The Behavioral Theory and Practice and the Hospice Phenomenon

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Introduction

In this paper behaviorist theories and practices which are utilized implicitly or explicitly in the hospice movement are discussed and examined. The begins by introducing the origins of the hospice movement and its philosophy. Then a description of a contemporary hospice care program which employs behavoristic practices in the treatment of the terminally ill is given. Some of these practices, illustrated by the hospice volunteers and staff, are especially significant to the dying patient (mentally, physically, and emotionally) and to the family.

The primary purpose of a hospice is to provide basic need and comfort for terminally ill patients. However, this does not present the entire picture of a hospice program. Underlying all of the care and comfort given to patients in a hospice is a psychological program based on the behavioristic model. For example, terminally ill patients are dependent upon a controlled environment. Another behaviorist characteristic is that reinforcement applied to the terminally ill elicits positive responses from such patients. This study will discuss the history of the hospice movement, its philosophy and standards, and will conclude by demonstrating how it incorporates behaviorist notions of psychology.

Origins of the Hospice Movement

Historically, hospices began during ancient times where they served as refuge for the poor, for travelers, for women in labor, for the needy, for the sick and dying, and for religious pilgrims. In the Middle Ages most hospices were governed by religious orders who felt that they were serving the Lord by serving the poor, sick, and those in need of shelter (Buckingham, 1983, p.53). Throughout Europe, hospices were received well in major villages, cities, towns, hermitages, and en route to the Holy Land. For instance, in the twelfth century A.D., the Knights of Hospitallers of the Order of St. John of Jerusalem aided pilgrims and the sick throughout Europe. The Knights instructed hospice workers to be kind to the patients and to serve to their fullest; and if the worker did otherwise, then they were to be whipped and given bread and water for a week. The Knights of Hospitallers lasted for six hundred years (Buckingham, 1983, p.11). A religious community, Sisters of Charity, continued to keep the hospice movement in existence during the nineteeth century. The movement of St. Christopher's was structered towards hospitality and care comparable to a modern hospital. After two thousand years of serving and offering sancutuary, the hospice movement continues to persevere. (Buckingham, 1983, p. 11).

Dying was considered part of living in the Middle

Ages. Therefore, travelers, pilgrims, and the dying were all housed together. A typical Medieval hospice was a combination of a guest house for travelers and lodging for the sick. These people were provided with shelter and food until they were ready to resume their journies or until their strength returned. Those who were dying were cared for until they died (Anne, 1983, p.28).

During the Reformation, monastaries were closing down, and as a result, specific distinctions arose between hospices and hospitals. In modern times, those distinctions have provided the basis for the ascendancy of hospitals as care-giving centers. Today the sick and the dying are administered to by public and governmental agencies. The discovery of new and life-prolonging techniques are due to advanced technology fostered by hospital settings. Hospitals are administrated by a bureaucracy over staff and patients. A hospital is well equipped for emergencies; however, it is not well equipped for comforting a dying patient. Hospices are continuing, as in the past, to care and assist the terminally ill and their families (Buckingham, 1983, p. 12).

The Modern Hospice Movement

Much of the credit for the modern awareness of the hospice movement is due to Cicely Saunders, from England. Dr. Saunders, in the late 1940's, was well acquainted with a man who was dying of cancer in a London hospital. Together

they shared ideas for a place where people who were terminally ill could die in peace and comfort. The man died in 1948 and left a legacy of 500 pound sterling. This money helped her start a center called St. Christopter's Hospice. The operation of St. Christopher's was structured towards hospitality and care comparable to a modern hospital (Buckingham, 1983, p. 12). St. Christopher's center was successful in its growth and it introduced a Domiciliary Service Program where it educated students, staff, and visitors. This program has been a model for other hospices in England and United States (Buckingham, 1983, p. 12).

The philosophy of a hospice care program emphasizes care, comfort, and guidance to families and friends as the terminally ill person approaches death. Jeraldine Kohut advocates ten fundamental practices for use with the terminally ill and their families and they are as follows:

1. Hospice is a humane way of caring for dying patients and their families
2. Admission to a hospice program is on the basis of patient and family need and not denied because of inability to pay.
3. The patient's comfort is the primary goal with an emphasis on pain and symptom control.
4. The patient, family, and other persons essential to the patient's care comprise the unit of care.

