Refusal of Oral Feeding and Nutrition or a Way to Speed Up Dying Without Asking Permission: Voluntarily Stopping of Eating and Drinking in the End of Life

Rechazo de la alimentación y nutrición orales o una forma de acelerar la muerte sin pedir permiso: interrupción voluntaria de la alimentación y la hidratación al final de la vida

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Abstract

Terminally ill patients experience conditions of life that can become unbearable resulting in the wish to end their life prematurely. One way to end one's life prematurely is by voluntary stopping of eating and drinking, however this can also be considered a way of refusing food and water like refusal of artificial nutrition and hydration.

Resumen

Los pacientes en fase terminal experimentan condiciones de vida que pueden volverse insoportables, lo que puede llevar al deseo de poner fin a su vida de manera anticipada. Una forma de hacerlo es mediante la interrupción voluntaria de la alimentación y la hidratación; sin embargo, esto también puede considerarse una forma de rechazo a la comida y el agua, similar a la negativa a recibir nutrición e hidratación artificiales.

Key words

Voluntarily stopping of eating and drinking; ethical issues; end of life; palliative care.

Interrupción voluntaria de la alimentación y la hidratación; cuestiones éticas; final de la vida; cuidados paliativos.

Fechas

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1. Introduction

Patients suffering from chronic diseases experience conditions of life which can become unbearable. Voluntary Stopping of Eating and Drinking (VSED) is remarkably understudied and the discussion about this kind of decision is recent in literature (Saladin, 2018).

In more recent days, ongoing debates about when to start or to stop using many types of end-of-life treatment date only to the 1960s. The option to hasten death by withholding or withdrawing these types of treatment did not exist prior to their development. In contrast, through time VSED is being considered a method of hastening death that dates back thousands of years. It is known that the use of this practice has been described at least since ancient Greece, for achieving a good death (Pinho-Reis et al., 2018).

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Between 1958 and 1967 Cicely Saunders achieved improved care and support for the dying patient, so the development of palliative and hospice care improved the situation of patients beyond therapeutic possibilities of cure (Ivanovic, 2014).

Palliative care and hospice remain the standards of care to relieve the total pain and provide support to seriously ill patients although this type of care can be delivered alongside disease-directed medical treatments, whereas hospice includes a system of care that emphasizes dignity, comfort, and quality of life. However, the final days or weeks remain a huge challenge to healthcare teams, patients, and family members. Unbearable suffering despite palliative care leads to requests for ending a patients' life prematurely (Quill et al., 2018).

For the past decades VSED has been more discussed as one possibility among several to preserve autonomy, to maintain control and to hasten death without infringing the bioethical principles of beneficence, nonmaleficence, justice, vulnerability, and autonomy. However, it is also being discussed if VSED is only a way of refusing food and water like refusal of artificial nutrition and hydration (Stangle et al., 2018).

VSED is very often incomprehensible by who is not living this issue in life and moral conflicts emerge in the healthcare team because of the meaning that food, nutrition and fluids may have in peoples' lives (Pinho-Reis, 2014a).

2. Voluntarily stopping of eating and drinking

2.1. The meaning of food and fluids

Food, nutrition, and hydration play a central role in patients' life, because they hold an emotional and symbolic significance and a physiological and psychological role which includes cultural, social, religious, and spiritual values (Pinho-Reis, 2012).

Due to the disease's evolution and trajectory, patients face many losses related to food. From the inability to feel flavour, swallow, digest food and absorb nutrients properly to losing the ability to self-feed or use the oral route. Eventually, all these changes may transform meals at an uncomfortable moment and lead the patient to depression, social isolation, loss of confidence and self-esteem, food refusal and consequently weight loss, and malnutrition (Pinho-Reis et al., 2022).

In some cases, at the request of the competent patient VSED to hastens death may occur and it is a topic that raises challenging clinical and ethical questions, representing at the same time a subject in palliative care that is remarkably understudied

Regarding the family, the importance of feeding increases as the disease progresses. Food and diet are the only ways to transmit life, care, and affection by which all changes mentioned above, as well as their consequences, can be understood as an approach to death. In some cases, the family perceives the refusal to eat as the desire of the patient to hastens his death. Thus, to reverse this situation, feeding may be forced, causing discomfort and conflict within family members (Pinho-Reis et al., 2018).

