

Swiss families' experiences of interactions with providers during assisted suicide: a secondary data analysis of an interview study.

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Abstract

Context: Families are known to be involved in assisted dying and their involvement can be influenced by many factors.

Objectives: To explore how Swiss families interact with health care professionals and right to die associations regarding assisted suicide and their choices around disclosure.

Methods: A secondary data analysis on a cross-sectional qualitative interview study conducted in the Italian and French speaking parts of Switzerland was conducted. Interviews with 28 bereaved family members were analyzed using framework analysis.

Results: Two main themes were identified: 1. Interactions with physicians and right to die associations. 2. Choices about disclosing their experiences. In general, families believed that assisted suicide is a private matter, to be pursued mainly outside the medical field and involved physicians only when necessary. Families appeared to deliberately limit interaction with physicians and to be more comfortable interacting with right to die associations. Some participants presumed a clear choice between assisted suicide or palliative care. Disclosing to others the decision, and preparation of assisted suicide emerged to be an important emotional burden for families. Some family members preferred to restrict disclosure before and after assisted suicide, by sometimes not informing other family members until the final days.

Conclusion: In Switzerland, there is limited interaction between families and health care professionals concerning assisted suicide decisions, while families reported more open interactions with right to die associations. It is recommended that the needs of families should be reflected in health policies, taking into consideration the different contexts where assisted dying is permitted.

INTRODUCTION

Assisted dying encompasses both euthanasia and assisted suicide (1). Terminology of these practices is often contested, as in the US there is a tendency to avoid the use of the term “suicide” to keep a more neutral stance and avoid faming effects. However, a recent survey tends to cast doubts on the potential prejudices that the terms suicide and euthanasia can raise (1-3). In Switzerland, both in professional and public language, “assisted suicide” is commonly used and the law refers explicitly to the term “suicide” (4). Assisted suicide, which is permitted in Switzerland under certain conditions, involves the patient obtaining a lethal substance, which is self-administered (5). One of the features of assisted dying is that death is the result of a patient’s conscious choice and decision. Although it is the patient who makes an autonomous decision to choose assisted dying, some members of the family can be closely involved at all stages of the process leading to the decision about assisted dying (6-8).

Depending on the model of assisted dying and the country, families may experience different interactions with health care professionals involved in the process (9). In jurisdictions where only assisted suicide is legalized, families offer instrumental and emotional support to patients (8). In the Netherlands, where euthanasia is predominately practiced, families tend to interact openly with their physicians and value a shared decision-making model (7). The Dutch model of euthanasia seems to be characterized by effective relationships, mutual respect for autonomy, clear communication and collaboration between physicians, patients and relatives, whereas the assisted suicide model in Switzerland appears to be characterized by less interaction between families and health care professionals (6, 7).

In Switzerland, assisted suicide is mainly performed with assistance from right to die associations (5, 10, 11). For more than 25 years, some Swiss right to die associations

have offered practical assistance and personal guidance to commit suicide to their members ¹. In general, they assess the patient and their medical documentation for assisted suicide eligibility, appoint a volunteer to each case, provide the lethal drug prescribed by a physician, and a lay volunteer evaluates the patient's mental capacity at the time of ingestion (11). These features underpin the so-called "civil model" of assisted suicide characterized by minimal input from physicians (13).

In Switzerland, it is known that families tend to perceive assisted suicide mostly as a civil right and not a medical act in a strict sense (6). Most patients and families pursue assisted suicide outside of their health care team with the help of right to die associations (5, 6, 10). They may face isolation and value confidentiality during and after assisted suicide (14, 15). Research indicates that, when involved in assisted suicide, physicians tend to seek reasons and offer alternatives to assisted suicide (4, 16). They appear to develop a stance reflective of each practitioner's personal and ethical belief system derived from their own experiences of assisted suicide (4). Swiss palliative care physicians prefer extended discussions with patients and families with the aim of eliciting their views on assisted suicide and offering alternative options(4). In Switzerland since 2009 a national strategy for palliative care has boosted its development. Despite major achievements, an international ranking of 80 countries ranked Switzerland 15th for the quality of palliative care (17).

