ABSTRACT

REHABILITATION STAFF PERCEPTIONS OF END-OF-LIFE CARE IN LONG-TERM CARE FACILITIES

By: Kathryn M. Stock

The purpose of this study was to identify case load size, utilization of services, overall stress levels and the overall clinical perspectives of rehabilitation professionals working with end-of-life (EOL) patients. Results revealed few rehabilitation professionals worked on palliative care teams and rehabilitation professionals reported low numbers of EOL care patients on caseloads. Eighty-five percent of the participants perceived they had a role to play in EOL care. EOL care education, years experience and field of practice were not significant predictors of rehabilitation staff stress levels. No significant difference was found between the three professional groups’ perceptions of key factors influencing quality-of-life, suggesting an overall agreement between perspectives related to professional roles and the goals of the rehabilitation team in EOL care.
REHABILITATION STAFF PERCEPTIONS OF END-OF-LIFE CARE
IN LONG-TERM CARE FACILITIES

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REHABILITATION STAFF PERCEPTIONS OF END-OF-LIFE CARE  
IN LONG-TERM CARE FACILITIES  

CHAPTER I  
Introduction  
An interdisciplinary approach to the treatment of end-of-life (EOL) patients is critical in providing comprehensive EOL care. Palliative care is a patient centered form of EOL care. The main objective of a palliative care team is to aid in the management of progressive disease by shifting the focus of care toward quality-of-life (QOL) (Pizzi & Briggs, 2004). Treatments focus on actively addressing issues of pain, psychosocial wellbeing, spirituality, and social interaction. Current literature (Varkey, 2006; Eckman & Roe, 2006; Pollens, 2004) focuses on the importance of the interdisciplinary palliative care team in addressing issues of quality-of-life (QOL) for EOL care patients. An interdisciplinary palliative care team consists of nursing staff, general practitioners, social workers and additional support staff (including recreational therapists, occupational therapists, physical therapists, speech-language pathologists, liturgical staff and pharmacists) (Levine, 2000). The team works together to address issues affecting a patient’s QOL, and individualizes treatment to address a patient’s specific needs. In a study conducted by Reynolds, Henderson, Schulman, and Hanson (2002), nursing staff and family members reported inadequate levels of pain management, emotional support, and personal cleanliness for EOL care patients at their time of death. An additional study by Flacker, Won, Kiely and Iloputaife (2001) found that the nursing aids’ and nursing staffs’ perceptions of QOL at the time of a patient’s death were statistically different than the perceptions of physicians. These studies provide important information on the differing perceptions of the palliative care team; however, the primary care team (i.e. physicians, nursing staff, and nurse aids) remain the main focus of these studies. Researchers have focused on the important roles of the occupational therapist (OT) (Rahman, 2000), physical therapist (PT) (Montagnini, Lodhi, & Born, 2003), and speech-language pathologist (SLP) (Salt, Davies, & Wilkinson, 1999) in EOL care; however, the perspectives of these professions have not been compared across fields.
Under the palliative care model the occupational therapist, physical therapist, and speech-language pathologist work jointly to provide a level of care which promotes patient centered QOL issues (Eckman & Roe, 2006). Rehabilitation professionals are shifting from traditional therapeutic roles and beginning to encompass therapies which enhance QOL in EOL patients (Pizzi & Briggs, 2004). By providing therapies which focus on EOL care, allied health care professionals are in a position to provide situation-specific assistance to patients and their families (Waldrop, Milch, & Skretny, 2005). To provide the best level of QOL care, rehabilitation professionals must have common perceptions of care models and goal outcomes. Differences in training or lack of understanding between the rehabilitation team members could lead to discrepancies in the care delivered. Further, researchers have not focused on job satisfaction and/or the personal beliefs of the rehabilitation team in the LTC facility setting. Rehabilitation specialists are being challenged to define their own roles within the EOL care model (Pizzi & Briggs, 2004). Understanding how each of the rehabilitation fields identifies with issues of QOL, scope of practice and emotional stressors will help to better define the role of the rehabilitation team in EOL care.

**Review of the Literature**

**Palliative Care**

The term palliative care is often used interchangeably with “hospice care” or “end-of-life care.” For the purpose of the present study, the term palliative care is being used to describe a form of care which focuses on the treatment of a patient diagnosed with a terminal disease by holistically addressing issues of QOL. Maddix and Pereira (2001) define palliative care as a comprehensive form of care focused on actively addressing issues of QOL by treating patients with compassion. Attention is given to the patients’ emotional needs, personal goals, and the social implication of their disability or terminal illness. Levine (2000) describes palliative care as an interdisciplinary form of care provided by a team, which consists of the primary nursing staff, general practitioners, and social service staff. The team is reinforced by “secondary members,” which include recreational therapists, occupational therapists, physical therapists, speech-language pathologists, pharmacists, and liturgical staff. Levine further defines palliative care as a comprehensive practice which integrates the patient’s needs, both medical and
emotional, into all aspects of care. The health care staff is encouraged to focus on QOL issues (i.e. symptom control, pain management, and family/patient support) rather than the actual treatment of the disease.

*The History of Hospice and Palliative Care*

The term “hospice” has roots in 8th century Greece, where the term referred to the custom of being hospitable to wanderers (Abu-Saad & Courtens, 2001a). Over time, the meaning of hospice has continually evolved. The term “hospice” has been used to describe a variety of forms of care, including the development of hospitals during the Middle Ages (476-1453AD), and the development of shelters for the sick, elderly, and insane during the Renaissance (1300-1600 AD) (Abu-Saad & Courtens, 2001a; Davy & Ellis, 2000). During the 20th century, the hospice movement as we know it began to emerge. Modern day hospice was developed by a group of individuals who stressed the importance of pain control in dying populations. Dame Cicely Saunders, through working at St. Joseph’s Hospital in Hackney, England led the development of hospice by experimenting with high levels of pain medications for pain management in cancer patients (Faull & Woof, 2002; Davy & Ellis, 2000). Through her research, key principles, which continue to influence the modern day mission of hospice care, were developed. These principles include; the health care providers acceptance of death, the use of an interdisciplinary team in the treatment of patients, the active control of common symptoms, the recognition of the patient’s family and friends as members of the care team, the use of medical care within the home, the more active bereavement for family and friends after a patient’s death, and the continuation of research and education in the field of hospice (Abu-Saad & Courtens, 2001a). At the beginning of the 20th century hospice movement, the term palliative care came into use. The term palliative care was first used by the Canadian physician, Balfour Mount, to describe a broader form of holistic care which could be incorporated into all health care settings (Abu-Saad & Courtens, 2001a). The term, palliative care, defined a new type of care for patients living with terminal disease, by providing more holistic care for patients during all stages of treatment, regardless of a patient’s life expectancy.
Hospital-based palliative care incorporates the key principles developed by Saunders (Bennahum, 1996), and then extends the concepts beyond the hospice unit. Hospice is rooted in the care of persons close to death; palliative care acknowledges that people are living longer with terminal illness and require a slightly different form of care (Davy & Ellis, 2000). Palliative care, by definition, is the holistic treatment of terminally ill patients; however, Davy and Ellis (2000) warn against the distinct separation of palliative care and treatments which aim to cure. They stress the importance of providing both quality-of-life and quantity of years for populations with progressive diseases such as AIDS, motor neuron diseases, and cancers. Still, opposition to the palliative care movement suggest medical professionals are moving too far from traditional hospice care by clouding the divide between holistic care and the medical prolongation of life (Davy & Ellis, 2000). Abu-Saad and Courtens (2001b) suggest palliative care should be neither strictly curative nor holistic, but a combination of the two forms of care. Models of treatment for palliative care patients fall into three phases: the curative stage, the palliative stage, and the terminal stage. These stages are fluid and require balance between treatment which aim to cure, and treatments which aim to comfort. During the curative, palliative, and terminal phases the type and purpose of treatment and care shift. During the curative phase the main objective is to prolong life at all costs. The second phase, or palliative phase, shifts the purpose of quantity of years to quality-of-life (QOL) during the time left. Lastly, during the terminal phase, care is focused on the dying process and support of the patient, caregiver, and family during this time (Abu-Saad & Courtens, 2001b).

