

THE ROLE OF OCCUPATIONAL THERAPY IN PALLIATIVE CARE:
IS IT PERCEIVED TO BE BENEFICIAL
BY THE PATIENT AND FAMILY?

A DISSERTATION

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BY

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DEDICATION

For my wife, Denise Theriot Ivy, and my children Sarah, Faith, and Mack.

Also to my parents, Mackey and Carolyn Ivy, along with my brother,

Russell Ivy. Thank you all for taking up more than your share

of household duties, for your patience and

love during this long process.

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ABSTRACT

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THE ROLE OF OCCUPATIONAL THERAPY IN PALLIATIVE CARE: IS IT PERCEIVED TO BE BENEFICIAL BY THE PATIENT AND FAMILY?

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Physicians often order “comfort care” and discontinue therapies including occupational therapy when an oncology patient no longer benefits from curative treatments. The purpose of this study was to determine if occupational therapy was beneficial to palliative care patients. Many standardized quality of life instruments were considered that assessed levels of symptom burden including pain and fatigue. However the standardized instruments did not ask specifically if the occupational therapy session was beneficial and/or “worth it.” A survey addressing these research questions was developed for the patients who met the inclusion criteria. It was determined that the best judges of whether an occupational therapy session was beneficial or not, were the palliative care patients and caregivers who just experienced an occupational therapy session.

This study included 27 patient surveys and 21 caregiver surveys. All 48 surveys indicated that the occupational therapy session was perceived to be beneficial. A secondary objective or research question was to estimate the satisfaction rate, which is defined as the percentage of patient and caregivers that answered “agree strongly” or

“agree” to the question, “Overall, participating in this activity today was worth it.”

Again, all of the 48 surveys indicated that the occupational therapy session was “worth it.” This was despite almost 30% of the surveys indicating that the activity increased pain and/or fatigue.

This study provided the quantitative and qualitative data to indicate that patients and caregivers perceived participation with occupational therapy was beneficial and worth it. An important implication of this study is that physicians may now be more comfortable ordering occupational therapy for their patients facing the end of life if palliative patients themselves reported quantitatively and qualitatively that occupational therapy was beneficial. With this research supporting the inclusion of occupational therapy as a part of end of life care, it is hoped that each patient may at least be given the opportunity to decide for him- or herself if he or she wishes to participate with occupational therapy or not. Another practice implication would also support having an occupational therapist be a part of the palliative care team.

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CHAPTER I

INTRODUCTION

Statement of the Problem

The World Health Organization (WHO, 2002) recognized that palliative care is a specialty in the healthcare domain and defined it as

an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (p. 84)

Among the nine additional goals listed below with this definition is goal five, which is of particular interest to occupational therapy (OT) as it states that palliative care also “offers a support system to help patients live as actively as possible until death” (WHO, 2002, p. 84)

1. provides relief from pain and other distressing symptoms;
2. affirms life and regards dying as a normal process;
3. intends neither to hasten or postpone death;
4. integrates the psychological and spiritual aspects of patient care;
5. offers a support system to help patients live as actively as possible until death;
6. offers a support system to help the family cope during the patients illness and in their own bereavement;

7. uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
8. will enhance quality of life, and may also positively influence the course of illness;
9. is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications” (WHO, 2002, p. 84)

The decision makers in the palliative care specialty are to be commended for acknowledging in this document that keeping a person active is a positive goal; however, it has not been made clear how to achieve this goal. The World Health Organization (WHO, 2014, p. 5) Global Atlas adopted the 2002 definition of palliative care with some further explanation of services; however it did not discuss occupational therapy. The profession of occupational therapy has a unique body of knowledge and the expertise to maximize participation in therapeutic activities (AOTA, 2008). Also only occupational therapy practitioners focus on the use of therapeutic activities and “occupations to promote health, well-being, and participation in life. Occupational therapy practitioners use therapeutically selected occupations and activities as primary methods of intervention throughout the process” (AOTA, 2014). However another guide from the WHO on palliative care states “health-care providers involved in palliative care may include physicians, nurses, social workers, psychologists, spiritual counselors, volunteers, pharmacists and traditional healers” (WHO, 2007, p. 27). This list of interdisciplinary

team members is impressive but it does not include occupational therapists or any other health profession that specializes in increasing one's ability to engage in meaningful activities.

Statement of the Purpose

The above literature indicates that occupational therapists can be beneficial in helping patients achieve the goal of remaining active; however, they are not always included in the palliative care team. The purpose of this dissertation was to explore the perceptions of patients on an oncology palliative care unit and their caregivers on the benefits of occupational therapy.

Research Questions

Hypothesis: Palliative patients and caregivers will perceive an occupational therapy session to be beneficial.

The primary objective or research question of this study was to estimate the satisfaction rate which is defined as the percentage of patients and caregivers that answered "agree strongly" or "agree" to the question, "This inpatient occupational therapy session was beneficial" to me/the patient.

A secondary objective or research question was to estimate the satisfaction rate which is defined as the percentage of patient and caregivers that answered "agree strongly" or "agree" to the question, "Overall, participating in this activity today was worth it."

CHAPTER II

BACKGROUND AND SIGNIFICANCE

Palliative Care

Higginson (2011) wrote that modern hospice and palliative care had its roots in the late 1960s, when Dame Cicely Saunders pioneered the first specialty hospice unit. The term palliative, from the Latin word ‘palliare’ (to cloak), was proposed in 1974 by Dr. Balfour Mount in Canada, as an alternative to the word hospice. To his patients who spoke French, this term hospice was associated with “a place of last resort for the poor and derelict, which made its global use difficult” (Higginson, 2011, p. 384). Palliative care is an appropriate term because the focus is not to cure a disease, but to cloak, cover-up, or shelter the patient by controlling symptoms and thus improve quality of life even if the patient is not yet ready for hospice. Emphasis on management of pain and other symptoms, physical, emotional, and spiritual, for individuals with life-limiting conditions is the nexus of palliative care (WHO, 2002).

Quality of Life and Occupational Therapy

Ferris et al. (2009) indicated that palliative cancer care requires an interdisciplinary team to address the multiple issues that cause suffering for patients and their families and impact their quality of life. Pizzi’s (2014) study interviewing occupational therapists, physical therapists, social workers, and registered nurses reported “that each discipline, as an interdisciplinary team member, recognized the value of the other team members and that quality of life, health, and well-being until death were the

ultimate goals in end-of-life care” (p. 220). As previously mentioned, occupational therapy has not been fully utilized even though the World Health Organization (WHO, 2002, p. 84; WHO, 2014, p. 5) has acknowledged that helping a person stay active until death would increase a person’s quality of life. Although this acknowledgement begins to address this issue, being active for the sake of being active can be viewed as tedious busy work. Having an occupational therapist on the team not only helps patients stay active, but also provides active participation in meaningful activities that maximize the patient’s quality of life. If occupational therapists continue not being a part of this team, it will “limit the breadth of support care, which in turn may perpetuate physical, cognitive, and emotional issues for clients while limiting function, participation, and quality of life” (Sleight & Duker, 2016, p. 6).

Occupational therapists provide skilled intervention to improve quality of life by facilitating engagement in daily life occupations throughout the entire life span including the time when one is approaching the end of life (AOTA et al., 2011). However, the importance of remaining occupied and engaged in meaningful activity continues to be overlooked when providing care for the terminally ill. Keesing and Rosenwax (2011) identified in their study:

... four themes emerged that impacted people who were dying and their carers.

These were; ongoing disengagement from usual activities with resultant occupational deprivation; disempowerment of both people who are dying and their carers within palliative care services; ‘occupation’ not being addressed adequately in palliative care and occupational therapists experience frustration

with limited opportunities to contribute to the care of people who are dying. (p. 329)

A common perception is that few, if any, improvements in function can be achieved while in palliative care. However, it is important to remember that autonomy and maintenance of independence are highly valued to clients diagnosed with terminal illness (Coyle, 2006). Palliative care recognizes that “whatever the disease, however advanced it is, whatever treatments have already been given, there is always something that can be done to improve the quality of the life remaining to the patient” (Woodruff, 2004, p. 1).

Kaye (2006) affirms this in *Notes on Symptom Control in Hospice and Palliative Care*: “Loss of independence and role can result in social death prior to biological death. Occupational therapy can help a person to adopt new and appropriate functions and roles and to maintain self-esteem” (p. 214). Egan and DeLaat (1997) illustrate how occupation can help one resume roles and relationships to avoid this premature social death: “It is through our occupations that we live out the relationships that bring meaning to our lives” (p. 116). Prominent palliative physicians also acknowledge that “palliative cancer care aims to give patients and their families the capacity to realize their full potential, when their cancer is curable as well as when the end of life is near” (Ferris et al. 2009, p. 3055).

