THE SOCIAL CONSTRUCTION OF THE “DYING ROLE” AND THE HOSPICE DRAMA

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ABSTRACT

The social construction of a “dying role” is emerging in response to terminal illness for which the “sick role” is no longer functional. When people are in the process of dying, in the absence of a “dying role,” they take on the rights and responsibilities of the “sick role” to which they have been socialized. This is problematic for the individual who will not get well no matter how hard the effort. Hospice, a professional community with a central purpose of bringing the drama of dying to an appropriate close, marks the transition from a sick role to a dying role. This article looks at how the hospice community directs this transition and redefinition of self for the dying and significant others. Utilizing the symbolic interactionist and phenomenological perspective and the sick role theory of Talcott Parsons, this view of the drama is demonstrated through stories of hospice patients.

American medicine has been successful in lengthening life, yet medical advances for some have caused emotional, physical, and financial pain. The medical drama, scripted to deal with those deemed “sick,” is not useful to actors unable to fulfill the expected role. What does it mean to be told one will not get well but rather will die? What is the role of a dying person and how is it different from the role of a “sick” person? How can the community define a dying role, teach a dying role, and support a dying role?

Talcott Parsons’ concept of the “sick role” provides a label for what happens when an individual is unable to fulfill their normal obligations due to some form of impairment. This role holds the expectation that it is temporary. If someone is labeled “sick” the normal obligations of the individual are

changed until they are “well.” For example, employers formally recognize this label with paid sick leave, schools recognize it through excused absences. What happens when this “sick role” does not fit? What if a person is not going to get well, is not going to get better, is not going to return to the normal obligations?

NEW CONTRIBUTIONS

This article is meant to create a unique theoretical perspective with which to examine the problems of the dying and the response of the Hospice community. It draws upon established theory and documented case studies from the literature and is supplemented by the author’s twelve years of hospice experience.

Phenomenological and symbolic interaction theory, Erving Goffman’s dramaturgical model (Goffman, 1973), and Talcott Parson’s functional definition of the “sick role” (Parsons, 1972) provide the base for this article. The contention here is that there is a “dying role” that has been created but not specifically identified. It is related to but different from the “sick role.” When people are in the process of dying, in the absence of a “dying role,” they fall back on the “sick role” to which they have been socialized. Yet when they do so, they are obligated to get well, and thus guaranteed to fail. The “sick role” and the “dying role” share a common ground in the sense that they both have rights and obligations. But in the case of sickness, the person is obligated to get well, while in the case of dying, the person is obligated to die. The two are polar opposites.

Hospice is a professional community with a central purpose of bringing the drama of dying to an appropriate close. It marks the transition from a sick role to a dying role. Caregivers assist individuals and their families in understanding dying and in doing it. The community defines who is eligible to play the role, what is expected (rights and obligations), as well as how families and others should play their roles in the drama. Hospice serves as an appropriate reference group for the dying person and close relatives. It advocates that the dying person and confidants write a script for the drama by co-directing with the hospice team to produce a performance that redefines the part of the lead actor from a “sick role” to a dying one. There is a body of knowledge hospice caregivers pass on to actors, allowing them to embrace the dying role and avoid confusion with, in this case, the dysfunctional “sick” one. It is a process of redefinition. Indeed, the social construction of a “dying role.”

The purpose of this article is to show how the hospice community symbolically and in real time renegotiates a “sick role” into a “dying role,” and in the process replaces a loss of meaning and purpose, fear and suffering, with a peace of mind, a sense of value and worth, and as a result appropriate death becomes socially constructed and validated. This serves as an example and a model for medicine as a whole as it seeks to improve care at the end of life.

THE SICK ROLE

A great amount of literature in medical sociology has focused on Talcott Parsons' concept of the "sick role." This functionalist perspective, and others similar to it, describe how society handles individuals who are unable to uphold their normal role expectations and obligations due to physical or mental impairments. These "sick" individuals, through no fault of their own, are given a designated role with rights and obligations.

The sick role has been identified by Parsons (1972) as an acceptable deviant role. He provides a description in *Definitions of Health and Illness in the Light of American Values and Social Structure*:

... it is a socially institutionalized role-type. It is most generally characterized by some imputed generalized disturbance of the capacity of the individual for normally expected task or role-performance, which is not specific to his commitments to any particular task, role, collectivity, norm or value. (p. 107)

The sick role has been described by David Mechanic as an ideal type that defines the social properties of sickness definitions, "the conditions under which persons can legitimately claim illness, and their responsibilities in responding to their illness" (Mechanic, 1968, p. 58). He explains that it is the social context that determines the conditions under which one can claim illness and be released from usual obligation and responsibilities without stigmas (Mechanic, 1968).

In *Definitions of Health and Illness in the Light of American Values and Social Structure*, Parsons identifies four unique features that are often referred to as rights or obligations of the role. First, individuals are not held responsible for their illness. They are not at fault for getting ill, it is something that happened "to them." Secondly, Parsons claims that the "illness is interpreted as a legitimate basis for the exemption of the sick individual, to varying degrees, in varying ways, and for varying periods according to the nature of the illness, from their normal role and task obligations." Thirdly, he points out that it is an undesirable state, and in order to legitimize being sick, the ill are expected to "get well" and to cooperate with others toward this end. The "sick role" is thus a temporary one. Finally, Parsons suggests that the sick person, and related others, are expected (obligated) to seek competent help, primarily through the medical system (pp. 107–108).

