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Occupational Therapy and Palliative Care:
A Survey of Attitudes and Knowledge

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May 2009
Abstract

The purpose of this study was to understand occupational therapists’ attitudes and knowledge of working with clients in a palliative care setting. No research on the attitudes of working in palliative care has been done on occupational therapists who do not currently work in a palliative care setting. The present study attempted to fill this gap of knowledge by surveying a random sample of 1000 practicing certified occupational therapists licensed in the state of Ohio.

One thousand surveys were sent out at the beginning of this study. Thirty one of those surveys were returned due to undeliverable addresses leaving a possible sample size of 969. Three hundred and thirty surveys were returned and 320 of those returned surveys were useable. Therefore the return rate was 34% and the sample population for this study was 320. Of the 320 participants, 10% were male, 90% were female and one participant left this section blank. The mean age of people who participated in this study was 40.82 years ($SD = 9.84; range = 23-70$). Participant’s average years of experience was 15.09 years ($SD = 9.43; range = 1-44$).

Of the 320 occupational therapists who participated in this study, 98% of participants agreed that there is a role for occupational therapy in palliative medicine. The top three roles chosen by participants were positioning, home modification, and caregiver education. The top obstacle that occupational therapists thought kept them from increasing their role in palliative care was lack of awareness of a need of occupational therapy in palliative setting.

The United States population is aging and over the next few decades the demands for palliative care will dramatically increase. As previously mentioned, participants reported that there is a lack of awareness of a need of occupational therapy in palliative setting. Therefore, there is a need for occupational therapists to advertise and educate to other health professionals and patients on the variety of services that they can provide.
Occupational Therapy and Palliative Care: A Survey of Attitudes and Knowledge

“Although people lie dying, they are still living – living with the hope for improvements in some area of life despite acceptance that death is inevitable.”
– Pizzi, M. A. & Briggs, R., 2004

Researchers and clinicians have found that the process of dying should coincide with living out the remainder of one’s life with meaning, purpose, quality, and dignity. Little research has been conducted regarding the role of occupational therapists in a palliative care setting. The studies that have been conducted focus on the perspectives of occupational therapists who work with terminally ill clients (Bye, 1998), how they view their role in a palliative care setting (Rahman, 2000), and their experiences in a palliative care setting (Prochnau, Lui & Boman, 2003). Our most important goal as occupational therapists is to increase our clients’ quality of life. This is especially important when a person is dying. Health professionals should remember that dying is still a part of living and that this part of life should not be neglected. The role of occupational therapy in palliative care is focused on how to maximize the client’s ability to engage in the former roles of self-care, work, and leisure. No research on the attitudes of working in palliative care has been conducted with occupational therapists who currently do not work in a palliative care setting. The present study will attempt to fill this gap of knowledge. In order to better understand the present study, a description of palliative care will be reviewed. A brief overview of the limited past research on the attitudes of occupational therapists working in palliative care will be presented followed by a description of the present study.

Hospice and Palliative Care

There is much confusion between the terms hospice and palliative care. Palliative care is the care for clients with a terminal illness. This type of medical care does not concentrate on
finding a cure. Instead it focuses on symptom control, quality of life, living life to the fullest, and preparing for death. Hospice is not necessarily a type of medical care, it is a philosophy.

When a cure is no longer possible, hospice provides the best in medical, nursing, emotional, and spiritual care. At the center of the hospice philosophy is respect for the decisions of each patient and family member. Hospice is not about dying; hospice is living every moment fully.”

(The American Hospice Foundation, 2009)

Hospice delivers palliative care as a service with its primary focus on pain management and the comfort of a client above all else. Hospice is specifically geared towards the very end of life or the final phase of a terminal illness. In the United States a person can not enter into a hospice program unless he/she is in his/her last six months of life. Hospice services can be provided at a hospice facility, the patient’s home, a hospital, or a nursing home. The Hospice Association of America reported that in 2006, 797,117 people were provided with palliative care in Medicare certified hospice settings alone.

The Role of Occupational Therapy in Hospice

The occupations that dying people experience are unique to each individual and span across both physical and psychological areas of need. Once a person is aware of an impending death, the occupations that he/she chooses to engage in take on greater importance. The actual experience of dying seems to intensify the significance of occupational choices for not only the dying person, but the families, friends, and staff as well (Jacques & Hasselkus, 2004).

Optimizing levels of function in meaningful activities, occupational roles, and in functional mobility for as long as possible is one of the benefits that occupational therapy offers the client in palliative care (Pizzi & Briggs, 2004).

