

Family caregivers' reflections on experiences of assisted suicide in Switzerland: a qualitative interview study.

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Keywords: assisted suicide, euthanasia, assisted dying, decision-making, families' experiences, palliative care, family relations, qualitative research.

Abstract

Background: Thousands of family members worldwide are annually involved in assisted dying. Family participation in assisted dying has rarely been investigated and families' needs typically are not considered in assisted dying legislation and clinical guidelines.

Objective: To explore family caregivers' reflections on experiences of assisted suicide in Switzerland.

Design: A cross-sectional qualitative interview study. Interpretation and analysis were performed using qualitative content analysis.

Setting: The Italian and French speaking regions of Switzerland.

Participants/setting: Twenty-eight close relatives and family carers of eighteen patients who died by assisted suicide in Switzerland.

Results: Family members perceived their involvement in assisted suicide as characterized by five phases; 1) Contemplation, 2) Gaining acceptance, 3) Gaining permission, 4) Organization and 5) Aftermath. Families can participate in these phases at diverse levels and with varying degrees of involvement. Important triggers for families and patients for transition between phases include patients' experiences of their life-threatening illnesses and related treatments, their increasing awareness of approaching death, and family member recognition of their loved one's unbearable suffering. Participating in assisted suicide created further demanding tasks for families in addition to their role of caregivers.

Conclusions: Families appeared to be involved in the preparation of assisted suicide along with patients, irrespective of their personal values regarding assisted dying. Support for family members is essential if they are involved in tasks preparatory to assisted suicide. Clinical guidelines and policies concerning assisted dying should acknowledge and address family needs.

Funding: This study had been funded by a Grant from HES Research and CG received a bursary for her Ph.D. studies from the Gottfried und Julia Bangerter-Rhyner-Stiftung (CH). The research was independent of any involvement from the sponsors of the study.

INTRODUCTION

This paper presents the reflections of Swiss family members on their experiences of involvement in an assisted suicide of a loved one. Assisted suicide is one of the possible end of life choices available to patients in jurisdictions allowing it. It is defined as *“a person intentionally helping another person to terminate his or her life, at that person’s voluntary and competent request”*¹. In contrast, active euthanasia is defined as *‘the intentional termination of life by someone other than the person concerned at his or her request’*². Assisted dying is a term that encompasses both assisted suicide and active euthanasia³.

Family participation in assisted suicide

During chronic illness, family caregivers may have various functions, including practical tasks, provision of emotional and social support to the patient, being a spokesperson, advocate and proxy decision maker, and coordinating aspects of the patient’s care⁴. In preparation for an assisted suicide, families may be required to take on extra responsibilities^{5,6}. A specific feature of assisted dying is that death is the result of a patient’s conscious and informed decision. Reaching that decision typically involves the patient and their family, with the participation of various health care professionals, in the legally required procedures^{7,8,9,10}. Annually, several thousand families participate in assisted dying and the subsequent bereavement,

including families supporting patients travelling from their own countries to have a assisted death in Switzerland or Belgium^{11,12}.

Assisted dying can be a complex experience for those involved and can represent one of the most difficult decisions a family ever makes⁶. It can be similarly challenging and demanding for both patients and families^{6,13}. Much of the research concerning family participation in assisted dying has been undertaken in The Netherlands, in the context of euthanasia. Cultural specificities should be taken into consideration when comparing models of assisted dying and families' experiences in different countries^{6,7,14,15,16}. Coming to a decision about assisted suicide can be characterized by an intensive period of sharing information and negotiating to reach an agreement^{17,18}. Acceptance of assisted dying within the family may vary. While family members may often support the patient's choice, family opposition is a common predictor of patients not achieving an assisted suicide¹⁹. There is a dearth of studies investigating the experiences of family members who oppose assisted dying decisions.

Assisted suicide in Switzerland

In Switzerland euthanasia is not permitted by law, but assisted suicide is permitted if certain conditions are met. Assisted suicide is available to anyone who reports unbearable suffering, a terminal illness is not a criteria. If the assistance has no selfish motivations, those providing it are not prosecuted. It has been estimated that approximately 10 out of 1,000 deaths in Switzerland result from assisted suicide^{20,21}. There is no federal law regulating protocols for assisted suicide provision in Switzerland, although two cantons (Vaud, and Neuchatel) have recently enacted legislation regulating assisted suicide in public institutions⁸. Switzerland constitutes a unique model of assisted suicide, the so-called "*civil model*"^{22,23}. Assisted suicide mainly occurs at the patient's home with the assistance of right to die associations

as few health care institutions permit it. The right-to-die associations assess the patient's medical documentation for eligibility, determine their mental capacity, refer to a physician to obtain a prescription for the lethal drug, and offer the support of a volunteer to assist the patient during this process. The assigned volunteer evaluates the patient's mental capacity prior to ingestion and assists during self-ingestion of the drug⁸. Crucial criteria to access assisted suicide involving right to die associations is the fact that the patient's suffering should be unbearable and without further options of care. Previous studies show that in Switzerland family involvement in assisted suicide is common with discussions during preparation restricted to a small circle of people^{24,25}.

