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**Voluntarily Stopping Eating and Drinking (VSED) with Hospice Support in America:
A Case Series**

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Abstract

Context: Despite increasing public awareness of voluntary stopping of eating and drinking (VSED), there are no descriptions of the clinical course of US patients who pursue VSED, with or without hospice support.

Objectives. We report on the socio-demographics and clinical experiences of US patients pursuing VSED with hospice support.

Methods: We employed retrospective chart review methodology to review a consecutive case series of 20 patients who requested and received hospice support for VSED.

Results: Average age was 80 years (standard deviation [SD] 14, range 50-95), 55% female, 85% white, 60% divorced or widowed, 100% spoke English as their primary language, 75% were living in a private residence, and 55% had a daughter as their informal caregiver. 100% of patients who started VSED with hospice support died, an average of 9.6 days (SD 4.1, median 9.0, range 4-23). Eleven (55%) had documentation of thirst, 3 (15%) had documentation of hunger, 19 (95%) had documentation of taking pain medication at least once and 17 (85%) had documentation of anxiety, agitation and/or delirium at least once, for which they received lorazepam (88%), haloperidol (47%) and/or quetiapine (29%). No patients required hospitalization or sedation.

Conclusions. While this study has significant limitations, VSED was completed by all who initiated the process and death generally occurred within 10 days. Therefore, those initiating VSED should be considered eligible for hospice care, with care initiated quickly. Symptoms during VSED were typical of hospice patients and can be managed using common hospice techniques and medications.

Key Message

Patients who pursue VSED with hospice support generally live 10 days or less and have a course similar to other hospice patients.

Key Words

Voluntary stopping of eating and drinking (VSED), symptom management, hospice, hospice enrollment

Introduction

Voluntarily stopping eating and drinking (VSED) is an increasingly recognized practice for patients seeking to hasten death.^{1,2} As VSED is legal throughout the United States (US) and does not require medical provider involvement, it may be the only option for US residents who live in a state in which medical aid in dying (MAiD) is illegal; who lack access to medical providers willing to participate in MAiD; or who do not have a 6-month prognosis despite having a terminal illness (such as amyotrophic lateral sclerosis [ALS] or Parkinson's disease). For some, VSED can be the preferred practice for hastening death as it may be perceived as less abrupt or more "natural" than MAiD.

Nonetheless, VSED has been described in the literature as "intense" and "fraught,"³ with concerns expressed about: 1. length of time to death; 2. delirium, sometimes of such severity that patients request hydration due to excessive thirst;^{3,4} and 3. anxiety and agitation.⁵ Indeed, some discussions of VSED mention continuous deep sedation⁶ and palliative sedation³ as possibly necessary for management of refractory symptoms. However, in Switzerland, where VSED is familiar to 85% of nurses, both physicians⁷ and nurses⁸ consider VSED a dignified way to die, leading some to characterize VSED as resulting in a "good death."⁹ Further, among physicians, the probability of considering VSED to result in a dignified death increased by 52% if a physician had overseen the care of a patient pursuing VSED.⁷

Regardless, a patient's desire to initiate VSED has often been viewed as insufficient for US hospice physicians to determine hospice eligibility, particularly in the absence of a qualifying diagnosis and 6-month prognosis, both of which are strictly defined and monitored by Medicare. This concern may limit the hospice support received by VSED patients. Further, few empirical data exist regarding US patient experiences when VSED is undertaken, with or without hospice support.

To address this, we report on a retrospective, consecutive case series of patients who pursued VSED with support from one hospice in the Pacific Northwest. We were interested in: 1. patient demographics; 2. primary underlying illness(es); 3. whether a prognosis of ≤ 6 months was present when VSED was begun; 4. involvement of support systems, including a patient advocacy group and/or a death doula; 5. time from VSED initiation to death; and 6. clinical course and management of symptoms including thirst, hunger, pain, anxiety, agitation, and delirium.

Methods

This research was reviewed by the Fred Hutchinson Cancer Center Institutional Review Board and was determined not to be human subjects' research.

As part of an ongoing quality improvement effort, EvergreenHealth Hospice (Kirkland, Washington) maintains and reviews a list of all patients who request support for VSED. Patients may either be enrolled on hospice at the time of VSED initiation or may request hospice support in advance of initiating VSED. The first author, an experienced hospice medical director (HAW), prospectively reviews all initial requests, evaluating the patient's age, diagnoses (including comorbid mental health concerns), prognosis, residence, social/ family support, and input from other medical providers. If concerns arise regarding the appropriateness of hospice support, Ethics and/or Psychiatry consultation is routinely obtained. If doubt remains, the request is discussed with the interdisciplinary leadership team including hospice physicians, nurses, and social workers. If a patient's request for hospice support is initially declined, an explanation of this decision is provided with recommendations for additional steps (such as further psychiatric evaluation and treatment) that could result in a future decision to provide hospice support.