Pizzi (1992) wrote that “quality of life is not simply about pain control and keeping people comfortable – it is about enhancing the ability to perform activity important to the person and family system... creating opportunities to live fully and productively until death” (p. 1). Pizzi (2014) later added “as health professions, we always have the opportunity to promote health, wellness, and quality of life for all clients,

even those at the end of life.” Penfold (1996) stated that when treating oncology patients “the primary drive and focus of the occupational therapist is to facilitate and enable an individual patient to achieve maximum functional performance, both physically and psychologically, in everyday living skills regardless of his or her life expectancy” (p. 75). Corr (1992) proposed a task-based approach for coping with dying that addresses four primary dimensions including the physical, psychological, social and spiritual realms. Occupation can be a primary source of purpose and meaning in one’s daily life which could include preparation for death (Hasselkus, 2002). Hasselkus and Jacques (1998) also discussed the importance of occupation to enable the patient to gain control of him- or herself and engage in meaningful occupations while also planning for a possible decline in function and eventual death. Occupational therapists can help empower patients with the knowledge and skills needed to adapt and function which can increase their sense of control over symptoms and situations that seem out of control.

Patients and caregivers have reported that they viewed occupational therapy as the “practical help needed for discharge home from a palliative care setting” (Marston, Agar, & Brown, 2015). The occupational therapy literature suggests that occupations are central to a person’s identity and competence, and they determine how one spends time and influence how one makes decisions (AOTA, 2014). Therapeutic use of occupations can empower a terminally ill patient with a renewed sense of control by adapting to physical, cognitive and psychosocial changes that occur rapidly. Clients can adapt to their current status allowing them to retain a sense of mastery over the environment even while experiencing a decline in function. “Occupation provides the means by which

human beings adapt to changing needs and conditions, and the desire to participate in occupation is the intrinsic motivational force leading to adaptation” (Schkade & Schultz, 1992, p. 829). By choosing to spend the remainder of their life actively participating and engaging in meaningful activities, palliative care patients can benefit from occupational therapy that allows them to retain their sense of mastery over the environment even while experiencing a decline in physical, cognitive and psychosocial function.

Significance of the Proposed Research

The palliative care literature accepts that the general concept of keeping patients active until death is important. However, in practice, many physicians do not order occupational therapy for patients with a terminal prognosis because they are not aware of its benefits to the patient. Although the literature contains rich qualitative data including case studies, literature was not found that specifically supports whether or not occupational therapy is perceived to be beneficial according to patients receiving palliative care using quantitative data. This exploratory pilot study proposed to determine that when patients on palliative care have the opportunity to participate in an inpatient occupational therapy (OT) session, it would increase their ability to engage in meaningful activities, routines, and roles. Physicians may hesitate in ordering inpatient occupational therapy for palliative patients because they may not be aware of how this intervention could benefit the patient. Physicians may also be concerned that increasing a patient’s activity level may increase their patient’s pain or fatigue. The data gathered from this study were intended to indicate whether or not participation in an inpatient occupational therapy session was perceived to be beneficial from the patients’ and

primary caregivers' perspectives. This information may help physicians decide if the risk of possible discomfort is worth the possible rewards of participating in an inpatient occupational therapy session. Many patients facing the end of life have become bedridden and passive recipients of comfort care. Occupational therapy can help palliative patients spend the remainder of their lives actively participating in occupations most meaningful to them. Patients can become empowered and overcome challenges that limit function while achieving activity goals that can restore dignity and individuality and resume cherished roles with an improved self-image (AOTA et al., 2011).

CHAPTER III

METHODOLOGY

Design

This study used a mixed methods approach that included both quantitative and qualitative data from a survey administered to both patients and their caregivers. According to Creswell (2009), “the embedded design is appropriate when the researcher has different questions that require different types of data in order to enhance the application of a quantitative or qualitative design to address the primary purpose of the study” (p. 91). Although gathering mixed measures is inherently complex, this study is enhanced by adding the qualitative data in order to reveal more understanding of the patients’ and caregivers’ perceptions during the therapeutic process. The interrelationship of both forms of data is appropriately recorded at the same time (concurrently) which gives a snapshot of the total picture and situation at the conclusion of the occupational therapy intervention.

Sample

The sample aimed to include patients on the Palliative Care unit and as many of their primary caregivers as possible. Patients were included in the study if they met the inclusion criteria and were receiving occupational therapy. Then, at the conclusion of the occupational therapy session with a patient that met inclusion criteria, the PI asked the patient if he/she wished to participate in this research study. If so, the PI explained the consent forms and had him/her agree to sign (Appendix A). If an eligible caregiver was

present during the OT session and wished to participate in the study, then the same procedure was performed. Prior to participating in the research, each patient (and caregiver if available) was given an Informed Consent/Authorization for Participation in Research (see Appendix A) with an explanation and asked to sign that they would be willing to participate in this research

Eligibility. All MD Anderson patients admitted to the Acute Palliative Care Unit (APCU or PCU) were eligible to participate. Patients were not excluded based on gender, race, cancer type, cancer stage, or time of diagnosis. Patients admitted to the unit were all 18 years and older since staff are not certified for pediatric care. The patient had to be able to choose a personal activity goal which was meaningful and appeared to be achievable to the patient and the therapist during that session; this chosen activity was documented.

Exclusion criteria.

- Patients or caregivers with physical limitations (visual or motor impairment) causing inability to read, complete, or sign the consent form and survey.
- Patients who the attending physician deemed unable to tolerate an occupational therapy session due to delirium, poor cognitive capacity, and/or acute physical distress.

Inclusion criteria.

- Patients had an inpatient occupational therapy order and were able to tolerate an OT session as judged by the attending physician.

- Patients had a cancer diagnosis and were admitted to inpatient Acute Palliative Care unit.
- Caregiver participation was optional, but the participant had to have been identified as the primary caregiver in order to have completed the Caregiver Satisfaction Survey.
- Caregiver (if participating) must have been present during the session.
- Patient (and caregiver if participating) must have been 18 years of age or older.
- Both patient (and caregiver if participating) were able to understand, read, write, and speak English.
- After not being excluded and then meeting all inclusion criteria, both patient (and caregiver if participating) signed an Informed Consent Form.

Patients may not be able to tolerate an occupational therapy session; however, if symptoms are controlled, he or she may be able to tolerate a session at a later time or date. Patients on palliative care tend to experience a variety of symptom burdens which inhibit function due to pre-morbid conditions, disease process of various forms of cancer, and the side-effects of the curative treatments (Penfold, 1996). Another challenge to researching the palliative patient population was that patients may discharge to hospice quickly, decline in condition, or expire. Because of this, it was determined that the most accurate and effective way to collect quantitative data was to use a short survey with one open-ended question at the conclusion of the questionnaire for qualitative comments.

Not all patients on the PCU were appropriate for this study due to symptoms including delirium. Delirium was assessed each day by the physician and if the patient was determined not to have the cognitive capacity to understand and sign a consent form, then the patient was excluded from the study. The PCU used the Memorial Delirium Assessment Scale (MDAS) located in the physician's daily note and the literature suggests two different thresholds (7/30 or 13/30) for a score that indicates the diagnosis of delirium (Friedlander, Brayman, & Breitbart, 2004). With this discrepancy in the literature, the final authority and gatekeeper decided if a patient has the cognitive capacity to participate was the attending palliative care physician. The patient's attending physician was consulted before a patient was considered appropriate for this study and demonstrated the cognitive capacity to sign consents required to participate in this research. If the patient was admitted to the PCU with an MDAS score greater than 8, then the patient's latest MDAS score was documented on the Patient Demographic Data and Participation Log (Appendix B). The patient's most recent Edmonton Symptom Assessment Scale (ESAS) numbers were also documented each day by the physician and included on the log for future research exploration. These scores reflect how high the patient rated his or her own symptom burden with twelve symptoms including pain, fatigue, shortness of breath and anxiety. The principal investigator (PI) provided and explained the required informed consents prior to any data collection.

Description of the Intervention

The intervention consisted of a standard inpatient occupational therapy session provided on the PCU by the PI who was an occupational therapist with over 10 years

of experience with this patient population. The sessions usually take between 30 to 120 minutes, depending on the patient's needs and activity goal for the day. This occupational therapy session was standard care and would have been provided regardless of participation in this research study. Skilled interventions during an OT session are individualized and can involve resuming a favorite leisure activity or a basic self-care task including transfers from the bed to a bedside commode or to a wheelchair for the first time since admission. Prior to this intervention, an occupational therapy evaluation was performed with each patient according to the guidelines provided in the AOTA (2008) Practice Framework and the AOTA (et al., 2011) statement: The Role of Occupational Therapy in End-of-Life-Care. However if the patient's dyspnea, pain, and/or fatigue was not controlled, the following flowchart (Figure 1) that the principal investigator developed during this study provided some general strategies to help control symptom burden before a meaningful activity could be tolerated.

