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Occupational therapy's role in hospice: Identifying occupational roles through the use of reminiscing and storytelling at end-of-life

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Occupational therapy's role in hospice: Identifying occupational roles through the use of
reminiscing and storytelling at end-of-life

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Despite purporting to serve the entire lifespan from birth until death, occupational therapy continues to search for its identity related to end-of-life services. Research exploring the role of occupational therapy in end-of-life care continues to be limited based on a small number of therapists practicing in the field and a misperceived role interpreted by other health professionals. This paper explores the expansion of occupational therapy's role in a hospice setting through the identification of occupational roles and meaningful occupation using reminiscence and storytelling at end-of-life. The Role Checklist, a modified version of the Role Checklist, and a semi-structured interview were used to assess four case study subjects. Interventions were implemented based on identified occupational roles and meaningful occupations at end-of-life. Three themes emerged including: reminiscing as assessment and intervention, the occupation of participation, and reminiscence, client-centeredness, and planting seeds. Findings suggest that reminiscence and storytelling can be used to identify occupational roles and occupation at end-of-life, enabling individuals to form deeper connections to the things they find most meaningful. Findings also suggest that reminiscence and storytelling can be used as occupation and can also build client-rapport throughout the assessment and intervention processes.

Occupational therapy's role in hospice: Identifying occupational roles through the use of reminiscing and storytelling at end-of-life

"Within every person is a distinct and unique being that is unlike any life that has existed or will ever exist again" (Moustakas, 1977, p. 1).

There continues to be debate among practitioners as to what role occupational therapy can play and what interventions are best put into practice regarding of end-of-life care in hospice. Despite the fact that occupational therapy proposes to serve individuals from birth until death, the profession continues to search for its identity as it relates to end-of-life care (Lala & Kinsella, 2011). According to Cantu (2005), the AOTA's 2000 *Compensation Final Report* lists approximately 1% of all occupational therapists in the United States working in general hospice settings. Even when accounting for other settings such as home health and long-term care facilities, this number is very small. Occupational therapists are generally underutilized in end-of-life care due to the fact that other disciplines often misinterpret or are misinformed about the role of occupational therapy (Haymaker, 2010) and what it can offer to someone who is terminally ill.

The literature posits important similarities between the foundation and philosophy of hospice care and occupational therapy. As stated, hospice "...exists to affirm life by providing support and care for those in the last phases of incurable disease so that they can live as fully and comfortably as possible" (American Journal of Occupational Therapy, 1986, p. 839). "Hospice recognizes that the dying process is a part of the normal process of living and focuses on enhancing quality of remaining life" (Trump, Zahoransky, & Siebert, 2005, p. 671). The profession of occupational therapy has long adopted a motto of "living life to the fullest." As a profession this motto is complementary to the stance of hospice, advocating for

a client-centered approach that assists clients “...to engage in everyday activities or occupations that they want and need to do in a manner that supports health and participation” (American Occupational Therapy Association, 2008, p. 626) in life. As it relates to hospice, “...occupations may provide a means of self-expression and engagement while also serving as a vehicle by which the client finds peace with the dying process and prepares for death” (Trump et al., 2005, p. 671).

While the literature is growing, research documenting the role of occupational therapists practicing in end-of-life care is lacking (Lala & Kinsella, 2011). Of the literature that does exist, a paradox regarding philosophical underpinnings and intervention strategies is apparent. Many therapists struggle with the contradictory nature of being a rehabilitation specialist that focuses on physical needs and regaining independence while caring for individuals who are at end-of-life and declining in functional abilities. The literature, however, also points to an approach that affirms the deterioration of function within an individual and focuses on a more holistic approach. This approach includes existential and spiritual factors, psychosocial well-being, legacy, and role competence through reminiscing, life review, and leisure participation (Bye, 1998; Haymaker, 2010; Hunter, 2008; Pizzi & Briggs, 2004; Rahman, 2000).

Role competence and the importance of leaving behind a legacy were discussed in the literature and are significant when thinking about intervention strategies. When someone approaches death, meaningful roles can be diminished or disappear all-together. In their work exploring the benefits of reminiscing with the elderly, Thorsheim and Roberts (2000) affirm that those who are dying can feel isolated and angry. The loss of lifetime

roles as one ages or is facing end-of-life may contribute to these emotions. As a result, individuals may feel less affirmed that their life has meaning, feel depressed and perceive lack of support from friends and family members and, ultimately, may not feel as if the “good death” is achievable. Haymaker (2010) suggests that occupation be used as a way to improve role competence in the face of declining function. Hasselkus and Jacques (as cited in Jacques and Hasselkus, 2004) also stress the significance of how meaningful occupation can empower the individual who is in decline to gain control over their self and their care and affirm important life roles.

The literature also indicates that it is important for individuals and families to come to closure with the impending death and “leave something behind”, or, leave a legacy in order to affirm their identity and solidify role competence. Hunter (2008) states that “It could be argued that human beings are connected through transmission of legacies” (p. 53). One way to leave a legacy, as the literature suggests, is through the use of reminiscence, storytelling, or life review (Birren & Svensson, 2013; Hunter, 2008; “Promote story-telling,” 2002; Trentham, 2007).

Personal Journey

This manuscript is in large part inspired by a personal experience while I was transitioning between my first and second years of a clinical doctorate program for occupational therapy. In June 2013 my dad lost his battle with esophageal cancer. Two short months later, in August 2013, my son was born. Their paths veered ever so slightly away from each other. Each has had an enormous impact both on my professional and personal life.

Upon hearing of my dad's admittance into hospice care, my life immediately paused and my brother, sister and I flew back to Michigan to be with my mom and be by my dad's side to help him die. Upon our arrival, to our surprise, he was cognizant and aware for the first couple of days. It was a strange juxtaposition – Dad, with his bellowing laugh and gregarious nature – seated on the bed of which he would die. In that time, knowing that our days with him were limited, my sister, being the family historian, suggested we interview Dad and ask him to speak about his life to his unborn grandson.

