

## The Job Teaches You, If Are Open to It:

### The Experiences of Hospice Occupational Therapists

Dame Cicely Saunders (1976), the leader of the modern hospice movement, captured the ethos of hospice care by stating, “You matter because you are you and you matter to the last moment of your life” (p. 1005). In its promotion of dignity, comfort, and personal meaning at the end of life, the hospice movement seeks to provide comprehensive and individualized care to clients and their families (Monroe, Hansford, Payne, & Sykes, 2007). Although occupational therapy’s traditional emphasis on rehabilitation may obscure its relevance to hospice, principles such as client-centered practice, holistic care, and the preservation and improvement of quality of life draw clear connections between hospice and occupational therapy. Individuals with life-threatening illnesses often encounter increasing barriers to participation in meaningful activities and roles, and the resulting occupational deprivation may lead to further deterioration of quality of life (Lyons, Orozovic, Davis, & Newman, 2002). By supporting individuals’ continued participation in meaningful occupations, occupational therapy may contribute to improved quality of life and help to ensure that all individuals “matter to the last moment of ... life” (Saunders, 1976, p. 1005).

As hospice services have spread throughout the United States, increasing evidence and expert opinions have emerged supporting the involvement of occupational therapy at the end of life (Lyons et al., 2002; Pizzi & Briggs, 2004). Nonetheless, little documentation exists of the current practice patterns of occupational therapists in hospice settings, their perceptions of ideal practice patterns, and the challenges and supports they experience in serving their clients. Some difficulties may be largely internal, consisting of therapists’ own efforts to reconcile the rehabilitative philosophy of occupational therapy with the inevitable declines experienced by clients at the end of life (Bye, 1998), limited professional competency due to inadequate training (Dawson &

Barker, 1995), or the experience of emotional burnout (Prochnau, Liu, & Boman, 2003). Other barriers may be more systemic, arising from reimbursement challenges and financial pressures, inefficient or inadequate referral processes, or from misperceptions of occupational therapy by other clinicians or by clients and families (Rahman, 2000).

In contrast to these potential challenges, the work of occupational therapists in hospice settings may be supported by a strong spirit of interdisciplinary collaboration (Rahman, 2000) and shared philosophies emphasizing holistic care and quality of life (Pizzi & Briggs, 2004). Interestingly, the same study that identified emotional burnout as a common experience also found that hospice occupational therapists derive a deep sense of “satisfaction” (Prochnau, et al., 2003, p. 198) from their professional role. Exploration of individuals’ perceived challenges and supports is essential to understanding further the reality of hospice-based occupational therapy and to ensuring the continued relevance and quality of occupational therapy at the end of life.

## **Background**

**History of hospice.** During the medieval period, hospices existed as places of respite for religious pilgrims and individuals facing illness and death (Tigges & Marcil, 1988). These historic roots were revived in the 1960s and 1970s, as clinicians and consumers began to reject the increasing institutionalization of healthcare services and to seek a holistic approach to end of life care (Connor, 2007). At the forefront of this movement was British physician Cicely Saunders, who founded Saint Christopher’s Hospice in 1969 in an effort to respond to the unmet physical, psychosocial, and spiritual needs of individuals with terminal illness (Monroe, et al., 2007). Saunders was devoted to outreach and education, and ensured that the nascent hospice philosophy spread well beyond the walls of Saint Christopher’s. One testament to this mission was her involvement in the opening of the first U.S. hospice program in 1973 (Monroe, et al., 2007; Connor, 2007).

During the 1970s, the hospice movement flourished in the United States, as evidenced by the emergence of hospice facilities and programs across the country, the founding of the National Hospice Organization (NHO, later renamed the National Hospice and Palliative Care Organization) in 1978, and the issuance of the first standards of practice guidelines by NHO in 1979 (Connor, 2007). The Medicare Hospice Benefit (MHB) was enacted in 1982 and allowed prospective reimbursement of primary services including physician care and support services such as occupational therapy (Connor, 2007). Following this development, the number of hospice programs in the U.S. continued to increase, from 1,500 programs in 1985 to over 4,000 in 2000, with increasing emphasis placed on community- and home-based programs and utilization of volunteers to support and extend services (Connor, 2007). Notably, the number of individuals served by hospice programs increased greatly during the same time period, from fewer than 200,000 clients in 1985 to over 1 million in 2005 (Connor, 2007).

**Occupational therapy and hospice.** As financial support and social awareness of hospice care have grown over the last three decades, so, too, has the literature supporting the involvement of occupational therapy at the end of life. In one early article, Holland and Tigges (1981) issued a call to action, at once justifying the involvement of occupational therapy in hospice care and documenting its possible benefits in terms of client outcomes. Other articles sought to define the role of occupational therapy in hospice care (Holland, 1984) and to explain the hospice philosophy in relation to occupational therapy (Lloyd, 1989; Pizzi, 1984). These articles suggest that, during this time, the profession was engaged in a discussion regarding its potential contributions to hospice care. Tigges and Sherman (1983) and Pizzi used case studies to orient readers to possible treatment strategies and outcomes for occupational therapy in hospice, portraying a profession engaged in the exploration of a new and significant area of practice, contemplating whether and how to provide care at the end of life.

**From expert opinion to evidence of effectiveness.** While these early articles provided an invaluable foundation for the initial involvement of occupational therapy in hospice care, their reliance on expert opinion highlighted the need for further research. Starting in the 1990s, the literature regarding hospice occupational therapy became increasingly sophisticated as researchers began to investigate the nature and outcomes of this practice area. Dawson (1993) conducted a small ethnographic study documenting participants' experiences in occupational therapy groups in a combined inpatient and day hospice program, and found that involvement in group activities gave participants a sense of support, control, and enjoyment. In 2002, Lyons, et al. completed a rigorous qualitative study assessing the occupational experiences of individuals with life-threatening illnesses. The researchers found that participation in, or observation of, meaningful activities generated a sense of purpose, enhanced clients' well-being, and facilitated social participation (Lyons, et al., 2002).

As evidence has begun to emerge regarding the effectiveness of occupational therapy in hospice and palliative care, other researchers have begun to explore the significance of occupation at the end of life. Hasselkus (1993) provided an intimate view of her personal experiences of caring for a dying relative. The article examined clinicians' and family members' gradual acceptance of an impending death and considered the therapeutic implications of shared emotional experiences at the end of life. Further documentation was provided by Jacques and Hasselkus (2004), who found that individuals with terminal illnesses employed occupation as a way to continue participating in everyday life and as a way to prepare actively for death.