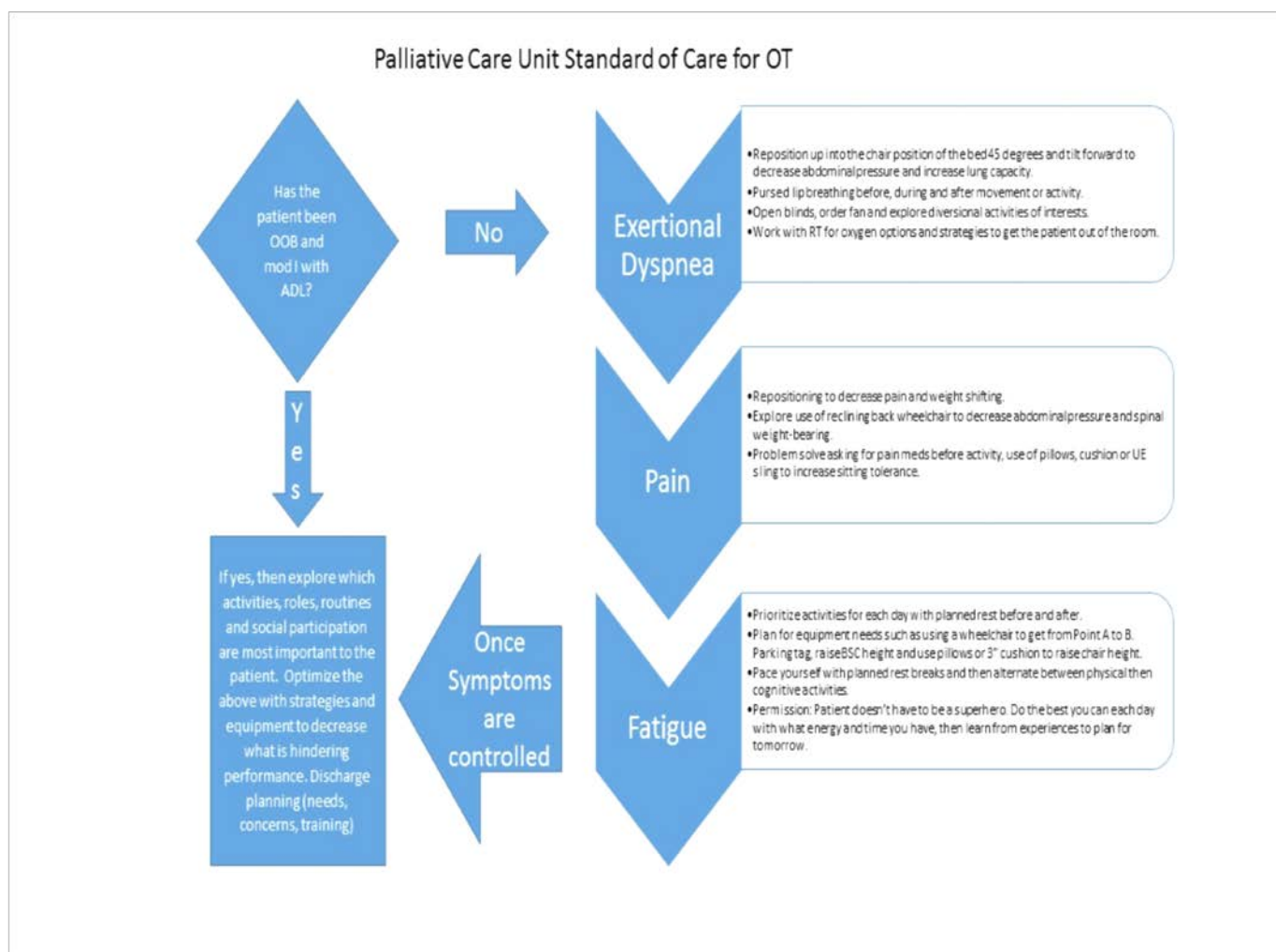


Figure 1: Palliative care unit standard of care for OT

Creation of a New Survey Questionnaire

When researching various standardized quality of life research tools available, a concern kept arising. Quality of life questionnaires tend to ask about levels of pain, fatigue, and other symptoms. However, the existing standardized instruments do not address the patient's perceived benefit of an intervention. This concern may be best expressed using the following analogy. Imagine a person were to leave the comfort of an air-conditioned car and approach the entrance to a trail at a National Park. If this person were to complete a quality of life questionnaire before starting to hike and compared this to the responses given at the conclusion of the hike, the person may indeed be in more pain, short of breath, hot, sweaty, and fatigued. However, this person may subjectively write in the bottom of the questionnaire that it was a great experience and worth it. This is part of the reason a new questionnaire was developed. Another concern was that each existing quality of life or similar questionnaire contained more than ten questions. Because this fragile population facing the end of life does not need another taxing questionnaire, it was decided that this questionnaire would only have 10 questions to reduce the burden of a survey. It was also determined that it would be important to explore if a patient's pain and/or fatigue increased while participating in the occupational therapy session while also offering an opportunity to report if the increased symptom burden was worth it. The other short standardized quality of life instruments do not offer one open-ended comment/question that would provide qualitative data to enrich the quantitative data.

Data Collection Tools

At the conclusion of the OT session, the PI provided the patient (Appendix B) and caregiver if available (Appendix C) with a self-administered satisfaction survey with instructions provided both verbally and also written at the top of the survey. The survey sought the perceived benefit of the OT session with 10 questions. The 10 questions were rated on a 5-point Likert scale (from strongly agree to strongly disagree) and the last question offered an opportunity to further describe whether or not the participation either was or was not “worth it.” The patient (and primary caregiver if available) was left alone to complete the 10 question satisfaction survey which took less than 10 minutes. The questionnaires were then sealed in an envelope and dropped into a locked box. The envelopes were not opened or seen by the therapist in order to protect the anonymity and prevented blinding/bias concerns.

The PI collected patient demographics from the medical records (gender, ethnicity, marital status, religion, and educational level) and clinical characteristics (types of cancer, cancer stage, etc.), performance status, Edmonton Symptom Assessment Scale (ESAS), and Memorial Delirium Assessment Scale (MDAS). The inpatient occupational therapy activity chosen by the patient and category of the activity was recorded on the form as well as the presence of a family member or visitor noted and whether or not he or she qualified as a primary caregiver. The primary caregiver’s relationship to the patient and demographics were recorded (age, gender, and ethnicity). Caregiver information was collected when survey was being completed by the patient. The patient and caregiver put the completed survey in an envelope which was then placed in a slot of a locked box so

that the PI never saw the finished survey. This locked box was then taken to the research assistant's office so she could unlock the box and enter the data without the PI seeing the completed survey; in this way, the PI remained "blinded" to the participants' survey responses. The PI also delivered the Demographic Data Collection Form (see Appendix D) to the research assistant at this time so that all of the data could be entered at the same time and be kept together.

Data Collection Procedures

The following explanation of the procedural process, requirements and guidelines were requested by the MD Anderson Cancer Center IRB:

- Patients without inpatient occupational therapy orders will not participate in OT sessions.
- If the patient on the PCU has an OT order and is on the unit, he or she will be asked by the therapist if he or she is willing and able to participate with inpatient occupational therapy.
- If the patient is able and willing, he or she will participate in the OT session. If the patient does not meet eligibility criteria of the research, the OT session is complete.
- If the patient meets eligibility criteria, he or she will be approached to participate in the research study. If the patient refuses to participate, the OT session is complete.
- If the patient is willing to participate, he or she will sign the consent form and complete the patient satisfaction survey. If the

patient's primary caregiver is not present, the OT session and research study is complete.

- If the patient's primary caregiver is present and eligible, he or she will be approached and explained the study. If the caregiver declines, the OT session and research study is complete.
- If caregiver is willing to participate, then he or she will sign the consent form and complete the caregiver satisfaction survey following the inpatient occupational session.
- This concludes the OT session and research study for the patient and caregiver. Completed survey will be placed in a sealed envelope and placed in a locked box in the unit.

Data Analysis

The primary objective of this study was to estimate the satisfaction rate which was defined as the percentage of patients and caregivers that answered "agree strongly" or "agree" in response to Question #1 asking whether or not the inpatient occupational session was beneficial. The MD Anderson statistician who assisted with the development of this study recommended the following: "in order to have at least a 70% satisfaction rate, but not lower than 50%; an nQuery + nTerim 2.0 for sample size justification was used". With 27 patients and 21 caregivers completing the surveys the statistician estimated that if 50 surveys were completed the study would have an "82% chance to detect a satisfaction rate of 70% against 50% using two-sided chi-squared test with a

significance level of 0.05. At the end of the study, the patient satisfactory rate was estimated with a 95% confidence interval, compared to 50%.”

The secondary objective of this study was to estimate the satisfaction of patients and caregivers using question #10 “Overall, participating in this activity today was worth it.” The data from the 10 questions on the survey were compared and contrasted with the data documented on the Demographic Data Collection Form (see Appendix D). At the end of the study, these covariates were crossed with satisfaction scale for patients and caregivers, using Fisher’s Exact Test on cells less than 5 in a cell or Chi-Squared Test if cells contained more than 4 data points. Statistical Software for the Social Sciences (SPSS) version 22 was used for the data analysis. All the secondary analysis was designed to be exploratory with potential for future use on larger study designs. Questions #2 through #7 asked about more specific possible benefits of occupational therapy in order explore for future research and to assess the validity of the instrument in the future. Questions #8 and #9 asked about pain and fatigue levels following the session and will be discussed in the next chapter.

CHAPTER IV

RESULTS FROM QUANTITATIVE DATA

Quantitative data for this study included sample description, demographic information, activities participated in during the occupational therapy session, and results of quantitative data analyses.

