The role of physical, occupational, and speech therapy in hospice: Patient empowerment

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Abstract

The use of physical, occupational, and speech therapy is a growing trend in hospice. The purpose of this paper is to define the role of the physical, occupational, and speech therapist as part of the hospice team in the context of the various therapies' objectives. A case study is presented and clinical implications are discussed.

Key words: hospice, occupational therapy, palliative care, physical therapy, speech therapy

Introduction

Hospice plays a vital role in the final stages of the terminal patient's life by allowing dignity and comfort in the home while preserving quality of life and fostering family involvement. A growing trend is to utilize therapy in its various forms (*i.e.*, physical, occupational, and speech) more frequently in hospice. As this trend continues, it is important to address and define the potential use of therapy in hospice. This article will explore the role of therapy in hospice, its emotional power for the patient, and benefit to the caregivers as well as its financial impact on the hospice program.

Therapies are being utilized more in general, and there is an increased awareness and openness in recognizing their potential effect. One difficulty is that little has been written regarding this trend. In fact, it is a trend that needs to be identified and discussed further. That is the purpose of this paper.

In my attempt to find resources in support of the premise that therapy is being utilized more in hospice, I searched extensively on the Internet under any hospice and palliative care-related topic as well as each of the therapies. I did not find a hospice program that listed a therapist as part of the care team. However, I found tables and tests to determine burden of care for the caregiver, and potential injury, as well as methods to determine psychological effect of functional loss. These were not presented as therapy-related or as tools to determine the need for therapies, but the search resulted in the realization that this subject has not been addressed sufficiently and there is a great need for clarifying the scope of practice of therapy in hospice.

The "function" of therapy: A play on words

As a physical therapist, I approach nearly ever situation in life by addressing two questions: "Why am I here?" and "What can I do?" Sitting in my first hospice meeting approximately a year ago, I found myself twiddling my thumbs, asking myself these two questions and wrestling to find answers. My experience has been that therapy is not a predominant part of the hospice program, but more of an occasional contributor. In fact, as explained to me when invited to join the hospice team, I might not see many patients, but my insights in case conference would be helpful. At the time, this made sense to me, since the philosophy of therapy is based on function. The term *function* is used in therapy to describe an individual's *ability to complete tasks necessary for survival* in the patient's day-to-day environment. The goal in therapy—if described most simplistically—is to determine the patient's functional loss, estimate functional potential, and implement a plan to progress from the measured loss to a quantifiable potential. If viewed strictly in these terms—as a map or method to reach functional potential from a

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point of functional loss—therapy should only play a small role in hospice, particularly when a hospice patient's loss is expansive, with 60 to 80 percent functional loss in a relatively short time. Additionally, there is questionable functional potential if a patient's life expectancy is less than six months. If the patient were not expected to recover, one would conclude that therapy, as a part of the functional recovery process, has no purpose. To add more weight to my questions, I soon found that the financial workings of hospice are vastly different from other settings, making therapy somewhat financially prohibitive—conceivably impractical. Understandably, hospice meetings became a time for me to reflect for an hour on big questions such as "Why am I here?" (globally and specifically) and to offer insight and advice as I listened to the cases discussed.

Restoration of dignity: A case study

About five months into my philosophical journey, I was asked to see Jack. The safety hazards I had pointed out along the way with other patients had developed all of our thinking. We began to feel, especially in this case, that the problems I identified from listening to the other team members were beyond what they could address. Perhaps, there were other problems I could resolve if I saw the patient and worked with him directly. Jack was the caricature of a bookie from Brooklyn. This tough guy walked several miles a week for exercise, drove his car, made money, heated frozen dinners, went to the store for his wife, and balanced his checkbook—until February, when the cancer was diagnosed and treatment was initiated. After an eight-week course of chemo and radiation therapy followed by three weeks of treatment for the complications, he was discharged home, armed with a front wheel walker, bedside commode, and an appointment for the hospice nurse to visit the next day. He went from a controlled environment with linoleum floors, air conditioning, elevating bed frames, grab bars, meals rolled bedside, catheters, and bedpans to a mobile home with four steps to the front and side door, deep shag carpet with throw rugs, a bathroom down a hallway too narrow for the front wheel walker, a low soft bed, and a strong fear that his wife would hurt herself if she assisted him in walking or transferring. He did not want his wife to help him with his toileting, since he felt this would damage her image of him in his role as a man and provider. He was predominantly weak and very achy from being confined in bed. This strong ox of a man had become as helpless as a newborn calf. Just the process of bed to toilet, which seemed so simple in the linoleum-floored hospital, was different and bursting with danger of possible injuries at home. It was a shock to him once in his home—as comforting as it was to be home—that he did not recognize himself in the environment where he used to be a man, the provider, the tough guy. He felt out of control and overwhelmed. A simple thing—this man was dying, but he wanted the dignity of turning in bed without calling his wife or exhausting himself and of managing his own bowel movements as much as possible without his wife's involvement.

