

Survey of Staff and Family Members of Patients in Bulgarian Hospices on the Concept of “Good Death”

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Abstract: The concept of a “good death” has been intensely discussed over the past decades. The objective of this study is to investigate this concept among staff and patients’ relatives in 29 Bulgarian hospices and 5 palliative care units. Self-administered questionnaires were completed by 190 members of staff and 216 patients’ relatives. Death without pain and suffering and death in one’s sleep were leading concepts in both the groups. Staff preferred death in the presence of relatives, while relatives preferred fast and sudden death. Although we were able to define the common concept of a good death as painless and sudden death in one’s sleep, death is unique phenomenon and good palliative care should be based on communication with patients about their idea of a good death.

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Key points:

- Good death is difficult to define.
- Universally, death without pain and suffering most important aspect across the board.
 - More staff members and relatives considered this as the most important for the good death of a patient as compared to their own good death
- There are differences between a staff or relative’s own good death versus the patient’s good death. Sudden death took second place for relatives about their own good death. This was much less important in staff members’ view of their own good death but still present. However, both groups did not indicate that a sudden death is a good death for the patient.
- Control over death was a category more often selected by hospice staff members and relatives as important for a patient’s good death as compared to their own good death.
- Differences in staff views between inpatient hospices and home care hospices
- Other category: included abstract ideas of a good death such as death with dignity, acceptance of death, desire not to involve relatives.
- Dignity of death was described by respondents to be a complex notion including the following meanings: lack of humiliation, lack of poverty, maintaining the ability to take care of one’s self.
- Overall a concept of good death is: painless, sudden, in one’s sleep and without agony.
- Ultimately every human being is unique and has their own beliefs about a good death.

Strengths:

Good blinding: questionnaires were distributed in individual envelopes among staff members and relatives of patients and returned to the investigator via postal mail.

Standardized questions regarding “what makes a good death” for both groups.

Large population sample and good coverage of the country: 82.9% of hospices in the country were surveyed.

Good response rate: 86% (hospice staff), 75% (relatives).

Relevant population to us: 190 staff members surveyed, 102 worked on inpatient hospice units, 27 in home care hospice settings, 61 in palliative care units. 74.2% nurses, 8.4% physicians, and 17.4% interdisciplinary team members (therapists, social workers, psychologists). Majority of relatives were patients’ children (53.2%) and patients’ spouses (23.1%).

Weaknesses:

Patients were not involved in the study itself. Reason was “vulnerability of patients in hospices”. Thus, the survey assumes that the relatives know the patients and their idea of a good death. This is not always true as seen in this paper and it would be interesting to see the differences between the patient’s idea of a good death versus a relative’s.

Five specific categories were given for the survey: “death without pain and suffering, death in the presence of relatives, death at home, death in one’s sleep, control over death” which may skew the popularity of these answers. Mitigated to an extent by initial “open ended question” and “cannot answer”, “other opinion” options.

Relevance to palliative care:

It is important to recognize the fundamental concepts of a “good death” and ensure that one’s own definition about it reflects the views of the patient and the relative.