The roles and involvement of family in assisted dying are under-recognized and remain largely ignored in clinical guidelines and institutional policies¹⁴. This study explored Swiss family members' experiences of, and reflections on, their involvement in assisted suicide.

METHODS

A qualitative cross-sectional study comprised interviews with bereaved family members and close friends of patients who had died by assisted suicide in the French and Italian-speaking regions of Switzerland between June 2011 and July 2013. Participant inclusion criteria were: being a relative or a close friend of a patient known to be deceased following assisted suicide; been informed by the patient of their intention to seek assisted suicide; being older than 18 years; able to give informed consent and to complete an interview in French or Italian. Since a central database was not available to identify potential participants, we started by contacting clinical colleagues to identify potential participants. This was followed up with snowball sampling. To complete the sample, we recruited via the right to die

association operating in the French-speaking regions (EXIT ADMD) by informing their associates about the study. Individual, face-to-face, semi-structured interviews in the participant's native language were conducted at a site of the participant's choice. Twenty-six interviews were conducted in the French-speaking and two in the Italian-speaking regions (representing the proportion of the Swiss Latin population in the total population). Interviews ranged from 60 to 90 minutes.

Topics explored were:

- Type of family involvement in assisted suicide
- Interactions that occurred prior to assisted suicide.

The interviews were audiotaped, fully transcribed and coded in the original languages. To ensure participants' confidentiality, all identifying information was removed from the transcripts and pseudonyms assigned. We decided not to return transcripts to participants for comments to avoid possible distress due to the sensitivity of the topic. Data analysis and interpretation used framework analysis²⁶. Researchers (CG and MP) made substantial theoretical memos during all phases of data collection, analysis and while drawing conclusions. We initially created a deductive coding framework, based on previous research^{24,25}. The coding framework was tested on five interview transcripts, evaluated and no further modifications were made. These interviews were included in the dataset for analysis. In a first step, single interview transcripts were analysed and coded using the framework. In a second step, all themes that emerged from the interviews were reviewed for content and grouped into categories. A higher level of interpretation, involved a continuum of reflection and comparison between concrete and abstract concepts, which allowed us to identify a temporal pattern of decision making in assisted dying and understand family experiences during each phase. Table 2 graphically represents the phases, the triggers to move between phases and related family

experiences. An iterative process of discussion resulted in a consensus between two of the researchers (CG and MP). International COREQ guidelines for qualitative research were followed to assure credibility of the research²⁷. Analysis of the data assumes that participants were reporting their own perceptions of their dying family member's experiences, in the context of a very close involvement with those experiences. Ethical approval for the study was obtained from the ethical committees of the cantons involved in data collection and Lancaster University (Ticino: ref 2424, Valais ref 004/11, Vaud ref 74/11).

RESULTS

The demographic characteristics of the 28 participants are summarized in Table 1: 11 males and 17 females associated with 18 deceased patients were included in the study. The participants were interviewed between six and 48 months after the assisted suicide occurred (median of 12 months). Emerging themes have been categorised based on the various phases family members went through during the patients' preparation for assisted suicide.

Phases of Assisted Suicide preparation:

Families' accounts suggest that they participate in five phases: 1) Contemplation; 2) Gaining acceptance; 3) Gaining permission; 4) Organization; and 5) Aftermath (see *Figure 1*).

It became apparent that during these phases family members made their own decisions concerning how they would participate and/or provide support to the patient in relation to the assisted suicide. Their decisions often appeared to be the result of a compromise between the family member's and the patient's values, with respect for the patient's decision being a common principle.

Transition between the phases of gaining permission and commencing organization of the assisted suicide appeared to be triggered by patients' specific experiences.

These triggers were commonly the patients' experience of their life-threatening illness, becoming increasingly aware of approaching death, and family member recognition of the patient's unbearable suffering (see *Figure 2*. Quotes 3-4; 11-15).

