Original Article

Why Now? Timing and Circumstances of Hastened Deaths

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Abstract

We interviewed 35 families to understand the timing and circumstances of hastened deaths. We estimated life expectancy for the 26 patients who hastened their deaths and used content analysis to identify patterns in their decisions. On average, patients had lived with their illness for 2.5 years and had actively planned their deaths for 3 months. Those with less than a week to live (n = 10) *were 'dying and done,' having experienced a final functional loss that signaled the end. Those with* <1 *month* (n = 8) *were 'dying, but not fast enough.' Those with 1–6 months* (n = 5) *saw a 'looming crisis' on their horizon that would prohibit following through with their plans. The 3 patients with* >6 *months were 'not recognized by others as dying, but suffering just the same.' Clinicians should regularly assess where patients perceive they are in the dying process and ask about their comfort with the pace of dying to identify opportunities for intervention.* J Pain Symptom Manage 2005;30:215–226.

Key Words

Death and dying, physician-assisted suicide, euthanasia, terminal care, qualitative research

Introduction

For patients who express a serious interest in hastening their death, what are the conditions that signal that the day to die has arrived? What aspects of a patient's suffering trigger the move from interest in hastened death as an abstract option to the concrete action of taking lethal medications? These questions have yet to be fully explored in the literature. They are important questions for clinicians to consider, as there are legitimate concerns that patients may consider hastening their death because of

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unmet needs that might respond to therapeutic intervention.[1–4]

Several issues have been identified as motivators for interest in hastened death, including inadequate treatment for pain or other symptoms;[2,5–11] psychological issues such as depression and hopelessness;[7,12–17] concerns about losses (including physical functioning, control, sense of community, and sense of self/autonomy);[4,9,10,18–22] and concerns about being a burden on others.[11,23] Reports from Oregon suggest that patients who are seriously interested in hastened death are typically people who have been involved in decisions about their care and want to have a say about the timing and location of death.[23–26] Their interest in hastened death is one way for them to manage their dying process and gain reassurance that they may maintain some control over the many uncertainties posed by serious, life-threatening illness. As their illness progresses, patients gain experience regarding which losses they can accommodate to and which ones become increasingly unacceptable. Time and uncertainty about the future become forces that challenge patients to find the balance between not letting go too soon and not hanging on too long, lest their circumstances change and they cross a threshold where their lives become what they consider to be a fate worse than death.

The following analysis is from a descriptive, qualitative interview study with patients and family members who were recruited because they had a serious interest in pursing a hastened death.[22,27,28] Previous articles published from this study have addressed clinician–patient interactions regarding requests for aid-in-dying, the role of depression in influencing requests, and the motivations for interest in hastened death as an option at the end of life. A future article will discuss the effects on family members of participating in a hastened death. The objective of this analysis was to examine the circumstances of the patients' illnesses and life experiences that led some to follow through with their plan to hasten death and others to die of their illness. We examine these issues from several angles. One addresses the different places along the trajectory of illness decline and the kinds of suffering associated with the decision to die at these different points in time. We also describe the situation of those who died of their illness and the factors that explain why they did not ultimately hasten their death. Finally, we discuss other issues related to the timing of death, including why some deaths were completed by patients alone and others included assistance from family members.

Methods

Participant Recruitment and Data Collection

A detailed account of the recruitment and data collection methods is described elsewhere.[27] Briefly, in the states of Washington and Oregon, we used intermediaries (such as Compassion in Dying, the Hemlock Society, hospice agencies, and grief counselors) that had current or previous contact with patients and families to recruit two participant cohorts. One included family members of persons who had already died (retrospective cohort). The other included patients and their family members (prospective cohort). We asked the intermediaries to distribute information statements to their clients who had expressed a serious interest in a hastened death. Interested participants called the study office and spoke with one of the investigators, who explained the study procedures, answered questions, obtained verbal informed consent, enrolled participants, and collected demographic data.

We thus recruited 60 individuals from 35 families: 28 family members reporting on 23 patients in the retrospective cohort and 12 patients and 20 of their family members in the prospective cohort. We assigned a case number and code name for each family to maintain confidentiality. All contact information was destroyed upon completion of all interviews. We did not ask anyone to sign a consent form nor maintain any documents with identifying information to protect participants from any potential legal issues.

We conducted a total of 159 semi-structured interviews with patients and family members. On average, we interviewed the 12 patients 2.9 times (range 1–6) and their 20 family members 3.6 times (range 1–6). Patients and their family members were interviewed at enrollment and at approximately three-month intervals until the patient's death, and then again within three months of the patient's death to obtain the