Palliative care utilizes holistic and curative treatments to treat disease as well as to control symptoms. An example of a curative treatment used to control symptoms is the use of physical therapy for patients experiencing symptoms of discomfort, stiffness and pain due to a terminal illness. Montagnini, Lodhi, & Born (2003) suggest terminally ill patients who received physical therapy as part of their treatment plans experienced a 56% decrease in pain and functional disabilities. Results of the study by Montagnini, Lodhi, & Born (2003) reveal the benefits of curative therapies in controlling symptoms related to terminal illness.
Long-Term Care Setting:

Deaths in modern day nursing homes or long-term care (LTC) facilities account for one out of four deaths in the United States (Teno, 2003). Experts estimate that by 2020, one out of two deaths will take place in nursing homes (Teno, 2003). The high number of older adults living and dying in nursing homes may be a result of factors such as demographic shifts and levels of chronic illness which increase with age. Older individuals often experience increases in chronic disability, which can become a major factor in determining care options. Figure 1 illustrates the findings of the U.S. Census Bureau’s (2000) report on the positive correlation between age and increased levels of chronic disabilities which affect a person’s sensory, physical and mental ability, as well as self-care. Levels of chronic disability increase an average of 30% between 65 years of age and 85 years of age for the four areas of disability. The U.S. Census (2000) estimated a 12% increase from 1990 for people 65 years of age and older, and approximately a 38% increase from 1990 for people 85 years of age and older (Gist & Hetzel, 2004). Figure 2 illustrates the increased utilization of LTC facilities as age increases. Seventeen percent of U.S. adults over 85 years currently live in group quarters (Federal Interagency Forum on Aging-Related Statistics, 2006).

Changing demographics are challenging health care professionals, including rehabilitation teams, to change the way they think about EOL care. Ersek and Wilson (2003) found that LTC facilities and nursing homes are expanding their purpose and role to encompass more EOL care issues, including continued EOL care education for LTC facility staff, as well as recommending the development of guidelines for the appropriate evaluation and implementation of EOL care. Patient “care” is moving from more traditional medical models of treatment to treatments more aligned with palliative care models. This philosophy includes care which aims to effectively control/prevent EOL symptoms while giving more attention to the psychosocial and spiritual needs of patients (Ersek & Wilson, 2003; Thomas, 1996).

Palliative Care in Long-Term Care Facilities

Nursing homes face many concerns regarding the incorporation of palliative care into the everyday practice of a LTC facility. Financial and reimbursement concerns are among the most troublesome for LTC facility administrators (Keay, Alexander, McNally,
Figure 1. Influence of age on reported presence of four types of disabilities for three age groups as reported in U.S. Census, 2000. (Adapted from U.S. Census 2000, Disabilities by Type).
Figure 2. Living arrangement for U.S. citizens over 65 years of age. (Adapted from Residential Services, In Federal Interagency Forum on Aging Related Statistics, 2006).
Medicare, for instance, is more likely to reimburse for life prolonging treatments such as the placement of a percutaneous endoscopic gastrostomy (PEG) tube, rather than for the additional staff needed if the patient chooses to reject PEG-tube placement. Often, LTC facilities have financial fears when it comes to the integration of more holistic palliative care models (Chapman & Bass, 2003). Although LTC facilities shy away from fully encompassing the palliative care model, research has found high levels of reported patient comfort in facilities which use some form of palliative care (Keay, Alexander, McNally, Crusse & Eger, 2003). Variability in these palliative care models highlight the difficulty LTC rehabilitation specialists have when defining their role within the EOL care team.

Another factor contributing to the low implementation level of palliative care in LTC facilities is the lack of adequate education for physicians, administrators, nursing staff, and other staff working in LTC facilities. The presence of EOL care training can dramatically affect the level of care an EOL care patient is receiving. Keay, Alexander, McNally, Crusse and Eger (2003) identified the importance of EOL care training by reviewing the terminal care delivered by 61 physicians, 12 of which had participated in EOL care training. Results revealed significant improvement in the level of EOL care provided by the physicians who participated in the educational training. An increase in reported comfort, pain management, hygiene and analgesics were reported when physicians had EOL care education.

Depending on the needs of the LTC facility, different palliative care models can be utilized. Care can be provided by an outside agency, within a designated unit, or by utilizing a consultant team (Ersek & Wilson, 2003). The implementation of palliative care in the LTC facility influences the care of all patients, even those not assigned to the palliative care team (Ersek & Wilson, 2003). Further, Munn, Hanson, Zimmerman, Sloane and Mitchell (2006) reported better pain management, oral care, and eating/drinking assistance for patients receiving EOL care. The above listed needs were among the most important listed by patients receiving EOL care (Haward, Amir, Borrill, Dawson, Scully, West & Sainsbury, 2003). Although many researchers are reporting increased symptom management when palliative care models are implemented, only a small number (5.4%) of residents in LTC facilities are receiving any form of EOL care.
(Munn et al., 2006). Reynolds, Henderson, Schulman and Hanson, (2002) found that families of recently deceased loved ones reported unmet needs related to emotion, cleanliness, pain management, and communication skills in the final days of their loved one’s life. Without the increased implementation of palliative care models in LTC facilities EOL patients’ needs will remain unmet.

Caring for the Dying: The Palliative Care Team

A well developed palliative care team consists of a large network of professionals working together to provide a high level of care which focuses on improving and maintaining quality-of-life (QOL) for EOL care patients. The understanding of individual roles within the palliative care team is imperative in providing comprehensive palliative care. According to a report conducted by the Institute of Medicine’s National Research Council (Lunney, Foley, Smith & Gelband, 2003), a patient’s QOL at the EOL is only as good as the quality of care the person is receiving. Together the team must address issues of symptom prevention, pain management, communication between family/patient/staff, and the social constraints of palliative care. Most important of the three areas is the development of good communication between all members of the palliative care team, which includes the patient, family, and caregivers (O’Connor, Fisher, & Guilfoyle, 2006).