This list, including medical record number, outcome of the request and vital status, was used to identify all patients who pursued VSED from March 2023 to May 2025. All patients were known to be deceased at the time of chart abstraction.

A draft chart review template and abstraction guide was conceptualized based on discussions between the authors regarding the study's goals. The chart review template was then created in REDCap by the senior author (ETL), an experienced end of life (EOL) researcher and palliative care clinician who had not participated in the care of any of the included research subjects. Five charts were randomly reviewed to determine the functionality of the chart review template and abstraction guide. Following further discussion, the template and guide were revised and finalized. All charts were abstracted by ETL.

Records were reviewed for the 30 days prior to the date of VSED initiation for evidence of pre-existing conditions and primary care and palliative care involvement. The hospice admission care plan was the source for hospice and VSED initiation dates and admission diagnosis. Hospice notes were the source documents for reasons for VSED election, symptoms, and management of those symptoms. Anxiety, agitation and delirium are reported collectively given the frequent use of these terms interchangeably in hospice documentation. EvergreenHealth Hospice supplies a "comfort kit" for all patients which includes morphine, lorazepam and haloperidol. Therefore, for abstraction of medication use, there must have been charted documentation of the use of a specific medication by a VSED patient, not just a prescription or a recommendation to use it.

All results were reviewed by both authors. To minimize the possibility of bias, we reviewed the JBI Critical Appraisal Checklist for Case Series to ensure concordance with the checklist. Descriptive results (e.g. averages and percentages) are presented. Given the small sample size, no multivariable analyses were attempted.

Results

Of twenty-one patients who requested hospice support for VSED, one patient was declined because of significant co-morbid mental health concerns for which the patient declined Psychiatry consultation. See Table 1 for details regarding socio-demographics of the remaining 20 patients who did receive hospice support while engaging in VSED. Average age was 80 years (standard deviation [SD] 14, range 50-95), most were female (55%), non-Hispanic white (85%), divorced or widowed (60%), and all spoke English as their primary language. Seventy percent were living in a private home, with the majority supported by a daughter as their informal caregiver (55%). Forty-five percent had received palliative care prior to VSED initiation, 50% had engaged with an end-of-life advocacy group and 35% worked with a death doula. Seventy percent had documentation of a mental health concern and 50% had documentation of having received medication for this prior to VSED initiation. All but one had interactions with the hospice social worker and three (15%) received Psychiatry consultations prior to VSED or hospice initiation. Eleven (55%) had documentation of physical pain (typically musculoskeletal) prior to VSED initiation.

See Table 2 for details of the patients' hospice diagnoses and other underlying illnesses, and the reasons for choosing VSED. Two patients were already enrolled on hospice at the time of VSED initiation and one additional patient was determined to be eligible for hospice due to a pre-existing condition at the time of VSED initiation. (A total of three patients were deemed to be medically eligible for hospice whether or not VSED was undertaken). Patients initiating VSED typically either had a pre-existing neurologic condition (40%) or were assigned a diagnosis of severe or moderate "protein calorie malnutrition" (60%). However, even among those assigned a malnutrition diagnosis, many had other serious and/or chronic pre-existing conditions. Average time from VSED initiation to hospice enrollment for the 18 patients not already on hospice was 1.6 days (range 1-3).

Seven (35%) patients had documented loss of consciousness prior to death. For these, loss of consciousness occurred on average 8.7 days after initiating VSED (SD 4.2, median 9, range 5-12) and 1.4 days prior to death (SD 1.3, median 1, range 0-3). For all patients, the average time from VSED initiation to death was 9.6 days (SD 4.1, median 9.0, range 4-23). The

caregiver of the patient who lived 23 days acknowledged providing liquids, for comfort. The next longest living patient lived 14 days. Excluding the outlier who lived 23 days, the average days to death would have been 8.8 days (SD 2.7).

