
Palliative Medicine Doctors Meeting



A GOOD DEATH

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This article reviews current literature about what constitute a good death, and how to facilitate people with advanced malignancy to die well from a caring process and from a health care system point of view.

TWO SCENARIOS

Mr. Chan, 43 year-old electronic worker married with one child, suffered from hepatocellular carcinoma since 1997. He had undergone many treatment modalities including subtotal hepatectomy, two years of chemotherapy, bilateral thoracotomy for multiple lung metastases, and radiotherapy for vertebral metastases with spinal cord compression. He was admitted into the hospice ward in severe respiratory distress with extensive lung metastases and required high flow oxygen. However, consistent with his strong will to fight the disease, he self-arranged to have another trial of chemotherapy in a private hospital despite death was approaching. He finally had one dose of chemotherapy given and died the next day. So, can this fighting to the last minute a good death? And, from whose point of view?

Mr. Wong, a 75 year-old gentleman with five children, was suffering from inoperable liver cancer. He was in cachectic state on admission and both the liver and kidneys were failing. Pain control was suboptimal and abdominal distension due to ascites was hard to control. He insisted to go home despite symptom control was not optimised and death was imminent. Both his family and the caring team were ambivalent about this but decided to respect his wish. He died one day after having home leave. Again, what is the nature of good death while facing the conflict of fulfilling patient's own wish but sacrificing symptom control?

ELEMENTS OF A GOOD DEATH

CS Chao has divided the constituents of a good death in Chinese individuals into three domains and twelve themes. (1) The 'physical peace domain' included: physical pain being minimized, dying process not long, mobility, and cleanliness and integrity. The 'psychological peace'

domain included yielding, letting go, not alone, no unfinished business, and enjoying nature. In the 'Peace of Mind' domain, living one day at a time, having lived a meaningful life, and the end of suffering were viewed as important.

In a review article published by a local worker, June Mak identified seven components of a good death (2):

1. comfort or relief from pain and suffering
2. openness or being aware of dying
3. completion or acceptance of the timing of one's death
4. control and autonomy
5. optimism and keeping hope alive
6. readiness or preparing for departure
7. living with one's choice about where to die

Through focus group discussion and in-depth interviews, Karen Steinhauser tried to gather descriptions of the components of a good death from patients, families and providers. (3) Six major attributes of a good death were identified:

1. pain and symptom management
2. clear decision making
3. preparation for death
4. completion
5. contribution to others
6. affirmation of the whole person

Each attribute has biomedical, psychological, social and spiritual components. There are discrepancies among the various parties. Physicians are more concerned about biomedical aspects, while families, patients and other health professionals are concerned about other perspectives like psychological, social and spiritual aspects.

In brief, death is a whole-person experience. A good death should be viewed in the context of each person's unique personhood and good symptom control is only one component of it.

WAYS TO ENHANCE A GOOD DEATH THROUGH THE CARE PROCESS

The six themes described by Steinhauser give us clues in which a good death can be facilitated in the caring process. The following are some examples:

1. Preparing for anticipated symptoms and reassurance of means to achieve good symptom control
2. Communication and patient/family participation in decision making,
3. Educating patients and families what to expect in the course of illness, the dying process,

- and events after death; educating family members about the physical and psychosocial changes as death approaches
4. Facilitating life reviews, conflict resolution, allowing more private time with family and friends, respecting patients' religious needs and rituals, and facilitating 'saying goodbye'
 5. Finding ways to let terminally ill patients to explore means to contribute to others
 6. Affirming the patient as a whole and unique person through processes and procedures as well as staff's attitudes

A REALISTIC GOAL OR AN UNREALISTIC IDEAL?

In a comparative study of the views of hospice staff and patients, Payne (4) pointed out that major differences existed between staffs' and patients' perception of a good death. Patients rated the following as important (in order of frequency): dying in one's sleep, dying quietly, dying suddenly, being not afraid or fatalistic, religion, and being pain free. On the other hand, staff ranked having no sign of physical pain, and family's acceptance as the two most important attributes of a good death.