5. Care is provided primarily in the patient's home, but when available, hospice inpatient and outpatient facilities supplement home care services.
6. Hospice identifies and coordinates appropriate community services to provide complete care of the patient and family.
7. Care is available seven days a week, twenty-four hours a day.
8. A medically supervised interdisciplinary team of professionals and volunteers plans and provides the necessary care.
9. Trained volunteers are an integral part of the interdisciplinary team supplementing and complementing the team's efforts.
10. Education, training and evaluation are ongoing activities in the program (Kohut, 1984, pgs. 6 & 7).

Contrary to being anti-technological, the hospice practice combines technology and care to bring a positive attitude towards the terminally ill. Contrary to being anti-institutional, the hospice practice provides maximum personalized support to the dying person whether in a institutionized facility or at the person's home. In addition, the hospice staff or volunteer worker has no specific role and all workers are expected to be flexible. In a hospice a doctor may carry a tray, a maintenance worker

may comfort a lonely patient, and a guest may offer a prayer (Munley, 1983, p. 30).

The hospice movement can be broken down into five catagories or types of models, but essentially these are models of either inpatient or home care. The first general type of hospice program is Hospital-Based program. This can be divided into three models of care. In the frist model, the hospital provides complete care for the terminally ill, which and includes total accommodations at the hospital (eg. assigned staff and a unit of the hospital building). In the second model, a special hospice team is distributed throughout certain areas of the hospital, where care is provided for the patients. In the third model, a hospital - based home care program sends a hospice team to homes of the patients. However, this program is separate from the home-care program (Kohut & Kohut Jr., 1984, pgs. 8 & 9).

A second general hospice program uses a hospital-affiliated free accommodating staff who care for the dying. Although it is located on the hospital premises, it is still located within the hospital building (Kohut & Kohut Jr., 1984 p. 9).

A third general program is the free standing independent hospice model. This is a program that has its own separate identity and charter so that it can care for the dying person with its own accommodations and staff (Kohut & Kohut Jr.,1983 p. 9).

The fourth general program is the extended care facility model or the hospice in a nursing home. An institution, like a nursing home, is able to convert certain areas within its complex for a hospice center. The institution is governed by its own staff and is operated as usual (Kohut & Kohut Jr., 1984, p. 9).

The fifth general program is a home care program or hospice without walls. This functions both financially and independently within the homes of the terminally ill. Aid is provided 24 hours by volunteer staff; however, home care cannot accommodate for other patients like the larger institution of a hospice center (Kohut & Kohut Jr., 1984, p. 9).

There are twelve standards for a hospice care program which assists the dying patients and their family with appropriate guides that are sensitive to their needs. According to Anne Munley, the twelve steps which are the standard ways of maintaining a hospice are as follow:

1. The hospice program complies with applicable local State and Federal law and regulation governing the organization and delivery of health care to patients and families.
2. The hospice program provides a continuum of inpatient and home care services through and integrated administrative structure.
3. The home care services are available 24 hours a day, seven days a week.

4. The patient/family is the unit of care.
5. The hospice program has admission criteria and procedures that reflect:
   a. The patient/family's desire and need for service.
   b. Physician participation.
   c. Diagnosis and prognosis.
6. The hospice program seeks to identify, teach, coordinate, and supervise persons to give care to patients who don't have family member available.
7. The hospice program acknowledges that each patient/family has its own beliefs and/or value system and is respectful of them.
8. Hospice care consists of a blending of professional and nonprofessional services, provided by an interdisciplinary team, including a medical director.
9. Staff support is an integral part of the hospice program.
10. Inservice training and continuing education are offered on a regular basis.
11. The goal of hospice care is to provide symptom control through appropriate palliative therapies.
12. Symptom control includes assessing and responding to the physical, emotional, social, and spiritual needs of the patient/family (Munley, 1983, pgs. 320 & 321).

When a terminal patient is admitted into a hospice program, it usually means that active treatment is no longer

effective for the patient. Hospice care is primarily for those who are beyond cure but are still living and need human concern and comfort. The hospice allows the patient to live out life as fully as possible and does not intend to rush the death of the patient. Death is not a failure, so hospices view death as a way of living in which they help guide their patients along this final journey in life. This journey is where patients and families express themselves with dignity and significant interaction so that death becomes as pain-free as possible because it is shared (Munely, 1983, pgs. 35 & 36).

