

Experiences of Family Caregivers Providing Support to Individuals Who Voluntarily Stop Eating and Drinking (VSED) to Hasten Death

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Objectives

- Describe the types of caregiving activities and explore the experiences of “family” caregivers supporting an individual who elects VSED

Learning Objectives

- Describe the types of caregiving needed by individuals electing VSED
- Describe the experiences of ‘family’ caregivers supporting an individual who elects VSED.

Original Research Background: Voluntarily stopping eating and drinking (VSED) is a method for individuals with serious illness to control the timing and means of their death. The process requires clinical and social support, but no research has investigated the experience of caregivers supporting someone through VSED.

Research Objectives: To explore the experiences of individuals who have supported a patient through VSED.

Methods: This qualitative study involved semi-structured interviews with 24 former VSED caregivers between November 2018 and June 2019. Interviews represented 20 VSED attempts (19 deaths) between 2009-2018. Interviews were transcribed and analyzed using thematic analysis.

Results: Caregivers included spouses, adult children, and neighbors. Patients’ diagnoses included cancer, COPD, ALS, and early dementia. All patients were enrolled in hospice or hired professional health aides. Caregivers supported patients’ decision to choose a “less bad” death. Types of care included help with medical and legal preparations, physical assistance such as help toileting or turning in bed, symptom management for thirst and anxiety, medication management, and support and encouragement to refrain from ingesting fluids. Caregivers frequently had time to prepare for VSED and had agency in choosing their role (e.g. full caregiving vs focus on being present as spouse). The duration of VSED (median = 10 days, range 2-28) offered opportunities for closure, but caregivers remained vigilant for events that could derail the patient’s efforts (e.g. falls requiring emergency care). Caregivers perceived deaths as comfortable and consistent with patients’ wishes and felt relieved and grateful to have helped.

Conclusion: VSED requires intensive, hands-on caregiving, but the certainty of death offers opportunity for closure.

Implications for Research, Policy, or Practice: Little is known about the VSED process. These findings may inform practice for clinicians caring for individuals with serious illness, including early dementia, who plan to control the timing and means of their death.