Occupational Therapy in Hospice Care

(hospice, locus of control, occupation, quality of life)

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As hospice care becomes more integrated in the overall health care delivery system, the profession of occupational therapy needs to analyze further its potential within this unique system. This article briefly discusses the goals and philosophy of the hospice concept from the perspective of the National Hospice Organization. Occupational therapy intervention in terminal care is examined, with emphasis on locus of control and occupation as determinants in enhancing quality of life for the terminally ill in a nontraditional rehabilitative environment. A brief case study illustrates some of the general principles discussed throughout the article.

The hospice concept is comparatively new in our health care system and is a nontraditional setting in which occupational therapists have begun to practice. It is new in that little has been researched, documented, or published with respect to occupational therapy intervention. It is nontraditional in that a different perspective has been added to occupational therapy practice in physical and psychosocial rehabilitation.

Picard and Magno (1) presented a brief overview of hospice care and shared their perspective of occupational therapy intervention. “Although it is generally understood that hospice patients already have or are in the process of confronting and accepting the reality of imminent death, the presence of an occupational therapist in the hospice array of services points to a continued meaning in life, even if that life is measured in days.” (1, p. 598) They also emphasized the need for therapists to make their work with hospices known.

Tigges and Sherman (2) shared their work in hospice care and illustrated occupational therapy intervention through a case study. Their article demonstrated how one dying man’s quality of life was enhanced by improving occupational performance in skill areas important to the patient. “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.” (2, p. 236)

Hospice

The philosophy of hospice has not changed since medieval times, that of being a caring community within which persons can be comforted and cherished. The hospice philosophy of care is as follows:

Dying is a normal process, whether or not resulting from disease. Hospice exists neither to hasten nor to postpone death. Rather hospice exists to affirm LIFE by providing support and care for those in the last phases of incurable disease so that they can live as fully and comfortably as possible. Hospice promotes the formation of caring communities that are sensitive to the needs of patients and their families at this time in their lives so that they may be able to obtain that degree of mental and spiritual preparation for death that is satisfactory to them. (3, p. 14)

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Hospice is a concept, not an institution. Hospice care is defined from the dying person's perspective in terms of the individual's needs rather than by a system of medical knowledge. The development of hospice is a response to the issue of appropriateness in matters of environment and an individual's choice of the environment in which he or she would prefer to die. Most terminally ill persons prefer the home setting because it is the environment that is most familiar and the one in which optimal control can more easily be maintained in occupational functioning.

The five major goals of hospice, which all hospices strive to achieve, are: a) to enable the patient to live as fully as possible; b) to support the entire family as the unit of care; c) to make it possible for the patient to remain at home as long as home care is appropriate; d) to supplement, rather than duplicate, existing services; and e) to keep costs down (4).

To achieve these goals, an holistic approach to patient care is required, including not only the interdisciplinary medical team, which includes the chaplain, but also hospice planners, executive directors, and volunteers. Most important, it is the patient's community (goal b) that must be included in assessment, treatment planning, and overall care of the terminally ill. The patient's community includes family, significant others, friends, and even favorite pets. These components of the patient's human environment may provide valuable information about the patient and may be important and valued members of the treatment team. This community is essential in assisting terminally ill individuals achieve a new locus of control in their lives and thereby enhance their quality of life.

Locus of Control/Quality of Life

The capacity to exercise control over one's life is a variable that fluctuates from one person to the next. It must be seen as a continuation of earlier life experiences. For persons who have been dependent all their lives, it may not be important to stress independence at the end of their lives. However, for those who wish to maintain independence and control in self-care, work, and play, it is essential that they have the opportunity to do so.

Maintaining control over self and one's environment for as long as possible is one of the most basic principles of hospice care. "Hospice care providers must support those strengths in care for recipients to assume control over themselves, the environment, and the situation." (5, p. 28) It is the provision of this control that may also determine the extent to which a care provider has enhanced or improved quality of life for the terminally ill.

Care providers must remember that, in working with the terminally ill, quality of life is determined by the individual. Those areas of occupational functioning in which the individual would like to improve or maintain control are also determined only by that individual and not by any given therapeutic intervention that does not meet the occupational needs of the individual.

Some examples of providing a locus of control for the terminally ill may include adapting an easel for a painter with declining motor function for continued self-expression, creativity, leisure, and work, or adapting an Italian homemaker's environment so that she may prepare her favorite sauce and pasta, thus enabling her to continue her occupational work role. As another example, one terminal patient was referred to occupational therapy for a self-care program; however, it was understood between the therapist and the patient that, despite her seemingly independent self-care status, she would "allow" the nurses aides to dress her. "After all," she stated, "it's my choice to let them do it (bathing and dressing) for me." From these examples, it may be assumed that it is in one's favored occupational role that maintenance of a locus of control is essential for a terminal patient.

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Quality of life. The quality of life and control over one’s life to the end of that life are essential to the maintenance of dignity and self-respect.