Individuals providing EOL care can face challenges such as large case loads, lack of communication or agreement between professionals, professional/patient relationships built around treatment, and low job satisfaction due to poor communication with patients and other professionals (Davy & Ellis, 2000). Communication is regarded as the most important variable in the equation for quality EOL care (Waldrop, Milch & Skretny, 2005; Bern-Klug, Gessert, Crenner, Buenaver & Skirchak, 2004). O’Connor, Fisher, and Guilfoyle (2006) reported the quality of care given to patients was directly impacted by the communication and collaboration among the members of the palliative care team. Programs which focused on the development of interpersonal communication within the palliative care team were most effective at increasing the success of the palliative care team (O’Connor et al., 2006). A well developed palliative care team is interdisciplinary because all members of the team take equal responsibility and involvement in the patients’ care plan (Abu-Saad & Courtens, 2001b).
Many professionals view their colleagues in terms of roles. To build a better team, there must be trust and respect for each member’s skills and abilities (O’Connor, Fisher, & Guilfoyle, 2006). Research conducted by Haward, Amir, Borrill, Dawson, Scully, West and Sainsbury (2003) reported increased positive attitudes and better team work for subjects who participated in educational EOL training programs. An additional study by Maddix and Pereira (2001) found that allowing professionals designated time to reflect on their role and experiences when working with EOL care patients was an effective tool for reinforcing a sense of purpose and understanding for professionals working as part of a palliative care team.

The Changing Face of Rehabilitation

Rehabilitation therapies are effective treatments in the care of terminal patients (Abu-Saad & Courtens, 2001b). Occupational therapists, physical therapists, and speech-language pathologists have unique therapies which focus on maintaining function and decreasing symptoms related to EOL (Frost, 2001). Physical therapists work with patients to improve and/or maintain transitional movements, reduce pain and weakness, increase range of motion, and decrease shortness of breath. Occupational therapists work with patients on activities of daily living (ADLs), posture to prevent further injury, balance, and energy conservation techniques which enable the patient to keep some control of bodily care. Lastly, speech-language pathologists, work with patients to maintain or improve swallowing function, cognitive abilities that allow patients to organize and make decisions, and language skills if a patient is experiencing language difficulties as a symptom of their terminal illness (Frost, 2001). The goal of the rehabilitation staff is to provide care which improves or maintains a patient’s QOL by providing comprehensive care which not only concentrates on physical symptoms but the emotional well being of the patient (Bello-Haas, Bene, & Metsumoto, 2002). Due to the intimate nature of many rehabilitative therapies, rehabilitation professionals are often in a perfect situation to address the emotional reactions of EOL care patients. Rehabilitation professionals may have to field difficult questions patients are afraid to ask, such as “when will I die?” (Bello-Haas et al., 2002). As a whole, rehabilitation professionals are most often interested in the restoration of function and may feel unprepared to field such questions (Bello-Haas et al., 2002).
The type and extent of therapy provided by speech-language pathologists, occupational therapists, and physical therapists differ; yet all three therapies are based on the same basic fundamentals. Fulton (1994) describes rehabilitation as “(therapy which)…aims to reduce the degree to which disabilities become permanent or interfere in everyday life,” and goes on to state “irrespective of how long that life may be (Fulton, 1994, p.831).” Still others define rehabilitation in terms of function. It is the rehabilitation professionals’ role to measure potential and loss, and to move forward through the use of therapy (Frost, 2001). Function is an individual’s ability to complete necessary tasks for living, and rehabilitation professionals can use a patient’s potential to maintain function, resulting in an overall sense of control for the terminally ill patient (Frost, 2001).

Rahman (2000) gathered information from three occupational therapists regarding their perceptions of hospice. The interviews revealed that a therapist’s view of death greatly influenced how they supported their EOL care patients. The occupational therapists were aware of the particular skills they could offer EOL care patients, however, they expressed concerns related to loss of patients and the difficult process of “working toward death (Rahman, 2000).” Subjects interviewed by Rahman also expressed their concerns regarding the effectiveness of the palliative care team.

Professionals working as part of the interdisciplinary palliative care team, including rehabilitation professionals, must constantly be aware of how the team can work together to achieve the patients’ and the family/caregivers’ goals. Ward and Robertson (2004) discuss the important traits of a palliative care team which result in improved quality of care for EOL care patients. First, the importance of shared assessments among all professionals is highlighted (Ward & Robertson, 2004). The rehabilitation team members must work together by using joint assessments to develop group goals. The palliative care team may consist of many professionals and there must be continuity between their expectations and their opinions regarding EOL care treatment. Clearly, developing realistic goals with patients and their family/caregivers, as well as professionals providing consistent joint resources to aid in the education of patients and family/caregivers in imperative in providing quality EOL care (Ward & Robertson, 2004). An excellent palliative care team works jointly by communicating
with each other, the patient and patient’s family. To achieve this, joint training programs are important, and provide the team members the opportunity to share perceptions and synchronize goals (Ward & Robertson, 2004).

Statement of the Problem

Rehabilitation professionals working in settings such as LTC facilities are challenged to integrate their skills into an interdisciplinary team. The end result of the interdisciplinary team is to “treat” patients with terminal diagnoses. Within the LTC setting roles are often not clearly defined and the goals of the rehabilitation team can often be overshadowed by greater influences such as reimbursement and productivity (Keay, Alexander, McNally, Crusse & Eger, 2003). Research in the area of the rehabilitation professional’s role in EOL care is limited, and often defines the roles separately. Although, research on rehabilitation staff has provided qualitative information, it has failed to define the population working in EOL care teams, the education received in respect to EOL care, and the cross disciplinary perceptions of factors influencing quality-of-life (QOL) in end-of-life (EOL) care patients.

A clear understanding of the factors influencing QOL care in EOL care patients could lead to a more strategic development of services among the rehabilitation team. Similar research has been conducted with primary health care professionals, including nursing staff, nursing aids, and general practitioners, which has led to a better understanding of the perceptions of roles and expectations of the primary fields working with EOL care patients (Flacker, Won, Kiely, & Iloputaife, 2001).

Purpose

This study sought to address the perceptions of rehabilitation professionals working with EOL care patients in LTC Facilities. The study was designed to answer the following questions:

- How many rehabilitation professionals are currently members of an EOL care team?
- What kind of education regarding EOL care are rehabilitation professionals receiving, and where are they receiving this knowledge?
- What roles do rehabilitation professionals believe they play in the EOL care team?
• How does a professional’s area of work influence their perception of key factors which influence an EOL care patients QOL?

• How do years of experience and EOL care education influence a professional’s level of emotional exhaustion and personal accomplishment when dealing with these populations?

• How consistent are rehabilitation professional’s opinions regarding the types of EOL care provided by rehabilitation professionals across all professions?

  **Research Hypotheses**

• When presented with profession specific factors influencing QOL care, professionals will rank factors in their given profession as having the greatest impact.

• Professionals with EOL care education will have lower emotional exhaustion and higher personal accomplishment scores than professionals who have not had EOL care training.

• Professionals with more years of experience will have lower emotional exhaustion and higher personal accomplishment score than professionals with fewer years of experience.