Sample Description

During the study period, 186 patients were on the Palliative Care Unit (PCU) with an OT order when the PI was covering the PCU. Of these, 112 were not able to participate in an OT session due to symptom burden (pain, dyspnea, fatigue, and/or delirium), being off the unit for a procedure, staff being in the room with patient, or because the patient expired that day. Another 38 patients were able to participate with an OT session, but did not meet inclusion criteria due to not having cognitive capacity to sign the consent form, inability to speak English, or being an off-service patient in a Palliative Care Unit (PCU) room. Another patient would have been able to complete the survey; however, his session involved putting on his clothes and demonstrating a safe transfer from his bed to a wheelchair so that his wife could quickly take him home before the rain began. Thirty-six patients remained who were able to participate in an OT session and met inclusion criteria. Of these, eight chose not to complete the survey due to fatigue, because staff was waiting to see the patient, and one needed to have a gastrointestinal procedure.

Patients meeting inclusion criteria and agreeing to participate totaled 27. Of these, 23 had caregivers present during the OT session. One caregiver was not eligible because she did not speak English although the patient did. Another caregiver met inclusion criteria, but had to leave abruptly at the end of the session to pick up his children from school. In total, 27 patients and 21 caregivers were able to sign consents and completed the survey. The demographic characteristics of these 48 respondents are provided in Table 1.

Table 1
Participant Demographics

Characteristic	Patient n=27	Caregiver n=21	Total n=48
Age			
Mean	61.9 (13.0)	55.9 (15.0)	55.8 (14.1)
Median	62.0 (56-72)	57.0 (45-67)	62.3 (51.5-70.7)
Gender			
Male	11 (40.7%)	12 (54.5%)	23 (46.9%)
Female	16 (59.3%)	10 (45.5%)	26 (53.1%)
Race			
Asian	1 (3.7%)	1 (4.5%)	2 (4.1%)
Black	2 (7.4%)	1 (4.5%)	3 (6.1%)
Hispanic	6 (22.2%)	5 (22.7%)	11 (22.4%)
White	18 (66.7%)	15 (68.2%)	33 (67.3)
Marital Status			
Single	6 (22.2%)	n/a	n/a
Married	16 (59.3%)		
Widowed	4 (14.8%)		
Divorced	1 (3.7%)		
Religion			
Catholic	9 (33.3%)		
Protestant	13 (48.1%)		
Muslim	1 (3.7%)		
Other	4 (14.8%)		
Education			

Less than 8 th grade	1 (3.7%)
High School	5 (18.5%)
Tech/Vocational	1 (3.7%)
Some College	9 (33.3%)
Bachelor's Degree	5 (18.5%)
Advanced Degree	6 (22.2%)

The mean age of patients was 61.9, while the caregivers' was 55.9. Most of the patients were female (59.3%) with most of the caregivers being male (54.5%). Most of the patients were married (59.3%) and most of the caregivers completing the survey were spouses (37%), with adult children being the next highest category (22.2%). Seventy-four percent of the patients reported completing at least some college education compared to the average of 57.2% with Americans 25 years old or over (U.S. Census Bureau, 2014).

Activities

During the planning process, it was decided that it would be worthwhile to classify the activities that the patient participated into leisure, Activities of Daily Living (ADL), and Instrumental Activities of Daily Living (IADL). However, in practice most of the leisure activities such as going outside also involved transfer training, trial of equipment including reclining back wheelchair and/or cushion, along with education on how to increase ADL/IADL performance. So the following classifications were subjective depending on the focus of the session. Of the activities that patients chose to perform, 48.1% were primarily leisure, 25.9% self-care Activities of Daily Living (ADL), and 18.5% were focused on Instrumental Activities of Daily Living (IADL).

An example of a meaningful Instrumental Activity of Daily Living for one female patient was her ability to resume handwriting by holding a pen using a universal cuff (elastic band attached to a small sleeve in her palm to hold items without needing to grasp with fingers) to write messages for the first time since experiencing incomplete quadriplegia. This was significant because she was not able to verbalize her needs due to a recent tracheotomy and her limited lung capacity made using a valve for speech too labored. This patient was also an artist and with the universal cuff was able to create a painting of a sailboat with yellow and green stripes on the sails gliding through the blue water that she remembered seeing years ago in her home country of Iran. By using a towel under her elbow and wrist while resting on a tray table in order to reduce friction, the patient was able to also write her first words since experiencing incomplete quadriplegia in both English and Persian. She quoted the PI with the following: “be a person not a patient.”

The total time of OT sessions varied from 9 minutes to 121 minutes depending on the activity chosen by the patient and the challenges required to overcome in order to participate. One common challenge involved transferring patient out of bed and onto a bedside commode or wheelchair for the first time since admission. Sometimes this involved spinal precautions due to bone metastasis, ergonomics due to general weakness, and/or breathing techniques to perform before, during, and after functional transfers out of bed. One patient’s first treatment involved re-positioning up into the chair position of the bed to maximize his lung capacity and functional use of his bilateral upper extremity (BUE) for self-feeding; however he was too fatigued to complete a survey. When he first

arrived, he was not able to tolerate more than being repositioned and was unable to leave the room with an oxygen tank due to requiring being connected to the wall valves for high flow oxygen at 30 liters per minute (LPM). Three days later he was able to tolerate leaving the room with only 5 LPM of oxygen. Five days after this, he reported that he was now strong enough to complete the survey while sitting in a wheelchair returning from an outing with family preparing to discharge home with hospice.

Common activities chosen by patients included getting out of bed and participating in a skilled community reintegration activity for the first time since admission. Patients chose outings to the garden outside to see the various flowers that attract butterflies, 24th floor Observation Deck with a piano and large windows, 2nd floor Park Area with coffee shop, gift shop, and the beauty/barber shop. While participating with the above, one patient took a photo with four generations of females within their family. Another celebrated her 27th anniversary with her husband in the rose garden. One patient had not been out of bed to a wheelchair in 10 days or outside for four weeks. Challenges for sitting in a wheelchair included not being able to tolerate sitting up at a 90 degree angle and the patient not being aware that a reclining back wheelchair was available to lean back as needed to maximize sitting tolerance by reducing abdominal pressure and weight-bearing on the lower spine. With increased sitting tolerance, activity tolerance and comfort were optimized to allow engagement in meaningful activity. An overview of meaningful activities chosen by the patient is listed below in Table 2 and the complete list of activities are in Appendix E.

Table 2

Overview of Activities Participated in During Occupational Therapy Session

Community re-integration outing, transfer training, and equipment trial.	19
Four involved shopping or eating	
One involved showering first	
Breathing techniques to resume standing and then to resume slow dancing.	1
Equipment demonstration for home hospice options without leaving room.	1
Planning for own funeral contrasting to songs at her son's funeral.	1
Climbing stairs preparing for stairs required at home with safety planning.	1
Transfer training to a chair or edge of bed in order to self-feed and groom.	2
Transfer training from bed to a bedside commode for the first time and hygiene.	1
Use of universal cuff to resume handwriting and watercolor painting.	1

Results of Quantitative Analyses

The primary objective or research question of this study was to see what percentage of patients and caregivers answered “Agree Strongly,” or “Agree” to Question #1, asking if the inpatient occupational therapy session was beneficial, after an inpatient occupational therapy session. Responses to this question was 100% with those two ratings. A secondary objective was to estimate the responses of patients and caregivers to Question #10, asking if overall participation in this activity appears to be worth it; data revealed 100% agreement that the session was worth it.

In order to explore the possibility of the survey becoming a standardized instrument in the future, the reliability of the 10 questions for the patients was determined

using and inter-item reliability analysis. The result indicated high reliability (Cronbach's $\alpha = .797$). Using the same analysis, the ten questions for the caregiver indicated a moderate level of reliability (Cronbach's $\alpha = .675$). The overall inter-item reliability analysis indicated a high correlation among the 10 questions (Cronbach's $\alpha = .751$).

In order to explore the possibility of the survey becoming a standardized instrument in the future, an independent sample t-test was conducted to compare satisfaction measured by the sum scores of the 10 questions between caregiver and patients. Results revealed no significant differences between the two groups, $p > .05$. Results were also confirmed with non-parametric Mann-Whitney U tests.

Of the 10 questions on both the patient and caregiver surveys, the only question where the patient and caregiver response differed significantly was Question #4. Question #4 on the patient survey was "This session helped me discover the equipment, adaptations and/or strategies that may be helpful to me in future activities." Patients responded with 48.1% "Agree Strongly" and 48.1% "Agree" (see Table 3 below). The caregivers responded to a similar question "This session helped the patient discover the equipment, adaptations and/or strategies that may be helpful to him/her in future activities" with 90.5% "Agree Strongly" and 9.5% "Agree." The difference between the responses of the patients compared to caregivers was significant by being less than .05 with a $p = .003$ and will be explored further in Chapter VI.

Table 3
Question 4 Analysis Using Fisher's Exact Test

Answer	Patient n=27	Caregiver n=21	Total n=48
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Agree Strongly	13 (48.1%)	19 (90.5%)	32 (66.7%)
Agree	13 (48.1%)	2 (9.5%)	15 (31.3%)
Neutral	1 (3.7%)	0	1 (2.1%)

Only two questions produced responses other than “Agree Strongly” or “Agree.”

Question 8 asked if the session caused more pain and 13 out of 48 surveys (27%)

indicated that pain was increased. This left the remaining 73% responding that the OT session did not cause more pain. Question 9 was the other question that produced answers of “Neutral,” “Disagree,” or “Disagree Strongly.” Patient and caregiver responses again did not differ significantly and revealed that 14 out of 48 surveys (29%) indicated that fatigue was increased. This left the remaining 71% responding that the OT session did not cause more fatigue. The importance of this data will be explored further in Chapter VI along with the result of 44 out of 48 surveys agreeing strongly that participating in the OT session was “worth it.”