Our lives as a family have been well documented. My dad always had one camera around his neck and another in his hand ready to shoot. As my dad went through rigorous rounds of chemotherapy and invasive procedures throughout numerous hospital stays, he insisted that pictures be taken of himself and his changing body. He also insisted to capture the nurses, doctors, aides and other medical professionals caring for him in order to, as he said, “document the experience of my illness.” Recognizing his lifelong occupation of videotaping family Christmas', sporting events, weddings, graduations, birthday parties, etc.... (he had a side business in which he videotaped special events), he did not hesitate to oblige in our request despite knowing what the heaviness of the experience would bring.

In the videotaped interview I decided, more or less, to have a conversation with my dad. I asked him to speak to his grandson about his life, to give advice, to recall fun or difficult memories. This was a way for my dad to leave his legacy though the medium of a valued occupation (videography). The objective was focused on creating a physical document that my son could watch years later. My son would get a tiny glimpse of my dad - of his grandfather - both in the message through his words, but also the idiosyncrasies that

made him him – the inflection in his voice, his pause, his gaze, the way he used words, the way he told stories, the way he expressed emotion, how, despite looking ill and being close to death, he was engaged in life. What came, however, was more than just the physical document that was originally sought out.

Occupation was a bridge that spanned across relations and made a connection from my dad to the ones he loved in his final days. Being able to reminisce with his family members and speak to my son through that video camera helped solidify his role as a husband, father, grandfather, brother, and friend. Through that physical document – and maybe even more so through the stories that he shared about his life – he was able to leave a legacy that helped him die and helped our family process the loss of him. It also gave him the slightest bit of control during a time when his body was failing him and his functional abilities were fading.

It wasn't until about a year after his death that I recognized the nuances of what happened in my dad's use of meaningful occupation in the final days of his life. Small things, such as telling us where the video camera bag was in the house, directing us to the correct pocket in the video camera bag to find the right battery, helping position the camera from his bed so that it was at the exact right angle before shooting, or making sure the tripod was set up right – these were extremely important ways in which my dad could use occupation to stay engaged in life at the end of his life. His passion for videography continued as he was the “expert,” allowing him to make connections with his children and communicate to his unborn grandchild until he was no longer cognizant to speak.

While the death of my father has been (and continues to be) an extremely personal experience, the lessons learned are some of which I wanted to share and find more about. If this powerful experience happened to my family and I, how could other individuals and their families also be affected? What role does meaningful occupation play at end-of-life? And how might reminiscing, storytelling, and life review help to identify meaningful occupation in order to solidify occupational roles and pass on legacy during the final phase of life?

This study focuses on the role of occupational therapy at end-of-life through a client-centered approach using methods of reminiscence, life review, and storytelling. Assessment and intervention are explored through four case studies using the Role Checklist (RCL), a modified version of the Role Checklist, and semi-structured interviews focusing on questions related to occupation throughout one's life. Emphasis for both assessment and intervention are placed upon identifying meaningful occupation throughout life and at end-of-life in order to address role competency, legacy, and form a deeper connection with loved ones as death approaches.

Methods

This project was completed at a local hospice organization in Western Washington. The hospice organization provides comfort care to individuals diagnosed with a terminal illness with a prognosis of six months or less to live. Individuals served by this hospice organization span across the lifespan from pediatrics to older adults and reside in personal residences, care facilities, and adult family homes throughout the local community.

Upon examination of the roles an occupational therapist assumes at this local hospice organization and conversations with a clinical manager (who is an occupational therapist), it was determined that within the organization there currently is no structured way to elicit information from patients regarding valued occupation and occupational roles throughout life and at end-of-life. While therapists within the organization stated they may integrate reminiscence and the importance of meaningful occupation into practice, on a daily basis their roles primarily focused on positioning, pain management, equipment modification, and the ordering of specialized durable medical equipment (DME) to maximize comfort. Each therapist emphasized time constraints as a contributing factor in not being able to follow-up with patients on a regular basis. All therapists expressed a desire to spend more time with patients in order to build client-relationship and use tools of reminiscence and life review to further explore meaningful occupation at end-of-life.

For this project, different assessment tools were considered in order to gather information from individuals about valued occupation. Initially, the Canadian Occupational Practice Measure (COPM) was considered based on its focus on client-centeredness, spirituality, and the identification of occupational performance problems for individuals (Law et al, 2014). However, after reviewing the literature and communicating with another occupational therapist working on the East Coast who has utilized the measure specifically with hospice patients, it was deemed the measure to be a mismatch for this project due to its emphasis on progress, outcomes and the time it takes to administer and follow-up with patients. Given how time is of the essence when working with patients in hospice, the aforementioned occupational therapist emphasized how she was experiencing difficulty

reaching specified goals and achieving outcomes before end-of-life. Thus, a paired down and simpler measure was sought out.

The Role Checklist (RCL) was ultimately chosen as a viable assessment. The RCL is a questionnaire that can be given or read to a variety of different age groups ranging from teens to older adults. The questionnaire focuses on the salient nature that roles play and seeks to capture basic information related to an individual's occupational roles throughout one's life (past, present, and future). It is a two part tool proven to be reliable and valid and can be administered in a relatively short period of time (between 20-30 minutes) (Avrech, Rubin, Gavriael-Tyjchman, & Jarus, 2013). As Avrech et al. (2013) state, "The RCL was developed in order to create a clinical tool emerging from the Model of Human Occupation (MOHO)...and provides information concerning the way a person perceives his/her various occupational roles along the life span, and the values ascribed to each" (p. 454). Because of its short administration time and ability to capture information regarding meaningful occupational roles and occupations throughout life, the RCL was used as a screening checklist to prequel a more in-depth interview process that would utilize the concepts of reminiscence, life review, and storytelling. In addition to the RCL, given the more formal nature of the checklist, a modified and informal version of the checklist was created and used for three patients. In this version, assigned occupational roles used in the original RCL (such as "student," "family member," or "religious participant") were integrated into and chosen based upon the natural flow of conversation.

A semi-structured interview that integrated outcomes of the RCL or the modified version of the RCL was utilized as a means to gather more in-depth information regarding

occupational roles and occupations both throughout life and in the current state at end-of-life. Questions for the semi-structured interview were created based on existing literature and this researcher's personal experience with hospice and end-of-life (see Appendix for the list of questions used). Questions were formed both in reply to patients' responses on the RCL, from literature as related to end-of-life, and were centered around the main question, "Is there anything you want to accomplish, create, or do during this final phase in your life?"

