

RESEARCH ARTICLE

Family caregivers' advocacy in voluntary stopping of eating and drinking: A holistic multiple case study

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Abstract

Aim: To gain insight into the experiences of family caregivers who accompanied a loved one during voluntary stopping of eating and drinking and to identify similarities and differences between cases of voluntary stopping of eating and drinking to develop a conceptual model.

Design: A qualitative holistic multiple case study.

Methods: We conducted narrative interviews with family caregivers ($N = 17$). We first analysed them inductively within the cases, followed by a cross-case analysis to merge the experiences into a conceptual model.

Results: Family caregivers who could accept their loved one's wish to die stood up for the last will, especially when the cognitive abilities declined. They had to take on the role of an advocate to protect their self-determination from others who tried to interrupt the process. In their advocacy, they found themselves constantly in moral discrepancies. Usually without support, they provided nursing care until death. The subsequent processing phase was characterized by evaluating the dying situation and placing voluntary stopping of eating and drinking in their value scheme.

KEYWORDS

case study, experiences, family caregivers, qualitative study, voluntary stopping of eating and drinking

1 | INTRODUCTION

Individuals suffering of a low quality of life, with insufficient symptom control, and the desire to control circumstances of death (Bolt et al., 2015; Ganzini et al., 2003; Lowers et al., 2020; Stängle et al., 2019; Wax et al., 2018) sometimes decide for voluntary stopping of eating and drinking (VSED), even though they are still able to do so (Rodríguez-Prat et al., 2018; Saladin et al., 2018). Family members likely become family caregivers (FC) for them, as it is assumed

that they often get involved in decision-making, support and daily care of a loved one who is considering or has decided for VSED (Fringer et al., 2018).

The experiences of FC in the accompaniment of a loved one at the end of life have already been identified for other diseases and contexts, such as in people dying with dementia (Broady et al., 2018) or from cancer (Rowland et al., 2017) and dying in nursing homes (Gonella et al., 2019) or at home (Pottle et al., 2020). At the end of life, FC spend every free minute caring for their loved ones and are

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confronted with the deterioration of their condition, the loss of perspectives and uncertainty about the future (Moon, 2016).

The extent to which these experiences overlap or differ in the context of VSED is not yet known, as so far, little qualitative research has been done according to the experiences of FC who accompanied a person during VSED (Lowers et al., 2020; Saladin et al., 2018).

For these reasons, it is essential to explore the experiences of FC accompanying a loved one during VSED. This creates a basis that thematically opens up the little-known field, thereby enabling conclusions about possible support needs and assistance for FC during VSED.

1.1 | Background

Voluntary stopping of eating and drinking is a deliberate planned action of a competent person who voluntarily and consciously chooses to stop eating and drinking with the intention to induce premature death (Ganzini et al., 2003; Ivanović et al., 2014; Quill & Byock, 2000; Quill et al., 1997; Schwarz, 2007). It must be distinguished from psychiatric diseases (Gruenewald, 2018; Wax et al., 2018), loss of appetite at the end of life (Pinho-Reis et al., 2018; Requena & Andrade Dos Santos, 2018) or eating disorders (Shinjo et al., 2019; Stängle et al., 2019). The occurrence of VSED is between 0.4% and 2.1% among all deaths in the Netherlands (Chabot & Goedhart, 2009; Onwuteaka-Philipsen et al., 2012) and Switzerland (Stängle, Schnepf, Büche, et al., 2019; Stängle et al., 2020; Stängle et al., 2020) which is confirmed by surveys of healthcare professionals, of which 32%–62% of those participating have already accompanied a person during VSED (Bolt et al., 2015; Ganzini et al., 2003; Hoekstra et al., 2015; Shinjo et al., 2019; Stängle, Schnepf, Büche, et al., 2019; Stängle, Schnepf, Büche, Häuptle, et al., 2020).

Voluntary stopping of eating and drinking can be planned and started independently by a person willing to die (Fringer et al., 2019). Indeed, after a few days, it requires the support of a second person, since the condition deteriorates with the progress of abstention of food and fluids and a need of care inevitably develops sooner or later (Fringer et al., 2018; Jox et al., 2017; Lachman, 2015; Lowers et al., 2020; Starke, 2020).

There have been different discussions about the classification of VSED from ethical, legal and healthcare professional point of views. However, interdisciplinary there is no consensus on whether VSED is suicide, physician-assisted suicide, passive euthanasia or an intentional natural death (Simon, 2018) and the discussions about that remains ongoing (Stängle, 2021) Against this background, often inhibitions arise among FC and professionals in accompanying someone who (wants to) carry out VSED (Fringer et al., 2018), but there is consensus that support of a person who is willing to die through VSED may only be offered if there is no doubt about the ability to make independent decisions (Walther, 2015). Discussions about this are increasingly taking place in the context of people with dementia (Marks, 2016; Pope, 2019; Trowse, 2019; Wright et al., 2019) and

with regard to inclusion in living wills (Christenson, 2019; Chuang & Flicker, 2018; Menzel, 2017). However, the German Association for Palliative Medicine states that assistance during VSED can be differentiated as assistance in dying and not as assistance to die (Simon & Hoekstra, 2015). In addition, Klein Remane and Fringer (2013) from Switzerland stated that as long as the intention in being there for people who carry out VSED aims to ease suffering and to care for the well-being but not to induce death, healthcare professionals and FC who offer their support are not liable to prosecution.

