

CHAPTER 15

THE ROLE OF RECREATION IN HOSPICE CARE

INTRODUCTION

According to the National Hospice and Palliative Care Organization (NHPCO, 2011), hospice is a coordinated interdisciplinary program of supportive services and pain and symptom control for terminally ill people and their families. It is a concept of care, not a specific place of care. The purpose of hospice is to provide support and care to those in the final phase of a terminal disease so that they can live as fully and comfortably as possible.

The philosophy of hospice care is based on the belief that everyone has the right to die pain free and with dignity and that family members should receive the necessary support to allow them to do so. Hospice focuses on care, not cure, and in most cases care is provided in the person's home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities (NHPCO, 2011).

Providing meaningful and enjoyable leisure activities for hospice patients and their families is an important concern because a major problem for many terminally ill patients is the boredom that comes out of not doing anything. The purpose of this chapter is to develop an understanding of how recreation can play a role in hospice care, especially in caring for its elderly patients.

LEARNING OBJECTIVES

After completing this chapter, the reader will be able to

- understand the purpose and philosophy of hospice care,
- cite statistics on the growth of hospice care in the U.S.,
- identify at least three benefits of hospice care,
- identify at least three benefits of recreation for hospice patients, and
- identify appropriate leisure activities for various examples of elderly hospice patients.

OVERVIEW OF HOSPICE CARE

Hospice care has been expanding rapidly in the U.S. The number of patients served by hospice has increased from approximately 160,000 in 1985 to over 600,000 today. However, it is an underutilized service, with only one third of all dying patients receiving hospice care. One of the main reasons for the underutilization of hospice care is the late referral to hospice by physicians. The median stay for a person in hospice is only 15.6 days (Smith, Seplaki, Biagtan, DuPreez, & Cleary, 2008).

Dr. Cicely Saunders started the hospice movement in 1967, when she opened St. Christopher's Hospice in London. Her work with St. Christopher's Hospice has been the inspiration for many of the newly formed hospice groups in the United States (Stoddard, 1976).

Although the modern hospice movement has its origins in England, traces can be found of the hospice philosophy in the ancient Greek and Roman "healing places." Similar to modern hospices, these Greek and Roman places of healing emphasized "total treatment" of the individual—maximization of comfort, physical and mental stimulation, as well as medical treatment. However, dying and terminally ill persons could not take advantage of these healing places because such persons were felt to have little value to the state. On the other hand, modern hospices are specifically designed to help terminally ill and dying persons live as fully as possible until death and to help them to die peacefully. Unlike the Greek and Roman philosophy of "value to the state," Dr. Saunders states that "an individual matters up until the last moment of his life," (Stoddard, 1978).

Because Dr. Saunders and St. Christopher's Hospice have been so influential in the evolution of the hospice movement, a description of St. Christopher's program can facilitate a better understanding of hospice care.

St. Christopher's Hospice is a freestanding facility surrounded by beautiful landscaping. There is a reflecting pool and flower beds, a lawn, a chapel, a study center, and an outpatient clinic. Large paintings are found on most walls inside the buildings. Staff, visitors, and patients of all ages are found; the sound of laughter fills the air (Stoddard, 1978).

St. Christopher's is perhaps a "model" hospice program; there is great variation among hospice programs. Some are freestanding facilities, such as St. Christopher's, while others are part of a hospital or nursing home. Hospice programs can offer services to dying and terminally ill people in the patient's place of residence (private home or institution) or in the hospice facility (on an inpatient or outpatient basis) (Osterweis & Champagne, 1979).

The goals and objectives of hospice programs vary, but some generally applicable goals and objectives are to help terminally ill and dying persons maintain a personally acceptable quality of life until death, to help patients maintain and/or improve their mental and/or physical functioning so as to

promote their independence, to keep pain to a minimum and comfort at a maximum for patients, to help patients find meaning in their life and death, and to facilitate patients' families to respond appropriately to their family member's death (Alsofrom, 1977; Cunningham, 1979; NHPCO, 2011; Osterweis & Champagne, 1979; Smith et al., 2008).

Hospice programs include an array of services designed to meet the aforementioned goals and objectives. Some of the components of hospice care are pain control through the use of drugs and comfort maximization; home health care or inpatient care including physician services, skilled nursing, and psychiatric consultation; physical, speech, and occupational therapy; day care for the patient; homemaker services; meal preparation at home; transportation to and from treatment centers; education about death, emotional counseling; spiritual support; and bereavement services after the patient has died. Above all, an essential aspect of hospice care is loving kindness (NHPCO, 2011; Osterweis & Champagne, 1979; Smith et al., 2008; Stoddard, 1978).

Some of the staff needed in a hospice program are a hospice administrator, a medical director, a director of patient/family services, a pastoral counselor, volunteers, and a volunteer coordinator, and a medical records consultant. In addition, an interdisciplinary hospice team should include a physician, registered nurse, social worker, nutritionist, occupational therapist, and other rehabilitation therapists (NHPCO, 2011).