Parsons (1972) further argues that the sick role has two distinct functions. First, it insulates a sick person from "mutual influence" with those who are not sick. He states "... motivationally as well as bacteriologically, illness may well be 'contagious' " (p. 108). He points out that this is an important feature because:

... the designation of illness as illegitimate is of the greatest importance to the healthy, in that it reinforces their own motivation not to fall ill, thus to avoid falling into a pattern of deviant behavior ... the mobilization of

considerable resources of the community to combat illness is a reaffirmation of the valuation of health and a countervailing influence against the temptation for illness, and hence the various components which go into its motivation, to grow and spread. Thus the sick person is prevented from setting an example which others might be tempted to follow. (p. 108)

Secondly, Parsons explains that the institutionalization of the sick role labels the individual as someone needing help and being obligated to receive it. It brings the deviant into contact with health care providers, and “. . . the sick role tends to place him in a position of dependency on persons who are not sick. The structural alignment, hence, is of each sick person with certain categories of non-sick . . . persons” (p. 108).

He writes that the most important feature of the sick role is that it is a deviant one and by being such it “. . . is only legitimized so long as it is clearly recognized that it is intrinsically an undesirable state, to be recovered from as expeditiously as possible” (p. 113). David Mechanic states that illness tends to be thought of as an individual concern. There are times that it becomes a threat to the community and may lead to community action. Indeed, if too many people in society are ill, there may be a work shortage (Mechanic, 1968). Parsons goes so far as to claim that maintaining adequate health of any group is a functional requirement of any social system. A definition of illness that is too lenient puts strains on society. Thus, the definition needs insure that too many persons in a given society not be let out of their normal responsibilities, otherwise the system suffers. Parsons argues that control is reestablished by the functional requirements of the sick role. Mechanic concurs by calling for a legitimate procedure for the adoption of the sick role (Mechanic, 1968).

THE SICK ROLE AND THE CHRONIC AND TERMINALLY ILL

Difficulty is encountered by individuals who are ill but may not be appropriately labeled as sick. The rights and especially the obligations of the role may not apply. Individuals with a chronic illness or a terminal illness cannot meet sick role obligations. Kassebaum and Baumann identified some major obstacles that individuals with chronic illness have in fulfilling the role. They argue that when expectations and obligations are applied, conflict within the individual is experienced. The role does not fit. The role is problematic because chronic illness is by definition permanent, not temporary, so role expectations based on a temporary nature of the “sick” label do not apply (Kassebaum & Baumann, 1972).

In *Dimensions of the Sick Role in Chronic Illness*, Kassebaum and Baumann claim that “. . . norms prescribing permissive treatment and exemption from role obligations in the event of acute illness may require respecification when prolonged adherence to them becomes a threat to the role-performance of the patient”

(p. 133). Resuming roles to pre-illness capacity may not be possible in the case of a chronic illness; sometimes adjustments to may be required. Finally, Kassebaum and Baumann (1972) state that chronic illness is not distributed randomly in a population, but is more often associated with old age:

Like the sick person, the aging individual is not held responsible for incurring his condition, nor can he arrest it by any act of volition . . . those usual role-obligations from which exemption is temporarily granted, and to which return is anticipated for the young patient with acute illness are far from clearly defined for the older chronic patient. (p. 133)

The most prevalent contrast with the sick role for individuals with a terminal illness is that they will not recover and will never return to even a partial state of previous normalcy. Former roles become not excused but eliminated, as life is now in question. They are forced to realize that even though fulfilling the responsibility of the sick role in seeking the help of competent providers, these practitioners often offer them no answers, no assurance of recovery, no "hope" as defined in the sick role. They come face to face with the fact that although they may have fulfilled the responsibilities and obligations of the role, it has failed them; they will not return to society.

Table 1 outlines the differences between the sick role, chronic illness, and the dying role.

This traditional, usually functional, concept of the "sick role" and the social institutions that provide legitimization for it fail, both from the perspective of the dying individual and from the perspective of the social institution. This often leads to frustration on the part of medical practitioners and guilt on the part of the individual. The "sick role" is thus dysfunctional to the drama of those who cannot fulfill it.

David Mechanic, in *Response Factors in Illness: The Study of Illness Behavior*, states:

Medicine has three principal tasks: to understand how particular symptoms, syndromes or disease entities arise either in individuals or among groups of individuals; to recognize and cure these or to shorten their course and minimize any residual impairment; and to promote living conditions in human populations which eliminate hazards of health and thus prevent the occurrence of disease. (Mechanic, 1972, p. 118)

However, medicine and traditional medical institutions are designed to deal with those who are "sick" and are unsatisfactory for individuals who are "dying." The particular tasks of medicine identified by Mechanic are only appropriate to serve those who have hope that their lives will continue not for those whose lives have permanently changed and will soon end.