Important side effects that can cause suffering during VSED are thirst (Chargot et al., 2019; Gruenewald & Vandekieft, 2020), hunger (Pinho-Reis et al., 2018; Radbruch et al., 2019), delirium (Gärtner & Müller, 2018; Quill et al., 2018) and restlessness or agitation (Saladin et al., 2018).

These can be a burden not only for the person who VSED, but also for FC who accompany them. Quill et al. (1997) described that the idea of dying of thirst and starvation was perceived by family members and healthcare professionals as immoral. It is known that the intake of food and fluid at the end of life has symbolic meaning for FC (van der Riet et al., 2008; Wallin et al., 2014). The supply of meals is seen as an expression of affection and the consumption of meals as a sign of life. Watching someone not eating and drinking can cause fears, helplessness and feelings of guilt. Besides, frightening notions of agonizing death due to starvation and thirst can arise (Spittler, 2005), though hospice staff experienced less emotional stress of FC who accompanied someone during VSED in comparison with sudden deaths due to suicide, as they were able to take care of the dying person and to say goodbye (Harvath et al., 2004).

Theoretical guidance for accompanying a loved one during VSED provides the phases of Fringer et al. (2019), which depict the course of the VSED process: (a) Decision-making, (b) Inclusion of the social network, (c) Planning of the VSED and (d) Implementation of the VSED. Still, how and whether the experiences of FC can actually be found within the framework of these phases has not yet been examined in depth. Nevertheless, experts suppose that FC involved in VSED are exposed to numerous burdens and difficulties (Stängle, Schnepf, Büche, et al., 2019; Stängle, Schnepf, Büche, & Fringer, 2020; Stängle, Schnepf, Büche, Häuptle, et al., 2020). Apart from case reports (DuBois et al., 2016) in which the experiences of FC have been described in isolated cases (Berry, 2009; Quill & Byock, 2000), there is still a lack of comprehensive knowledge across different cases that explore FC' experiences towards VSED of a loved one.

1.2 | Research question

On this basis, the following research questions were examined: First, what are the experiences of FC who have accompanied a loved one during VSED, and second, what are similarities and differences between single cases?

1.3 | The study

1.3.1 | Design

To explore the experiences of FC who accompanied a loved one during VSED and the similarities and differences between cases, we drew on several cases, as this achieves a deeper understanding of the phenomenon (Baker, 2011). Since we considered the multiple cases as holistic units of analysis and did not contain any further embedded units, the study design is referred to as a Holistic Multiple Case Study Design (Yin, 2017). This study design is suitable to intensively and comprehensively describe and analyse a phenomenon and its various manifestations in individual cases within their contexts (Yin, 2017).

We followed the procedure of casing and defined the case (VSED of someone willing to die) and its unit of analysis (FC who accompanied a loved one during VSED) (Casey & Houghton, 2010; Sandelowski, 2011). We applied an inductive data analysis approach according to Saldaña (2015), since the research questions had an exploratory character. While the first part of the research question focussed on the phenomenon of accompanying a loved one during VSED in the individual cases, the focus of the second was on the similarities and differences between them.

This research approach provided insights into the perspectives of FC who have accompanied a loved one during VSED, as it is well suited to represent personal experiences and meanings of subjects (Denzin & Lincoln, 2011).

2 | METHOD

2.1 | Data collection

We conducted narrative interviews, as it has a strongly explorative character and is the most open interview form (Mayer, 2019) without using an interview guideline. Depending on the participants' preferences, we conducted the interviews face-to-face or via telephone in 2017–2018. Three authors started the interviews with the following narrative invitation: "Please tell me your story accompanying your loved one during VSED starting with the decision-making to VSED until the person died, and what things are going through your mind in general." The interviews ended with the collection of socio-demographic data of the participants and questions about the person willing to die, which were considered in the analysis. The interviews lasted between 50 min and 2 h with 59 min on average and were recorded digitally and transcribed verbatim. Ten interviews were conducted face-to-face and six via telephone. Notes were written during and after the interviews and were included in the analysis. One participant was not interested to participate in an oral interview but was willing to write down her experiences and sent us this online. Available letters and notes of the participants and the persons willing to die during the course of VSED were included in the analysis just like the interviews in order to gain even deeper insights into the

experience of FC and to increase the credibility of data (Baxter & Jack, 2008).