Reminiscence, life review, and storytelling

Reminiscence, life review, and storytelling were naturally integrated into the questions and were an integral part of the assessment process as individuals were discussing occupational roles throughout life. In some cases, reminisce, life review, storytelling started out as part of the assessment process but evolved into becoming the actual intervention (this will be discussed later).

Reminiscing, life review, and storytelling were chosen as various benefits have been found in the literature as it relates to older adults and end-of-life. Reminiscing, defined by Kelly and Mosher-Ashley (2002) as "...a process of recollection where autobiographical memories are retrieved " (p. 37), has been used throughout the literature as a way to solidify identity and reinforce life roles in preparation for death (Haymaker, 2010). It has also been used as a means of empowerment and reciprocal communication to connect across generations in order to leave behind a legacy (Hunter, 2008; Thorsheim & Roberts, 1990). Storytelling, defined by Trentham (2007) as "...the process or occupation of sharing one's life story with others" (p. 23), has primarily been used to orally communicate the

meaningful life events that may occur throughout one's life (Trentham, 2007). Birren and Svensson (2013) suggest that with the advent of technology and the internet, individuals are becoming more isolated and less connected to each other. Storytelling is a way to increase self-esteem and build a strong family narrative (Birren & Svensson, 2013). The act of storytelling, too, has also been suggested to be an occupation (Trentham, 2007).

The benefits of reminiscing are well documented. In their 10 year-long study, Thorsheim and Roberts (2000) found that as individuals grow older the opportunities for social support – the ability to share and receive stories with others – decrease. They also found that as individuals age, the chances to receive esteem through communication decline. People lose interest in activities as their physical and cognitive functioning begins to deteriorate. As the *Occupational Therapy Practice Framework (OTPF)* emphasizes the importance of quality of life, participation in occupation, and role competence regarding outcomes (American Occupational Therapy Association, 2014), reminiscing and storytelling, used as a form of occupation, can help individuals feel as if they are being heard (Trentham, 2007). This can add meaning to lifelong roles and, in turn, affect quality of life. Individuals, when they are affirmed in their identity and roles, feel empowered. Similar to the experience of my dad, this can give them a sense of control and well-being (Thorsheim & Roberts, 2000), especially at end-of-life.

Thorsheim and Roberts (2000) have also discovered links between meaningful reminiscing to improve physical health including lowered blood pressure and heart rates in participants. Additionally, Birren and Svensson (2013) comment on the benefits of sharing stories stating that reminiscing can "...increase self-acceptance, decrease anxiety/tension,

increase positive view of others, increase meaning and purpose in life, and connectedness with others” (p. 5). Furthermore, reminiscence can help with comfort measures such as pain relief as individuals are prompted to focus on aspects of their life that are meaningful (Pizzi & Briggs, 2004). Occupational therapists working in hospice can use reminiscing to “...facilitate quality of life through engagement in occupations during the client’s remaining days” (Trump et al., 2005, p. 671).

Case Study

Recruitment

Four individuals were recruited and asked to participate in order to gather information for this study. Recruitment took place under the direction of a clinical manager at a hospice organization in Western Washington. A combination of snowball sampling and clinical observation during site visits of hospice team members (occupational therapists, social workers, RNs, chaplains, and hospice aides) resulted in referrals of participants. Criteria for individuals to participate included receiving hospice services through a local hospice organization during the time that information was being gathered. In order for individuals to be eligible for services individuals must have been given a prognosis of six months or less to live by two practicing physicians, one of whom represented the hospice organization (U.S. Government Publishing Office, n.d.). Participants were notified that a doctoral student was doing a ‘student project’ and asked if they wanted to participate. There were no specific criteria regarding age or diagnosis. As related to cognitive status, individuals needed to be oriented regarding receptive and expressive communication in order to process questions being asked and respond to those questions in some form.

Generally speaking, participants were recruited in the less acute stage of their disease (closer to the prognosis of 6 months) than to the more acute stage (closer to the time of death). This was done in order to proceed through as much of the assessment and intervention process as possible.

Patients participating were interviewed in the place they were receiving services (which in all cases was a personal residence in their home or in a long-term care facility). During the first visit, for all sessions, this occupational therapy student was accompanied by a practicing and licensed occupational therapist. Follow-up sessions were completed either independently or with a licensed occupational therapist present. Standard occupational therapy was delivered with the addition of the Role Checklist.

Participants

Pseudonyms were used for all participants in order to adhere to HIPPA regulations.

Janice. Janice is a 99 year old Caucasian female. Patient records reveal that primary diagnosis for services into hospice include malignant neoplasm of breast, unspecified, comorbid with various other disease processes. She was admitted into hospice care approximately two months prior to assessment for this project. She had previously seen an occupational therapist regarding durable medical equipment to alleviate pressure sores and for environmental modifications due to increased fall risk because of macular degeneration. At the time of assessment for this project, Janice was living in an assisted living facility in which she shared a room with another resident. Janice reports that she has one adult son who lives on the other side of the state. Her son calls her daily and comes to visit when he is able. Her other child, a daughter, died several years ago from cancer. She

has a granddaughter who lives in the same city and visits on a weekly basis which she enjoys. Her main mode of mobility is a power wheelchair. Recently she reported that the battery was beginning to fail inhibiting her mobility around the facility. It was encouraged by the practicing occupational therapist to occasionally transfer into a manual wheelchair in order to elevate lower extremities in order to reduce edema. Janice was referred to this project due to her cognitive capabilities and natural gregarious affect. She identified early in the assessment process that she has always been a very social person and “wanted to help a student do their project.” As a doctoral occupational student, I was present for initial sessions with the practicing occupational therapist. After discussion with the practicing occupational therapist, the clinical manager, and Janice, she was deemed an appropriate fit for the project and asked if she wanted to participate. The initial assessment, in which the RCL was used in checklist format, was attended by the practicing occupational therapist. Sessions thereafter were done independently by the occupational therapy student.

