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Occupational therapy for client empowerment in end-of-life care

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OCCUPATIONAL THERAPY FOR CLIENT EMPOWERMENT
IN END-OF-LIFE CARE

by
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A Scholarly Project
Submitted to the Occupational Therapy Department
of the
University of North Dakota
in partial fulfillment of the requirements
for the degree of
Master’s of Occupational Therapy

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This Scholarly Project Paper, submitted by Emily Johnson, and Sarah Landsem in partial fulfillment of the requirement for the Degree of Master’s of Occupational Therapy from the University of North Dakota, has been read by Jan Stube, faculty advisor, under whom the work has been done and is hereby approved.

Jan Stube
Faculty Advisor

12-30-08
Date
PERMISSION

Title Occupational Therapy for Client Empowerment in End-of-Life Care

Department Occupational Therapy

Degree Master's of Occupational Therapy

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ABSTRACT

Purpose: To enable clients in end-of-life care (EOLC) the opportunity to continue engaging in meaningful activities throughout their remaining days to increase QoL and experience a “good death.”

Methods: To complete our Scholarly Project we conducted a literature review using PubMed, CINAHL, OTsearch, and AOTA publications search engines. We also conducted an informal information session with local hospice staff and from this information we chose model/theory to guide product development.

Results: Upon completion of the literature review, we found the following problems existed in regard to utilization of Occupational Therapy in end-of-life care setting; 1) hospice care team members and clients lack knowledge of OT, 2) Volume of hospice clientele is increasing, 3) Clients and caregivers are not receiving the needed services, and 4) There is limited funding for OT services in hospice care. In order to address these problems a toolkit was created. This toolkit has four components including educational materials for both the medical professionals and the clients/caregivers; recommended assessments and evaluations which have been shown to be effective within the EOLC setting; recommended grant funding sources to provide initial funding for OT within EOLC; and an additional resources section with information related to utilization of OT services within EOLC. The intention of the toolkit is to provide an easy to use guide for Occupational Therapists who wish to become an active end-of-life care team member.

Conclusion: Increasing utilization of Occupational Therapy in End-of-Life settings has been shown to empower client/family, promote a “good death,” decrease costs, provide a preventative approach to care in order to decrease secondary injuries and can serve as a means to balance utilization of team members by acting as a liaison between the client and the end-of-life care team. Having a toolkit available for Occupational Therapists who wish to be more active in the end-of-life care setting can provide a means for increasing referrals and utilization of OT services in order to empower the client.
CHAPTER I
INTRODUCTION

*Within every person is a distinct and unique being that is unlike any life that has existed or will ever exist again.* (AOTA, 2005, p.671).

The United States population is aging and the number of persons approaching retirement age is expanding with the baby boomer’s generation. As of July 1, 2005, there were 78.2 million baby boomers within the United States. This amounts to approximately 7,918 baby boomers turning 60 years old each day in 2006 or 330 per hour (U.S. Government Census, 2006). According to the National Hospice and Palliative Care Organization “Four out of five hospice clients are 65 years of age or older and one-third of all hospice clients are 85 years of age or older” (NHPCO, 2007). Thus, as the U.S. population ages, the number of people requiring palliative care and hospice care is anticipated to increase also. Meeting this need will require a reorganization of the current end-of-life care team.

With the current United States economy declining, it will be vital to employ all resources to maintain cost-effectiveness and high quality care. By promoting Occupational Therapy (OT) and the benefits associated with incorporating OT in an active role on the hospice care team, this increased end-of-life care need could be met more readily (Frost, 2001). Although most hospice clients are over 65 years old, hospice clients may also be children. The top diagnoses in hospice are cancer, end-stage liver and kidney disease, dementia, and end-stage heart failure (Kinsella, n.d.).
Palliative care and hospice care are vital components within the medical setting for those individuals who are terminally ill. Understanding the differences between the two can often prove difficult. The following working definitions are provided for reference. The World Health Organization website (2008b) defines palliative care as "an approach that improves the quality of life of clients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and intervention of pain and other problems, physical, psychosocial and spiritual".

Palliative care is often utilized during the early stages of a progressive illness in conjunction with interventions intended to prolong life. In addition to these interventions, the World Health Organization states that palliative care utilizes a team approach to: provide pain relief, affirms, neither hastens or postpones death, provides psychological and spiritual care, acts as an extended support system, and offer bereavement support in hopes of positively influencing the course of the clients’ illness (World Health Organization, 2008).

Hospice is defined by Marcil (2006) as “both a philosophy and a system of care that embody an individualized, humanistic approach to care for people who are dying” (p. 26). Hospice is on the continuum with palliative care but has different criteria as indicated by Medicare and hospice care organizations. In order to be considered eligible for hospice care the medical director and client’s physician must concede the client has six months or less to live. In addition to this, the client must have a caregiver readily available at all times and no longer be receiving curative or prolonging interventions for their illness. Hospice care is available in hospitals, long-term care facilities, freestanding hospice agencies, and in the client’s home. Hospice care is based on five basic tenets:
“pain and symptom control, quality of life, diagnostic honesty, 24-hour care, and follow-up bereavement care for the survivors.” (p.26)

“Hospice provides end-of-life care, with a focus on living and dying” (AOTA, 2005, p. 671). Hospice care helps clients who are in their final stages of life to live as easily and completely as possible. The ultimate goal is to live life while embracing death (Rahman, 2000, p.808). To expand further on this concept the National Hospice Organization (1996) philosophy states:

Hospice is a special kind of care designed to provide sensitivity and support for people in the final phase of a terminal illness. Hospice care seeks to enable clients to carry on an alert, pain-free life and to manage other symptoms so that their last days may be spent with dignity and quality at home or a home-like setting.

The philosophy of hospice merges well with the statement of Occupational Therapy and Hospice (AOTA, 2005). The statement made by the American Occupational Therapy Association (AOTA) indicates that “personalized care and engagement in occupations” are within the realm of the OT profession and that “Occupational Therapy practitioners are uniquely qualified to help the dying person to engage in meaningful daily occupations within the hospice community of care” (AOTA, 2005, p. 671).

Occupations are defined as those things that are carried out day-to-day that are meaningful to the person. The occupations in the end-of-life care context are meant to help the client establish “mastery, control, adaptation and closure” (Rahman, 2000). In light of these four criteria, the occupations employed in an end-of-life care situation are not meant to challenge but to provide a means for the clients to transition as smoothly through the dying process as possible. These four concepts are vital components to a successful and meaningful transition.
Literature exploring the value and role of Occupational Therapy in hospice care settings indicate that the profession has the “potential to decrease costs and balance the utilization of team members...OT empowers the family and client, diminishes anxiety, decreases the incident of injury, and most importantly restores dignity” (Frost, 2001, p. 402). These benefits become apparent when using a proactive and preventative approach to palliative care. Early referrals to OT for caregiver and client education become vital to prevention education. Schlismann (2006) states that not having the right equipment or improper use of mobility devices, can increase falls leading to hip fractures which leads to a decreased quality of life (QoL). Providing instruction on completing client transfers and in-bed mobility safely as well as how to utilize mobility devices empowers the clients and caregivers to prevent secondary injuries related to lack of training. Completing proper transfers and bed mobility will decrease the risks of developing pressure ulcers which require higher levels of care which correlates to more expensive care and decreased QoL (Trump, 2001). By taking a proactive approach to care and addressing safety issues before they arise, the OT can decrease the workload of other team members by reducing rates of falls, fractures, depression, anxiety, and stress before they occur.

Medicare certified hospice programs are required to have an Occupational Therapist (OT), Physical Therapist (PT), and Speech Language Pathologist (SLP) on staff. However, the use of the services available is not outlined by Medicare (Pizzi & Briggs, 2004). Often the allocated funds are lumped together and services offered are prioritized according to need of the clients by the case manager or hospice team. Often, Occupational Therapy is one of the first services to be cut. While the hospice care philosophy indicates that quality of life coupled with comfort is the objective, often this
is provided in form of medication rather than meaningful occupation which has been shown to be equally effective in controlling pain. Occupational Therapy intervention provides both pain relief and facilitation for greater quality of life which may not be occurring solely with medication treatment. Encouraging clients to be more active and involved in their care not only increases their quality of life but promotes life role participation. The lack of education on the value and abilities of the OT profession increases the likelihood that OT is perceived as not necessary, which leads to the underutilization of OT services. If education were provided to the hospice care team and administration it would serve as a means to increase understanding and referral for OT intervention for palliative and hospice care clients as well as decrease cuts to OT intervention due to budgeting issues (Pizza & Briggs, 2004).

Despite the documented value of OT within an end-of-life care setting, scholarly literature shows OT continues to be underutilized in hospice. Rahman (2000) found that cost and lack of a place on the hospice team contributed to underutilization of OT. Again, understanding the value and benefit of incorporating OT services into the palliative care and hospice setting could reverse this underutilization (G. Schroeder, personal communication, September 12, 2008). While the OT profession understands their role and the benefits of providing care to the terminally ill, many other professions do not. Occupational Therapy is traditionally associated by other professions with a rehabilitation or health promotion approach to care. Through proper utilization of Occupational Therapy services within the end-of-life care continuum both the hospice care team and the client will reap the benefits.
Project Leading Statement: It is the position of the authors and the Occupational Therapy community that Occupational Therapists are in an optimal position to provide many facets of care within the palliative and hospice care setting (AOTA, 2005; Frost, 2001; Jacques & Hasselkus, 2004; Kealey & McIntyre, 2005; Marcil, 2006; Rahman, 2000). Hospice care clients should be provided with the opportunity to access all facets of care including Occupational Therapy services. The authors propose that all hospice care clients receive an OT evaluation in order to provide them with the means to acquire this type of care. A literature review of scholarly articles was conducted and is presented in Chapter II. This literature review outlines the current issues regarding under-utilization of OT within the end-of-life care setting, as well as the roles, benefits and value of having an Occupational Therapist on the palliative and hospice care team.
CHAPTER II
LITERATURE REVIEW

Frost (2001) defined Occupational Therapy (OT) in end-of-life care as “the recovery of dignity, systematically giving the client his or her sense of self, ... the client is taught to have control and responsibility within their physical limitations at home, where environment is not controlled” (p. 399). Client-centered care is a core principle of Occupational Therapy (AOTA, 2005); hospice care is centered on this perspective as well. As indicated by the literature, hospice care and Occupational Therapy’s approach to care is similar and correlates well to meet the needs of clients in their final stage of life. Pizzi and Briggs (2004) believe that Occupational Therapy has the ability to promote quality of life as well as encourage “wellness and healthy living until death” (p. 120). Both hospice care and Occupational Therapy hold the client’s perspective, experience, and comfort to be of utmost importance and strive to meet the ever-changing needs of this delicate client population in order to promote adaptation and control over their declining health.

Occupational Therapy in end-of-life-care is provided to improve quality of life through use of occupations meaningful to the client during the remainder of their life (AOTA, 2005). In addition to providing care to the terminally ill client, the OT is also qualified to provide caregiver education and physical, emotional, psychological, and spiritual support throughout the process of care. The AOTA Occupational Therapy and Hospice statement indicates that the “ultimate outcome of hospice is a good death, with
the focus on the client’s and family’s quality of life during the time that is left” (AOTA, 2005, p. 673). The term “good death” is defined by each client and therefore, takes on an individualized meaning.

