Occupational Therapy in Hospice Home Care: A Student Tutorial

David Folts, Kent Tigges, Tina Weisman

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The number of hospices in the United States has grown from 20 in 1978 to 1,500 in 1985. The projected need is for 4,000 to 5,000 new hospices to serve the terminally ill by the end of the century. As the hospice philosophy advocates a holistic approach (i.e., the amelioration of biological pain and physical symptoms, diagnostic honesty, and the maximization of the quality of life), occupational therapy, operating from an occupational behavior perspective, can contribute to maximizing the quality of life for the terminally ill patient. There is an urgent need to train occupational therapists to meet the potential demand inherent in the rapid growth of hospice care.

Because there are at the present time no formal course offerings on the treatment of the terminally ill hospice patient, this paper proposes a tutorial in the form of a five-phase model for an undergraduate independent study in hospice care. Certain principles of the model are illustrated through case studies.

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The existing medical model has a curative and rehabilitative orientation, which promotes a positive attitude towards the future. Although this orientation is appropriate for the majority of patients, it is not appropriate for the patient with advanced cancer who has a life expectancy of 6 months or less. In the early 1960s, Cicely Saunders (1960) recognized that traditional medical practice, as well as the practice of allied health personnel, could not meet the special needs of dying patients, because their models were based on cure, rehabilitation, or the prolongation of life. Saunders, a nurse, then a social worker, and subsequently a physician, initiated, developed, and opened the first hospice in London, England, in 1969. Her model of care featured physical pain and symptom control, diagnostic honesty, and the maximization of the quality of life.

Occupational therapy, from the 1920s (Meyer, 1922), has recognized that a balance between work, rest, and play not only influences a person’s mental state but also has a significant impact on a person’s quality of life. This concept was reemphasized by Reilly (1966). Patients must be allowed to experience a natural order in daily living. Tigges, Sherman, and Sherwin (1984) state that being denied the opportunity to engage in occupational roles deprives persons of the opportunity to be contributing members of society and their family and thus sets into place the pain of isolation and abandonment.

In traditional medical situations patients expect to have a temporary disruption of their balance between work, rest, and play and a displacement in the natural order of daily living. In the case of terminal illness the issues of a temporary disruption/loss of life roles and balance become permanent when the patient is cared for in a traditional medical environment. This is not because traditional medical personnel doesn’t care about the needs of the terminally ill, but rather because their education, focus of practice, and resources are geared toward those who will live.

Saunders suggests that the orientation for those who care for the terminally ill should be founded on a humanitarian model, which is then blended with medical principles and ethics (1976). Saunders’s model and focus of care is parallel to occupational therapy philosophy (Tigges, Sherman, & Sherwin, 1984).

Undergraduate Students and Hospice Care

Traditional undergraduate occupational therapy education focuses on physical disabilities and psychiatry. In class, during student training or in fieldwork, students are presented with a wide variety of disabling conditions and chronological age groups. They also must complete 6 months of Level II fieldwork experience in physical disabilities and psychiatry. Although many curricula offer students a third fieldwork
experience, few do prior to the completion of the 6-month requirement.

It is not uncommon for students to experience a high level of anxiety shortly before they begin their Level II fieldwork because there is a wide gap between orientation and observation at Level I and practice at Level II. The two authors of this paper who were students were eager not only to reduce their anxiety by gaining more practical skills in interviewing, assessing, treatment planning, and direct treatment, but also to become more knowledgeable about hospice care. Therefore they enrolled in a hospice care independent study course, a tutorial in which they would be guided by their professor.

This independent study is recommended as a 4-semester credit hour course because it requires students to have an official relationship with an outside agency (in our case, Hospice Buffalo, Inc.), attend team meetings, and be involved in direct patient care. The course instructor arranges patient treatments around the students’ free time, in the evenings and on weekends. A practical schedule is 1 hour of formal lecture/discussion, 2 hours of attendance at team meetings, and 4 hours of direct patient care per week. This distribution varies depending on the needs of the patients and the availability of the student.

Since this independent study involved treating patients who would die within an average of 47 days, the students informed their other professors of the likelihood of their being absent from a class or two to attend a funeral.

This paper presents a 5-phase model formulated from the authors’ experiences with the hospice care independent study. Similar independent study courses could be developed, with this model for other areas of occupational therapy practice.

Phase 1: Formulation of Knowledge Base, Selection Process

As undergraduate students are unlikely to be familiar with the hospice philosophy and model of care, the first assignment was to review the literature, especially the topics of physical pain and symptom control, diagnostic honesty, death and dying, quality of life, and the role of occupational therapy in hospice care. The purpose of this initial study of hospice was not only to provide students with a more complete picture of hospice care but also to explore their personal and professional suitability for working with the terminally ill. If the mentor or the student did not feel comfortable, the student was given the opportunity to withdraw from the independent study without penalty.