• When asked to define perceived roles of the three professionals, a subject’s Likert scale rating will reflect their own area of practice.
CHAPTER II

Methods

Participants

Participants recruited for this study were comprised of practicing occupational therapists, physical therapists, and speech-language pathologists in the state of Kentucky. Participants were recruited from the Kentucky Association for Occupational Therapy (KOTA), Physical Therapy (KPTA), and Speech-Language Pathology (KSHA). Each participating association searched their database for professionals working in long-term-care facilities. The database also included interest topics (i.e. pediatrics, geriatrics), which could be used to sort members. Members with a specific interest in gerontology were also selected for inclusion. Kentucky was selected as the sample state due to its demographics, which closely resemble overall demographic shifts in the United States for two population age groups, 65 years and older and 85 years and older (U.S. Census, 2000).

Inclusion Criteria

Participants currently registered with their appropriate professional association were included in this study. They must also have been registered as having a primary work setting of long-term-care (LTC). Professionals who selected a profession other than occupational therapy, physical therapy or speech-language pathology were excluded from statistical analysis.

Survey

A survey was developed to collect information regarding rehabilitation professionals’ perspectives of EOL care in LTC facilities (Appendix A). The survey was comprised of four sections, and totaled four pages in length.

The first section included descriptive questions regarding the subjects’ place of practice, field of work, years of experience, size of caseloads, end-of-life care educational levels, and the subject’s overall opinions on the need for rehabilitation professionals in the EOL care setting. This section consisted of 15 check box questions and one optional free response. The free response allowed subjects to further define their role within the palliative care team.
The second section utilized a five point Likert scale to assess rehabilitation professionals’ perceptions of key factors influencing a patient’s quality-of-life (QOL). Professionals were asked to rank the impact of 13 factors related to EOL care, from 1 (not at all impacts) to 5 (greatly impacts). The 13 factors influencing QOL divided equally under the three field’s scopes of practice. Examples of the 13 factors include: “a patient’s ability to ambulate” (physical therapy), “a patient’s ability to feed him/herself” (occupational therapy), and “a patient’s ability to communicate with loved ones” (speech-language pathology).

The third section was adapted from the Maslach Burnout Inventory (MBI) to assess levels of “Emotional Exhaustion” (EE) and “Personal Accomplishment” (PA). The MBI uses three subsections (emotional exhaustion, depersonalization (Dp), and personal accomplishment) to determine an overall level of employment “burnout” (Maslach, Jackson, Leiter, 1996).” Levels of EE and PA were targeted to identify if a subject’s area of practice, years of experience, or EOL care education resulted in a significant difference in these subtest scores. A composite score of the EE, Dp, and PA subsections was not calculated, due to the overall range of “burnout” scores and the high level of variability highlighted by the MBI’s authors (Maslach, Jackson, Leiter, 1996).

The final section of the survey was developed to investigate the subjects’ perceptions of the three rehabilitation professions. To aid in survey development, a set of four questions were asked in regard to the three professionals delivery models. Subjects ranked their level of agreement using a five point Likert scale. Ranking ranged from 1 (strongly disagree) to 5 (strongly agree). Participants were asked to complete the three sections indicating their overall agreement/disagreement with statements regarding each professions role as part of the EOL care team.

Procedure

The survey was sent by mail to 212 occupational therapists, physical therapists, and speech-language pathologists in the state of Kentucky. Each survey was accompanied by a recruitment letter (Appendix B), which included information regarding the participant’s informed consent. Participants were instructed to return completed surveys in the provided self-addressed and stamped envelopes. Envelopes were removed from the accompanying survey and destroyed. Completion of the survey was strictly
anonymous and no personal identification markers were required to complete the questionnaire. All procedures were approved by the Miami University Research Internal Review Board.

Statistical Analysis

The returned surveys were entered into Microsoft Excel, and analyzed using SAS version 9.1. Data analysis consisted of descriptive statistics to identify key descriptive information of means, standard deviations, and ranges regarding the test population. Data was sorted for analysis and a factor analysis was utilized to reduce data into two key factor groups. The factors were explored using analysis of variance (ANOVA) to determine the significance of the factors analyzed. A Pearson $|r|$ correlation coefficient test was used to describe the effect of years experience on “Emotional Exhaustion (EE)” and “Personal Accomplishment (PA)” over time. An ANOVA was conducted to determine if EOL care education results in a significant difference between EE and PA scores ($p < 0.05$).
CHAPTER III

Results

Participants

Subjects were recruited via the Kentucky Associations of Occupational Therapy (KOTA), Physical Therapy (KPTA), and Speech-Language and Hearing Pathology (KSHA). To maximize the number of rehabilitation professionals working with EOL care patients, individuals who reported working in LTC facilities or with a selected interest in gerontology were targeted. As a result, a total of 212 participants were sent surveys. Of the 212 surveys sent, 73 were sent to occupational therapists, 55 sent to physical therapists, and 84 sent to speech-language pathologists. Table 1 shows the return rates of each professional group. A total of 93 surveys (44%) were returned to the researcher. Of the 93 surveys returned, 34 (36.6%) were from occupational therapists; 21 (22.6%) from physical therapists; 34 (36.6%) from speech-language pathologists; and the remaining 4 (4.2%) were professions other than OT, PT, or SLP.

The majority of the study population was comprised of female participants; 81 were female (88%), and 11 were male (12%), one participant did not declare their sex. A majority (60%) of the participants reported having an educational level of a Masters Degree or higher. Participants’ years of experience ranged from 1 to 47, with a mean of 16 years (SD=11.5).

Subjects were asked to identify the staff members they perceived as integral team members in a palliative care team. The list consisted of 11 possible positions including: physicians, nursing staff, physiologists, social workers, occupational therapists, physical therapists, speech-language pathologists, liturgical staff, the family, the patient, respiratory therapists, etc. Responses are ranked by percent in Table 2, percents were calculated using the frequency each participant (N=93) selected a palliative care member. Physicians were selected most often, followed by nursing staff, social workers, the family, the patient, speech-language pathologists, liturgical staff, physical therapists, occupational therapists, psychologists, and respiratory therapists. Thirteen participants added additional staff by selecting other, these professionals included certified music practitioner (1), dietary staff (3), hospice (1), the activities department (1), pharmacist
Table 1

*Percent of Subjects Represented in each Profession*

<table>
<thead>
<tr>
<th>Profession Category</th>
<th>Frequency</th>
<th>Percent of Total (N=93)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational Therapist or Occupational Therapy Assistant</td>
<td>34</td>
<td>36.6%</td>
</tr>
<tr>
<td>Physical Therapist or Physical Therapy Assistant</td>
<td>21</td>
<td>22.6%</td>
</tr>
<tr>
<td>Speech-Language Pathologist</td>
<td>34</td>
<td>36.6%</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>4.2%</td>
</tr>
</tbody>
</table>
Table 2

*Ranked Frequency of Professions Perceived to be Part of the Palliative Care Team*

<table>
<thead>
<tr>
<th>Profession</th>
<th>Frequency</th>
<th>Percent of the Total (N=93)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician</td>
<td>91</td>
<td>99%</td>
</tr>
<tr>
<td>Nursing Staff</td>
<td>90</td>
<td>98%</td>
</tr>
<tr>
<td>Social Workers</td>
<td>90</td>
<td>98%</td>
</tr>
<tr>
<td>Family</td>
<td>90</td>
<td>98%</td>
</tr>
<tr>
<td>Patient</td>
<td>90</td>
<td>98%</td>
</tr>
<tr>
<td>Speech-Language Pathologist</td>
<td>75</td>
<td>81%</td>
</tr>
<tr>
<td>Liturgical Staff</td>
<td>75</td>
<td>81%</td>
</tr>
<tr>
<td>Physical Therapist</td>
<td>72</td>
<td>78%</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>71</td>
<td>77%</td>
</tr>
<tr>
<td>Psychologist</td>
<td>69</td>
<td>75%</td>
</tr>
<tr>
<td>Respiratory</td>
<td>64</td>
<td>69%</td>
</tr>
<tr>
<td>Other</td>
<td>13</td>
<td>14%</td>
</tr>
</tbody>
</table>
(1), friends (1), members of rehabilitation staff, only as needed (3), massage therapy (1), and pastor/religious affiliate (1).