We undertook a study to explore Swiss family members' experiences of, and reflections on, their involvement in assisted suicide and data from this study has been

1. Five main organizations, 'Exit Deutsche Schweiz', 'Exit ADMD' ('Association pour le Droit de Mourir dans la Dignité'), 'Dignitas', "LifeCircle" and 'Exit International' provide, in the different Cantons, practical and bureaucratic assistance to patients who wish to die 12. Gauthier S, Mausbach J, Reisch T, Bartsch C. Suicide tourism: a pilot study on the Swiss phenomenon. *Journal of medical ethics*. 2015;41(8):611-7.. Some of them offer help only to Swiss citizens, others are open to requests from foreigners 12. *ibid.*.. The right to die associations are privately funded by thousands of members, and their activities play an important role in the diffusion of information about the topic among the population. They also undertake political lobbying.

published elsewhere, including a detailed account of sampling, data collection and data analysis (6). Little is known about families' experiences of interactions with professionals prior to assisted dying in countries where it is legalized (9). The research question of this study emerged from previously published data warranting further exploration of how families in Switzerland interact with physicians and right to die associations about assisted suicide and their choices around disclosure (6).

METHODS

This paper presents a secondary data analysis of a dataset of in-depth interviews with 28 bereaved family members and close friends of patients who died from assisted suicide (6). A secondary data analysis was appropriate because it allows examination of a sensitive topic and participants were a difficult to access population (18, 19). The dataset consisted of 26 interviews conducted in the French and two in the Italian speaking Cantons of Switzerland. This reflects the proportion of these language groups in the Swiss population (30% French and 5% Italian-speaking).

Sampling:

The study was advertised through the press (French speaking Cantons), the authors' professional network (both settings) and a right to die association operating in the French-speaking regions (EXIT ADMD-*Association pour le Droite de Mourir dans la Dignité*). Inclusion criteria were: being a family member or a close friend of a patient who died by assisted suicide, older than 18 years, able to give informed consent and to complete an interview in French or Italian. Participants needed to have been aware of the patients' wish for assisted suicide. The topic guide was developed based on existing literature and authors' findings from previous research about families' experiences of assisted suicide. Topics explored during the interviews are shown in *Table 1*.

Interviews were conducted in participant's first language, in person by the first author

(CG) and supported by MP for those in French. Interviews were conducted between June 2011 and July 2013 in a location of the participant's choosing and in their native language. Demographic data were collected (e.g. age, profession, civil status, relationship with the deceased). Most interviews lasted approximately one hour. Interviews were digitally recorded, transcribed verbatim and edited to remove any information that may have identified participants.

The dataset was analyzed using framework analysis (20, 21). Framework analysis is a method to *“explore data in depth while simultaneously maintaining an effective and transparent audit trail, enhancing the rigour of the analytical processes”* (20, 22).

Analysis was conducted in the original language of the transcripts and selective translation into English was done for publication. Attention was paid to words and tone and paralinguistic features. CG and MP developed a specific coding frame that was independently checked against the research question to ensure fit on four transcripts. The coding frame was developed to identify the nature of the interactions participants had with health care professionals and right to die association volunteers and the choices about disclosing their experiences of assisted suicide. Related codes were grouped into themes. CG analyzed each theme, noting any variation in perceptions within each type of interaction, and discussed findings with MP. The research team discussed any divergences in coding or interpretation until consensus was reached. Quotations were selected that both represent the typical experiences and reflect the diversity of family members' views (“majority” refers to approximately 50%-75% of the sample and “minority” less than 30%). International COREQ guidelines for qualitative research were followed to assure the credibility of the research (23). Ethical approval was obtained from the ethical committees of the Cantons involved in data collection (Ticino: ref 2424, Valais ref 004/11, Vaud ref 74/11).