Every Medicare certified hospice is structured to have an occupational therapist on staff. As the number of hospice programs nationwide continues to increase, occupational therapists...
need to assert the importance of their role in this setting. With many therapists working in home settings and 79% of hospice clients dying in a private residence (National Hospice and Palliative Care Organization, 2006), a major opportunity is presented for home evaluations and the provision of assistive equipment.

There are many challenges when working with terminally ill clients. Occupational therapists working in palliative care must be able to redefine their goals and objectives and be able to work in the immediate present, without a definite future to plan (Dawson, 1993). Therapists need to help clients live in the moment, have quality of life, and live out their last days engaged in activities they enjoy doing (Bye, Llewellyn & Christl, 2001). Therapists also should seek ways to help clients make the transition from life to death by addressing their need for closure in life and facilitating the necessary care they will require when they are no longer able to care for themselves (Bye et al., 2001). The aim is to affirm clients’ remaining lives while helping them prepare for their death (Bye et al., 2001). In doing so, therapists can feel that they have made an important contribution to clients’ lives, even when the final outcome is death (Bye et al., 2001).

Occupational therapists in a palliative care setting should adopt a client centered approach to assessment, intervention, goal setting, and evaluation. They should frame therapy on comfort and quality of life rather than on rehabilitation (Trump, Zahoransky & Siebert, 2005). This helps to provide the patients with a sense of control and dignity. Interventions can include, but are not limited to, activity modification, environment modification, therapeutic activity, relaxation, stress management, client and caregiver education, preparing for death, and caregiver support. Occupational therapists have the ability to focus on how to maximize the patient’s
ability to engage in the former roles of self care, work, and leisure (Folts, Tigges & Weisman, 1986).

In the early stages of the dying process slow-stream rehabilitation strategies can be allied for small improvements and maintenance of function for as long as possible (Bye et al., 2001). Throughout the middle stages of the dying process a traditional rehabilitative approach may no longer be an option. Therefore, compensatory strategies are introduced. With equipment and modified techniques, clients and families are assisted to maintain quality of life as function begins to decline (Bye et al., 2001). In the end stages of the dying process further decline in functional ability limits many activities and the client may require significant care and support from others. The individual is supported and assisted to engage in daily life as desired. At this time, therapists work with the family and the health team to assist clients and loved ones to have quality of life and to manage care at this stage (Bye et al., 2001). During the last stage of life, assessment targets the caregivers and the care environment more than the client and his or her functional status (Bye, 1998).

The outcomes of therapy should help clients live as normally as possible within their otherwise changing reality to help clients achieve a sense of control in their lives. Helping clients and caregivers to manage the required care needed during the terminal stages allows them to feel safe and supported. Occupational therapy has the ability to facilitate a sense of closure in life by engaging in desired activities for a final time and making farewells to people, places, and things (Bye et al., 2001).

Past Research on Occupational Therapy and Palliative Care

Allan Kellehear (1990) emphasized the importance of having a good death and stated that there are five things that must occur to ensure this. First, the individual and others need to
understand that the dying process has begun. Next, social adjustments and personal preparations for death need to be arranged. Once these have been accomplished it is time to attend to any changes at work and any public preparations. Making last farewells to others is the final stage to be accomplished in order for a person to experience a good death. As health professionals, occupational therapists can help clients achieve a good death.

Little research has been conducted regarding the role of occupational therapists in a palliative care setting. Rosalind Bye (1998) studied the perspectives of ten occupational therapists who worked with terminally ill clients in a hospice setting. Her qualitative analysis of their interviews showed a common theme between all ten therapists. They believed in an “affirming life, preparing for death” approach that does not focus on rehabilitation. Instead, this approach focuses on valuing an individual’s remaining life above all else. These ten occupational therapists help patients to live in the present while acknowledging and preparing for death. Nine conceptual categories detailing the process of therapy help facilitate clients reaching the common theme of “affirming life, preparing for death”; referral to occupational therapy, assessing the situation, goal setting, building against loss, normality within a changed reality, client control, supported and safe care, closure, and making a difference. The results of Bye’s study showed the need to step away from the traditional rehabilitative frame of reference used by most therapists, and illustrated the importance of allowing the client to live his/her last days while simultaneously preparing him/her for death. When working in palliative care occupational therapists must remember to address both aspects of life and death throughout their treatment.

Hasfa Rahman (2000) conducted an explorative study of the perspectives of occupational therapists with regard to their role in the hospice setting. Rahman was interested in seeing how occupational therapists dealt with the dual status of living and dying while providing therapy.
The four occupational therapists that were interviewed revealed the common theme of using a holistic approach to treatment, while addressing issues of care in physical, social, emotional, and spiritual domains. Through the use of a holistic approach, occupational therapists were able to explore and identify the needs of the patient and the family. More importantly, they were able to identify what was most important to the patient and meet the patient at the specific stage of life they were currently experiencing. This study relates to the present study by examining occupational therapists’ perspectives toward working the patients receiving hospice care.