Eight (9%) subjects were currently part of a palliative care team, 77 (85%) participants were currently not part of a palliative care team, and 5 (6%) were unsure if they were part of a palliative care team (N = 90). Figure 3 illustrates the percentage breakdown for occupational therapy, physical therapy, speech-language pathology, and a composite percent for all three professions.

Of the eight subjects currently part of a palliative care team, six were OTs, one was a PT, and one was an SLP. Seventy-seven (85%) of the participants perceived their profession had a role to play in the care of EOL patients. A majority (84%) of the participants currently had zero to five EOL care patients on their caseload. Of the 33 occupational therapists who completed this section, 28 (85%) currently had zero to five EOL care patients on their caseload, and 5 (15%) had five to ten EOL care patients on their caseload. Seventeen physical therapists completed this question, 15 (88%) currently had zero to five EOL care patients on their caseload, and 2 (12%) had five to ten EOL care patients on their caseload. Of 33 surveyed speech language pathologists; 28 (85%) currently had 0-5 EOL care patients on their caseload, 3 (9%) currently had 5-10 EOL care patients on their caseload, and 2 (6%) currently had 10-15 EOL care patients on their caseload.

The type and percent of reported EOL care education is found in Figure 4. A total of 54 (59%) subjects reported having no training in the area of EOL care. A smaller number of participants, 33 (36%), reported having some level of EOL care training. Of the 33 subjects with EOL care training five types of training were listed for possible selection (in-service education, university course work, conferences, continuing education, and other). In-service education, accounted for 19 (58%) of the participants with EOL education, and was the most common form of EOL care education. In-service EOL care education was followed by university courses (52%), continuing education (21%), conferences (15%), and other (9%). Other forms of EOL education listed by participants included reading materials, hospice training, and competency training.
Figure 3. Percent of subjects working on a palliative care team, as reported by individuals in each profession.
Figure 4. The type and percent of reported end-of-life care education received by subjects who reported having end-of-life care education (N=33).
Professionals who perceived they had a role to play in the care of EOL care patients were then asked to further define this role with a free response. The free responses were sorted by frequently used themes within a profession and across all professions. Of the 93 subjects, 77 (83%) felt they had a role to play in EOL care, 5 (5%) felt they did not have a role in EOL care, 9 (10%) were unsure if they had a role in EOL care, and 2 (2%) did not complete this question. Of the occupational therapists who believed they had a role to play in EOL care, specific tasks such as patient positioning, splinting to reduce pain, and providing assistive equipment education to EOL care patients were among the most often listed roles. Additional themes listed by the occupational therapist included: increasing a patient’s QOL, addressing pain and emotional issues, improving/maintaining function, and promoting patient dignity. Physical therapists defined their role in terms of skills related to pain management. Physical therapists also defined their role as providing situation specific education to patients and their families. Speech-language pathologists were most concerned with a patient’s ability to safely swallow and communicate their needs to family/friends and medical staff. Speech-language pathologists also defined their roles as consultants providing education regarding safe feeding techniques and counseling for patients discerning the placement of a percutaneous endoscopic gastrostomy (PEG) tubes. Only two subjects mentioned their role in relation to the palliative care team. For example, one occupational therapist responded, “(our role is) to maintain the highest level of function as well as working with the team to keep (the) patient comfortable (positioning, activities of daily living (ADLs), etc).” Professional concerns of QOL were mentioned by all three professions; however, occupational therapists were the only profession to address concerns regarding a patient’s emotional well-being and social concerns related to EOL care.

A factor analysis was performed to separate 13 key factors related to QOL by the participants’ response patterns. The key factors, which divided equally among the three surveyed fields, fell into two response groups named, Factor 1 and Factor 2. Factor 1 consisted of everyday patient care such as dressing, bathing, and range of motion. Factor 2 consisted of medically specific needs such as swallowing, pain management, and communication. Participants ranked key factors of care which were more medically specific as having a greater influence on a patient’s QOL. Additional statistical analysis
Figure 5. The perceived impact of 13 key factors, as reported by subjects in each profession.
was performed by conducting an ANOVA to determine if a professional’s actual role influences their perception of perceived factors which influence QOL in EOL care patients. Figure 5 illustrates the response patterns of the three surveyed fields. An alpha level of .05 was used for all statistical tests. A subjects profession did not significantly impact their rank of key factors influencing QOL care, $F(4, 170) = 2.05, p = .0895 > .05$. Regardless of the actual profession, perceptions of key factors influencing QOL life care significantly differed between the three fields roles, $F(2, 170) = 131.36, p < .0001$. The professionals ranked the roles provided by the speech-language pathologist as the most significant factors affecting the QOL of an EOL care patient, followed by the care of physical therapists and occupational therapists. Subjects ranked the 13 key factors on a five point Likert scale, 1 indicates “does not impact” and 5 indicates “greatly impacts.” All mean response ranks were between 3.7 (impacts) and 4.7 (greatly impacts), which indicates the subjects perceived that all 13 factors have some level of impact on a patient’s QOL.

An ANOVA table was constructed to identify if EOL care training significantly influenced a professional’s level of self reported “Emotional Exhaustion (EE)” and “Personal Accomplishment (PA).” An alpha level of .05 was used for all statistical tests. Levels of EE were not statistically different between professions, $F(2, 82) = 1.37, p = 0.2596$. Levels of PA were not statistically significant between the three subject populations, $F(2, 82) = 0.17, p = 0.8413$. EOL care training was not statistically significant for reported levels of EE, $F(1, 82) = .43, p = 0.5147$, or reported levels of PA, $F(1, 82) = .39, p = 0.5328$. The mean EE score for professionals with EOL care education was slightly lower, and the mean PA score was slightly higher for professionals with EOL care education; however, these finding were not statistically supported.

A Pearson $|r|$ correlation coefficient test revealed no significant correlation between years of experience and a professional’s reported level of EE and PA. Results indicated that participant’s year experience and EE shared a weak negative correlation ($|r| = -0.13220$), also years experience and levels of PA shared a weak positive correlation ($|r| = 0.02848$), however, these relationships where not statistically significant.