Yuri. Yuri is a 91 year female of Japanese descent who is a fluent English speaker. Records indicate a primary diagnosis of central nervous system lymphoma, unspecified, comorbid with various other diseases. She was admitted into hospice care approximately two months prior to assessment for this project and had previously seen an occupational therapist regarding weakness in her lower extremities and a fall. Yuri currently lives alone in an independent living facility. She reports that she moved to the facility a few years ago to be closer to her daughter and grandchildren. The occupational therapist made a referral to this project as she had been seeing Yuri on nearly a weekly basis to order appropriate durable medical equipment and to educate regarding comfort and safety. Additionally, the occupational therapist reported that she developed strong rapport with Yuri and

subsequently had meaningful conversations regarding existential orientation and end-of-life. Throughout the duration of assessment and intervention with Yuri, the practicing occupational therapist was present. Because a relationship had already been established between the two, it was decided that a modified version of the RCL be administered for the purposes of this project. As mentioned previously, aspects of the RCL, including significant occupational roles throughout life, were broached through casual conversation and semi-structured interview rather than a formal checklist.

Al. Al is an 88 year old Caucasian male. Patient records reveal that primary diagnosis for services into hospice include malignant neoplasm of prostate with secondary diagnosis of malignant neoplasm of bone and bone marrow. He was admitted into hospice care approximately nine months prior to assessment for this project and had previously seen an occupational therapist once regarding safety around his home. At the time of assessment for this project, Al was living with his wife in their home in Western Washington. Al and his wife have three daughters, all of whom live out of state. Al and his wife report that all of their daughters are engaged in the plan of care for Al and come when they are able in order to assist. At the time of assessment, Al was observed getting in and out his chair and walking around his home as modified independent (using a cane and stabilizing on furniture when needed). It became apparent very quickly that Al's worldview of advocating for a sustainable planet was a priority. Using the modified version of the RCL in conversation, Al identified his love for building structures (his lifelong job was in the construction industry) and doing projects around the house as significant occupational roles throughout his life and currently in his life. Al was referred to this project by the hospice RN because of his desire to continue engaging with meaningful projects as his

disease progressed. He was also referred based upon his affable personality and his willingness to engage with healthcare professionals. In addition, he identified a desire to be of help in gathering educational information for individuals at end-of-life. A certified occupational therapist from hospice was present for the initial assessment and interview with Al. Further visits were conducted independently in consultation with the practicing occupational therapist.

Abbie. Abbie is a 60 year old Caucasian female residing in Western Washington. She is married and has three daughters, two of whom live out of state. She reports having moved to Washington about seven years ago due to her husband's work. Hospice records reveal a primary diagnosis of multiple myeloma without having achieved remission. Upon admission for this project she has been complaining of recent bouts with pneumonia and fatigue due to chronic respiratory failure and her cancer. Abbie was admitted into hospice services approximately three months prior to an initial assessment for this project. She had not been seen by an occupational therapist previously. Abbie's referral for this project came from a hospice social worker who had seen her recently. The social worker discussed Abbie's passion for family genealogy and relayed that she was working on a project making 'memory books' in which she was tracing her family's roots back several decades. Included in the books were pictures, maps, letters, and other documents tracing her family's history back to her heritage home in Europe. At the time of the initial assessment with Abbie she was receiving supplemental oxygen and able to ambulate independently throughout her house. She reported, however, that she was experiencing an increase in fatigue throughout the day and sleeping more. She said that, despite her increase in fatigue, she wanted to continue with her project (she had been working on it for about seven years) and finish as

much as it as she could before end-of-life. She relayed that her daughters and family were not entirely interested in the project and that she wanted to leave her work behind as a legacy document. "I want someone to be able to see it and use it" (Abbie, personal communication, July 2, 2015). The modified version of the RCL was used upon initial assessment to identify meaningful occupation and occupational roles currently and throughout Abbie's life.

Results

Case Study Results from Reminiscing

Janice. Meaningful occupations that were identified during the process included: talking with her son on the phone, visiting with her granddaughter, listening to music, having volunteers read books to her, and socializing with interested parties.

Yuri. Meaningful occupations identified included: casual walks around the independent care facility, eating Japanese food with her daughter and grandchildren outside of her facility, and socializing with interested parties.

Al. Meaningful occupations included: working on projects at home (building a gurney for his body to be placed on after end-of-life, creating a 'sustainable house' model, and building a rain flow gutter system), talking about his worldview/ideas with others, and caring for his wife.

Abbie. Meaningful occupations identified by Abbie include: talking about family heritage, working on her memory book project, and spending time with her sister and her family.

Emergent Themes from Assessment and Intervention

During the assessment and intervention processes participants conveyed a breadth of knowledge and insight regarding meaningful human occupation at end-of-life. As a result, three different themes emerged from clinical observations, clinical notes, and consultation with practicing healthcare professionals, including occupational therapists. Those themes included: reminiscing as assessment and intervention, the occupation of participation, and reminiscence, client-centeredness, and planting seeds.

Reminiscing as assessment and intervention. For all participants, when posed with the central question, “Is there anything you want to accomplish, create, or do during this final phase in your life?” each had a difficult time answering the question directly and concretely. In most situations there was not a ‘bucket list’ of things to accomplish or do before end-of-life. Especially for the two oldest participants, Yuri and Janice, 91 and 99 respectively, the response was of the tone, “I’ve lived a long life. I’ve already done a lot. What more else is there that I can do?” As Janice stated, “All I really want to do is sit here, be comfortable, and enjoy the rest of my life, however long that may be” (Janice, personal communication, May 29, 2015). For Al, the tone was slightly different. Through the process of administering the modified RCL he was able to identify large projects and life goals aligning with his worldview that he was hoping to achieve before his death. Pinning down specifics and corralling ideas tended to be a challenge initially as he wanted to achieve everything on his list. Abbie’s picture project was similar. While administering the assessment through the use of the modified RCL she identified that making “memory books” of her family heritage and genealogy was a meaningful occupation that she had

taken part in over the past seven years. Before she passed away she stated that she would like to scrapbook the 11 boxes worth of pictures and information sitting in her bedroom in order to leave a legacy for her loved ones.