CHAPTER V

RESULTS FROM QUALITATIVE DATA

Qualitative findings for this study included one open-ended request for comments in the form of “please explain” at the conclusion of the 10 question survey. This chapter presents the themes and comments written down by the patients and caregivers.

Qualitative Comments and Themes

Comments on the bottom of the survey were not required, but offered as an option to gather qualitative data from both patients and caregivers. This allowed their own words to be included on the survey in order to help give insight as to why they recorded the quantitative data as they did. Some comments are reported in this summary of comments and themes; however, the complete record of patient and caregiver comments may be found in Appendix F and Appendix G.

Two experienced reviewers conducted an analysis of the data and reached agreement on these two themes. Of the 27 patients who completed the survey, 9 did not write any comments; of the 21 caregivers, 8 did not provide any comments. From these data of 31 participants, two themes emerged that align with the quantitative findings. The first theme was the ‘influence of the pain experience.’ As mentioned above, the patients who reported pain or fatigue increasing due to the OT session were less than 30%. Some comments reflected this, but qualified it by indicating that it was beneficial or “well worth it.” One caregiver comment summed up this theme “although some pain was experienced, we think it was beneficial. It let us know we have choices of doing things

instead of being confined to a bed.” However with over 70% reporting that pain and fatigue were not increased, it is not surprising that patients commented “energized” and another patient reported “very much enjoyed hearing about home solutions to practical some of the ways to get out of bed, sit, walk, get up and down has reduced pain a lot.” A caregiver wrote “helped my daughter with getting out of bed and back in bed with no pain.”

The second theme was ‘return to meaningful activities’. Visiting the beauty/barbershop was important to “Mrs. B,” so the physician asked if the PI could prioritize her treatment because she required skilled intervention for transfers and was medically fragile. This patient later explained her urgency by stating that “this will be my last haircut before people see me at my funeral.” Mrs. B’s comment suggests deep emotional and existential thoughts were experienced while participating in this meaningful activity which could have also contributed to the high satisfaction rate given by the patients and caregivers. The previous comments about practical education along with strategies to reduce pain and fatigue during activities may give some insight about why 100% of the patients indicated that OT was beneficial or “worth it.” Here are some patient comments about the OT session:

- “As a cancer patient it enhanced my outlook on life in general.”
- “It gave me hope for a better life.”
- “It was good for my brain, good for my mental and physical state to get out of the room and see outside world and see clouds and get a smoothie.”

- “..personable way of explaining things that helped me see how they apply to me. Excellent sessions.”
- “Was the most enjoyable day since being admitted to the hospital. Very helpful and enjoyable.”

Caregivers also commented on the less tangible benefits of OT:

- “Enjoyed doing “normal” activities. Important to focus on living instead of cancer.”
- “Got suggestions based on her interest for activities to enjoy her time she had considered.”
- “...helpful and gave my mother the support she needed to be able to feel like herself again.”

When discussing and discerning why the patients and caregivers may have quantitatively rated the OT sessions as beneficial, it is also important to compare and contrast the qualitative data that was provided to explore reasons for their high satisfaction rate.

The above comments were anonymous; however, one married couple chose to write the activity in which the patient participated. Their willingness to disclose their comments allowed more insight and explanation about why this session appeared to be so significant to the couple. “Mrs. D” had a negative experience by becoming short of breath while transferring out of bed before transferring to the PCU. Because she reported that she never wanted to feel that way again, she had chosen to remain in bed. “Mrs. D’s” choice was to restrict herself to “bed-rest” which she later commented would have been her “death bed.” This comfort zone had become the barrier that kept her from resuming

roles and routines important to her and her husband. An introduction to occupational therapist's role on the PCU was provided along with strategies for pursed lip breathing and positioning. A pulse oxygen sensor is not always used for this patient population, however it was a useful tool to help increase her confidence in her newly discovered breathing techniques (SpO2 always remained above 95%). With the above education and confidence "Mrs. D." agreed to attempt bed mobility and sitting at the edge of bed. She demonstrated this with modified independence along with cues for not holding her breath. With renewed confidence she agreed to attempt standing which she did at the same level of independence. "Mrs. D." reported being happy with this success and wanted to repeat the sit to stand transfer several times. However it was remembered that when we were exploring activities of interest, "Mrs. D." had mentioned that she liked to dance with her husband. The patient was reminded of this and she then disclosed which song she enjoyed most dancing to and was asked if she would like to attempt a slow dance with her husband. This appeared to startle them both, since she had already taken such a big step just to stand again; however, a secondary goal from this activity would be that they both would become more comfortable with working as a team with cues for breathing and getting out of bed in the future. A smart phone was used to play their favorite song as they slow danced together with her husband reminding her to breathe and eventually the patient began leaning her head on her husband's shoulder with confidence and peace. The couple's own words are testimony to the value of occupational therapy. The husband's commented: "learned new ways to cope, the dancing was awesome! Thanks to OT. Awesome job." The patient's comments were "OT made me feel good

having my husband dance with me. I felt the spiritual closeness between us.” Corr’s (2007, p. 112) following statement supports holistic interventions such as this “the key point was refocusing attention on patients as persons. Not just on their diseases and not merely on what could or could not be done for them or on what resources were or were not available at the time. But on these people as vital human beings in all their physical, psychological, social, and spiritual dimensions.”

The comments that the patients and caregivers wrote down provide insight on why the quantitative data indicated that 100% perceived that the occupational therapy session was beneficial. However, many verbal comments and acts of appreciation were not included in this qualitative description, but hopefully will be remembered by all participants. For a complete list of the activities participated in, please refer to in Appendix F and Appendix G.

CHAPTER VI

DISCUSSION AND CONCLUSION

This chapter provides a discussion of the mixed quantitative and qualitative data that emerged from the survey. It also provides observations and perspectives discovered during this research study, and concludes with a discussion of limitations, implications for practice, and directions for future research.

Discussion of Mixed Methods Data

Question #4 provides an interesting comparison of quantitative data with the qualitative data. A greater proportion of caregivers agreed strongly that the education of “equipment, adaptations and/or strategies” were beneficial. The quantitative data comparison was 70.4% caregivers agreed strongly, compared to 48.1% of patients. Patients split their responses evenly between “Agree Strongly” and “Agree.” When transitioning from the hospital’s care and planning for what will be needed for home hospice, it is understandable why caregivers tend to be overwhelmed and concerned about being the primary caregiver. During this study, primary caregivers usually asked more questions about equipment use and options. Primary caregivers also asked for more education on transfer training from bed to the bedside commode or wheelchair since they will be the ones assisting the patient at home as the patient’s function declines. Caregiver comments reflecting this are: “simply make things easier for me to take care of my mother,” and “many practical pointers that addressed our

situation. From my perspective, he has been a highlight of our time on this floor.” These comments and the high value that caregivers gave for family education indicates why it is important for OTs to include family with as much training as possible so that caregivers may feel confident in considering discharging home with hospice as an achievable option and goal. The interest in education noted in this study by caregivers and lack of education prior to the occupational therapy session is supported in the nursing literature. “A review of the literature found that society depends on family caregivers to continue providing care for their loved ones, but does little to teach them how to do it and support them in this stressful work” (Reinhard, Given, & Bemis, 2008).

As mentioned earlier in Chapter IV, there were only two questions which produced responses other than “Agree Strongly,” or “Agree.” Question #8 asked if the session caused more pain and 13 out of 48 surveys (27%) indicated that pain was increased. This left the remaining 73% responding that the OT session did not cause more pain. Question #9 was the other question that produced answers of “Neutral,” “Disagree,” or “Disagree Strongly.” Patient and caregiver responses again did not differ significantly and revealed that 14 out of 48 surveys (29%) indicated that fatigue was increased. This left the remaining 71% responding that the OT session did not cause more fatigue.

Qualitative data referring to these questions included the caregiver comment “although some pain was experienced, we think it was beneficial. It let us know we have choices of doing things instead of being confined to a bed.” In contrast, one patient commented “energized” and another patient reported “very much enjoyed hearing about home solutions to practical some of the ways to get out of bed, sit, walk, get up and down

has reduced pain a lot.” A caregiver wrote “helped my daughter with getting out of bed and back in bed with no pain.”

One of the reasons that patients may have quantitatively reported that the session was worth it and qualitatively reported that activity made them feel “energized” is that each occupational therapy session was focused on the client’s individual needs and activity goals. Client centered care was important because if the goal was to facilitate function, participation and performance, it was important to know what the client’s priorities were. Occupational therapists understand that a person who is intrinsically motivated to participate in an activity can often gather the needed reserves of energy in order to accomplish a highly valued task , when compared to performing activities which are not viewed by the patient as being meaningful (Yoder, Nelson, & Smith, 1989). A foundational concept for this is that “occupational therapy can increase the awareness that some activities may be more beneficial than others, because there is a significant difference between just being active, and “...actively doing things that are personally meaningful and purposeful, in other words, through occupation” (Nelson, 1997, p. 11). Having choices about participating in an activity that is meaningful is important with any population; however, it is apparent from the comments of the patients and caregivers in this study that it may be even more critical for patients on palliative care to have a choice in their activities due to their limited time and activity tolerance as they approach the end of their lives. This was recently supported with the following statement: “Occupational therapists recognise that personal growth and development can occur even in the last

phase of life and that participation in occupation can be transformational especially for those approaching the end of life” (WFOT, 2016).

