

# Voluntarily Stopping Eating and Drinking at the End of Life (VSED) and Its Troubling Implications for Nursing Practice

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ABSTRACT: Recent publications in nursing literature have presented the policy of voluntarily stopping of eating and drinking (VSED) as an ethical alternative to physician-assisted suicide and recommended training hospice nurses to facilitate this practice. In this article I highlight some of the false claims made by the proponents of this practice, in particular those claims made by Judith Schwarz in a case-study published in the *Journal of Hospice and Palliative Nursing* in 2014. Through an analysis of these claims I hope to show that VSED is a process with troubling implications for hospice nurses.

IN 2012 JUDITH SCHWARZ of the organization Compassion and Choices, a nonprofit that “works to protect and expand end-of-life options,” was a guest on the NPR talk show “Fresh Air” with Terri Gross.<sup>1</sup> Schwarz told the story of how she and an experienced hospice nurse were called in by a patient they had both known for sometime. The patient had asked to speak with them because she was ready to die and wanted help in hastening her own death. When the hospice nurse said “I can’t help you with that” Judith Schwarz quickly said, “Yes, I can help you!” Terri Gross asked why it was that Schwarz could help but that the hospice nurse could not. Schwarz replied: “Because we work for different organizations. That is not what hospice does.” Yet Judith Schwarz has recently published a case study that argued that hospice nurses can and should support patients in the practice of voluntarily stopping one’s eating and drinking as a means of hastening death.<sup>2</sup> In this essay I hope

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<sup>1</sup> Judith Schwarz, interview by Terri Gross, *Fresh Air*, October 9, 2012. <http://www.npr.org/2012/10/09/162570013/when-prolonging-death-seems-worse-than-death>.

<sup>2</sup> Judith K. Schwarz, “Hospice Care for Patients Who Choose to Hasten Death by

to illustrate some of the false claims that Schwarz made and to show that nurses should not support this practice.

In 2011 Compassion and Choices led a campaign to promote the practice of voluntarily stopping eating and drinking (VSED) as a means to hasten death. Compassion and Choices promotes this approach as a practice available to anyone who wants to “bring peace at life’s end anywhere.”<sup>3</sup> There have been various stories in the media discussing the use of this practice. The most prominent has been the death of the husband of Diane Rehms, a national talk show host for NPR. He had Parkinson’s Disease and asked for physician-assisted suicide. His doctor told him that this practice was illegal in his state of Maryland, but that he could stop eating and stop drinking. He did so and died in ten days.<sup>4</sup>

It is important to clarify exactly what VSED refers to in the current end-of-life discussions. Supporters define it as the choice of a decisionally capable individual to refuse all food and fluid with the intention of bringing about one’s own death.<sup>5</sup> It does not refer to a diminished desire for food and fluids that often arises naturally in patients with some terminal conditions. It is also different from the policy of not feeding a patient with dysphagia, a condition in which oral food or fluid would result in aspiration. This practice is also different from patients not receiving food or drink because they are too lethargic or too weak to swallow. As used in this context, VSED does not address issues relating to what has been classified as “artificial nutrition and hydration” feedings and/or fluids delivered via gastric, nasogastric, or intravenous routes. The process of VSED results in death by dehydration (sometimes called “terminal dehydration”) that, on average, results in death in about two weeks.<sup>6</sup> When referred to as an “end-of-life option” by groups like

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Voluntarily Stopping Eating and Drinking,” *Journal of Hospice & Palliative Nursing* 16 (2014): 126-31.

<sup>3</sup> Compassion and Choices, “Your Life Your Priorities,” accessed June, 2016. <https://www.compassionandchoices.org/wp-content/uploads/2016/02/your-life-your-priorities1.pdf>

<sup>4</sup> Michael S. Rosenwald, “NPR Host Diane Rehm Emerges as Key Force in the Right-to-Die Debate,” *Washington Post* (Feb. 14, 2015) [https://www.washingtonpost.com/local/npr-host-diane-rehm-emerges-as-a-key-force-in-the-right-to-die-debate/2015/02/14/12b72230-ad50-11e4-9c91-e9d2f9fde644\\_story.html](https://www.washingtonpost.com/local/npr-host-diane-rehm-emerges-as-a-key-force-in-the-right-to-die-debate/2015/02/14/12b72230-ad50-11e4-9c91-e9d2f9fde644_story.html).

