

Improving quality of life through rehabilitation in palliative care: Case report

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ABSTRACT

Objective: Occupational and physical therapists can have a significant impact on the quality of life of terminally ill cancer patients. In the critical care setting, rehabilitation is often overlooked. However, occupational and physical therapists work with critically-ill patients to create realistic and meaningful goals for improving comfort, mobility, socialization skills, and ability to care for oneself regardless of disease state and medical status. The following case report describes rehabilitation intervention with a young woman diagnosed with osteosarcoma and leukemia during the final stage of her life.

Method: This case report highlights the use of patient-centered goals and the importance of close collaboration between the patient, occupational therapist, and physical therapists to achieve a higher quality of life.

Results: A collaborative effort by the occupational and physical therapists yielded positive outcomes as defined by the patient, patient family, and the medical staff in the critical care setting.

Significance of results: Palliative care patients may benefit from occupational therapy (OT) and physical therapy (PT) intervention. Rehabilitation specialists are skilled at working with patients to set realistic and meaningful functional goals. Further study on rehabilitation treatment to improve quality of life among patients in palliative care is needed.

KEYWORDS: Rehabilitation, Quality of life, Cancer, Palliative care, Goals

INTRODUCTION

According to the National Cancer Institute (2009), one to two children of every 10,000 are diagnosed with cancer each year in the United States. Cancer is considered rare in childhood, but rehabilitation professionals must be aware of the psychosocial aspects of working with these patients, especially during the last weeks and months of life.

Osteosarcoma is a relatively rare type of cancer that develops in the long bones of the body. It ac-

counts for ~5% of childhood tumors. Approximately 900 new cases of osteosarcoma are diagnosed in the United States annually. The risk for developing this type of cancer is highest during the adolescent growth spurt, which suggests that there is a correlation between rapid bone growth and tumor formation (Gurney et al., 1999). According to the National Cancer Institute, >50% of these tumors arise from the bones around the knee (Osteosarcoma and malignant fibrous histiocytoma of bone [PDQ®], 2009). The overall survival rate for osteosarcoma is ~7 years (Lewis & Gloeckler Ries, 2007).

According to recent research, a combination of surgery and chemotherapy represents the most common and effective treatment for osteosarcoma

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(Osteosarcoma and malignant fibrous histiocytoma of bone [PDQ®], 2009). Depending upon the extent of tumor involvement as well as consultation with the patient and family, surgeons choose to perform either a limb-sparing procedure or a more invasive surgery such as an amputation, to resect the primary tumor. More than 80% of patients with localized tumors are able to undergo a limb-sparing procedure (Osteosarcoma and malignant fibrous histiocytoma of bone [PDQ®], 2009). Pakos et al. (2009) found that those patients who had amputations had a poorer prognosis than those who underwent limb-sparing procedures, because of the initial extent of disease involvement. Most patients receive neoadjuvant chemotherapy prior to surgery and more extensive adjuvant chemotherapy following surgery to ensure maximal tumor eradication. The most commonly used chemotherapy drugs for the treatment of osteosarcoma are high-dose methotrexate, doxorubicin, and cisplatin. Radiation is occasionally used following surgery if clean margins are not achieved. Radiation can also be used to control local symptoms such as pain and swelling if the cancer has recurred or if surgery is not an option because of the tumor location (Osteosarcoma and malignant fibrous histiocytoma of bone [PDQ®], 2009; Lewis & Gloeckler Ries, 2007).

The risk of developing a second malignant neoplasm in childhood cancer survivors is three to twenty times greater than that of the general population (Inskip et al., 2006). One of the most commonly reported secondary malignancies is acute myeloid leukemia (AML), or acute nonlymphocytic leukemia, a malignancy of the myeloid line of stem cells. These cells are responsible for the formation of red blood cells, platelets, and white blood cells (other than lymphocytes). In patients with AML, an abnormally high number of immature myeloid cells are present in the bloodstream (American Cancer Society, 2009).

Treatment for AML usually occurs in two phases. The first phase, induction, aims to achieve remission through the administration of a combination of chemotherapy drugs, including cytarabine, daunorubicin, mitoxantrone, fludarabine, vincristine and etoposide. Once the child achieves remission, the second phase of treatment, post-treatment consolidation or intensification, begins. This phase includes further combinations of chemotherapy and/or stem cell transplantation (Smith et al., 1999). Stem cell transplantation is a method of replacing the blood-forming cells that were destroyed by high-dose chemotherapy in order to achieve continued production of normal, healthy blood cells. The replacement cells can either be harvested from the patient (autologous) or from a donor (allogeneic). Graft-versus-host-disease (GVHD) is a complication that can occur after allogeneic stem cell transplantation in which the donor

stem cells begin to attack the recipient's body. The most commonly damaged organs are the skin, liver, and intestines. Symptoms vary in severity and duration (Smith et al., 1999).

