraduate coursework. After exploring the field, I was certain that occupational therapy was the best fit for me, as it would allow me to engage future clients in purposeful tasks to enhance their participation and performance through daily occupations.

Once I started the occupational therapy program, I was eager to expand upon my research knowledge and skills by beginning a thesis journey. With a passion to help people with ADRD, it was obvious that Dr. Wendy Wood would be the best advisor fit for me as she has immensely contributed to ADRD literature. During these past two years, I have developed a great working relationship with Dr. Wood. Her knowledge and expertise in regards to dementia and occupational therapy astound me; I find myself continually learning and growing as a young professional as she offers constructive feedback to support my thesis journey.

In the beginning stages of the thesis project, I quickly realized that I knew very little about ADRD and what occupational therapy looks like in LTC settings. As I started a literature review to familiarize myself with significant dementia related concepts, panic began to set in. I was feeling overwhelmed as there was an abundance of literature to be read and, more significantly, I had a weak grasp of theoretical models, the prognosis and characteristics of stages of the disease, and what exactly occupational therapists do with people with ADRD. Through self-searching in the beginning stages, I discovered that I held the assumption that people with ADRD slowly lose all abilities, associated with the degenerative nature of the condition, and consequently, all hope for a quality life was lost for this population. Additionally, I held the assumption that people who reside in LTC experience a lower quality of life in comparison to those who had the means and support to remain at home. Reflecting back to visiting family members in LTC facilities, I remember thinking that all the residents appeared isolated and

unhappy. Furthermore, I thought I could never work with "these" people in a place like that. It amazes me how quickly my passion developed for this population and practice setting through my educational experiences.

It was in participating in the data collection and the first phase of data analysis that my beliefs and assumptions really began to transform. Through each individual interview my previously held assumptions began to break apart. All participants strongly spoke of the importance of actively engaging with the residents to promote optimal performance and participation in daily activities. Furthermore, occupation-based strategies employed by these participants yielded positive impacts for the residents and slowly affected larger systems changes to occur. The passion in their voices and the convictions they held about working with this population really inspired me to continue with the thesis project and enhance my dementia care knowledge.

During the data analysis process in phase one, I struggled with how to make sense of the countless examples of rich descriptions and how I would focus my thesis. I wanted to make sense of the data in order to understand the details more accurately. With a deep understanding of the interviews, I began to realize that using specific, concrete examples from the data could serve as a foundation for novice occupational therapists to turn to when working with this population in LTC. This is when I decided that an associated process model for the LELQ Model was imperative. At first, it was difficult for me to come to a clear understanding of both types of models, but my map metaphor helped immensely. All the knowledge gained from phase one allowed me to move into phase two of data analysis, in which a process model was constructed for occupational therapists to utilize in LTC with the dementia population. This research further

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contributes to evidence-based practice by sharing, through the process model, the common

rationales and approaches used by the occupational therapy participants in the LELQ study.

This research project has transformed my beliefs and assumptions dramatically in a way

that will forever impact my future best practice. First, I am amazed at the power and impact that

occupational therapists have when working with the ADRD population in LTC. It became clear

to me that occupational therapists serve as both the medium and means in their practice in order

to enhance the quality of life for residents and quality of care within LTC facilities. Prior to this

thesis, I did not view occupational therapists as having a central role in dementia care, as I had

not observed any occupational therapy service interaction with progressive diseases such as

ADRD in my own professional experiences. This project has significantly shaped how I view my

future best practice. I will take it upon myself to be greatly involved in working with persons

with dementia, as I believe the profession of occupational therapy has a true place in dementia

care. I will utilize both the LELQ Model and the associated process model in order to deliver

best occupational therapy services for persons with dementia. Through these models, I am able to

grasp the importance of the transactional nature of the person, the environment, and the person's

desired occupation and how these transactions press or elicit certain quality of life outcomes.

Utilizing the given specific assessment strategies in the process model will guide me in the right

direction for intervention planning. Implementing the directed approach or approaches and

selecting associated activities will then lead my client to optimal outcomes, subsequently

enhancing quality of life. As I enter the workforce, I will use self-reflection to ensure that I am

implementing these occupational therapy based means and media. Furthermore, by implementing

and sharing knowledge gained from this paper, I will contribute to best future practice in

dementia care. Through this thesis process, I discovered that I want to become an occupational

therapy detective and problem solver for persons with dementia in order to enhance evidenced

based practice through science-fostered innovation. Therefore, contributing to the occupational

therapy profession's centennial vision, specifically by focusing in on the necessity to link

research, education, and practice. By doing so, I am contributing to the profession by better

arranging itself to become a, "powerful, widely recognized, science-driven, and evidenced based

with a globally connected and diverse workforce meeting society's occupational needs" (Baum,

2006). In conclusion, this thesis process has been a valuable personal and professional

experience that has certainly shaped how I perceive myself in future practice and has immensely

contributed to the goals and principles that I aim to achieve.