As the role of occupational therapy in hospice care has become better established, researchers have proposed a variety of approaches to supporting client and caregiver wellbeing at the end of life. Noting that "rehabilitation in palliative care is a paradox," Pizzi and Briggs (2005, p. 122) suggested the use of comfort measures,

adaptive techniques, home modification, and psychosocial and spiritual care to promote quality of life. A position paper from the American Occupational Therapy Association provided similar guidance, asserting that hospice occupational therapy interventions should focus on “comfort and quality of life rather than on rehabilitation” (Trump, Zahoransky, & Siebert, 2005, p. 271; see also Trump, 2001) and outlining strategies for home modification and prevention of physical and psychosocial complications.

**Exploration of current practice.** As occupational therapy has become increasingly, though not extensively, integrated in hospice and palliative care, researchers have begun to document the practice patterns of occupational therapists in this area. In a survey of hospice and palliative care administrators, Boyce (2000) found that occupational therapists are largely underutilized in end of life care and that colleagues of other disciplines often address areas that fall within occupational therapy’s scope of practice. The survey’s modest response rate (32.5%) and a lack of direct input from hospice occupational therapists may influence the generalizability of Boyce’s findings. A more recent study found that 29% of hospice occupational therapists’ time was devoted to direct patient care and that that time was divided between assessment (40%), education on adaptive equipment (19%), interventions to promote symptom management (18%) and self care (16%), and other activities, including work and leisure (8%) (Cooper & Littlechild, 2004). Because the study did not assess therapists’ rationale for time allocation, it is difficult to assess how these patterns impact therapeutic experiences and outcomes (Cooper & Littlechild, 2004). Further exploration of hospice occupational therapists’ practice patterns may provide a more thorough assessment.

Studies documenting client and caregiver perspectives on the role of occupational therapy in hospice also offered insight into the realities and possibilities of this area of practice. A survey of palliative care clients and caregivers found that participants were largely satisfied with the availability and quality of occupational

therapy, but noted that symptoms of pain, fatigue, and weakness were inadequately addressed by occupational therapy; the findings of the study were bolstered by the combination of quantitative and qualitative data (Kealey & McIntyre, 2005). Furthermore, a survey of clients' priorities for palliative care revealed that clients valued therapeutic behaviors such as listening, empathy, and understanding as highly as the provision of specific services, such as interventions to promote safe functional mobility (Schleinich, Warren, Nekolaichuk, Kaasa, & Watanabe, 2008). Although small, this pilot study suggested that effective therapeutic use of self is an essential component of occupational therapy in hospice and palliative care (Schleinich, et al., 2008).

During the research process, the researcher was unable to locate documentation of the numbers or percentages of hospice patients who receive occupational therapy services in the U.S. The difficulty in obtaining this information underscores the emergent nature of research on this area of practice, and the need for additional investigation.

**Perceived challenges and supports in hospice occupational therapy.** As in any setting, occupational therapists in hospice and palliative care may experience barriers to serving their clients. Some challenges may be internal to the therapist or to the profession of occupational therapy, while others may be external and more systemic in nature. One significant internal challenge is the conflict occupational therapists may find between the rehabilitative focus of occupational therapy with the functional declines associated with the end of life (Bye, 1998). Research has found, however, that with experience, many hospice occupational therapists are able to reframe their role and to use occupation as a way both to "affirm life...and prepare for death" (Bye, 1998, p. 8; see also Rahman, 2000). As found by Prochnau, et al. (2003), another challenge encountered by some occupational therapists in hospice and palliative care is the emotional exhaustion, anxiety, and grief that stems from frequent encounters with death. Although therapists may develop and employ effective coping strategies to support

personal and professional wellness, it is important to note that such challenges persist and may, at times, become overwhelming (Prochnau, et al.). In contrast, Hooley (1997) found that burnout was not a significant phenomenon among occupational therapists working with clients with HIV/AIDS, as clinicians were able to utilize numerous supports to navigate the emotional challenges of their practice area. It is possible that occupational therapists in hospice care may draw on similar resources to avoid burnout.

Another significant challenge experienced by occupational therapists in hospice and palliative care is that of inadequate training and research. Dawson and Barker (1995) found that 64% of hospice occupational therapists surveyed indicated that they had received no preparation in hospice or palliative care during their undergraduate training, suggesting a need for enhanced curriculum to address this area of care. Bye (1998) noted that occupational therapy literature addressing end of life care frequently places greater emphasis on the skills and activities of living than on the importance of preparing for death; thus, hospice occupational therapists may find limited support in the professional literature. Furthermore, the paucity of evidence regarding the effectiveness of occupational therapy in hospice and palliative care underscores the need for further research and exploration (Kealey & McIntyre, 2005; Pizzi & Briggs, 2004).

In addition to these internal challenges, occupational therapists in hospice and palliative care may experience systemic barriers to client treatment. Rahman (2000) found that involvement of occupational therapy often depended upon timely referrals, and that the efficiency of referral systems varied greatly by facility. Both Rahman and Boyce (2000) noted that healthcare professionals often misinterpreted the role of occupational therapy in end of life care, leading to the underutilization of services or the provision of occupation-based interventions by colleagues of other disciplines.

In spite of these potential barriers, an emergent body of evidence indicates that occupational therapy is a valued and often integral part of many hospice and palliative

care programs (Pizzi & Briggs, 2004), suggesting that supports exist for occupational therapists in this area of practice. Prochnau, et al. (2003) found that, in addition to gaining a profound sense of “satisfaction” (p. 198) from their work, hospice occupational therapists also attributed meaningful personal “growth” (p. 201) and development to their role in end of life care. Furthermore, participants expressed that their “spirituality” (Prochnau, et al., 2003, pp. 200-201) not only supported their work, but that their professional experience further enriched their spiritual beliefs. Rahman (2000) found that hospice occupational therapists gained a profound sense of fulfillment and gratitude from their involvement with clients and families at the end of life, suggesting that these emotional rewards serve to nurture and support occupational therapists in this area of practice. Pizzi and Briggs noted that therapists in hospice and palliative care may find personal and professional support through interactions with other members of the healthcare team and also emphasized the importance of self-awareness and reflection.

In hospice settings, occupational therapists are uniquely prepared to support clients’ ability to live fully, even and especially as death draws near. Only limited information is available, however, regarding the current realities of this specialized area of practice. The purpose of this study, therefore, was to explore the experiences of hospice occupational therapists, identify the therapeutic approaches they employed with their clients, and understand the nature and stages of their professional development.