Prochnau, Lui and Boman (2003) conducted a qualitative study where they interviewed eight occupational therapists working in a palliative care setting on their experiences. Five common themes emerged: satisfaction, hardship, coping, spirituality, and growth. These themes were all described through the “personal-professional connections” that are made by the therapist and patient in this type of setting. All of the themes crossed the border of these occupational therapists’ professional lives into their personal life. The occupational therapists interviewed in this study reported a high sense of being valued and appreciated by patients and patients’ families resulting in a high rate of satisfaction with their work. Consequently, the therapists interviewed also described the hardships related to working with this population due to the numerous deaths. Therefore, coping strategies and a personal and professional understanding of spirituality are must for maintaining mental and physical health. The final theme to emerge from this study was growth. Occupational therapists who work in this setting deal with life and death on a daily basis, allowing them to develop a deeper understanding of themselves and grow as individuals. This study shows how working in a palliative setting allows occupational therapists to connect to your patients on a higher level. It also conveys how rewarding it is to be a part of a palliative care interdisciplinary team
Lyons, Orozovic, Davis and Newman (2002) believed that a life-threatening illness enormously affected people’s occupational functioning, however continuing occupational engagement was crucial to their health. They performed a qualitative study with 23 participants who were on hospice to explore dying persons’ occupational experiences. This was done through a combination of focus groups, individual interviews, and participant observation. They found that when a person is dying he/she is mostly concerned with losing and maintaining occupations. The participants strive to preserve mental and physical functioning, social relationships, self expression, and a sense of contribution. All of these experiences are directly related to the occupational therapy profession. This study relates to the present study by showing that just because a person is dying it does not mean he/she is giving up on life. It also stresses the importance and benefits of engaging in meaningful and purposeful occupations during the last stages of life. Most importantly it exemplifies the need for occupational therapists to be part of a hospice interdisciplinary team.

As Lyons’ et al. (2002) confirmed in their study, patients have very specific occupations to fulfill throughout the process of dying and they should not be ignored. Being denied the opportunity to engage in occupational roles deprives a person of the benefit of being a contributing member of society and, thus, creates a sense of isolation and alienation (Dawson, 1993).

Present Study

The purpose of the present study was to understand occupational therapists’ attitudes towards and knowledge of working with clients in a palliative care setting. Studies have been conducted inquiring about the perspectives of occupational therapists who currently work with hospice and palliative care, but there is no research on the attitudes of working in palliative care
has been conducted on occupational therapists who do not currently work in a palliative care setting. The present study will attempt to fill this gap of knowledge.

Methods

Participants

Participants solicited for this study were certified occupational therapists licensed in the state of Ohio. A data base of all licensed therapists within Ohio was obtained at no cost by an e-mail request made to the Ohio Occupational Therapy Licensure Board. The data base included the names and current addresses of 4,255 licensed occupational therapists. A random sample of 1000 practicing occupational therapists was used as the participants.

Instruments

The questionnaire consisted of three sections. Please see Appendix A. All three sections of the questionnaire were developed by the authors because no present scale exists for measuring the attitudes and knowledge of occupational therapists who do not currently work in a palliative care setting. A review of similar past surveys and a current survey used by hospice to measure the attitudes and knowledge of medical students were used to develop our survey. The first part requested personal demographic information about the participants.

The second part of the questionnaire contained The Palliative Care Knowledge Test. This test consisted of twelve true and false questions that assessed the level of knowledge of palliative care a practitioner possesses. The test was scored by the number of correct responses a participant gave, therefore a higher score on the Palliative Care Knowledge Test correlates with a higher awareness and understanding of palliative care. Content validity was assessed by hospice professionals who reviewed the survey prior to mailing it out to the participants.
The third and final part of the survey was the Attitudes toward Palliative Care Assessment. This scale was compiled of seventeen statements that assessed the participants’ attitudes toward palliative care along with three fill in questions. The participant was asked to rate his or her agreement on each statement on a five point Linkert Scale where 1 was strongly disagree and 5 was strongly agree. Questions three, five, eight, twelve, and thirteen were reverse scored items. A higher score suggests that the participant understands the role occupational therapy plays in the palliative care setting. A higher score also suggests that the participant has a positive view of working in a palliative care setting and feels educated and fully prepared to do so. Scoring is accomplished by adding the participants’ assigned numbers of each statement.

Procedures

Surveys were mailed out to one thousand occupational therapists randomly chosen from the Ohio Occupational Therapy Licensure Board database. The mailing contained a cover letter, the three part questionnaire, and a return envelope with postage provided. A reminder postcard was sent to all possible participants approximately three weeks after the initial mailing.