Medical practitioners and medical institutions struggle daily to deal with individuals who will not improve, but who will instead die. Treatments that traditionally are used to save lives often prolong suffering when provided to a

Table 1. Comparison of the "Sick Role", Chronic Illness, and the "Dying Role"

"Sick Role"	Chronic Illness	"Dying Role"
<i>Rights and obligations of a role by T. Parsons</i>	<i>Differences from sick role by Kassebaum and Baumann</i>	<i>Difference's from sick role by Oliver</i>
1. Individual is not held responsible for condition.	1. Individual is not held responsible, chronic disease is not randomly distributed, associated with age.	1. With some diseases, individuals may be seen as responsible (AIDS).
2. Person is expected to get well—temporary condition.	2. Not a temporary condition.	2. Person will not recover.
3. Illness is reason to excuse from normal roles and tasks.	3. Incapacity is more partial than total. Resuming previous role may not be possible. Adjustments to a previous role may need to be made.	3. Former role is not excused, but is eliminated.
4. Sick person is responsible for getting competent help and to cooperate in treatment requirements.	4. Person is responsible for getting help and cooperating, but will continue to need assistance and make adjustments to role.	4. Person seeks help, cooperates, but does not improve. Competent help may not be available; treatment will not help person to recover.
(Parsons, 1972)	(Kassebaum and Baumann, 1972)	(Proposed in this article)

dying person (e.g., administration of intravenous fluids). In Hospice, medications traditionally used for one purpose may actually be used for something quite different with a dying person. For example, it is not uncommon to administer morphine, traditionally used for pain control, to a patient experiencing shortness of breath. Respiratory suppression is a beneficial side effect which brings comfort. The more medical practitioners fight to keep a person alive, the less alive the individual is allowed to be. And worse, the dying person suffers from the side effects of the treatment that is supposed to heal them. Dr. Ira Byock, in an article for the *New York Times*, correctly states that "... high tech medicine can

inadvertently deprive dying patients of what they say they want: a death free from burdensome procedures and machines" (cited in Stolberg, 1977)

A significant empirical research project that demonstrates the struggle of medicine with death, is the SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments). Published in 1995, it includes 9,105 adults hospitalized in five teaching hospitals with one or more of nine life threatening diseases. The study concludes that patients and families are not included in discussions and decision making, that estimates of outcomes are unrealistic, pain is under treated, and dying is prolonged and occurs in hospitals far too often. Despite a follow up intervention phase involving education of professionals, outcomes did not change (SUPPORT, 1995). This study supports the dysfunctional nature of the "sick role" as well as the institutions established to validate it.

THE "DYING ROLE" AND THE HOSPICE COMMUNITY

As a result of the dysfunction and frustration created for dying patients forced into a "sick role," and the traditional healthcare system that represents it, Cecily Saunders founded an institution and a philosophy designed to create a new legitimate role for dying individuals and a new type of medical care to go with it. That institution is Hospice, and the new role is a "dying role" with different, often opposite, role expectations and obligations.

Dr. Saunders recognized the need for a different type of medicine for those whom traditional care could not help. This new approach places comfort ahead of a cure and quality of life ahead of prolonging life. Initially started in England and concentrating on inpatient care, the concept and practice has moved to the United States within the last twenty five years. "Hospice" in medieval times was a place for weary travelers to find shelter and rest. The modern concept is a comprehensive model of care for the terminally ill entering their final journey of life. The movement gained momentum in direct response to the fragmentation of the health care system (Kilburn, 1997). Following a rocky beginning, it was eventually supported by local communities as well as by medical professionals. The latter recognized the inadequacy of existing systems as failing to meet the needs of the dying person and his or her family (Kilburn, 1997). Kathy Charmaz (1980), in *The Social Reality of Death*, writes:

Acknowledging death makes for a different kind of death work. First, it enables patient and family to participate in decisions about how care is to be handled. Second, emphasis shifts to quality of life experienced while dying, rather than quantity. Third, pain control is likely to become more individualized, reflecting the diverse needs of patients. Fourth, greater attention is given to the social-psychological aspects of dying. Fifth, when acknowledging death is a general practice, patients are more apt to become involved in each other's lives as there is no need to keep the dying separate and invisible. (p. 181)

Charles Corr stresses that the hospice movement began due to the belief that dying patients are living human beings. Hospice does not see these patients as merely examples of malfunctioning lungs or defective kidneys, they are living persons (Corr, 1991). This point may seem obvious, but it is missing in traditional *health care*.

Hospice care focuses on pain control and symptom management by an interdisciplinary team of professionals approaching problems in a holistic, individualistic manner. The goal is not to prolong life, but to enhance its quality and help individuals renegotiate meaning and purpose by redefining their lives, not in terms of being “sick,” but in terms of living until they die. This is in direct contrast to traditional health care for those in a “sick role.” Corr (1991) illustrates in his article, *A Task-based Approach to Coping with Dying* by writing:

One might think that an emphasis on pain relief and the control of distressing physical symptoms would be a major concern of all medical and health care systems. In a sense, this is true, but it was precisely the lack of adequate relief of distressing symptoms in a context of a terminal illness that stimulated the development of early hospice programs. This deficiency may have evolved for many reasons: a tendency to withdraw from dying persons because of a sense of frustration or inadequacy, a fear of failure, or concerns about one's own mortality; inadequate understanding of pain and other symptoms; misplaced fears of addiction; or an overemphasis on cure-oriented interventions associated with distressing side effects. Whatever the reasons, reforms in palliative care—the management of distressing symptoms—were clearly needed. (p. 84)

