The Treatment of the Hospice Patient: From Occupational History to Occupational Role

(cancer, occupational behavior, work, play)

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The nature of hospice care, particularly from the point of view of the occupational therapist, is presented in respect to the treatment of a 26-year-old patient. This case study demonstrates the role of the occupational therapist in helping a patient deal with his feelings of isolation, in helping him cope with severe physical limitations to maintain a maximum level of independence, and in helping him to deal with relationships with his fiancé, family, and friends. The reader is given a sense of the quality of communication between therapist and patient. Finally, a view of what the therapist can expect realistically when offering hospice care is considered.

For occupational therapists to play an active role in a hospice program, they must reconsider and reorder some of their current priorities. The efforts of hospice care are directed toward control of pain and alleviation of feelings of isolation. In order to attack pain, it is essential to understand the patients' former and present coping mechanisms, their views of life, their relationships with their family and friends, and their capacities and desires to maintain their independence.

People dying from cancer experience physical isolation, an actual withdrawal by family and medical personnel. The doctor and nurse spend less time in the room, examinations become more cursory, and physical contact is minimal. Family and friends visit less often and cut their visits short; vigils are kept in silence. Spiritual isolation, which is a little more subtle, occurs when the professional team and family stop caring for the patient as a human being. Feelings of isolation are exacerbated when the physician, family, and patient pretend that the prognosis is different from what it really is. Under such circumstances, meaningful communication is impossible.

Once hospice patients' pain is controlled, their attention turns to an appraisal of their lives. Their physical limitations can be traumatic. They can no longer predict from one day to the next what they will be capable of doing. Especially, they fear loss of control, of ability to care for themselves, and of ability to make major decisions concerning their everyday lives and future. At this time, every effort must be made to foster patients' independence in their occupational roles: namely, their self-care, work, and leisure.

Hospice care focuses on the quality of life, not by misleading patients about their prognosis, or oversedating them so that they do not have pain, and not by propping them up in bed and giving them something to do to make them feel useful. To divert patients' attention from their life, from their prognosis, from their feelings, and from their sense of personal worth is contrary to the hospice philosophy. Rather, the intent of hospice care is to assist the patient to cope, to adapt, and to feel needed, loved, productive, and above all, valued.

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Wilkens substantiates this point: "The way a patient feels about his health depends very much more on his attitude to his work, his family, and his society than to any mere physical or psychiatric diagnosis." (3, p 873) Kielhofner (4) states that
each patient must be viewed not simply as a physical or psychological creature, or both, but as a complex being with multiple needs—physical, psychological, spiritual, social, and economic. According to Shannon, "how one occupies time, as demanded by daily living activities of work and play, rest and sleep, can be the key to restoring productive involvement in life." (5, p 234) Of 50 cases personally studied over the past 2 years in England and Buffalo, 40 stated that their greatest need was to be independent in their self-care, and 46, that their second most important need was to resume their occupational (work) role, be it spouse, parent, and/or worker.

To assure that quality is to be the primary focus of the hospice patient's treatment, occupational therapists must take a biosocial as well as biomedical approach, which requires that patients be given every opportunity both to spell out and clarify what quality means to them and to manage and control their lives insofar as is possible (2). In the hospice setting, the occupational therapist must concentrate on making the most of patients' capacity and independence in self-care, work, and play within the constraints of their physical limitations. The "occupational therapist must serve an apparently paradoxical set of ends: hope without a future, a future without time." (1) A case study is presented to illustrate an occupational therapist's approach to treating a hospice patient.

Case Study

History. According to the occupational therapy assessment (6), Mark, the second eldest of eight children from an upper middle-class Native African family, had received the majority of his primary and secondary education in private Catholic boarding schools. By the time he had graduated from high school he had made numerous trips to England and Europe. From an early age he had demonstrated unusual interpersonal and leadership skills, and, at the age of 18, he was "tapped" by his uncle, the titular head of the family, to be the family's next leader. The medical history revealed that when he was 26, Mark underwent corrective heart surgery at Buffalo General Hospital while a student at the State University of New York at Buffalo. Upon completion of his degree, he went to London, England, and completed his master's degree. Shortly thereafter he returned to his native country as a chemical engineer. Six months later he had insidious onset of back pain and lower extremity weakness that progressed to paraplegia. An emergency medical visa was obtained so that he could return to Buffalo. Exhaustive work-up culminated in exploratory surgery confirming the diagnosis of liver cancer, which had metastasized to the spine. Mark's cancer was not curable by surgical excision. A course of radiation therapy and chemotherapy was initiated. At that time Mark was transferred to the Palliative Care Service of the hospital. He was severely depressed, withdrawn, and in pain.