Cancer and its many treatments can lead to poor physical functioning and therefore decreased quality of life. Jordhoy et al. (2001) reported that older age is associated with better emotional and social functioning, lower pain scores, and fewer sleep disturbances in patients approaching the end of life. They also found that higher education was associated with less pain, better emotional functioning, and greater general well-being in this population. Gerber et al. (2006) explored life satisfaction in long term survivors of pediatric sarcoma. Sixty-five percent of the subjects felt that their functional losses had a negative impact on their vocational plans. Study participants also had significantly decreased scores on a standardized measure of ADL (activity of daily living) performance when compared to their age-matched peers. Jalmsell et al. (2006) explored the symptoms that most often have a negative impact on children with malignancies during their last month of life. Parents reported that physical fatigue, reduced mobility, and pain had a moderate-to-severe adverse effect on their child's quality of life. Similarly, Elmqvist et al. (2009) researched quality of life in a large sample of terminally-ill patients and found that patients more often complained about decreased physical functioning and fatigue in the last 3 months of life. The authors expressed the opinion that physical rehabilitation with these patients could play a large role in palliative care to improve the quality of life of these patients.

According to the World Health Organization, palliative care is defined as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual" (World Health Organization, 2009). A recent qualitative study by Dahlin (2009) found that physical therapy (PT) intervention allowed patients to participate more fully in their daily routine, improved their motivation for physical activity, created a sense of independence, provided a physical and mental sense of well-being, and supplied an improved sense of hope and security to patients with incurable cancer. The author also emphasizes that communication and coordination of care help the patients understand the role of rehabilitation and enhance treatment outcomes (Dahlin, 2009). In a 2009 systematic, Lowe et al. found six studies that met the inclusion criteria and concluded that although most studies displayed favorable

outcomes, the quality of the studies was poor. The authors recommended further research with large samples and sound methodology to discover the potential role for physical activity as an intervention in palliative patients. Schleinich et al. (2008) concluded that both occupational and physical therapists take into consideration the patients' values and hopes when establishing realistic goals to help patients maintain function and a positive atmosphere at the end of life.

The Model of Human Occupation (MOHO) is a theoretical framework that drives much of occupational therapy (OT) practice in the United States today (Hogan-Kelley, 2005; Kielhofner & Barrett, 1998). The MOHO theory provides therapists with an explanation of how volition, habituation, performance capacity, and environmental context integrate to help them understand occupational performance. It is especially applicable to patients in the palliative care setting because the model encourages therapists to work on activities that are motivating and culturally meaningful for these patients in a physical and social environment that is relevant to their everyday lives. The emphasis is on quality of life. MOHO helps therapists understand the patients' strengths and weaknesses and enables them to provide successful treatments to address their functional problems at any stage of life. MOHO also facilitates the collaboration between the patient, therapist, and the social support system (Kielhofner & Barrett, 1998; Hogan-Kelley, 2005). A qualitative study by Hinds et al. (2005) looked at viewpoints of terminally ill children at the time of an end-of-life decision. Based on the interviews conducted, the authors concluded that children and adolescents \geq 10 years of age with a diagnosis of advanced cancer can and should participate in making end-of-life decisions. In a 2009 study, Julkunen et al. explored quality of life in relation to cancer patients' support systems. The results indicated that patients with cancer who perceive high levels of social support are better able to cope with their illness.

The aim of this report is to describe the course of treatment for a young girl with a long and complicated cancer history. We will highlight the interventions provided by OT and PT during the last few weeks of the patient's life in order to illustrate the benefits of rehabilitation in palliative care.

CASE REPORT

The patient was a very athletic and active female who was in her usual state of good health until age 16. She lived in a suburban town in a private house with her parents and two younger siblings. She valued spending time with her family and friends and she enjoyed

playing the harp. The patient also participated in organized sports, such as lacrosse and field hockey, despite her history of exercise-induced asthma. She underwent a surgical repair of a right lateral meniscus tear when she was 14 years old, but continued to exercise and play sports vigorously. She attended the local high school and consistently achieved excellent grades.

During her sophomore year of high school, she was struck in the right knee with a lacrosse ball. She continued to experience right knee soreness that increased with stair-climbing and bending the knee. The pain was not relieved by taking non-steroidal anti-inflammatory drugs or by using ice. She also noticed some mild swelling in the area, so she made an appointment with her orthopedic surgeon, where X-rays were taken of her distal femur. Based on these films, the doctor recommended a CT scan and MRI of her right leg which revealed a lesion in the distal femur, suspicious for malignancy. Doctors then performed a biopsy which confirmed a diagnosis of high grade osteosarcoma. A bone scan revealed that there were no other osseous lesions, and a chest CT at the time showed no pulmonary metastases.

The patient was started on a clinical trial of multiple chemotherapy drugs which included cisplatin, doxorubicin, and high-dose methotrexate. After 2 months of this treatment course, the patient underwent a surgical resection of her tumor. The surgery involved a wide en bloc excision of the right distal femur, a rotating hinge total knee replacement, and a bone graft from her tibia to the proximal bone prosthetic junction with complex wound closure. After the surgery, the patient completed another course of chemotherapy over a period of 5 months and was then deemed cancer-free. She resumed her previous activities and went away to college. She returned to her oncologists frequently for routine follow up screening.

Approximately two years after her initial diagnosis, the patient's doctor detected pulmonary nodules on a routine CT scan. The patient subsequently underwent a left thoracotomy and a thorascopic excision of several left upper lobe lesions, one of which was found to be metastatic osteosarcoma. The patient then had another cycle of chemotherapy including ifosfamide and etoposide for a period of 5 months. She remained cancer free for almost 2 years, during which she went back to college. Her follow-up visits with her orthopedic surgeon revealed full range of motion and stability in her right knee.