RESULTS

The sample included 11 men and 17 women, associated with 18 deceased patients. The average age of participants was 60 years old, and they were interviewed between 6 and 48 months after the assisted suicide (median 12 months). A more detailed description of participants is published elsewhere (6). The participants reported that most of the patients had a cancer diagnosis, although it was noted that some had other life-limiting illnesses, such as amyotrophic lateral sclerosis, and a minority of patients suffered from other distressing conditions. Most participants were family members (partners or spouses and adult children) and seven were friends or members of the extended family circle involved in the care.

Participants interacted with health care professionals and right to die associations, starting from when they were coming to terms and making sense of the assisted suicide decision, to obtaining legal documentation and finally organizing and being present on the day of the death. Two main themes were identified:

1. interactions concerning assisted suicide with:
 - a. health care professionals including palliative care
 - b. to right to die association volunteers
2. choices about disclosing their experience of assisted suicide

Interactions concerning assisted suicide with health care professionals including palliative care.

In the interviews, families mainly reported about interactions with physicians. Most of the interactions occurred when the patient was in an acute hospital, nursing home or at home. Overall, interviewees reported that patient's underpinning reasons for assisted suicide were related to personal values. For example, one participant said

that assisted suicide choice was *“intimate, private and personal choice”* (ID3). For example, one participant expressed the wish that physicians should leave the prescription for the lethal drug in the letterbox outside the house, thus allowing the person freedom to choose if, when, how and under what circumstances to use it (ID7). Families expected physicians to prescribe the lethal drug and/or provide a certificate of eligibility; even though it appeared from interviews that the responsibility to obtain the required documentation was predominately in families or patient hands.

You (the physician) have to do it, we want the medical certificate for Exit; so, they said: "Yes, we will do it". But you (the physician) will not do it when you want, you will do it now that WE want it. ID6.

If physicians refused to provide certificates, most families decided to find another physician, acting in some cases under the pressure of the perceived suffering of the patient and the perception of limited time left.

Physicians in the hospital told us: “Well, listen, it gets complicated... maybe your family doctor should do it (the certificates and prescription) for you”. And we said: "but he had not seen her (the patient) in a year and a half”. So, we phoned to the family doctor, and he said: "Listen, I cannot... I cannot. I have not seen her, and you're in the hospital” ... and the hospital physicians were saying: “Oh no, no, here it's not possible...”. And my wife was there ... and she was suffering! ID14

In addition, one participant mentioned a physician who openly described himself as against assisted suicide, questioned the patient’s mental capacity and refused to provide medical certificates.

In some cases, relatives recalled a positive interaction with health care providers. One

participant talked openly with hospital staff about her father's assisted suicide intention and they organized the hospital discharge to allow the patient to go home and pursue assisted suicide. In two cases, the general practitioner (reported to be supportive of assisted suicide) was involved in the decision-making and was present at home at the moment of ingestion. In these cases, the interviewees perceived their general practitioner's presence at the death predominately as in their role of family friend.

In general, assisted suicide was not perceived as a medical decision. According to the interviews, the focus of the interactions with professionals was on gaining symptom management for their family member. However, a three participants reported they were concerned that opioids might impact upon mental capacity thus influencing their chances of obtaining assisted suicide. The families reported that they mostly avoided discussing reasons for assisted suicide and their emotions with professionals. One of the reasons to avoid these discussions with health care professionals was assumed or suspected conflict of values.

The nurse came in, saw that there was the Exit phone number and he said: "Look... I do not know how to tell you... but make sure that the people in the department do not see this number too much... because it is not in the ideals of the department".

ID4.

Family members reported that if informed about the assisted suicide wish, treating physicians tended to prefer to discuss reasons underpinning the decision. Families reported that many of the physicians they met in the hospital refused to collaborate in assisted suicide for example by not being willing to prescribe the lethal medication. Some family members experienced several physicians as judgmental about assisted

suicide.

There was a new staff member who constantly was telling her: "but madam... do you realize that we cannot do that (assisted suicide). Do you realize what you're doing to your family? "And so on.... So, from that moment on, it was torture for her... A real torture, also for the whole family. ID13.

Opposing values between professionals and the patient were described as understandable but unhelpful.