Currently referral for OT services for individuals in palliative and hospice care is low. A study by Rahman (2000) indicated that Occupational Therapists felt that their profession was perceived by other healthcare professionals as “more of a rehabilitative service and less of a holistic service” and that this resulted in “low OT referrals in hospice” (p. 815). Pizzi and Briggs (2004) reported that a “positive approach” to dying has long been recognized by OT and Physical Therapy (PT) as an important concept. They believed that there remain professionals within the rehabilitative realm who do not recognize this role within the palliative and hospice care setting (p. 120).

The belief that OT is only rehabilitative in nature can lead healthcare professionals to discredit the use of OT services in the palliative and hospice care setting because the goal for the client is not to get better. Other medical professionals may also feel it gives the client a sense of false hope for recovery (Rahman, 2000). What is not realized is OT interventions in this setting are not focused on recovery, but in helping the client live life to the fullest and prepare for death. It is a concept of “rehabilitation in reverse” (Pizzi & Briggs, 2004, p. 123). OTs have a dual role involving a combination of providing therapy to “support life and living, while also supporting death and dying” (Rahman, 2000, p. 815). The ability to promote health while dying leads to the client increasing their ability to master their current roles, maintain control over what they are able and adapt more readily to the changes that are occurring. There is much literature exploring this dual role and its impact on practicing OTs. Frost (2001) investigated the
concept of a dual role conflict reported in the literature by interviewing current OTs practicing in an end-of-life care setting. It was found that the OTs viewed this dual role as a unique opportunity to “empower the client” to make decisions concerning their care and preparation for death. They also found that the OTs did not report any internal conflict in regard to helping the client in the opposing roles of living and dying which was conflicting with earlier literature findings. Another study by Prochnau, Liu, and Boman (2003) also reported similar findings. The authors discovered Occupational Therapists think of their role differently in the end-of-life care context: as promoting quality of life with the expectation to continuously adapt therapy to the client’s decline. Lack of communication to the team on this role contributes to a consistent finding of a misunderstanding of OT’s role in end of life care within in the medical community. This is detrimental to receiving referrals for OT intervention within end-of-life care and an additional contributing factor to under-utilization of OT services.

Occupational Therapy is often associated with being too biomechanical in nature to be of benefit to the hospice client (Rahman, 2000). Yet, Pizzi and Briggs (2004) argue that there is a place for exercise and functional tasks in the palliative and hospice care settings. By providing functional exercises, such as going on family outings, sitting up for meals or engaging in recreational or leisure activities, the client will benefit from increased endurance, energy, independence in activities of daily living (ADLs), and quality of life (QoL). These physical components play a vital role in providing a means for decreasing secondary problems throughout the dying process such as unnecessary falls or loss of client roles, which also decreases overall care costs.
In addition to the physical component, clients are faced with discomfort, emotional and spiritual pain. OTs are in an optimal position to provide care for these issues as well. Occupational Therapy core educational curricula include an extensive psychological component, which contributes to the holistic nature of OT services and prepares the therapist to address these non-physical symptoms effectively. “The ability to identify a person’s occupational roles and values, and to address these roles and needs through appropriate intervention to ensure a quality of life in the dying process, makes Occupational Therapy an important contributor to hospice care” (AOTA, 2005, p. 674).

In order to understand how Occupational Therapy can be beneficial to clients and caregivers in palliative and hospice care settings it is helpful to know the issues they face at the end of life. In the following section, client and caregiver issues found in the literature will be presented.

Client and Caregiver Issues

When an individual finds out that they have a terminal illness, they have many issues to address and process. They are thrown into the grieving process from that day forward. The family, friends and caregivers also become a part of this process and begin the grieving process as well. The grieving process is only one of the issues that the client and caregivers experience. Declining overall health becomes a day-to-day concern as well. Adapting and adjusting day to day in order to maintain control over fluctuating physical, mental, emotional, and spiritual health can often be an overwhelming ordeal. Without the proper supports in place, these individuals may feel a loss of control, comfort and dignity. Ultimately, dying becomes the context that is lived each day (Farber, Egnew, Herman-Bertsch, Taylor, & Guldin, 2003, p. 21). Examples of issues hospice care clients
report difficulty with include the following: 1) trouble getting through the day; 2) stress of financial burdens; 3) difficulty maintaining evolving relationships; 4) loss of physical abilities, roles, and independence and 5) pain and symptom management (Farber et al., 2003). The hospice care philosophy provides a means for the client to address these issues; however, the core care team often includes a nurse and a social worker whom are often allocated to multiple clients. This limits their ability to interact with the client for more than what is expected of their services. Often, the social workers are left in a position to address psychological concerns related to the grieving and dying process, which they are not qualified to address. For example, H.V., a daughter of a hospice care client indicated that her family felt that they were not receiving adequate care from hospice for her father while he was dying (personal communication, October 17, 2008). She stated that the nurse was very “cold” and came and went quickly with little time to answer questions that the family had. The social worker allotted to their family appeared to be “spread thin” and was not able to address many of the families’ psychological concerns. The experience was not a happy one for H.V. and her family. She stated she would like to have had a chance to discuss and evaluate the changes as they came, and support for her mother while she was a caregiver for her dying husband. She also stated that having someone to listen and adapt the environment to meet her father’s ever-changing needs would have been helpful. A more client-centered approach to care where the professional took the time to address all of their concerns more holistically would have made their hospice stay more meaningful. The type of services she was describing is exactly what OT services provide. The authors inquired to whether they received OT services during the hospice experience. She indicated that they hadn’t, though
retrospectively she felt that this would have definitely improved her father’s QoL throughout the dying process (H.V., personal communication, October 17, 2008). Skilled OT services could bridge this gap in professional service coverage increasing referrals and client/caregiver QoL.

Another potential problem encountered in hospice described by Payne (1998), is how hospice often employs volunteers to provide nursing and bereavement support with little or no training. It is also more difficult for volunteers to establish personal boundaries than paid staff in completing these tasks. The educational background that OTs have in addressing psychosocial factors would be beneficial to the team when concerns of this kind arose.

Farber et al. (2003) discussed how difficult it was for caregivers to prepare for the loss of a loved one. Some of the issues caregivers reported included continuing to meet all their obligations while taking on added responsibilities of care-giving; gaining adequate resources; maintaining the stamina to care for their loved one; and increasing emotional toll as a result of managing financial issues of their loved one now and in the future. Caregivers reported increased distress due to seeing their loved ones suffer, and many felt ill prepared to provide care or meet the increasing demands of care giving. On the other hand, caregivers also found satisfaction in mastering their new caregiver role while maintaining or strengthening their relationship with their loved one. Caregivers appreciated when they were included as an important member of the care team because they felt they were able to positively influence care given.

The ability for Occupational Therapy to address multiple concerns: physical, psychological, emotional and spiritual through promoting mastery, control, and
adaptation over their illness provides a means for the client to find acceptance and closure as they progress to the end of their lives. These characteristics are unique and valuable assets to the palliative and hospice care teams and settings. A greater understanding of these assets and benefits for the clients are one more avenue to increasing utilization of Occupational Therapy in the end-of-life care setting.

**Occupational Therapy Role**

Occupational therapists promote optimal independence and privacy while allowing the clients to still be themselves throughout the dying process. OTs help clients transition to accepting death while still living their life to the fullest possible potential. When a client is dying many feel helpless, feel they have no control over their disease, and life no longer has meaning (Kealey & McIntyre, 2005; Vrkljan & Miller-Polgar, 2001). Utilization of OT services can address these issues through client-centered collaboration to promote life-role participation and engagement in meaningful occupation.

An important part of client care in hospice is addressing pain management and safety. OTs can provide pain management through positioning, instruction on joint protection and energy conservation, and applying physical agent modalities (Kealey & McIntyre, 2005). Educating clients on proper positioning and transfer techniques and importance of bed mobility decreases the likelihood of developing pressure ulcers. Another safety issue is frequency of falls and risk of secondary injury among the terminally ill. Occupational Therapy can address falls prevention through education on proper mobility device use. Proper mobility device use has been shown to directly correlate to decrease secondary injuries such as hip fractures (Schlissmann, 2006;
Kinzbrunner, Weinren, & Policzer, 2002). Rahman (2000) stated that providing comfort through positioning and establishing safety were high priorities in OT and can be accomplished through home modification, caregiver education or use of meaningful occupations.

According to Marcil (2006), Occupational Therapists are able to address the psychological pain of isolation, abandonment, and loss of roles that often accompany a terminal illness. This is achieved through active involvement in occupations while providing a sense of competence and a feeling of contributing something of value. Pain can affect quality of life. Depression from loss of roles can increase physical pain. The OT can find occupations and activities that will serve as a diversion to pain and give clients a purpose for their life until the end. The Occupational Therapist finds the right match of occupation that will provide the client with pleasure by administering occupational history and occupational interest assessments. Use of these pleasurable occupations provides a natural means of pain relief. For example, one client enjoyed making birdhouses in his workshop. He indicated that while he was working he wasn’t as aware of his pain (Rahman, 2000). The author also states many times caregivers tend to treat the client like a child and do everything for them in order to protect them from unnecessary pain; however, it is sometimes necessary to risk pain in doing occupations to be happy. The things that we do each day give us identities and make us individuals. Clients who are going through the dying process need to be engaged in occupations as well (Marcil, 2006).
Another type of pain that Rahman (2000) described is “soul pain”. Although difficult to define, Rahman used a verbatim quote from a study participant in order to define this term:

...soul pain, when it’s so deep it’s in your being, it’s deeper than emotional pain. It is deeper to where it’s really at the center of your being. A pain of people who may not have a feeling that there might be an afterlife and feeling like I am disintegrating, I am going. What is happening? At the very, very center of who you are...to feel that you’re disintegrating, and you don’t want to disintegrate, that can be very painful. (p. 811)

This type of pain requires a different approach to intervention. Taking a spiritual approach may be beneficial in helping the client to cope with this type of pain. Involving family and community supports may also be necessary to help the client combat their “soul pain.” Occupational Therapists are trained to provide such support as this is part of Occupational Therapy’s domain of practice (AOTA, 2002). For example, Rose (1999) surveyed 44 HIV and AIDS, Oncology, Palliative Care Education (HOPE) specialists in the United Kingdom regarding their perception of spirituality within palliative care. More than half of the participants indicated that the clients needed spiritual help from the OTs and that addressing these needs was part of their practice/profession. The participants also indicated that spirituality was vital to their job and considered spirituality to be a vital component of Occupational Therapy. Literature by Egan and DeLaat (1997) and Howard and Howard (1997) (as cited by Rose, 1999) stated, “the spiritual task of OT may be to empower the individuals, enable them to engage in meaningful activity and connect them to their past and future through occupations” (p. 310). A study by Udell and Chandler (2000) explored OTs role of addressing the spiritual needs of their clients. The researchers found that spirituality can affect a client’s function. While the role of the OT was not seen as a spiritual counselor, it was thought that acknowledgement, respect, and
incorporation of spiritual aspects into choice of activities was important for building rapport, motivation and restoring spiritual well-being.

Occupational Therapists are in a unique position to address multiple needs of hospice care clients. Vrkljan and Miller-Polgar (2001) described how a terminal illness disrupted the client’s daily routine and affected the things they were able to do. OT is able to adapt to meet the clients ever changing needs, which facilitates development of new routines that help clients regain control over their lives. Through discussion with clients, Occupational Therapists help clients find meaningful occupations, prioritize activities, and pace themselves thus minimizing the anxiety clients have over their disease progression. As the disease worsens the therapist and client need to continue to make adjustments to the occupations the client participates in to match their capabilities and psychological mindset.