Phase 2: Confrontation of Students' Personal and Professional Values

This phase is designed around role-playing and challenges the student to articulate his or her personal and professional values and attitudes about terminal illness, death and dying, and the intervention of occupational therapy. The mentor created a series of events and played the role of the patient, family member, and/or significant other. The students were expected to play the role of the student/therapist and had to respond extemporaneously to any question the mentor posed. Through these role plays, students were forced to scrutinize their own attitudes and respond appropriately. These role plays are difficult situations for the students; yet they are invaluable in helping them focus on the role of intervention as well as desensitize their personal feelings.

Typical questions posed by the mentor to the student are as follows:

- Am I really going to die?
- Why am I getting so weak? I thought after my surgery that I would get better.
- I know that I have cancer and am going to die. Why should this happen to me when I have just begun my professional career?
- Why has God done this to me?

Through role-playing, the student gains experience in responding to highly charged questions. This provides a measure of confidence so that when students are in an actual patient situation they will not fear saying the “wrong thing.”

Phase 3: Observation of Team Meetings

As in any health care model, achieving effective and appropriate care is the responsibility of the entire health care team. The opportunity to participate in hospice team meetings gave students the chance to observe how the team implemented the tenets of hospice care and how they defined professional roles.

At the first team meeting that the students attended, each team member explained how his or her contribution would blend with the contributions of the other professionals to effectively serve the dying patient. The physician’s role was to manage the physical status of the patient in pain and symptom control. The nurse was concerned with the day-to-day physical/personal care and comfort of the patient. The occupational therapist focused on how to maximize the patient’s ability to engage in the former roles of self-care, work, and leisure. The social worker was responsible for addressing interpersonal, social, and economic problems. Each staff member depended on regular communication with other team members. A
staff member treating a patient individually was expected to assess the need for intervention by other team members and to make appropriate contact with that member. The students learned the importance of attending not only to the occupational therapy needs but also to the other needs of patients.

Once the students were comfortable observers of team meetings, the mentor encouraged them to become more active by responding to questions posed by team members. The initial discomfort of participating in team discussions gradually disappeared as the students gained confidence when team members responded favorably to their questions or suggestions and accepted them as equal members of the team.

During each team meeting, the student observed how assessments and treatment plans were developed. In the beginning, the most difficult discussions for the students were those that occurred after a patient had died, because they had never before participated in open conversation, at a team meeting, about dying and death.

After the student had attended and participated in team meetings for 3 to 4 weeks, the mentor and student met to discuss the independent study program. The mentor used this opportunity to thoroughly evaluate the student’s academic progress and personal suitability. Once again, as in the previous phase, the mentor and student have the opportunity to end the independent study at no penalty to the student.

Phase 4: Assessment and Treatment Planning

In this phase, the student accompanies the occupational therapist assigned to a new case. Hospice Buffalo is primarily a home care program, assessment and treatment occur in the patient’s home. Before the first home visit the student is reminded of three principles. First, the patient’s home is his or her personal territory, and the therapist and student, although there on professional business, are guests. They can never presume to “take charge” or “demand” that minor or major changes in the patient’s life be made without the patient’s complete consent. Second, if the patient or the family offers refreshments, it is not only appropriate but also important to accept. Third, since home care is somewhat informal, the therapist or student could easily be tempted to befriend the patient and/or the family. It is essential to remember the professional reasons for being in the patient’s home and to be a therapist first and a friend second.

After the appropriate introductions the occupational therapist administers the occupational history (Tigges, in press) by interviewing and assessing the patient. The student learns through observing. After the initial assessment, the mentor discusses important points and asks for the student’s input.

Through these discussions students learn how to draw relevant assessment data and how to use the data to develop appropriate treatment plans. As soon as the students are comfortable observing patient assessments, the mentor involves them in the assessment process. Later the student does the assessment and treatment planning with minimal assistance from the mentor, and finally, when the student is comfortable with the patient and the family, he or she is allowed to make visits independently. During this phase it is essential for the student to have regular contact and discussions with the mentor.

Phase 5: The Vigil and the Death of the Patient

Most families express the desire to have their loved one die at home. However, for those few families who become fearful or apprehensive about being on their own at the time of death, the hospice offers the service of a vigil for the last 24 to 48 hours of the patient’s life.