## **Method**

### **Research Design**

Qualitative research methodology was selected due to its ability to capture and explore complex aspects of human experience (Portney & Watkins, 2009). Because relatively little is known about the experiences of hospice occupational therapists, grounded theory was identified as an appropriate qualitative approach. Strauss and Corbin (1990) explained that “a grounded theory is one that is inductively derived from...

the phenomenon it represents. ...It is discovered, developed, and provisionally verified through systematic data collection and analysis” (p. 23). The use of grounded theory was intended to allow the researcher to develop a theory of the professional development of hospice occupational therapists, and to anchor the theory in the experiences of the participants.

According to Guba (as cited in Krefting, 1991), potential shortcomings of qualitative research include limited credibility due to the selection of inappropriate participants, poor choice of methodology, or faulty research execution; limited transferability due to the uniqueness of the experiences and contexts explored; decreased dependability due to inconsistent behaviors or phenomena; and biased approaches to data collection and analysis. Krefting provided several strategies for enhancing the strength of qualitative research. In this study, the use of member checking and peer examination was intended to enhance the credibility of the findings (Krefting, 1991). Data collection and analysis were concurrent in order to facilitate member checking, and the researcher identified an experienced hospice occupational therapist who served as a consultant and provided peer examination of the findings and analysis. While maintaining participant confidentiality, thorough description of the context of the study was used to increase transferability (Krefting, 1991). Documentation of the research methods, peer examination, and repeated coding were used to increase the dependability of the findings (Krefting, 1991). Finally, the collection of raw data, use of field notes, reflexive analysis, and consultation with the research committee were intended to limit bias and bolster the confirmability of the findings (Krefting, 1991).

### **Participants**

Four participants were identified through purposeful sampling of hospice occupational therapists in western Washington. Inclusion criteria consisted of: current full- or part-time employment as an occupational therapist in a hospice program, at least

one year of experience in this area of practice, and willingness to participate in one 90 minute interview and up to two subsequent 45 minute interviews. To recruit participants, the researcher conducted a mailing and the research consultant contacted potential participants to explain the purpose of the study and to put them in contact with the researcher. Two participants, Diane and Victor, worked at the same facility and were employed exclusively in hospice and palliative care. Another participant, Ozzy, was employed in a combination of home health and hospice and palliative care, while the fourth participant, Lucy, worked primarily in outpatient rehabilitation and served as an occasional consultant for hospice care. Among the participants who worked primarily in hospice, Diane had the most experience, a total of 15 years in the setting, while Victor had four years of experience and Ozzy had three. Lucy had worked on three or four hospice cases per year for the last three years. All participants lived and worked in urban areas of western Washington. Additional demographic data were gathered regarding the duration of participants' practice in occupational therapy (see Table 2).

### **Instruments**

The researcher conducted interviews using semi-structured and open-ended questions intended to explore the experiences of the hospice occupational therapists involved in the study (see Appendix). The first interview with each participant began with a card sorting activity. Prior to the interviews, the researcher prepared two identical sets of cards with concepts found throughout the literature on hospice and occupational therapy, and in conversation with the research consultant (see Table 1). Participants were asked to sort one set of cards into categories of their choice and were provided with additional cards to label with terms they perceived to be missing. Then, the researcher asked the participants to define and discuss the categories into which the cards had been sorted. Next, the researcher collected the first set of cards and asked the participant to sort the second set of cards into fixed categories of "Current Practice,"

“Ideal Practice,” “Supports,” and “Barriers.” Participants were again provided with blank cards to address additional terms or concepts. The purpose of this activity was to complete an initial exploration of participants’ experiences and to provide participants an opportunity to reflect on the nature of their practice in a more structured way before proceeding to the interview portion of the session.

### **Procedures**

Prior to the start of the study a mock interview session was held with the research consultant and was observed by an experienced qualitative researcher. Card sort terms and interview questions were revised following feedback from the research consultant and research chair. Participant recruitment began following study approval from the University of Puget Sound Institutional Review Board. Interviews took place at restaurants or public meeting spaces selected by the participants and were recorded digitally. In appreciation of their time, participants were provided with a \$20 gift card upon completion of their participation in the study.

### **Data Analysis**

During each interview, the researcher completed field notes to record the participants’ responses and to document her observations and reflexive experiences. The initial interviews lasted between 60 and 120 minutes and the follow-up interviews lasted between 30 and 50 minutes. Upon completion of each interview, the researcher allowed time for the participant’s questions and asked the participant permission to contact him or her for further discussion of the data and preliminary interpretations for member checking. The interview process was continued until the researcher and the research committee determined that saturation has been achieved (Krefting, 1991). To protect their confidentiality, all participants provided a pseudonym for use in the study.

A combination of *a posteriori* and *a priori* open coding was used to analyze the data and to identify key themes (Portney & Watkins, 2009). By engaging extensively with

the interview transcripts and field notes, the researcher identified key phenomena and grouped them into categories. Subsequently, open coding and further analysis of the data were used to identify salient themes and concepts (Strauss & Corbin, 1990). Themes were labeled using participants' own language, a practice known as "*in vivo* coding" (Strauss & Corbin, 1990, p. 69). To enhance the credibility of the findings, the researcher reviewed the results with occupational therapy educators and student peers at the University of Puget Sound, and with an outside consultant. The researcher also discussed preliminary findings and analysis with the participants; member checking was another strategy employed to improve the credibility of the findings.

### **Results and Discussion**

During the interview process, participants conveyed a breadth of responses, yet most of the data collected were complementary and consistent, suggesting that the experiences of hospice occupational therapists share many common themes and characteristics. It is notable that one participant, an occupational therapist who worked primarily in an outpatient rehabilitative setting, had a significantly different perspective on many aspects of hospice care. Data were most similar among the three participants who worked primarily or exclusively in hospice settings. Five principal themes were identified during data analysis: Enhancing clients' quality of life, Therapeutic use of self, Advocacy, Interdisciplinary team involvement, and Images of ideal practice. These themes represented salient aspects of the participants' experiences and provided the basis for an emergent theory of professional development in hospice occupational therapy.