To give an illustration of a day in a hospice and the interactions involved, Anne Munley documents an account of her hospice experience. At Pennwood Hospice the nurses alternate shifts at 7:00 a.m. Each patient's day begins individually. Given that hospice patients have various energy level nurses, physicans and volunteers work at a patient's own level. Breakfast is served in the dining hall and is offered to those who care to eat there. Patients who are too ill to be moved are provided with breakfeast in bed. Special attention is given by staff and family to the terminally ill who are near death. After breakfast, staff members make their rounds to each patient's room to distribute medication or treatment so that the patient can function through the day. The Brompton narcotic mixture, and oral drug given with phenothiazine, relieves severe pain. Dosage is given to the patient according to his/her

needs. This mixture is given throughout months or even years to the patient, but the dosage does not escalate in amount (Kutsher et al., 1983). Thus, all throughout the day, staff members and volunteers visit with each patient and tend to any needs they may require (Munley, 1983, pgs. 44 & 45).

During Anne Munley's visit, she encountered many patients at various levels of their illnesses. Ruth, a tiny woman from New York, dying of cancer and physically deteriorating, was one of Anne's visits. Ruth was hot, and mentioned that her pillow case was wet. Immediately a volunteer worker refreshed Ruth with clean linens. The volunteer listened to Ruth talk about her children and later gave her a book to read (Munley, 1983, p. 54). Anne observed great concern among the staff and volunteers as they comforted the terminally ill. At Pennwood Hospice, there are certain functions to entertain the patients; such as, entertainment, as live music, sing-a-long, birthday parties, movies, etc. (Munley, 1983, p.54). During supper, there is the separation of those who will eat in the hall with the able patients and those who are unable to do so and, therefore, eat in their rooms. Afterwards, patients are free to do as they please. Family members or friends visit while staff members make their rounds with the other patients. Patients are found watching television, playing cards or listening to music. Throughout the evening, staff

members are maintaining control of the patients' needs, such as care, medication, or company (Munley, 1983, p. 55) Therefore, the staff presents all the care and attention necessary for the terminally ill to be as comfortable as possible. In the United States, it is becoming more of a standard practice for physicians to admit the terminally ill into a hospice programs. This is particularly true for cancer patients. At Pennwood Hospice, for example, cancer patients with a life expectancy of six months are admitted into their care program. Pennwood cared for 582 patients over a two year period. The average inpatient attendence at Pennwood was fifteen days and the average stay for home-care was twenty-five days. (Munley, 1983, pgs. 38 & 39). Today, cancer is the primary cause of death by disease in children. One in ten thousand children are diagnosed annually. These figures are high compared to other life threatening illnesses in children; however, these figures are rather low compared to adult cancer patients, whose rate is 10 times higher. There are 2,500 new cases reported annually of children who are diagnosed of lymphocytic leukemia, which is the major childhood type of cancer and who are treated in hospice programs. All illnesses afflict children emotionally, physically, socially, spiritually and psychologically just as they affect adult terminally ill patients. According to the National Hospice Organization, there are eight hundred hospicre programs in the United States, and yet less then twenty offer care to children.

This is because parents of the terminally ill child prefer to keep them in their home environment where they are comfortable rather than in a hospital (Buckingham, 1983, pgs. 86 & 87).

Terminally-ill children need to have an open communication with their doctors as well as with his/her parents. It is significant for children to share openly with their fears; such as dying and the reaction of their parents to their impending death. Children generally accept their own death quicker than their parents do. During one therapy, a dying child drew a picture of his father without ears. This illustration of the father without ears signifies a father who is not willing to accept the child's death. The care given to children, whether inpatient or home-care is very similar that given to adults who are in hospices. Home-care is more effective for terminally ill childern than hospital care, because in the home they are cared for by parents and siblings. When a dying child is home he/she can be part of the family with social funtions and home entertainment (Buckingham, 1983, p. 103).

The concern given to children care is similar to the care given to the geriatric patients in the hospice program. On the other hand, geriatric hospice patients are also treated with care and compassion, but the paradox is that old age is part of the life-cycle. Geriatric patients not only fear their illnesses, but also they fear death,

abandonment, and pain (Buckingham, 1983, p. 111). The terminally-ill geriatric patient is a person sixty five and over. Hospice care for the geriatric patient consists of caring for them physical, spiritually and socially. The staff and volunteers assist the elderly in any ways possible to keep the patient content and comfortable. The elderly struggle with self-denial. Being old and dying, they feel as though they are useless and have lost the respect of society. The death of an elderly person is considered less tragic as it is seems as part of the natural process. However, the philosophy of hospice care emphasizes the dignity of each individual and his/her life. Therefore, the terminal geriatric patient is given as much attention care and comfort as any hospice program would give to any dying person (Buckingham, 1983, p. 111).