Occupational Therapy intervention strategies in a hospice setting is summarized as follows by Kealey and McIntyre (2005); Pearson, Todd, and Futcher (2007); Bonder and Wagner 2001, p. 515):

- Activity modification
- Fatigue management
- Caregiver assistance and safety training
- Environmental modifications through home modification
- Adaptive equipment and reduction of safety hazards
- Therapeutic activity engagement
- Creative activities
- Leisure and recreational activities
- Relaxation and stress management through meditation, progressive muscle relaxation, coping strategies, music and aroma therapy and environmental adaptations
- Client education
- Reminiscence Therapy
- Emotional support for client and caregiver
- Home assessment

Kealey and McIntyre’s (2005) study found clients and caregivers were not aware that OTs were able to provide caregiver specific interventions or address psychological
aspects of care for both caregiver and clients. The authors found clients and caregivers would have taken advantage of these services if they would have known. This knowledge is indicative of a need for increased education of the role of Occupational Therapy within the end-of-life care setting.

The AOTA (2002) indicates that a primary role of Occupational Therapists within the end-of-life care setting is to facilitate a “good death.” Weisman (as cited in Chochinov, 2006) described a good death for the clients as having fear and loss of control minimized, maintaining a sense of identity, enhancing relationships, resolving interpersonal conflicts, and continuing to do things that are meaningful. Jacques and Hasselkus (2004) described a good death as doing the things that matter; getting everything in order for their death such as planning their funeral, taking care of finances, giving away things to loved ones, and reconciling with family; and accepting their death.

Occupational Therapists can help facilitate clients experiencing a good death through engagement in creative activities such as making something to pass down to family as a legacy. Creative activity could include making a video to give to family after the client dies, writing a journal to help process feelings associated with dying, or creating a craft that has symbolic meaning for the client and helps them cope with their situation. Creative activity can also be used by clients as a life review to serve as a venue to develop closure. laCour, Josephsson, and LuBorsky (2005), found through producing something, clients had a greater sense of self and took pride in completing a project that was purposeful and worthwhile. Through creative activities, clients shared their life stories and made connections between past experiences, their present situation, and their possible future. Creative activity is especially effective in a palliative care setting where
there are other clients going through the same thing. It provides a medium for people to share and connect with others.

Psychosocial support from peers provides multiple benefits for hospice care clients. Larkin, Dierckx De Casterlé, and Schotsmans (2007) state that being in the presence of others who were also dying has positive influences on the client’s psychological adjustment to death. It is easier to cope when others are going through the same thing and are there to support the client. Depression and anxiety often accompany the terminal illness and are not always addressed as fully as the physical symptoms. These psychological symptoms also decrease the client’s quality of life (Chochinov, 2006). Creative activity can be a way for clients to deal with their depression and anxiety in a positive way. It can increase the client’s self-esteem and a sense of well-being.

Models of Care

Two models of care for hospice emerged within the literature: the Dignity-Conserving Care Model and the Doing-Being-Becoming Model of care. Dignity is defined in many ways and can take on varying meanings depending on the person defining it. A participant in a study by Chochinov (2002) defined dignity as, “a state of the soul...a sense of peace that passes all understanding” (p. 2254). Another participant in the study defined dignity as “trying to preserve the person as they are ... the sensible things like keeping them clean, keeping them comfortable, but also enabling their way of being, what made the person that person” (Chochinov, 2002, p. 2253). Chochinov proposed that through the Dignity-Conserving Model, the medical care team may be able to better understand the needs and desires of the client and their families in order to help the client transition into their last days with the greatest comfort, ease, and dignity. This
may include addressing physical, mental, spiritual, emotional, environmental, and caregiver issues specific to the client.

The Doing-Being-Becoming Model is an approach to care that focuses on helping the client prepare for death while embracing life through engagement in occupations. This model, proposed by Wilcock (as cited by Lyons & Davis, 2002), indicates that Occupational Therapists utilize a client-centered approach to identify the roles and activities that are meaningful to the client in order to better serve their needs and help them transition through the last stage of their lives. This model incorporates three aspects of an individual’s life as explained through: doing, being and becoming.

**Doing**

Wilcock (as cited by Lyons & Davis, 2002), indicates that each client has a drive to engage in occupations through “doing” during their lives. Through engagement in occupations that are meaningful to the client, identities are formed and their life meaning and purpose emerges. Life role engagement and occupation participation is present in all that we do; such as play, work, social engagement, leisure and recreation. Without “doing,” or engagement in occupations, Wilcock proposes that we are not balanced. This imbalance leads to occupation deprivation. This term, refers to the state that clients go through when they are sick or hospitalized due to inactivity or inability to carry out self-care, work or leisure roles. Occupation deprivation or inability to “do,” contributes to a state of ill-being and clients having a decreased perception of their own health and well-being. When clients are terminally ill and deemed appropriate for hospice care, the client has to be able to transition their focus from a “doing” individual to that of a “being” individual. This can prove difficult for clients. OTs can provide a means for clients to
find meaning within their now more prominent role of “being,” in order to acceptance their current life situation.

Being

Transitioning from focusing on the “doing” aspects of life to “being” aspects of life can be a complicated transition for a terminally ill client. Through this transition, Wilcock suggests clients experience a “self-discovery” process. Through this process, clients are able to reflect on their former role of being predominantly a “doing” individual in order to find meaning and purpose to guide their purpose of “being.” Through “being,” the client is able to focus more on themselves and what is intrinsically motivating to them in order to achieve a greater quality of life. Allowing the client to be one’s self through the dying process and giving them a sense of control over their lives despite their illness gives them a sense of “being.” Throughout the self-discovery process activities that are motivating to the client are found in order to promote well-being. These activities that are associated with the “being” stage may include leaving a legacy for family through providing stories of former life roles or family history, leaving a video diary, or completing creative activities which focus on remembering who they were prior to becoming terminally ill. When the client is able to accept and find meaning from both the “doing” and “being” aspects of themselves the client is able to transition to what is known by Wilcock as the “becoming” stage of the model.

Becoming

Clients in hospice care have the ability to find meaning and purpose with their current life situation. By reflecting on prior life roles and embracing declining abilities, and completing activities that provide closure, clients are able to find peace and develop
acceptance of their illness. This is termed the “becoming” stage of the Doing-Being-Becoming Model. During this “becoming” stage, the client experiences a “flow or transformation” at which point balance between the three concepts becomes one (Lyons & Davis, p. 286).

Lyons and Davis (2002) used the Doing-Being-Becoming Model to explore use of occupation in a day hospice program. Clients were found to have an increased quality of life, locus of control, and sense of well-being when engaged in occupation. The clients reported a greater sense of “dignity and worth” from engaging in occupation and through establishing new social relationships at the day hospice program (p. 290). Participants in the day program also felt they were able to maintain more of their physical and mental capacities through “doing” and learning new activities. One participant stated, “I will work on my crosswords for brain exercises cause if it’s not used it will curl up and die”; another client indicated that she partakes in a game of “words” because “we might be disabled in one way, but we’ve still got brains, and you can’t let that go to sleep, can you!” (Lyons & Davis, 2002, p. 2-3). This research showed how engaging in meaningful occupations can maintain functional capacities.

A participant in the program stated that being able to do and learn at this stage of his life made him “feel exhilarated...when learning something new” (Lyons & Davis, 2002, p. 292). Another stated, “you don’t realize what you can do until you try, when you’ve never done it all your life” (Lyons & Davis, 2002, p. 292). Contributing to the group, or “being” also gave the participants meaning. One said, “like its coming back that I can contribute...there’s probably quite a bit I can contribute” (Lyons & Davis, 2002, p. 293). Lyons and Davis (2002) indicated the participants reported observing others
completing occupations can be an occupation in itself for patients at the end of life. They authors indicated that for therapists to be effective they must be able to balance the three concepts of Doing-Being-Becoming.

By incorporating the Doing-Being-Becoming Model in hospice care, therapists are provided with a framework to promote engagement in each stage of their clients’ illness and dying process. By encouraging participation in “doing” and “being” occupations, the client is able to transition to a “becoming” individual. By accepting and identifying that both the “doing” and “being” aspects of themselves are valuable and meaningful, the clients are better equipped to accept their prognosis and current stage of their life.

Through these models and the literature reviewed, it is obvious that Occupational Therapy has much to offer clients receiving hospice care. Occupational Therapy’s holistic view and client-centered nature can contribute to a clients’ overall well-being and successful transition toward death (AOTA, 2002). OT is unique in its ability to provide client-centered, holistic care through the use of meaningful occupations. Ultimately, the OT’s role in palliative and hospice care is to “add life to days rather than days to life” (Marcil, 2006, p. 28).

While Occupational Therapy provides a valuable addition to the hospice experience, measurement of progress or outcomes can be difficult as the result of care is death. The AOTA (2005) described the progress in a hospice setting as “acceptance and improved quality of life...even as a client’s body systems and performance skills decline” (p. 672). Research cited in Pearson, Todd and Futcher (2007) indicated clients were happier when engaging in occupations and this increased their quality of life (QoL). The
researchers explored available QOL measurement tools, which could be used by Occupational Therapists to measure OT outcomes and QoL of clients receiving end-of-life care. These quality of life assessments provide a means for demonstrating the value of Occupational Therapy and use of occupations within an end-of-life care setting. A few of the instruments mentioned were Assessment of QoL at End-of-Life (AQEL), Missoula-Vitas QoL Index (MVQoLI), Brief Hospice Inventory (BHI), Needs at the End-of Life Screening Tool (NEST), Care-Notebook, Palliative Care Assessment (PACA), City of Hope QoL Tool (CoH), Palliative Care Outcome Scale (POS), and the Client Generated Index (CGI).

While each client is different and requires different types of occupations as interventions, the themes within the literature are the same. Clients who are at the end of their life cycle use occupation as a means of living a normal life, for use as coping strategies, a means to say goodbye by providing loved ones with tokens they have made such as crafts or goodbye letters, and as a way to remain as independent as possible. The literature is clear that occupation definitely has a place in hospice care. Often the reason that OT is not present within palliative care is due to the lack of understanding regarding what OT’s role is within the hospice environment (AOTA, 2005). Through education and promotion, Occupational Therapy’s place in this setting could be increased and would benefit clients partaking in hospice care as a means for transitioning in to death.

There is evidence, as indicated in the literature review, that Occupational Therapy would provide benefit to clients and caregivers when facing end of life issues. Yet there is limited OT referral due to other disciplines lack of knowledge regarding Occupational Therapy’s scope of practice. If OT could provide each hospice care client with an initial
evaluation, greater understanding and utilization of OT would occur. This would also lead to greater client QoL and client experience of good death. It is proposed that through increased awareness through education and promotion of Occupational Therapy’s scope of practice, value, and place within the palliative care and hospice team, that OT services would be more utilized and valued within the medical community. The *Occupational Therapy for Client Empowerment End-of-Life Care Promotion Toolkit* is located in appendix A.

In the following chapter, the methodology utilized for gathering information and developing the product, *Occupational Therapy for Client Empowerment End-of-Life Care Promotion Toolkit*, will be presented.
Chapter III

METHODOLOGY

The idea for the scholarly project was formulated based upon discussions in an OT gerontics class regarding care of geriatric patients during the final phases of their lives. It was obvious from these discussions that Occupational Therapy would be beneficial for these populations within the hospice care context. Further exploration through conversations with OTs at a local health care facility, revealed that OT in hospice care was underutilized and a need was evident. We decided to focus on this need for completion of a scholarly project.