Food and fluids, whether offered orally or by the artificial route, represent a form of affection and care and because of that, over time, the concept of nutrition and hydration started to be compared with food and drink as an extension of care, and support. From this perspective, withholding or withdrawing ANH means denying food and fluids to the patient. ANH is not synonymous with feeding someone, nor eating or drinking. The person eats from a social point of view — orally or by mouth — and using normative social equipment — knife, cup or fork. ANH is not encompassed in the normative social component that oral feeding and drinking have. In fact, only just over a decade ago feeding tubes were called "forced-feeding" (De Oliveira, 2021).

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2.2. Terminology and definitions

In the literature, VSED has been variously referred by several other names, including voluntary refusal of food and fluids, voluntary terminal dehydration, voluntary death by dehydration, terminal dehydration, stopping eating and drinking, patients' refusal of hydration and nutrition, and indirect self-destructive behaviour (Cavanagh, 2014).

VSED is described as an action of a competent, capacitated person, who voluntarily and deliberately chooses to stop eating/nutrition and drinking/hydration with the primary intention to hasten death because unacceptable suffering persists. This definition does not include the cessation of nutrition or hydration for other reasons, such as loss of appetite or inability to eat or drink due to disease's progression (Bolt et al., 2015).

VSED is distinct from illness-associated anorexia-cachexia, which reflects the natural history of certain diseases, rather than a voluntary choice. VSED is physiologically like discontinuation of artificial nutrition but presents unique symptom management,

anticipatory guidance for families, and ethical underpinnings because it is not a withdrawal of invasive medical intervention (Lowers, 2020).

VSED has two forms: the concealed and the implicit form. They differ particularly in the fact that the desire to die or the reason for the refusal to eat and drink is not explicitly communicated. The concealed form is a previously unknown form of VSED where the patient stops consuming fluids but not food. The implicit form is ambiguously communicated, often silent, reduction of food and fluid intake. This form is usually found in old age or in the transition phase to the last stage of life (Stangle et al., 2019).

Patients may decide to stop eating and drinking without explicitly expressing their decision, and they also do not hide their intention. In this case, patients usually follow this process but do not want or cannot communicate their decision. In this case, the multidisciplinary healthcare teams involved may misjudge this situation. What is an active act by the person who is willing to die can be interpreted by them as a dying process, generalizing the behaviour of patients (Stangle et al., 2020).

3. Motivations

People with serious illness have priorities besides simply prolonging their lives. Some patients are motivated by physical factors such as debility, weakness, physical and psychological pain or simply to avoid dementia. However, in most cases, reasons to the request for hastening death are weariness with the dying process, desire to control the circumstances of death, feeling that quality of life is poor, desire to die at home and feeling that life lacks meaning. Other reasons pointed out are deterioration of health status, the burden of leaving outweighing any associated benefit, having no perspective or reason for life, because palliation is ineffective and cannot relieve discomfort which reinforces the wish to hasten death (Schwartz, 2007).

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Pain, fatigue and maintaining dignity are also reported as the most important causes of unbearable suffering although under palliative care and with adequate pain control, pain is less frequent stated as a reason, and the motivations given for VSED include existential-spiritual and non-physical ones (Fringer & Stangle, 2020).

Patients usually experience a combination of these and other factors. In this context, all patients have the right to refuse food, fluids or artificial nutrition and hydration, because it is a legally and medically acceptable decision of a competent patient (Dees et al., 2011). Table 1 refers to patients' remarks about the reasons to hasten death extracted from qualitative studies.

Table 1. Motivations and reasons pointed out by palliative care patients to hasten death