#### **Enhancing Clients' Quality of Life: "My Job Is not to Rehabilitate the Client."**

**Physical Needs: Positioning for Comfort, Safety, and Participation.** In their discussions of hospice occupational therapy, participants emphasized their focus on enhancing clients' quality of life by addressing physical, psychosocial, and spiritual needs. Interventions directed toward clients' physical comfort included provision of

durable medical equipment (DME) and adaptive devices as well as positioning for comfort and prevention of physical complications. Participants also worked to address safety and functional mobility by providing education on fall prevention and transfers. Noting funding and time constraints, participants indicated that their interactions with hospice clients were often limited to a single visit to address positioning and physical comfort. Consequently, participants expressed the hope that these interventions would enhance more than physical comfort alone. For Ozzy, successful therapeutic positioning meant that “the client [was] comfortable and able to interact with their family.” Thus, these interventions had the dual benefits of facilitating clients’ participation in social interactions and meaningful activities, in addition to preventing or ameliorating physical complications, resulting in a greater impact on the client’s overall quality of life.

Notably, Lucy was the only participant to refer to treatment within the rehabilitative frame of reference. She described the provision of home exercise programs in order to promote improved dexterity following a cerebrovascular accident, and stated, “It just varies and sometimes people want to get better and people do come off hospice.” Although all participants discussed previous clients whose health status had improved and who had been discharged from hospice, Lucy appeared to be the only clinician utilizing the rehabilitative frame of reference with some of her hospice clients. By contrast, Ozzy stated, “My job isn’t to rehabilitate the [client],” and explained to families that her role was to support the comfort and quality of life of the hospice client. While Lucy, like the other participants, denoted quality of life as the highest priority for hospice occupational therapy, her use of the rehabilitative frame of reference indicated a significant digression from the therapeutic approaches used by the other three therapists involved in the study. This difference may be associated with the nature and duration of participants’ experience in hospice occupational therapy: while Lucy worked chiefly in a rehabilitative setting and saw only 3-4 hospice clients annually, the other participants

had worked primarily or exclusively in end of life care for between three and 15 years each. Interestingly, Victor had predicted this distinction, suggesting that it could be “difficult” and “a challenge” for an occupational therapist to “go from a...setting where somebody is rehabilitating and...into another setting where the focus is comfort and quality of life.” These contrasting approaches may support the involvement of occupational therapists in hospice on a regular, rather than occasional, basis, and underscore the importance of hospice occupational therapists’ deliberate and intentional focus on quality of life rather than rehabilitation.

**Role Competence: “Leaving Something Behind.”** Participants also sought to address quality of life by working to improve clients’ role competence in the face of declining physical and/or cognitive function. For example, Victor described his work with a woman who wished to finish crocheting a blanket as a way to “leave something behind for her family.” When it became clear that she would be unable to finish the project even with the support of adapted equipment, Victor collaborated with her to transform the blanket into smaller pieces that were then framed, which the woman gave to members of “her family as a piece of art.” By working with his client to adapt both the tools and the outcome of a meaningful task, Victor helped to restore her role as a mother and grandmother and facilitated her ability to leave a legacy to those she loved. As found by la Cour, Josephsson, Tishelman, and Nygard (2007), participation in creative activities provided hospice clients with a sense of satisfaction and autonomy, and, “when creations were used as gifts, the participant became the ‘giver’ rather than a recipient patient” (p. 248). The researchers noted that such exchanges restored “patterns of reciprocity” (la Cour, et al., 2007, p. 248) that are often lost at the end of life and that are crucial to supporting role competency throughout life.

**Leisure: “Inviting People Back Into What They Enjoy Doing.”** Similarly, Diane discussed the use of leisure as a means for enhancing clients’ quality of life by

providing a sense of enjoyment and satisfaction. She described “inviting people back into what they...enjoy doing or helping them identify what they can still do” at a time when clients’ physical and cognitive functions may have become extremely limited. By collaborating with families to modify activities or identify adaptive equipment, Diane supported clients’ return to valued occupations. Examples of this included suggesting a client select recipes and plan a menu rather than cooking an entire meal, and creating a card holder to enable a client to continue to play cards. Other participants discussed the use of energy conservation techniques to help clients continue to participate in meaningful activities in spite of increasing fatigue.

**Life Review: “Finding a Way to Cope.”** Helping clients and families to cope with grief and loss was another way in which participants addressed quality of life. Noting the myriad losses that occur at the end of life, Diane described the importance of understanding the source and characteristics of clients’ grief in order to intervene effectively. “Understanding what they are grieving the loss of the most,” Diane explained, “...can really help...in finding a way to cope.” Exploring whether the loss was related to roles, occupations, physical function, or spiritual beliefs, Diane said, could help to shape the therapeutic relationship and identify priorities for intervention. Other participants discussed the use of reminiscence and life review as a way for clients to revisit valued roles and accomplishments. As documented by previous researchers, participation in life review is associated with improved quality of life, decreased anxiety, and improved pain and symptom management at the end of life (Steinhauser, et al., 2008; Ando, Morita, Okamoto, & Ninosaka, 2008; Hanaoka & Okamura, 2004).

**Therapeutic Use of Self: “I Am Able to Be Present.”**

Although therapeutic use of self is an important tool in all areas of occupational therapy, participants in this study appeared to place a special importance on their ability to connect with hospice clients and families. For participants in this study, therapeutic

use of self included being present, providing spiritual care, participating in therapist self-care, and engaging in professional growth. Ozzy described her use of “active listening” and “being present” during her visits with clients, and many participants referred to the use of therapeutic touch as a means to provide comfort, convey empathy, and develop a sense of connection to the client. The concept of “presencing” (Benner, 1984, p. 57, as cited by Hasselkus, 1993, p. 720), defined as the ability to form a compassionate and human connection with the client, is a valuable tool in allowing occupational therapists and other healthcare professionals to provide non-curative care at the end of life.

Empathy was another important aspect of therapeutic use of self as employed by the participants in this study. Victor reflected on his experience of caring for his aging grandmother and struggling to incorporate the many suggestions provided to him. “Knowing what it is like to be a caregiver or to have somebody come into your home and tell you that you should do this or that,” he explained, helped him to understand and accept that not all of his professional recommendations would be maintained after his visit. Victor’s ability to engage with clients on both personal and professional levels demonstrated his use of empathy, which Peloquin (1995) described as therapists’ willingness to develop a “kinship” (Buber, as cited by Peloquin, 1995, p. 26) with clients and to “feel and think at once” (Buber, as cited by Peloquin, 1995, p. 26). A key aspect of therapeutic use of self, empathy allows occupational therapists to achieve a profound and personal connection with clients, while at the same time retaining their role as professionals and clinicians (Peloquin, 1995). Within the context of hospice, the use of empathy allows occupational therapists to appreciate the experiences of clients and families on both intellectual and emotional levels, and to provide more holistic care.