While experiencing VSED, 11 (55%) patients had documentation of thirst, while 3 (15%) had documentation of hunger. Management of thirst included: oral swabs of water or glycerin; frozen rings, ice packs or ice cubes; oral rinses/sprays/gels; coconut or olive oil; and lip balms. All but one patient had documentation of taking a medication for pain at least once during the VSED process, typically morphine or oxycodone. Seventeen (85%) had documentation of anxiety, agitation and/or delirium at some point in the VSED process and all received at least one medication for this, typically lorazepam (88%), haloperidol (47%) or quetiapine (29%). No patient required hospitalization or transfer to an inpatient hospice unit for symptom management. Fifteen (75%) patients and/or families declined one or more hospice services during VSED. Specifically, 11 (55%) declined a spiritual health clinician visit, 8 (40%) declined visits from either a nurse, a social worker or both, and 6 (30%) declined visits from an aide.

Discussion

To our knowledge, this is the first quantitative study to describe the demographics and clinical experience of US patients who pursued VSED while receiving hospice care. In this study, all who initiated VSED died of VSED. The average time from self-reported initiation of VSED to death (9.6 days overall) is consistent with expectations, particularly when patients fully abstain from drinking, and is similar to other reports in the literature.^{2,10,11,12,13} This finding should reassure hospice medical directors that death will occur within 6 months of initiating VSED for patients who are earnest in their intent and stands as an argument for hospice eligibility.

Our study sample represents a hospice population predisposed to the very elderly, with 9 of 20 (45%) over 90 years of age. This VSED population is also comprised of those with serious, pre-existing neurologic conditions, such as Parkinson's (n=5), stroke (n=4), dementia (n=3), ALS (n=1), and multiple sclerosis (n=1). Based on these factors and the documented reasons for pursuing VSED, they appear to be individuals who have been considering their own mortality for some time and have engaged others (e.g. palliative care, death doulas, patient advocates) to help assess their options. One individual specifically reported preferring MAiD but not being eligible. While the study sample mirrors the general hospice population, these individuals do not appear to be members of traditionally vulnerable groups based on the high rate of English-speaking, White, and retired professionals. On the other hand, there is a notable rate of pre-existing mental health concerns and at least three individuals did receive Psychiatry consultations prior to hospice support being started. Future studies should investigate whether our findings are generalizable to other US-based, VSED patient populations, particularly in states where MAiD is illegal.

While retrospective chart review studies may underreport complications,¹³ the prevalence of thirst among VSED patients in this study was high (55%). While expected, this rate is also on par with prior reports of thirst in the literature (50-83%) for general hospice populations.^{14,15} In contrast to thirst, we have been unable to find high quality reports of the prevalence of hunger among the general hospice population or among those imminently dying. This paucity of data limits our ability to place the observed rate of 15% into a greater context.

However, for other symptoms, patients in this study appeared to have rates at least equal to the general population of hospice patients who are nearing EOL. For example, studies have estimated the prevalence of pain to be 52-76% in outpatient hospice populations^{16, 17} Recchia et al reported rates of delirium or agitation of 22.8% among outpatients with a prognosis of 4 days or more and 56.7% in those with a prognosis of 3 days or less.¹⁸ Similarly, Gerlach et al reported 63.3%, 60.6% and 38.3% of hospice patients were prescribed opiates for pain, benzodiazepines for anxiety or agitation and an antipsychotic for delirium, respectively.¹⁹ In the current study, we found 95% of patients had evidence of taking at least one medication

for pain and 85% received at least one medication for anxiety, agitation and/or delirium. There may be multiple reasons for these findings, besides the rigor of the VSED experience itself, including but not limited to: 1. the cumulative nature of the reporting; 2. the provision of highly attentive care by both clinicians and informal caregivers during a rare clinical experience (i.e. VSED); 3. a study population enriched for individuals with neurologic conditions, such as dementia, stroke, and ALS; and 4. a study population enriched for individuals with pre-existing pain (55%) and mental health concerns (50%). Regardless, all symptoms were managed using well-established hospice tools; no patients required higher levels of care, such as hospitalization or palliative sedation; and patients and/or families appeared to decline hospice services, consistent with other non-VSED users of hospice.

While novel, this study does have significant limitations, including the retrospective review methodology, which is subject to multiple biases and restricts findings to what was documented in the medical record. This study also lacks comparative chart abstractors (due to a lack of funding). Further, this case series represents a small number of patients from one hospice based in the Pacific Northwest, which serves a relatively affluent and homogenous population. This study does not include the perspectives of the clinicians providing care, the patients who received it, or the caregivers who supported patients pursuing VSED. Despite these limitations, this study remains valuable as a guide for US clinicians and future researchers who may develop prospective studies of VSED, with or without hospice support.