Motivations	Remarks about unbearable suffering
Fatigue	"The way to my bed is endless and finally I get there. It takes a lot of energy, but once I'm in bed, it takes an hour just to gather my strength again."
Pain	"I am in pain all the time, I wake up with pain and I go to bed with pain. If they can only take half away my pain." "Pain affects everything. It makes you tired. It affects how you can eat. It affects other people, and the fact is that even if you try to hide it, you can't. Pain takes that life out of you." "It is torturous… thinking when I am going to die to escape from this suffering. But when I am not in pain, I want to live. When the symptoms disappear, I want to continue living, as I do not want to depart from my loved ones."
Cognitive symptoms	"[…] I have less interest in the outside world. My brain no longer works and to me there is a part of human dignity and of unbearable suffering." "You lie in bed and none of the normal functions come back. They will never come back and it will only get worse."
Psychiatric symptoms	"I suffer so much that I can´t recall when life was lovely and happy. My life is hell. My life is inhuman. I have such deep pain inside." "It is worse than death itself."
Dependency	"I can't do anything anymore; they live me lying here until 10 o'clock and they only wash me when they feel like it." "When I need someone to help me, they just hurt my self-esteem."
Social Pain	"I was a very handy man […]. I feel useful to this society. I can´t do it anymore, but I lived a worthy life."
Autonomy	"[…] because in the little time that is left to me I want quality of life, not quantity of life." "It's horrible the whole situation. Not being able to get out of it, and every morning the same thing: waking up, being washed, lying there till the evening, the same pain."
Being a burden	"I have become so weak because of the pain. I can´t walk anymore. I can´t eat anymore. My children have suffered enough."

Source: Pestinger et al., 2015; Ohnsorge et al., 2019; Kremeike et al., 2022

3.1. Dying without food and fluids

If VSED is the option, death will occur approximately 10 to 15 days, but survival may vary depending on the underlying disease states, debility, and hydration. The aspect of time offers patients the possibility to reconsider the decision, and it allows family members to mentally prepare themselves for this situation. Humans constantly lose water through sweating, respiration, and urination. The only way to compensate for this water loss is intake via food and fluids. Once a person stops eating and drinking only water loss occurs, causing dehydration (Quill et al., 1997).

During the first twenty-four hours the only symptoms that patients feel are hunger and thirst although not all patients feel hungry. The feeling of thirst comes from the slow process of dehydration that occurs in kidneys and in the brain. Receptors in the

brain detect a change in the concentration of solutes in the body, causing secretion of vasopressin. Through the nephron, this hormone informs the kidneys the amount of water in the body is decreasing. As a response, the kidneys begin to conserve water to some extent. The feeling of thirst is easily overcome without rehydrating because receptors in the mouth inform the brain that thirst is quenched even before the water enters the bloodstream. In this phase xerostomia may be ameliorated by moistening mouth and lips using ice cubes or artificial saliva, as appropriate. After the twenty-four hours, patients' urine content is reduced as the kidneys reabsorb the water into the blood. The kidneys also reabsorb hydrogen into the blood, making the blood acidic. Due to the chemical reaction that the body uses to maintain acid-base balance, the concentration of hydrogen and carbon dioxide causes metabolic acidosis. Then patients start to hyperventilate to compensate for the increased carbon dioxide and the acidic nature of the blood. Unless the patient suffers from respiratory distress there is no need to make patients comfortable (Pope, 2011).

VSED also has some disadvantages. The process may take too long to respond to those with severe immediate physical suffering effectively. VSED works best for disciplined, resolute individuals who can resist drinking despite thirst

From twenty-four to forty-eight hours when the body has exhausted its carbohydrate stores, muscle tissue starts to be metabolized. Ketones are released into the bloodstream sending the body to a phase called ketosis. This phase is characterized by euphoria, impairing hunger, relieving pain, and increasing the quality of life and comfort of the patient. Euphoria state may last for several days depending on patients' state before starting VSED (Pope, 2011).

Many patients will also develop weight loss, lethargy, weakness and increasing immobility. Reduced food intake causes reduced gastric contractions and leads to reduced hypothalamic stimulation and anorexia. With glucose and protein lacking from diet the body will turn to the metabolism of fat stores. As a result, ketone levels will be raised and suppress hunger and thirst (Wax, 2018).

The use of fat as the main energy source may lead to muscle breakdown, greater endogenous water production and a reduced need for fluid intake. Decreased urea production means that less water needs to be excreted by kidneys. Eventually, brain cells which require water and ions to function, won't be able to exchange molecules with their surrounding environment and, consequently, they will become less excitable, allowing the person to enter a coma (McGee, 2017).

The last cause of death is usually a cardiac arrhythmia despite the comatose state would prevent the patient from feeling pain. In persons stopping only eating and reducing fluid-intake during several days or weeks, death is expected after sixteen to thirty days (Friesen, 2020).