A literature review was conducted through searching journal article databases. The databases searched included CINAHL, PubMed, OT Search, and www.OTseeker.com. Specific websites included in our search included the AOTA website and hospice and palliative care organization websites. Terms used for the searches included: Occupational Therapy and Hospice; Hospice; Palliative Care; Occupational Therapy; Occupational Therapy and End-of-Life Care; Occupational Therapy and Terminally Ill; and Occupational Therapy and Comfort Care. From these searches articles that focused on the role of OT within this area of practice were chosen, as well as articles that outlined the utilization of OT services, end-of-life care client perspectives, and articles related to funding within this context. From here it was determined that there was a need for increased knowledge and education regarding the
role of Occupational Therapy within the end-of-life care context; that OT was underutilized in this setting and had many roles to benefit clients within this setting. The next step was to obtain information specifically related to the utilization of hospice within our community. The authors contacted a local hospice organization and set up an informational meeting in order to verify or deny the information that was presented in the literature. The authors found that OT was not effectively utilized and likely misunderstood. Based upon these findings, an educational approach to increase utilization was chosen.

The Doing-Being-Becoming Model was utilized to guide development of our project. These three concepts guided us in product development, concept formation, and presentation of progression of interventions within the end-of-life care setting. Additionally, the concepts build off of each other and simulate the progressive use of occupations as therapeutic tools for facilitation of a good death which is the ultimate outcome of OT services within this setting. Education on all components of utilization of OT services within the end-of-life care setting was produced using the Adult Learning Theory, in the form of Microsoft PowerPoint™ presentations and brochures for targeted audiences: 1) medical professionals and 2) clients receiving hospice care and their caregivers. The following pages contain an *Occupational Therapy for Client Empowerment End-of-Life Care Promotion Toolkit*, for Occupational Therapy practitioners who are in a position to promote greater utilization of OT services within the end-of-life care setting. This *Occupational Therapy for Client Empowerment End-of-Life Care Promotion Toolkit*, will include Microsoft Office PowerPoint™ presentations, which can be used for educational purposes toward specific audiences; brochures to supplement these presentations;
resources including funding information, assessments/evaluations for various stages of
the process of care, websites, journal articles and books that provide additional
information on the role of OT within the end-of-life care setting. This information will
also be stored on a CD that will be included within this toolkit for the OT to use and
customize as needed. These resources will provide a means of persuading and informing
these two populations of the benefit of incorporating OT services into this setting.

The ability of the Occupational Therapist to promote mastery, control, adaptation
over their illness and find closure while they are dying are important concepts of OT care
in the hospice setting. By utilizing the toolkit, the intent of this project is to promote an
understanding and better utilization of Occupational Therapy services in palliative and
hospice care within the medical community as well as the public sector. Through greater
OT involvement in this setting, the ultimate outcome is providing client and caregiver
empowerment in the hospice setting, while preserving dignity and sense of self worth.
CHAPTER IV
THE PRODUCT

As the United States population continues to get older, the need for more holistic end-of-life care will be needed. Currently, hospice care in the United States is addressed most often by a care team consisting of a physician, nurse and social worker. The scholarly literature reviewed indicated that while these caregivers provide care to meet the basic needs of these clients, there remains a large component of care that is not addressed within this population including life role participation, engagement in meaningful occupations, reminiscent therapy, education on relaxation and coping techniques, education for caregivers, and availability of adaptive equipment.

Occupational Therapists have the knowledge and skills to better serve the unmet needs of this growing client population (AOTA, 2005). The literature reviewed indicated that while OTs are able to provide the necessary treatments, their services are underutilized often due to misinterpretation of the role of OT in an end-of-life care setting.

Occupational Therapists need to respond to this underutilization by being proactive in promotion of their valuable skills through education of medical professionals and end-of-life care clients/caregivers in order to be more active members of the hospice care team. In order to do this, the authors of this scholarly project have created a useable resource guide entitled: Occupational Therapy for Client Empowerment End-of-Life Care Promotion Toolkit. The primary audience for this toolkit is an Occupational Therapist who wants to become more involved in hospice care. The toolkit contains resources to help them achieve this goal including educational component for the medical professionals and
hospice care clients/caregivers to increase OT utilization. The models/theories that were used to guide the development of our product included the Doing-Being-Becoming Model (Wilcock, 1999), and the Adult Learning Theory (Bastable, 2006; Knowles, Holton III, & Swanson, 2005). The use of the Doing-Being-Becoming Model helped to guide introduction of topics and progression through OT roles in the toolkit. This model proposes that typically humans are “doing” beings. We are driven to be actively engaged in occupations, which lead to development of meaningful roles and intrinsic motivation. In the case of the terminally ill, the transition from filling the role of a “doing” person to that of a “being” person can often be difficult. This transition, while part of the grieving process while dying, can be a meaningful experience if incorporated into treatment through OT intervention. By helping the client to see themselves as a being person, the client can begin to progress through the grieving process and begin to find new roles and meaning. This role of a “being” person provides the person with limited or diminishing physical capacity a chance to reflect on their former “doing” roles in order to finding meaning in their current life context. By retelling stories to loved ones or caregivers, sharing photographs or memorabilia the client is able to move toward finding closure within their current situation and begin to progress toward a “becoming” person. When the client becomes a “becoming” person, they are able to fully incorporate their “doing” and “being” selves into one. This occurs by providing a means for the client to remain in previous roles which provides them with a greater locus of control over their situation while still embracing the act of a “being” in order for them to see the benefits and meaning in both roles. The combination and equalization of the “doing” and the “being” lead to the “becoming” stage. Once the client has reached the “becoming” stage, the
client has reached full acceptance of their terminal status and has found new meaning and closure within their lives, ultimately peace with their situation. This concept is also known as facilitation of a providing a means for a “good death” (Lyons & Davis, 2002).

The Adult Learning Theory helped to guide development of Microsoft Office PowerPoint™ presentations and brochures. This theory proposes introducing new concepts in an overview and then presenting these overviews in smaller parts. During presentation of the smaller parts of the whole, each concept is built off of the one presented prior. These parts are linked together in order to provide greater meaning toward the target audience. Activities were included within the presentations to foster the learning process and apply the individual’s learning to present situations. We took into account adults may have their own ideas about OT, thus we aimed to educate and persuade them to come to a new understanding of OT in end-of-life care.

In the following pages, the Occupational Therapy for Client Empowerment End-of-Life Care Promotion Toolkit will be presented. The resources included in the toolkit include Microsoft Office PowerPoint™ presentations, brochures, recommended assessments/evaluations, possible funding sources, additional resources (websites, journal articles, and books), and a CD copy of the provided resources within the toolkit. The goal of our product is to educate, inform and persuade medical professionals providing end-of-life care and hospice care clients/caregivers on the value and benefits of utilization of OT services within this context, and give the OT resources to increase to visibility of OT in end-of-life-care. This will ultimately lead to the outcome of increased OT referrals and utilization of OT services yielding increased client satisfaction within end-of-life care.
Education

The educational component of the *Occupational Therapy for Client Empowerment End-of-Life Care Promotion Toolkit* was created for two separate target audience: the medical professionals and the hospice care clients/caregivers. Implementation for these educational components varies by target audience.

**Medical Professional**

The medical professional educational resources include a Microsoft Office PowerPoint™ presentation with supportive brochure. The OT can use the educational materials at varying times according to need. The PowerPoint™ presentation is intended to persuade, inform and educate and therefore may be used as a recurrent in-service or as a means of initial education to promote the role of OT within the end-of-life care setting.

**Hospice Care Client/Caregiver**

Within the *Occupational Therapy for Client Empowerment End-of-Life Care Promotion Toolkit*, the client/caregiver educational resource also includes a Microsoft Office PowerPoint™ presentation with supportive brochure. The OT should use these educational materials for current hospice care clients/caregivers who are in the initial stages of hospice care intervention. It is recommended by the authors that a 90-day rotating schedule be used in order to educate all new hospice care clients/caregivers as the average length of stay is typically 47 days.
Assessments/Evaluations

Within the *Occupational Therapy for Client Empowerment End-of-Life Care Promotion Toolkit*, a variety of proposed assessments are provided for use as initial evaluations, ongoing assessments and outcome measures. The assessments are organized according to the categories and should be used according to the therapists’ discretion. It is vital that the OT utilizing these assessment tools be aware of the ever-changing needs of this population in order to be thorough in addressing the client’s changing needs.

Funding Sources

Within the *Occupational Therapy for Client Empowerment End-of-Life Care Promotion Toolkit*, grant funding sources for implementation of OT services within the end-of-life care context are provided. The implementation of these grants is dependent on the needs of the facility and the nature of the grants. They can be utilized for gaining funding for incorporating OT services that are not currently being implemented as well as for developing greater access and availability of services in a hospice care environment where OT is being utilized.

Resources

Within the *Occupational Therapy for Client Empowerment End-of-Life Care Promotion Toolkit*, a multitude of resources are provided to assist the OT in providing evidence-based practice within the Hospice Care setting. Recommended websites, journal articles, and books are provided in order to supplement the knowledge that the OT currently has and should be used as needed to strengthen and support the therapist within treatment planning, intervention and task analysis.
Occupational Therapy for Client Empowerment

End-of-Life Care Promotion Toolkit

Emily Johnson, MOTS & Sarah Landsem, MOTS
Educational Component

Medical Professional
Occupational Therapy in End-of Life-Care
Objectives:

• Understand the role of OT and uncover the current issues regarding OT's role in end-of-life care.

• Realize how OT correlates with palliative and hospice approach to care.

• Describe the needs that can be addressed by OT within end-of-life care.

• Discuss the underutilization of OT services in end-of-life care settings.
End-of-Life Care on The Rise

• “Four out of five hospice clients are 65 years of age or older and one-third of all hospice clients are 85 years of age or older”


According to the National Hospice and Palliative Care Organization (NHPCO) (2007)...

This means healthcare will have to expect palliative and hospice care client numbers to increase because the baby boomer generation is coming into this age category. How will end-of-life care be prepared for this with the amount of understaffing we have already? I will show how involving OT will solve this problem and be cost effective.
What is End-of-Life Care?

- End-of-life care involves:
  - Palliative care
  - Hospice
What is End-of-Life Care?

- Palliative care philosophy:
  - Support system
  - Coping and bereavement services
  - Pain and symptom relief

www.who.int/cancer/palliative/definition/en/

Why OT in end-of-life care? To understand this question it is helpful to look at the philosophies of palliative care, hospice care, and Occupational Therapy. You will see they match well together. Palliative care philosophy:
Provides a support system to help clients live as actively as possible until death to enhance quality of life.
Helps the family cope during the client’s illness and in their own bereavement.
Offers pain relief and interventions for physical, psychosocial and spiritual concerns.
What is End-of-Life Care?

- Hospice Philosophy:
  - Alert, pain-free life
  - Manage other symptoms
  - Dignity and quality of life at home or home-like setting

National Hospice and Palliative Care Organization (2007)
Facilitate greater independence in valued occupations/roles and increased quality of life: Achieved by looking at all aspects of the person, the environment, and social context. All philosophies focus on quality of life and a holistic approach to care, i.e., Facilitating a "good death".

Weisman (as cited in Chochinov, 2006) described a good death for the clients as having fear and loss of control minimized, maintaining a sense of identity, enhancing relationships, resolving interpersonal conflicts, and continuing to do things that are meaningful. Jacques and Hasselkus (2004) described a good death as doing the things that matter; getting everything in order for their death such as planning their funeral, taking care of finances, giving away things to loved ones, and reconciling with family; and accepting their death.