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APPENDIX A: LELQ MODEL CODES

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	Parts of a story or example that signify at least one of the three

Occupational Disengagement	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 B: PROCESS MODEL CODES

PROCESS-LE-CM-Assessment

- Any concrete action-oriented steps in regards to the caregiving microsystem; things to do and/or how things were carried out that are relevant to assessment in a process model. This code does NOT include more abstract/conceptual considerations related to guiding clinical reasoning, as these are encompassed in the LELQ Model itself.

PROCESS-LE-PWD-Assessment

- Any concrete action-oriented steps in association to the person with dementia; things to do and/or how things were carried out that are relevant to assessment in a process model. This code does NOT include more abstract/conceptual considerations related to guiding clinical reasoning, as these are encompassed in the LELQ Model itself.

PROCESS-LE-EP-Intervention

- Any concrete action-oriented steps, things to do and/or how things were carried out that are relevant to intervention in a process model. This code does NOT include more abstract/conceptual considerations related to guiding clinical reasoning, as these are encompassed in the LELQ Model itself.

PROCESS-EP-TU-Intervention

- Any concrete action-oriented steps in regards to time use; things to do and/or how things were carried out that are relevant to intervention in a process model. This code does NOT include more abstract/conceptual considerations related to guiding clinical reasoning, as these are encompassed in the LELQ Model itself.

PROCESS-LQ-TU-Outcomes

- Any concrete action-oriented steps in regards to time use that are relevant to outcomes in a process model. This code does NOT include more abstract/conceptual considerations related to guiding clinical reasoning, as these are encompassed in the LELQ Model itself.

PROCESS-EP-RC-Interventions

- Any concrete action-oriented steps in regards to retained capacities; things to do and/or how things were carried out that are relevant intervention in a process model. This code does NOT include more abstract/conceptual considerations related to guiding clinical reasoning, as these are encompassed in the LELQ Model itself.

PROCESS-LQ-RC-Outcomes

- Any concrete action-oriented steps in regards to retained capacities that are relevant to outcomes in a process model. This code does NOT include more abstract/conceptual considerations related to guiding clinical reasoning, as these are encompassed in the LELQ Model itself.

PROCESS-EP-EE-Interventions

- Any concrete action-oriented steps in regards to the emotional experience; things to do and/or how things were carried out that are relevant to intervention in a process model. This code does NOT include more abstract/conceptual considerations related to guiding clinical reasoning, as these are encompassed in the LELQ Model itself.

PROCESS-LQ-EE-Outcomes

- Any concrete action-oriented steps in regards to the emotional experience that are relevant to outcomes in a process model. This code does NOT include more abstract/conceptual considerations related to guiding clinical reasoning, as these are encompassed in the LELQ Model itself.

APPENDIX C: PROCESS MODEL

Level and Focus of Assessment	Process for Gathering and Integrating Data
Caregiving Microsystem:	As an OT detective, gather data by:
• Where does the facility fall on an optimistic vs. pessimistic spectrum of its culture of care? • How are days predominantly structured and why?	• Exploring the facility's webpage, physical layout and dementia-related programming • Considering levels of staff training, the facility's values/beliefs, and communication styles and means • Observing routine activity situations and informally interviewing key stakeholders to determine structures and routines of days
Person with Dementia:	As an OT detective, gather data by:
• What defines the resident as an occupational being?	• Exploring who are key informants and how they can assist you? • Reviewing residents medical chart • Assessing physical, social, cognitive, and emotional capacities
Emergent Environmental Press:	As an OT detective, gather data by:
• How does the resident typically spend his/her time in predominant activity situations? • What barriers and enablers exist that are impacting performance and participation during activity situations?	• Observing fluidly various levels of interaction between the resident, the activity, other residents, and staff members • Monitoring behavioral changes
Data-based Intervention Planning:	As an OT problem solver, develop an intervention plan by:

• How will you optimize quality of life across the day through meaningful occupation?	• Integrating data to determine where, when, and how best to infuse occupation-based activities across the day in order to optimize the resident's quality of life
	• Determining which role(s) you will need to carry out (self-reflection):
	    ○ Collaborator
	    ○ Consultant
	    ○ Educator
	    ○ Advocate
	    ○ One-to-One Interventionist
	    ○ Paradigm Shifter
	    ○ Responsibility Taker
	• Taking into consideration the LELQ Model, your past experiences/expertise

Level and Focus of Intervention	Approach	Purpose	Roles	Activity Strategy
Caregiving Microsystem	Education	To increase facility and frontline caregiver competence	• Educator • Consultant • Collaborator • Paradigm Shifter	*Language* Common area of frustration; educate about the importance to listen to key words and understand nonverbal communication *Functioning of the Facility* Provide in service presentations on the impact of policy and procedures, staff support and education, staffing patterns, and structure of day for the resident
Person with Dementia	Maintenance	To preserve capacities through meaningful time use to support optimal emotional well-being	• One to One Interventionist • Advocate • Responsibility Taker	*Physical Activity* Provide a planned walking routine or group exercise class *Reminiscence Opportunities* Assist the person in rediscovering their history through the use of a memory box
Emergent Environmental Press	Modification	To enable the resident to compensate for ineffective actions	• One to One Interventionist • Collaborator • Educator	*Context* Use a quiet location for small groups or one on one occupational tasks *Cueing* Provide simple, 1 step directions
	Prevention	To reverse excess disability and prevent adverse secondary health conditions	• One to One Interventionist • Collaborator • Consultant	

Level and Focus of Outcomes	Type of Outcome	Definitions	Outcome Measures
Time Use, Functional Competence, & Relative Well-Being	Reversal of Adverse Health Complications	The promotion of a healthy, positive lifestyle at all system levels (resident, caregiver, facility)	Physical Assessments, Activity in Context and Time, and Observation Tool: Dementia Care Mapping
Time Use	Occupational Engagement	The ability to meet the demands of the occupation both physically and emotionally	Observation Tool: Dementia Care Mapping & Activity in Context and Time
Functional Competence	Occupational Performance	An enhancement in the ability to do meaningful daily life activities	Abilities Assessment Instrument
Time Use and Relative Well-Being	Social Participation	An enrichment in the human connection	Screens & Activity in Context and Time
Time Use, Functional Competence, & Relative Well-Being	Restorative Personal Factors	The ability to elicit prominent characteristics of the resident into daily life	Observation Tool: Dementia Care Mapping & Activity in Context and Time

APPENDIX D: COMMONLY UTILIZED ASSESSMENTS

From Data

- Global Deterioration Scale (GDS)

- Allen Cognitive Level Scales (ACL)

- Orientationx3

- Mini Mental Status

- St. Louis University Mental Status check (SLUMS)

- Observation

- Informal Interviews

- Theory of Retrogensis

- Cognitive Performance Test (CPT)

- Functional Behavioral Profile

Other Useful Assessments

- Family Questionnaires

- Activity in the Context of Time

- Functional Activities Questionnaire (FAQ) and Activities of Daily

- *Living* (ADL) from Alzheimer's.org

- Environmental assessment

- Problem Behavior assessment

- Abilities Assessment Instrument (AAI)

- Dementia Care Mapping (DCM)

APPENDIX E: BEHAVIOR MONITOR SHEET

Name:

Dementia Severity:

Primary Challenging Behavior:

Description of Behavior:

Frequency:

Antecedents:

Consequences:

Strategies Tried and by Who:

Consistency of Strategies:

Successful Strategies:

Unsuccessful Strategies:

Adapted from: Sunnybrook Health Sciences Veterans Centre (2010)

APPENDIX F: ROLES & DEFINITIONS

Collaborator: therapist is involved with family, treatment team, and/or administration; relationships are an equal partnership

Consultant: therapist provides specific actionable recommendations and/or referrals for resident, family, staff, and administration

Educator: therapist shares resources and knowledge, which can be both informal and formal means of communication and further supports rapport building

Advocate: therapist acts on behalf of resident and ADRD population in order to facilitate change in quality of care

One-to-One Interventionist: therapist provides direct assessment and intervention with the resident

Paradigm Shifter: therapist works to implement changes at the administration and community level to elevate quality of care for residents

Responsibility Taker: therapists seeks out direct interactions with resident or works with other vital caregivers; therapist uses first person language and goes out of their way to consciously support and advance care for residents

Adapted from: Alvord, C. (2014)

APPENDIX G: EXAMPLE OF RETROGENESIS STAGES