This case series suggests that, with careful planning and hospice support, VSED may be a viable option for individuals wishing to hasten death, without requiring hospitalization or sedation. It also indicates that death typically occurs within 10 days. Based on this study, US hospice medical directors should not fear prognostic uncertainty in those who are earnest in pursuing VSED. Given the likelihood that a person committed to VSED will die not only in less than 180 days, but in less than 15, it is more appropriate to question the justification for denying such a patient access to a federal benefit than it is to question whether such access should ever be granted. As is true of any EOL situation, hospice staff are uniquely positioned to provide anticipatory guidance; symptom management; and psychosocial, emotional, and spiritual support for patients and caregivers. Conversely, lack of hospice support for those pursuing VSED can be anticipated to result in lower quality symptom management and additional risk of distress and complicated grief in caregivers.

If our results hold in future studies, training clinicians to recognize VSED as an autonomous patient choice that is usually completed in under ten days, with manageable symptoms when hospice support is provided, may result in patients and caregivers receiving complete and accurate information regarding this EOL option and higher-quality EOL care. Finally, larger prospective studies to further investigate the demographics, clinical courses, and reliability of VSED as a predictor of hospice eligibility are needed, particularly as more patients seek a hastened death, whether or not they reside in states in which MAiD is legal. Such studies should also explore clinician, family and caregiver perspectives on VSED before and after death to more completely understand the impact of VSED on survivors.

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Table 1: Demographics and Clinical Characteristics for Patients Receiving Hospice Support While Enacting Voluntary Stopping of Eating and Drinking (VSED).

| Patient Characteristics | Total N=20 |
|--|---|
| Age, in years | Mean: 80, Standard deviation: 14 Median: 83 Range: 50-95 |
| Female (%) | 11 (55%) |
| White^a | 17 (85%) |
| Non-Hispanic or Latino^a | 16 (80%) |
| English as Primary Language | 20 (100%) |
| Marital Status | |
| Married/Significant other | 8 (40%) |
| Widowed | 9 (45%) |
| Divorced | 3 (15%) |
| Housing at VSED Initiation | |
| Private home | 14 (70%) |
| Independent/Assisted living facility | 5 (25%) |
| Nursing facility | 1 (5%) |
| Religion or Spirituality^a | |
| Christian | 9 (45%) |
| Buddhist | 1 (5%) |
| None | 5 (25%) |
| Caregiver Relationship to Patient | |
| Spouse/Significant other | 7 (35%) |
| Daughter | 11 (55%) |
| Other | 2 (10%) |
| Palliative Care Involvement Prior to VSED Initiation | 9 (45%) |
| On Hospice or Hospice Eligible Prior to VSED Initiation | 3 (15%) |
| Hospice Admission Diagnosis | |
| Protein calorie malnutrition (moderate or severe) | 12 (60%) |
| Parkinsons | 4 (20%) |
| Other neurologic condition | 4 (20%) |
| Mental Health Diagnosis (MHD) Prior to VSED Initiation (patient can appear in more than one category) | |
| Yes | 14 (70%) |
| Depression | 10 (50%) |

| | |
|--|-----------------|
| Anxiety or Panic | 7 (35%) |
| Adjustment disorder | 4 (20%) |
| | |
| Use of Medications for MHD prior to VSED Initiation | 10 (50%) |

a= missing data: White 3 missing; Non-Hispanic 4 missing; Spirituality 5 missing.

Table 2: Patient Level Data for Individuals Enacting Voluntary Stopping of Eating and Drinking with Hospice Support.

| Age (years) | Sex | Occupation | Hospice Admission Diagnosis | Other Diagnoses if Different from Hospice Admission Diagnosis | Clinician Documentation of Reason for VSED | Documentation of Direct Patient Quotes |
|-------------|--------|----------------------|-------------------------------|---|--|--|
| 95 | Female | Art museum curator | Protein calorie malnutrition | Secondary hyperparathyroidism of renal origin, chronic anemia, right nephrectomy, chronic kidney disease stage 3b | Her husband died 10 months ago after "lingering" with dementia, and she has decided that is not how she wants to die. She does not wish to get to the point where she is dependent on others for daily living. | |
| 83 | Male | University professor | Parkinson's | | End stage Parkinson's disease | |
| 65 | Male | Real estate broker | Amyotrophic lateral sclerosis | Pulmonary embolus, sleep apnea | After discover of pulmonary embolus he has decided to initiate VSED. Pt states wish for comfort measures through VSED | |