**Occupational Therapy in Terminal Care**

When curative efforts have failed and the time of death is near, the patient requires relief from pain and other distressing symptoms, and the freedom to live in the manner of his or her choosing during final days and hours. Terminally ill persons should not be abandoned or isolated from usual sources of spiritual and emotional support, and they need to know they matter as human beings.

Allowing terminal persons to live in a pain-free environment permits them to feel safe. This sense of safeness gives them independence to be and to live, to get on with life. Occupational therapy enables terminal patients to maximize that independent state of being and living in the areas of self-care, work, and play, and thus achieve mastery and control over the self in both the human and nonhuman environments. Adaptation to a variety of changes in occupational behaviors is essential.

In view of the hospice philosophy, with the following two assumptions, occupational therapists can help provide relief from “other distressing symptoms” and allow for freedom of choice and permit exploratory behavior during an individual’s final days and hours. Therapists need not abandon or isolate the terminal patient, but rather they should promote spiritual and emotional support, and finally, treat their patients in such a manner that the terminally ill know they matter as human beings.

Assumption. For the terminal patient, involvement with occupation will help to enhance occupational performance and roles in the lifestyle areas that are important to the individual, within the limitations of the individual’s biomedical status.

Based on interdisciplinary input, Burke states that “occupation is a behavior motivated by an intrinsic urge to be effective in the environment in order to enact a variety of individually interpreted roles that are shaped by cultural tradition and learned through the process of socialization.” (5, p. 136)

Diagnosis of a terminal illness prevents, in most instances, those individuals with such a diagnosis from realizing maximal occupational functioning. With a thorough understanding of the occupational behaviors of the terminally ill, occupational therapists can assist those individuals, through occupation, to control the situation and the self better within respective environments.

The philosophical base of occupational therapy espouses that purposeful activity (occupation) facilitates the adaptive process, which may be impaired due to biological, psychological, and/or environmental factors. Occupational tasks provided to terminal individuals must be adaptable commensurate with declining physical and/or cognitive status. With the knowledge of impending decline in health, ultimately leading to death, occupation can be provided that is meaningful to the dying person’s lifestyle, helping the person maintain maximal occupational functioning, and thus pre-

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serving dignity, self-respect, and self-esteem for as long as possible.

It can be assumed that occupation, as the tool of the occupational therapist, can enhance the quality of life for the terminally ill by, but is not limited to, the following: a) achieving some degree of mastery over the self, the environment, and the disease process; b) promoting skill acquisition; c) promoting a sense of competence, productivity, and resourcefulness; d) maximizing occupational roles in self-care, work, and play/leisure; and e) providing for appropriate occupational choice with regard to patient needs and desires.

Assumption. Since the life goals of the terminal client and significant others, equally affected, have been threatened, former goals must be realigned, and new goals must be established and prioritized.

Upon diagnosis of a terminal illness, the client and significant others begin to realize a potential death trajectory, and they experience a mobilization of either integrative or disintegrative mechanisms with this knowledge of impending death.

Life’s activities must be rearranged. This taxes the psychological resources, since rearrangement is beyond one’s traditional problem-solving methods.

Using the occupational behavior paradigm of occupational therapy, the therapist can facilitate a reorganization of the disorganized family unit, can help the individual set priorities and maximize occupational roles, and can facilitate traditional or new problem solving in this novel and never-before-explored situation.

Throughout human development, persons tend to explore new objects, situations, and environments and make choices along the developmental continuum as to what is and is not pleasurable. Role models are provided to assist an individual with role transitions throughout life. However, dying is a one-time experience, with no choices given as to one’s future and no prior experience upon which to explore one’s capabilities.

The ability to control and master life situations suddenly vanishes, and one’s efficacy in the world is questioned, as life goals may no longer be realized. Temporal adjustment may be difficult; the terminally ill are suddenly confronted with the here and now.

In order for occupational therapists to assist the terminally ill person effectively in establishing and prioritizing new life goals, they must formally assess role performance in the areas of self-care work and play/leisure, and address during treatment primarily those areas in which the individual would prefer to remain in control.

Fear of the unknown is one of the greatest fears experienced by the terminally ill. The process of dying is a novel experience, one filled with unknowns. Fear of this unknown may be related to those fears experienced by the child who enters novel situations and explores his or her environment. Just as the child exhibits exploratory behavior to facilitate role transition, the terminally ill need to continue with exploratory learning in order to reorganize and prioritize life goals. Tigges and Sherman provide an excellent account of one dying man’s ability to continue exploring his environment and occupational choices to have a direct or indirect effect on current occupational functioning. An occupational history may also reveal the ability to manage time and the attitude toward control over temporal issues. An assessment of temporal adaptation, in the context of daily life occupations, is essential with the terminally ill, as most hospice patients generally have six months or less to live. Immediate occupational therapy intervention is indicated to assist in prioritizing goals in view of imposed time constraints on the terminally ill. The therapist must also provide a biomedical assessment, however, only in view of occupational functioning. This
can be most easily accomplished during assessment of self-care, work, and play/leisure occupations. The biomedical assessment, along with other sources, will provide feedback about pre-existing limitations and precautionary measures (e.g., seizure prone), and need not be formally assessed (e.g., manual muscle test, range of motion, perceptual testing), except in few cases, in light of the progressive nature of any terminal illness.