RESEARCH AND CASE STUDIES

Value of Hospice Care

Hospice care is a more desirable means of caring for the terminally ill for several reasons. Economic savings is one clear-cut benefit of hospice care. The costs of hospice care are much lower than the costs of care in a hospital.

Although economic benefits are fairly easy to document, it is more difficult to find clear-cut evidence that hospices actually help dying patients enjoy life more or maintain better physical and mental health in their last days. Hospice care is an area that does not readily lend itself to well-controlled, experimental study, thus the difficulty in inferring cause-and-effect relationships based on the literature.

However, case studies of hospice programs support the notion that hospice care is beneficial for its patients and their families (Ingles, 1974; Stoddard, 1978; Wentzel, 1976; Wald, 1979, and Ward, 1978). Ingles' article provides insight into the value of hospice through an in-depth description of St. Christopher's Hospice program. According to Ingles, St. Christopher's provides the love, kindness, and attention that dying patients so desperately need. The well-being of patients is enhanced through the provision of activities and services such as discussion groups, arts and crafts, group sing-alongs, flowers and plants in patients' rooms, television and radio, preparation of patients' favorite foods, and above all, companionship.

Wentzel's (1976) description of St. Christopher's Hospice also indicates that hospice care has a positive effect on terminally ill persons. According to Wentzel, many patients at St. Christopher's feel better than they have in years. Wentzel's article indicates that patients at St. Christopher's are relatively free of pain and surrounded by love. Both Wentzel's and Ingles' articles create the impression that St. Christopher's hospice patients are living their last days to their fullest.

Stoddard (1978) presents an overview of the Marin Hospice in California and the New Haven Hospice in Connecticut. Both of these hospice programs emphasize a humane approach toward treatment of terminally ill persons. Much like St. Christopher's, the Marin and New Haven hospices attempt to enrich the lives of its patients through the devoted efforts of paid staff and volunteers.

In a related vein, Ward (1978) describes the development and implementation of a hospice home care program connected with Overlook Hospital in Summit, New Jersey. The intent of this program is to help terminally ill persons live in their own home for as long as it is feasibly possible. Ward concludes that through an expansion of home care services, the hospital was able to better meet the needs of terminally ill patients and their families.

Wald's (1979) article conveys the value of hospice care through quotes from hospice patients and staff of the New Haven Hospice, Hospice Orlando, and Hospice of Central Pennsylvania. According to a spokesman for the New Haven Hospice, "There's never a point at which nothing can be done to make the patient more comfortable." This statement accurately sums up the rationale for hospice care.

Although the aforementioned studies provide evidence that hospice care can be beneficial for dying persons and their families, there is a need for more scientific evaluation research on hospice care. Clearly, not only is further research needed on evaluation of hospice programs, but evaluation research is also needed on specific components of hospice care. One such component of hospice care in need of further study is recreation.

Value of Recreational Activity to the Dying

Several case studies and programs discussed in the literature lend support to the notion that recreation and related activity therapies can work well with dying patients. Rogers (1978) cites the need to support the creativity of dying patients. Rogers describes the value of creative activities such as poetry writing, music, arts and crafts, dance, and drama to patients of the Hillhaven Hospice in Tucson, Arizona. According to Rogers, artistic stimuli helped create a more relaxed atmosphere for the Hillhaven Hospice patients.

According to Gilbert (1977), music therapy is a potentially beneficial resource for terminally ill patients and their families. Gilbert states that music is an activity that helps draw people closer together and that music therapy can open lines of communication between patients and their families.

Similarly, Cannon (1974) states that recreation can help an individual find meaning in one's death. Furthermore, Lovelace (1974) points out that in play, one's ego can feel superior to time, space, social, and physical limitations (all of these limitations are particularly relevant to terminally ill persons).

Both Newman (1974) and Cannon (1974) describe how recreational activity can help improve the quality of life of a dying person in the final stages of life. Newman states that recreational activity can help dying persons keep their mind off their disease; recreation gives a person something to do and something to talk about. Cannon cites an example of how recreation activity can be adapted for a terminally ill person in poor physical condition. The author describes how a sports-minded boy too sick for participation in active sports became the "sports editor" of his hospital ward—the boy collected sports information from newspapers, television, and radio sports reports and wrote a sports newsletter for the other patients on his floor.

RECREATIONAL ACTIVITIES FOR ELDERLY HOSPICE PATIENTS

The case studies and programs discussed in the previous section lend support to the notion that recreation can benefit hospice patients. Theory also dictates that recreation can benefit elderly hospice patients. According to hospice philosophy, the health, overall functioning, morale, life satisfaction, and self-esteem of clients are all very important concerns. Research indicates that recreation can effect positive change in these areas of elders' lives. Thus, why not provide recreational activities and programs for dying and terminally ill elders?

An often-cited argument against providing recreational activities and programs for elderly hospice patients is that dying and terminally ill elders have very limited abilities or desires to recreate. As illustrated in the following examples, this argument is false. Almost any person in a conscious state can enjoy and benefit from recreational activities.