So I said: "Then I will call Exit." At that moment, the doctor got upset and he said: "Finally Madam... Exit it's not something we decide in two seconds". I found it very inappropriate because he did not know us and knew nothing. ID16.

Some interviewees were told that assisted suicide was not part of the care offered and in ten cases, interviewees reported that professionals seemed to avoid discussions concerning assisted suicide intentions or preparation.

And the four doctors ... I had the impression that they were hiding behind the other...So I ask myself the question: why? So, it could be that they were by definition against people who want to die where and how they want; such as in their houses with their relatives around. As it was for us ... a criterion! Or perhaps it is a matter of principle that hospitals do not want others to organize an active end of their life. ID7.

Four family members' views concerning eligibility criteria were different from those of physicians', and they decided to strongly advocate for the patient to obtain these certificates.

Because we needed a physician's medical certificate stating that she was in full possession of her faculties...- the doctor refused to do that, stating that she was in a serious depressive state with suicidal thoughts. This obviously caused a big problem... and at that point my father had to get angry and he had to threaten legal action. He took legal advice... he had to go up to the management... he had to send letters. ID13.

Although specific questions concerning the interactions with palliative care providers were not included in the interview topic guide, some participants reported their experiences and ideas concerning palliative care. Palliative care was mostly perceived as a medical service which imposed control over the dying process. For example, a participant highlighted the need of care tailored to patient's values, needs and suffering.

Palliative care cannot do everything; and palliative care is not all-powerful! ... From my experience there are situations where palliative care has limits, it (PC) is not almighty! And I think that sometimes, palliative care professionals are taking some power ... a power they should not take. Palliative care it's also sometimes a way to repossess the power of medicine... sometimes it (PC) can avoid it (assisted suicide) but it is not panacea! Who can take the person's position?... I do not like Exit dogmatism; equally I do not like palliative care dogmatism! Neither of them are the panacea. ID9.

Some participants felt there was a choice to be made between assisted suicide and being cared for by a palliative care team. For example, one participant argued that palliative care and assisted suicide should not be mutually exclusive:

We cannot say that we need to develop palliative care as an alternative to Exit (a right to die association); for me it's a mistake to think that by developing palliative care, people will use Exit less. It's just two different things. ID17.

Only one family member reported having valued the palliative care assessment done on her mother. It had been reassuring for her that all physical symptoms were addressed and controlled. It gave her reassurance that everything was tried and assisted suicide could be performed with her mother in the best possible physical condition.

While three interviewees described palliative care as a way to avoid suffering and enhance quality of life, some others questioned whether palliative care could alleviate the existential suffering that some patients experienced at the end of their life.

...But palliative care does not solve the existential question of life and end of life as it is. Palliative care offers.... an alternative to a medicine focused in maintaining life ... it is an accompaniment to death, in my perception...in best possible conditions, but it (Palliative care) cannot take the place. ID15.

The three participants that reported discussing assisted suicide with palliative care professionals were offered referral to a psychologist or a chaplain, and neither patients nor participants appreciated these referrals.

Interactions and requests to right to die association concerning assisted suicide:

Once the necessary certificates and prescription were obtained, interviewees reported turning their focus entirely towards the right to die association. Participants

interacted with right to die associations mostly in a climate of trust and recognized them as competent to evaluate patient's existential suffering and to confirm that assisted suicide was possible.

In most cases the right to die association care pathway was judged as appropriate by family members. Many reported that the right to die association volunteer visited the patient several times and in a few cases also talked with the interviewees. Most of the family members relied greatly upon the right to die association's competence to judge the patients' eligibility for assisted suicide and valued them as partners in decision-making. None of the family members perceived the discussions and assessments made by the right to die association as intrusive or upsetting. Only a few participants perceived the right to die association involvement as another formality to fulfil before assisted suicide. In a three cases the assisted suicide was organized speedily within days, but for most it was carefully planned over weeks. The attitude of the right to die association was perceived mostly positively because it was believed to strengthen the conviction that assisted suicide represents a *"personal choice and a personal journey"* (ID12). One participant said: *"the criteria for Exit ADMD are largely sufficient We must leave assisted suicide within the strictly private domain of the person."* (ID6).