A three way level of analysis of the variance (ANOVA) was performed to determine if the subjects’ profession significantly influenced their level of agreement
regarding roles of each field. Participants indicated their agreement with the possible roles of each field using a five point Likert scale, 1 (strongly disagree) to 5 (strongly agree). No statistical difference was found between the three professional groups perceptions of the role of an occupational therapist, $F (2, 79) = 1.68, p = 0.1931$, physical therapist, $F (2, 77) = 0.38, p = 0.6843$, and a speech-language pathologist, $F (2, 78) = 0.46, p = 0.6357$. Results were further analyzed by the overall mean group response to roles of the rehabilitation professional. Table 3 lists mean responses of the rehabilitation team on their level of agreement with four possible roles. Rehabilitation professionals strongly agreed their role as a therapist should focus on QOL and the mean rank for this question was the highest ranking. Professionals agreed it was appropriate to provided disease specific therapy and consultation services to the primary palliative care team. Lastly, subjects disagreed that they had no role to play in EOL care.
Table 3

*Subjects’ Mean Level of Agreement with 4 Roles of the Rehabilitation Team*

<table>
<thead>
<tr>
<th>Rehabilitation Team Role</th>
<th>Mean Rank</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) To provide direct holistic intervention that focuses on treating the whole person.</td>
<td>4.5</td>
<td>0.7</td>
</tr>
<tr>
<td>Efforts are focused on improving quality-of-life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(2) To provide intervention that directly treats the disease process.</td>
<td>3.5</td>
<td>1.1</td>
</tr>
<tr>
<td>(3) To provide indirect therapy to patients by offering consultation services to the</td>
<td>4.3</td>
<td>0.7</td>
</tr>
<tr>
<td>palliative care team.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(4) The Occupational Therapist, Physical Therapist, and Speech-Language Pathologist do</td>
<td>1.5</td>
<td>0.8</td>
</tr>
<tr>
<td>not have a role in the care of end-of-life patients.</td>
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</tbody>
</table>
CHAPTER V
Discussion

The purpose of this investigation was to evaluate rehabilitation staffs’ perceptions of end-of-life (EOL) care in long-term care (LTC) facilities. The perspectives of primary EOL care staff (i.e. physicians, nursing staff, and nursing aids) have been studied extensively (Keay, Alexander, McNally, Crusse & Eger, 2003; Flacker, Won, Kiely, & Iloputaife, 2001), however, the perspectives of supporting fields such as occupational therapy, physical therapy, and speech-language pathology have not been studied. Furthermore, the caseload size, educational background, and type of care provided by rehabilitation staff are not generally described. The purpose of this study was to define: (a) the number of rehabilitation staff working with EOL care patients, (b) to describe the type and frequency of EOL care education, (c) to understand the perspectives of rehabilitation staff regarding key factors influencing quality-of-life, (d) to find if continued education and/or experience aids in job satisfaction, and (e) to determine if there is a consensus between the three fields perspectives of palliative care delivery models.

Results reveal 85% of the rehabilitation professionals working in LTC facilities perceived that they have a role to play in the care of EOL patients, however, only a few (9%) reported being part of a palliative care team. The contradicting data between perceived presence of need and the actual use of rehabilitation professionals may be explained by the small sample size, work setting, or the region where this study was conducted. Survey completion was above average at 44%, however, the sample sizes of the three professional groups were small. Further, the study was narrowed to only one setting, LTC facilities, which may not have resulted in the most accurate data for all rehabilitation professionals. Other work settings such as home health, hospitals, and/or private agencies may have higher rates of rehabilitation professionals working with EOL care individuals. The Federal Interagency Forum on Aging-Related Statistics (2006) reported a decrease (2%) in the rate of the oldest old (85 and older) living in nursing homes over the last 20 year. The findings of the Federal Interagency Forum on Aging-Related Statistics may explain the low number of rehabilitation professionals working with EOL patients. Similarly, the region to which this study was conducted only
accounts for a small portion of the U.S. rehabilitation professionals’ opinions and the utilization of rehabilitation staff in the care of EOL patients may differ by region.

If the results of the study are representative they highlight the underutilization of rehabilitation staff in EOL care. Frost (2001) acknowledges the uses of rehabilitation staff in EOL care is a “growing trend,” but states that the utilization of these professionals may not be widely accepted. Frost (2001) suggest that the interest in therapies such as occupational therapy, physical therapy and speech-language pathology is growing as the primary health care team is beginning to explore other forms of symptom management, such as rehabilitation services, to improve QOL by increasing dignity and patient/family involvement. Although rehabilitation services are a growing trend (Frost, 2001), results from the current study suggest continuing education of medical professionals and advocacy on behalf of the rehabilitation professionals and patients is needed.

Researchers in the fields of occupational therapy, physical therapy, and speech-language pathology are currently publishing research on the effectiveness of varying rehabilitation services as valuable treatments in EOL care (Salt, Davies, & Wilkinson, 1999; Pizzi & Briggs, 2004). Without this continued research on the efficacy of rehabilitation services and educational course work for rehabilitation staff and primary care staff alike, OTs, PTs, and SLPs may not be fully utilized.

Lack of primary care staff education is just one component which may be contributing to decreased numbers of rehabilitation staff working as valuable members in the palliative care team. Issues of reimbursement may also contribute to the reported lack of rehabilitation services for EOL care patients. Ersek and Wilson (2003) describe a number of challenges that professionals face when providing EOL care; among the top challenges are LTC facility reimbursement and inadequate staffing. One survey participant voiced their concerns over reimbursement by writing:

“Patients who are admitted to palliative care are rarely referred to SLPs, PTs, and OTs. In my experience the discipline who receives the most referrals from a palliative care team is speech-language pathology, to address dysphagia. Typically, only one evaluation and one treatment are permitted due to financial issues. I have rarely known of an OT or PT to receive referrals from a patient who is receiving palliative care.”
Research demonstrating the efficacy of rehabilitation services, paired with increased education of administrative staff may lead to LTC facilities changing their delivery models and encompassing more holistic forms of care.

Results of the survey revealed an imbalance of reported fields currently working on a palliative care team. Of the eight professionals who were part of a palliative care team, six were occupational therapists, one was a physical therapist, and one was a speech-language pathologist. The high number of occupational therapists currently part of a palliative care team suggests that their role may be viewed by the primary care team as being more valuable than other rehabilitation fields. Rehabilitation professionals perceived factors such as swallowing, communication, decision making, and pain as most heavily affecting a patient’s quality-of-life. Further information is needed to understand why occupational therapists reported working on palliative care teams more often than their colleagues.

Analysis of the subjects’ free responses revealed occupational therapists working with EOL patients used themes of “quality-of-life,” “emotional support,” and “self-dignity” more often than their rehabilitation colleagues. One occupational therapist wrote:

“The most important role I have is to show and feel empathy for others pain. It is also imperative to seek out what the patients desires are for his/her future and plan therapy to follow. "Being there" for the patient, especially when no family is involved, is also a very important role. All of these roles can be easily incorporated into your everyday therapy.”