OT is a Holistic approach to care like end-of-life care: OT is a discipline that will focus on areas including the physical, cognitive, social, psychological, spiritual, and contextual to help the client live the last days of life to the fullest possible degree.

No other discipline focuses on occupations like OT. Remaining active in occupations while dying gives the client a sense of self-worth which matches with hospice and palliative care focus on maintaining the dying person's dignity. OT gives the client the opportunity to have control over their environment by helping them adjust to their decline while preparing for death. Hospice and palliative care are centered on this perspective as well.
Who is the End-of Life Client?

- **Age**
  - Over 65 (81.4%)
  - 45-65 (14.10%)
  - Under 45 (4.5%)

- **Diagnosis**
  - Cancer
  - End-Stage Liver Disease
  - End-Stage Kidney Disease
  - Dementia
  - End-Stage Heart Disease

www.cdc.gov/nchs/data/nhcsd/curhospicecare00.pdf

Statistically clients in end-of-life care are the elderly. Occasionally there are middle aged adults and children.
How can hospice help Jim?

- Jim has cancer. He has a wife and two young children. He is an avid outdoorsman enjoying hunting and fishing. His physical function is declining rapidly, and he is unable to do the things he used to do. Jim worries about what will happen to his family when he dies, and he is slipping into depression. He feels he is not prepared for death.

Here is a fictitious example of a client in end-of-life-care. Think for a moment what typical interventions would Hospice provide for this client. We will revisit Jim’s case again at the end of the presentation.
What If....

- You were diagnosed with a terminal illness and only had 6 mo. to live? Put yourself in the client’s shoes:
  - What would be your psychological response?
  - What would you want to accomplish before you die?
  - How would you prepare, and what would you want help with in accomplishing your goals before dying?

Take 5 minutes to think of these questions and write down your answers
Issues Clients Face in End-of Life Care

- Depression
- Anxiety
- Loss of roles/Independence
- Pain and symptom management
- Loss of physical abilities
- Difficulty maintaining evolving relationships
- Financial burdens
- Feel helpless and have no control over their lives
- Feel a burden to others
- Loss of meaning

Depression from loss of roles/decreased function can increase physical pain. The OT can find occupations and activities that will serve as a diversion to pain and give clients a purpose for their life until the end. Occupations also elevate anxiety.

Loss of roles/independence- not able to fulfill all the duties of being a mother/father/grandma/grandpa due to physical limitations and pain.
How are OTs Qualified to Work in Palliative or Hospice Care?

- “Personalized care and engagement in occupations”
- “Occupational Therapy practitioners are uniquely qualified to help the dying”

(AOTA, 1998, p. 872)

“Personalized care and engagement in occupations” are within the realm of the OT profession and that “Occupational therapy practitioners are uniquely qualified to help the dying person to engage in meaningful daily occupations within the hospice community of care”
How are OTs Qualified to Work in Palliative or Hospice Care?

- OT curriculum has extensive coursework in:
  - Pediatric, adolescent, adult, and geriatric populations: evaluation & intervention
  - Anatomy and Muscle Function
  - Medical Science and Neuroscience
  - Psychology
  - Assistive Technology
  - Leadership and Teaching

Knowledge of human development to deal with physical, emotional, cognitive, social, and spiritual issues of clients of all ages.
Knowledge on how to train muscles to maximize function.
Knowledge of disease progression to aid in intervention and anticipate problems before they occur.
Knowledge of how illness affects the psychological response and equipped to provide coping skills, relaxation techniques.
Knowledge of assistive technology to provide adaptive equipment to increase function and independence.
Background in leadership and teaching helps OTs be effective in advocating for the client and their needs, and also educating the client and caregiver.
How Can OT Work with the End-of Life Care Team?

• Focus on client issues
  ◦ Physical
  ◦ Cognitive
  ◦ Psychological
  ◦ Psychosocial

Many professions may be unclear as to what OT is and the role of OT. Because of this, OT is underutilized in palliative and hospice care so I want to provide an overview of this profession.

OT works with people of all ages to guide them in reaching their full potential, and maximize functional independence in daily activities: (including self care, meal preparation, leisure, play, social participation, financial and home management, education, and work).

OT’s work with the Physical, Cognitive, Psychological, and Psychosocial issues to help maximize their strengths and compensate for their deficits in order to complete occupations that are important to them.

OT stresses the importance of occupations to an individual. Occupations are anything a person does that has purpose and/or meaning. When a client is unable to perform valued occupations they lose a sense of identity and self worth. OT looks at ways to adapt occupations to allow participation or incorporates new occupations to challenge the individual and thus increasing the client’s quality of life.
OT Helps the Client…

- Perform essential roles
- Find meaning in occupations/activities
- Reach individual potential
- Maximize functional independence

Use of functional activities, coping strategies, adaptive equipment, and assistive technology to aid clients in performing their essential roles and completing daily activities. We want the client to live the life they have left to the fullest possible, and increase the quality of life to the highest possible given the circumstances.
OT is about...

- **Doing**
  - Engaging in occupations

- **Being**
  - Being one's self
  - Reaching one's full capacity
  - Having a sense of autonomy

- **Becoming**
  - Self-actualization
  - Having a sense of peace

Wilcock (1998)

In end-of-life care Doing in OT means- Helping clients do what they normally do, along with activities to prepare for death.
Being- allowing the client to be in control of their lives and be themselves despite their illness through the dying process. Facilitating their ability to utilize their personal strengths and capacities as fully as possible.

Becoming- facilitating the client’s acceptance of death, and a feeling of satisfaction with life so far, and where they are going.
Underutilization of OT in End-of-Life Care

- Medicare certified hospice programs are required to have an Occupational Therapist available
- OT is often viewed as rehabilitative but it's much more!

Due to limited amount of funds for Hospice care, funds are often lumped together and services prioritized. OT is not always seen as a priority. The value of OT for clients in this setting is not recognized.

Currently OT is mostly utilized in order to provide adaptive equipment for bathing or toileting. This is only a limited scope for OT involvement in this setting. A reason OT may receive little referrals in end-of-life care might be due to the medical community’s misconception that OT is only rehabilitative. OT’s work in areas of prevention, wellness, and improving quality of life.

OT in this setting helps the client complete occupations to prepare for a good death and alleviate pain/depression.
OT gets clients involved in daily activities which gives them increased endurance, energy, independence, and improves their quality of life. Improved QoL is the goal for all of us on the medical team.
OT’s Role

• Pain/symptom management
• Provide psychological support
• Home modification
• Caregiver education and support
• Prevention
• Providing adaptive equipment/assistive technology
• Facilitating a “good death”

Pain management-through positioning, instruction on joint protection and energy conservation, and applying physical agent modalities.

Psychological support- active listening, facilitating client life review. Also guided imagery, relaxation techniques, and coping skills training.

Home modification- for energy conservation, safety.

Caregiver education and support- caregivers often have difficulty continuing to meet all their obligations while taking on added responsibilities of care-giving; and maintaining the stamina to care for their loved one. The caregiver takes on an increasing emotional toll as a result of managing financial issues of their loved one now and in the future. Caregivers often report increased distress due to seeing their loved ones suffer. Caregivers are also afraid of hurting the client or themselves so OT provides training on proper transfer techniques and bed mobility to prevent strain/injury to themselves and client. OT educates caregivers on how to support their loved one, help them cope with their role and feelings of loss, and instruct on energy conservation for the caregiver. OT focuses on the caregiver as much as the client.

Prevention- promote healthy living and healthy relationships, prevent depression, prevent falls and further injury through home modification and adaptive equipment, and instructing clients on proper use of mobility devices. Falls from improper use of mobility devices can lead to hip fractures and further decrease the client’s QoL. OT can also provide lymphodema care and dysphagia services as needed.

Facilitating a good death- Help clients with tasks for preparing for their death through activities to provide closure such as planning for the funeral and expenses, saying goodbye to loved ones, and accepting their death.
OT Interventions Used in End-of-Life Care

- Functional activities
- Reminiscence therapy
- Therapeutic activity
- Relaxation and coping skills training
- Activity simplification/energy conservation
- Continuously adapt to declining function
- Play therapy for children

Functional activities to keep the client active and doing something meaningful increases their quality of life.

Reminiscence therapy- Help clients reflect on the past and reconcile differences with people, forgiving themselves and others.

Therapeutic activity- Use journaling, writing letters to people, making something that has meaning to give to family as a legacy. It helps clients to be able to contribute something of value to pass on to others (such as a dying mother making a video to be given to a daughter on her wedding day so the mother can give her wishes and be there in spirit).

Coping skills training/stress reduction for the client and caregiver.

Activity simplification/energy conservation/Adapt for declining function by finding new occupations or adapting old ones, environmental modification, adaptive equipment, assistive technology. Things to make occupations easier to complete and that the client will be able to do things on their own (doing things themselves so as not to be a burden is important to clients). Structure the day to conserve energy. Doing an activity for 10-15 minutes and then resting.

Play therapy- to help children cope and discuss their fears and relate to others. Play is their natural occupation that OT wants to maintain as long as possible.
Potential Problems with End-of-Life Care

- Clients isolated and lack participation in occupations/activities
- Poor symptom control
- Not enough time or staff to care for clients
- Hospice volunteers who cannot meet client needs for skilled services

Providing occupations that are the just right challenge for the client will keep them from being disengaged and thinking about their pain. Doing something; even light activity makes a person feel better. Occupations is a form of symptom control along with relaxation techniques, and proper positioning.

There is not enough time to provide all the support that is needed, and not enough staff for the amount of clients, and the time it takes to travel to homes makes staff stretched thin.

Some volunteers are qualified such as a retired nurse, but according to a study by Payne (1998) many provide nursing or bereavement services without proper training. Payne also states sometimes hospices trains volunteers on bereavement support but it is more difficult for volunteers to establish personal boundaries than skilled staff in delivering this service. Also, the training given at hospice cannot compete with professional academic training in higher education.
How OT will Benefit Other Disciplines

- Reduce the cost of healthcare
  - Prevention
- Reduce the workload on other disciplines
- Serve as liaison between client and the team

- Involvement in occupations and client/caregiver education can increase endurance and energy which can in turn decrease the likeliness of injury from falls due to weakness or improper use of a mobility device requiring further hospitalization from a hip fracture, by providing adaptations to the clients routine/environment and providing assistive technology/adaptive equipment. Falls can lead to decreased mobility because of fear of falling again, depression, and loss of confidence.
- Adapting the environment so the client can be more independent, and educating the caregiver to do tasks reduces the number of nursing and social worker visits. Caregiver and client education on proper bed mobility, transfer techniques, and frequent position changes, will prevent clients from developing decubiti ulcers requiring a higher level of care and therefore, cost, and decreased QoL for the client.
- Balance the utilization of team members- Nursing staff and Social Workers are stretched thin as it is. Having OT would allow team members to do their job instead of taking on other roles when an OT is not involved.
- Some problems are beyond what the team can address and if OT is not on the team an outside agency has to be contacted and paid for. Having OT on the team will save time and reduce costs in the long run. Because OT contributes to quality of life through occupation and increasing one’s coping skills, OT can decrease the likelihood of the need for crisis intervention which is costly. Through OT interventions clients have a sense of mastery and control and feel good about themselves. OT can save on expenses by training volunteers to carry out nonskilled interventions. Involving volunteers in the treatment plan will also fulfill the requirement for Medicare reimbursement which requires a percentage of volunteers equal to the paid staff hours.
- Providing meaningful occupations to clients will make them will be happier and less anxious thus reducing the amount of medication needed and psychological services needed.
- Liaison- OT’s are skilled at making use of each of the team member’s abilities to the best advantage for the client and utilizing the skills of all staff in the best efficient way.
Client-Centered Practice Involves OT in End-of-Life Care

• Offer at least one OT evaluation and follow-up for each client

OT realizes funding is slim in hospice, but all clients in this setting deserve the opportunity to have an OT evaluation if they so wish. This is best offered to them upon admission.
How can OT help Jim?