Results

Demographics

One thousand surveys were sent out at the beginning of this study. Thirty one of those surveys were returned due to undeliverable addresses having a possible sample size of 969. Three hundred and thirty surveys were returned and 320 of those returned surveys were useable. Therefore the return rate was 34% and the sample population for this study was 320. Of the 320 participants, 10% were male, 90% were female and one participant left this section blank. The mean age of people who participated in this study was 40.82 years (SD = 9.84; range = 23-70). Participant’s average years of experience was 15.09 years (SD = 9.43; range = 1-44).
percent of participants achieved a bachelor’s level of occupational therapy education followed by
28 percent achieving their master’s degree, 1 percent achieving their doctorate, less than one
percent achieving their associate’s degree, and 2.7 percent of participants did not provide an
answer to this question. Eighty nine percent of participants reported receiving no palliative care
education as part of their occupational therapy program curriculum. Only 17 percent of
participants had attended a conference or in-service program on palliative care. When asked if
anyone close to him/her had ever died of a terminal illness, 30 percent of participants reported
having a loved one die ten years ago or longer, and 25 percent reported having a loved one die
five to ten years ago. Twenty eight percent of participants reported having a loved one die less
than five years ago, and 16 percent reported having a loved one die in the last twelve months.
Twenty five percent of participants reported that no one close to them has ever died of a terminal
illness.

Knowledge
Participants were asked twelve true or false questions testing their knowledge of
palliative care (see Table 1). The overall mean of the twelve questions totaled was 10.46 ($SD =
1.37$).

The top three items answered incorrectly follows. Less than half of participants, 46
percent, correctly answered that hospice care does not mean home care or nursing home care.
Thirty three percent of participants incorrectly believe that by choosing hospice the patient has
accepted dying. Thirty percent of participants reported that they did not understand palliative
care to mean a form of medicine provided to a person with a terminal illness.

The top three questions answered correctly are as follows. Ninety nine percent of
participants understand that every person receiving palliative care has different needs. When
asked if people receiving palliative care can enjoy life, ninety seven percent of participants correctly answered true. When asked if hospice is for people who have only a few days left to live, 97 percent of participants correctly answered false.

**Attitudes**

Consistent with Portney and Watkins (2000), Cronbach’s alpha was calculated at .88, a good level of reliability for the 17 item scale (see Table 2). The overall mean of the seventeen questions totaled was 62.39 ($SD = 9.38$, $range = 32-85$, $total\ possible\ range = 17-85$). Eighty one percent of participants strongly agreed that palliative care clients are entitled to the same care as any other client/patient. Eighty five percent of people agreed or strongly agreed that they are comfortable touching people receiving palliative care. Although conflicting with the previous findings, seventy one percent of participants agreed or strongly agreed that they feel uncomfortable being around people receiving palliative care and 80% of participants agreed or strongly agreed that they could not imagine caring for someone who is receiving palliative care. These conflicting findings of occupational therapists’ attitudes toward palliative care are better explained through the following results. Only 5 percent of participants strongly agreed that they feel prepared clinically to care for a dying patient. When asked if participants are very familiar with palliative care, the majority, 62% of participants, answered neutrally or disagreed. Only 19% of participants agreed or strongly agreed that they know the difference between palliative medicine and hospice care. Finally, 50 percent of participants agreed or strongly agreed that they feel confident around people receiving palliative care.

At the end of the Attitudes toward Palliative Care Assessment, participants were asked if there is a role for occupational therapy in palliative medicine and 98 percent of participants answered yes. To further understand the roles that occupational therapists could fill in palliative
Participants were given ten roles and asked to check all that apply (see Table 3) along with an “other” option. The top three roles checked by participants are as follows. Ninety nine percent of participants thought that caregiver education was a role occupational therapists could fill. Ninety eight percent of participants checked positioning, and 96% of participants thought home modification was a role occupational therapists could fill in a palliative care setting.

Forty nine participants chose to provide an “other” option. Twenty six percent of these participants thought that an important role occupational therapists could provide in palliative care was working with the patient on activity modification through ADL and IADL retraining and providing adaptive equipment. Twenty one percent of participants thought that increasing life satisfaction through meaningful activities was a role that occupational therapists could fill. Sixteen percent of participants thought pain/comfort management was a role occupational therapists could provide in palliative care. Ten percent of participants thought that occupational therapists could help with the psychiatric needs of the palliative patients through reflective listening, self expression, and spiritual seeking. Eight percent of participants thought they could help palliative patients with life review activities (i.e. scrapbooks, photo albums, audio and visual recordings), and an additional eight percent of participants thought they could help by focusing on the patient’s self identified end of life goals. Maintenance therapy (i.e. P/AROM and splinting) was a role that occupational therapists could fill in the palliative setting. Finally, two percent of participants thought humor was and important role, and an additional two percent of participants thought that oral hygiene was an important role that occupational therapists could fill in the palliative setting.