Less than two years later, at age 21, the patient began complaining of body aches, sinusitis symptoms, and malaise. The medical team noticed that her laboratory values were abnormal so they sent her for a bone marrow aspirate. She was diagnosed with

AML and began chemotherapy again with a protocol including vincristine, methotrexate, and asparaginase. She was hospitalized once to manage sepsis. She achieved morphologic remission after 1 month of chemotherapy and initiated preparations for a stem-cell transplant.

The patient underwent an allogenic hematopoietic stem-cell transplant from a 9/10 HLA matched non-relative. She did very well during her hospitalization. She told the medical team that she wanted to stay in shape, so they referred her for PT, which she received throughout her hospital stay. The patient continued to do well and was eventually discharged. Six months later, however, the patient was diagnosed with GVHD of the skin. The doctors prescribed steroids and several cycles of photopheresis to manage the GVHD. Other complications that the patient incurred at this time included steroid-induced hypertension, hyperglycemia, renal insufficiency, and Fanconi syndrome. The patient had several hospitalizations for acute flare ups of GVHD. One year after her transplant, she was able to return to college and receive her necessary treatments close to the college campus. She scheduled regular follow-up appointments with her oncology team.

At age 23, the patient began to develop some respiratory dysfunction. She had a productive cough and bilateral infiltrates were seen on her chest X-rays. One day, she experienced severe shortness of breath and was admitted to the hospital. She was consequently admitted to the intensive care unit (ICU) with marked dyspnea on exertion, severe hypoxemia, and progression of pulmonary infiltrates. In the ICU, the patient developed fungal pneumonia, sepsis, renal insufficiency, and metabolic acidosis. Her overall medical status remained critical throughout her hospital stay.

The patient expressed the desire to have an active role in her decision making with medical information. She asked the team daily for her laboratory results and for information about new treatment options. Once she was relatively medically stable in the ICU, after ~4 weeks, the patient expressed the desire to move more independently. The medical team requested consultations from both OT and PT.

EVALUATION AND TREATMENT

At this time, the patient was in the ICU attached to a cardiac monitor, pulse oximeter, and a bi-level positive airway pressure (BIPAP) machine for oxygen delivery. She also had a femoral arterial line, multiple intravenous lines, a Foley catheter and patient-controlled anesthesia for pain control.

On the day of the initial occupational and PT evaluations, the patient was alert and oriented to

person, place, and time, and she followed multi-step directions. The therapists found intact sensation and proprioception in all extremities. She displayed normal fine and gross motor coordination during functional reaching. The flexibility and strength portions of the assessment were limited by the patient's respiratory status. She displayed shortness of breath with very minimal activity.

The patient displayed decreased shoulder flexibility to at least half of the normal range of motion for both upper extremities. Manual muscle testing of her elbows and wrists revealed strength of 3+/5 for both flexion and extension and her grip strength for both of her hands was fair. However, the patient easily fatigued when combining active shoulder flexion with grasping objects. The patient required minimal assistance for daily grooming skills such as combing her hair and washing her face. She required maximal assistance for upper and lower extremity dressing. Bathing was not assessed during the evaluation due to her fragile medical status and feeding was not addressed because she had NPO (nothing by mouth) orders.

The patient displayed full passive range of motion throughout both lower extremities but exhibited difficulty with anti-gravity movements of the hip. She was unable to achieve full active hip flexion in the semi-Fowler position. Upon manual muscle testing, the patient achieved a grade of 3-/5 for bilateral hip flexion, 3/5 for bilateral knee flexion and extension, and 3/5 for bilateral ankle dorsiflexion and plantar flexion. The therapists provided verbal cues to the patient to avoid Valsalva maneuvers during strength testing.

In terms of functional mobility (Table 1), the patient required maximal assistance of two people to roll to the left side and she was unable to tolerate rolling to the right side due to complaints of increased lower back pain. She could maintain lying on her left side for ~40 seconds holding onto the bed rails for

Table 1. Levels of assistance provided by OT and PT

Level of assistance	
Independent	Performs 100% of the task without assistance, safely, and in a timely manner.
Supervision	Performs 100% of the task without assistance, but requires supervision for safety.
Minimal assistance	Performs ~75% of the task. Requires assistance for remaining 25%.
Moderate assistance	Performs ~50% of the task. Requires assistance for remaining 50%.
Maximal assistance	Performs ~25% of the task. Requires assistance for remaining 75%.
Dependent	Requires assistance for 100% of the task.