Families' choices about disclosing their experiences of assisted suicide.

In general, participants highlighted confidentiality when disclosing issues to both family members and their community during and after assisted suicide. They carefully choose a selected circle of people and mostly refrained from contact and discussions with assisted suicide opponents within and outside the family (*We called Exit and I would just like it to stay between us* (the family). ID13).

Disclosing and sharing with others the intention and the preparation for assisted suicide appeared to add an important emotional burden to families. Some family members preferred to act in secrecy; sometimes keeping other members of the family uninformed until the final days before assisted suicide took place

And I think it would have been very, very (emotionally) costly for my husband, for example, to tell his mother: "I'm going to die by Exit". ID14.

In many cases, it appeared that the patient constructed a close relationship with one family member in relation to their assisted suicide choice and tasks. Some family members described that assisted suicide preparation brought “*complicity*” in their relationship. They opted to progressively disclose to only relevant persons. When and who to inform was planned, with a clear rationale and precise strategy, managing different levels of secrecy and confidentiality. For example, ID15 reported that “*...disclosure should be pertinent...relevant to the context*”.

Some participants reported a certain sense of isolation persisting during bereavement. While they reported not having an intention to avoid social contacts, they perceived some uneasiness in others approaching them. Recalling her grief after her sister’s assisted suicide, a participant commented; “*When there is such a difficult death (referring to both assisted suicide and classical suicide of her teenager son), it is up to the grieving person to make the effort to move towards the others*”. (ID9)

Discussion

The evidence from this study suggests that Swiss families interpret assisted suicide as a civil right; interact with physicians and right to die associations and often advocate

for patients to help them obtain assisted suicide under the pressure of the perceived patient's suffering and the apparent limited time left. While families expected physicians to provide certificates proving unbearable suffering and incurable disease and prescriptions for lethal medication, they preferred to discuss motivations and eligibility with right to die associations. The necessary step of interacting with physicians was mostly done at the end of their decision process and perceived as a sort of formality to be carried out to access right to die association services. Families regarded assisted suicide to be a family and not medical matter, and they reported their experiences as complex when challenged to disclose the decision publically within their community.

The Swiss model of assisted suicide is different from those legalized elsewhere (24). Switzerland is the only country where right to die associations are actively supporting patients and families in assisted suicide (11). It is an accepted practice based on a set of rightful expectations on the part of patients, family members, right to die associations and physicians (10). In our study, families interpreted assisted suicide as a civil right, and felt free to navigate the system when necessary to help the patient obtain assisted suicide. In Switzerland, it is considered that patients making requests for suicide assistance have a right to be protected against unwarranted obstruction of their choice. Since a medication prescription is required, physicians can refuse to provide the prescription without explaining their reasons. Physicians tend also to give importance to the duty to beneficence, prioritizing mental capacity evaluation and offering alternatives (4, 25). Clinical assessment of the existential suffering expressed by the patient is not yet a medical routine and the Swiss law does not specify requirements in terms of suffering (26).

Freedom of choice is a core value in the Swiss healthcare system (27, 28). The system offers the patient different choices; choice whether to use private or public healthcare services, freedom to choose who to consult about health conditions,

including for example complementary therapies (28, 29). The Swiss federalism and its multiculturalism are also the expression of the tension between self-rule, shared rule and solidarity (29, 30). Families, by interpreting assisted suicide as a right and as the expression of a system of values, rely on their right to choose as citizens. This interpretation of assisted suicide as a right may have framed their interactions and negotiations with physicians and right to die associations.

The negotiations with physicians and right to die associations seemed to be regarded by families as partly their responsibility. Many of the interactions with physicians appeared to happen in a climate of stress and conflict of values, similarly to that depicted in the US by Starks et al. in the context of assisted suicide before its enactment (31-33). In fact, when patients express assisted dying requests for information, they could also be interpreted as a request for a more open discussion around end of life issues. In these cases, physicians should be able to identify patients' needs and be competent in responding to them (34).