<sup>5</sup> Vicki D. Lachman, “Voluntary Stopping of Eating and Drinking: An Ethical Alternative to Physician-Assisted Suicide,” *MEDSURG Nursing* 24 (2015): 57.

<sup>6</sup> *Ibid.*, p. 58.

Compassion and Choices, VSED also entails a declared wish that the patient going through VSED will receive physical support with hygiene and oral care. It also presupposes that the patient will receive the needed medications from a clinician or family member to treat the pain, agitation, and nausea that might arise during the process.

Do people really do this? There are some studies suggesting that it could be utilized by a significant number of people. A study published in 2003 in *The New England Journal of Medicine* surveyed hospice nurses in Oregon. Some 41% reported that over the previous five years they had cared for at least one patient who voluntarily chose to stop eating and drinking so as to hasten their deaths (a total of 126 attempted the practice, with 102 deaths). Of the hospice nurses surveyed, 18% reported that they had a patient who died of physician-assisted suicide (a total of 55 deaths). These statistics show that deaths from VSED were double those deaths from physician-assisted suicide.<sup>7</sup> A more recent (2015) study published in *Annals of Family Medicine* surveyed physicians in the Netherlands. Some 46% of the respondents (708 physicians) stated that they had cared for at least one patient who hastened death by VSED. That study also cited a statistic that in the Netherlands 0.4% to 2.1% of total deaths each year (around 2,800) are attributed to VSED.<sup>8</sup> It is of note that these studies were carried out in a context where physician-assisted suicide or euthanasia is legal, possibly indicating that the patients received counseling on the topic. I was unable to locate any further data. No other studies have attempted to quantify the numbers of people who have engaged in this practice.

How have nurses responded? The American Nurses Association does not specifically discuss VSED in its 2013 position statement “Euthanasia, Assisted Suicide, and Aid in Dying.”<sup>9</sup> This statement does “prohibit nurses’ participation in assisted suicide and euthanasia because these acts are in direct violation of the Code of Ethics for Nurses.” The ANA position clearly states that “the nurse may not administer the medication that will lead to the end of the

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<sup>7</sup> Linda Ganzini et al. “Nurses’ Experience with Hospice Patients Who Refuse Food and Fluids to Hasten Death,” *New England Journal of Medicine* 349 (2003):359-65.

<sup>8</sup> Eva E. Bolt et al. “Primary Care Patients Hastening Death by Voluntarily Stopping Eating and Drinking,” *Annals of Family Medicine* 13 (2015): 421-28.

<sup>9</sup> American Nurses Association Position Statement, “Euthanasia, Assisted Suicide, and Aid in Dying” (April 24, 2013), <http://www.nursingworld.org/MainMenu/Categories/EthicsStandards/Ethics-Position-Statements/Euthanasia-Assisted-Suicide-and-Aid-in-Dying.pdf>

patient's life" but does indicate that nurses "need to support patients' autonomous decision making." The Hospice and Palliative Nurses Association 2011 position statement "The Role of the Nurse when Hastened Death is Requested" states that "patients can select several legal options to hasten death and avoid suffering" and specifically mentions the option to "voluntarily stop eating and drinking."<sup>10</sup> When a request for death is made, "the nurse shares information about Health choices that are legal and supports the family regardless of the choices made."

According to Judith Schwarz's case presentation, her patient (EM) is an 83-year-old female living in a senior apartment who had been referred to home hospice for increasing weakness and the presence of metastatic disease, including a pelvic tumor for which there was no recommended treatment. EM had pain that was well managed with small doses of opiates. She was alert and oriented. She was continent of bowel and bladder, but experiencing difficulty with elimination and there were fears of possible obstruction. There are no details about her functional status. Schwarz explains that EM "was ready to die, that the burdens of life consistently outweighed the benefits. She knew she was dying but was frustrated at the slow pace. She had heard about VSED from other residents who had watched the peaceful death of a patient who suffered with ALS who began to fast when his symptoms became intolerable."<sup>11</sup> I will illustrate that in this case-presentation Schwarz makes several claims that are false and I will highlight important reasons why nurses should not support this practice.