Participants were then asked what they think keeps occupational therapists from increasing their role in palliative care. Four options were provided along with an “other” option
where participants could fill in any response not provided (see Table 4). The top obstacle that participants agreed with was lack of awareness of a need of occupational therapy in palliative setting.

Seventy three participants chose to provide an “other” option. Forty eight percent of these participants thought that lack of knowledge and training in this area was a barrier that keeps occupational therapists from increasing their role in palliative care. Twenty five percent of participants thought that a barrier was lack of awareness by other disciplines of what occupational therapists can offer palliative patients. Fear of working with palliative care patients was the response provided by 15% of participants. Ten percent of participants thought that a barrier was caused by insurance companies limiting the amount of therapy provided to palliative patients. Finally, 3% of these participants thought that a barrier that keeps occupational therapists from increasing their role in palliative care was the lack of job opportunities in this area.

Additional Analysis

A statistically significant correlation between the participant’s age and his/her attitude towards palliative care was found ($r = .12; p = .04$). The older the participant, the more positive his/her attitude was towards palliative care. Another statistically significant correlation was found between the percentage of the participants time working with patients requiring palliative care and their attitude towards palliative care ($r_s = .25, p < .001$). Participants who spent more time working with patients requiring palliative care had a more positive attitude towards palliative care. Another statistically significant difference was found between participants who have attended a conference on palliative care and their overall attitude towards palliative care ($t = 3.6; p < .001$). Those who had attended a conference had higher attitude scores. There was a statistically significant difference with participants who have had a close family member die in
the last twelve months of a terminal illness and their attitude towards palliative care ($t = 2.88, p = .004$). It is interesting to note that participants’ level of education did not influence neither knowledge nor attitude scores. No other correlations or differences were found between attitudes and knowledge.

**Discussion**

The purpose of the present study was to understand occupational therapists’ attitudes and knowledge of working with clients in a palliative care setting. Participants clearly answered our inquiry at the end of the survey when asked if there is a role for occupational therapy in palliative medicine with an overwhelming 98 percent of participants answering yes.

Of the 320 occupational therapists who participated in this study, 89% of participants reported receiving no palliative care education as part of their occupational therapy program curriculum, and only 17 percent of participants had attended a conference or in-service program on palliative care. Participants had a great amount of knowledge regarding palliative care. Participants understood that hospice is for people who have only a few days left to live, and that these individuals can still enjoy life. On the other hand, over one third of participants incorrectly believe that by choosing hospice the patient has accepted dying.

When attitudes toward palliative care were surveyed the findings were more diverse and somewhat conflicting. Over eighty percent of participants strongly agreed that palliative care clients are entitled to the same care as any other client/patient and that as therapists they are comfortable touching people receiving palliative care. Nevertheless, seventy one percent of participants agreed or strongly agreed that they felt uncomfortable being around people receiving palliative care and 80% of participants agreed or strongly agreed that they could not imagine caring for someone who is receiving palliative care. These ambiguous findings of occupational
therapists’ attitudes toward palliative care could possibly be the result of a lack of education of the role of occupational therapy in palliative care. Only 5 percent of participants strongly agreed that they felt prepared clinically to care for a dying patient and only 19% of participants agreed or strongly agreed that they know the difference between palliative medicine and hospice care.

At the end of the survey, participants were asked what role occupational therapy has in palliative medicine. The top three roles chosen by participants were positioning, home modification, and caregiver education. The top obstacle that occupational therapists thought kept them from increasing their role in palliative care was lack of awareness of a need for occupational therapy services in a palliative care setting.

It is interesting to note that the older the participant, the more positive his/her attitude was towards palliative care. Participants who had attended a conference had higher attitude scores. Also, participants who spent more time working with patients requiring palliative care had a more positive attitude towards palliative care.

*Implications for OT*

The United States population is aging and over the next few decades the demands for palliative care will dramatically increase. Nevertheless, participants in the current study reported that there was a lack of awareness of the need for occupational therapy services in a palliative care setting. Therefore, there is a need for occupational therapists to educate other health professionals and patients on the variety of services that they can provide to patients in any stage of life.

Occupational therapy helps to facilitate and enable patients receiving palliative care to achieve maximum functional performance, both physically and psychologically, in everyday living skills regardless of his or her life expectancy. As Rosalind Bye (1998) found in her study,
occupational therapists help patients to live in the present while acknowledging and preparing for death. The results of Bye’s study express the need to step away from the traditional rehabilitative frame of reference used by most therapists. The alternative role for occupational therapy should be the basis for future continuing education workshops.