For the next 2 months Mark received traditional care in the form of aggressive chemotherapy. He was also helped to come to terms with his prognosis. Because he was in considerable pain, he was given potent narcotics. As his pain subsided, analgesics were gradually reduced until he no longer required medication for pain. Mark was given physical therapy to strengthen his upper extremities and trunk so that he could transfer from bed to a wheelchair. He was also interested in learning intermittent self-catheterization of the bladder. Mark was, as well, given free access to the Palliative Care Service kitchen, which allowed him both to prepare foods and to gain some degree of environmental control and independence.

Eventually, the staff considered him sufficiently independent in self-care that he could move to his brother's apartment.

Assessment. The initial assessment, an adaptation of Moorhead's occupational history (6), was made in the two-story apartment Mark shared with his eldest brother and cousin. During the entire assessment, Mark lay in a hospital bed in the living room staring at the ceiling.

Mark demonstrated a strong work ethic and a personal desire to work before he died. He expressed a sense of failure at being incapable of fulfilling his responsibilities to his family, especially to his uncle. He was resentful because he could no longer participate in competitive sports; he expressed anger toward his disease; and he demonstrated a genuine sense of loneliness at not being able to leave his apartment and participate in social activities with his friends. His relationship with his fiancée had become excessively strained since he had become paraplegic. Larrington's temporal adaptation assessment (7) revealed that Mark spent between 12 and 14 hours a day watching television with minimal self-initiated productive use of time. He stated that he yearned for meaningful day-to-day activities.

A self-care assessment (Occupational Therapy—Hospice Assessment, Tigges, unpublished) revealed that Mark could transfer from his bed to wheelchair and return. He was independent in 50 percent of his bathing and dressing.
Although wheelchair independent, he was confined to the first story of the apartment, unable to leave at will since there was no ramp to the sidewalk level. He very much wanted to learn to transfer from his wheelchair to the davenport and to take a bath in the bathtub, which was on the second story of the apartment.

A physical assessment revealed muscle strength in the upper extremities to be normal. Trunk stability was good, and lower extremities were flaccid with good range of motion. There was no sensation from the nipple line down.

Treatment Goals. The biomedical and biosocial goals were established and agreed upon by the patient and therapist with an understanding that his life expectancy was approximately 6 months. Mark's biomedical goals were to learn to: 1. put his lower extremities through range of motion twice weekly; 2. transfer from wheelchair to floor to davenport twice weekly; 3. ascend and descend 15 steps, transfer into the bathtub with assistance. His biosocial goals were to: 1. entertain friends once weekly while sitting on the davenport; 2. bathe in bathtub independently once weekly; 3. engage in work appropriate to his educational experience; and 4. engage in play/leisure activities outside his apartment once weekly.

Initially, treatment sessions were scheduled twice weekly, 3 hours each. At the end of 2 weeks, Mark had accomplished the biomedical goals and the first two biosocial goals. He derived his greatest satisfaction from taking a bath in the bathtub independently and in private.

At the fifth treatment session the therapist and Mark discussed the realities of securing employment. As various strategies were discussed, Mark became visibly distressed. "I must work. I must be a self-sufficient person. I must be able to prove to my family and friends that I am a man. I must be able to prove to Anna (his fiancée) that I can be a productive and useful husband. Why couldn't I just have cancer? Why do I also have to be paralyzed?" Over the next 2 weeks six resumes were sent out and four interviews were held. As the last interview passed without results Mark became overtly angry, hostile, and resentful. He lashed out at his brother, the hospice physician, his nurses, the social worker, the lay volunteer, and the occupational therapist.

Mark had not seen Anna for 2 months and had talked with her only twice by telephone. On both occasions the conversations were strained, and Anna avoided talking about wedding plans. The hospice team realized that if Mark did not resolve the ambiguity in his relationship with Anna, he could not achieve a reasonably satisfactory quality of life under the circumstances. Since the occupational therapist had the most significant relationship with Mark, it was decided that he would attempt to help resolve the conflict. He met with Anna first and then with Anna and Mark. After 6 hours of discussion, it was agreed that there would be no marriage. The single most important reason for which Mark had stated he was living was now gone.