VSED also has some disadvantages. The process may take too long to respond to those with severe immediate physical suffering effectively. VSED works best for disciplined, resolute individuals who can resist drinking despite thirst. It also requires that family members and caregivers provide support and help manage symptoms as VSED progresses. The most difficult situation occurs later during VSED when patients

become delirious, lose decision-making capacity, and may repeatedly request fluids. The patient and the health care proxy should have already discussed and documented the patient's wishes for this situation. The late stages of VSED also require substantial support from others and a formal do not resuscitate-do not intubate order should always be considered. Many authors suggest that healthcare professionals are substantially more accepting VSED than Physician Assisted Suicide (PAS) (Jox et al., 2017).

3.2. Eating-related symptom control

In the literature, Recommendations for xerostomia symptom management during VSED include oral swabs, mist sprays, lotion, and room humidification to ease dry mouth and other symptoms of dehydration as even small sips of water or ice chips adding up to 50 mL/ day or more can slow dehydration and prolong dying. Dry mouth and throat are the most common and troublesome symptom. Both humidifying the surrounding air and providing meticulous mouth care are important in reducing discomfort. When a patient is conscious, teeth, gums, and tongue should be brushed regularly. In addition, the mouth may be moistened with spritzes of water from an aerosol bottle top or with moistened mouth sponges or artificial saliva, and lips should be lubricated at regular intervals. For patients with decreasing consciousness, moistened mouth sponges, frozen teething rings to hold in the mouth, frozen wet washcloths held to the face, frozen drops of coconut oil, and lip balm can all be helpful. It is important that patients and caregivers are aware that even small amounts of water or ice chips can markedly prolong the dying process, so hydration in any form should be minimized for patients who remain committed to completing VSED. It may help to review the benefits of dehydration, including decreased respiratory secretions, less bother with urination, and decreased oedema. Hunger tends to be most intense in the first few days and may correlate with the time of day. Some clinicians report that decreasing intake of calories at least one week prior to beginning VSED can reduce hunger. We are all used to punctuating our days with meals, so when not eating, days seem much longer. It is therefore very helpful to provide as much sensory and mental stimulation as the patient desires during this early phase, including visits with loved ones, music, movies, reminiscing over photo collections. Focusing on the other senses can ameliorate the loss of the sensations of taste and oral stimulation. Prior to the start date, patients can be asked to identify ways they derive comfort and pleasure using their other senses by offering a checklist of possible distractions that involve senses other than taste. Related to constipation and cramping, at the beginning of the process, many patients find it useful to do some sort of bowel cleanse to decrease the chance that stool will collect and harden in the colon as dehydration proceeds. Ideally the method chosen would not include a large amount of hydration. Instead, bisacodyl, polyethylene glycol, or enemas can be used (Menzel, 2023).

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3.3. Suicide or euthanasia

Some authors refer that VSED is considered suicide, because hastening death is intentionally with certainty ensuring it and being the primary cause of it make the act of VSED morally wrong (Menzel, 2013). The characteristics of VSED's relationship to death — intention, certainty, causation — may make VSED suicide. Other authors claim that VSED is an act of self-killing although it does not consist of an action but an omission (Table 2).

Table 2. Definitions and terms

Terms	Definition
Suicide	Self-caused death
Assisted Suicide	Someone makes the means of death available but does not act as the direct agent of death
PAS	A medical provider writes a prescription for a lethal dose of a drug to be self-administered by a competent, terminally ill patient
Hastened Death	Someone who acts on their desire to control the circumstances of their death with or without assistance from another individual
Euthanasia	A medical professional administers a lethal dose of medication ri intentionally end a patient's life

Source: Lachman, 2015; Menzel, 2017; Friesen, 2020

Other authors state that VSED may be considered an alternative to PAS and voluntary active euthanasia (Table 3) and patients that cannot have any of this medical assistance in dying usually choose VSED to hastens death (Stangle & Fringer, 2022).