Schwartz repeatedly makes the claim that VSED could be utilized because it is "legal" without considering some of the charges that nurses participating in VSED could face. She states that because "because VSED is a legal option, it can be openly discussed in a thoughtful manner with loved ones and caregivers."<sup>12</sup> Supporters of VSED often claim that it is a legal option to hasten death where there is no legalized physician-assisted suicide (currently available in six states).<sup>13</sup> One could claim that VSED is legal because one

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<sup>10</sup> Hospice and Palliative Nurses Association Position Statement, "Role of the Nurse when Hastened Death is Requested" (2011), <http://hpna.advancingexpertcare.org/wp-content/uploads/2015/08/Role-of-the-Nurse-When-Hastened-Death-is-Requested.pdf>.

<sup>11</sup> Schwarz, "Hospice care for patients Who Choose to hasten Death by Voluntarily Stopping Eating and Drinking," p. 127.

<sup>12</sup> *Ibid.*, p. 129.

<sup>13</sup> Lachman, p. 56.

cannot force food or drink on anyone, which would constitute legal battery. One could also claim that VSED is legal because suicide is also legal. But nurses could certainly be open to the charge of assisting in a suicide, which (as Maureen Cavanaugh points out) is considered second-degree manslaughter in some states.<sup>14</sup> It is also possible that a nurse could be charged with neglect or elder abuse. Elder malnutrition is a type of elder abuse with which caregivers can be legally charged.<sup>15</sup>

Participating in VSED or counselling patients toward VSED would open nurses up to malpractice litigation. Schwartz states that in EM's case it is the nurse who "discusses the pros and cons, ensures she has a realistic understanding of the process, any alternatives, and answers any questions she might have."<sup>16</sup> What she describes here is the process of obtaining informed consent for a treatment. This is beyond the scope of practice for nurses. Additionally, it would be obtaining consent and implementing medical care that is not standard.<sup>17</sup> This would leave the nurse vulnerable to malpractice. The group "End of Life Washington" points this out clearly in a patient guide that states: "If you are already on hospice, you only need the help of your nurse for the process, and there is no need for a physician to be involved."<sup>18</sup> This puts nurses in the position of directing an unapproved treatment that would result in patient death.

Schwarz falsely claims that VSED is the act of an autonomous patient in which "control remains with the patient throughout the process: whether and when to begin the fast and whether to continue to fast each day until consciousness is lost."<sup>19</sup> This is not a true claim because as VSED is envisioned by Schwarz, the patient is receiving support during this time, including nursing care for hygiene and oral care along with medications. The nurse would be

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<sup>14</sup> Maureen Cavanaugh. "How Should a Catholic Hospice Respond to Patients who Choose to Voluntarily Stop Eating and Drinking in Order to Hasten Death?" *The Linacre Quarterly*, 81 (2014): 279-85.

<sup>15</sup> Nursing Home Abuse Guide. <http://nursinghomeabuseguide.com/abuse-injuries/malnutrition/>.

<sup>16</sup> Schwarz, p. 127.

<sup>17</sup> Lynn A. Jansen, "Voluntary Stopping of Eating and Drinking (VSED), Physician-Assisted Suicide (PAS), or Neither in the Last Stage of Life? PAS: No; VSED: It Depends," *Annals of Family Medicine* 13 (2015):410-11.

<sup>18</sup> End of Life Washington, "Voluntary Stopping of Eating and Drinking." <http://endoflifewa.org/wp-content/uploads/2014/01/VSED.Packet.10.2015.pdf>.

<sup>19</sup> Schwarz, p. 129.

actively engaged in carrying out the suicide of the patient by providing physical support and medication to ensure the VSED was successful. Additionally, the nurse would be actively involved by not providing hydration and nutrition, one of the key roles of a nurse. Since death in this process occurs by dehydration, this process could readily be deemed “nurse-assisted suicide” because it would not be a single act carried out through medications prescribed by a physician but through a series of acts withholding food and fluids, carried out by caregivers, nurses in any healthcare facility or family members in the home setting. No patient could carry out VSED without the help (or the neglect) of a care-giver.