The stretching and exercise program Jack and I developed made him feel like there was a continuum between who he was and who he had become. Even while talking about exercise, he adopted a different tone, not of someone who felt helpless, but of a tough guy. As I explained safety in the home, he and I discovered how his functional limitations would affect his mobility in this environment. Jack and I modified the use of equipment, using the hallway walls instead of the walker, which he was too weak to lift and was too wide to use. We developed a bowel and bladder program that involved the times of day he felt strongest or hospice staff would be present, using techniques that conserved his strength, placing the commode strategically so that his strongest muscle groups would be used predominantly, and requiring his wife to stand by, armed with safety techniques, only once in a while. We reviewed falling safely and how to get up, since he insisted on walking. I taught the husband and wife how to work together during transfers. Jack learned how to sit and position himself to assist with his breathing and relieve discomfort.

Clinical implications: A shift in our thinking

In consideration of all the avoidance of injury, safety hazard resolution, pain relief, and reassurance therapy provided, I believe that the greatest thing therapy did for Jack was to restore his sense of self. He felt in touch with his body and more in control of his environment, although he was progressively weaker. This had an incredible influence on his quality of life, decreased the frequency of nursing and social worker visits, and avoided the potential for injury in the home for the patient and physical strain on the wife. Why am I here? To save time and money! What can I do? To help a bookie from Brooklyn who was weak and depleted, frail as a calf, to be in control and self-possessed, enabling him to die in touch with the ox of a man he still was inside. Finally, I had some answers.

My understanding and appreciation of therapy's role in hospice has expanded. True, therapy is functionally based, but, squinting our eyes and looking deeper, it is clear that therapy is vital in hospice. Therapy reaches broadly, answering questions and calming fears of which caregivers and patients may not have been aware, able to pinpoint, or to express, such as:

- Caregiver's fear of injuring the patient while assisting in transfers or ambulation;

- Patients' concern that assisting or caring for them may cause injury to the caregivers; and
- Caregiver anxiety and hopelessness, emerging from the powerlessness of not knowing what can be done physically to comfort, position, and relieve the patient.

Illness in our medical system involves a progressive removal, sometimes an immediate removal, of responsibility and control. Therapy is the recovery of dignity, systematically giving the patient his or her sense of self, as the patient is taught how to have control and be responsible within his or her physical limitations in the home, where the environment is not controlled.

The range of functional activities is divided into three major categories, which are addressed by each of the three therapy disciplines with some shared territory. Activities categorized as *gross functional mobility* fit in physical therapy's (PT) territory. Gross functional mobility is related to a *change in body position* as well as *physical states affecting the ability to change position* (Table 1).

Table 1. Physical therapy: Gross functional mobility

Emotional task	**Components/description**
Bed mobility	• Rolling (supine to side lying—right and left) • Positioning for comfort • Positioning for pressure relief • Bridging (lifting pelvis off the bed) • Supine to sit • Sit to supine
Transfers	• Set up (*i.e.*, positioning of wheelchair in relation to bed) • Sit to stand • Pivot (or slide) • Stand to sit
Ambulation or gait	• Assistive device placement • Gait assessment • Foot placement
Body mechanics	• Potential physical strain due to body mechanics or positioning during this activity to the patient and/or person assisting the patient

These tasks are also referred to as *transitional movements*. An example would be moving from sitting in a car to standing next to the car with the transition described as a "car transfer." A physical therapist would address all components involved: related grossly and specifically from hand placement on the door to preserve safety within functional limitations, such as weakness and poor balance or the specific ability to tilt the pelvis.

Additionally, a physical therapist addresses limitations that influence transitional movements such as pain, weakness, range of motion, and shortness of breath (Table 2).