Dying individuals are often deemed “hopeless” by physicians. Mechanic suggests the goal of physicians is to improve health and restore sick persons to their previous state. When this is not possible, patients are viewed as not having hope because they cannot be cured (Mechanic 1968, p. 81). An important role for hospice is to assist them in redefining their situation and discovering hope they so desperately crave. Corr writes that the difference between hope and wishing is that the former is grounded in reality. Hospice assists the dying and their families in redirecting hope into achievable, realistic outcomes. It assists the dying to redirect their focus from cure to the achievement of other goals such as freedom from suffering, living to experience some significant event, achieving reconciliation, or controlling what will happen following death. To do this, hospice listens carefully to the goals, dreams, and expectations of patients, helping them to identify the “definition of meaningfulness in living” (p. 87).

Philippe Aries (1981), in his classic book *The Hour of Our Death*, points out the importance of this alternative approach. He writes:

Death is not a purely individual act, any more than life is. Like every great milestone in life, death is celebrated by a ceremony that is always more or less solemn and whose purpose is to express the individual's solidarity with

his family and community . . . The three most important moments of this ceremony are man's acceptance of his active role, the scene of the farewells, and the scene of the mourning. (p. 603)

The hospice community seeks to assist patients and families in accepting a new role, in scripting and controlling as many aspects of the drama of dying as possible, and in directing the drama through participation in medical care along with emotional and spiritual support. The goal of the community is to help produce a drama so the performance fulfills the needs of the dying person and their significant others. Marcia Lattanzi-Licht (1997), in *The Hospice Choice*, says it so well: "Hospice presents families the opportunity to play out their own themes, to sing their own songs" (p. 12). It redefines the concept of "sick care" into terminal care, the "sick role" into a "dying role."

SYMBOLIC INTERACTION THEORY AND DEATH

In describing the hospice community, it is useful to utilize symbolic interaction theory. The symbolic interaction perspective was influenced by the writing of George H Mead. In *Mind, Self, and Society*, Mead describes a world based in the social interaction of individuals rather than a reliance on social structure or personality characteristics (Mead, 1934). Joel Charon describes the perspective as creating an active image of interacting individuals, taking one another into account, acting, interpreting, and acting again (Charon, 1979). The symbolic interaction school of thought contends that society is made of individuals who interact, communicate, and develop shared meanings for everyday life. Humans are dynamic and changing based on their interpretation of the symbols and meanings they create (Mead, 1934).

In looking at death, symbolic interaction theory holds that our conceptions of death, our images of where "dying" occurs, and what happens in the "dying process" are socially constructed. Although death is a biological event, the meanings that it holds and the customs and institutions affiliated with it are socially defined. Just as in life, in death interaction is characterized by agreed-upon symbols and meanings that shape our experience. Symbolic interaction theory explains that all persons reinterpret previously accepted views and roles and construct new meanings based upon new experiences. In *The Social Reality of Death*, Charmaz (1980) says:

. . . the Symbolic Interactionist perspective expects conscious, dying persons to be capable of interpreting their worlds and of participating actively in whatever decisions are made regarding them. Essentially from this perspective, meaning shapes experience and experiences shape meaning. (p. 18)

As individuals choose new meanings and new modes of action, the definition of the situation changes, new behaviors and roles are enacted, support is provided

by new reference groups, and new methods of handling death emerge. Interpretation and meaning are rooted in the value people have concerning the act, the definition of the situation, and key interactions in their world (Charmaz, 1980). The hospice community seeks to become the new reference group for the “dying” and to assist in the process of interpretation and redefinition of the situation. Ira Byock (1997), in his new book *Dying Well*, points out that the hospice community believes that “when the human dimension of dying is nurtured, for many the transition from life can become as profound, intimate, and precious as the miracle of birth” (p. 56).

THE DRAMA OF DYING

Scene One: Introduction of the “Dying Role”

Individuals are introduced to the hospice community in many ways, but all must be referred by a licensed physician. The physician is the gatekeeper and must “certify” that the patient is indeed appropriate for hospice care. In this manner, just as with the “sick role,” the legitimate authority designating the “dying role” is the physician. Although trained to find a cure for the “sick,” these same physicians identify those who do not meet the “sick role,” and give them instead a “dying” one. It is perhaps the confusion of the two roles that often prevents physicians from identifying non-cancer patients for hospice admission. Determining the designation of “dying” rather than “sick” is a difficult task for those trained exclusively to treat the “sick.” Cancer diagnosis, with more explicit indications of disease progression, are more readily identified than chronic diseases with slower, less noticeable signs of decline. However, this trend does seem to be changing as hospices have developed clinical guidelines to assist physicians with this gatekeeping responsibility.

Officially, the requirement for admission into the hospice community requires a physician to certify the patient as having a terminal condition with a life expectancy of six months or less. In addition, the goal of the care must be to manage symptoms rather than to prolong life. The focus is on quality of living rather than extending it. Patients and families must consent to hospice care. They agree to a philosophy. Denoting an understanding, this initial screening is the first step in the initiation of a dying role as the patient and family give written consent to enter a hospice community. This important prerequisite assures that everyone has been told the truth about the prognosis and that there are no “secrets” between those providing care and those receiving it. This truthfulness is sometimes an obstacle to hospice admission. Physicians, and usually well-intentioned family members, may try to protect the “dying” patient, believing that in being honest they may very well take away hope.