- Jim has cancer. He has a wife and two young children. He is an avid outdoorsman enjoying hunting and fishing. His physical function is declining rapidly, and he is unable to do the things he used to do. Jim worries about what will happen to his family when he dies, and he is slipping into depression. He feels he is not prepared for death.

Now that you’ve had a chance to learn more about the role of OT, what more could be done for this client than you previously chose for him. Refer back to your original treatment plan and see if you were missing any components of case that could be met by OT services. Based on our discussion today what do you think OT can do for this client?
Summary

- OT is currently underutilized
- OT has the knowledge and training to be effective team member
- Completing valued occupations increases quality of life
- OT is cost effective and reduces the workload on other staff

Underutilization- not serving the clients well if not providing all services available. OT's Knowledge will make sure interventions are appropriate for the clients' current function and anticipate changes to be made as the clients declines.

Occupation increases quality of life- this is the core belief of OT and matches the philosophies of palliative and hospice care. This proves how OT should be an integral part of the team. OT can increase the client-centered focus of end-of-life care. OT is a profession that has the capability to maximize the skills of all team members to work together for the client.

Staff in palliative and hospice systems are overworked and don't have the time to do all that should be done for their clients. OT can help fill this gap and reduce costs at the same time through prevention and better utilization of all services. Also, client and caregiver training can alleviate the number of visits needed by all staff.
How will you make OT a part of your client’s life and your hospice care team?
Any questions?
References


References


Payne, S. (1998). To supplant, supplement, or support. Social Science and Medicine, 46(11), 1495-1504.


OT's Role in End-of-Life Care

• Initial evaluation & ongoing assessment
• Address safety issues and concerns
• Pain/symptom management
• Home modification
• Recommendation of adaptive equipment
• Caregiver education and support
• Prevention of secondary symptoms
• Play therapy for children
• Coping skills training
• Stress reduction
• Reminiscence therapy

Referrals to Occupational Therapy...

OT will increase your client's quality of life in order to promote living life to the fullest until the end.

An OT Ready to Provide Care:

Placeholder for Business Card

Pictures obtained from: Microsoft Office Clip Art™
OT in End-of-Life Care

- Helps clients to perform essential roles in their lives
- Helps clients gain a sense of autonomy
- Helps clients complete occupations that are important to them
- Helps clients live life while preparing for death
- Restores clients' life purpose and meaning throughout the dying process

OT Qualifications for Providing End-of-Life Care

Extensive training in:
- Pediatric, adolescent, adult and geriatric populations
- Anatomy and muscle function
- Medical Science and Neuroscience
- Psychology
- Assistive Technology
- Leadership and Teaching
- Biomechanics
- Ergonomics
- Activity Analysis

Occupational Therapy uses occupation as an intervention

OT reduces costs & decreases other team members' workloads
- Prevent secondary injuries through home modification and providing adaptive equipment
- Educate caregivers to do tasks, reducing the number of team visits
- Promote healthy living/relationships, and self worth through occupations to alleviate costly crisis management and a higher level of care
Educational Component

Client & Caregiver
Occupational Therapy within Hospice: Client Empowerment

By Emily Johnson, MOTS
&
Sarah Landsem, MOTS
Within every person is a distinct and unique being that is unlike any life that has existed or will ever exist again.

-AOTA (1998, p. 872)
To provide information about Hospice Care and benefits of having Occupational Therapy services in Hospice Care.
Objectives

Audience will learn about the:

- Philosophy of Hospice & fit with OT
- Composition of the traditional hospice care team
- Role of OT in the hospice care setting
- Benefits of receiving OT in the hospice care setting
Hospice Care Basics

- Hospice Care Philosophy:

Designed to provide sensitivity and support for people in the final phase of a terminal illness. Seeks to enable clients to carry on an alert, pain-free life and to manage other symptoms so their last days are spent with dignity and quality of home or in a home-like setting.

-National Hospice Organization (1996)
Hospice Goal:

To assist the patient in living as comfortably and fully as possible at home.

http://www.wregional.com/body.cfm?id=106
Traditional Hospice Care Team

- Hospice Care Team
  - Clergy or other counselors;
  - Home health aides;
  - Hospice physician (or medical director);
  - Nurses;
  - Social workers;
  - Trained volunteers;
  - Personal physician;
  - Speech, physical, and occupational therapists.

*http://www.caringinfo.org/LivingWithAnIllness/Hospice/TheHospiceTeam.htm*

Do you feel that you are an integral part of your hospice care team? What impact does this have on your level and satisfaction of care?
Registered Nurse
- Coordinates team care for patients
- Provides direct patient nursing care
- Provides patient and family education

Social Worker
- Provides advice and counseling to both patient and family
- Works with team with understanding of family dynamics
- Accesses community resources

Physician
- Provides physician care
- Approves team health care plan for patient and family

Home Care Aide
- Provides assistance with personal hygiene, such as bathing, shampooing, shaving, nail care

Homemaker
- Provides light housekeeping and meal preparation

Volunteer
- Provides emotional support
- May offer services such as shopping, babysitting, and car pooling
- If you are interested in volunteering with a hospice provider, click here to find a hospice near you.

Physical, Occupational, and Speech Therapies
- Help patients develop new ways to conduct everyday tasks that may have become difficult, such as walking, dressing, bathing, or feeding oneself. The role of OT is often misunderstood and therefore referrals are not made. The role of the OT can address much more than what was just stated. The hospice care client may have other life roles that are meaningful to them that require intervention that the other team members have not addressed, which would be vital to increased QOL and meaning throughout the remainder of their lives.

Religious/Spiritual Counselor
- Clergy and other spiritual counselors are made available at the patient's request.

Continuous Care in the Home
- Under special circumstances nursing care may be provided in the home from eight to 24 hours per day.

24-hour on-call Availability
- A member of the team is on call and available 24 hours a day, seven days a week.

Respite Care
- The patient may be temporarily put into care of an in-patient facility to provide relief for family members.

Medical Appliances and Supplies
- Necessary medical appliances and supplies may be made available to the patient and family, including drugs and biologicals.

Bereavement Support
- A team member works with the family to deal with the loss of a loved one and the process of grieving.
- Bereavement programs are often open to anyone who has experienced a loss, regardless of their use of hospice care.
Occupational Therapy is provided to increase quality of life for all involved through meaningful occupations.

What does that mean exactly? Occupation used in these terms is quite different than many realize. What do you think occupation consists of?
• Many clients receiving Hospice services are not aware that OT is a covered service.

• Use of Occupational Therapy in Hospice often is under-used.

• Use of Occupational Therapy in Hospice provides clients with greater satisfaction with life, greater independence, and greater control over their situation.

• Occupational Therapy is also provided for family members who are providing care.
Self Reflection Exercise

- What are the current concerns, needs and problems in your life or the life of your loved one?
- What aspects of Hospice Care are currently working well for you and your family?
- Do you have any unmet needs?
- Are you or your loved one currently receiving Occupational Therapy intervention as part of your Hospice Care experience?
What roles do you have and find most satisfying on a daily basis? “Finding satisfaction and meaning within the role of having a terminal illness is often the biggest challenge for clients (Carey, 1975). The OT can help with this challenge by facilitating continuation of roles as possible through adaptation of context.

During your group discussion, did any of you talk about loss of roles as an issue? If not, do you feel that this is an issue that you face? Please share...what is difficult about losing these roles? Are they vital to your QoL, why or why not?

Occupational Therapy can assess and provide a way for clients to continue with family rituals such as going on family outings, sitting up for meals, and engaging in leisure/recreational activities to encourage the physical components listed above. Family rituals are often overlooked during the Hospice care experience. Do you feel that these family rituals serve a purpose within your care, why or why not?
Physical decline is a common complaint within the terminally ill population. Referring to your compiled list, how many of you listed this as a concern? Does anyone of you who raised your hand currently have interventions incorporated into your daily care to meet this concern? Please explain further...or why do you feel that this is not addressed?

Physical assessments need to be completed on a daily basis as physical decline occurs at different times. By providing exercises, the client’s have increased physical endurance, energy, independence in ADLs, QoL, and a potential for decrease of secondary problems such as falls/loss of roles as the physical needs are addressed and evaluated in each OT visit.
Assess a Client & Caregiver Issues
- Physical
- Emotional
- Psychological/Social
- Spiritual
Again, in your groups, how has pain impacted your QoL during your illness? What is currently being provided to you for pain management? Call on someone and have them explain or share their experiences. Ask if anyone else has had the similar experience. Do they want to share or elaborate?

Pain management is a huge concern for client’s in Hospice Care. By assessing the client’s level of pain and times of pain, the OT can address issues specific to the client.

- Providing proper positioning in bed, while in sitting or carrying out activities can provide a way for pain relief. Providing proper cushioning and supports that fit the client are beneficial.
- Home modification and caregiver training are also effective tools contributing to pain management (Rahman, 2000). Education on joint protection and energy conservation are also important components of pain management as they allow the client to continue to carry out meaningful activities in a manner that is less painful for them.
- Using PAMs is another option for pain control. Hot, cold and electrical intervention (TENS unit) are a means for pain management which can be used by the OT.
- Also using occupation as a means to control pain has been documented in research to be beneficial for pain control. A hospice client in a research article by Rahman (2000) indicated that he liked to make birdhouses in his workshop prior to his illness. Through working with his OT he was able to return to this leisure activity. The client indicated that when he was working on his birdhouse he was not aware of the pain as he was so involved in the task he was no longer aware of it while engaged.
Occupational Therapy is also able to provide psychological intervention in conjunction with OT-based intervention.

Through assessment/evaluation the OT is able to match the client to occupations that are meaningful and fulfilling. These occupations/activities also provide pleasure (endorphins) which act as pain relievers as well.

Restoring control over lost roles is also an asset to having OT in Hospice Care. The OT can complete a task analysis and provide modified ways for the client to remain in their valued roles for as long as possible in order to increase their independence. Spiritual Support is also part of OT practice. Spiritual support provided by OT can take many forms and is also client specific. The OT is able to listen and provide direction for the client. Specific occupations can be geared toward spiritual exploration or closure.

By providing intervention specifically geared toward the client regaining control over what they can, the client is able to decrease anxiety as they are more able to complete the grieving process and find closure.

How many of you currently find that you have some form of depression, low mood or anxiety? It is very common to be experiencing these types of feelings. How do you deal with these issues currently? Are they goals of your Hospice Care? Have they been discussed? Have some of the audience share...

Addressing depression and anxiety is a major component to a successful transition throughout the dying process. Education and training in relaxation techniques also has an added benefit of helping the client to see the causes of the stressors and be able to counteract them before they get too great. Additionally, being active helps you challenge your mind and body to engaging in activity. This is known to release endorphins which also promote well-being.

Remembrance tokens are an occupational based activity where the client (you) can partake in creating a special project (craft, picture, video, write a letter, leave a memento with a note) to leave for a loved one, friend or family member. These are beneficial in helping the client to find meaning and closure throughout the last days of their lives.
All of the previous concerns and symptoms can lead to not being able to fulfill meaningful roles that previously were a part of your life. Loss of roles can be very troubling. This can lead to a feeling of loss, depression/anxiety, guilt, anger and defeat or loss of control. Does this sound familiar? Or is this a concern? OTs can help to alleviate some of these feelings by offering solutions to losing roles and helping the clients and their families to identify ways of retaining roles that are meaningful.