2.2 | Sample

In this study, FC who accompanied a loved one during VSED were defined as the unit of analysis. On this basis, we determined the bounded system (Sandelowski, 2011) that corresponded to FC who have experienced VSED from the beginning or from the first idea until death of a loved one occurred. We selected typical cases for the purposive sample, thereby considering the criteria of usefulness and appropriation for the sample and sample size as described by Morse and Field (1998). We referred the term FC according to Bozett (1987) to all persons who were described by the persons willing to die as family, including primary nurses because they felt a special bond with them due to several years of nursing, which went beyond a professional relationship. To ensure that the cases were a matter of VSED, the person willing to die had to be capable of decision-making and the decision had to be made voluntary and consciously with the intention to induce death prematurely (Ivanović et al., 2014), according to the assessment of the FC.

2.3 | Recruitment

We recruited participants through an interview, which was broadcast on Swiss television (Niedermann, 2017). The interview called on FC to come forward and share their stories. To get a picture of the experiences of FC across the German-speaking countries, we also recruited participants in Austria and Germany. Since recruitment via television was not possible there, we have contacted an expert of this field from Germany, who has provided us with the contact details of interested persons. To recruit people in Austria, we contacted inpatient hospices, mobile hospices and mobile palliative care teams by e-mail and by telephone.

2.4 | Analysis

First, we conducted a within-case analysis to gain an in-depth understanding of the specificities of each case. As first step, we read and re-read the transcripts and further data material of the individual cases one after another. Afterwards, vignettes were written for each individual case, in which they were systematically summarized and described. Then, first cycle coding was conducted, by coding all individual cases openly and then axially to explore the single individual experience and develop initial concepts. Using selective coding, central phenomena were elaborated for each case. To enable comparability of all cases in the cross-case analysis, we used the coding paradigm of Grounded Theory for all cases already in the within-case analysis. Therefore, causal conditions, contextual factors, intervening conditions, strategies and consequences were used

for creating a theoretical basis (Corbin & Strauss, 2015) about the experiences of FC during VSED.

Crucial for theory building, we afterwards analysed across the cases to identify similarities and differences and to develop a theoretical conceptual model for describing and explaining the common experience of FC (Fringer & Schnepf, 2015). By means of second coding cycle, the single cases were merged into generic sub-categories and broader categories and compared by using axial and selective coding (Saldaña, 2015). Subsequently, the phenomena for the context, the causal conditions, the strategies and the consequences could be identified across all the cases. Finally, we synthesized these results into one central phenomenon (Gerring, 2007) to achieve a dense and complex interpretation (Denzin & Lincoln, 2011) and to express the core meaning on the basis of a word or phrase (Hycner, 1985).

For the conceptual model, we took into account the phases by Fringer et al. (2019) for accompanying a person willing to die during VSED so that we could present the experiences of FC in a structured way during the course of VSED. Grounded from the data of this study, we inductively added a fifth phase thematizing the processing of the VSED. We performed data management and analysis using the software MAXQDA (Analytics Pro, 2018).

2.5 | Trustworthiness

The credibility of the results was ensured by discussions within the research group to clarify the development of emerging codes and categories until consensus was achieved. Furthermore, by descriptions of participants and recruitment procedure (transferability), and review of the study by André Fringer and Hanna Mayer, who are senior researchers with focus on qualitative research (validity and transparency). Finally, credibility was supported by the multiple case study design, which enables in-depth exploration of experiences in the real-life context (authenticity) (Guba & Lincoln, 2002).

2.6 | Ethics

Since VSED is discussed controversially about whether it is a suicide, an intentional natural death or something else and participants were asked to report on a potential borderline experience, we adhered to the three basic ethical principles: respect for persons, beneficence and justice (Belmont Report, 1978). Of particular importance was to preserve the psychological integrity. Therefore, the participants were invited to a follow-up discussion at a second date to reflect on any content that may have caused discomfort and to offer support. However, none of the participants made use of the offer.

The responsible institutional review board of the Greater Region of Eastern Switzerland (EKOS 17/083) approved this study. Participation was voluntary and could be cancelled at any time without giving reasons.

3 | RESULTS

In this article, we present the common experience of 17 FC accompanying a loved one during VSED, which we have identified through a cross-case analysis.

The central phenomenon "Advocacy of FC during VSED of a loved one" corresponds to the strategy that FC had to follow in the accompaniment of a loved one during VSED. We furthermore developed three main categories that have influenced the central phenomenon: (a) "Accepting the will to die through VSED of a loved one" describes the causal conditions, (b) "Becoming an advocate for the loved one during VSED" subsumes the context factors and intervening conditions and (c) "Processing the VSED of a loved one" stands for the consequences. The main categories point out how FC accepted the decision for VSED of a loved one, under what circumstances they became advocates during the implementation of VSED, how their advocacy was characterized and how they finally processed the experience, once their loved ones have died. The central phenomenon and its influences are demonstrated as a conceptual model in Figure 1.

Participants were from Switzerland ($N = 15$), Germany ($N = 1$) and Austria ($N = 1$). Their age ranged from 55–79 years with a mean of 60 years. The mean duration of VSED until death was 23 days. Further characteristics of the cases are presented in Table 1.

