

Opinion

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Transforming End-of-Life Care

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Currently, hospice care which focuses on caring for a terminally ill person delivers holistic, supportive, interdisciplinary, and patient-centered management. There have been numerous efforts to establish hospice care for people who are in the end-stage of their illness.

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO). Hospice care which is a subset of palliative care focuses on controlling pain and other symptoms of illness so patients can remain as comfortable as possible near the end of life. The meaning of hospice care throughout this study is a supportive care to people in the final phase of a terminal illness and focus on comfort and quality of life.

Hospice care for people with end-stage illnesses, which can involve complex end-of-life care in a wide variety of settings, including bio-psycho-social symptom management, care related to cultural and ethical issues, bereavement care, and after-death care. Hospice care affects the end of life experience tremendously.¹ However, let us consider hospice care at this time. Does hospice care really deliver the right care for people in the endstage of their lives? What level of hospice care do most hospice patients receive? How many people can be supported with hospice care by the government for a dignified death? For how long is hospice care required for an appropriate or good death? How much respect is there for the human rights of people in hospice care?

Human dignity and human rights in end-of-life care are very important in terms of a person's identity and values, and they are accorded to and respected in everyone using hospice care services.²⁻⁵ It is the responsibility of every hospice professional to know how to provide high quality care to people with end-stage illnesses in view of their human dignity.⁵⁻⁷

This paper provides an overview of transforming end-of-life care. It describes not only the highest quality care for people who have had a life-limiting illness but also the trends of preparation for death, respect for the free will of people, receiving professional hospice care, and quality care after death.

The goal of this paper is to contribute to the development of future hospice care from the perspective of the dignity of people. Much needs to be improved in areas such as hospice philosophy and practical support for transforming end-of-life care.

HIGHEST QUALITY CARE

The highest quality care in Hospice refers to the quality, compassionate care of people facing life-limiting illnesses. Compassionate care is also holistic care. People facing life-limiting illnesses need compassionate access to a more systematic way to meet their holistic needs. Compassionate care becomes a strong and powerful interaction that encourages the patient to participate.

The approach of compassionate care takes into account the physical, emotional, and spiritual needs of each person. The method of delivering compassionate patient care is a ready-to-go solution to a very real problem, which involves supporting the patients and helping to meet their needs.⁸⁻¹¹

The hospice care profession also provides spiritual and emotional support to hospice patients. Hospice providers encourage individuals to discover meaning and purpose as peace-makers. They provide support during difficult decisions while respecting individual beliefs. Spiritual care may or may not include religious care.

PREPARING FOR DEATH

Preparing for death is one of the most empowering actions. As people approach the end of their lives, they commonly face many decisions that range from simple to extremely complex. Dying persons and their families are faced with choices about what they want or need. These people can be prepared for death when they know their exact situation in detail.

These decisions may be physical, psychosocial, spiritual, or legal in nature. Each decision should ideally be considered in terms of relief of suffering and the values and beliefs of the dying individual and his or her family.¹²⁻¹⁴

At the moment, when people die, they leave their physical bodies behind. They pass through a dark tunnel to a transcendent spiritual existence. After they die, their family and friends remain. The emotional-spiritual-mental function involves a different kind of process.¹⁴ The spirit of the person in the final process may need resolution of unfinished issues and relationships with life. The spirit completes its natural process of reconciling and finishing in a way that is appropriate and unique to the values, beliefs, and lifestyle of the dying person. Some may want to reflect on the meaning of life, some may decide to conduct a final life review or deal with psychologically unfinished business, and some may want to participate in planning rituals before or after death. The most appropriate responses to the emotional-spiritual-mental changes are support and encouragement about the resolution and the transition.

Waldrop and Meeker¹⁵ identified five decisions that people make before the end of their lives: (1) operationalizing advance care planning, which is a renewed focus on decisions about care at the end of life; (2) surrogate decision making, in which caregivers begin making both informal and formal decisions for the dying person; (3) meaning-making, in which the foreshortened time brings into focus decisions about seeing special people, attending events, and creating memories; (4) location of death, which involves decisions about whether the person wants to, and can remain, at home to die; and (5) final acts, in which decisions about funeral arrangements, wills, and leaving a legacy become central.

Gauthier¹⁴ mentioned that terminally ill adults make decisions based on a broad set of factors that influence how one responds to everyday challenges. In his study of decision making near the end of life, he also reported that open and honest communication about sudden functional changes in the context of chronic illness might allow individuals to choose hospice or palliative care earlier in the trajectory of their illnesses. Therefore, a hospice care team prepares the dying person to respond in ways that will help him or her to accomplish this transition. These teams also support and understand the responses of people in the final stage.

Preparing for death is a great gift of love as this moment approaches. The person is ready for this release emotionally, spiritually, and mentally because others will continue to live until the shutdown process ceases. All end-of-life choices and decisions have a significant impact on suffering, quality of life, and dying. People in this context may make choices about how to spend their limited time and energy. The time of preparing for death is a time to give full acceptance, support, and comfort. People also frequently make legal decisions about wills, advanced directives, and durable powers of attorney at this time.