For all participants, working through the RCL as an assessment, whether in its original form (Janice), or the modified form (all other participants) presented an opportunity to reminisce about meaningful occupational roles and occupations that they held throughout their lives. In turn, for all participants, storytelling and reminiscing actually became a meaningful occupation as the process unfolded. Specifically, for Yuri and Janice, the process of assessment took its own form to the point in which, in subsequent sessions, reminiscing and storytelling became a focal point of the intervention. Through the use of the RCL Yuri was able to identify walking as an occupation that she had valued throughout her life. Walking on the facility campus where she lived was used as a bridge to be able to reminisce about her early life living in wartime Japan, talk about being part of the first wave of females to access higher education in Japan, discuss her transition to living and working in the United States, and recall her many trips to foreign countries. As Yuri stated on several occasions after walking and reminiscing, “Doing this makes me feel so much better. I always feel so good after we walk and after I can talk to you” (Yuri, personal communication, May 21, 2015). Regarding her role as it relates to end-of-life, “I’ve told you some things that I haven’t told anyone before. I didn’t think anyone was this interested in my life and what I’ve done. I think I’ve actually done a lot” (Yuri, personal communication, May 28, 2015). Janice shared a similar sentiment. Through the RCL she identified herself as someone that has always enjoyed people and being social. At times, however, she described living a very challenging life. Growing up and working in the fields of Mississippi and being

raised by her grandparents because her parents where not present was not easy, she explained. She talked of two tumultuous divorces, being a single mother, moving several times, and the loss of her daughter to cancer. She also reminisced of adoring times - her love of country and jazz music, the fondness of her aunt, the specific details of the house she grew up in, and first television she ever saw. Being able to reminisce and socialize “...has really been wonderful. I think it’s helped me. I’m a ‘backwoods’ type of girl and I didn’t think that I had much to offer at this point in my life. My mood feels brighter after talking with you” (Janice, personal communication, May 29, 2015).

In his article, Trentham (2007) describes the occupation of storytelling as significant for older adults as these stories “...convey the meaning-making process, the worldview and value system of the story-teller” (p. 23). From an occupational therapy perspective, Trentham discusses how storytelling is not simply just a way to gather information or create an occupational profile, but rather can become the enabling occupation of the person telling the story. As stated, “Not only does storytelling serve as a means to help us understand our lives, but it also assists older adults to adjust to identity threats associated with aging” (Trentham, 2007, p. 23). Kirsh (1996) confirms that a narrative approach is increasingly used by occupational therapists to “...facilitate the *employment of one’s life*” and states it as “...an approach directed at the individual as a whole – his or her feelings, thoughts, perceptions, and beliefs – rather than the pathology itself” (p. 56). With all participants this was seen as a common thread – the ability to make sense of life as death approaches. To be heard and understood as a whole person in the face of death and to know that their personal narrative was of significance was valued by each participant.

The occupation of participation (in the project). For this project each member was recruited in a similar vein and asked a question of the like, “Would you like to participate in a project that a doctoral occupational therapy student is doing about meaningful tasks at end-of-life?” The resounding response was affirmative. Janice, Al, and Yuri were particularly eager to “help out the student.” Aligning with Al’s worldview of being a purveyor of life-long education and a “global citizen” willing to help others, he repeatedly stated expressions of, “I am willing to help you however I can, “Are you getting enough information about me?” and “Let me know if you need more. I want to make sure that you are getting what you need.” Through conversations the importance of education also came through from Yuri. While more muted than Al, on several occasions she expressed the importance of education and was happy that she was able to help contribute to this project during a time when physical losses related to her body were beginning to take place. The reciprocal relationship added to her role as a “teacher” and an “educator” – as someone who had something to contribute at end-of-life. This was conveyed to Yuri from myself and the accompanying occupational therapist in the form of, “You are like our teacher. We learn from you every time we meet with you.” Statements like this affirmed her role. Janice, too, in her sociable nature, was excited to be able to contribute to a noble cause of furthering education. “I’m not sure how this is helping you but I hope it is. I am happy to participate if this is helping you do what you need to do to be successful in school” (Janice, personal communication, May 29, 2015). These roles and the ability to participate as outlined in the OTPF, helped to support occupational performance at end-of-life, whether participants were cognizant of them or not (American Occupational Therapy Association, 2014).

For all participants, the actual participation in the project became an occupation integrated into their lives at end-of-life. Each participant shared how they looked forward to the subsequent visit as a way to connect with the world outside of their illness. The time spent with occupational therapy became a part of the weekly routine in which all stated that, in some way, they looked forward to. Lala and Kinsella (2011), in their study exploring the embodied nature of occupation at end-of-life, came to similar conclusions stating, "...this suggests that research with people at end of life may not simply provide a voice for people who are dying, but may also be a meaningful occupation for them" (p. 253). As Janice stated, "I look forward to our regular time together. While I meet with my granddaughter on a regular basis and talk to my son over the phone, I enjoy laughing and talking about my life with you" (Janice, personal communication, June 30, 2015).

As a student under the age of 40, I was able to witness the effects of a generational gap and the importance of passing on valued information (often times in the form of wisdom) and a legacy from older adults to a younger generation. For older adults, providing problem-solving guidance for current social challenges to younger generations is of significance in leaving a legacy (Trentham, 2007). As Hunter explains, "The ability with age and experience to distill experiences down to what is most important to each individual and then pass along those nuggets of wisdom is considered the most important type of legacy..." (p. 53). Myerhoff purports (as cited in Thorsheim and Roberts, 1990) that to "...receive their experiences' ...is important for them (older adults), and for us who are younger. Their accumulated experiences are available through their stories" (p. 115). Coleman (as cited in Trentham, 2007) affirms this, stating, "...healthy psychological functions are those that are beneficial not only to the individual but also to society and to

future generations” (p. 25). For Abbie, in particular, the occupation of creating a family genealogy revealed a duality. Participation in this project affirmed the many years of work that she had accomplished in recording her family history. Furthermore, being able to pass that work on to the next generation was significant as it represented the wisdom and hard work that generations of family before her possessed and that she valued (and also possessed).