More recent US and Canadian studies, showed that families play a pivotal role in offering practical and emotional support to patients (8, 35). Nevertheless, some physicians remained available to families and offered practical support during the procedure (8). In the Netherlands, families value a shared decision-making model, clear and open communication and appreciated that physicians mainly manage the procedure of euthanasia (7, 36, 37).

The need to negotiate to obtain assisted suicide, could have reinforced family interpretation of a sort of free market, and a right for a free choice. In fact, the requested medical documentation appeared to be a sort of merchandise that some families considered as their right, whereas physicians considered it as a medical act. Whether health care in general should be considered as a commodity or as a right is

an ethical question. In this wider debate, these social and medical aspects of assisted suicide in Switzerland may raise the same question.

Strengths and limitations of the study

This study is the first study conducted in Switzerland and one of the few international studies exploring families' experiences with physicians and right to die associations in relation to assisted dying. The sample was drawn from French and Italian speaking cantons of Switzerland, whereas further studies are needed to explore families' experiences in the German speaking Cantons. To assure trustworthiness and clarity, the secondary data analysis was conducted by the same researchers that conducted the initial study and particular attention was given to issues of methodological rigor, data saturation and ethical principles (18, 38, 39). In the analysis, no differentiation on the base of kinship was made. The sample was characterized by a range of participants, those openly advocating for assisted suicide, opponents of assisted suicide and those with neutral views. However, families' accounts may have been influenced by a possible fear of being judged or by an intention to promote assisted dying on political grounds. Reflexivity regarding the first author's experiences and interaction with the participants was an important aspect during data collection and analysis. Constant awareness of their personal and professional background as a palliative care physician, allowed them to maintain critical reflexivity (40, 41).

Implications for practice, theory or policy

The results of this study are relevant in Switzerland and internationally for health care professionals and policy makers. Families need to be recognized as closely involved in the assisted suicide, and physicians and other providers should be conscious of and respectful towards families' experiences in assisted suicide. Family's needs, experiences and points of view should be taken into account. To foster open and

transparent communication, physicians may proactively inform patients and families about policies and responsibilities that they are required to adhere to when requested to provide medical certificates and prescriptions. Clinicians should be aware of the possible emotional burden experienced by family members when disclosing assisted suicide decision, and use an appropriate style of communication or conscientiously object to be involved in assisted suicide.

Conclusions

Our study highlighted that families have multiple interactions with physicians and right to die associations during assisted suicide and that they have diverse expectations and needs. Families also appeared to face some emotional burden and struggled to disclose openly about assisted suicide during the process and in bereavement. Growing numbers of families worldwide will be involved in assisted dying. In countries that have legalized these procedures, it is important to raise public awareness concerning all aspects of assisted dying and foster access to information. The family's role in supporting patients and its potential implications in bereavement should be investigated in all countries with assisted dying legislation.

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- We declare no competing interests.
- Contributions: CG conceived the study, CG and MP collected the data, CG and MP analysed the data and prepared results. CG, MP, SP, NP participated in the design of the study and the discussion of the results, and CG wrote the manuscript with input from all other co-authors. NP and SP oversaw the research. All authors read and approved the final version of the paper. CG and SP are the study guarantors.
- Data sharing: Additional data from the study are available from the corresponding author (claudia.gamondi@eoc.ch)

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Figure 1: Summary of topic guide used for interviews.

<p>How were you involved in the process leading to assisted suicide?</p> <ul style="list-style-type: none"> • The process of the assisted suicide preparation • What helped? what hindered? <p>How did you interact with health care professionals during the process of assisted suicide?</p> <ul style="list-style-type: none"> • What was discussed and how was it managed?

- What was the process to obtain prescription and certificates?

How did you interact with right to die association volunteers during the process of assisted suicide?

- How were the discussion arranged?
- What was your experiences?

Choices that families made around disclosing assisted suicide

- What choices did you make about disclosure?
- What helped? what hindered?