The person approaching the dying process keeps in his or her mind the unresolved or un-reconciled important issues or some significant relationships even as all of their physical systems cease to function. Preparing for death needs to happen in a way that is appropriate and unique to the values, beliefs, and lifestyle of the dying person. It is closely interrelated with his or her physical, psychosocial, spiritual, and economic situation. Therefore, well-intentioned care by health care providers may overlook a particular person's wish not to discuss death.

RESPECT FOR FREE WILL

Free will is a freedom of choice and self-determination without external restraint when there is a choice of possible actions. Respect for the free will of people who are in the last days, weeks, and months of life requires hospice health professionals to understand the extent to which their preferences are being met. Respect for the free will of people who are in their last days means improving the understanding of their needs and wishes by capturing their preferences and sharing the information when caring for the dying people. For example, a hospice health care team should consider how and where people hope to die and what they are concerned about. Each team should consider which type of care makes the most sense for each person. Hospice care in general can take place in different settings, including hospitals, outpatient palliative care clinics, nursing homes, certain other specialized clinics, and the home. The Patient Self-Determination Act (PSDA) of 1990 was developed to ensure that these rights were protected, including the fundamental rights to treatment choices, informed consent, truth-telling and open communication with health care providers, and control over the individual's own life and death. The core values of hospice care emphasize autonomy and individual rights to make life choices, especially

health care choices. The health care provider in a hospice must have a clear understanding and recognition of the patient’s desire. It is important to remember that people are aware of their own values, hopes, and beliefs.

PROFESSIONAL CARE

The professional care of people who are dying is mandatory for all hospice health professionals involved in end-of-life care, which includes skills for communicating with and supporting families and their advocates.^{16,17} The hospice care providers include hospice nurses, doctors, social workers, physical, speech, occupational, or dietary therapists, home health aides, spiritual counselors, and volunteers as well as someone who is available as the primary caregiver at home. This person may be a spouse, partner, or other relative, such as a son or daughter, or even a neighbor or a team of people from the community.

Hospice care is most affected by the differences of the social and cultural recognition and the policy of the countries. So, professional hospice care should be made by considering the cultural aspects.

Professional hospice care is intended to help people who should be respected during every moment of their final days. Hospice professionals should help them using their professional knowledge and experience because they support the final-stage patients who have special psycho-socio-spiritual problems.^{18,19} Hospice care providers serve not only to reduce physical suffering but also to help patients and their families spend meaningful time together. Hospice care professionals have helped patients and families to hold a family meeting to reassure the patient that everyone is ready to let go. Therefore, the members of hospice care teams want to know what to expect and how to respond in ways that will help the people who are in transition with support, understanding, and ease. Also, Chochinov³ proposed a model dignity and dignity-converting intervention for patients serving nearing death by therapeutic conversation. Through dignity therapy, patients will be able to reduce psychological, spiritual and existential distress and to send the end of life with dignity.

QUALITY CARE AFTER DEATH

Human dignity is that all humans should be treated with respect regardless of sex, race, gender, class, nationality, religion, or other divisions. The dignity of the deceased is not overemphasized because he or she had an individual experience.^{15,21} A dignified death means not only the alleviation of bodily suffering and pain but also the meaningfulness of death. The quality of care after death largely depends on whether staff members have received training in the care of dying patients.²² Quality care after death reflects the importance of caring for the deceased body and the family because they have had their own individual experiences.

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End-of-life care calls on the skills of many different professionals and individuals to meet the patient’s many requirements. Crucially, there is only one opportunity to ensure good care after death, and it is not easy to coordinate everything that needs to happen. Guidance, therefore, is a good practice, as is confirming a process by which everyone who is involved can ensure that the experience for those coping with the loss of someone important to them is as good as it can be. This whole process should be set within the context of the deceased’s wishes about care arrangements, and family members should be given information and support. Stuart et al²² identified after-death care as care/counseling of the family, religious/cultural requirements, staff availability, and the presence of funeral directors and pastoral caregivers.

CONCLUSIONS AND RECOMMENDATIONS

The goals of this paper were to explain the transformation of end-of-life care with a foundation of dignity for palliative patients and to develop a conceptual framework for the future perspectives of people approaching death. The quality end-of-life care in future should involve the highest quality care, preparation for death, respect for free will, professional hospice care, and quality care after death with a view to human dignity (Figure 1).



Figure 1: Transforming end-of-life care.

It is complex and challenging, but the principal aim is to support people to die well in their preferred death. Good end-of-life care aims to treat people with dignity and respect in care. Some people who are able to access hospice and special pallia-

tive care in communities or hospitals receive high standards of care in their final weeks, days, and hours, but many others do not. Despite the higher quality of end-of-life care and increasingly high-level qualitative data to support this, there is still a significant fragmentation of services and widely variable quality of care. A goal should be set for hospice and end-of-life care involving quality of care to increase annually.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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