3.1 | Accepting the will to die through VSED of a loved one

Family caregivers, mostly spouses, were either involved in the decision-making of their loved ones or were confronted with the decision made as it was most likely to occur with children of persons willing to die. Once they knew about it, they considered their attitude towards the dying will through VSED of their loved ones and following whether they could accept the decision or not. Their acceptance was influenced by the traceability of the reasons for the will to die, the health condition of the loved ones and the ethical and religious values of FC.

Reasons that promoted acceptance of the will to die through VSED were the wish to end life independently, to end symptom burden, to anticipate the foreseeable course of a disease with a bad prognosis or to exit a life without sense. These reasons were associated by the FC with self-determination and a reduced quality of life and were therefore understandable and worthy of support to them. The following quote illustrates how the desire for self-determination in ending one's own life seemed to be a significant reason for choosing VSED from the perspective of a wife who accompanied her husband:

We have always discussed: we do not want to be dependent on help. That is no longer life for us. My husband always said: 'I'd rather die self-determined than having a life, that is determined by others'.

(Case 15)

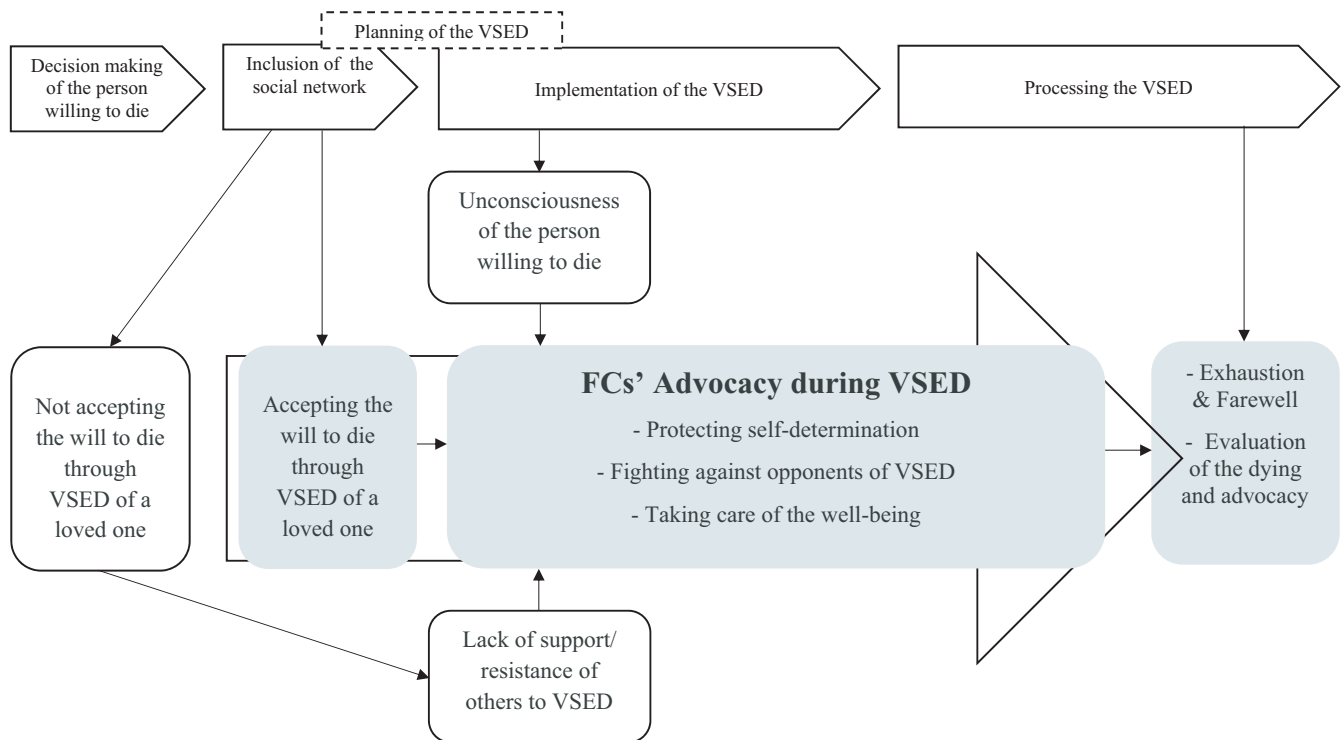


FIGURE 1 Conceptual model of FC advocacy during VSED of a loved one

Furthermore, FC' acceptance for VSED was based on the health condition of their loved ones. The will to die through VSED of someone who was objectively ill was more easily understood and morally acceptable than of someone who seemed to be in a good and life-worthy condition. One sister reported of first struggles because her brother was in general good health, but no longer wanted to live because he felt lonely all his life:

Then I went to bed and didn't close an eye. My brother was really pushing me. And then I told him in the morning, it's not working.

(Case 1)

Just as influential were religious values in which VSED was considered unnatural and a sin and so not justifiable for FC who adhered to these religious beliefs.