Physical therapy is effective in treating patients with lymphatic system involvement such as AIDS, lympedema, cancer, infection, filariasis, multiple abdominal surgeries, post-radiation, status post-lymph-node dissection in the groin or abdomen, and status post-axillary-lymph-node dissection.[4] Specific interventions include connective tissue massage, manual lymphatic drainage, soft tissue mobilization and manipulation, and therapeutic massage[5] as well as instructing the patient and family in various pain distraction techniques.

Activities of daily living (ADL), which include self-care and home management, is occupational therapy's (OT) area of expertise. (See Table 3.)

OT has some cross-over into PT, since it addresses gross mobility while completing activities of daily living. An example of overlap would be in the task of brushing teeth. It encompasses gross mobility (PT) as it relates to movements involved within the specific patient's ability such as wheelchair mobility to the sink. OT concentrates particularly on the components of the task, such as posture and balance during all components, support of upper extremity for energy conservation and avoidance of pain during the task, and positioning for spitting into the sink. *Occupational therapy focuses on helping clients assume or return to valued day-to-day activities*[6] with the word "occupation" referring to the activity, not a profession.[7]

Speech therapy and pathology (ST) includes functional tasks involving the *oral-pharyngeal-laryngeal function as well as cognitive components involved in the process of communication* (Table 4).

ST has some similar activities to OT insofar as eating or feeding is a part of ADL. The clear demarcation is that OT may specifically address the ability to get the food to the mouth (*i.e.*, from the plate to the mouth on a spoon), while ST will address what occurs between the lips and the stomach[9] (*i.e.*, lip closure, tongue use, pocketing, effective mastication, epiglottal use, esophageal tone and contraction, etc.).

Dysphasia, or difficulty in swallowing, is a commonly documented problem for surgically treated head and neck

Table 2. Limitations of transitional movements	
Pain	To what extent does pain interfere with or negatively affect functional movement? Physical therapy can alleviate pain, prevent onset and progression of impairment resulting from injury or disease; restore, maintain, and promote optimal quality of life as related to movement and health.[1] A PT will address: What is the source of the pain/discomfort? Edema, muscle tightness/loss of ROM or contracture, positioning. Can the pain level be decreased by nonpharmalogical pain control methods: stretching, massage - myofascial technique - acupressure - application of heat, application of cold, modalities (ultrasound, electrical stimulation, TENS, interferential, etc.), mental distraction, traction or compression, change in position or posture.
Weakness	Is there a decrease in strength (trunk, pelvis, upper extremity or lower extremity) that affects gross functional mobility or stability?
Range of motion (ROM) limitations	Is there a loss of ROM (trunk, pelvis, upper extremity or lower extremity) that affects gross functional mobility or stability?
Shortness of breath	Is there decreased function due to breathing difficulty? A PT can perform airway clearance techniques to improve physical function,[2] increase quality of life and alleviate anxiety. Specific direct interventions may include assistive cough techniques, autogenic drainage, breathing strategies (*e.g.*, paced breathing, pursed-lip breathing), chest percussion, vibration and shaking, forced expiratory techniques, pulmonary postural drainage and positioning to maximize ventilation.[3]

cancer patients.[10] Dysphasia occurred in 79 percent of hospice patients with end-stage head and neck cancer, 53 percent of whom had been treated with surgery and radiotherapy, and 37 percent treated with radiotherapy alone.[11] Nutrition, hydration, safety, and eating pleasure are negatively affected by dysphasia.[12] Individuals with swallowing disorders are at risk for aspiration, which occurs when food enters the airway due to weak or paralyzed pharyngeal and laryngeal muscles' inability to control food. ST can be used in a variety of ways as an alternative to limiting or completely eliminating oral intake. Simple remedies can be made by modifying position (using gravity to aid weakened muscles directing food toward the esophagus and reducing the risk of aspiration), cuing (another person sitting with the patient to remind him or her to chew and swallow each bite of food before putting another bite in his mouth as well as to cue to keep eating), bolus modifications (modifying consistencies and bite sizes), and swallowing strategies (dipping chin, additional dry swallows, etc.).[13] More recently, ST dysphasia treatments have been used more dramatically in hospice by integrating *deep pharyngeal neurological stimulation* (DPNS). This method applies stimulation exercises that the caregiver can execute independently after very little training. Success of this technique is not cognitively dependent and entails overstimulation of the swallowing reflex for 15 to 20 minutes to prepare for swallowing of medication.[14]

Components of functional ability

All three disciplines assess the support that the home environment provides the patient during execution of a functional task, looking for barriers or physical impediments that prevent the patient from functioning optimally in his or her surroundings.[15] The three disciplines break down each action or functional task into components and evaluate *quality*, *assistance*, and *equipment*.