Table 3. Comparison of VSED to PAS

Issue	VSED	PAS
Method	Stopping Eating and Drinking	Killing oneself by ingesting prescribed lethal medication
Assistance Provided	Support of caregivers to manage palliative care needs	Supplying the medical means of causing death
Time	1-3 Weeks	Within minutes-hours
Outcome	Death through terminal dehydration	Death trough overdose of barbiturates

Source: Downie, 2018; Stinson, 2014, Menzel, 2014; Friesen, 2020

VSED cannot be viewed simply as a different form of PAS/ aid in dying. Physicians often provide supportive care to patients who have opted for VSED. However, physicians who oppose aiding in dying for non-terminally ill patients can provide supportive care to them, to relieve their physical distress, not as mean to ending their lives (Menzel, 2017). Despite this, some authors argue that from an ethical point of view VSED has the advantage of being neither physician-ordered nor — directed. Moreover, healthcare professionals who provide palliative care for patients undergoing VSED cannot be regarded as agents of these patients' deaths, unless they do something to accelerate death. They also do not accelerate death with VSED to a greater extent than it is already being accelerated by the patients themselves. Thus, VSED is different from PAS, where the physician prescribes lethal medication, and thus where the act of causing death is not entirely in the patient's own hands. In VSED, the doctor simply makes the patient as comfortable as possible when respecting the patient's autonomous decision to forego food and water (Menzel, 2017).

Providing palliative care to patients seeking to die by VSED does not constitute assisted suicide. However, some authors claim that the ethical permissibility of PAS continues to be an issue of ongoing ethical dispute reinforcing the idea that the ethical permissibility of it and VSED are linked (Jansen, 2019).

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VSED is positioned between the personal freedom of every human being to decide how and when to end life and the duty of the state and every person to protect another human being's life. The renouncement of food and fluids may be regarded as an expression of self-determined dying by way of an autonomous decision towards one's own life but should not be confused with severe depression or disease related lack of appetite. Regarding the issue of euthanasia, at the request of the patient the healthcare professional makes the means for that act but it is also the professional who administers the lethal drugs. Compared to VSED, euthanasia has the advantage of being a fast and effective process. In this case, the physician should ensure that the patient is competent, and that request is voluntary, free and all issues and doubts clarified so that the act does not hold the doctor morally responsible. Renouncing food and drink may be considered an expression of self-determined death by an autonomous decision regarding a person's life. However, it should not be confused with severe depression or illness related to lack of appetite, because in most cases suicidal acts occur in a psychopathological context in which depression predominates. By this, if the desire to hasten death from VSED is based on depression, deciding for VSED can hardly be considered an autonomous decision (De Oliveira, 2021).

To demonstrate capacity to pursue VSED, patients should be able to demonstrate consistency over time in choosing VSED and they should be able to indicate an understanding of the underlying diagnosis and prognosis with and without VSED, including thirst and dryness of the mouth and throat as well as the extent to which those can be managed. It is important to notice that when several patients are near

death, they often develop cognitive impairment which can lead to questioning whether VSED remains voluntary. If there are refractory symptoms as well as the need to sedate the patient with his consent, there may be a period from which the patient can hardly decide to change his decision to maintain VSED. A slight to a moderate *delirum* should be expected. In this case, the patient may forget his decision and demands for food and drink. This possibility must be foreseen and must be previously discussed with the patient if it hypothetically occurs and in a way that does not seem to be coercion. In this context, if the option is to give food and drink the death process will be delayed which is contradictory to what the patient previously defined (De Oliveira, 2021).

Issues regarding PAS and euthanasia are complex ones, because they involve healthcare professionals doing something that may be apparently opposite to what it is normally supposed to do, namely helping to kill, or killing which stands in contrast to cure diseases and saving lives. These questions are complicated because it can sometimes be very hard to judge whether a life situation is truly hopeless and undignified. Or whether there are still solutions to be found that would lead to a life worth living for the person who wants to die (Jansen et al., 2019).

3.4. Reflection about ethical issues

VSED is a decision of a competent patient who intentionally chooses to die without eating and drinking with the aim of anticipating death, which is an action that has only recently been more discussed in the literature. The literature reports that VSED can be considered an alternative to assisted suicide or euthanasia, so that patients can die whenever they want and according to their own criteria. However, there are still some ethical issues in this area that need to be better discussed. Nevertheless, VSED seems to be an option to hastens death more acceptable than other ways to end life, such as euthanasia or assisted suicide because it is not necessary the intervention of healthcare professionals. In addition, the notion that there is no legal framework in many countries for these issues makes VSED the most common option to hasten death. Therefore, there is no effective legal impediment to its realization, but there may be varying degrees of acceptance of VSED compared to other forms of hastening death. Healthcare professionals must consider ethical values and principles that should guide their professional performance and competences, valuing the general principles of autonomy, non-maleficence, beneficence, and justice. In this sense, it is also important to discuss VSED in the light of the ethical principles which it may collide with analyzing ethical principles, VSED may conflict with the principles of beneficence, non-maleficence, and autonomy (De Andrade et al., 2017).