When exploring which activities a patient reports are most meaningful, it may be best to keep the discussion informal and conversational where the patient may feel more relaxed while exploring which factors are inhibiting the performance of the patient’s activity goals. One surprise during this process was a patient who was planning her own funeral and mentioned that she had not been able to listen to her son’s favorite song played at his funeral. The PI asked her if with planning her own funeral, she felt comfortable listening to his favorite song again. She emphatically replied “you know, I think I want to since I will be seeing him again soon!” The PI found the song on his smart phone, with the lyrics, and she belted out the chorus with visible emotion. She reported that “I should have done that a long time ago, but no one asked.”

An interesting observation was time of admission on the PCU unit and length of time to death; date of death was found in the electronic medical record. If the patient died on the Palliative Care Unit (PCU), then a date of death was listed; however, if the patient was under hospice care, the date of death was not always listed in the medical record at this facility. During this study, for the patients that had a date of death listed, the patients lived from 5 to 66 days after the completion of the survey form. This range is important to keep in mind because although the patient may be approaching the end of life, it is not always clear how long a person may live once he/she is admitted to the PCU. Although “Mr. M.’s” responses were anonymous, his date of admission, date survey completed, and his date of discharge are known. “Mr. M.” was a patient mentioned in the last

chapter. He was admitted requiring a 100% high flow oxygen and did not appear to have long to live; however, he was able to complete the survey 8 days later as he prepared to be discharged home. In contrast, “Mrs. N.” was admitted to the unit requiring only minimal assistance to transfer out of bed to a wheelchair. “Mrs. N.” had not been out of bed recently, but tolerated community reintegration to the 24th floor with her son learning how he may get her out of the room by himself in the future. They were both very pleased with her new level of independence with plans to leave the room every day to locations introduced by OT. This, however, would be her last time out of the room due to a rapid decline in function; she died less than 5 days after this outing and survey. During this study there were several occupational therapy sessions that had to be timed during a short window of opportunity. Some patients performed better when they first arrived on the unit, while others required more control of their symptoms first. This timing requires regular monitoring by the occupational therapist to determine when or if a patient can tolerate an occupational therapy session.

Limitations

Limitations of this study include that the sample is from a cancer institute that has an inpatient palliative care unit. All of the patients have a cancer diagnosis and MD Anderson has the only inpatient unit dedicated to palliative care in the Texas Medical Center. It had been suggested that a limitation could be that an occupational therapist or other investigator was not in the room when the surveys were completed. This was necessary in order to keep the occupational therapist blind to the individual responses; however, it is not known how much the caregiver assisted the patient with the completion

of each survey. Participants and caregivers may have also not wanted to write down any negative responses even though it was clearly stated during consent process that the responses would be anonymous. This may be due to “positive satisfaction” also known as “positive skew” when respondents tend to give positive answers when answering questions on satisfaction levels on health surveys (Aday, 1996; Choi & Pak, 2005).

Future Research

Another limitation with this study was that only 27 patients and 21 caregivers completed the survey. Because of this, a direction for future research would be to increase the sample size. Other patient populations also could be considered for future study including inpatient hospice patients, home hospice patients and terminally ill patients who do not have a diagnosis of cancer.

Conclusion

As stated earlier, the purpose of this dissertation was to explore the perceptions of patients and their caregivers on an oncology palliative care unit to determine whether occupational therapy was beneficial or not. The primary objective of this study was to estimate the satisfaction rate which is defined as the percentage of patients and caregivers that answered “Agree Strongly” or “Agree” to the question, “This inpatient occupational therapy session was beneficial” to me/the patient. All 48 surveys indicated that the occupational therapy session was perceived to be beneficial. A secondary objective or research question was to estimate the satisfaction rate which is defined as the percentage of patient and caregivers that answered “Agree Strongly” or “Agree” to the question, “Overall, participating in this activity today was worth it.” Again all of the 48 surveys

indicated that the occupational therapy session was “worth it.” This was despite almost 30% of the surveys indicating that the activity increased pain and/or fatigue.

Many physicians do not order occupational therapy for patients facing the end of life and this may be due to concerns that the sessions may increase pain or fatigue. This study provided the quantitative and qualitative data to indicate that patients and caregivers perceived participation with occupational therapy was beneficial and worth it. Who better to address this concern than the perceptions of the patient and caregiver who just participated in an occupational therapy session? An important implication of this study is that physicians may now be more comfortable ordering occupational therapy for their patients facing the end of life if palliative patients themselves reported quantitatively and qualitatively that occupational therapy was beneficial. With this beginning of research supporting the inclusion of occupational therapy as a part of end of life care, it is hoped that each patient may at least be given the opportunity to decide for themselves if he or she wishes to participate with occupational therapy or not. An occupational therapy order may give each patient more options and control over his or her own quality of life. Another practice implication would also support having an occupational therapist be a part of the palliative care team. This clinical implication was recently supported with the following: “Regardless of clients’ life expectancy, occupational therapists provide a unique service that enable function, comfort, safety, autonomy, dignity and social participation through engagement in occupation” (WFOT, 2016, p. 1).

Personal Reflection

When I began working at MD Anderson over 12 years ago, occupational therapists were not usually treating patients on the Palliative Care Unit. I wanted to change this because I observed that the patients reported feeling better with symptom control, but appeared to be occupationally deprived. I remember thinking that the palliative patients were not dead yet, so why not live a little more. I felt as though I were alone inventing the wheel as I learned from every positive and negative patient interaction. However, I did not realize until the internet developed more fully and I began the literature review for this research study that there were many fine occupational therapists around the world trying to find their own way with this underserved patient population. As I became more comfortable working with patients facing the end of life, I witnessed many life changing experiences that would not have been possible without occupational therapy. However, these qualitative data were considered only anecdotal by the physicians I spoke to without the quantitative data to back it up. Research was needed to reveal whether the interventions were truly beneficial or not using quantitative as well as qualitative data. I have been humbled during the dissertation process and now realize how much I need the help of others and how much I was not aware of. Upon reflection, I now understand the value of proactively searching the literature regularly for emerging best practice and clinical protocols with every patient population that I serve. I also have a renewed motivation to continue researching questions and concerns that occur in my clinical practice and publishing these research findings for the remainder of my

career. In this way, I will be paving the way for current and future clinicians who may feel alone and overwhelmed when they begin treating an unfamiliar patient population.

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APPENDIX A

Sample of Patient and Caregiver Informed Consent

SAMPLE ONLY:



Please Do Not Use for Patient Consent

**Go to the PDOL Homepage to access the
Informed Consent Printer Database**

Consent Revision Date: 06/25/2015

**INFORMED CONSENT/AUTHORIZATION FOR
PARTICIPATION IN RESEARCH**

Is Inpatient Occupational Therapy Perceived to be
Beneficial by the Palliative Patient and Caregiver?
2015-0350

Subtitle: Patient Consent

Study Chair: Paul W. Walker

1

Participant's Name

Medical Record Number or Study
ID

You are being asked to take part in this [psychosocial](#) research study at The University of Texas MD Anderson Cancer Center ("MD Anderson"). This consent and authorization form explains why this research study is being done and what your role will be if you choose to take part. This form also describes the possible risks connected with being in this study. After reviewing this information with the person responsible for your enrollment, you should know enough to be able to make an informed decision on whether you want to take part in the study.

You are being asked to take part in this study because you have cancer and are planning to receive inpatient occupational therapy.

2. PURPOSE OF STUDY

The goal of this research study is to learn if inpatient occupational therapy can help patients in the Palliative Care Unit (PCU).

3. DESCRIPTION OF STUDY

If you agree to take part in this study, you will complete a questionnaire about your opinion of the inpatient occupational therapy session you just had. The questionnaire should take about 10 minutes to complete. You will be left alone in the room to complete the questionnaire.

Length of Study

You participation on this study will be over after you complete the questionnaire.

This is an investigational study. There will be no cost to you for taking part in this study.

50 patients and up to 50 caregivers will take part in this study. All will be enrolled at MD Anderson.

4. RISKS, SIDE EFFECTS, AND DISCOMFORTS TO PARTICIPANTS

You should discuss the risks of **questionnaires** with the study chair. The known risks are listed in this form, but they will vary from person to person. Some questions may make you feel upset or uncomfortable. You may refuse to answer any question. If you have concerns after completing the questionnaires, you are encouraged to contact your doctor or the study chair.

This study may involve unpredictable risks to the participants.

5. POTENTIAL BENEFITS

Future patients may benefit from what is learned. There **are** no benefits for you in this study.

6. ALTERNATIVE PROCEDURES OR TREATMENTS

You may choose not to take part in this study.