Many hospice programs emphasize holistic approaches to care, such as the approach outlines by Kutscher (1983):

1. The holistic approach "reflects the philosophy that hospitals and hospital staff can no longer be responsible only for patients' well being, but also must be responsible for providing services that will aid the patient in other aspects of life that may be affected by the disease (Kutscher et al., 1983)."
2. Kutsche argues that terminal care is more than a regimen of medical care he asserts that "supportive therapy cannot be confined to drugs alone. As defined under the heading of "Holistic Medicine," psychosocial

measures are necessary adjuncts equal to supportive drugs in surgery, to radiotherapy and to chemotherapy as these are given to cancer patients. In our work, we attempted to develop a team concept of patient evaluation and support that made visible the economic and social benefits gained in providing for the total needs of patients with catastrophic disease- the relief of symptoms, the shortening of hospital time, and rehabilitation of patients for more effective survival (Kutscher et al., 1983)."

3. One of the most promising approaches to holistic care is the concept of the "living window." Kutscher describes it in the following way: "the existing stimulation provided for patients in most hospitals or nursing home situations consists of a television set, a radio, and a window.... What we seeking to create was a "kinesthetic room" and/or "living window " that could be tailor-made to suit the needs of individual patients, or patients in selected disease categories, face with sensory deprovation because of chronic illnes or confinement (Kucher et al., 1983)."

In order to understand how the behavioristic philosophy underlying the hospice program, a dicussion of these principles is in order.

Behavioral Theories and Practices

A behavorist studies the interaction between an

organism and its environment because behavior can be best understood by understanding this relationship. This relationship is active, so that the environment effects the organism and the organism effects the environment. Rarely can the nature of either the environment or the organism be understood by looking at the characteristics of one alone. Determining the result of such interactions depends on the fact that the environment and organism are part of nature and are thus governed by natural laws (Hull, 1943, p. 16).

Behavior is an external phenomenon such that the behavior is a function that can be studied by causal or functional analysis. Functional analysis is based on prediction and control of particular behaviors of individual organisms. This involves the use of a "dependent variable," (where the cause is the result of the effect) and an "independent variable," (where the behavior causes the function of the behavior to elicit external conditions). The laws of science are determined by these cause and effect relationships (Skinner, 1953, p. 35).

Skinner outlines the following principles for a science of behavior:

1. Our casual observations are not to be dismissed entirely. They are especially important in the early stages of investigation. Generalizations based upon them, even without explicit analysis, supply useful hunches for further study.

2. In controlled field observation, as exemplified by some of the methods of anthropology, the data are sampled more carefully and conclusions stated more explicitly than in casual observation.
3. Clinical observation has supplied extensive material. Standard practices in interviewing and testing bring out behavior which may be easily measured, summarized, and compared with the behavior of others.
4. Extensive observations of behavior have been made under more rigidly controlled conditions in industrial, military, and other institutional research.
5. Laboratory studies of human behavior provide especially useful material. The experimental method includes the use of instruments which improve our contact with behavior and with the variables of which it is a function (Skinner, 1953, p. 37).

The classification of variables, entails a process that enables behavior to change when any of the variables change.

These changes allow one to make discoveries so as to explain behavior. Primary behavioral studies are conducted in a controlled environment with specified conditions. When transferring terminology from animal control experiments to human control experiments, one moves into the realm of "behavior modification," or "applied behavior analysis" (Nye, 1981, p. 54).

According to Skinner, behaviors fall into two catagories: respondent and operant. "Respondent refers to a specific kind of behavior that is elicited by a specific kind of stimulus" (Nye, 1981, p. 55). This elicits a reflexive type of response, so the stimulus is the antecedent of the behavior. For example, a change with light intensity that contracts the nerves in the eyes or a tap on a nerve that contracts a muscle are respondent behavior. What Skinner called "respondent conditioning," Pavlov called "classical conditioning" and essentially both have the same meaning. Respondent behavior is a condition when a stimulus elicits a specific behavior and then a neutral stimmulus is associated of with the stimulus which produced the original behavior. For example, in respondent conditioning, the repondent behavior is salivation in classical conditioning. When food is presented, salvation occurs in response to the food. But when a bell is presented, salivation occurs as a result of the association of the food with the bell (Nye, 1981, p. 55).

Operant behavior is the other category, where the consequence is the product of the environment. The active organism emits the behavior rather than the environment per se eliciting the behavior. Examples of operant behaviors would include writing, reading, driving, and eating with a fork and knife. Operant behaviors are responses that constitute our everyday life, responses that define us as

individuals. The consequence of an emitted behavior may be its reinforcement. A reinforced behavior will become strengthened, there by increasing probability of occurence of a specific behavior in the future. It is important to remember that the specific behavior will be repeated, but a similar behavior as well might occur when one is reinforced (Nye, 1981, p. 58).