Reevaluation of the hospice patient should be done once a week or as deemed by the by-laws of each individual hospice. This is essential in order for the therapist to adapt occupations commensurate with declining occupational performance in self-care, work, and play/leisure.

During the occupational therapy process, and with a realignment of new life goals as determined by the therapist and patient, the terminally ill person can once again become productive, resourceful, and competent in occupational functioning. Terminally ill persons can remain an integral part of their social community and maintain their integrity, self-esteem, and dignity.

Case Study
The initial assessment, using an occupational history, revealed George to be a 78-year-old male, a former chef and restaurant owner who had lived in a trailer with his wife, helped George remain an integral part of their social community and maintain their integrity, self-esteem, and dignity. He was independent in bathing and minimal assistance was required to come to sit from supine. He was independent in bathing and eating, and he wore only hospital gowns. His leisure interests were sparse, and he stated that he enjoyed playing rummy and watching television.

After much consideration, George outlined for me exactly what it was he wanted to do. George's goals, all biosocial, were the following: a) to participate in playing cards three times a week; b) to prepare an Italian meal; and c) to wear street clothes daily.

After immediate occupational therapy intervention, George was able to dress independently in street clothes supplied by his wife, using proper positioning and some adaptive equipment. He also participated in playing rummy, with necessary adaptive equipment due to fatigue in holding the cards. After becoming competent in this skill, with problem solving facilitated by the therapist, George began to seek out other rummy players, and he found some fellow patients with whom he could play.

Georges wife was not aware of the activities in which George could continue in the nursing home environment and became quite interested in his program.

During the next treatment session, George became bedbound, with the cancer metastasizing much faster than the physicians had anticipated. Increasing moments of confusion and much weakness encroached upon George, making him incapable of performing any self-care, except eating some finger foods. When presented with a card game, George was unable to focus his attention long enough for even the simplest game. This session was to incorporate the Italian meal George so much desired, and I had supplied the materials. A kitchen on his nursing station was to be used.

After minimal discussion with George and his wife, it was decided that the meal would go as planned. Due to his being bedbound, I assisted George up in bed and supported his upper extremities, enabling him to break the spaghetti and stir the sauce, tasks in which he was cognizant and in which he displayed great pride and satisfaction. George's wife insisted that she prepare the meat because this was something she alone would like to do for George. As this was her need and a continuation of a role that she would soon have to relinquish, I stayed with George to ensure comfort and support when needed.

After the meal was prepared and brought to his room, George, upon smelling the food, propped himself up in bed with less assistance than during the preparation
stage, and, with some physical support, was able to feed himself some spaghetti using utensils.

Two days later, George died with his wife at his side and the hospice coordinator as a supportive member. During the funeral, George's wife related that the Italian meal in which George had participated was the first time he had eaten any solid food in three days and that it was the last time he had eaten. She also said it was her feeling that George had improved in his life quality by being able, once again, to perform those things that were meaningful to him.

George's wife was very much included in the occupational therapy process, and her need to continue to be a productive caregiver during this crisis period was also met.

Most important, this case study demonstrates the potency of occupation with a terminally ill individual, as demonstrated by a continuation in self-care, work (the Italian meal), and play/leisure (playing cards) roles. His occupational need to be an active participant in tasks meaningful to him, along with an intrinsic sense of motivation, precluded his obvious debilitated self. His dignity and self-esteem had been restored through his participation in occupation.

Conclusion

If occupational therapy is to provide a viable, useful, and meaningful service in hospice care, our profession needs to look at care of the terminally ill from an occupational behavior perspective, from a care-versus-cure perspective, and to extend beyond the traditional biomedical focus that is so often used in current practice.

Occupational therapists can emphasize that the dying are still living persons, with feelings, abilities, hopes, and dreams. Our professional calling is to promote maximal adaptation and to maximize occupational roles in accordance with the needs and desires of our terminal patients. Occupational therapy can enhance an individual's quality of life through purposeful occupation, which can provide a sense of competence, mastery, and control over the self and environment for the terminally ill. We can do this by using our knowledge and talents to make life meaningful and worth living for these people who deserve a chance to continue to be productive members of society.

Acknowledgments

Thanks to Kent Nelson Tigges, M.S., OTR, for his advice and constructive criticism, and to Sharon Hess, OTR/L, for her support. This paper was presented in part at the AOTA Annual Conference, Portland, Oregon, April 19, 1983.

REFERENCES