When a vigil is required, a team of professionals or lay volunteers is organized to be with the family on an around-the-clock basis. Schedules are planned so that at least one member of the vigil team is with the patient and the family at all times through the death of the patient. The members of the vigil team are carefully picked from those people who played a significant role in the patient’s care.

Attending the wake and funeral is a professional responsibility of occupational therapists working at a hospice. It is the time when the therapist and the student help the survivors realize what an excellent job they, the survivors, did for the deceased and how appreciative the deceased was; they also help them recall the accomplishments of the deceased and how the deceased enjoyed the last few weeks or months of life.

By attending the wake and funeral the student says farewell to the family and the patient. As family members have become accustomed to the student’s presence, it is not uncommon for them to expect that the student will continue to visit them. Gently, but clearly, the student must convey the idea that he or she will no longer be making visits. Saying goodbye to the patient is especially important; professional and personal closure must be made if the student and therapist are to begin the next day with renewed vigor and enthusiasm. Professional closure is accomplished through objectively reviewing the role that occupational therapy had in maximizing the patient’s quality of life. Personal closure is subjective and rests on the student’s personal/religious beliefs and values. The mentor helped each student find what was right or necessary for him or her. For the Jewish student it was reciting the Kaddish at the grave and attending the shiva. For the Christian student it was kneeling at the casket, reciting the rosary, and participating in the requiem mass.

It is also important that the students be knowledgeable and capable in responding appropriately to patients and families whose religions are substantially different from theirs.
Case Study 1

John, a 65-year-old male, had a diagnosis of advanced metastatic disease of the brain, which left him with a prognosis of less than 6 months to live.

The occupational history revealed that John's work role, including 42 years at General Motors, had been very important to him. A strong work ethic was projected when he spoke of his Polish father being a butcher. In his own words, "My pop worked 15 hours a day, 6 days a week so his kids could have shoes to wear." At retirement, John and his wife carefully planned how they were going to live their life. Their plans had included participation in a senior center, and minivacations with the senior citizen group.

After work and leisure roles had been addressed, self-care was assessed and seen as problematic. John explained in a distressed voice that he did not have the coordination to button his shirt or zip his pants, which made him feel helpless and dependent.

Because of the nature of the cancer, dressing was an unrealistic goal since John's sensory-motor problems could not be reversed. Areas of leisure were then explored in the hope of providing John a semblance of an improved quality of living. He was asked, "If you could choose, how would you like to spend tomorrow enjoying yourself?" His answer was, "I would like to go swimming." For many years, he had gone out once a week to swim or "be out with the boys." At retirement, John and his wife carefully planned how they were going to live their life. Their plans had included participation in a senior center, and minivacations with the senior citizen group.

A treatment plan was developed to foster the patient's independence through the leisure activity of swimming and to relieve his wife from the task of caring for him 24 hours a day.

To accomplish the occupational therapy goals, the occupational therapist and student arranged to take the patient swimming at a private club. There he could realize and appreciate his time out with the boys.

When the student and therapist arrived the next day to take John swimming, he was crying and upset about leaving his wife. However, with encouragement from all concerned, he agreed to go.

Since he had moderate difficulty with standing balance, he was assisted down the front steps of his house. Once in the car, John stated that this was the first time he had been outside in a month.

While riding in the car, John became more animated describing the various city landmarks passed on the way to the center. By reminiscing, he could share his important memories of the city. At the center, the normal environment stimulated John to be more like his former self, an outgoing person. In this setting John could partially shed the sick role, and he grinned widely when a female lifeguard commented on how natural a swimmer he was.

Swimming for John served a number of ends. It gave him a chance to get away from home for a short time, which was beneficial to both him and his wife. It gave him a sense of independence. That he was able to do something that he had not thought possible became a source of great satisfaction. Finally, by getting out and having new experiences, he had something new and fresh to discuss with his wife.

Three weeks later John's condition deteriorated, and it was no longer appropriate to continue occupational therapy. Two days after that John slipped into a coma. Since there had been a strong bond between John, his wife, and the student, the student was asked by the team to participate in the vigil to give John's wife emotional support.

During the vigil, the student witnessed many loving acts by the patient's wife. As John had a fever, she cooled his forehead with a damp cloth while saying, "I love you, darling." She did this many times during the night. On other occasions, she held his hand and told him what a good husband and father he had been and how his children loved him.

Early in the evening John's children came to visit and to give support to their mother. His son said it was reassuring to know that someone would be with his mother when his father died.

After the children left, his wife shared with the student the family photograph album. Having someone there who would listen to her and even sometimes laugh with her meant a great deal to her. She told a humorous story of how they had first met and how proud she had been when he had returned from World War II. These things had given a special meaning to their life.