| | | | | | | |
|----|--------|------------------------|-------------------------------------|---|---|--|
| | | | | | process with support of hospice | |
| 87 | Female | Preschool teacher | Parkinson's | | | I have been planning this for 15 years. I know I have a choice. I am ready. I have read books. I don't want to keep going. |
| 94 | Male | Professor | Severe protein calorie malnutrition | Pacemaker, stent, myocardial infarction, congestive heart failure, stroke | Has decided to stop all PO intake which is something he has been planning to do for a while. | |
| 50 | Male | Electrical engineer | Multiple sclerosis | | Pt has been planning his EOL for the last few years. Diagnosed with MS in (year). Wheelchair bound and declining mobility since (year). Planned VSED to begin after his birthday. | |
| 65 | Female | RN; Hospital inspector | Severe protein calorie malnutrition | Frontotemporal dementia | Goals of Care: to enjoy her last few days at home and end her life on her own terms rather than from dementia | |
| 95 | Female | Homemaker ; Volunteer | Severe protein calorie malnutrition | Hypertension, hypothyroidism, Vitamin B12 deficiency | Female who is currently doing VSED because she is "ready to die" and is | |

| | | | | | | |
|----|--------|---------------------|-------------------------------------|--|--|--|
| | | | | anemia, chronic atrial fibrillation | "ready for the next chapter". | |
| 91 | Male | | Severe protein calorie malnutrition | Atherosclerotic heart disease, chronic kidney disease stage 3a, recent brainstem infarction, prostate cancer | Patient states that he is the "last of his generation" and that "all friends/relatives his age have died. He does not wish to continue to slowly lose his functional ability. | |
| 94 | Female | Drug store worker | Severe protein calorie malnutrition | Congestive heart failure, atrial fibrillation, depression, hypothyroidism | She is frustrated by her declining functional status and feels like she is a burden to family. Pt is dependent for all ADLs, wc/bedbound. She reports that she has had a great life but is tired and ready to go | |
| 96 | Female | Administrative work | Severe protein calorie malnutrition | Hypertension, mitral valve prolapse, atrial flutter | 96 yo female who has had long-standing food allergies, and it has gotten to the point that food makes her feel sick, and now it is nearly all foods, so she is hardly eating due to the discomfort and pain, she is drinking a lot of water. | |

| | | | | | | |
|----|--------|---------------------------------|---------------------------------------|---|--|---|
| | | | | | Wants comfort care, and avoid hospitalization | |
| 68 | Male | | Parkinson's | | Rapid decline in function due to Parkinson's disease | |
| 91 | Female | | Moderate protein calorie malnutrition | Chronic kidney disease, stage 3, thrombocytopenia, Vitamin B12 deficiency | | I want to die. I'm (too) healthy to die, and I'm too sick to live. |
| 67 | Female | Ran a small electronics company | Severe malnutrition | C5 Quadriplegia, Hashimoto thyroiditis, rheumatoid arthritis | Patient reporting she has no quality of life and wants to hasten EOL. | I understand, but this situation is just not good enough for me to keep living like this. She states "There are worse things than death, and this is it." |
| 66 | Female | Banker; Plant nursery | Protein calorie malnutrition | Atypical Parkinsonism, brain neurostimulator device in situ, Rapid Eye Movement behavioral disorder | This is not a QOL that is acceptable to her. (Patient) would have preferred to have MAiD available to her but due to the timeline she wishes to proceed with VSED. | |
| 81 | Male | Book store worker and owner | Protein calorie malnutrition | Lewy body dementia, Parkinsonism | Patient verbalizes that it is very important to die at home and not a facility. Patient also verbalizes that he doesn't want to get to | |

| | | | | | | |
|----|--------|---------------|---------------------|---|---|---|
| | | | | | the point where he doesn't know his own children. | |
| 94 | Female | Social worker | Severe malnutrition | Stroke, atrial fibrillation, ascending thoracic aortic dilation | Patient wants a 'graceful way to end my life at 95' before her cognition or function deteriorates further. | I have had a great life and I'm old and there isn't any more I want to do, I have been losing weight slowly and can't imagine continuing to decline to a point that I am not able to care for myself. |
| 68 | Female | Attorney | Senile degeneration | Dementia, neuropathic pain, carotid stenosis | (Patient) reports that her mother had dementia and she advocated for her not to receive a feeding tube, which her brother wanted her to receive. Her experience with her mother's dementia informed her feelings about what she would want if she were to have dementia | |
| 71 | Male | Engineer | Stroke | Stroke with hemiplegia and hemiparesis, traumatic brain injury | Pt described [his current condition] as suffering and a loss of dignity. Pt consistently | |

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|----|------|--|-------------|--|---|--|
| | | | | | expressed the perspective that he would not want to live long term with functional impairment. | |
| 83 | Male | | Parkinson's | | Have had extensive conversations; he worries about his cognitive ability and does not feel that he can interact with this loved ones in the way he wishes to. | |