By evaluating the home and creating a asset challenge assessment, the OT is prepared to offer solutions to current functional mobility problems and decreased independence in life tasks/occupations. Once the home assessment has been completed, the OT can begin to make recommendations/suggestions and changes per the discretion of the client and caregivers. Arranging the home to be more accessible and easily used by the client is often a priority. Access and ability for the client to care for themselves is usually a top priority.

Assessing ability to dress, bath and toilet is part of this process. Adaptive equipment and techniques for ease of completion can be beneficial for increasing independence. Examples are: involving the caregiver throughout this process is vital as they will be the ones facilitating these tasks on a daily basis. The caregiver must be In trained on the proper and safe methods for transfers, assisting the client and how to use the adaptive equipment.

Another component to lost roles is being able to facilitate the client to go on outings with family/friends as able. Troubleshooting and problem-solving are part of the IT intervention for the task to be completed. Once complete, the OT can make recommendations in order to either partake in the outing or bring as much of the outing as possible to client if unable to venture out.
Soul Pain is addressed through:

- Occupation as a Means
- Leisure Activities
- Recreational Activities
- Remembrance Activities
- Spiritual Support
- Involving family and community supports

Marcil (2006); Rahman (2000)

A hospice client explained soul pain as...“it’s so deep it’s in your being, your very being, it’s deeper than emotional pain. A pain of people who may not have a feeling that there might be an afterlife and feeling like I am disintegrating, I am going – and I don’t want to.” (Rahman, 2000, p. 811)

Has anyone here ever experienced what this man referred to as soul pain?

The process of addressing soul pain is difficult. The first step according to this researcher is to support the caregivers. The reason being is that often the caregiver can project their pain to their loved one resulting in greater distress of the patient.

Engaging the client in activities that he/she can control is next step. The ability for the client to be able to make choices, regardless of how simple/complex they are, often contributes to decreasing pain as it allows greater control over the situation and provides a way for the client to maintain some of their lost roles.
Was this a concern for anyone? Why or why not?

As previously mentioned, addressing caregiver needs is a huge part and number one step to decreasing client pain. Examples of caregiver support (Rahman, 2000, p. 811) are: helping a mother to hold her dying child comfortably, teaching caregivers about energy conservation as well as providing them with emotional support by being there to talk or address concerns that arise.
How do each of you currently address spiritual needs? Ask for examples or concerns.

Spirituality is a very individualized experience. It can be religious in nature or determined by what's meaningful to you personally.

Two definitions suggested by Andrew Rose were 1) spirituality is the experience of meaning in everyday life and 2) spirituality relates to our thoughts, feelings, and actions concerning the meaning that we make of our daily lives.

The use of spiritual intervention in an OT setting is to carry out activities of spirit in order to help create meaning, gain control and nourish the soul (p. 307). Proposed activities include reading, expressive arts, visiting museums and galleries, music, walking and retreating to nature, gardening and letter writing.

Other ideas that were shared included use of talking/listening sessions for exploration of current state of life; guided questions to establish goals/motivation for day to day living; inquiry into daily socialization/religious participation to see if a need exists for intervention for promotion of these activities; and organization of meetings with religious/family members to increase spirituality in life.
After exploring the roles of the OT in this setting, the benefits and values become apparent.
Please split into groups of four people each.

Based on your self-reflection at the beginning of this presentation, discuss your top concerns with the group if you feel comfortable doing so.

After hearing the presentation, are there current unmet needs that you feel could be addressed by an Occupational Therapist?

If your answer is yes or maybe, please list these needs on the form that is labeled “Current OT Needs”.

Discuss what you have written with your group members. If you don't feel you are in need of OT services at this time, please share your reasons for this as well.
**Conclusion**

- Occupational Therapy can be beneficial for improving Quality of Life for persons who are terminally ill and their family members.
- OTs are able to address concerns that are often not met by other members of the Hospice Care team.
- Providing mastery, adaptation, acceptance and closure throughout the Hospice Care experience are the main goals of OT intervention.
- Referrals to OT are often minimal, as the Physicians and clients are not aware of the needs or that OT is available.
- Asking for any service can be challenging; however; by presenting the form you completed, you are better prepared to address these issues with your Physician or primary care provider.
References


Does Medicare Cover Occupational Therapy in Hospice Care?

Yes. According to the Medicare benefits manual, section 40.1.8 indicates that occupational therapy services may be provided for the purposes of symptom control or to enable the individual to maintain activities of daily living and basic functional skills. Also, if a client lives in an unurbanized area the client may apply for a waiver to receive OT services if they are not on the Hospice Care staff.

References


Within every person is a distinct and unique being that is unlike any life that has existed or will ever exist again (AOTA, 1998, p. 872)
Do you need Occupational Therapy?

Many clients in Hospice Care may be in need of Occupational Therapy and not know it. Occupational Therapy provides client-focused care to promote independence, control and dignity in the face of a terminal illness. In addition to client-focused care, Occupational Therapists are also educated to address caregiver concerns. Education, training, and psychological/emotional care are available through Occupational Therapy services.

What is Occupational Therapy?

In Hospice, Occupational Therapy is provided to increase quality of life, promote independence in daily activities, increase safety, establish continuation of meaningful roles, and maintain dignity throughout the remaining days of the clients' lives.

Occupational Therapists assess the client to ensure that the ever-changing physical, emotional, spiritual and psychological needs are addressed as they arise.

What Roles do Occupational Therapists Serve on a Hospice Care Team?

- Activity Modification
- Fatigue Management
- Caregiver Training/Education
- Environmental Modification
- Adaptive Equipment
- Safety Promotion
- Therapeutic Activities
- Psychological/Emotional Concerns
- Relaxation/Stress Mgmt.
- Coping Activities
- Life Role Participation

Do Occupational Therapists have the educational background to address all of my needs?

Yes! Occupational Therapists have a Bachelor's or Master's degree with coursework emphasis in areas of anatomy, neuroanatomy, human body biomechanics, psychology, kinesiology, physical disabilities, task analysis, environmental concerns/ergonomics, disease pathology, assistive technology/adaptive equipment and problem-solving.
Assessments/Evaluations
Assessments/Evaluations

When assessing or evaluating the client who is terminally ill, many considerations must be taken into account. Due to the unique situation of end-of-life care, showing progress or outcomes for reimbursement purposes often proves difficult as the client is not going to be progressing but rather, slowly becoming more impaired. Within this setting, the assessments should be relatively short in nature due to the fraility of the client while addressing losses but also noting remaining strengths (Boog & Tester, 2008). In order to accomplish this, researchers Pearson, Todd and Futcher (2007) determined that a quality of life (QoL) measurement tool could encompass these qualities in order to prove the value of OT intervention. An additional component that Pearson et al. (2007) suggest is finding a tool that can be rated by the client being assessed. According to Pearson et al. (2007) the QoL tools should also be able to assist in identification and prioritization of problems, facilitate communication, and promote a shared decision making processes.

Clients have reported that the process of assessment can be therapeutic in nature. This is helpful within the end-of-life care setting as assessments may need to be conducted more than once to address declining health.

The evaluations and assessments in this toolkit are intended for use in initial evaluations, ongoing assessments, and/or outcome measures. They were chosen based upon their ability to be client-centered, short administration time, reliability and validity, and ability to address multiple areas of concern.
Brief Hospice Inventory (BHI)

**Purpose:** To determine the needs and attitudes of the client in order to guide interventions. It can be used as an initial assessment, for ongoing assessment, and outcome measures.

**Description:** The inventory consists of 17 questions that are rated on a likert scale. It combines measures of what patients identify as the most common physical and psychological symptoms and items on their general quality of life, such as attitudes related to hospice care, satisfaction, and overall quality of life. It also has a professional caregiver survey asking the same questions about their perception of the client's experiences.

**Reliability:** Test-retest reliability will vary due to the declining function of the client.

**Validity:** This assessment was rated as valid for use in Occupational Therapy in a hospice setting by Pearson, E., Todd, J. G. & Futcher, J. (2007). How can occupational therapists measure outcomes in palliative care? *Palliative Medicine 21*, 447-485.

Canadian Occupational Performance Measure (COPM)

**Purpose:** This clinical outcome measure was developed by Occupational Therapists in order to provide a client-centered approach to detect changes in the client’s perception of well-being and progress over time.

**Description:** This outcome measure was developed according to the Canadian Model of Occupational Performance. The measure has three subareas, which are part of an interview format and include self-care, productivity and leisure. The client identifies current occupations in each area and their satisfaction with their ability to carry out these occupations. The client rates the activities at the beginning of intervention as well as at the end in order to see if their perception of performance and satisfaction changed over time with the development and implementation of client-centered goals.

**Reliability:** Test–retest reliability at 1 and 2 week intervals ranges from 0.63 to 0.89 for performance and from 0.76 to 0.88 for satisfaction.

**Validity:** The COPM has been shown to be responsive to self-perceived occupational performance over time. The COPM has research studies to prove it to be a valid measure across many populations.

**Source:** Canadian Association of Occupational Therapists, CTTC Building 3400-1125 Colonel By Drive, Ottawa, ON K1S 5R1, Canada Tel.: 800-434-2268, ext. 236 Fax: 613-523-2552

**References:**


Missoula-Vitas Quality of Life Index (MVQOLI) - Version 15R

**Purpose:** To measure client’s quality of life in order to assist the therapist in understanding the client’s perception on function and well-being in order to guide intervention.

**Description:** The MVQOLI has 15 questions about 5 dimensions or domains of quality of life: Symptoms, function, interpersonal, well-being, and transcendence. Clients rate satisfaction and importance of these areas on a likert scale. Repeat administrations of the MVQOLI are recommended to monitor changes in patient quality of life.

**Reliability:** Test-retest reliability will vary due to the declining function of the client.

**Validity:** This assessment was rated as a valid for use in Occupational Therapy use in a hospice setting by Pearson, E., & Todd, J.G., & Futcher, J., (2007). How can occupational therapists measure outcomes in palliative care? *Palliative Medicine 21*, 447-485. It has been reported this assessment was moderately to strongly relevant in assessing clients’ quality of life (Schwartz, Merriman, Reed, & Byock, 2005).

**Source:** VITAS Healthcare Corporation, Miami, FL and Ira R. Byock, MD, Missoula, MT.

**References:**

Occupational Performance History Interview-II (OPHI-II)

**Purpose:** This was based upon the Model of Human Occupation (MOHO) with the purpose of obtaining a broad, in-depth look at the clients' life history, specifically related to diagnosis or illness. It also rates the clients' competence, identity, and impact of occupational behavior settings.

**Description:** Five topic areas are addressed through a semi structured interview including; occupational roles, daily routines, occupational behavior settings, activity/occupational choices, and critical life events. The interviewer rates the answers using 4-point rating scales (4 = exceptionally competent occupational functioning; 1 = extreme occupational dysfunction).

**Reliability:** Information of reliability is limited; however, the second edition has made adjustments to the rating information in order to increase inter-rater reliability.

**Validity:** The OPHI-II has been shown to detect differences in occupational performance according to a Rasch analysis.