Additional Information

7. You may ask the study chair any questions you have about this study. You may contact the study chair, Dr. Paul W. Walker, at 713-792-6085. You may also contact the Chair of MD Anderson's Institutional Review Board (IRB - a committee that reviews research studies) at 713-792-2933 with any questions that have to do with this study or your rights as a study participant.
8. Your participation in this research study is strictly voluntary. You may choose not to take part in this study without any penalty or loss of benefits to which you are otherwise entitled. You may also withdraw from participation in this study at any time without any penalty or loss of benefits. If you withdraw from this study, you can still choose to be treated at MD Anderson.
9. This study or your participation in it may be changed or stopped at any time by the study chair, or the IRB of MD Anderson.
10. You will be informed of any new findings that might affect your willingness to continue taking part in the study.
11. MD Anderson may benefit from your participation and/or what is learned in this study.

STUDY COSTS AND COMPENSATION

If you suffer injury as a direct result of taking part in this study, MD Anderson health providers will provide medical care. However, this medical care will be billed to your insurance provider or you in the ordinary manner. You will not be reimbursed for expenses or compensated financially by MD Anderson for this injury. You may also contact the Chair of MD Anderson's IRB at 713-792-2933 with questions about study-related injuries. By signing this consent form, you are not giving up any of your legal rights.

Unless otherwise stated in this consent form, all of the costs linked with this study, which are not covered by other payers (health maintenance organization [HMO], health insurance company, etc.), will be your responsibility.

There are no plans to compensate you for any patents or discoveries that may result from your participation in this research.

You will receive no compensation for taking part in this study.

Authorization for Use and Disclosure of Protected Health Information:

- A. During the course of this study, the research team at MD Anderson will be collecting information about you that they may share with the parties named in Section D below.

- B. Signing this consent and authorization form is optional. However, if you refuse to provide authorization to use and disclose your protected health information for this study, you will not be able to participate in this research study.

C. MD Anderson will take appropriate steps to keep your protected health information private when possible, and it will be protected according to state and federal law. However, there is no guarantee that your information will remain confidential, and it may be re-disclosed at some point. Federal agencies (such as the Office for Human Research Protections [OHRP – a regulatory agency that oversees research in humans]), the study sponsor, and the IRB of MD Anderson might view or receive your record in order to collect data and/or meet legal, ethical, research, and safety-related obligations. In some situations, health authorities could be required to reveal the names of participants.

D. Your study information may be shared with the following parties:

- The OHRP
- The IRB of MD Anderson
- Officials of MD Anderson
- Study monitors who verify the accuracy of the information
- Individuals who put all the study information together in report form

E. There is no expiration date for the use of your information as stated in this authorization. You may withdraw your authorization to share your protected health information at any time in writing. Instructions on how to do this can be found in the MD Anderson Notice of Privacy Practices (NPP). You may contact the IRB Staff at 713-792-2933 with questions about how to find the NPP. If you withdraw your authorization, you will be removed from the study and the study chair and staff will no longer use or disclose your protected health information in connection with this study, unless the study chair or staff needs to use or disclose some of your research-related protected health information to preserve the scientific value of the study. Data collected about you up to the time you withdrew will be used and included in the data analysis. The parties listed in Section D above may use and disclose any study data that were collected before you canceled your authorization.

- F. A description of this clinical trial will be available on <http://www.ClinicalTrials.gov>, as required by U.S. Law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

Please Do Not Use for Patient Consent

**Go to the PDOL Homepage to access the
Informed Consent Printer Database
CONSENT/AUTHORIZATION**

I understand the information in this consent form. I have had a chance to read the consent form for this study, or have had it read to me. I have had a chance to think about it, ask questions, and talk about it with others as needed. I give the study chair permission to enroll me on this study. By signing this consent form, I am not giving up any of my legal rights. I will be given a signed copy of this consent document.

SAMPLE -- NOT FOR USE IN CONSENTING PATIENTS

SIGNATURE OF PARTICIPANT

DATE

LEGALLY AUTHORIZED REPRESENTATIVE (LAR)

The following signature line should only be filled out when the participant does not have the capacity to legally consent to take part in the study and/or sign this document on his or her own behalf.

SAMPLE -- NOT FOR USE IN CONSENTING PATIENTS

SIGNATURE OF LAR

DATE

SAMPLE -- NOT FOR USE IN CONSENTING PATIENTS

RELATIONSHIP TO PARTICIPANT

WITNESS TO CONSENT

I was present during the explanation of the research to be performed under Protocol **2015-0350**.

SAMPLE -- NOT FOR USE IN CONSENTING PATIENTS

SIGNATURE OF WITNESS TO THE VERBAL CONSENT
PRESENTATION (OTHER THAN PHYSICIAN OR STUDY
CHAIR)

DATE

A witness signature is only required for vulnerable adult participants. If witnessing the assent of a pediatric participant, leave this line blank and sign on the witness to assent page instead.

PERSON OBTAINING CONSENT

I have discussed this psychosocial research study with the participant and/or his or her authorized representative, using language that is understandable and appropriate. I believe that I have fully informed this participant of the nature of this study and its possible benefits and risks and that the participant understood this explanation.

SAMPLE -- NOT FOR USE IN CONSENTING PATIENTS

SIGNATURE OF STUDY CHAIR
OR PERSON AUTHORIZED TO OBTAIN CONSENT

DATE

APPENDIX B

Patient/Participant Satisfaction Survey

Date _____

Participant Satisfaction Survey

Instructions: Please rate your degree of satisfaction with each of the following (check only one for each statement. If you make a mistake or change your mind, place an X through the wrong answer and mark the circle indicating your correct answer. When you completed, please place participant and/or participant and caregiver surveys in the envelope, seal it, and place in the locked box.

1. This occupational therapy session was beneficial to me.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

2. I would recommend to other patients with similar cancer challenges participation in an occupational therapy session.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

3. I enjoyed exploring which activities were possible for me to perform.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

4. This session helped me to discover the equipment, adaptations and/or strategies that may be helpful to me in future activities.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

5. This session increased my ability to manage and control symptoms.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

6. This session helped me understand that I can participate in more activities that are meaningful to me.

☐
Agree
Strongly

☐
Agree

☐
Neutral

☐
Disagree

☐
Disagree
Strongly

7. This session helped me feel like I can enjoy each day more.

☐
Agree
Strongly

☐
Agree

☐
Neutral

☐
Disagree

☐
Disagree
Strongly

8. This session caused me to have more pain.

☐
Agree
Strongly

☐
Agree

☐
Neutral

☐
Disagree

☐
Disagree
Strongly

9. This session caused me to feel more fatigued.

☐
Agree
Strongly

☐
Agree

☐
Neutral

☐
Disagree

☐
Disagree
Strongly

10. Overall, participating in this activity today was worth it.

☐
Agree
Strongly

☐
Agree

☐
Neutral

☐
Disagree

☐
Disagree
Strongly

Please explain:

APPENDIX C

Caregiver Satisfaction Survey

Date _____

Caregiver Satisfaction Survey

Instructions: Please rate your degree of satisfaction with each of the following (check only one for each statement. If you make a mistake or change your mind, place an X through the wrong answer and mark the circle indicating your correct answer. When you completed, please place participant and/or participant and caregiver surveys in the envelope, seal it, and place in the locked box.

1. This occupational therapy session was beneficial to the patient.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

2. I would recommend to other patients with similar cancer challenges participation in an occupational therapy session.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

3. The patient appeared to enjoy exploring which activities were possible for him/her to perform.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

4. This session helped the patient discover the equipment, adaptations and/or strategies that may be helpful to him/her in future activities.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

5. This session appeared to increase that patient's control over symptoms.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

- 6. This session appears to help the patient participate more in activities that are meaningful to him/her.**

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

- 7. This session appears to increase the patient's awareness of more ways to enjoy each day.**

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

- 8. This session appeared to increase the patient's pain.**

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

- 9. This session appeared to increase the patient's fatigue.**

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

- 10. Overall, participating in this activity appears to be worth it for the person I care for.**

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

Please explain: _____

APPENDIX D

Patient Demographic Data and Participation Log

Patient Demographic Data and Participation Log

Patient's Medical Record Number : _____ Patient's Accession Number : _____

Date of OT session: _____ Time of OT session : _____

Gender: ☐ Female ☐ Male Date of birth: _____

Ethnicity :

☐ American Indian/Native American ☐ Asian/Pacific Islander ☐ Black (African American)
☐ Hispanic ☐ White ☐ Other _____

Marital status:

☐ Single ☐ Married ☐ Widowed ☐ Divorced ☐ Separated ☐ Other: _____

Religious preference:

☐ Buddhist ☐ Catholic ☐ Christian/Protestant ☐ Jewish ☐ Hindu ☐ Muslim ☐ Other

Highest Educational Level Completed :

☐ Less than 8th grade ☐ Vocational/technical school ☐ Advanced Degree
☐ 9th – 11th grade ☐ Associate degree/some college ☐ Others
☐ High School ☐ Bachelor's Degree

Cancer diagnosis: _____ Stage of Cancer : ____ Local ____ Advanced/Metastatic

ECOG performance status before today's OT session : 0 1 2 3 4 5

ESAS scores : Pain __, Fatg __, Nau __, Depr __, Anx __, Drw __, Ap __, Wb __, Dysp __, Slp __, Fin __, Spir __,

Was the patient MDAS score ≤ 8 upon admission to the PCU ? Yes / No

If not, what was the MDAS score gathered today ? _____

Activity chosen by the patient : _____

Category of the activity : _____ ADL _____ IADL _____ Leisure

Environment or settings for this activity : _____

Was a family member or visitor present during the OT session ? Yes / No

Does this visitor qualify as an eligible primary caregiver ? Yes / No

If yes, complete the data for the primary caregiver below.