One FC told of her sister-in-law's family who could not accept the women's will to die due to a long lasting and painful cancer disease because of their belief in the Catholic Church:

She was not taken seriously. Her dying will was actually betrayed for years and they kept saying, you're not going to heaven, you're going to hell.

(Case 4)

Family caregivers' who could not accept the decision for VSED, as it was rather the case with children or siblings of someone who planned to conduct the VSED at home, reacted angrily and shocked, starting to act against the wish to die by trying to talk the willing

person out of it. Others withdrew at this point in time. They said goodbye in advance, as they were not able or willing to accompany the loved one under the circumstance of VSED.

3.2 | Becoming an advocate for the loved one during VSED

Once FC had accepted their loved ones' will to die through VSED, they agreed to accompany them. They sought support from outpatient or inpatient healthcare professionals to ensure professional care for the dying person. To the detriment of FC, some of the requested healthcare professionals did not want to provide support for patients dying through VSED for reasons of professional ethics and legal uncertainties. This often triggered an inner moral conflict among the FC':

And I just had to look at their faces. They clearly showed: 'Do you want to kill your mother?' And that's very depressing. Then you have to be really strong.

(Case 14)

Therefore, FC were forced into their advocacy role and to start their accompaniment during VSED of their loved one by themselves. In retrospect, they would have liked to be prepared with information for how long the process would take, how the condition of the dying person would change, and what legal and organizational aspects would have to be considered in advance, such as a living will of

TABLE 1 Characteristics of the participants and the 17 cases

Case #	Family caregiver	Nationality	Age in years	Occupation	Sex of the accompanied person	Age in years of the accompanied person	Year of starting VSED	Setting of VSED	Days of VSED until death
1	Sister	Switzerland	75	Psychologist	Male	76	2016	At home	13
2	Daughter	Switzerland	64	School council	Female	91	2016	Nursing home	28
3	Daughter	Switzerland	60	Telephonist	Female	86	2014	Nursing home	10
4	Sister-in-law	Switzerland	55	Nursing management	Female	^a	2014	Hospital	35
5	Primary nurse	Switzerland	^a	Registered Nurse	Female	85	^a	At home	10
6	Primary nurse	Switzerland	69	Registered Nurse	Female	85	2003	Nursing home	^a
7	Daughter	Switzerland	64	Retired	Male	95	2015	At home	11
8	Son	Switzerland	56	Head of a children's charity	Female	66	2001	Nursing home	14
9	Daughter-in-law	Switzerland	55	Registered Nurse	Female	87	2015	Nursing home	7
10	Daughter	Switzerland	71	Retired	Female	91	2010	Nursing home	66
11	Mother & father	Switzerland	^a	Mother: Accountant Father: Unemployed	Male	27	2014	At home	42
12	Son	Switzerland	56	Computer scientist	Male	80	2017	At home	14
13	Wife	Germany	61	Educator	Male	79	2017	At home/ hospice	7
14	Daughter	Switzerland	75	Retired	Female	92	2012	Nursing home	15
15	Wife	Switzerland	79	^a	Male	87	2016	Hospice	14
16	Daughter	Switzerland	^a	^a	Female	96	2012	Hospital	21
17	Daughter	Austria	61	Saleswoman	Female	92	1997	At home	63

^aMissing data.

the person willing to die and remedies for care. In two cases, where professionals accompanied the decision-making process for VSED from the beginning, these things were communicated and planned, so that the FC' felt more prepared. However, the primary nurses who were included as FC' in this study primarily assured themselves about legal protection. Otherwise, they knew approximately what to expect, since they had already gained experience with persons who had not actively decided to stop eating and drinking, but who had nevertheless stopped due to weakness and inappetence.

Nevertheless, FC' became advocates by standing behind their loved ones under the circumstances that other family members or nursing colleagues did not accept the will to die through VSED. Although in some cases there was greater resistance through other healthcare professionals and family members, trying to prevent the person willing to die from stopping eating and drinking, all persons willing to die managed to start VSED with support from their committed FC. Even after the start of the VSED, other healthcare professionals and family members continued to encourage those willing to die to stop VSED. Persons who stopped eating and drinking were in the beginning still capable of decision-making, largely self-sufficient and able to resist this external pressure among stopping VSED themselves. However, as the VSED process progressed they became physically and mentally affected. The longer and more consistently the VSED was carried out, the sooner the person willing to die lost consciousness. From that moment on, FC' not only took over the nursing care, but also started to stand up for the dying wish of their beloved person and became their advocate immediately. This was necessary because other healthcare professionals and family members were still pressuring the person willing to die verbally to eat and drink or placing cups of liquids directly on the lips to make them drink, as long as they were responsive. In one case, a woman suffering from severe cancer pain and willing to die by VSED was administered parenteral nutrition in the hospital, as she was no longer considered capable of decision-making by healthcare professionals, but by her trusted FC. Also, the daughter of another case expressed a similar experience in a hospice, where the administration of fluids could be stopped though:

And when we brought him to the hospice and the nurse (...) simply said vehemently: 'You can't do that! I must administer at least 500ml subcutaneously, that's torturous!' That completely destroyed me.