Staff's perception of a good death based on the medical model may be different from patients' and as health professionals; we have to be cautioned about over emphasis on symptoms and negligence of other aspects.

In a qualitative study exploring palliative care nurses (PCN)' perceptions of good and bad deaths and care expectations, (5) a good death is perceived by PCNs to comprise of the following: a whole patient, a connected family, a smoothly functioning team, the illness in control, and a peaceful death scene. Are these expectations in the presence of a terminal illness realistic? Or are PCNs driving themselves too hard to achieve some ideals that are not attainable in most cases?

The author made four recommendations for health care teams in order to help staff cope with situations in which a 'less-than-ideal' death has happened and they are listed below:

1. Develop a process for identifying high risk deaths to allow anticipation of difficulties and a plan of care for staff
2. Assess more formally the care expectations of patients and families
3. Promote healthy teamwork and cross-discipline communication
4. Incorporate grief work support such as counseling resources and team death review to allow staff to process and integrate death experience.

A GOOD DEATH FROM A HEALTH SYSTEM POINT OF VIEW

In the article *The Promise of A Good Death* by Ezekiel and Linda Emanuel(6), a framework for a

good death is proposed so that the health care providers and caregivers can put different aspects of a death experience into context so that appropriate interventions from a systems perspective can be instituted according to the needs of the dying patient. The Framework consists of four critical components:

1. Fixed characteristics of the patient:
 - a. Clinical status: disease, prognosis
 - b. Socio-demographic characteristics
2. Modifiable dimensions of the patient's experience:
 - a. Physical symptoms
 - b. Psychological and cognitive symptoms
 - c. Social relationships and support
 - d. Hopes and expectations
 - e. Economic demands and care-giving needs
 - f. Spiritual and existential beliefs
3. Care-system interventions:
 - a. Family and friend interventions
 - b. Social interventions
 - c. Medical provider interventions
 - d. Health-care-institution interventions
 - e. Economic interventions
4. Outcome: the overall experience of the dying process

This framework puts care of the dying in a broader perspective. It emphasizes the multi-faceted characteristics of the dying experience, and it helps clinicians to systematically evaluate and optimize the care of dying in all areas. It emphasizes that dying is not just a medical experience and that the patient's full social network can significantly influence their experience.

The framework outlines a systematic mechanism to implement and evaluate two elusive concepts that are fundamental to improving care of dying patients: a good death and suffering. It delineates potential interventions appropriate for circumstances and it identifies areas in which further research and training are needed.

To ensure a good death as the standard of care, four initiatives are outlined:

1. Basic Research:
 - a. Overall experience of dying: predictors of patients at high risk for suffering
 - b. Assessment instruments of modifiable experience
 - c. Psychological symptoms intervention
 - d. Caregiving needs: predictor of patients with significant needs and effective interventions
 - e. Spiritual and existential beliefs: predictors and interventions

- f. Health services research: best organization of health care delivery
- 2. Clinician Training
 - a. Use of standardized assessment tools for physical and psychological symptoms
 - b. Communication skills specific to death and dying: breaking bad news, advanced care planning
 - c. Routine inclusion of dying patients in patients' management conferences
 - d. Development of mentors
 - e. Guideline-based training on withdrawing life-sustaining interventions
- 3. System Design
 - a. Availability of palliative care physicians or services at all health care institutions caring for dying patients to provide consultation and education
 - b. Integration of home based, community based, hospice based, and hospital based care
- 4. Reimbursement
 - a. Ensuring that the payment system will not limit the use of appropriate care or inhibit cooperation between the different health care providers

CONCLUDING REMARKS

In enhancing a good death of a dying patient, we need to view each person as a unique whole person. The processes and procedures of caring should aim to help each person to live as fully as possible until death. Adopting a systems-approach will help the health care system to make implementation of such 'ideal' a realistic possibility, though we still have a long way to go.

Reference

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