support, but would then need to roll back to supine because of fatigue and complaints of low back pain. During the evaluation, the patient expressed her excitement about rolling as an active participant as opposed to being dependently rolled for nursing care. She smiled and reported how happy she was to relieve the pressure from her back. The patient also assumed the long sitting position with maximal assistance of two people. She displayed poor sitting balance in this position as evidenced by her inability to maintain her balance without maximal assistance and the use of both bedrails. Sitting at the edge of the bed was not attempted during the initial evaluation due to significant changes in her vital signs and respiratory status during rolling and long sitting. Additionally, sit-to-stand and ambulation were not tested due to her overall deconditioned state. The patient requested exercises to perform on her own to build up her strength and endurance. The occupational therapist provided the patient with a home exercise program at the time of evaluation. The program included gluteal clenches for pressure relief, a Hand Helper® with one red band (moderate resistance) to increase her hand strength for ADLs, and a basic upper extremity active range of motion (AROM) program to increase overall activity endurance for ADLs. The patient was also given a yellow Theraband® for bicep curls in preparation for bed mobility and transfers. The physical therapist also provided the patient with a written exercise program composed of non-resistive therapeutic exercises. These exercises, to be performed in the semi-Fowler position, included active–assisted range of motion into hip abduction, assisted knee extension over a towel roll, assisted heel slides, and assisted ankle pumps. Both the patient and her parents received education on how to perform the exercises and demonstrated them correctly. The patient's parents were also educated in assisting their daughter to roll to her side for pressure relief.

Based on the patient's wishes and evaluation findings, the OT and patient collaborated to create the following 2-week goals to increase her functional independence:

1. The patient will perform basic grooming activities such as washing her face and combing her hair with modified independence and minimal rest breaks demonstrating energy conservation techniques in the semi-Fowler position.
2. The patient will require moderate assistance with rolling right and left for pressure relief.
3. The patient's family will be independent in providing moderate assistance to the patient for rolling right and left in bed.

4. The patient and family will be independent with a home exercise program to increase her strength and endurance for her ADL's.

The PT and the patient collaborated to create the following 2-week goals to increase her functional independence:

1. The patient will exhibit an increase in bilateral lower extremity strength of 0.5 grade to facilitate bed mobility and in preparation for out-of-bed transfers.
2. The patient will roll from supine to side lying right and left with minimal assistance for pressure relief.
3. The patient will be independent in performing a home exercise program to maximize bilateral lower extremity strength gains in preparation for standing transfers.
4. The patient will improve sitting balance to sit at the edge of the bed with minimal assistance and upper extremity support in preparation for sit-to-stand transfers.

Shortly after the initial evaluation, the occupational and physical therapists decided to work as a team with this patient, because of her decreased activity tolerance for two separate sessions each day. The combined OT and PT sessions focused on improving the patient's tolerance for movement in general, as well as progressing her mobility toward sitting at the edge of the bed. The therapists also administered an exercise program to the patient, her family, and the nurses in order to improve her functional mobility and endurance for ADLs. Once the treatment plan was established, the patient requested a specific time of the day to participate in therapy. She mentally prepared for each treatment session by relaxing with some of her favorite soothing music. She alerted the nursing staff to postpone any non-emergent treatments until after the rehabilitation session so she could focus on improving her mobility skills. The therapists rearranged their schedules to accommodate this patient and give her a sense of control.

During the first week of rehabilitation, the occupational therapist engaged the patient in light grooming tasks such as washing her face and combing her hair in the semi-Fowler position in order to improve her range of motion, endurance, and sense of independence. She performed biceps and triceps strengthening exercises with the yellow Theraband® as well as bicep curls using a water bottle for resistance in preparation for using her upper extremities to assist with rolling and transfers. She used the

Hand Helper® with one red band and moderate assistance in order to improve her ability to use the call button and hold onto grooming tools and other small objects. She also performed ankle pumps, hip abduction AROM, heel slides (hip and knee flexion AROM), terminal knee extension over a towel roll, isometric hip extension, isometric knee extension, and isometric knee flexion in the semi-Fowler position with the physical therapist. The patient was also educated to perform inspiration and expiration in conjunction with therapeutic exercise and functional tasks to decrease fatigue and anxiety, and to maintain stable vital signs.

Functionally, the therapists focused on facilitating independent pressure-relieving techniques. The patient performed bridging exercises with minimal assistance in order to prevent shearing, decrease pressure on the sacrum, and participate more actively during routine nursing care. The patient also practiced rolling during each therapy session. The therapists encouraged the patient to flex both knees and reach toward the opposite bed rail with her upper extremity using both visual and verbal cues. She required moderate assistance to roll from supine to lying on her left side but required maximal assistance to roll onto her right side.

By the end of the first week of treatment, the patient was able to transfer from supine to sitting at the edge of the bed with maximal assistance of two people. As her endurance improved and she became more comfortable with the routine, the patient transferred from supine to sitting at the edge of the bed with moderate assistance of one therapist and minimal assistance of the other therapist. One therapist would assist at the patient's trunk to help physically lift the patient into the sitting position. The other therapist would assist at the patient's lower extremities to help them safely move off the edge of the bed. At times, the PT would facilitate the transfer and the OT would focus on relaxation techniques and deep breathing to achieve optimal results. Some days, the roles would be reversed. The therapists would also help facilitate smooth movements and provide gentle manual therapy to her lower back during the transfer as she had extreme back pain from being bed-bound for weeks.

After the first week of rehabilitation, the patient's respiratory status improved and the medical team progressed her oxygen delivery system to a high-flow nasal cannula (Opti-flow) instead of the BIPAP machine. Also, her vital signs started to become more stable and her endurance improved so that she required less time to recover after functional mobility tasks. Occasionally, during the rehabilitation sessions, the patient required more supplemental oxygen in order to decrease the work of breathing during functional training. The

rehabilitation team requested the presence of respiratory therapy at these times to ensure adequate respiratory support and quick delivery of extra oxygen as needed. The physical therapist worked on chest PT during this period as well. The patient performed exercises including pursed-lip breathing, tissue blowing, and incentive spirometry in a variety of functional positions. The therapist assisted with low costal and lateral costal expansion via tactile facilitation in order to improve lung capacity and facilitated coughing to promote secretion clearance.