Physical therapists and speech-language pathologists used themes of “quality-of-life,” “emotional support”, and “self-dignity” less often and were more inclined to define their specific role in terms of type of therapy and delivery models. One speech-language pathologist wrote:

“Safest route of nutrition, ensure safe PO intake until death, ensure the patient can communicate at the end of life if possible”

Communication was acknowledged as an important factor for patients during EOL care, however, speech-language pathologist and physical therapist definitions of care seemed to remain one dimensional and to not explore the social and emotional implications
which chronic illness has on quality-of-life and emotional well-being. Concluding, occupational therapists’ have a better understanding of the social and emotional implications of EOL care may be over generalizing the findings, however, the increased number of “empathetic” comments in the occupational therapists responses suggests some difference in their views. One explanation may be attributed to differences in therapy provided by each of the three professions. Additional research conducted to fully understand these themes and perhaps the underlying philosophies of how each profession was developed may lead to a better understanding of teaching models which incorporate issues of emotional, spiritual, and physical well-being (Keay, Alexander, McNally, Crusse & Eger, 2003).

Thirty-three (36%) of the participants had some form of previous EOL care education. In service training was among the highest reported form of EOL care education, followed by university courses. The results indicate topics of EOL care are being discussed and courses are available for rehabilitation professionals. Results revealed no statistical significance between the levels of EE and PA and the presence of EOL care education. These findings contradict with the findings of Haward et al. (2003), which indicated the significant impact reflection and training had on professionals working with EOL care patients. Research conducted by Keay, Alexander, McNally, Crusse and Eger (2003) found a statistically significant improvement in the care provided by the physicians with EOL care education as compared to their untrained counter parts. Similarly, researchers Maddix and Pereira (2001) found prearranged time for professionals to reflect on their role and experiences when working with EOL care patients was effective in reinforcing a sense of purpose and understanding of the palliative care team goals. The contradiction between the results of this study and the results of other studies may be attributed to smaller sample size. A decrease in EE and an increase in PA were noted, however, the findings were insignificant. Further research in the area of EOL care training is needed to draw further conclusions.

Participants’ years of experience were found to have no statistical significance on the level of EE or PA in rehabilitation professions. A weak negative relationship was found between years experience and EE, and a weak positive relationship was found between years experience and PA. The inconclusive results may be attributed to small
sample size, and research regarding years of experience and job satisfaction is needed to show stronger correlations.

Limitations of the Study

The study suffers limitations in the design and implementation of the survey. This study is limited by geographic location and only defines a small population of rehabilitation professionals. Although the region was chosen because of its demographics which closely mirrored U.S. demographics, differences in rehabilitation staff’s perceptions due to region were not considered. The sample size was relatively small, and may have influenced the significance of the findings. Only trends were noted and a larger sample size would be needed to determine statistical significance of the noted trends related to EOL care education and years of experience.

Additional limitations include possible survey bias. The survey was developed by a speech-language pathologist, and while the sections were carefully developed to remain unbiased, results seemed to favor the role of the speech-language pathologist, because participants selected swallowing, communication, and decision-making as factors most likely to affect a persons’ quality-of-life. While these are important factors in quality-of-life the remaining 10 factors highlighted in the survey may have been too broad. The utilization of a team of occupational therapists, physical therapists, speech-language pathologists, and additional rehabilitation staff in the development of the key factors influencing quality-of-life in addition to occupation specific questions might have resulted in a more unbiased questionnaire.

Future Research

The study of the rehabilitation staff in EOL care is warranted and should extend beyond the actual perception of occupational therapists, physical therapists, and speech-language pathologists. Research focused on developing efficacy of rehabilitation services for EOL care population should be explored. Adding to the already growing research will help professionals in rehabilitation become advocates for their services in EOL care. The development of standards of EOL rehabilitation services may help in the development of educational programs and the synchronization of services. Research and education is the pathway to the acceptance of occupational therapists, physical therapists,
and speech-language pathologist as professional partners with invaluable skills to offer to the palliative care team.

Each field should be addressed independently, to explore practice utilization and techniques most appropriate in EOL care. Taking a more concentrated look at each profession will lead to better foundations for further research across all fields. Without a well developed understanding of each fields’ role within the palliative care team, additional research on the rehabilitation teams’ perspectives cannot be conducted.

In addition, research should be conducted on the overall stress levels and job satisfaction of rehabilitation professionals working with dying populations. Research exploring compensatory strategies and programs designed to aid in professional development may help in having a better understanding of how professionals working with the dying grieve.

Lastly, research should focus on discovering if perceptions of EOL care differ by geographic region in the United States, for example do therapists in the northwest have more holistic views of care than therapists in the south. Understanding the social beliefs of each region may help discover what is fueling these different perspectives.

Conclusion

Results of this study suggest the need for research and continued education in the area of end-of-life care. A relatively small number of the study participants’ were part of an EOL care team, suggesting an underutilization of rehabilitation staff in the care of chronically and terminally ill patients. A majority of the participants agreed they had a role to play in the care of EOL patients, however, few had more then five EOL care patients on their caseload. Rehabilitation professionals are being called to become advocates of their services. Additional research of the efficacy of rehabilitation services for EOL care patients will lead to more utilization of rehabilitation services. Continued EOL care education and programs which encourage team reflecting and group discussions of the impacts of EOL care may lead to more collaboration among medical staff, as well as increasing awareness of the unique therapy options which can be utilized within palliative care.
References


APPENDIX A
END-OF-LIFE CARE SURVEY:
FOR THE REHABILITATION TEAM WORKING WITH END-OF-LIFE CARE PATIENTS

1) **Your Gender:** ___ (1) Male  ___ (2) Female

2) **What is your ethnic background?** (Check one)
   ___ (1) Asian/Asian American  ___ (2) Black/African American  
   ___ (3) Latino/Hispanic/Mexican American  ___ (4) Native American  
   ___ (5) Caucasian  ___ (6) Other (please specify)

3) **What is your religion?** (Check one)
   ___ (1) Protestant  ___ (2) Roman Catholic  
   ___ (3) Jewish  ___ (4) Other (Please specify)  
   ___ (5) none, no religion

4) **How religious would you consider yourself?** (Circle one)

   1  2  3  4  5  6  7

   Very Religious  Not at all religious

5) **What is your primary area of work?** (Check one)
   ___ (1) Occupational Therapy/ Occupational Therapist Assistant  
   ___ (2) Physical Therapy/ Physical Therapist Assistant  
   ___ (3) Speech-Language Pathology  ___ (4) Other (please specify) ________________

6) **What is your highest degree received?** (Check one)
   ___ (1) Associates Degree  ___ (2) BA/ BS  
   ___ (3) MA/MS  ___ (4) PhD

7) **How many years have you been practicing in your profession?** _____ Years

8) **What is your current primary work setting?** (Check one)
   ___ (1) Acute Care Hospital  ___ (2) Home Health  
   ___ (3) Long Term Care  ___ (4) Rehabilitation Facility  
   ___ (5) Private Practice  ___ (6) Other (Please Specify) ________________

9) **How long have you been in this setting?** _____ Years

10) **Have you received formal training in the area of end-of-life care?**
    ___ (1) Yes (Please answer question 11)  
    ___ (2) No (Please continue to question 12)  
    ___ (3) Unsure (Please continue to question 12)

11) **Where did you receive your formal training?**
    ___ (1) In-service  ___ (2) University Course Work  
    ___ (3) Conference  ___ (4) Continuing Education  
    ___ (5) Other (please specify) ________________
12) Are you currently part of a Palliative Care Team? (1) Yes (2) No (3) Unsure

13) Approximately how many end-of-life care patients are on your case load in a given month?
   ___ 0-5 ___ 5-10 ___ 10-15 ___ 15 or more

PLEASE CONTINUE TO THE BACK OF THIS PAGE.