In addition to being present and empathetic to clients’ needs, compassion was another important skill discussed by participants. Victor described compassion as “understanding where [clients] are at,” without imposing one’s own values or

experiences upon the interaction, while Diane observed that her work in hospice had “given [her] a lot of compassion about both the good choices and the bad” that individuals make throughout life. As noted by Hasselkus (1993), “Deep Compassion,” the fifth and final stage in Harper’s (1977) model of clinical social workers’ coping skills, is characterized by the ability to be present throughout the client’s dying process and to gain a sense of satisfaction through one’s role in supporting a good death. After 15 years in hospice occupational therapy, Diane was able to respect and appreciate clients’ life choices without feeling burdened by the outcomes of these decisions. Her unconditional acceptance of her clients exemplifies compassion in therapeutic practice.

**Spiritual care: “The strongest parts of all of us.”** The ability to engage with clients on a spiritual level was another aspect of therapeutic use of self in hospice care. For Diane, this meant “seeing what is essential in a human being and loving that because ultimately...you are beautiful because you exist. ...All the other is extraneous.” This existential approach served to recognize and appreciate the client’s core identity as “a human being” at a time when role loss predominates. Rather than working to restore role competency through adaptive techniques, Diane sought to honor the most basic and universal roles. This offered both the client and the therapist a new way of appreciating life in the face of death. Similarly, Ozzy described her relationship with a hospice client and the client’s husband, “He reminded me of my [late] father...[and] she reminded me of the strongest parts of all of us.” The blending of professional and personal experiences is clear in Ozzy’s discussion: although her work with the couple was within a professional and therapeutic context, the experience allowed her to revisit and resolve some of the challenges associated with her own father’s death. Ozzy’s sense of seeing “the strongest parts in all of us” in a single client echoed Diane’s discussion of working with the “essential” humanity of each of her clients.

By addressing spirituality, occupational therapists in hospice care may help clients to redefine their roles on a more universal level (American Occupational Therapy Association, 2008). Developing a profound sense of connectedness appeared to be a valuable way for hospice occupational therapists to convey empathy and to address the psychological or spiritual pain associated with lost roles and relationships. Previous researchers have explored the significance of spirituality to hospice occupational therapists, noting the dynamic relationship between therapists' personal and professional feelings toward death and dying, but did not document the use of spirituality as a therapeutic approach for clients at the end of life (Prochnau, et al., 2003). Broader research, however, found that occupational therapists in a variety of settings employed spirituality as a way to alleviate clients' physical and psychological pain and to identify and honor clients as unique and motivated beings (Egan & Swedersky, 2003). Participants' comments appeared to support the relevance of these findings for hospice practice, a setting in which issues of suffering and role loss may be especially acute.

**Therapist self-care: "The less of ourselves that we have in the way."**

Participants discussed the importance of self-care in order to sustain their hospice practice and to continue to employ therapeutic use of self on a daily basis. For the occupational therapists in this study, self-care included participation in leisure activities (dance, travel, spending time with friends and family), engaging in spiritual practices, working in hospice less than full-time, having a flexible schedule, and taking part in workplace support programs. Participants also referred to the support and inspiration provided by spouses, family members, and friends. Lucy noted, "It's a tough field," and characterized self-care as essential for "self-preservation." For Diane, though, self-care went beyond "self-preservation" to nourishing her professional practice and personal life:

I have a lot of things that I do for self care and I believe that the less of ourselves that we have in the way, the more likely we are to be enjoying what is really out there. So I work a lot on my own personal growth....

Diane's intentional engagement in self-care activities allowed her to address personal barriers and to achieve a more compassionate and client-centered practice: by clarifying and resolving her personal challenges, she was able to focus more clearly upon those faced by her clients. Diane's deliberate choice to attend to "personal growth" contrasts with Lucy's efforts to engage in self-care as a means of "self-preservation" and underscores the substantial differences in the two therapists' philosophies of practice and duration of professional experience.

**Professional development: "The job teaches you, if you are open to it."**

Throughout the research process, participants spoke of their ability to incorporate the lessons of hospice care into their personal and professional lives. In these conversations, it became apparent that participants' efforts to negotiate the challenges of work served, ultimately, to inform and enrich their therapeutic practice and to support their ongoing and evolving therapeutic use of self. While all four participants indicated that they felt fortunate to work in hospice care, it was clear that the work was not easy, particularly during one's initial involvement in the setting. Diane explained:

The first year of doing hospice...is really tricky. You are navigating...where you can be emotionally—how you can enter into that...and be a real human being... [but] also not to be opened up to all the loss that can be a part of that.

When asked if these challenges had eased with time, Diane responded, "Definitely. The job teaches you how to do that if you are open to it." The ability to attend to and incorporate the lessons of the work allowed Diane to find a realistic and sustainable balance of personal and professional involvement. Hooley (1997) found that the development of an empathic practice was a key support for occupational therapists

working with clients with HIV/AIDS which enabled them to engage in the grieving process while maintaining their identity and relevance as professionals. Likewise, Diane's ability to navigate the challenges of her early years and to develop a balanced therapeutic approach served as an important support to her continued practice.

Ozzy felt similar challenges in balancing personal and professional boundaries, stating, "I do not want to get too involved...because then I am not taking care of myself. But I also don't want to not take care of myself by continuing with my head in the closet...." In order to maintain self-care behaviors and to continue to employ therapeutic use of self with clients, Ozzy worked to find a balance between professional distance and personal engagement. During a follow-up interview, Ozzy, like Diane, noted that these challenges had become easier with increased experience in the hospice setting. These two participants' descriptions of the challenges of end of life care reflect Peloquin's (1995) exploration of empathy as the ability to "enter into the experience of another" (p. 30) while maintaining "the power to recover from the connection" (p. 30). By navigating these seemingly contradictory demands, participants worked to achieve an enduring and empathetic model of practice.

It was apparent that Victor also worked to find a similar balance between personal and professional involvement. He described taking a few minutes before each visit "to focus and get to know about my patients" and after each visit "to digest what the interaction was and be able to recenter myself." While these reflective pauses were invaluable to his practice, Victor noted, "I don't do it as much as I should, or as I would like, but I am still working on that." As described by Victor, the ability to engage with clients and families and, alternately, to "recenter" one's self following these moments of connectedness was a continual process that could either support or hinder one's practice as a hospice occupational therapist.