The occupational therapist focused on guided imagery to decrease muscle tension and guarding during functional mobility. Relaxation techniques helped to decrease the patient's anxiety level during performance of new tasks. Another strategy employed by the therapists to lessen her anxiety was to break down functional activities into small parts to improve her understanding of each task. She was able to ask questions and prepare mentally prior to initiating each movement. The therapists provided step-by-step instructions for each component of movement. The patient was then able to direct the actions herself, creating a better sense of control.

Through continued practice of mobility skills as well as performance of the exercise programs and relaxation techniques, the patient made significant progress after the first 2 weeks of rehabilitation. The therapists facilitated small changes during practice of each functional task to move toward higher levels of independence. Initially, the patient required assistance at both the trunk and the lower extremities to transition from supine to sitting. At each session, the therapists asked the patient to perform one specific part of the task with less assistance. One day, the patient would be asked to move her legs to the side of the bed without help while assistance was maintained at the trunk. The next day, the therapists would assist with the lower extremities and provide the patient with functional strategies to use the upper extremities more actively to assist the trunk. Weight-shifting in the sitting position was also performed in preparation for sit-to-stand transitions along with dynamic reaching activities using unilateral upper extremity support to facilitate more independence with ADLs. Sit-to-stand was attempted toward the end of the first 2 weeks, but the patient required maximal assistance of two people to complete the task.

At the 2-week re-evaluation (Table 2), the patient rolled to the right and to the left from supine with the use of the bed rails and with minimal assistance from a therapist to help flex her right knee. She was able to transfer from side lying to sitting at the edge of the bed with minimal assistance. She continued to require maximal assistance of two people to transition

Table 2. Patient's functional status at the time of each evaluation

	Functional status			
	Initial evaluation	Re-evaluation at 2 weeks	Re-evaluation at 4 weeks	Discharge at 7 weeks
Rolling right	Not tested (pain)	Min assist	Close supervision	Not appropriate
Rolling left	Max assist × 2	Min assist	Close supervision	Not appropriate
Supine to sit	Not appropriate	Min assist	Close supervision/ Min assist	Not appropriate
Sit to supine	Not appropriate	Max assist	Max assist	Not appropriate
Sit to stand	Not appropriate	Min assist × 2	Mod assist	Not appropriate
Bed to chair	Not appropriate	Not appropriate	Max assist (sliding board)	Not appropriate
Ambulation	Not appropriate	Not appropriate	Not appropriate	Not appropriate
Grooming	Min Assist	Setup of tools	Setup for tools	Max assist
Feeding	Not tested (NPO)	Dependent (TPN)	Setup of tray	Not tested (feeding tube)
Dressing	Max Assist UE's Not tested LE's	Setup for gown, Max assist for socks	Setup for gown, Max assist for socks	Dependent
Bathing	Not tested	Not tested	Setup for UB, LB not tested	Dependent
Toileting	Dependent for Bowel and Bladder	Dependent for Bowel and Bladder	Mod Assist	Dependent

UE = upper extremity; LE = lower extremity; UB = upper body; LB = lower body.

from sitting to supine due to fatigue at the end of the session. She also required maximal assistance from both therapists to perform sit-to-stand transfers. She could remain standing for <10 seconds.

At this time, the patient was much more motivated to participate in therapy because the therapists were helping her realize new functional goals each day. She became a more active participant in setting treatment goals. These new goals demonstrated that the patient was willing to push herself to higher levels of function than she thought possible on initial evaluation. The patient began to think back to her days when she was involved in sports and other activities. She displayed an increased drive and motivation to gain independence in order to get out of the hospital and back to her daily routine.

The therapists and patient worked together to create the following new 2-week short-term goals for therapy:

1. The patient will roll right and left from supine with modified independence for pressure relief.
2. The patient will transition from supine to sitting and sitting to supine with modified independence and compensation techniques to improve functional mobility and ability to perform ADLs.
3. The patient will tolerate 30 minutes sitting at the edge of the bed performing ADLs or other therapeutic activities with minimal rest breaks to improve overall endurance for activity.

4. The patient will perform functional reaching activities in standing with maximal assistance to prepare for ambulation and increased ADL performance.
5. The patient will transfer from the bed to the chair with maximal assistance to promote increased socialization with family and friends.

The third and fourth week of therapy focused on assisting the patient to get out of bed and into a wheelchair. The therapists allowed her ample time to mentally prepare for this major transition. Again, the therapists broke down the task and encouraged practice of component parts including increasing sitting tolerance at the edge of the bed with and without upper extremity support and performing sit-to-stand transfers using a walker. Initially, the patient required the above-described techniques to decrease her anxiety with this new task. The therapists broke down the transfer into small steps and allowed the patient to control the pace of the session. She required maximal assistance to physically achieve the standing position, maximal assistance to block her knees to maintain the standing position, and maximal positive reinforcement and encouragement to give her the confidence to be successful for at least 30 seconds. Eventually, the patient only required moderate assistance for sit-to-stand transfers and was able to perform several trials in one therapy session for 2 minutes at a time.