Schwarz refuses to mention the physiological reality that VSED is starvation, a physically torturous experience, and instead refers to it as a “peaceful” process. Her patient E.M. is described as remaining alert and oriented for the first five days of fasting and denying that there was “any significant discomfort.” She then “slipped into a coma at the end of the fifth day and died peacefully.” She states that the nurse in the case said that “the discomfort associated with VSED could be readily managed by good bedside care.” This is presupposing that the patient would receive considerable analgesic, anxiolytic, and anti-emetic medication along with adequate oral care to treat dry mouth, which has been admitted to be one of the more “discomforting aspects.”<sup>20</sup> The report does not mention that there could be other scenarios experienced, like those where some patients in England attempting this option were “howling with anguish” and “being tortured in a desert.”<sup>21</sup>

Schwarz’s claim that VSED is a “peaceful” process does not take into consideration the experience of family members witnessing the process. Schwarz notes that EM’s son had reservations about the process and admits that it could be difficult for families to witness the death of their family members through VSED. She claims to address this concern by referring EM’s son for bereavement counseling, even though his mother was not yet deceased.<sup>22</sup> Family members have recounted that they felt that their loved one

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<sup>20</sup> End of Life Washington, “Voluntary Stopping of Eating and Drinking.” <http://endoflifewa.org/wp-content/uploads/2014/01/VSED.Packet.10.2015.pdf>.

<sup>21</sup> Patients’ Rights Council, “Voluntarily Stopping Eating and Drinking: Important Questions and Answers” (accessed June 2016) [http://www.patientsrightscouncil.org/site/wp-content/uploads/2013/03/VSED\\_Questions.pdf](http://www.patientsrightscouncil.org/site/wp-content/uploads/2013/03/VSED_Questions.pdf).

<sup>22</sup> Schwarz, p. 128.

was being tortured when undertaking VSED until they died.<sup>23</sup> It thus seems clear that nurses could be exposing family members to undue burden and trauma by supporting this process.

Schwarz claims that professionals opposed to the process can be protected by conscience clauses. She says: “Some clinicians believe that any act that intentionally hastens or causes death is always morally wrong” but then dismisses this concern on the ground that the hospices can create “a conscientious objection policy that supported a process for those with a moral objection to VSED to withdraw from the patient’s team.”<sup>24</sup> Schwarz suggests that those with strong moral opposition to the practice would still be obliged to “inform their patients of all legally available treatment options, including VSED, or else would have to refer the patient to another who would provide the information.” This would result in any nurses with moral or ethical concerns being excluded from this area of practice, as has already been the case for nurses in perinatology, obstetrics, and community health where abortion could be a concern.<sup>25</sup>

Schwarz claims that nurses would be denying patients a benefit by not offering them the option of VSED. She claims that merely offering VSED provides benefit to the patient because “the patient’s knowledge that he/she has ‘a way out’ seems to provide relief from feeling of desperation and entrapment.”<sup>26</sup> There is no evidence to support this claim. This option could just as easily introduce an undue burden on patients constantly to justify their existence.

Schwarz makes a fallacious claim about absolving nurses of responsibility when she claims that VSED is a process in which the patient remains in control at all times. For Schwarz, “VSED is patient directed and controlled, rather than clinician imposed.”<sup>27</sup> This would presuppose that the patient could start eating or drinking at any time. But this is a false claim. As the directives prepared by “End of Life Washington” about VSED show, once the process begins the caregivers “may need to be vigilant to ensure that the patient’s wishes are

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<sup>23</sup> Patients’ Rights Council, “Voluntarily Stopping Eating and Drinking: Important Questions and Answers.”

<sup>24</sup> Schwarz, p. 129.

<sup>25</sup> Eric Shulzke, “Pro-life health professionals in conflict between conscience and career,” *Deseret News* (March 17, 2012), <http://www.deseretnews.com/article/765560407/Abortion-creates-conflict-for-pro-life-medical-workers.html?pg=all>.

<sup>26</sup> Schwarz, p. 128.