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Regarding the principle of beneficence, it consists in doing good to the patient because morally it is required of each health professional to contribute to the good of the patient, through concrete acts and attitudes of help to improve health and quality of life. In other

words, this principle not only requires health professionals to just act in a way that avoids harming patients but also to seek effective measures to help them. On the other hand, the principle of nonmaleficence is the obligation of not causing harm, prohibiting any action that may cause it. This damage characterizes situations in which a particular action results in the intentional prejudice of the patients' interests or rights. Under VSED, healthcare professionals accompanying or informing the patient of this possibility when questioned do not cause intentional harm to the patient (De Oliveira, 2021).

It is also necessary to consider that putting into practice the principle of beneficence in situations of VSED is quite challenging, because this principle is constantly confronted with the principle of autonomy because it is not possible to act without the consent of a free moral agent — the patient. Thus, determining what is good or bad constitutes a personal decision, because what the healthcare professional may consider good the patient may not. In this context it should also be noticed that the principle of beneficence is largely associated with paternalism. However, some authors argue that beneficence cannot be confused with paternalism because it implies the usurpation by healthcare professionals of the moral right that patients have as individual human beings who decide what is the best for their own interests, in this case, opting for VSED (De Andrade et al., 2017).

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It is also verified that the principle of respect for autonomy is the one that emerges in this discussion since according to some authors, the competent patient has the right to refuse treatment even if that compromises their survival. Artificial nutrition and hydration, as a form of treatment, can legitimately be refused by the patient which in general is not a contested right. Eating and drinking are not considered treatments but rather basic human care. However, it may be considered that voluntary stopping to eat and drink is an extension of this right. It may also be considered ta form of suicide and thus be considered illegitimate for the patient to voluntarily stop eating and drinking, there is no right to coercion or otherwise to impose alternative forms of feeding and hydrating orally (De Oliveira, 2021).

It should be noticed that it is extremely important that the patient is evaluated by psychology and psychiatry before starting VSED to assess whether there are possible processes of depression, inadequately treated mental illness, uncontrolled symptoms, existential suffering, and signs of coercion as well as other cognitive alterations, that call into question the decision to start VSED and the autonomy of the patient. In addition, it is necessary to exclude other factors leading to the option of VSED such as: social, economic or lack of family or institutional assistance, since these reasons may be amenable to correction or improvement culminating in cancelling VSED. In this way the decision-making process is sought to be truly autonomous and unconditioned. However, the patient may choose to refuse this type of assessment. It is important to consider that for institutionalized patients, this autonomous decision may be difficult to accept, so there is no support for the patient's decision, especially if beliefs, faith, religion, and cultural aspects are involved (McGee, 2017).

These institutions and the professionals who work there may view the follow-up of these patients as putting them at risk of being accused of negligence or feeling obliged to report VSED as suicide. In this context it is important that clinical records of the multidisciplinary team accompanying the patient remain clear, well-founded and up-to-dated. The records that some institutions must comply with, and which aim to assess the quality of services being auditable may raise doubts as to the justification of the nutritional status and hydration of patients and the associated mental impairment. Whenever patients maintain their determination to die without eating and drinking, healthcare professionals of the multidisciplinary team have an obligation to continue to accompany and provide palliative care to them by controlling emerging symptoms or other issues that reduce quality of life and comfort but there may be cases of objection of conscience (De Oliveira, 2021).

4. Conclusion

VSED seems to be more common than PAS or euthanasia because it falls beneath the level of legal scrutiny except in some cases involving institutional settings. VSED requires a prolonged act of will and motivation by the patient and generally some level of support from caregivers and healthcare professionals, but it seems to be an extension of refusing food and fluids by mouth as it would be if it was by artificial means.

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