Because the patient could now tolerate sitting at the edge of bed for longer periods of time with

supervision only, the therapists modified the exercise program to include seated upper extremity Thera-band® exercises and seated lower extremity AROM exercises. The patient also performed ADLs while sitting along with dynamic reaching tasks across midline to prepare for transfers to the chair. To accomplish this task, the therapists chose to dependently assist the patient into sitting at the edge of the bed prior to attempting the transfer, to avoid fatigue and increased stress. They also used a sliding board initially to relieve some of her anxiety and to decrease her energy expenditure so that she could have a positive experience sitting in the chair bonding with her family. She required maximal assistance to achieve this transition.

The patient progressed significantly in terms of her ability to transfer out of bed and her ability to tolerate sitting in the chair for longer periods of time each day. The therapists trained the family and nursing staff to provide the maximal assistance necessary for the patient to transfer to the chair using the sliding board. As she gained more strength and endurance, the patient tolerated sitting in the chair more than once a day and felt exhilarated by the ability to perform these movements without relying on the therapists. Also, because the family and nursing staff were willing to perform these transfers at the patient's request, therapy could focus on higher level transfers and mobility skills. Sessions included providing maximal assistance for squat-pivot and stand-pivot transfers to the chair, marching in place, mini-squats to practice slow and controlled descent to sitting, dynamic reaching activities with unilateral upper extremity support in standing, and finally progressing to taking several steps with maximal assistance of both therapists. The patient also requested working on toileting out of the bed rather than using a bedpan. Therefore, once the patient was confident with squat-pivot transfers, the therapists trained the family to provide maximal assistance to transfer to the commode.

By the end of the fourth week of therapy, the patient's endurance and tolerance for activity improved significantly. She could tolerate at least 45 minutes to an hour of therapy utilizing energy conservation techniques and was more efficient with functional mobility as stated above. The patient's wrist and hand strength improved to a grade of 4/5 as a result of her dedication to her exercise program and increased participation in transfers and bed mobility. She was able to wash her face with a wash cloth and comb her hair with both of her upper extremities when sitting unsupported at the edge of the bed. However, daily living activities were not one of the patient's main priorities. Therefore, she did not improve these skills as significantly as she improved her ability to perform functional mobility and general exercise.

She remained dependent with her toileting as she had a Foley catheter and required assistance with hygiene after a bowel movement on the commode. She did not want to expend her energy on bathing or dressing skills because she did not find these activities meaningful at this point in her recovery.

Although the patient made tremendous gains since evaluation, she still required the teamwork from both the occupational and physical therapist. She required frequent rest breaks and facilitation from both therapists to promote safe and fluid movements. Participating in activities that motivated the patient and her family enabled the sessions to be productive and meaningful. She participated actively in the setting of new goals on a daily basis in order to allow her to be consistently successful.

After 4 weeks of therapy, the patient overcame medical and physical complications by achieving goals that surprised and delighted the primary care team. The therapists and patient worked together to create the following new 2-week short-term goals for therapy:

1. The patient will perform sponge bathing with modified independence to increase her ADL performance.
2. The patient will roll right and left from supine with modified independence for pressure relief.
3. The patient will transfer from bed to chair, bed to commode, chair to bed with minimal assistance of two people to facilitate more independence with mobility.
4. The patient will ambulate 10 steps with moderate assistance of two people and a rolling walker to allow more independent mobility.
5. The patient will tolerate 10 minutes of ADL activities in the standing position with minimal assistance to improve overall endurance for activity.

Shortly after this re-evaluation, however, the patient's medical status began to significantly decline. Unfortunately, her kidneys were failing and she required frequent hemodialysis. Her respiratory status declined, making it difficult for her to speak. Her blood pressure became unstable and she could no longer tolerate much mobility. The critical care team deemed it unsafe for her to participate in edge-of-bed or out-of-bed activities and the patient was not seen for therapy for 3 days. The patient and her family, however, remained determined to participate in some sort of physical activity despite her medical deterioration.

Also at this time, the patient displayed increased weakness and muscle atrophy in her left upper extremity and hand. The occupational therapist requested

to continue services with the patient in order to maintain as much function as possible and to provide the patient and family with continued activities to improve quality of life. The physical therapist discharged the patient from therapy to avoid duplication of services as she could no longer participate in edge-of-bed or out-of-bed activities.

The short term goals were modified as follows:

1. The patient and family will be independent with a modified home exercise program for active assistive and passive range of motion as well as upper extremity positioning to prevent further muscle atrophy and to promote functional position of the hand.
2. The patient and family will be independent with precautions for wearing left wrist splint and with schedule for wearing splint to prevent pain and dysfunction and promote improved functional abilities.
3. The patient's family members will be independent in assisting the patient with bed mobility for pressure relief.

The occupational therapist worked with the patient on gentle range of motion activities in bed to maintain function of her left arm. The occupational therapist also provided the patient with a wrist cock-up splint for her left hand to be worn at night. The family was educated on how to don the splint at night and how to position the patient's hands using towel rolls during the day to encourage functional grasp. The occupational therapist also educated the patient on light resistance putty exercises to improve strength in her left hand. Lastly, the patient, family, and nursing staff were educated to assist the patient into different positions in bed to prevent skin breakdown.