(Case 3)

Such situations were conducive to the development of FC into advocates, as they saw their loved one's self-determination threatened without intervening.

3.3 | Advocacy of FC during VSED of a loved one

As central phenomenon of the 17 cases, the advocacy of FC during VSED of a loved one was identified (see Figure 1). FC' who accepted

the will to die through VSED developed into advocates, because they wanted to protect the self-determined decision of the loved one. Their advocacy arose under the circumstances that the loved one lost consciousness as the VSED progressed, and thus the possibility of standing up for the will to die. As the implementation of the VSED was often criticized by other family members or healthcare professionals, attempts were made to stop it by them. The trusted FC had to defend these attempts and stand up for the loved ones.

As advocates, they intervened with professionals or other family members to ensure that the dying person's will to die was respected and recognized, mostly through discussions that could range from debates to disputes. One participant described the seriousness of her support as follows:

I promised her that I would fight to the death. Fight to her will!

(Case 4)

They monitored almost around the clock, who came close to their loved one and whether fluids or food were being forced or administered against his or her will. They did this as long as it was necessary and the implementation of the VSED was no longer hindered. However, the role of the advocate was sometimes impeded, because FC were often threatened with legal consequences, as they were accused of letting their loved ones die of thirst, of torturing them and of supporting suicide. In most cases, there was no living will that legally documented the will to die by VSED as soon as the persons could no longer communicate it themselves. Therefore, FC' often lacked a legal basis for argumentation with healthcare professionals in their advocacy which increased their burden. Nevertheless, FC who were legally or morally threatened remained in their advocacy role and continued to provide support, although they were constantly in a moral discrepancy. However, those who had been able to inform themselves in advance about the legal basis felt more stable and self-confident in their advocacy functions and perceived challenges by others less as a burden.

The advocacy role of FC further required to ensure the care and emotional and physical well-being of the loved one, as support of the person conducting VSED was often refused by healthcare professionals and the family. FC' who did not receive professional counselling or actual support were left alone in worrying about what condition of the loved one they could expect in the course of VSED, taking care of their hygiene all by their selves and how to react on occurring symptoms during the dying process. The daughter of a woman who conducted VSED in a nursing home explained her desperation due to the lack of professional support as follows:

I was thinking: Do something! Nobody (of the staff) was coming towards us. And I was not able to approach the staff. We were really left there alone for days, no one of the nursing staff talked neither to my husband nor to me about the situation.

(Case 9)

While the uncertainty of the further course and the sole management of care could lead to excessive exhaustion, family cohesion proved to be helpful for FC' advocacy in VSED. A daughter emphasized her profit due to her family that payed attention to her needs, while in the intensive company of her dying father she was exclusively focussed on fulfilling his needs as following:

And then you can do a lot together, when you pull together in the same direction. Then you can bear it, then the difficult things also become bearable.

(Case 7)

3.4 | Processing the VSED of a loved one

Family caregivers' carried out this advocacy tirelessly, putting themselves behind until the loved one died. Consequently, their advocacy was associated with excessive exhaustion, satisfaction or disappointment, depending on the appraisal of their advocacy and the dying situation.

After the loved one died, the intensive advocacy of FC ended abruptly. This sudden end contributed to them feeling alone and left behind. From now on, they had to shift their focus on their selves, which felt unfamiliar for them after several weeks where they mainly took care of the dying person. In doing so, they caught up on sleep, did something good for themselves, such as going for long walks or stayed alone for a certain period. During this time, they tried to recharge their batteries, reflect on what had happened and took their time to consciously mourn. However, some of them appraised the accompaniment of their beloved person during VSED negatively due to dissatisfaction with their support in the process, for example when the dying person was obviously suffering.

They viewed their advocacy as unsuccessful, were excessively exhausted or traumatized and struggled with a prolonged period of mourning and recovery. Those FC mostly experienced the situation not manageable due to the bad condition of the loved one during VSED and the lack of support from family and healthcare professionals in daily care, managing the symptoms of VSED and protecting the dying will against others. One of the FC described the agonizing death of her brother this way:

I just keep seeing this picture from the last three days. It just wasn't good. It's not a good way to die (...) If you ask me, I say perish.

(Case 1)

These FC' tended to mourn for a longer period compared to other FC and had to fight with feelings of guilt and morally struggled with themselves whether they had done the right thing with their accompaniment during the VSED. One FC who appraised her sister-in-law's death in a negative way was still shaken at the time of the interview three years after her death:

I was exhausted. I still am today when I go to her grave. It oppresses me.