Reminiscence, client-centeredness, and planting seeds. As discussed in the introduction of this manuscript, client-centered care and enhanced quality of life are the cornerstones of the hospice approach. As some studies suggest, physical symptoms resulting from pain and discomfort may be of less concern for terminally ill individuals than issues resulting from psychological and existential pain (Chochinov et al., 2005). For this project, reminiscing with participants about meaningful occupations became a tool to build client-rapport and thus explore spiritual, psychological, and existential needs, and, ultimately, assisted with future interventions as disease progressed.

Both the RCL and the semi-structured interviews were used not only as a means to gather more information about occupational roles and identify meaningful occupation, but ultimately were utilized to “get to know the patient” and build a relationship of trust. As Thorsheim and Roberts note (as cited in “Promote story-telling,” 2002), asking the patient about something specific that is likely to have significance is important. However, learning not to probe too deeply too soon is also key. As was seen throughout this project, typically there are cues on display within a person’s environment (pictures, mementos, souvenirs, etc...) that hold meaning in which a person is willing to discuss (“Promote story-telling,”

2002). Asking about these items and engaging in active listening can lend to a powerful experience of connection for both the patient and the therapist. As Thorsheim and Roberts state (as cited in "Promote story-telling," 2002), "It feels good when people listen to us, express their appreciation for us, are open with us, and include us. When we are asked to tell stories of our life experiences and someone listens to us, we feel empowered" (p. 116). All participants relished the opportunity to "be interviewed" and share the patchwork of stories which made up their lives.

This strategy was used with all participants for this project and helped to "...find common ground...and engage in a social process that brings about mutual support that is empowering" ("Promote story-telling," 2002, p. 115). For Al, the process of sharing his life occupations came readily. His affable nature lent to conversation and prolific sharing. The conversations went deep and, as he stated, "...tell you about who I am and why I want to do these meaningful projects at the end of my life" (Al, personal communication, June 18, 2015). For Yuri, Janice, and Abbie it was a more deliberate process. Each, through a fusion of reminiscing and meaningful occupation (walking, talking, and scrapbooking, respectively) was able to open up about their lives and give credence to the meaning behind them.

As disease progressed, in some instances, the trust that was garnered through reminiscence, participation in meaningful occupation, and active listening was used as an opportunity to 'plant seeds' regarding the loss of physical function for what was to come. For both Al and Yuri, the loss of physical function highlighted an inevitable decline and loss of control. Both had been fiercely independent throughout their lives and had a desire to

continue their autonomy. Gently reminding Yuri that dependable medical equipment could be ordered “once you feel ready” was eased by the reciprocity of the established relationship. Eventually a wheelchair and a Hoyer lift were placed in her room for “if the time comes that you need to use it.” For Al, the suggestion of environmental modifications and the thought of potentially moving tasks to the main floor of his house (as opposed to his workshop in the basement) was softened based on the reception of his thorough explanation of what mattered most to him and why it mattered. For Abbie, simply displaying interest in her memory book project and asking about the history of her family led her to consider paring down what she felt like was most meaningful in order to leave a legacy. As Thorsheim and Roberts state (as cited in “Reminiscing benefits,” 2000), “The research that we did showed that when people are engaged with others in meaningful way, there is an increase in trust and a greater sense of well-being” (Reminiscing benefits elderly section, para. 3). For each participant, the bond that was created through the process of reminiscing and storytelling enabled a more holistic approach to assessment and intervention, and gave voice to what mattered and what they hoped to achieve at end-of-life.

Application to Occupational Therapy Theory

Core concepts of Model of Human Occupation (MoHO) - volition, habituation, personal capacity, occupational identity, occupational competence - were seen throughout this project. Turpin and Iwama (2011) note that, “...volition explains why people select occupations, habituation outlines how they organize their occupations, and performance capacity attends to the skills and abilities that enable them to perform their occupations”

(p. 139). As client-centered care remains central to both hospice and occupational therapy it was apparent that the client-centric ideas of MoHO resided deep within the individuals that I came into contact with – and, in fact, due to the proximity to death, may become more pronounced and profound than any other time throughout life. “Living with the knowledge of impending death frequently informed the nature of occupational engagement at end-of-life” (Lala & Kinsella, 2011, p. 250). Set to different language, the motivations that drive occupation come into greater focus as death approaches. As Al stated, “When you have a terminal illness, life looks a lot different. Throughout my 88 years of life, I have never felt this way before” (Al, personal communication, June 9, 2015).

At end-of-life, multiple facets of MoHO are affected – volitional aspects shift based on a defined life expectancy (“Now that I have limited time, what are the most important things in life?”), habits are rearranged based on a gradual decline in health, and performance capacity is bound by a slide in physical capabilities. Volitional aspects of MoHO were used by most all patients and participants while receiving services from hospice. Before significant illness and an eventual admission into hospice care, patients had specific roles, interests, values and occupations in which they were engaged in throughout their lives. With a decline in physical function and a proximity to end-of-life, some of these roles, occupations, habits, and routines were diminished, lost, or changed in an impactful way. Thus, in the form of reminiscence and storytelling used as a guide for treatment, volitional aspects of the person, values, interests, habits, and routines were assessed and infused into treatment in order to engage individuals in meaningful occupation and connect them to the life that was surrounding them. In the end, the volitional aspects of life drove the care at end-of-life - nothing could substitute for an individual’s own voice as to how

they wanted to live out the final phase of life. I was able to 'see' MoHO in the wide variety of individuals receiving hospice care and participating in this project. This was evident as they chose to participate in the aspects of life that were most meaningful. These concepts, while unique to each individual person, are foundational and help explain the "whys" of what drives individuals to participate in meaningful occupation throughout the lifespan, especially at end-of-life. Ultimately the goal was to get individuals involved in occupations that had significance and meaning and were incorporated back into their own ethos.