During the last few sessions, the patient became extremely fatigued and was unable to actively participate in therapy. She had a difficult time keeping her eyes open during therapy sessions and her vital signs fluctuated dramatically. The occupational therapist then deemed it unsafe for the patient to engage in therapy. Although the patient was not participating in therapy anymore, the patient and her family verbalized appreciation to the therapists for consistently working with her throughout her hospital stay. The patient died 2 days after being discharged from the therapy program.

DISCUSSION

Recent research demonstrates the impact that rehabilitation can have on the quality of life of patients

with terminal diseases. Increased physical activity and ability to participate in ADLs can provide relief from distressing symptoms of disease and have a dramatic effect on perceived levels of independence (Dahlin, 2009; Lowe et al., 2009). Research also demonstrates that the patient's goals should be integrated into the treatment plan, and that collaboration between the patient and the medical team is imperative to achieve optimal results (Schleinich et al., 2008; Dahlin, 2009). Patients who are terminally ill often have doctors, nurses, and other medical staff making decisions for them. They frequently have little control over their physical environment and ability to function (Elmqvist et al., 2009; Jalmisell et al., 2006). Rehabilitation professionals help facilitate active decision making and goal setting so that the patient can develop a sense of control over his or her life again (Schleinich et al., 2008). As the occupational and physical therapists working with this patient, we confronted these issues directly.

The MOHO (Kielhofner & Barrett, 1998; Hogan-Kelley, 2005) is a client-centered and holistic theoretical framework that shaped our treatment with this particular patient. We focused on the patient's values to improve her sense of self and to afford her some control over the events of her day. We worked on activities that were motivating and meaningful to her and used her strengths and weaknesses to create a treatment plan to address her functional problems in a setting relevant to her everyday life. This strategy was extremely effective in improving her overall quality of life during her last weeks.

At the time of her initial evaluation, the patient stated that she wanted to be able to move more easily in bed. The therapists focused on helping the patient increase her independence with bed mobility through facilitated rolling and pressure relieving techniques coupled with family education to provide the necessary assistance. Soon thereafter, the patient generated a more challenging goal for herself. She wanted to sit in a chair to socialize more effectively with her family. She worked on different aspects of this process until she was finally able to combine them effectively in order to transfer out of bed to the chair with assistance. Because these goals were developed by the patient and justified by the therapists, the patient was highly motivated to achieve them. In contrast, because the patient did not find certain daily living activities meaningful to her, the occupational therapist did not address these areas during intervention.

Similarly, the therapists worked hard to translate the patient's ambitions into realistic and achievable goals. This facilitated a positive atmosphere at an otherwise negative time in this patient's life. The patient hoped to be able to walk to the commode

rather than using a bedpan for toileting. Both therapists were concerned about the feasibility of this task so we modified this objective to the more realistic goal of being able to perform a pivot transfer to the commode. She accomplished this task with assistance, giving her a sense of success and improving her perceived quality of life. It is our belief that patients benefit from having their goals adjusted by the therapist in order to facilitate success. We also recognize that the patient's physical and medical status will influence these goals tremendously.

Another factor that added to her success in OT and PT was that the rehabilitation team consistently treated her together and at the time that she requested. She could not tolerate more than one therapy session each day due to her poor endurance. It was more important for the patient to have one successful treatment session rather than two separate sessions to address OT and PT goals individually. The therapists were able to facilitate both her physical mobility and her ADL training at the same time. This also allowed the therapists to spend more time with her to permit her the frequent rest breaks that she needed in order to maintain her vital capacity throughout the session. The therapists utilized the services of the respiratory therapy and nursing departments during the scheduled sessions as well to further the patient's progress. We strongly recommend that occupational and physical therapists working in palliative care recognize the limitations of their patients and alter the treatment schedule accordingly to maximize success, especially in the critical care setting.

Participation in physical activity and ADLs also allowed the patient to continue her strong relationship with her family. Research has explored quality of life in relation to the cancer patient's support systems. The results indicate that patients with cancer who perceive high levels of social support are better able to cope with their illness (Julkunen et al., 2009; Jordhoy et al., 2001). This particular patient had an incredibly supportive family who was consistently present and attended every therapy session. They provided encouragement and motivation for the patient and positively influenced her medical treatment, therapy goals, and overall functional progress. At one point during her hospital stay, the medical team recommended intubation and mechanical ventilation due to worsening respiratory distress. However, the patient expressed an incredibly strong desire to be able to communicate verbally with the medical team and, most of all, with her family. This prompted the team to seek other options such as the high-flow nasal cannula, which decreased her work of breathing without compromising her ability to communicate. Also, several of the patient's goals

revolved around interacting with her family. Many have already been stated. There was one occasion where the patient improved her sitting balance to sit at the edge of the bed with only minimal support. She looked at her mother and said, "Mom, can I have a hug?" Not only was the patient working on improving her strength and balance, but she was also participating in a social, meaningful, and emotional activity with her mother.