Family caregivers, who considered their advocacy in protecting the will and the welfare of a loved one as fulfilled, felt satisfied and grateful about the successful support of a self-determined and peaceful dying situation. Those FC described their experiences with VSED as enriching though exhausting and some of them could imagine carrying out VSED someday too. A daughter who made good experiences with VSED of a loved one liked to look back on the time:

These were the most beautiful fifteen days in my life with my mother. Yes. Because I could do anything for her.

(Case 14)

The primary nurses of this cases were satisfied with the dying situation they had fostered as professionals and were able to say goodbye well. Although this type of end-of-life care represented something new and unusual, they were nevertheless able to process the dying process well and felt grateful for this experience. As they were able to distance themselves better during the VSED, they were less exhausted afterwards than the related FC when their loved ones had died.

4 | DISCUSSION

This qualitative holistic multiple case study presents the results of its cross-case analysis and shows the common experience from 17 cases about the VSED of a loved one. The central phenomenon of our study shows that FC accepting the will to die through VSED had to act as advocates during VSED in order to protect the self-determination and the well-being of their loved ones.

To the best of our knowledge, this is the first time that the experiences of FC' accompanying a loved one during VSED have been investigated qualitatively and comprehensively. However, the advocacy of caregivers supporting a patient through VSED has already been identified (Lowers et al., 2020). The advocates role of FC at the end of life has furthermore been recognized in other contexts, matching our results for VSED. Family advocacy at the end of life was discussed in the context of end-of-life care in nursing homes. The results show that advocacy experiences of FC arose under the circumstances of poor quality nursing home care (Shield et al., 2010). The difference to the advocacy role in the context of VSED becomes noticeable, as FC mostly did not even get the chance to advocate for better care but first for respecting the will to die and for self-determination of their loved one. Nevertheless, it can be assumed that the poor quality of care in nursing homes might also at least partly be associated with a lack of self-determination on the part of residents. However, in the hospital setting FC took on the advocacy role because there were no perceived advocates, since staff seemed

not to understand their loved ones' needs (Hynes et al., 2012; Mehta et al., 2010).

The development of FC advocacy during VSED was influenced by the acceptance of their loved ones' will to die. This in turn was affected by the compatibility with their own values. FC who accepted the will to die by VSED of a loved one mostly did so because self-determination was an important value for them. In this respect, also Heller and Kränzle (2019) and Lowers et al. (2020) stated that for individuals, that chose VSED, it was the best available option to die. The compatibility with one's own values also played for healthcare professionals a role, just as their duties in protecting life. Saladin et al. (2018) described that healthcare professionals of a long-term care institution were not always open to take care of a person dying by VSED. This depended next to their moral values on their experiences, the disease, the clinical condition of the person willing to die and their knowledge about the legal conditions.

From a legal and ethical perspective, it is still unclear how VSED is classified. However, for most authors of this field, the presence of decision-making competence is a prerequisite for defining VSED (Ivanović et al., 2014). In contrast, FC or healthcare professionals who are convinced of the self-determined decision of a person who wishes to implement VSED may, according to Ivanović et al. (2014), not prevent them from implementing it. The right to self-determination must be respected even if the person is no longer fully conscious and can no longer communicate. According to the German Society of Palliative Medicine, assistance during VSED is part of the duties of healthcare professionals in the context of end-of-life care (Simon & Hoekstra, 2015). However, there has been no clear legal regulation about the classification of VSED, but from a criminal law perspective, it can be assumed to be unobjectionable (Klein Remane & Fringer, 2013).

However, FC willing to support a loved one during VSED should plan the implementation in advance, best with healthcare professionals and the person wishing to die in order to clarify and discuss moral uncertainties (Fringer et al., 2019). The procedures for various scenarios in which the person willing to die may no longer be conscious should be defined, to ensure that the will of the unconscious person will be respected. It should be discussed whether medical and therapeutic measures will be discontinued or continued. FC and the person wishing to die should be informed by a healthcare professional in detail about the process of VSED and about expected tasks for FC.

Nevertheless, professional planning of the VSED took place in only two cases of this study, mostly due to legal uncertainties of the healthcare professionals. The lack of support in the other cases was a significant influence on the development of the FC' advocacy and subsequently led to their burdens during the implementation of the VSED. This has already been reported in other studies focussing the experiences of FC at the end of life, where they felt that they were forced into a role of negotiating access to services on behalf of the patient. They furthermore noted staff members who did not fully inform them about what to expect in the dying process (Shield et al.,

2010). Following they experienced uncertainty over how to manage the situation and a lack of knowledge of necessities due to missing support of healthcare professionals (Hebert et al., 2009; McConigley et al., 2010; Stajduhar et al., 2013; Waldrop & Meeker, 2012). Also, in this study, participants developed under these circumstances to advocates for their loved ones.