**Source:** Model of Human Occupation Clearinghouse, University of Illinois at Chicago Department of Occupational Therapy (MC 811), College of Applied Health Sciences 1919 West Taylor Street, Chicago, IL 60612-7250, Tel.: 312-413-7469, Fax: 312-413-0256, Email: moho_c@yahoo.com, Web site:www.moho.uic.edu

**References:**


Home Environment: Assessment Tool

**Purpose:** Evaluative: to assess occupational performance in the home and identify physical and social environmental solutions to promote greater autonomy within the home.

**Description:** The structured interview is completed along with further observation and physical assessment of client function within the home as needed. The four parts of the questionnaire include characteristics of the client, characteristics of the home, analysis of ADLs and IADLs, and conclusions/recommendations. Data is summarized for conclusions and recommendations.

**Reliability:** Rigor is adequate: one to two well-designed published studies support the measures validity. Content is rated as excellent and is established through consultation with experts including seniors, architects, and OTs using focus group methodology; field testing. There is no evidence available for criterion and construct.

**Validity:** Rigor is rated as adequate with ~ 2 published studies supporting its validity. Content rating is excellent and established through expert consultation using focus group methodology and field testing. There is no evidence available for criterion and construct.


**Reference:**
Palliative Performance Scale

**Purpose:** To modernize and improve the well-established Karnofsky Performance Status (KPS) tool. Developed by the Victoria Hospice Society in 1999, the PPS assesses a patient’s level of ambulation, activity, evidence of disease, self-care, intake, and consciousness.

**Description:** The PPS is an 11-point scale designed to measure patients' performance status in 10% decrements from 100% (healthy) to 0% (death) based on five observable parameters: ambulation, ability to do activities, self-care, food/fluid intake and consciousness level. The PPS scale was designed to assess a patient’s functional level in order to assist healthcare providers in allocating resources, assessing medical care needs, and in patient prognosis and has also been used to identify and track the needs of palliative care patients.

**Reliability:** PPS has shown to have good overall inter-rater reliability in a study conducted at an outpatient palliative radiation oncology clinic.

**Validity:** The results of a reliability study conducted by: Ho, F., Lau, F. M. Downing, M., & Lesperance, M. (2008), demonstrated that PPS is a reliable tool. The validity study found that most experts did not feel a need to further modify PPS and, only two experts requested that some performance status measures be defined more clearly. Areas of PPS use include prognostication, disease monitoring, care planning, hospital resource allocation, clinical teaching and research. PPS is also a good communication tool between palliative care workers.

**Source:** Victoria Hospice Society, 3rd Floor, Richmond Pavilion, Royal Jubilee Hospital, 1952 Bay Street ~ Victoria, British Columbia, Canada ~ V8R 1J8, Telephone/24 hours: (250) 370-8715 ~ Fax: (250) 370-8625.

**References:**

Grant Funding
Grant Funding

Within the end-of-Life care continuum, funding plays a role in receipt of services and client quality of life. As an Occupational Therapy practitioner, reimbursement becomes even more difficult as OT is an adjunctive service on the hospice care team. Scholarly literature indicates that due to the lack of funding, OT is usually one the first services to be discontinued if there are funding issues despite the client benefits of its use. Due to these issues, the authors have included examples of grants that could be utilized to improve access to OT services within the end-of-life care setting. The grants provided could be used in a variety of ways to help fund OT services and are able to be customized to your facilities specific needs.
The Kenneth B. Schwartz Center
http://www.theschwartzcenter.org/grants/guidelines.html

Mission
To support and advance compassionate health care in which caregivers, patients and their families relate to one another in a way that provides hope to the patient, support to caregivers and sustenance to the healing process.

Guidelines
Program Interests/Philosophy:
The Center seeks to strengthen the relationship between patients and caregivers through education, training and support, and public education. Research is funded in limited circumstances only. The Center supports initiatives that promise both immediate and long-term improvements to the patient-caregiver relationship. It also favors initiatives which, assuming they are successful, can be used as models by other health care organizations.

Eligibility
Any health-related organization is eligible to apply for a grant, including hospitals, health centers, physician practices, hospices, long-term care providers, and health-related educational institutions. Not-for-profit entities or organizations are preferred. Individuals are also eligible to apply. The Schwartz Center generally will not pay for permanent salaries but grant dollars can be used to pay for a portion of an employee’s time. The Center does not pay for overhead expenses.

Grant Range
Grants can be as much as $20,000 per year, although the average grant is in the $10,000 range.
Department of Health and Human Services
Agency for Healthcare Research and Quality (AHRQ)- PA-07-243

Objectives
1) Supporting improvements in health outcomes,
2) Improving quality and patient safety, and
3) Identifying strategies to improve access and foster appropriate use and reduce unnecessary expenditures.

Guidelines
This FOA expresses AHRQ priority interests for ongoing extramural grants for research, demonstration, dissemination, and evaluation projects to:

Support improvements in health outcomes. Drawing from literature on variations in clinical practice and associated outcomes, the documented increase in the prevalence of chronic disease, and growing interest in the impact of different delivery modalities and financing arrangements on the outcomes of care, AHRQ seeks to support research to understand and improve decision-making at all levels of the health care system, the outcomes of health care, and, in particular, what works, for whom, when, and at what cost.

Strengthen quality measurement and improvement. AHRQ is interested in a broad array of research topics, including studies to develop valid and reliable measures of the process and outcomes of care, causation and prevention of errors in health care, strategies for incorporating quality measures into programs of quality improvement, and dissemination and implementation of validated quality improvement mechanisms.

Identify strategies to improve access, foster appropriate use, and reduce unnecessary expenditures. This area focuses on issues pertaining to the types of health care services Americans use, the cost of these services and sources of payment, determinants of access to care, and whether particular approaches to health care delivery and financing, or characteristics of the health care market, alter behaviors in ways that improve access and promote cost-effective use of health care resources.

Eligibility
Public or non-profit private institution, such as a university, college, or a faith-based or community-based organization; units of local or State government; eligible agencies of the Federal government; Indian/Native American Tribal Government (Federally recognized); Indian/Native American Tribal Government (other than Federally recognized); and, Indian/Native American Tribally Designated Organizations.
Robert Wood Johnson Foundation
http://www.rwjf.org/

Mission
To improve the health and health care of all Americans with a clear goal to help Americans lead healthier lives and get the care they need.

Program Areas:
1) Building human capital,
2) Childhood obesity
3) Coverage
4) Pioneer
5) Public Health
6) *Quality/Equality
7) Vulnerable populations

*The program area of Quality/equality has proven to be a successful program area for funding related to end-of-life care.

Purpose
This program supports policy analysis, research, evaluation and demonstration projects that provide policy leaders timely information on health care policy and financing issues. This Call for Proposals is intended to support projects that: 1) examine significant issues and interventions related to health care financing and organization and their effects on health care costs, quality and access; and 2) explore or test major new ways to finance and organize health care that have the potential to improve access to more affordable and higher quality health services.

Eligibility
Researchers, as well as practitioners and public and private policy-makers working with researchers, are eligible to apply. Projects may be initiated from within many disciplines, including health services research, economics, sociology, political science, public policy, public health, public administration, law and business administration. Multi-disciplinary teams and researchers who are just beginning their careers—perhaps teaming with a more senior researcher to develop the analytic approach—are especially encouraged to apply.

Preference will be given to applicants that are public agencies or are tax-exempt under Section 501(c)(3) of the Internal Revenue Code and are not private foundations as defined under Section 509(a).

Grant Range
In October 2007, the Foundation reauthorized this initiative for $11 million over three years. Small grants for projects requiring $100,000 or less and projected to take 12 months or less. Large grants for projects requiring more than $100,000 and/or projected to take longer than 12 months.
Additional Resources
Additional Resources

Adaptive Equipment/Assistive Technology

Assistive Technology Online Store. This site is an online catalog for assistive technology devices used to enable greater independence. http://www.abledata.com

Client and Caregiver Issues


Thirteen; Before I Die. This site offers insight into the issues surrounding the phenomenon of being a client or caregiver experience of terminal illness, dying and hospice care. http://www.thirteen.org/bid/


End-of-Life Care Organization(s)/End-of-Life Care Information


Caring Connections. This website offers information for hospice care clients and caregivers in regard to a multitude of issues that are common concerns for this client population. www.caringinfo.org

Growthhouse.org. The primary mission of this organization is to improve the quality of compassionate care for people who are dying through public education and global professional collaboration. The website provides access to a search engine specifically geared toward death and dying related searches. www.growthhouse.org


This web based fact sheet provides basic information on cancer related Hospice care questions including those related directly to the dying process.

National Care Planning Council. www.longtermcarelink.net


**Funding/Reimbursement**


Medicare specific hospice benefit insurance information. http://www.medicareadvocacy.org/FAQ_Hospice.htm

Payne, S. (1998). To supplant, supplement, or support. Social Science and Medicine, 46(11), 1495-1504.

**Good Death**


**Health Promotion**


**Occupational Therapy Role Information**

American Association of Occupational Therapy. This is the website for the United State organization of Occupational Therapists. Information specifically related to OT and Hospice care is available at this web address. [www.aota.org](http://www.aota.org)


**Outcome Measures-Hospice Specific**


**Prayer**

Relaxation


Spirituality


Safety/Prevention


Theories/Frame of Reference


CHAPTER V

SUMMARY

The *Occupational Therapy for Client Empowerment End-of-Life Care Promotion Toolkit* is designed to provide Occupational Therapists easy access to scholarly resources needed to promote Occupational Therapy use in an end-of-life care setting. While the AOTA (2005) acknowledges the role that Occupational Therapists play in the end-of-life care setting through their statement on OT and Hospice, they do not provide a framework to guide the practitioner through the process of obtaining more referrals in this setting. It is our hope that through utilization of this toolkit, the role of OT within the end-of-life care setting will be more understood and utilized. The goal of this toolkit is to provide a means for acquiring at least a one-time evaluation for each hospice care client in the targeted context.

Current literature indicates that Occupational Therapists can be valuable team members within the end-of-life care setting. The role of the OT in hospice takes on a more holistic approach and tends to move away from the traditional rehabilitative approach. The core OT skills that hospice clients may benefit from include collaboration, assessment, enablement, problem-solving, activity as a therapeutic tool, promotion of life roles, and environmental adaptation (Creeck, 2003). While the benefit of utilizing OT services within this setting is obvious to OTs, the literature indicates that the role of OT within the end-of-life care setting is often misunderstood, underutilized and seen as an unnecessary. Through use of the *Occupational Therapy for Client Empowerment End-of-Life*
Life Care Promotion Toolkit, Occupational Therapists will have the tools they need to educate, inform and persuade the health care community and hospice care clients of OT’s role, value and needed place on the hospice care team.

Recommendations

The literature regarding Occupational Therapy and hospice care is lacking. The authors recommend further research in the areas of reimbursement to validate OT’s role in hospice care from a funding perspective. Occupational Therapy in hospice specific assessments and outcome measures, OT intervention specific studies, and more detailed medical professional perspectives of Occupational Therapy use in hospice care are also needed. An additional area of research is the value of OT within end-of-life care settings. While conducting the literature review, there were instances were OT was referred to as adding value to the team and lowering overall costs, however, supportive data was minimal. Further research is needed in this area to strengthen the argument for greater utilization of OT services in end-of-life care settings.

Implementation

Use of the Occupational Therapy for Client Empowerment End-of-Life Care Promotion Toolkit provides a great resource for Occupational Therapists who would like to begin to practice in the end-of-life care setting. The use of the toolkit is intended for the OT to utilize in order to become a vital member of the hospice care team with the ultimate goal of empowering the client to experience a “good death.”
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