BURDEN AND BENEFIT OF END-OF-LIFE RESEARCH WITH THE TERMINALLY ILL

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Objective: To assess the burden and benefit of participation in research investigating attitudes toward hastening death and other physical and psychological symptoms associated with end-of-life suffering among patients receiving palliative care.

Method: Fifty terminally ill cancer patients participating in a psychosocial research study were administered a brief self-report questionnaire to assess the burden/benefit of participation in end-of-life research and specific factors which contributed to these perceptions.

Results: The majority of patients reported no burden associated with participation and rated the experience as moderately to highly beneficial. Factors most frequently identified as burdensome were the length of the interview, structure of the questionnaires, and difficulty discussing end-of life issues. Factors most frequently identified as beneficial were the social interaction, sense of contributing to society, and discussing their illness. Although some patients reported distress discussing end-of-life issues, significantly more patients benefited from the discussion of these topics.

Discussion: There is a growing need for research in palliative care. Ethical concerns regarding the relative risks and benefits of research in vulnerable populations such as the terminally ill have been raised, yet the impact of participation has not been systematically determined. However, patients are unlikely to experience significant burden and may benefit from participation in end-of-life research.

Conclusion: End-of-life research can be conducted with sensitivity to patient burden and may offer positive aspects for participants.