Hospice staff often report being confronted outside a home upon arrival and asked not to tell the patient he or she is dying. Staff find themselves in a delicate

position in that they cannot easily fulfill their role and enact a drama when the actor cannot be told his or her part. Staff respond by explaining that they will not directly confront a patient about dying or initiate conversation on the subject; however, they will not lie or withhold information if they are asked questions. This usually is agreed upon by family, and the staff then have the opportunity to begin producing the script. Shortly after developing a relationship, staff will usually be confronted by a patient asking if they are dying or why they are not getting better. The staff then have the obligation and opportunity to introduce the “dying role.”

Even if patients have previously been provided the truth about their condition, meeting hospice for the first time brings formalization to the “dying role.” Leland Russell (1997), a former hospice family member, in his account *Saying Goodbye*, describes the introduction:

When Marcia’s oncologist recommended that we call hospice for assistance, we both knew that by accepting his recommendation, we were admitting to ourselves and to the world that Marcia’s disease had reached its final stage. Yet, we welcomed his suggestion. Our experience with my terminally ill and hospice-assisted father gave us confidence that hospice staff would help Marcia lead as “normal” a life as possible, while also helping us to prepare for her death at home. Peacefully dying at home in quiet, familiar surroundings was one of Marcia’s paramount goals. (p. 19)

The realization of the “dying role” may be met in differing ways by family members as well as patients. How is the family dealing with the fact that this person is dying? What are the goals of the family and the patient? How secure are they with the dying process; how willing are they to let hospice assist in the process; and how committed are they to the hospice philosophy? Have the patient and family given up the “sick role?” Are the patient and family ready and willing to find new meanings and develop a new script for the rest of the drama? If the hospice community assesses that the family and patient are ready for their assistance, then the production may begin.

Settings for the Drama of Dying

The setting for the act of dying is critical. Erving Goffman (1973), in *Presentation of Self in Everyday Life*, describes the importance of setting, appearance, and manner in the staging of drama in everyday life. He points out that a successful drama must include an appropriate *stage*, with necessary *props*, an *appearance* that is appropriate for the role, and an appropriate *manner* that “warns us of the interaction role the performer will expect to play in the oncoming situation” (p. 25).

In America, there are two primary settings for hospice care—an individual home or a nursing home. A home may be the home of the dying person or a significant other. It will be transformed from its traditional form into a place of caring

for a dying person. It will usually be redesigned in several ways to serve new functions in a new drama until death brings down the final curtain.

A hospice secretary with little experience reported being surprised by what she found when she was asked to deliver something to a patient's home. She returned to the office and exclaimed, "They keep him in the living room!" She was startled that in the middle of a living room was a hospital bed with a dying person in it. "He was out where everyone could see him!" Her expectation was to find the individual hidden away, kept out of site of others and from daily living. She understood the rules of the "sick role" but was unfamiliar with the "dying role." Hospice encourages that the setting for dying be in the middle of the scenes of a family's living. They advocate that the patient stay a part of everyday life, rather than being isolated and alone. It is from the middle of the set that the actor can best direct the drama, not from backstage. This setting involves many adaptations of the traditional one. New props, especially a hospital bed, are brought into the family living room. Other props may include a commode, bedside table, urinal or bed pan, oxygen concentrator, walker, or wheelchair. These *hospital* props, characteristic of the "sick role," now become a part of the "dying role," in a new place, the *home*. Ira Byock (1997), in *Dying Well*, describes the setting in his home as he cared for his dying father:

Over these few weeks our one-bath, two-bedroom stucco Spanish-style home had gradually acquired a quasi-clinical decor. A front room that doubled as a guest room was now the sickroom. We rented a queen-size bed with a firm mattress and placed our dilapidated sofa bed in storage. The urine bottle became a familiar fixture in the room, and a portable bedside commode had been tucked in behind the closet door since Sy's (his father) most recent trip to the hospital. In the living room stood an aluminum walker that he refused to use. In the kitchen, cans of Ensure formed a pyramid on the counter. Jars of Metamucil and plastic bottles filled with medicines and vitamins were neatly arranged between the toaster and the windowsill. A three-ring binder containing the current medication log, selected medical records, and a copy of Sy's living will stood upright alongside the cookbooks. We had cleared the vegetable drawer in the refrigerator for other medicines, a liquid morphine solution, and two types of suppositories, one for constipation, another for nausea . . . (p. 18)

Within the home the family may choose the living room, a bedroom, family room, whatever best meets their needs. It is the hospice community that teaches them these options and supports these acts which otherwise might be seen as "deviant." This otherwise deviant action reinforces the fact that something is different and cannot be ignored. The settings and the props reinforce the work of the hospice community and socialization to the "dying role."