Example #1

The Client

Mr. C is 68 years old, a cancer patient diagnosed to have only a few months left to live. He is in a weakened state and is unable to walk. He is able to sit up in a chair, but usually for no longer than two hours at a time. Mr. C. still has use of his arms, although his muscles are deteriorating due to lack of use. His favorite leisure activity throughout his life has been tennis. Unfortunately, he is physically unable to play tennis due to his weakened state.

Appropriate activities

Based on Mr. C's love for the game of tennis, and considering his level of functioning, there are numerous appropriate recreational activities he could enjoy.

- Adapted forms of wheelchair tennis, for example:
 - Playing on a regulation-size tennis court, modifying the rules and boundaries to enable a desirable level of success. If the tennis racket is too difficult to manipulate, a small wooden paddle can be tried.
 - Playing an adapted version of tennis on a smaller court with a lower net.
 - Mr. C could practice hitting tennis balls against a backboard, hit balls driven at him by a ball machine, tossed gently to him by someone, or even practice hitting a stationary tennis ball attached to a string.
- Mr. C might enjoy playing a tennis video game, while sitting in his wheelchair, or sitting up in bed (if a portable unit is available).
- Giving bedside tennis lessons could enhance Mr. C's self-esteem and provide much needed mental stimulation. Mr. C could demonstrate proper grips and explain strokes to tennis students.
- A simple, yet physically beneficial activity would be to periodically squeeze tennis balls, in order to increase arm and hand strength.
- Tennis-related spectator activity might also be stimulating. Mr. C could watch tennis matches on television and keep abreast of tennis news by reading newspapers and magazines. Mr. C might also enjoy going to nearby tennis courts to watch some local players in action.
- Mr. C might also enjoy playing racket sports similar in nature to tennis, such as table tennis and badminton. Such sports could probably be performed at a higher skill level than tennis by a person in a weakened state. Also, playing new sports and learning new activity skills can be an exciting challenge.

Thus, there are a variety of recreational activities Mr. C could enjoy, based on his love for tennis, and adapted to his level of functioning.

Example #2*The Client*

Mrs. A is 75 years old, suffers from lung cancer, and is diagnosed to have only a few months to live. She has been widowed for the past 15 years and has one daughter who lives 2,000 miles away.

Mrs. A lives in a personal care home and receives assistance with most of her personal care needs. She spends most of her time lying in bed or sitting up in a chair because she suffers from shortness of breath with the smallest amount of exertion. Mrs. A has had very few recreational interests throughout her life. She was a dedicated housewife and mother who "never had time to do much

else.” She never sought a career and had few friends. However, one aspect of housework Mrs. A always enjoyed was cooking. She said it was always important to her to serve her family good, nutritious meals.

Appropriate activities

Based on Mrs. A’s interest in cooking and considering her level of functioning, there are numerous recreational activities she could enjoy.

- Writing a cookbook would be a time-consuming, involving activity that could enhance Mrs. A’s self-esteem and maintain Mrs. A’s interest for a sustained period of time. Mrs. A could dictate the recipes from her bedside and the recipes could then be typed and placed in a folio. The cookbook project would be exciting and challenging, yet it would be an activity Mrs. A could definitely engage in despite her poor physical condition.
- An excellent activity for strengthening the fingers and hands would be to help knead bread as part of a bread baking activity.
- Mrs. A could act as a consultant for meal planning for the impaired elders residing in the personal care home.
- Home economics students from a local school could visit with Mrs. A for tips on bread baking or other aspects of cooking.
- Mrs. A could be involved with a local nursing home in helping to plan the refreshments to be served to the residents for parties.
- Mrs. A could subscribe to various nutrition magazines and be informed of any cooking or nutrition-related television programs that might be of interest to her.
- Mrs. A could assist in the preparation of simple snacks or meals at the personal care home.

Obviously, there are numerous recreational activities Mrs. A could enjoy, based on her interest in cooking and adapted to her level of functioning.

Exercise 15.1 presents another client example and asks you to use your imagination to identify appropriate activities for this person.

SUMMARY

Through recreational activity, a new dimension of meaning can be added to the final stages of life. Recreation can serve as a major motivational force to continue living. Is life worth living if it means an existence of pain, devoid of enjoyment? Recreational activity not only provides enjoyable experiences and laughter, which can be a motivational force to continue living, but it can also give an individual feelings of competence and self-esteem.

Both theory and practice indicate that recreational activity can greatly benefit hospice patients. Recreational therapists, volunteers, and even family members can employ leisure activities as a tool in improving the lives of hospice patients.

Exercise 15.1

Identifying Appropriate Leisure Activities for an Elderly Hospice Patient

The client

Mrs. B is 80 years old, a cancer patient diagnosed to have only a few months left to live. She is able to sit up in a chair for short periods of time, but spends most of her time in bed. Her favorite activities when she was younger were playing the piano and dancing. List and describe at least 10 activities that would be appropriate for this patient.

Appropriate activities

1. _____

 2. _____

 3. _____

 4. _____

 5. _____

 6. _____

 7. _____

 8. _____

 9. _____

 10. _____

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