Among the four participants, Diane appeared most adept at navigating these challenges, perhaps due to her 15 years of experience in hospice care. When asked what she had gained from her work, she explained, “The work teaches you how to love without being attached.... ..It’ll break my heart when [a client] dies...but by the same token, it really doesn’t break my heart anymore. ...It opens my heart up, but it doesn’t break it.” The greatest challenges of end of life care, in Diane’s explanation, were also its greatest rewards: lessons on love and loss, and how to find “joy” in the connection without mourning its end. The ability to learn from the work, as well as ongoing attention to self-care, may explain the absence of burnout among participants in this study. Previous research by Prochnau, et al. (2003) found that occupational therapists in palliative care tended to experience anxiety, urgency, and occasional burnout in spite of their satisfaction with their work, yet such issues were not significant themes in the experiences of the participants in this study. These differences may be due to attention to self-care, balancing hospice work with work in other settings, utilization of support systems, or other factors, and would be worth exploring in further research.

Interestingly, Lucy was the only participant who did not recall experiencing a significant transition during her initial involvement in hospice care, stating that she felt that her prior experience in home health had prepared her for working in end of life care. It is arguable, however, that Lucy’s use of the rehabilitative frame of reference in hospice care, as well as her only occasional involvement in hospice cases, indicated that she was not as fully or deliberately involved in end of life care as the other three participants.

**Advocacy: “As Human Beings, We Want to Be Heard.”**

Another significant theme identified during data collection and analysis was that of advocacy: participants described their role in advocating for hospice clients and families, for alternative approaches to care, and for the role of occupational therapy in hospice care. Ozzy frequently referred to herself as an “advocate” or “mediator” for

clients in care facilities and identified herself as a “liaison” between the facility staff and the client and family members. Victor indicated that he felt a special obligation to advocate for and attend to clients’ “psychosocial needs” while the rest of the care team addressed issues such as pain control and medication management. Diane described her role in helping family members to “listen to” and accept the needs of a dying parent or grandparent: when a family requested that occupational therapy provide an exercise program for a hospice client, Diane would make a visit to the home and interview the client in the presence of the family. When it became clear that the client had neither the interest in, nor the energy for, a rehabilitative program, the family members would often reach a new stage of acceptance and understanding. “My job is often to help everybody hear what is really going on and to really give voice to the patient,” Diane explained. Later, she reflected, “All through our lives, as human beings, the main thing is we want to be heard.” For Diane, as well as Ozzy and Victor, the ability to listen and to “give voice” to the client emerged as vital components of their role on the hospice care team.

Within the *Occupational Therapy Practice Framework II* (American Occupational Therapy Association, 2008), advocacy is listed as one of the primary intervention approaches used by occupational therapists throughout the profession and is defined as “efforts directed toward promoting occupational justice and empowering clients to seek and obtain resources to fully participate in their daily life occupations” (p. 654).

Participants’ comments regarding their role as advocates and mediators illustrate the ways in which hospice occupational therapists strive to communicate clients’ needs and interests within the larger system of care as well as in the more intimate context of the family and home. As noted by Jacques and Hasselkus (2004), occupation takes on special significance at the end of life. The chosen occupations of a person on hospice may be familiar and routine, such as the goal of sharing a final family meal, or may be dynamic and tied specifically to the dying process, such as the goal of crafting a final gift

for family members (Jacques & Hasselkus, 2004). Given the significance of occupation at the end of life, the role of the occupational therapist as client advocate may also take on greater significance, perhaps explaining participants' frequent and vivid descriptions of their involvement in this role.

**Advocating for alternative approaches to care: “The quick fix is always a pill.”** Overlapping with participants' advocacy for clients' needs and interests were their efforts to incorporate alternative approaches to pain and symptom management into the hospice setting. Participants frequently conveyed frustration with the prevailing models of care, which some perceived as relying too heavily on pharmacological measures and not enough on therapeutic approaches such as positioning, participation in meaningful activities, and attention to spiritual or psychological struggles. Diane observed, “The quick fix is always a pill, but it is not always the best one and I think that [symptom management is] one of the things OTs can...really provide.” She and other participants emphasized the importance of working with the care team to identify the source of clients' pain and addressing the cause of suffering through a variety of approaches, including spiritual and bereavement counseling, massage and therapeutic touch, music therapy, reminiscence, and relaxation and visualization activities. Supporting this point, Trump (2001) noted that occupational therapists in hospice settings were often compelled to advocate for the provision of occupational therapy services to address clients' pain and agitation and to improve quality of life during hospice interventions.

**Advocating for hospice occupational therapy: “I wish there was more of a community out there.”** Participants' advocacy for alternative approaches to client care was inherently linked to their advocacy for increased incorporation of occupational therapy in hospice care. Lucy noted that clinicians' limited understanding or misperceptions of the role of occupational therapy sometimes resulted in inappropriate referrals, and Victor and Diane both described the importance of keeping all members of

the care team informed of the role of occupational therapy in supporting client comfort and safety. Participants also voiced concerns regarding the difficulty of obtaining DME and adaptive equipment whose costs exceeded the hospice per diem rate. Diane spoke of her efforts to advocate for clients' access to these pieces, and referred to "battles" with agency administrators to secure specialty mattresses or wheelchair seating systems. The absence of a network of hospice occupational therapists made the task of representing the profession even more challenging for some of the participants in this study. While nurses and social workers had a more visible presence in hospice settings, Victor observed, it was difficult to find conferences and continuing education opportunities directed toward occupational therapists in end of life care. "I wish there was more of a community out there where therapists...could collaborate about end-of-life issues," he stated. Victor went on to say that the existence of a network could provide opportunities to advocate for occupational therapy in end of life care and provide therapists with a forum for exchanging ideas and supporting each other.

#### **Interdisciplinary Team Involvement: "A Part of the Mosaic."**

Participants cited a collaborative and interactive hospice team as a key support for their practice. As discussed by Diane, the delivery of services by an interdisciplinary team added depth and breadth to the resources available to hospice clients. She explained, "It is almost beautiful...to feel yourself a part of the mosaic [of care providers]. ...I see myself as a piece of that beautiful mosaic but I have to be realistic about how big my piece is." While appreciating the dynamic and collaborative nature of working on an interdisciplinary team, she was also aware of the boundaries of her role as a hospice occupational therapist. In identifying herself as a piece of a larger "mosaic" of care, Diane conveyed the magnitude of the team's collaboration, and her contribution to it, yet also noted her relatively modest role within the larger system of care.