The second most common setting for hospice care in America is the nursing home. It holds different challenges for the creation of the drama of dying. The

nursing home is already equipped with the previously described props. They are a part of everyday life for the majority of persons in the nursing home, dying or not dying. The props do not support or reinforce the "dying role" but rather confuse it with the "nursing home role," which, while appropriate for the physical needs of the patient, do not meet spiritual or emotional needs. The setting often feels sterile and is not "homelike." It continues to present a fiction that somehow the "sick role" still applies. The "dying role" in a nursing home is, however, characterized by what Goffman calls *appearance* and *manner* (Goffman, 1973).

Support for the "dying role" in the nursing home setting, and the thing that seems to set it apart from very much alive nursing home residents, is that the "dying" have a new advocate and a new fleet of visitors. The dying person is getting more attention, has his or her own special outside nurse, and has unending visitors. In contrast to isolation often accorded to traditional nursing home residents, especially those who have been in the home a significant length of time, "dying" hospice patients experience a new community to visit and help them. This is sometimes met with jealousy on the part of the other residents, and even on the part of regular nursing home staff. Both groups crave this attention. "Dying persons" feel special and unique, their new role now gives them status and honor among the others, and lifts their self esteem. With the help of the hospice community, "dying persons" can direct the drama; the nursing home resident cannot.

Appearance for the hospice patient in the nursing home is another important issue. Attempting to maintain an appearance of home, patients and families do many things to help create an appearance of normality in the middle of an abnormal setting and time. For example, it is very common for family members to place colorful sheets and comforters on patients hospital beds instead of the drab white and solid colors. Patients will usually continue to wear "normal" clothing for as long as possible and avoid "sick" hospital gowns. In one hospice, a nurse's aide would voluntarily make colorful gowns for her nursing home patients. Volunteers in this same hospice made festive pillow cases for all the patients, attempting to bring a cheerful look and homelike appearance to an otherwise depressing setting.

The manipulation of appearance is also a practice of hospice staff. The actors in the hospice community desire to have an appearance that sets them apart from other actors in the drama. Traditional medical attire, while invoking credibility and an aura of professionalism, is too sterile to convey the needed impression. Manner presented by hospice staff is one of engagement, warmth, concern, and compassion. It solicits conversation and reinforces honesty and sincerity that is critical in the formation of community.

Goffman's discussion of *manner* has relevance for the dying role. It brings forward the presentation of the drama. Author Marcia Littanzi-Licht describes hospice staff manner with an image of a competent stranger coming to the door to help (Littanzi-Licht, 1997). Staff seek to portray comfort and knowledge about death and dying, taking the mystery out of the process and replacing it with

influence and control. In the process, hospice staff allow the patient to assume the “dying role,” and to relinquish the burdens of the “sick role.”

Scene Two: Fulfilling the Dying Role

The hospice community assists the patient in finding new meaning in the new role, a new concept of self, a new identity. In the *Social Reality of Death*, Kathy Charmaz (1980) discusses the importance of self in this situation when she writes:

For the dying, maintaining a positive sense of self can often become a significant problematic issue. Since selves are socially created and socially maintained, the social identity conferred upon the individual typically has profound implications for any personal identity the individual claims. (p. 26)

As stated earlier, traditional medicine and society, in general, label dying individuals as being without hope and as failures due to their inability to fulfill the obligations of the “sick role.” In addition, individuals’ sense of self can be challenged when and if their physical bodies are altered. The dying process for some can be so cruel as to render the dying person as unrecognizable to close friends and relatives. Hospice serves as a new reference group for these individuals, redefining hope, identifying new meanings, giving control where none existed before. In *Dying Well*, Ira Byock (1997) says that “in the very shadow of death one’s living experience can yet give rise to accomplishments, within one’s own and one’s family’s system of values” (p. 32).

A hospice priest once wrote that he had trouble counseling with an elderly widow who was bitter over how her friends and family had treated her. At the same time he had been working with a young mother with four small children whose father had recently died. The priest lost his patience with the elderly woman who was feeling sorry for herself and told her the story of the young mother. He suggested the woman use her dying as a way to help others. By the next visit the woman had transformed and her life had taken on a new meaning. Her thoughts had become focused on how she could dedicate her dying as a way to alleviate the suffering of others (Boundry, 1998).

Another hospice patient, in the Missouri Hospice Organization’s (1997) *Sacred Stories* writes:

Happiness comes from giving your best in life, taking a break and enjoying the fresh air and spending time with loved ones. It is hard to explain happiness to someone unless they face death. That is when one realizes what makes them happy. I never realized until I spent time in the hospital with children how unimportant material things become when we face death. Happiness is an inner peaceful feeling that you get when you try to right all your wrongs and be the best person you can be. So few people realize how lucky they are in life. There are so many things to be thankful for, but one never realizes it until it is too late. My view of happiness may not be the same as everyone else, but

try to live life to the fullest, put on a smile, help a stranger and see if that doesn't make you happy. (p. 94)

President of the Academy of Hospice Physicians, Ira Byock (1997) in *Dying Well* writes:

Over the years our hospice team has become adept at helping people work toward end-of-life goals that have meaning *for them*. And it has become common for the people we encounter to achieve a sense of inner well-being even as they die, and for families to express that their loved one's dying was as precious as it was painful. (p. 34)