Before going to bed John's wife told him that it was all right if he died and that she loved him very much, and she told the student to wake her if anything happened. When John died, the student woke his wife, and the two of them bathed the body and then telephoned the funeral director.

When first walking into the funeral home, the student and therapist were welcomed by the wife with a hug and a kiss. On several occasions the student gave a hand squeeze or kind word to John's wife. Before leaving the wake, the student and the therapist...
approached the casket, knelt and prayed silently. This was the appropriate time to pay the last professional and personal respects.

**Case Study 2**

When the therapist and student arrived at Mrs. M.’s apartment, they found her in bed, happy and cozy under a warm quilt blanket. She had her television, cigarettes, ash tray, medicine, and books at arm’s reach. It was apparent that she had created an environment that was comfortable and safe for herself. The therapist introduced himself and the student and explained that the student would be the primary therapist.

With the permission of the patient, the student sat on the edge of the bed and began the occupational history, while the therapist withdrew from the bedroom to interview the home health aide. Mrs. M.’s occupational history revealed that she was a 74-year-old woman with a diagnosis of cancer of the breast with metastasis to bone, liver, and lung. The student was aware of the diagnosis and found it reassuring that the patient acknowledged her illness. Mrs. M., feeling comfortable with the student, stated that her two children had lots of responsibilities since they could not take her into either of their homes, she had hired a home health aide to live with her. Prompted by the student, the patient told her life history of the past 60 years.

A physical assessment was administered next. The findings revealed that Mrs. M. had significant muscle weakness in both the upper and lower extremities and that she was unable to ambulate independently. Mrs. M. was assisted in a stand-pivot transfer to the wheelchair and wheeled into the living room, where an in-depth conversation about politics and the upcoming election took place.

The student subtly redirected the conversation to determine what the patient would like most to do with the time she had left to live. Mrs. M. thought for a minute and said, “I think, I would like to have one very nice luncheon and card party for all my friends. If you think this is possible, I would have to do something about the way I look.” With this information the student developed two goals and a treatment plan:

1. Assist patient in bathing and grooming, with special emphasis on washing and setting hair.
2. Assist patient in planning a luncheon and card party.

For the next 3 days the student and the patient made elaborate plans regarding the time, invitations, food preparation, and table arrangements for the party. Although the home aide was to do all the shopping, Mrs. M. was to plan the menu and take charge of all the arrangements, thus enjoying a sense of control over the preparations and her role as hostess.

Three days before the event, the student found Mrs. M. withdrawn and uncommunicative. When asked if there was something on her mind, Mrs. M. quietly stated after a long silence, “I am a little frightened. When am I going to die?” While gently touching her hand, the student responded, “No one can actually tell you when the time will come, but it will be in less than a month.” Understanding the gravity of such a statement, the student allowed some time before continuing, “I'm sorry to have to tell you that the end is so near.” Mrs. M. responded, “You know, deep down inside I sensed it. You will never know how much I appreciate your honesty.” With a twinkle in her eye she slyly exclaimed, “Well, I guess I will be the first to know when I die, won’t I?” With that, Mrs. M. suggested she had best get organized if she was going to entertain.

The morning of the party the student and the therapist arrived. Together they installed a hydraulic bath seat. While the student assisted the patient in bathing, grooming, and fixing her hair, the therapist discussed the final preparations for the party with the home health aide. Shortly before the first guest arrived the student and the therapist left. The card party was a success.

A week later Mrs. M.’s condition deteriorated, and she was confined to her bed. The student continued to make daily visits, and the time was spent allowing Mrs. M. to reminisce. As Mrs. M. stated, reminiscing is “a fitting way to finish out one’s life.”

**Conclusion**

The hospice model of health care is gaining increased recognition in the public and medical sectors as an appropriate alternative for patients with advanced metastatic disease. Therefore, it is increasingly important for health professionals to become knowledgeable about the practice of hospice care.

In an attempt to meet this need for occupational therapists, the State University of New York at Buffalo initiated an independent study course in hospice care. As described here, this course has five phases. The theoretical aspects of the course provided an understanding of hospice philosophy and the roles of the occupational therapist in maximizing roles in self-care, work, and leisure. The clinical component provides students with an opportunity to treat patients on a one-to-one basis under the guidance of their professor. This practical experience helped course participants to bridge the gap between Level I and II fieldwork.

An independent study at the undergraduate level, prior to Level II fieldwork, may be considered inappropriate by many, and it certainly is not appropriate for every student. However, the opportunities afforded students in this experience helped them become more sensitive and effective occupational ther-
apists regardless of the field of practice they will enter after graduation.

References

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Related Readings