Discussion

Upon initially setting out do this project I had a vision to follow a psychologically-based model called dignity therapy. In dignity therapy the medical professional asks the terminally ill individual to express the issues that matter most and how they want to be remembered as death approaches. This process can be done through the mode of reminiscence or storytelling. Responses are audio recorded, transcribed, edited, and then made into a 'generativity document' - a physical piece of literature - which can be bequeathed to a loved one at end-of-life (Chochinov et al., 2005). Research shows the reciprocal benefits of dignity therapy as it helps both the family of the terminally ill person and the terminally ill person in the bereavement process. Going through the process of dignity therapy brought memories, thoughts, and feelings to the surface and reaffirmed individuals of their sense of continued self-worth (Chochinov et al., 2005). Being able to view, touch, and appreciate their own albums helped patients to re-evaluate and appreciate the roles that they were able play throughout their lives (Ando et al., 2007).

My initial plan for this project was to infuse occupational therapy in the form of meaningful occupation into the dignity therapy model. My vision included identifying and using occupational roles to create a physical 'document' – a letter, a song, a recording, a piece of artwork, a valued artifact or heirloom, a story, spoken word, etc... What I found, however, was that end-of-life is an extremely personal and unique process. "Asking" a patient or a patient's family to "come up with" something meaningful felt forced and ultimately contrived. These precious moments needed to happen organically and come from the hearts, mouths and minds of those who were experiencing them in order to be meaningful. As mentioned above, the volitional aspects at end-of-life – the 'whys' behind certain decisions and actions– are extremely personal and an integral part of the dying process. The more time I spent in hospice the greater evident this became.

As Hassulkus (1993) describes in her article about her personal journey caring for her terminally ill mother, "Occupational therapists, because of a focus on the everyday meanings of life, have powerful avenues available for connecting with clients" (p. 722). She goes on to state that, "A therapist can be truly present in the dying process by using his or her unique knowledge and understanding of occupation to promote connecting" (p. 722). This statement resonated throughout my experiential internship as I learned the role of occupational therapy in hospice. As my clinical instructor Donna, a 21 year veteran of hospice, stated on several occasions, "Our role as occupational therapists in hospice, ultimately, is to facilitate placing patients in a position in which they can more easily connect to the world that is around them" (Donna, personal communication, May 15, 2015). This connection may be in the form of their loved ones, caregivers providing services, or themselves. "The end goal" she says, "is to assist them in getting to a place

where they can share precious moments with the things that they are connected to in life” (Donna, personal communication, May 15, 2015).

The idea of an occupational therapists becoming a catalyst to facilitate meaningful occupation has become a familiar narrative while reviewing the literature and gathering information for this project. Specifically, at end-of-life, the occupational therapist assumes a significant part in the dying process as the linkage to meaningful occupation takes on a larger role as life comes to a close. Pizzi (as cited in Hasselkus, 1993) embodies this concept in talking about working with a former chef to achieve the meaningful occupation of cooking a final meal at end-of-life,

“Many components of connecting – the shared experiences, the response to idiosyncratic needs, the patient’s need for reciprocity, the circle of care – were part of this cooking activity. The occupational therapist connected as he entered and shared the dying experience with the patient and family through the use of occupation” (Hasselkus, 1993, p. 722).

Bye (1998) affirms the power to connect individuals to what is most important, stating, “It is about the occupational therapists helping clients to realize their goals to connect with life, and people in their life, on a level beyond illness and receipt of care. The achievement of this outcome affirms clients’ lives” (p. 19).

Through this experience, in order to gain a deeper understanding of occupational therapy’s role as it relates to end-of-life care, I have often likened the idea of utilizing meaningful occupation as a way to connect those at end-of-life to the metaphor of building a bridge in order to link parts A to parts B.

In this case, occupation acts as the bridge that connects those who are terminally ill with the meaningful aspects of life that surround them. It is through the roles, habits, routines, idiosyncrasies, the small (and large) passions, and sometimes the mundane aspects of life in which one is able to affirm who they are and what place they hold in this world. Through these familiarities – these occupations - individuals are able to gain a sense of control over their world and share their individual selves with the things that they love. Identity continues to be a reflection of occupation, albeit in a more pronounced way, as death approaches.

Reminiscence and storytelling can act as the scaffolding surrounding the bridge, providing structure to the process in helping to identify and ultimately create the construct of the connecting bridge. It is a way to look at the whole picture of one's life, hand pick the most meaningful aspects of it, and then "do" those aspects. It is also a way to connect in the present, to the here and now. As was seen in this project, reminiscence acted as a tool to help participants express who they were and who they have become through their occupational lives. It was meant to be used as an assessment, but, for some, became the intervention.

Occupational therapists, in this metaphor, are the engineers, considering all the parts and pieces that need to come together to facilitate connection at end-of-life. While they do not actually build the bridge, they facilitate and offer structure to the process, lending expertise to the "hows" and "whys" of occupations that connect individuals to what is meaningful in life.

The “doing” of the occupation – whether it be videotaping a legacy document for a grandson (my dad), socializing and chatting about the details of her life or having a book read to her (Janice), constructing a sustainable model house (Al), walking and reflecting upon her life lived in two countries (Yuri), or completing a family heritage project with her sister in order to leave a legacy (Abbie) – becomes the vessel in which those participants are carried, and, ultimately, in which they are connected.

Limitations

There were limitations when considering this project. When this researcher set out to recruit individuals a sample size of 10 participants was the focus. Given the nature of hospice care and this researcher’s new orientation to the hospice organization, it was decided early on in the process that 10 participants was too ambitious. While a large sample size is not required for qualitative research, clinical observations and data can be enhanced by a larger pool. This can result in a greater amount of information collected and, in the case of this project, more themes that could have emerged. Subsequently, the participation of more individuals could have diversified the sample including a wider range of age, socioeconomic status, ethnicity, gender, and disease processes.

Time constraints were also a factor when considering information gathered. In total, this experiential doctoral internship spanned a course of 16 weeks. This researcher spent several weeks becoming acclimated to the setting in order to learn the roles of all team members (RNs, social workers, hospice aides, chaplains, and occupational therapists) and the mission of this particular hospice organization. Because recruiting took place through snowball sampling and clinical observations, it was important to build connections and

give a thorough explanation about the purposes of the project to hospice team members. Ultimately, over the course of 16 weeks, it was difficult to educate team members on the project, recruit participants, conduct assessments, and carry out interventions. A study that spans the course of six months to one year may elicit more comprehensive results and themes.