One of the most important ways hospice assists patients reestablish meaning and hope is by controlling their pain and managing the physical symptoms of dying. It is only when patients are physically comfortable that they may deal with other end-of-life issues and find meaning and purpose to their situation. In *Facing the More Terrible Lord* (Lubieniecki, 1997), one hospice nurse writes:

My philosophy on pain management is summed up in two statements. The first is from Albert Schweitzer, who said "Pain is the more terrible lord of mankind than death itself." The second now appears in the Goodman & Gillman pharmacology textbook. It says "No patient should ever wish for death because of a physician's reluctance to use adequate amounts of effective opioids." (p. 15)

Pain and suffering is considered an emergency in the hospice community. Hospice staff receive specialized training in pain control and symptom management. The culture dictates that these physical issues are dealt with decisively, immediately, and without hesitation. This is accomplished through constant assessment by nurses, advocacy with physicians, and constant education of care providers.

Through the control of pain and other symptoms, the physical and emotional suffering of the patient can be eased. But there is another kind of pain. Many dying patients struggle with the concern that their physical care will be a burden for those who are caring for them. They may also be concerned that physical losses and problems may rob them of their dignity. Ira Byock (1997), in *Dying Well*, writes:

For someone confined to a bed with a rapidly deteriorating physical condition and increasing dependency, conversations about being a burden and the meaning of dignity can have an immediate impact. To the person dying these are not idle philosophical musings. The conversation often picks up a stream of thought that is constantly on his mind and about which he has been thinking on a moment-to-moment, hourly basis, turning it over in an almost obsessive fashion. (p. 97)

The author of this article remembers that one of her first hospice patient's proudest moments came when we discovered a unique way to allow her to continue

to smoke in her bed. Helen had smoked for as long as she could remember and she did not intend to let dying stop her. She was on a high dose of pain medication and could become very tired. She had lit a cigarette behind her daughter's back one day, fell asleep and the ashes fell to the bed. Luckily the daughter discovered this before a fire occurred. After discussing the dangers of smoking in bed, she said she would die in a fire before giving it up at this point in her life. Hospice discovered a new gadget that held a cigarette securely in an ash tray with a tube hooked onto it, allowing a patient to smoke without touching the cigarette. Getting a "fix" from the tube seemed like a solution. It looked rather strange, like a piece of foreign drug paraphernalia; however, it was worth a try for Helen. The gadget was purchased and brought to Helen's home one day and she asked to try it. She did and was pleased with the result. When her daughter entered the room she began laughing as she saw her mother puffing on this gizmo. Mom felt so proud of herself, dying, and still smoking. She asked the hospice team to take a picture with a Polaroid instant camera. We showed her the picture and she beamed, looking at herself. Although frail, hair a mess, circles under her eyes, this woman found her dignity in the thing most important to her, a cigarette. She taped the picture to the wall beside her bed and it remained there until she died. When this author thinks of dignity, she thinks of Helen's picture.

One of the most difficult adjustments for the "dying role" is dependency. It leads dying persons to feel like burdens as they see strain on the faces of caregivers. For dying individuals, independent in the past and familiar with being caregivers themselves, the reversing of roles is a difficult process. Hospice attempts to restore meaning and relieve the patient of this burden by sharing stories and experiences that restore and rekindle meaning. Hospice seeks to help patients understand that by letting their loved ones care for them at this special time they are helping them with the grief that will follow their death. Often when the dying person is encouraged to take the role of the other, they begin to understand what a gift caregiving can be. In *Dying Well*, Ira Byock (1997) shares:

I believe Wallace gained a renewed sense of dignity in his passing when he shed his previous notion of dignity, which had been wrapped around physical independence and helping others. He came to understand that care for the frail and dying is a vital part of the life of the community. By accepting his new role and acknowledging his continuing contributions to his family and community, Wallace achieved a renewed sense of self-worth. Despite his physical dependence—and, in a sense, because of it—he retained his dignity. (p. 98)

Scene Three: The Death Bed Scene

There comes a point when a patient is labeled "actively dying." The nurse makes this assessment when a patient is usually within hours of actually completing the drama. Barney Glaser and Anselm Strauss discuss this in their book

A Time for Dying. They term this phase a “death watch.” Glaser and Strauss point to this as an “empty time” in hospitals when staff must constantly monitor patients to assure attention to their physical needs and control verbal “outbursts” that disturb the ward (1968, p. 197).

Hospice takes another approach. It seeks to educate patients and families on the signs and symptoms of impending death so the players in the drama can watch for signs of decline and begin to anticipate when the end is approaching. A family will call as they notice changes or the nurse will discover on her routine call that the patient’s body is simply shutting down. Respiration will slow, the heart rate and blood pressure will drop, the patient may lose consciousness, and often the arms or legs will begin to turn blue as the oxygen supply drops. It is with this “active dying” assessment that the final deathbed scene begins.