1. Quality of technique:

- Is the patient's safety at risk with the method currently used?
- Are muscle groups working together or against each other in Coordination of movement?
- Does the sequencing of movement utilize momentum?
- What is the caregiver's ability, safety, coordination, and sequencing when assisting or supervising?

2. Assistance required:

Table 3. Occupational therapy: Activities of daily living

Functional task	Components/description
Self-care	• Bathing • Dressing • Grooming • Toileting • Self-feeding
Transfers (as they relate to ADL or home management)	• Shower or tub transfers • Toilet transfers • Retrieving objects from the floor, cupboards, high shelves • Carrying objects
Home management	• Food preparation • Managing faucets, lights, doors, drawers • Use of remote controls, phone, home appliances • Food management (grocery list compilation, grocery shopping) • Social management (transportation, calendar, communications) • Money management

- Set-up
- Initiation
- Verbal cues, supervision, stand-by, contact guard; minimum, moderate, or maximum assistance.

3. Equipment utilized or available:

- Appropriateness of currently used devices
- Effective and safe use of devices
- Need for different or additional devices

Of vital importance is to train the caregiver on how to increase the assistance provided safely as the patient's abilities decline. We are saving money and making money (*i.e.*, more potential referrals) by protecting the caregiver as well as the patient against injury. If a patient is minimally functional, transfers require a family member, who might be 130 pounds or so, essentially to lift 200 pounds of dead weight.[16] The person assisting a patient encounters problems when he or she falls and the person assisting moves to catch the patient, or when the assisting person is working with an aide or another caregiver and there is miscommunication.[17]

Proactive palliative care

One of the major problems identified in hospice care is the frequency of late referrals. If part of the solution is to present hospice as an opportunity to benefit from quality over quantity of life as "palliative care,"[18] we can anticipate that therapy will become more involved as a part of quality of life for the patient and caregiver. As the hospice period lengthens into a longer term of palliative care, it becomes apparent that caring for terminally ill family members or loved ones can be stressful and psychologically and physically exhausting. Dr. Nijboer and colleagues conclude that health care providers have to be more aware of the demands, problems, and rewards in store for home caregivers when they assume responsibility for a terminal loved one.[19] Therefore, the hospice and palliative care team needs to address these demands and potential problems before they become disasters. In this way, palliative care empowers the caregivers to be more effective in their care with less anxiety and danger. This proactive approach would build the program's reputation and success, reduce injury to the patient and caregiver, and decrease the expense as well as intensity of other team members' involvement. Therapy is elemental to the hospice intent of enhancing dignity and comfort and enlisting family involvement in the home.

Conclusions

I had the opportunity to attend Jack's funeral, rubbing elbows with powerfully built men with cauliflower ears and bent noses—colorful characters-and, as I mingled, I listened to bits of stories told with Brooklyn-accented great affection about the ox of a man I had the honor of knowing. I was proud to realize that I had experienced the man as his friends described him. Our team had empowered Jack to possess himself and die as a man in his house.

Table 4. Speech therapy: cognitive and oral function

Functional task	Components/description
Receiving information	• Auditory comprehension • Visual comprehension • Reading comprehension
Communicating information (expressing needs)	• Verbal expression • Nonverbal and graphic expression • Speech intelligibility • Voice quality and volume • Prosody (change in pitch, stress, intensity and duration of sound)[8] • Latency of response
Oral motor	• Tongue coordination • Lip closure (loss of food or drinking • Bolus control • Transit time • Food management (pocketing, etc.) • Swallow reflex • Cough or choke • Vocal quality following intake • Pocketing • Consistency of foods or liquids tolerated (*i.e.*, thin vs. thickened, puree, soft, mechanical or regular solids) • Presence of regurgitation

This is why I am here. This is why therapy is a part of Hospice. Therapy has the potential to decrease costs and balance the utilization of team members. Therapy allows concentration on elements of care within the scope of practice, empowers the family and patient, diminishes anxiety, decreases the incident of injury, and, most importantly, restores dignity.

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