Participants indicated that being a part of an interdisciplinary team not only increased their professional competence, but also provided a supportive environment for addressing some of the personal challenges associated with hospice work. Ozzy reflected that her participation in such meetings helped her to stay abreast of “pain management and medical issues,” but also allowed her to listen to and share stories of grief, which she found “very healing” and “unburdening.” The importance of being involved on an interdisciplinary team was noted by Rahman (2000), who found that hospice occupational therapists were supported by their colleagues in other disciplines and were appreciative of the holistic approach taken by the care team.

For those participants employed in a setting with multiple occupational therapists on staff, interacting with fellow therapists provided another valuable support. Diane felt that the benefits of having two or three occupational therapists on the care team included being able to exchange ideas and compare perspectives. She stated, “It is another advocate. ...If I am saying, ‘We have...to get this particular mattress for patients because they really need...it,’ if I am standing there alone, my voice is not the same as if I have...another person standing there.” Ozzy, too, found support and guidance in her interactions with the other hospice occupational therapists on the care team.

Participants also discussed the challenges of belonging to an interdisciplinary team, yet practicing largely alone: because they worked primarily in clients’ homes and at area care facilities, some participants felt that they had less face-to-face time with their colleagues than they would have wished. Diane explained, “The team is so intricate to the work... but then the reality is we work so alone out in the field, so [the team is] important but in a different way....” She felt that the paucity of opportunities to interact with colleagues impacted the team’s holistic approach to care. Citing financial limitations and time pressures, she continued, “when there is less time to actually sit down [together], then there is less teamwork and...more isolation in terms of roles.” Working

within a prevailing culture of curative medicine and pharmacological approaches to symptom management, physicians and nurses in end of life care may struggle to balance the hospice philosophy with the predominant medical model. Given the complexity of this task, increased role isolation within the team often resulted in prescribers' reliance on traditional medical approaches, rather than more holistic interventions such as occupational therapy, to address clients' pain and agitation. This pattern was noted by Rahman (2000), who found that hospice occupational therapists felt that their skills in psychosocial care, pain management, and quality of life were often under-recognized by the care team, particularly when occupational therapists were not employed as in-house care providers.

**Images of Ideal Practice: "I Would Love to Do More Last Goals."**

Participants described numerous characteristics of ideal hospice occupational therapy practice, consisting primarily of enhancements to current practice patterns. Participants expressed the desire to be able to offer clients "Cadillac [durable medical] equipment" without having to struggle with financial and institutional barriers. Diane wished that she had more time to incorporate touch, massage, and myofascial release into her interventions, techniques she had been trained in but rarely had the opportunity to employ due to productivity pressures. Other participants spoke of a desire to attend more to the psychosocial wellness of their hospice clients. Victor recalled working with a man who had been bed-bound but wished to share one last meal at the table with his family, and also described helping a woman to create a final gift to leave to her children. He stated, "I would love to do more last goals," but that time constraints made it difficult to complete these time-intensive psychosocial interventions with clients. Lucy noted that the use of group activities could provide clients with opportunities for social participation, as well as offering caregivers a break from their responsibilities, but that the absence of an appropriate venue limited the feasibility of this concept. The use of occupation,

creative activity, and group activities to alleviate pain and to address issues of identity, meaning, and legacy at the end of life has been documented by researchers outside the U.S. (Lyons, et al., 2002; la Cour, Josephsson, Tishelman, & Nygard, 2007; Reynolds & Prior, 2006), yet it is unclear how frequently hospice occupational therapists are able to employ these strategies in typical treatment settings.

Another aspect of ideal practice was increased attention to the spiritual needs of hospice clients and their families, as noted by Diane in her discussion of the limitations of the medical model. She explained that, ideally, “finding out what the spiritual pain is and addressing it” would be the central focus of hospice care by all members of the team, and that occupational therapy’s role in providing spiritual support would be recognized and incorporated into practice.

Interestingly, when encouraged to envision a practice free of practical constraints, rather than offering radical alterations to the current model, participants tended to propose a magnification or refocusing of current patterns of practice. Or, as Diane indicated during the card sort activity, “There are so many things [that]... I do some of... [but] I would like to do a lot more than that.”

### **Toward a Theory of Professional Development**

Throughout participants’ discussion of their work as hospice occupational therapists, three key stages of professional development began to emerge. During the initial stage of involvement in hospice care, exemplified by Lucy’s experience, occupational therapists may seek to rehabilitate clients and may fail to appreciate the contrasting philosophies of hospice care and rehabilitative medicine. The intermediate stage of professional involvement is characterized by the struggle to balance personal involvement and professional objectivity, and by therapists’ efforts to incorporate the lessons of the work and to attend to self-care and personal growth. Both Ozzy and Victor appeared to be at this stage of professional development. In the ultimate stage, the

occupational therapist draws on a wealth of personal and professional experience and deliberately incorporates these lessons into his or her practice. After 15 years of hospice experience, Diane appeared to be in this third stage of professional development.

This pattern of professional development bears some resemblance to Harper's (1977) five-stage model of the coping skills utilized by social workers in an oncology setting, yet also possesses significant differences. In Harper's model, social workers progressed rapidly from Stage I, "Intellectualization" (p. 113), to Stage II, "Emotional Survival" (p. 113), Stage III, "Depression" (p. 113), and Stage IV, "Emotional Arrival" (p. 114). Within the first few years of practice, the "anxiety" (Harper, 1977, p. 113) and turmoil of the earliest stages were replaced by increasing emotional stability and "acceptance" (Harper, 1977, p. 114). Those who remained in the practice setting progressed to Stage V, "Deep Compassion" (p. 114), a phase characterized by personal and professional fulfillment. Although Harper's model has continued relevance, it is important to note that the professional development of the hospice occupational therapists in this study occurred over decades, rather than months, and that a powerful shift in the philosophy of practice occurred during this period of growth, a development not observed by Harper. Further research may help to confirm and refine this emergent theory of professional development among hospice occupational therapists.