The nurse explains to the family that this is the beginning of the end and advises all to say their final goodbyes. Occasionally a hospice family will even ask the nurse to stand at the bedside as one by one family members give their final hugs, and say their final farewells. A young child might bring in the family dog to say goodbye and provide Grandpa a chance to touch his dog one final time. In a separate room the social worker will usually console the family, encourage them to say their farewells, and listen as meaning is found in the final hours. After everyone has bid farewell, the patient’s closest confidant will go to the bedside, take the hand of the loved one, and give assurance that all will be okay. The confidant gives thanks for years of togetherness, expresses love, gives permission for death, and tells the individual it is time to go. Death usually follows soon after. Leland Russell (1997), in *Saying Goodbye*, shares final moments by writing:

As I entered the bedroom, I immediately sensed a change in Marcia’s demeanor. Her breathing was shallow and rapid, her eyes tightly shut. I quietly walked to the bed and sat down next to her. I took her hand and lightly caressed her arm. A gentle breeze passed through the open windows.

Except for the finches unobtrusively twittering in the maples and the cicas lazily droning, all was quiet. I began to speak. I told Marcia how much I loved her, what a wonderful life we had led, what beautiful children she had given us, and what a wonderful wife and mother she had been. I thanked her for all these things.

I promised her I would, as always, be the best father I could be to our precious little girls. I reminisced about our wedding day. I was quiet for a few moments and held her tenderly. Then, I told her it was alright to leave us now. I reminded her everything was taken care of, that our girls understood it was not her choice to leave, and that I would miss her terribly. I again told her that I loved her. I stopped talking, and gently squeezed her hand.

She took three more shallow breaths. Then, she was still. It was a perfect magical moment. All was quiet. I felt no sadness, pain, sorrow, or anguish. I only felt perfect love. I felt only inner peace. (p. 19)

It is important that hospice nurses accurately assess this “active dying process.” If the assessment is too premature, the death bed vigil becomes lengthy and stressful for the family. It is difficult for a family to say goodbye, position themselves for the actual death, and have the patient linger, holding onto life with no apparent purpose. When this happens, the hospice community works with the family once again, supporting and listening, and searching for meanings in the process.

After the death, the hospice nurse will contact the funeral home and prepare the body by cleaning it. This custom comforts the family as the mortuary arrives and the deceased has the best presentation of self, even in death. It is an important way to preserve the individual’s dignity and the family’s comfort. Funeral directors often report they always like getting “hospice calls” because they know the family will be comfortable with their arrival on the scene and the body will be in the best possible shape for removal. The family usually is involved in what Glaser and Strauss (1968) call a “last look” at the body prior to its removal (p. 213). This is the last opportunity for the family to touch a warm body and recognize that the drama is over.

After the body is removed, the hospice community pulls back to allow the natural support system of the family to follow established rituals. Staff often attend funerals or funeral home visitation. The production of the drama is almost complete. The hospice community will continue to offer bereavement care to the survivors.

It is important to hospice staff, as well as to families, that they are allowed to be part of the final drama. In *The Hospice Choice* (Littanzi-Licht), a hospice nurse writes:

Being with the family at the time of death is one of the most important services that hospice offers. It is a difficult time and almost sacred time. There is a feeling that something very human, and yet also mysterious, has happened. I stay with the family while they say good-bye to their loved one. There are usually soft tears that family members cry. Its not a shock. It’s just very sad and hard to see someone you love go. (p. 235)

Although death is expected in every case, when it comes quicker than expected hospice staff can feel shortchanged. The death scene is a time for hospice staff to add their goodbyes and to evaluate the success of the drama. This is unique to the hospice community. Glaser and Strauss (1968) report that in the hospital setting, nurses prefer not to be present at the moment of death and they employ many strategies to stay occupied in an effort to not be there (p. 202).

When a death is announced to other staff, the usual question often asked by every staff person is “how did it go?” They want to know about everything, about how the family responded, did the good-byes get said, did the goals get fulfilled. If the final act was considered successful by the family then the community was successful.

IMPLICATIONS FOR FURTHER RESEARCH

Goffman's dramaturgical model emphasizes many other aspects of a drama, including the "secrets of the backstage." There are secrets in the backstage of the hospice community. However, this is a subject large enough for a paper of its own. Perhaps a look at this part of the drama would share insight to medical practitioners about the methods which can be utilized to cope with the drama of the dying.

This article has not meant to imply that there are not individuals who are able to socially construct a dying role outside the hospice community. Hospice is used only to illustrate how a community can facilitate a "dying role" and help actors to preform it. It is also important to note that at times the expectations of the "dying role" from the hospice community can place burdens on patients, especially if they are not dying "quick enough" or in the "normal" manner. This is a subject for further analysis.

CONCLUSIONS

The purpose of this article was to show how the hospice community facilitates a dramatic transition from being "sick" to "dying." This transition involves the redefinition of an actors self, a search for a new meaning of life, and a reestablishment of hope from cure to comfort. The SUPPORT study summarized its conclusions by stating "To improve the experience of seriously ill and dying patients, greater individual and societal commitment and more proactive and forceful measures may be needed" (p. 1591). Hospices need to realize how they produce this drama in an effort to help the medical community as a whole recognize the "dying role" and respect its rights and obligations.

If the normative order requires individuals to seek competent medical care when they are sick, it surely can allow a person to die within a community dedicated to and knowledgeable about death. There comes a time when seeking medical care is a charade and only the "dying role" can bring authenticity to the moment. The hospice community is one major vehicle in modern industrial societies to accomplish this. Perhaps in time the redefinition of sickness and dying will be a reality for all. It depends on the players in the drama—all of whom will die.

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