Occupational therapy interventions allow patients to gain control over their lives, manage pain and symptoms, and provide support for the clients’ loved ones. Therapeutic interventions help to optimize levels of function in meaningful activities and functional mobility for as long as possible. An individual can benefit from occupational therapy intervention at any stage of an illness from diagnosis, through treatment to palliation. Again, through educational in-services that outline the role of occupational therapy in a palliative care setting an increase in occupational therapy services may be seen. With these educational efforts occupational therapists may also become more comfortable with their role in the palliative care setting and seek out additional clinical experience in this setting.

**Limitations and Future Research**

Several limitations in the current study deserve consideration. The first limitation is the use of survey research as the method of inquiry. When using survey research there is potential for response bias and non-response bias that can influence the results of the study. Response bias could have occurred in our study in a two different ways. Participants might not have been able to recall information accurately, or they might have interpreted the meaning of a question differently than the meaning intended. There is also the chance of having a non-response bias with this study where respondents selected for the sample elected not to respond because of how they felt toward the topic.
Second, because the sample was limited to certified occupational therapists licensed in the state of Ohio, it may not be representative of all practitioners in the United States. Future research should attempt to solicit occupational therapists licensed in numerous states throughout the country in order for the results to be more generalized.

Participants achieved high scores on the knowledge portion of the survey. This result illustrates another limitation of our study. In future studies the degree of difficulty needs to be increased when testing occupational therapists’ knowledge of hospice and palliative care.

Conclusion

Occupational therapists believe that there is a role for our profession in palliative care settings. Whether direct care providers or consultants, occupational therapists are an important part of the interdisciplinary palliative care team. Occupational therapists can provide patients with energy conservation techniques, assistive equipment, home modifications, ADL/IADL retraining, education and support. Occupational therapists need to work more to educate other health professionals and patients on the variety of services that occupational therapy can provide throughout all stages of life.
References


Appendix A

Part A: Demographics

1. Age: _____

2. Gender: _____ Female _____ Male

3. How many years have you been in the occupational therapy field? _____

4. What is the highest level of occupational therapy education that you have completed?
   _____ Associate’s degree   _____ Master’s degree
   _____ Bachelor’s degree   _____ Doctoral degree

5. What type of setting do you currently work in the majority of time? _______________

6. What percentage of your time do you work with patients requiring palliative care? ___

7. Did your occupational therapy program, per your recollection, have a specific palliative care curriculum?
   _____ Yes   _____ No

8. Have you ever attended a conference or in-service program on palliative care?
   _____ Yes   _____ No

9. Has anyone close to you ever died of a terminal illness?
   Check all that apply
   _____ In the last 12 months
   _____ Less than 5 years ago
   _____ 5 to <10 years ago
   _____ 10 years ago or longer
   _____ No
Part B: Please answer the following questions to the best of your ability, without the use of reference material. Please circle the letter that corresponds with your answer.

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<tr>
<th>True</th>
<th>False</th>
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<td></td>
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<td>1. I understand palliative care to mean a form of medicine provided to a person with a terminal illness.</td>
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<td>2. I understand palliative care to mean pain relief for a person with a terminal illness.</td>
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<td>3. I understand hospice care to mean home care or nursing home care.</td>
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<td>4. I understand hospice care to mean support and counseling for people as they approach death.</td>
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<td>5. Every person receiving palliative care has different needs.</td>
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<td>6. It is important to know the past history of people receiving palliative care.</td>
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<td>7. People receiving palliative care can enjoy life.</td>
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<td>8. We can do a lot to improve the lives of people receiving palliative care.</td>
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<td>9. Choosing hospice means that the patient has accepted dying.</td>
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<td>10. Referring a patient to hospice means the physician has “given up” on providing care.</td>
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<td>11. Hospice is for people who have only a few days left to live.</td>
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<td>12. Hospice is for patients who do not need complex care.</td>
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Part C: Please circle the number that best corresponds with your agreement to each statement below.

1. I feel confident around people receiving palliative care.

   1  2  3  4  5
   Strongly Disagree
   Strongly Agree

2. I am comfortable touching people receiving palliative care.

   1  2  3  4  5
   Strongly Disagree
   Strongly Agree

3. I feel uncomfortable being around people receiving palliative care.

   1  2  3  4  5
   Strongly Disagree
   Strongly Agree

4. I am very familiar with palliative care.

   1  2  3  4  5
   Strongly Disagree
   Strongly Agree

5. I feel relaxed around people receiving palliative care.

   1  2  3  4  5
   Strongly Disagree
   Strongly Agree

6. I feel frustrated because I do not know how to help people receiving palliative care.

   1  2  3  4  5
   Strongly Disagree
   Strongly Agree

Please Turn Over
7. It is rewarding to work with people who are receiving palliative care.