The nature of working with hospice patients also presented unique challenges. The natural progression of disease at times rendered some individuals too ill to participate limiting the amount of information collected. In particular, one participant's health began to decline during the intervention phase. While information was gathered from her, after her decline the plan of care focused primarily on pain management and comfort and thus no additional visits were deemed appropriate to make.

Next Steps

As mentioned in the beginning of this manuscript, research documenting occupational therapy's role in hospice is sparse (Lala & Kinsella, 2011). This may be due to the fact that there are very few occupational therapists throughout the country practicing in end-of-life services (Cantu, 2005). The model of employing three occupational therapists at my experiential site is unique across the United States and should be further researched to inquire about the effectiveness of therapy at end-of-life. Ultimately a larger study of occupational therapy services spanning multiple hospice organizations across a wide geographic area could be beneficial in advocating for the unique skill set that the profession can offer in end-of-life care.

Research inquiring about the use of reminiscence in occupational therapy is mentioned throughout the literature, however, very few studies focus solely on the effectiveness of reminiscence or storytelling at end-of-life. As Trentham (2007) suggests, a further comprehensive inquiry exploring reminiscence and storytelling as occupation could be a beneficial contribution to the field.

Furthermore, the infusion of dignity therapy into occupational therapy could be beneficial for patients (and their families) and for the field of occupational therapy. A larger study in which participants are recruited to contribute a “generativity document” based on meaningful occupation (in place of a just transcribed written document) may be a way to incorporate reminiscence further and thus explore existential orientation, role competency, legacy, and reciprocity between the terminally ill individual and their loved ones.

Conclusion

While there are striking similarities between the philosophies of both hospice and occupational therapy, limited research and a lack of practicing therapists in hospice care continue to spawn a debate regarding the depth and breadth of occupational therapy’s role in end-of-life care. As this case study reveals, occupational therapy at end-of-life is not only a beneficial service in the conventional sense of providing pain management, positioning, environmental modifications, wheelchair assessments, and durable medical equipment expertise, but also extends into the existential and spiritual realm. The use of reminiscing and storytelling can help identify occupational roles and, ultimately, meaningful occupation at end-of-life. Through this it can also help connect individuals to the things they find most

meaningful in their lives. In some cases, as was seen in this study, the act of reminiscing and/or storytelling actually became the meaningful occupation in the quest of identifying occupation at end-of-life. It was also discovered that identifying occupational roles through reminiscing and storytelling, in the process itself, helped solidify roles at end-of-life as a “helper” or “contributor” and built a unique patient-therapist relationship. Over time this reciprocity and trust allowed for a smoother transition to comfort care as disease shifted towards decline. In sum, it was seen that this integrated approach, examined through a unique occupational lens, helps to define and redefine the role of occupational therapy as a profession that serves the whole individual across the entire lifespan, from birth until death, not from birth until the prognosis of death.

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Appendix: Semi-structured interview at end-of-life.

What is your understanding of your illness?

What are your biggest fears and concerns?

What goals are most important for you?

(Gawande, 2014)

What is important to you right now?

a. What is important for you to discuss today?

b. What do you see as your future?

What are you hoping for?

What are you concerned (worried, afraid) about?

What else do you want me to know about who you are or what you believe to help us take better care of you?

(Farber, 2009)

Info related to how patient spends time:

Can you paint a picture for me of what a typical day is like for you?

a. What do you do?

b. In what ways do you experience a typical day now as similar or different compared to prior to your illness?

c. What priorities do you set regarding what you do in a day?

What kind of activities do you like to engage in on a regular basis?

a. In what ways do you decide what you will do and when?

b. What kinds of priorities do you set with respect to your activities?

In what ways do you spend your time?

a. What sorts of activities do you spend your time doing?

b. What factors influence how you spend your time?

Where do you spend most of your day?

Who do you spend most of your day with?

Do you reflect upon your past?

a. What types of things or memories do you reflect back on?

b. What past experiences stand out?

How will you spend your time (what will you do) in next days, weeks, and months?

a. What is it about these activities that are important to you?

Drawing on your experience, what advice would you give to others who are living with advanced, life-threatening illnesses?

Is there anything else about your experience living with an advanced, life-threatening illness that you would like to tell me about that we have not discussed?

(Park Lala, 2011)

Questions related to occupational roles:

Did you work? What did you do?

- a. Did you enjoy your work?
- b. What was meaningful about the work that you did?
- c. How did your work influence others?

Who are some people in your life that are especially meaningful to you (spouse, partner, long-time friend, child, mother/father, grandmother/grandfather, mentor)?

- a. Why are they meaningful to you?
- b. What experiences can you remember with them that stand out? Why do they stand out?
- c. Would you like to leave any advice for these people?
- d. Would you like to leave a memento or legacy item for any of these people?
 1. If so, what would you like to leave? Why?

What have some of your hobbies been throughout your life?

- a. Why did you decide to engage in those hobbies? What meaning did/do they have?
- b. Were they life-long hobbies? Or hobbies that you picked up and left off?
- c. Are you still able to engage in these hobbies?
 1. If not, would you like to continue in some capacity if possible?

What has leisure time looked like for you throughout your life?

- a. Why did/do you consider it leisure time?
- b. Are you still able to engage in this leisure time? If not, would you like to continue if made possible?

Looking back at your life, what are you proud to have accomplished? What has been very difficult? Why?

What has given you strength and meaning throughout your life? Why?

What roles have you found significant throughout your life (husband/wife, grandmother/grandfather, worker, coach, teacher, gardener, musician, etc...)? Why?

- a. Since your illness, have those roles diminished? Or continued? How?

Where did you grow up?

- a. How was that experience for you?
- b. How has where you grew up affected other facets of your life?

Are there any things at end-of-life that you would like to complete?

- a. Are there any things that you would like to create for loved ones?
- b. Are there any items that have meaning to you that you would like to bequeath to loved ones?
 1. Why do those items have meaning? Would you be willing to tell/write down why?

Is there anything you want to accomplish/create/do during the final phase of your life?