Please use your personal belief and current knowledge regarding treatment of end-of-life care patients to answer the following questions:

14) Please select the professions you consider to be part of the Palliative Care Team:
   ___ Physician ___ Physical Therapist
   ___ Psychologist ___ Speech-Language Pathologist
   ___ Nursing Staff ___ Respiratory Therapist
   ___ Social Worker ___ Family
   ___ Occupational Therapist ___ Patient
   ___ Liturgical Staff ___ Other (please specify) ___________

15) Does your profession have a role to play in the care of end-of-life patients? (1) Yes (2) No (3) Unsure

16) If you answered yes to # 15 please describe, in your own words, the role you play in the care of this population:

__________________________________________________________________________________
______________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
______________________________________________________________

How do you feel each of the following factors influence quality of life in end-of-life care patient?

<table>
<thead>
<tr>
<th>Factor</th>
<th>Not at All</th>
<th>Very Little</th>
<th>Somewhat</th>
<th>Impacts</th>
<th>Greatly Impacts</th>
</tr>
</thead>
<tbody>
<tr>
<td>A patient's ability to make their own decisions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A patient's ability to perform ADLs</td>
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<tr>
<td>A patient's ability to ambulate</td>
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<tr>
<td>A patient's ability to shower her/himself</td>
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<tr>
<td>A patient's ability to toilet her/himself</td>
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<td></td>
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<tr>
<td>A patient's ability to dress her/himself</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>A patient's ability to feed her/himself</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A patient's ability to swallow</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain management</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range of motion</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self Care</td>
<td></td>
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<td></td>
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<tr>
<td>The patient's ability to communicate with loved ones</td>
<td></td>
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<td></td>
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<tr>
<td>The patient's ability to have control over end-of-life care discussions</td>
<td></td>
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</tr>
</tbody>
</table>

PLEASE CONTINUE TO THE NEXT PAGE
Rate how often you feel the following statements.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Never</th>
<th>A few times a year</th>
<th>A few times a month</th>
<th>A few times a week</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel emotionally drained from my work</td>
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<tr>
<td>I feel used up at the end of the workday</td>
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<tr>
<td>I feel fatigued when I get up in the morning</td>
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<tr>
<td>I easily understand how my recipients feel about things</td>
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<tr>
<td>I feel that I treat some recipients as if they were impersonal objects</td>
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<tr>
<td>I feel that working with people all day is really straining</td>
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<tr>
<td>I deal very effectively with the problems of my recipients</td>
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<tr>
<td>I feel burned out from my work</td>
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<tr>
<td>I feel I've positively influenced other people's lived through my work</td>
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<tr>
<td>I've become more callous toward people since I took this job</td>
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<tr>
<td>I worry this job is hardening me emotionally</td>
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<tr>
<td>I feel very energetic</td>
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<tr>
<td>I feel frustrated by my job</td>
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<tr>
<td>I feel I am working too hard in my job</td>
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<tr>
<td>I don't care what happens to some recipients</td>
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<tr>
<td>I feel working with people puts direct stress on me</td>
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<tr>
<td>I can easily create a relaxed atmosphere with my recipients</td>
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<tr>
<td>I feel exhilarated after working closely with my recipients</td>
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<tr>
<td>I feel that I have created many worth while things in this job</td>
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<tr>
<td>I feel that I am at the end of my rope</td>
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<tr>
<td>In my work, I deal with emotional problems calmly</td>
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</tbody>
</table>

Please complete all the boxes below
Please check if you agree or disagree with the following statements regarding the role of the **Occupational Therapist** in the end-of-life care team.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Undecided</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>To provide direct holistic intervention which focuses on treating the whole person. Efforts are focused on improving quality of life.</td>
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<tr>
<td>To provide intervention which directly treats the disease process</td>
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<tr>
<td>To provide indirect therapy to patients by offering consultation services to the palliative care team.</td>
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<tr>
<td><strong>A Occupational therapist does not have a role in the care of end-of-life patients.</strong></td>
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</tbody>
</table>

Please check if you agree or disagree with the following statements regarding the role of the **Physical Therapist** in the end-of-life care team.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Undecided</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>To provide direct holistic intervention which focuses on treating the whole person. Efforts are focused on improving quality of life.</td>
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<tr>
<td>To provide intervention which directly treats the disease process</td>
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<tr>
<td>To provide indirect therapy to patients by offering consultation services to the palliative care team.</td>
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<tr>
<td><strong>A Physical therapist does not have a role in the care of end-of-life patients.</strong></td>
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</tr>
</tbody>
</table>

Please check if you agree or disagree with the following statements regarding the role of the **Speech-Language Pathologist** in the end-of-life care team.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Undecided</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>To provide direct holistic intervention which focuses on treating the whole person. Efforts are focused on improving quality of life.</td>
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<tr>
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<tr>
<td>To provide indirect therapy to patients by offering consultation services to the palliative care team.</td>
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<tr>
<td><strong>A Speech-language pathologist does not have a role in the care of end-of-life patients.</strong></td>
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</tbody>
</table>

**THANK YOU FOR YOUR PARTICIPATION, IT IS GREATLY APPRECIATED!**
APPENDIX B

Dear Professional:

Professionals estimate by the year 2030 there will be an estimated 64.5 million people over the age of 65 years of age. As a professional in a long-term care facility you are being challenged to look at issues of end-of-life care and examine the effectiveness of current delivery models. Current literature focuses on the importance of the multidisciplinary team in addressing issues of end-of-life care. Rehabilitation professionals, such as yourself, are challenged to take a deeper look at their role as health care providers and how their skills can help the end-of-life patient.

The attached survey is being distributed as part of a study being conducted to gather information from specialists, like you, to gather perceptions of issues related to working in long-term care facilities. I am a graduate student conducting the research under the supervision of faculty at Miami University in Oxford, Ohio. We believe it is important to fill the gap in the present literature regarding your viewpoint in these important issues.

Your participation in this survey would be greatly appreciated and hopefully the results will lead to a better understanding of the need for services in this population. Clinicians may only participate in the survey one time and all surveys are anonymous. Return envelopes will be immediately separated from the surveys and destroyed. If at anytime during the survey you feel uncomfortable you may choose to skip a question or discontinue the survey. Filling out the survey is an indication of consent to participate. If you wish to be part of this study please fill out the enclosed survey and use the pre-stamped envelop to return your survey, for privacy purposes please do not include your return address.

For more information concerning this study, please contact Kathryn Stock at stockkm@muohio.edu or Laura Kelly, Ph.D. kellylj@muohio.edu.

For information concerning your rights as a research subject please contact the Office for the Advancement of Research and Scholarship at humansubjects@muohio.edu or call (513)-529-3734

Thank you again for your help in this important work.

Sincerely,

Kathryn Stock, B.A.