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<tr>
<td>Strongly Disagree</td>
<td></td>
<td></td>
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<td>Strongly Agree</td>
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8. I can not imagine caring for someone who is receiving palliative care.

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<tbody>
<tr>
<td>Strongly Disagree</td>
<td></td>
<td></td>
<td></td>
<td>Strongly Agree</td>
</tr>
</tbody>
</table>

9. People receiving palliative care like to have familiar things nearby.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td></td>
<td></td>
<td></td>
<td>Strongly Agree</td>
</tr>
</tbody>
</table>

10. It is possible to enjoy interacting with people receiving palliative care.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td></td>
<td></td>
<td></td>
<td>Strongly Agree</td>
</tr>
</tbody>
</table>

11. Palliative care clients are entitled to the same care as any other client/patient.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td></td>
<td></td>
<td></td>
<td>Strongly Agree</td>
</tr>
</tbody>
</table>

12. Working with dying patients is sad and depressing.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td></td>
<td></td>
<td></td>
<td>Strongly Agree</td>
</tr>
</tbody>
</table>
13. Hospice is for patients who have “no hope”.

   1  2  3  4  5
Strongly  Strongly
Disagree    Agree

14. I feel comfortable talking about dying to a patient who is dying.

   1  2  3  4  5
Strongly  Strongly
Disagree    Agree

15. I feel prepared emotionally to care for the dying patient.

   1  2  3  4  5
Strongly  Strongly
Disagree    Agree

16. I feel prepared clinically to care for the dying patient.

   1  2  3  4  5
Strongly  Strongly
Disagree    Agree

17. I know the difference between palliative medicine and hospice care.

   1  2  3  4  5
Strongly  Strongly
Disagree    Agree

18. There is a role for occupational therapy in palliative medicine.

   _____ Yes (if yes continue to next question)
   _____ No (if no continue to question #20)
19. What roles do you think occupational therapy could fill in palliative medicine?

Check all that apply

_____ Positioning
_____ Energy conservation
_____ Provision of assistive technology
_____ Safe methods and risk reduction
_____ Home modification
_____ Progressive muscle relaxation
_____ Active coping techniques
_____ Transferring
_____ Caregiver education
_____ Grief and bereavement support
_____ Other__________________

20. What do you think keeps occupational therapists from increasing their role in palliative care?

Check all that apply

_____ Confusion of role in palliative setting
_____ Lack of awareness of a need of occupational therapy in palliative setting
_____ Lack of interest from Ots to work in palliative setting
_____ Lack of reimbursement
_____ Other______________________________________

Your participation in this survey is greatly appreciated! Please place the completed questionnaire in the postage paid envelope that was provided in this mailing. If you have any questions, please contact Barbara Kopp Miller at 419-383-4289 or Kristin Pitzen at kristin.pitzen@utoledo.edu.
Table 1
Survey of Knowledge Results

<table>
<thead>
<tr>
<th>True of False Question</th>
<th>Percent Correct</th>
</tr>
</thead>
<tbody>
<tr>
<td>I understand palliative care to mean pain relief for a person with a terminal illness.</td>
<td>84%</td>
</tr>
<tr>
<td>I understand hospice care to mean support and counseling for people as they</td>
<td></td>
</tr>
<tr>
<td>approach death.</td>
<td>97%</td>
</tr>
<tr>
<td>It is very important to know the past history of people receiving palliative care.</td>
<td>96%</td>
</tr>
<tr>
<td>We can do a lot to improve the lives of people receiving palliative care.</td>
<td>95%</td>
</tr>
<tr>
<td>Referring a patient to hospice means the physician has “given up” on providing care.*</td>
<td>97%</td>
</tr>
<tr>
<td>Hospice is for patients who do not need complex care.*</td>
<td>94%</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Top 3 Correct</td>
<td></td>
</tr>
<tr>
<td>Every person receiving palliative care has different needs.</td>
<td>99%</td>
</tr>
<tr>
<td>People receiving palliative care can enjoy life.</td>
<td>98%</td>
</tr>
<tr>
<td>Hospice is for people who have only a few days left to live.*</td>
<td>97%</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Top 3 Incorrect</td>
<td></td>
</tr>
<tr>
<td>I understand hospice care to mean home care or nursing home care.*</td>
<td>46%</td>
</tr>
<tr>
<td>Choosing hospice means that the patient has accepted dying.*</td>
<td>68%</td>
</tr>
<tr>
<td>I understand palliative care to mean a form of medicine provided to a person with</td>
<td></td>
</tr>
<tr>
<td>a terminal illness.</td>
<td>70%</td>
</tr>
</tbody>
</table>