CONCLUSION

Palliative care patients benefit tremendously from OT and PT intervention. Rehabilitation specialists are skilled at working with patients to set realistic and meaningful goals. In the critical care setting, something as simple as adapting a call bell so that the patient can better communicate his or her needs to nursing staff can significantly improve the individual's quality of life. In more medically stable patients, providing assistance to transfer from the bed to a chair in order to socialize with family members may be more appropriate and meaningful. Occupational and physical therapists consistently advocate for rehabilitation services for palliative patients to help improve mobility, independence, and therefore, quality of life. Further study in this area would greatly enhance the field of knowledge and provide further testament to the impact that rehabilitation can have in palliative care.

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REFERENCES

- American Cancer Society. (2009). *Detailed guide: Leukemia-Acute Myeloid*. http://www.cancer.org/docroot/CRI/CRI_2_3x.asp?dt=82.
- Dahlin, Y. (2009). Patients' experiences of physical therapy within palliative cancer care. *Journal of Palliative Care*, 25, 12–20.
- Elmqvist, M.A., Jordhoy, M.S., Bjordal, K., et al. (2009). Health-related quality of life during the last three months of life in patients with advanced cancer. *Supportive Care in Cancer*, 17, 191–198.
- Gerber, L.H., Hoffman, K., Chaudhry, U., et al. (2006). Functional outcomes and life satisfaction in long-term survivors of pediatric sarcomas. *Archives of Physical Medicine and Rehabilitation*, 87, 1611–1617.
- Gurney, J.G., Swensen, A.R. & Bulterys, M. (1999). Malignant bone tumors. In *Cancer Incidence and Survival among Children and Adolescents: United States SEER Program 1975–1995*, Ries, L. A., Smith, M.A., Gurney,

- J.G., et al. (eds.), pp. 99–110. Bethesda: National Cancer Institute, SEER Program.
- Hinds, P.S., Drew, D., Oakes, L.L., et al. (2005). End-of-life care preferences of pediatric patients with cancer. *Journal of Clinical Oncology*, 23, 9146–9154.
- Hogan-Kelley, D. (2005). Occupational therapy frames of reference for treatment in the ICU. *OT Practice*, 10, 15–18.
- Inskip, P.D., Ries, L.A.G., Cohen, R.J., et al. (2006). New malignancies following childhood cancer. In *New Malignancies Among Cancer Survivors: SEER Cancer Registries, 1973–2000*, Curtis, R.E., Freedman, D.M., Ron, E., (eds.), pp. 465–482. Bethesda: National Cancer Institute.
- Jalmsell, L., Kreicbergs, U., Onelov, E., et al. (2006). Symptoms affecting children with malignancies during the last month of life: A nationwide follow-up. *Pediatrics*, 117, 1314–1320.
- Jordhoy, M.S., Fayers, P., Loge, J.K., et al. (2001). Quality of life in advanced cancer patients: The impact of socio-demographic and medical characteristics. *British Journal of Cancer*, 85, 1478–1485.
- Julkunen, J., Gustavsson-Lilius, M. & Hietanen, P. (2009). Anger expression, partner support, and quality of life in cancer patients. *Journal of Psychosomatic Research*, 66, 235–244.
- Kielhofner, G. & Barrett, L. (1998). Theories derived from occupational behavior perspective. In *Willard and Spackman's Occupational Therapy* (9th ed.), Neistadt, M.E., Blesedell Crepeau, E. (eds.), pp. 527–529. New York: Lippincott-Raven Publications.
- Lewis, D.R. & Gloeckler Ries, L.A. (2007). Cancers of the bone and Joint. In *SEER Survival Monograph: Cancer Survival Among Adults: U.S. SEER Program, 1988–2001*, Ries, L. A., Young, J.L., Keel, G.E. (ed.), pp. 81–88. Bethesda: National Cancer Institute, SEER Program.
- Lowe, S.S., Watanabe, S.M. & Courneya, K.S. (2009). Physical activity as a supportive care intervention in palliative cancer patients: A systematic review. *Journal of Supportive Oncology*, 7, 27–34.
- National Cancer Institute. (2009). *Childhood Cancers: Questions and Answers*. <http://www.cancer.gov/cancer-topics/factsheet/Sites-Types/childhood>.
- National Cancer Institute. (2009). *Osteosarcoma and Malignant Fibrous Histiocytoma of Bone (PDQ®)*. <http://www.cancer.gov/cancertopics/pdq/treatment/osteosarcoma/healthprofessional>.
- Pakos, E.E., Nearchou, A.D., Grimer, R.J., et al. (2009). Prognostic factors and outcomes for osteosarcoma: An international collaboration. *European Journal of Cancer*, 45, 2367–2375.
- Schleinich, M.A., Warren, S., Nekolaichuk, C., et al. (2008). Palliative care rehabilitation survey: A pilot study of patients' priorities for rehabilitation goals. *Palliative Medicine*, 22, 822–830.
- Smith, M.A., Gloeckler Ries, L.A., Gurney, J.G., et al. (1999). Leukemia ICCI. In *Cancer Incidence and Survival among Children and Adolescents: United States SEER Program 1975–1995*, Ries, L.A., Smith, M.A., Gurney, J.G., et al. (eds.), pp. 17–34. Bethesda: National Cancer Institute, SEER Program.
- World Health Organization. (2009). *WHO Definition of Palliative Care*. <http://www.who.int/cancer/palliative/definition/en/>.