<sup>27</sup> *Ibid.*, p. 130.

honored and that no one offers the patient food or drink.”<sup>28</sup> This statement also notes that it is important to “keep any smells of food away from the patient” and to place signs near the patient’s bed stating “No Food or Drink.” This is certainly calling on the nurse to strictly control the environment of the patient so as to prevent nourishment. In the final stages of the VSED process, the patient becomes unconscious, completely lacking any control.

Schwartz is wrong in suggesting that nurses would be more trusted by offering VSED. Schwarz also suggests that the nurse offering VSED would be more compassionate by not abandoning the patient when she asks for a hastened death. In her case study, she offers the example of a social worker who was “judgmental” about EM’s request to hasten her death and concludes that EM did not want to speak with the social worker after that encounter.<sup>29</sup> Nurses are consistently ranked as the most trusted of professionals in national Gallup polls.<sup>30</sup> Having nurses suggest and implement starvation for patients could have severe impact on the trust that patients place in the profession.

Schwartz claims that VSED can be integrated into hospice care. EM was a hospice patient and at the conclusion of the case it was the hospice service that facilitated her death by dehydration. This is completely contrary to the philosophy of hospice care. The National Hospice and Palliative Care Organization states: “Hospice affirms life and neither hastens nor postpones death.”<sup>31</sup> Schwarz creates her own definition when she says that hospice care is helping patients come to death “on their own terms.”<sup>32</sup> Promoting VSED could do irreparable harm to the practice of hospice. As one hospice physician states: “If people feel hospice is hastening death, hospice will never recover.”<sup>33</sup> Hospice and palliative physicians have invested years of effort to educate patients and providers about their role in order to assist people to a more

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<sup>28</sup> End of Life Washington, “Voluntary Stopping of Eating and Drinking.” <http://endoflifewa.org/wp-content/uploads/2014/01/VSED.Packet.10.2015.pdf>.

<sup>29</sup> Schwarz, p. 127.

<sup>30</sup> American Nurses Association, “Nurses Rank as Most Honest, Ethical Profession for 14th Straight Year” (accessed June 2016), <http://nursingworld.org/FunctionalMenuCategories/MediaResources/PressReleases/2015-NR/Nurses-Rank-as-Most-Honest-Ethical-Profession-for-14th-Straight-Year.html>.

<sup>31</sup> National Hospice and Palliative Care Organization, “Hospice Philosophy Statement” (accessed June 2016), <http://www.nhpco.org/ethical-and-position-statements/preamble-and-philosophy>.

<sup>32</sup> Schwarz, p. 127.

<sup>33</sup> Cavanagh, p. 282.



comfortable death. They have been successful, and the number of patients making use of these services has greatly increased.<sup>34</sup> But a fear of practices like VSED could reverse that process. Schwarz takes palliative care out of the specialty of symptom management. It is clear that EM's symptoms were controlled, and yet Schwarz feels that even when all symptoms are controlled and all needs met, some patients still experience unacceptable suffering. Schwarz therefore concludes that clinicians have a duty to meet that need.<sup>35</sup>

In Judith Schwarz's interview with Terri Gross, it is good to see that she recognizes that there is a divide between what she does with Compassion and Choices and what hospice nurses do. But as her case study of EM clearly shows, she means to bring the practice of VSED into mainstream palliative and hospice care. She wants nurses to believe that this is a legal, peaceful, patient-centered practice that can be directed by nurses. I have tried to show that the contrary is true. Nurses could be legally charged with assisting in a suicide and with negligence as well as with operating outside their scope of practice. They could be directing a torturous process that would cause distrust for the profession and for the practice of palliative care. Nurses should voice their concerns to protect their role in the very crucial care they provide in hospice and palliative care.

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<sup>34</sup> National Hospice and Palliative Care Organization, "Growth in US Hospice Programs: 1974 to 2013" (accessed June 2016), [http://www.nhpco.org/sites/default/files/public/Statistics\\_Research/ProviderGrowth.pdf](http://www.nhpco.org/sites/default/files/public/Statistics_Research/ProviderGrowth.pdf).

<sup>35</sup> Schwarz, p. 130.