*Reverse scored items
Table 2
Survey of Attitude Results

<table>
<thead>
<tr>
<th>Questions</th>
<th>Mean Score</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel confident around people receiving palliative care.</td>
<td>3.50</td>
<td>.93</td>
</tr>
<tr>
<td>I am comfortable touching people receiving palliative care.</td>
<td>4.29</td>
<td>.85</td>
</tr>
<tr>
<td>I feel uncomfortable being around people receiving palliative care.*</td>
<td>3.90</td>
<td>1.14</td>
</tr>
<tr>
<td>I am very familiar with palliative care.</td>
<td>2.76</td>
<td>1.10</td>
</tr>
<tr>
<td>I feel relaxed around people receiving palliative care.</td>
<td>3.48</td>
<td>.92</td>
</tr>
<tr>
<td>I feel frustrated because I do not know how to help people receiving</td>
<td>3.44</td>
<td>1.01</td>
</tr>
<tr>
<td>palliative care.*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is rewarding to work with people who are receiving palliative care.</td>
<td>3.60</td>
<td>.94</td>
</tr>
<tr>
<td>I can not imagine caring for someone who is receiving palliative care.*</td>
<td>4.21</td>
<td>9.11</td>
</tr>
<tr>
<td>People receiving palliative care like to have familiar things nearby.</td>
<td>4.40</td>
<td>.70</td>
</tr>
<tr>
<td>It is possible to enjoy interacting with people receiving palliative</td>
<td>4.60</td>
<td>.64</td>
</tr>
<tr>
<td>care.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Palliative care clients are entitled to the same care as any other client/patient.</td>
<td>4.74</td>
<td>.63</td>
</tr>
<tr>
<td>Working with dying patients is sad and depressing.*</td>
<td>3.46</td>
<td>1.00</td>
</tr>
<tr>
<td>Hospice is for patients who have “no hope”.*</td>
<td>4.28</td>
<td>.92</td>
</tr>
<tr>
<td>Questions</td>
<td>Mean Score</td>
<td>SD</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>------------</td>
<td>-----</td>
</tr>
<tr>
<td>I feel comfortable talking about dying to a patient who is dying.</td>
<td>3.00</td>
<td>1.06</td>
</tr>
<tr>
<td>I feel prepared emotionally to care for the dying patient.</td>
<td>3.00</td>
<td>1.08</td>
</tr>
<tr>
<td>I feel prepared clinically to care for the dying patient.</td>
<td>2.91</td>
<td>1.11</td>
</tr>
<tr>
<td>I know the difference between palliative medicine and hospice care.</td>
<td>2.57</td>
<td>1.10</td>
</tr>
</tbody>
</table>

*Reverse scored items

**Note.** Score Code: 1 = Strongly Disagree, 2 = Disagree, 3 = Neutral, 4 = Agree, 5 = Strongly Agree

*Reverse Score Card: 1 = Strongly Agree, 2 = Agree, 3 = Neutral, 4 = Disagree, 5 = Strongly Disagree*
Table 3
Roles Occupational Therapists can Fill in Palliative Care

<table>
<thead>
<tr>
<th>Role</th>
<th>Percent of participants who agreed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positioning</td>
<td>98%</td>
</tr>
<tr>
<td>Energy conservation</td>
<td>90%</td>
</tr>
<tr>
<td>Provision of assistive technology</td>
<td>90%</td>
</tr>
<tr>
<td>Safe methods and risk reduction</td>
<td>82%</td>
</tr>
<tr>
<td>Home modification</td>
<td>95%</td>
</tr>
<tr>
<td>Progressive muscle relaxation</td>
<td>77%</td>
</tr>
<tr>
<td>Active coping techniques</td>
<td>85%</td>
</tr>
<tr>
<td>Transferring</td>
<td>92%</td>
</tr>
<tr>
<td>Caregiver education</td>
<td>99%</td>
</tr>
<tr>
<td>Grief and bereavement support</td>
<td>72%</td>
</tr>
<tr>
<td>Other</td>
<td>16%</td>
</tr>
</tbody>
</table>
Table 4

Barriers that Keep Occupational Therapists from Increasing Their Role in Palliative Care

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confusion of role in palliative setting</td>
<td>63%</td>
</tr>
<tr>
<td>Lack of awareness of a need of occupational therapy in palliative setting</td>
<td>76%</td>
</tr>
<tr>
<td>Lack of interest from OTs to work in palliative setting</td>
<td>37%</td>
</tr>
<tr>
<td>Lack of reimbursement</td>
<td>54%</td>
</tr>
<tr>
<td>Other</td>
<td>22%</td>
</tr>
</tbody>
</table>