Relationship to patient : _____ Age : _____ Gender : Male / Female

Ethnicity :

☐ American Indian/Native American ☐ Asian/Pacific Islander ☐ Black (African American)
☐ Hispanic ☐ White ☐ Other _____

Signature of OT/investigator : _____ Date : _____

APPENDIX E

Activities Chosen by Patients

ACTIVITY CHOSEN
24th floor, butterfly garden, library and out of the room for the first time since admission
Attempt walking steps in preparation for returning home with 5 levels and outing to 24th floor with husband
First outing in 5 days first time to 24th floor observation area with 4 generations of females, also bought and drank Starbucks "fancy" favorite coffee
Go outside for the first time in several weeks and he enjoyed the variety of flowers some of which are in his garden at home
go outside to the butterfly garden and fountain with son and grandchildren before discharging tomorrow with home hospice
Go to 24th floor & outside garden with family on her 27th anniversary
going outside to sit in the sunshine
going to the gift shop & buying something for herself
Out of bed and in wheel chair to 24th floor observation deck with family
OUTING WITH FAMILY TO 24TH FLOOR OBSERVATION AREA AND PARK AREA
Planning for meaningful activities at home tomorrow and "listened to the song played at my son's funeral that i have not been able to bear listening to until this moment"
planning for returning home with hospice, reclining back wheelchair and tub bench use& planning his funeral
Preparing to ride home in personal car & ADL dressing, transfers, talking & washed hands
Pursed lip breathing training while slow dancing with her husband to their favorite song
sit up in chair and eat breakfast with wife
Sitting at the edge of bed for first time in over 10 days then self feeding
sitting on a toilet for the first time in over a week and having a productive BM
Take her first shower since admission&community reintegraion after weaning from optiflow today going to observation deck &then outside to the butterfly garden with husband and 11 y/o daughter
to get out of bed to a wheelchair & BSC(10 days since last attempt) and outside to the butterfly garden (4 weeks since last being outside)
To get out of the room for the first time in 2 weeks and visit staff and patients on the pediatric unit where her grandson has received treatment for 3 years
to go outside for the first time since admission

TO USE A UNIVERSAL CUFF TO HOLD PEN AND WRITE QUOTE IN
ENGLISH AND PERSIAN

Trail of reclining back wheelchair up to 24th floor

Transfer training so wife can perform at home and integration up to 24th floor
observation

visiting the observation deck and Starbucks in the park

was on 43 LPM Optiflow now 15LPM non breather so able to go outside of his
room for the first time in 2 weeks outside garden & 24th floor

APPENDIX F

Patient Comments

OT with Palliative Care DATA [Read-Only] - Microsoft Excel

File Home Insert Page Layout Formulas Data Review View PDF Workbook Views

Normal Layout Preview Custom Full Views Screen

Show Ruler Gridlines Headings Formula Bar Zoom 100%

Window Split Hide Arrange Freeze New Window All Pans Unhide Synchronous Scrolling Reset Window Position Save Switch Workspace Windows Macros

Count: 20 OneDrive 3:47 PM 8/30/2016

	A	B	C	D	E	F	G
1	Patient Comments						
2	No comments (9 patients)						
3	Although I experienced pain, it was informative and useful						
4	As a cancer patient it enhanced my outlook on life in general						
5	Caused slightly more pain but overall was well worth it!						
6	Energized						
7	Exertion was beneficial to me						
8	I got to go out and enjoy fresh air and got to push my limit						
9	I was glad to get out of room						
10	It gave me hope for a better life						
11	it was good for my brain, good for my mental and physical state to get out of my room and see outside world and see clouds and get a smoothie. While causing small increases in immediate discomfort such as fatigue or pain. This activity actually provided insight knowledge and hope for my long term care and quality of life plans. Thanks!						
12	It was great getting out of the room and visiting some friends that work in the hospital. Mack and Jerry were very friendly and accommodating						
13	Mack has a personable way of explaining things that helped me see how they apply to me. Excellent sessions						
14	Mack is a great OT. His visits were very beneficial to me						
15	OT made me feel good having my husband dance with me. I felt the spiritual closeness between us						
16	Re #9 - I would disagree strongly except I felt little change Re #4. Very much enjoyed hearing about home solutions to practical probs. Re#8 - I actually felt less pain following session.						
17	some of the ways to get out of bed, sit, walk, get up and down has reduced pain a lot						
18	Thank you Mack for all your help!						
19	this has been very helpful. I feel much more relaxed and happy						
20	Was the most enjoyable day since being admitted to the hosp. Very Helpful and enjoyable						
21							
22							
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36							
37							

Ready Survey_2015-0350combined Activity Chosen Patient Comments Caregiver Comments CORE DataSet

Search the web and Windows

APPENDIX G

Caregiver Comments

Caregiver Comments

No Comment (8 caregivers)

Although some pain was experienced, we think it was beneficial. It let us know we have choices of doing things instead of being confined to a bed

Enjoyed doing "normal" activities. Important to focus on living life instead of cancer

Explored so many new activities he can experience through

Got suggestions based on her interests for activities to enjoy her time she had considered. Discussed foods she can tolerate & questions to ask about hospice

helped my husband mentally and physically

Learned new ways to cope, the dancing was awesome! Thanks to OT. Awesome job

Mack did a great job and trip to 24th floor was good for Brooke's mental attitude

MACK IVY MADE THIS 82 YEAR OLD PATIENTS DAY. HE HAS GREAT COMPASSION AND UNDERSTANDING OF PEOPLE HE HELPS SO MUCH.

Mack was great, sincere and genuine. It was very nice to see the hospital offer such nice services. A++

Mack was professional & courteous. Explained things clearly & precisely & had a wonderful demeanor. Mom seemed to enjoy the stroll around the building & getting out of bed

Mack was so helpful in very small way to simply make things easier for me to take care of my mother and help my mother.

Mack was very helpful and gave my mother the support she needed to be able to feel like herself again. He did a great job!

Mr. Mack really helped my daughter with getting out of bed and back in bed with no pain

Mr. Mack was very kind and considerate in helping my wife, daughter-Katie, and me enjoy the day away from her room. Again, thank you so much for all you did for us!

New surrounding, fresh air, positive attitude. Great for the patient

The OT is the best I have ever met. Very positive person which gave us a very positive out look in my husband's performance. We have spend lot of time talking about how blessed we are to have an OT. So professional & positive. Thank you

The transfer training is helpful

Therapist is extremely personable, encouraging, polite, knowledgeable, practical, kind. He gave pt many practical pointers that addressed our situation. From my perspective, he has been a highlight of our time on this floor.

THESE ACTIVITIES IMPROVE THE PATIENT'S EMOTION AS WELL

APPENDIX H

University of Texas MD Anderson Internal Review Board (IRB) Approval

THE UNIVERSITY OF TEXAS
MD Anderson
Cancer Center
Office of Protocol Research

Institutional Review Board (IRB)
Unit 1637
Phone 713-792-2933
Fax 713-794-4589

To: Paul W. Walker 07/14/2015
From: David A. Kennedy
CC: Julio A. Allo, Susan Frisbee-Hume, Vera J. DeLaCruz, OPR Protocol Activations
MDACC Protocol ID #: 2015-0350
Protocol Title: Is Inpatient Occupational Therapy Perceived to be Beneficial by the
Palliative Patient and Caregiver?
Version: 02
Subject: Contingencies Met - Protocol 2015-0350

Official IRB Approval Date: 06/12/2015

On 07/14/2015 the Institutional Review Board 4 committee, chair, or designee granted approval to the above named and numbered protocol since the contingencies outlined by the IRB 4 on 06/12/2015 have been met.

It was noted that the protocol, informed consent documents (ICDs) and/or the Waivers of ICD and Authorization are satisfactory and in compliance with federal and institutional guidelines. No participants may be entered on this protocol until it has been officially activated by OPR.

In keeping with the requirements outlined in 45CFR46.109(e) and 21 CFR56.109(f), the IRB shall conduct continuing review of all protocols at intervals appropriate to the degree of risk, but not less than once per year.

You are responsible for promptly reporting to the IRB:

- any severe adverse events;
- any death while patient is on study;
- any unanticipated problems involving risks to subjects or others;
- any proposed changes in the research activity (changes may not be initiated without IRB review and approval, except where necessary to eliminate apparent immediate hazards to the subjects).

The IRB expiration date for this protocol is 6/12/2016

To activate this study, please compose and send a "Request for Activation" memo in PDOL.

The existing Informed Consent and/or Waivers of Informed Consent and Authorization cannot be used until the protocol is Activated.

If a Material Transfer Agreement (MTA) is required, it must be obtained prior to Activation.

In the event of any questions or concerns, please contact the sender of this message at (713) 792-2933.

David A. Kennedy 07/14/2015 03:51:26 PM

This is a representation of an electronic record that was signed and dated electronically and this page is the manifestation of the electronic signature and date:

**David A. Kennedy
07/14/2015 03:46:46 PM
IRB 4 Chair Designee
FWA #: 00000363
OHRP IRB Registration Number: IRB 4 IRB00005015**