For the next 2 weeks Mark became intolerably hostile toward his brother and questioned the intentions of the entire hospice team. Conversations with the occupational therapist were guarded and curt. "It would be best for everyone if I would die—the sooner the better. I am a burden to everyone. Why do you persist in wanting to help me?" He rejected further chemotherapy for pain control and refused to get out of bed. He spent 14 hours a day watching television. Since Mark's drive and need to work had hinged on his desire to be married and support a wife, the incentive to be gainfully employed was now gone.

The therapist decided to re-approach the work goal by reconstituting the occupational choice process through play. The goal of reconstitution was to rekindle the incentive to work and thereafter explore options for full-time employment. The successful reconstitution of occupational choice must occur in a sequential manner, beginning with exploration, and continuing with crystallization and specification that involve opportunities for choice, risk taking, practice in learning and defining physical and emotional limitations/capacities, and options for exploring new decision-making strategies (8). The initial phase, exploration, is approached most effectively through the risk-free environment of play. Play encourages and allows for risk taking and for trial and error, which are essential for the development of problem solving and decision making. As Shannon has stated, "play also provides for identification with the worker role through the simulated experience of role playing. Most important, the repetitious nature of play leads...to the development of self-confidence and competence." (8, pp 290-291)

For adults, the vehicle for play is sport and recreational activities. For the purpose of reconstituting the occupational choice process, sport activities were selected because Mark had stated that a high priority for him was engaging in sports. The patient and therapist discussed...
a variety of spectator and participant activities. The spectator sports Mark chose were hockey and soccer. He chose to participate in basketball and swimming. The lay volunteer, who had been visiting Mark for several months, arranged to take him to hockey and soccer games on a regular basis and played basketball with him at a nearby court. The occupational therapist, a certified water safety instructor, focused on swimming because the buoyancy of the water affords maximum body freedom and physical independence and therefore assures a degree of success.

A private in-ground pool was made available. Mark transferred independently from his wheelchair to the edge of the pool. For 3 hours at the session the therapist taught Mark how to control his paraplegic body in the water. At the end of the treatment session, Mark was literally euphoric. "When we started out today, I knew I would not be able to swim; I was only an average swimmer before I got cancer. For the first time since I became paralyzed, I was able to move and control my body without a wheelchair or transfer board. You will never know how important this day has been for me." The first stage of occupational choice, exploring what one is capable of doing, had been initiated.

The next treatment session introduced risk-taking experiences such as swimming and floating unassisted. Successful risk-taking experiences lead to increased confidence and self-esteem, all necessary prerequisites for work. During this treatment session, the therapist subtly directed the conversation toward considering employment options other than engineering. His newfound capabilities in swimming permitted Mark to consider this idea without the hostility characteristic of his responses when work had been discussed previously. Also, the hostility that had been directed toward his brother and the hospice team was decreasing noticeably.

The following treatment session began with the request from Mark to walk. "More than anything I would like to stand upright and walk. My confidence is secure enough to take the chance, even though I may not succeed." The occupational therapist assisted Mark in standing upright and in walking on the floor of the pool. Although fully aware that he could not walk, the experience prompted Mark to initiate a conversation regarding alternative work opportunities that would match his educational background.

The exploration phase of occupational choice involves matching what is available with what one is capable of doing. The therapist suggested that Mark begin looking through the classified ads in the newspaper for positions available. Mark identified several types of employment that would match his skills. The crystallization stage, "narrowing of the choice field where the individual moves toward the choice of a specific occupation," (9, p 287) was realized when Mark chose teaching as the best possible option. Specification resulted when Mark chose to tutor handicapped university students in calculus and chemistry. During the next 3 weeks Mark accomplished more and felt more satisfied than he had since the onset of his illness. Quality of life peaked for Mark at this time. He was 70 percent independent in self-care, he was engaging in sports activities, and he was immensely involved in productive work.

Four weeks after Mark began working, he died. He died without pain, and he was surrounded by friends, his nurse, and therapist. Although he did not die willingly, he died having met most of his goals within the constraints of the time he had left and his remaining abilities. For the occupational therapist, whose goal is to help people make the most of their occupational roles, given their limitations of physical ability and time, Mark’s case presented a great challenge. That Mark was able to achieve the goals he identified for the therapist—working productively, taking care of himself to a great degree, and engaging in sports and recreational activities for the short time that he had left to live, must be regarded as success.

REFERENCES


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