It has been shown that FC acting as advocates experienced comparable burdens to those who accompany someone at the end of life outside the context of the VSED and show a similar willingness to sacrifice (Dawson & Kristjanson, 2003; Funk et al., 2009; Giles & Miyasaki, 2009; Hasson et al., 2009; Hupcey et al., 2011; Hynes et al., 2012; Kalnins, 2006; O'Brien et al., 2012). FC in other end of life situations, such as in people with motor neurone disease (O'Brien et al., 2012), chronic obstructive pulmonary disease (Hynes et al., 2012) and heart failure (Hupcey et al., 2011), also considered that the responsibility for negotiating on behalf of the patient was solely theirs. The recognition of the need to fight for the patient's best interest within the healthcare system required persistence and energy of FC acting as advocates (Funk et al., 2009; Kimberlin, Brushwood, Allen, Radson, & Wilson, 2004). Finally, the advocacy of FC at the end of life was described as a constant burden, which was promoted by fear that basic care needs would be neglected if they were not present with the patient (Hynes et al., 2012; Teno et al., 2001; Thuné-Boyle et al., 2010).

However, in this multiple case study, FC final evaluation of VSED and their advocacy depended on the condition of their loved ones during the dying process and on the level of support received by family or healthcare professionals in taking care. Some of the participants in this study rated quality of dying as "dignified, peaceful and humane" and the experience of being involved as "valuable and enriching." Other few FC spoke of perishing and felt excessively traumatized for a long time. Also, Chabot and Goedhart (2009) assessed the dying quality from the perspective of FC. Most FC found the dying process through VSED to be "dignified." However, in the work of Ganzini et al. (2003), most nurses stated that FC and close family members could accept the decision and half of them felt that they were better prepared for the death than FC of other hospice members. However, depending on FC assessment of the dying situation in the context of VSED, we found a difference about the processing and mourning phase, as those who rated the experience negatively felt traumatized and emotionally exhausted for longer.

It is already known that caregiving at the end of life affects FC grief, quality of life and general health and that it can take up to a year for them to process the impact of caregiving and bereavement (Breen et al., 2019). About six to eight per cent of FC even experience prolonged grief disorder, a persistent and pervasive grief distress (Nielsen et al., 2017), that is associated with increased risk of suicide (Latham & Prigerson, 2004), serious illness (Boelen & Prigerson, 2007; Prigerson et al., 1997), sleeping problems (Boelen & Lancee, 2013), social and occupational impairment (Simon et al., 2007) and lower quality of life (QoL) (Boelen & Prigerson, 2007). While being a partner, low educational level, young age and female gender have previously been identified as

predictors of complicated grief in bereaved caregivers (Nielsen et al., 2017), our work offers evidence that lack of support from professionals and family members, threats about the support of the loved one conducting VSED, as well as the occurrence of severe symptoms in the dying process—all resulting in being morally torn, may be potential predictors of a disturbed processing phase in FC who have accompanied a loved one in VSED.

4.1 | Limitations and strengths

With this holistic multiple case study of 17 cases, the lived experiences of FC who accompanied a loved one withdrawing from life through VSED were researched for the first time qualitatively and comprehensively. In addition, the analysis showed that code saturation could be achieved, as no other categories could be identified in the second cycle coding process (axial coding). Since we have analysed 17 interviews, we assume that meaning saturation according to Hennink et al. (2017) have also been reached. However, as the study was designed with a qualitative descriptive design, no definitive statement can be made on that. Furthermore, it must be considered that our recruitment strategy did probably not reach FC opposing the decision, although this is often emphasized in the literature (Fringer et al., 2019; Saladin et al., 2018; Starke, 2020). A further limitation concerns the high probability that a search for voluntary interview participants will not reach those persons who were particularly burdened by the situation of VSED or who still are, and who feel unable or unwilling to share their experiences.

5 | CONCLUSION

Family caregivers accompanying a loved one during VSED that felt left alone by healthcare professionals and other family members took over an advocacy role since they were not supported and in some cases were even tried to be stopped, often induced by legal and moral uncertainties. Following, first there is an urgent need for official national clarification of the legal basis of VSED and for individual occupational approval for healthcare professionals by their workplace (Fringer et al., 2019).

Nevertheless, the findings of this study can be useful for various healthcare professions by strengthening their understanding of VSED and of FC' advocate role in the accompaniment of a loved one during VSED and for laypersons, since VSED is often practised at home.

The results further open possibilities for healthcare professionals to provide preventive or acute support for FC. By knowing about FC' advocacy, professionals can adapt and optimize their support actions, for example in sensitizing FC to their possibly unconscious advocate role. Suitable would be specialists with expertise in palliative care, especially mobile palliative care teams as VSED is often carried out at home and as they focus on the dying person and their FC and cover the needs at the end of life.

Nevertheless, we recommend further studies on VSED using phenomenology and grounded theory to shed light on the topic with greater methodological rigour to achieve the aspect of transferability.

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CONFLICTS OF INTEREST

The authors declare that they have no conflict of interest.

AUTHOR CONTRIBUTIONS

Conception: JM, SS, AF. Interviews: JM, SS, AF. Data analysis: JM, SS, HM, AF. Manuscript: JM. Review of the manuscript: SS, HM, AF. Project responsibility: AF. All authors read and approved the final manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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