

Care for Imminently Dying Cancer Patients: Family Members' Experiences and Recommendations

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Reference: Shinjo T, Morita T, Hirai K, Miyashita M, Sato K, Tsuneto S, Shima Y. J Clin Oncol s27. Published ahead of print November 6th, 2009.

ABSTRACT

Purpose

The aim of this study was to clarify the level of emotional distress experienced by bereaved family members and the perceived necessity for improvement in the care for imminently dying patients and to explore possible causes of distress and alleviating measures.

Methods

A cross-sectional nationwide survey was performed in 2007 of bereaved families of cancer patients at 95 palliative care units across Japan.

Results

Questionnaires were sent to 670 families, and 76% responded. Families reported their experiences as very distressing in 45% of cases. Regarding care, 1.2% of respondents believed that a lot of improvement was needed, compared with 58% who believed no improvement was needed. Determinants of high-level distress were a younger patient age, being a spouse, and overhearing conversations between the medical staff outside the room at the time of the patient's death; those reporting high-level necessity of improvement were less likely to have encountered attempts to ensure the patient's comfort, received less family coaching on how to care for the patient, and felt that insufficient time was allowed for the family to grieve after the patient's death.

Conclusion

A considerable number of families experienced severe emotional distress when their family member died. Thus, we propose that a desirable care concept for imminently dying cancer patients should include relief of patient suffering, family advisement on how to care for the patient, allowance of enough time for the family to grieve, and ensuring that family members cannot overhear medical staff conversations at the time of the patient's death.

ANALYSIS

Strengths

This was a multicentre study with a high response rate, which examined specific elements of communication which family members of imminently dying patients perceive to be important for optimal patient care.

Weaknesses

Weaknesses include the retrospective nature of the study, recall bias with a delay of 9-26 months between patient death and survey reply, and the fact that the applied measurement instruments had not been previously validated. The questionnaire administered required yes/no answers and therefore may have overlooked other aspects which may have been important for family members and which may have been identified through open-ended questions or in-person interviews. There is also the potential for cross-cultural variability in responses.

Relevance to Palliative Care

End of life care impacts not only the patient, but also members of their family. A perception of inadequate care by families contributes to the emotional distress experienced during the last few days of the patient's life and following their death. An understanding of family members' needs will allow the health care team to better support them, focusing on the importance of empathy and communication in the provision of end of life care.