### **Implications for Occupational Therapy**

The experiences documented in this study speak to the importance of occupational therapy in enhancing the quality of life of hospice clients and their families. The approaches and perspectives shared by the three participants employed primarily in end of life care, in contrast with those of the participant who engaged in hospice care only a few times per year, demonstrate the differences that arise when occupational therapists are fully and consistently integrated into the interdisciplinary hospice team. Occupational therapists who work in this setting may educate their colleagues on the

importance of occupational therapy in addressing the physical comfort, psychosocial well-being, and spiritual expression of hospice clients, and may advocate for the standard inclusion of occupational therapy in end of life care. Although the number of occupational therapists working in end of life care appears to be relatively small, professionals in all areas of practice may at some point experience the death of a client. By looking to the techniques employed by occupational therapists involved primarily in end of life care, occupational therapists throughout the profession may gain support and insight on dealing with issues of grief, loss, and death in their own practice. Additionally, the participants' deliberate and thoughtful utilization of therapeutic use of self provides a guide for occupational therapists in all areas of practice.

### **Limitations**

Although the researcher had intended to complete two follow-up interviews with each participant, time constraints and scheduling difficulties resulted in the actual completion of only one follow-up interview with three of the participants and no follow-up interviews with the remaining participant. Consequently, opportunities for member checking were limited. While a large sample size is not a requisite for qualitative research, the data may have been enriched by a more diverse sample: all participants lived and worked in a relatively small geographic area, and only three employers were represented. The inclusion of participants from additional geographic regions and other hospice agencies might have provided differing perspectives or further substantiated the themes presented by the four participants involved in the study. It is important to note that Lucy was the only participant who worked in hospice on a consultative basis. The inclusion of additional participants with similar work patterns could have helped to determine if Lucy's experience was representative of a larger phenomenon among occupational therapists who engage in hospice care on a similar basis.

## **Future Directions**

As noted by Rahman (1999), additional research is needed regarding clients' and families' experiences of hospice occupational therapy. Given the emotional complexity of the end of life, it may be difficult to engage clients and families in research during the actual dying process. It may, however, be feasible to explore the experiences of surviving family members following the death of a loved one who received hospice occupational therapy. Another research project would be to collect data on the state or national level regarding the availability, prevalence, and characteristics of occupational therapy in hospice and palliative care. Such a study could provide a foundation for the growth of occupational therapy in this practice setting. Additional research on the issue of burnout among hospice occupational therapists might yield important insight on the causes and prevention of emotional exhaustion in this area of practice. Finally, although some research has been completed regarding occupation at the end of life (Jacques & Hasselkus, 2004; Hasselkus, 1993; Lyons, et al., 2002; la Cour, et al., 2007; Reynolds & Prior, 2006), further exploration of this area would provide greater insight to occupational therapists working in hospice and palliative care, and could also serve to support the inclusion and expansion of occupational therapy in this setting.

In addition to research ideas, several potential projects arose out of this study. The creation and coordination of a local, statewide, or regional network of hospice occupational therapists could provide a valuable forum for exchanging ideas and advocating for occupational therapy in end of life care. This network could also facilitate mentoring relationships between hospice occupational therapists in different stages of their professional development. Additionally, in order to support the provision of psychosocial care for hospice clients, future students may wish to collaborate with practicing hospice occupational therapists to develop a set of psychosocial activities that could be completed by clients and families with the support of hospice volunteers.

**Conclusions**

As we strive to address the needs of an aging population (Bonder, 2009), occupational therapists are increasingly likely to be involved in end of life care. Among the participants in this study, attention to advocacy and deliberate utilization of therapeutic use of self underscores the commonalities between the core tenets of occupational therapy (American Occupational Therapy Association, 2008) and the philosophy of hospice care (Monroe, et al., 2007). The stages of professional development observed in the experiences of the participants indicate the growth and evolution that hospice occupational therapists may undergo during their work in this setting. As found in this study, hospice occupational therapists' attention to comfort, safety, and quality of life ensures that they are worthy stewards of Saunders' commitment to convey meaning, dignity, and humanity to individuals "until the last moment...of life" (Saunders, 1976, p. 1005).

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## Appendix

## Interview questions

Discussion question	Follow-up question(s)
Please tell me about your experiences as an occupational therapist in hospice or palliative care.	Please tell me about your workplace. How did you become involved in hospice? Did you feel there was a transition associated with coming to hospice?
What activities comprise a typical workday for you?	Could you walk me through a typical day? What proportion of your time is spent on direct client contact? Client-related activities? Non-client related activities?
What does success mean for you as an occupational therapist in hospice and palliative care?	What might an ideal day look like? Have you ever had an experience that you felt was unsuccessful? Can you tell me more about that?
How would you describe ideal practice for occupational therapy in hospice and palliative care?	How do you define “best practices” in this setting? In a perfect world, hospice occupational therapy would look like what?
Are there things that support you in trying to achieve ideal practice? What are some supports you experience?	What would help occupational therapists in this setting to achieve ideal practice? Who would you like to pass this job on to when you retire?
Are there challenges that you face in trying to achieve ideal practice? What are some challenges you experience as an occupational therapist in hospice and palliative care?	In other words, what limits your ability to achieve ideal practice? What’s the difference between your typical day and your ideal day?

Adapted from Sliefert (2009).

Table 1

*Terms and Concepts Used in Card Sorting Activity*

Activities of daily living	Independence	Scheduling
Adaptive equipment	Instrumental activities of daily living	Sharing and remembering
Assessment	Intervention	Skin integrity
Assistive technology	Leisure	Social participation
Bereavement support for hospice team	Medical director	Social work/social workers
Caregiver education	Medication management	Spiritual care
Caregiver support	Nursing/nurses	Supervisor
Chaplain	Occupational adaptation	Swallowing
Collaboration with healthcare team	Occupational profile	Therapeutic positioning
Creative activity	Pacing	Therapeutic use of self
Delegating activities and tasks	Pain management	Therapist self-care
Dementia education	Preparing for death	Touch
Distraction	Prioritizing activities	Travel time
Documentation	Psychosocial care	Unfinished business
Energy conservation	Quality of life	Vendors
Fall prevention	Referrals	Visiting with client
Grieving	Reimbursement	Visualization
Group activities	Relaxation activities	What is OT in hospice?
Incontinence management	Role change	Wheelchair use

Table 2

*Participant Demographics*

Pseudonym	Years as occupational therapist <sup>a</sup>	Years as hospice occupational therapist	% full time employment (FTE) in hospice
Diane	21 years as OTR/L	15 years	100% of FTE
Lucy	5 years as COTA + 6 years as OTR/L	3 years	3-4 cases per year
Ozzy	23 years as OTR/L	3 years	50% of FTE
Victor	15 years as OTR/L	4 years	100% of FTE

<sup>a</sup>COTA = Certified occupational therapy assistant, OTR/L = Occupational therapist, registered and licensed

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