There is a distinction between reinforcement and reward that should be clarified. A reward strengthens behavior, but reinforcement might or might not strengthen behavior. The reward may vary from each individual organism and situation; however, the significance remains that the behavior must be strengthened. Reinforcement is an essential element for operant behavior. Responses like eating, speaking, and dressing may be reinforced through praise or approval by peers, teachers and by others; these are important social reinforcers towards conditioning behavior. Therefore, responses which are reinforced become repeated, thus escalating in frequency and establishing a common response in the individual organism (Nye, 1981, p. 49).

Affection, approval, and attention elicited from others become conditioned reinforcers because of their association with primary reinforcers such as food, shelter and love. For instance, parents who deliver praise and approval to their children also provide primary reinforcement such as cuddling, warmth, food, and so forth.

Another situation that affects human behavior is when the environment is manipulated (Nye, 1981, pgs. 64 & 65). It is in this area of environmental manipulation that we find our first link between behaviorism and the hospice movement. Much like behaviorist practices, hospices maintain a controlled environment to provide whatever is suitable for the dying patient. When a behaviorist manipulates, or controls, an environment, it is to elicit specific responses. Similarly, the hospice movement controls the environment to satisfy the terminally ill so they may approach death in a comfortable and peaceful manner. In Robert Buckingham's controlled study, during the years 1974-1976, he found that patients and families concluded that hospice services benefitted them immensely. Buckingham controlled primary care from staff and volunteer members. This control resulted in patients responding to death with less hostility and less anxiety than patients who did not receive primary care and support (Buckingham, 1983, p. 14).

Upon analyzing a hospice care program, it is apparent that staff and trained volunteers provide reinforcement for their patients. Within a controlled environment, whether inpatient or home-care environment, reinforcements are successfully managed for the dying patient. Staff and volunteer members elicit primary reinforcement to the terminally ill. The primary reinforcement care of food and

shelter are provided to the dying with affection,as well as with acceptance and attention. Reinforcement from parents, family, and staff are operants for the patients. This reinforcement insures the patient that they will be guided towards their death and that they are not experiencing death alone. The daily reinforcement that the terminally ill receive in a controlled environment, such as watching television, reading, conversing, are basically modes of special attention which affirm a positive response towards death. The operant response of the terminally ill is reinforced daily and thus has increased the success of the hospice movement.

Psychologists William Regelson and Brian West (Kutscher, et al., 1983) introduced technological ways to treat terminally ill patients in a controlled environment. In fact, Regelson and West (Kutscher, et al., 1983) argue that the best way to treat the terminally ill is in a controlled environment, because the dying cannot control his/her own environment. Kutscher (1983) describes the folowing ways offered to assist in a program for a dying person:

1. The living window: This used pictures of flowers, trees, familiar scenes, and exotic imagery presented by color slide projection and film techology.
2. The living window sequence was enhanced by music accompaniment to the changing images.

3. The kinesthetic technologist: the development of programs to require the training of a new technologist was begun in conjunction with the art and music and psychology departments of Virginia Commonwealth University.
4. Olfactory Stimulation: we had a chemical engineer who developed a program to give us up to 14 different odors, for example, roasting coffee, pine scent, chocolate, and flowers.
5. Sun Wall: we hoped to have a special lighting techniques that could imitate the sun migrating across the sky and provide morning shadows, mid-day overhead light, or afternoon shadows that again change the character of mood.
6. Feel Texture: we also planned to use the opportunity to stimulate touch (Kutscher, et al., 1983).

This program illustrates visual images and music, attitude and mood control that can be altered whenever patients experience lonelinesses, boredom and anxiety. Kutcher argues that environmental stimulation and control technology should be supported by the National Institutes of Health and hospices because this concept demonstrates new therapy for the terminally ill (Kutcher et al., 1983). When controlling a hospice environment, the consequences in resolving boredom, loneliness, confinment to a room aids to terminally ill patients as they approach death.

Conclusion

In reference to the hospice movement and its practices, it is evident that terminally ill patients are dependent upon a controlled environment. The staff and volunteer members provide the primary reinforcement (independent variable) to the the terminally ill there by improving their behavior (dependent variable). Reinforcement applied to the dying patient elicits positive response from the patient. Patients are given care and concern and are also treated as individuals. Thus, the philosophy of the hospice movement, where the hospice is to care in a humane way to the dying and family members, is in fact structured in a fashion that is congruent with behavioristic research and practice.

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