1) *Contemplation* (see *Figure 2*. Quotes 1-2): Families reported that most of the patients contemplated assisted suicide for a long period of time. For some, this started long before their illness, while for others right after diagnosis. Most participants described seeking assisted suicide as a long process for the patient, a "*thoughtful, mastered and justified pathway*" (ID9). Few patients discussed their thoughts at early stages with family members, most of them shared their interest in assisted dying after having been diagnosed with a life-threatening disease. Patients' reasons for seeking assisted suicide were often understood by family members as having been established over a lifetime. They were mostly related to fears for the future and actual loss of meaning in life (loss of dignity, loss of independence, fear of being a burden to the family); fears of suffering and having to face "*decay*" (ID6). These fears were often coupled with patients' perception of medical practice as being aggressive, inhumane, and invasive, involving tubes and artificial devices. Participants commonly reported that assisted suicide had been chosen by the patient to avoid an intrusive, medicalized death or to avoid hospitalizations and nursing home stays. Some participants described patient's perceptions of medicine and living in health care facilities as depersonalizing and as "*pathways to bereavement*" (ID3).

2) *Gaining acceptance* (see *Figure 2*. Quotes 5-10): After the diagnosis of a life-threatening disease, patients had commonly expressed fears to family members about indignity, loss of control and loss of independence and begun to discuss assisted suicide intentions with selected family members. Participants had the impression that patients were 'testing' family members for a match in values about

assisted suicide to avoid confrontations with those who might oppose it, and commented that they were assessing health professionals in the same way. During this phase, interactions between patients and family members sharing the same values facilitated the patients' understanding that assisted suicide was a civil right. It was in this phase that family members who had confirmed their support for assisted suicide started building a strong collaboration with the patient. During this phase, participants not supportive of assisted suicide reported experiencing a search for a balance between their own values and their need to be respectful of the patient's choice.

3) *Gaining permission* (see Figure 2. Quotes 16-21): This phase appeared to be triggered by the patient's experience of unbearable suffering, which led them to actively seek assisted suicide. Their exhaustion from disease-focused treatments and the awareness of approaching death were cited by participants as strong patient motivators. The ineffectiveness of medical treatments was reported by family members to exacerbate patients' and some participants' low regard for medicine, increasing fears of hospitalization and reinforcing their desire to avoid a medicalized death. Some participants had contact with palliative care professionals during patient's illness but only a few of them shared their concerns about assisted dying with these professionals.

In this phase, the patient's aim appeared to be ensuring that all requirements were in place to achieve a timely assisted suicide. Family members assisted with a range of essential tasks towards that goal. For example, some participants helped the patient search for a physician to provide medical certificates and the prescription of the lethal drug. In a few cases the family member acted as an advocate for the patient, personally obtaining the required documents. Initial contacts with the right to die associations were mostly made by the patient and a family member together. In some cases, family members led the process of preparing for assisted suicide in

close collaboration with the patient. All participants reported having to overcome dilemmas concerning their involvement in assisted suicide. The acknowledgment of the patient's suffering as unbearable was the most common reason given for those participants to justify assisted suicide and their involvement. For example, one daughter (ID 4) disagreed with assisted suicide on general grounds and was therefore reluctant to offer practical help to her father in contacting the right to die association. Nonetheless, she described herself as ultimately respecting her father's decision and decided to be with him at the moment of ingestion.

4) *Organization* (see Figure 2. Quotes 22-24): This phase was characterized by the practical organization of the assisted suicide. Patients and families met with the right to die association volunteers to be assessed for assisted suicide eligibility. Various negotiations then occurred with the right to die association volunteers concerning the choice of the day of assisted suicide. Most family members were undecided about when was the right time. There needed to be a balance between undue further deterioration of the patient's condition, without hastening the patient's death excessively. Many patients were described by participants as spending time planning for funerals and rituals after their death and deciding who should be present at ingestion. Many of participants recalled feelings of ambivalence, distress and exhaustion during this period. Some experienced a feeling of burden in carrying the responsibility for actioning the patients' choice during this phase and were worried about a certain ambivalence expressed by some patients concerning the assisted suicide decision and its timing.

5) *Aftermath* (see Figure 2. Quotes 25-29): All participants recalled how important it had been to respect the patient's decision about assisted suicide, irrespective of their level of active or passive involvement. Some participants recalled that they only understood the depth of the patient's suffering after the assisted suicide. The actual assisted suicide allowed them to acknowledge the intensity of the patient's

suffering. All participants shared the reflection of having experienced a very intense process.

Disclosure after death was experienced by family members as careful and partial, depending on the participants' capacity for anticipating or overcoming actual or anticipated stigma. Many participants felt that assisted suicide disclosure to people within or outside the family should be pertinent and relevant to the context where it is discussed. Some participants had been asked by the patient to disclose their assisted suicide only at the time of the funeral or in their obituary, while others spoke of retaining "*intimacy*" (ID1) when expressing their reasons for not disclosing at all. While most participants felt unable to share their story after the death, this appeared to be due largely to fears of peoples' possible reactions and of feeling judged. None of the participants received nor asked for professional support during bereavement.

DISCUSSION

A key aspect of our findings is the diversity of the family members' involvement in assisted suicide. Participants' experiences indicated that family members may be involved during all phases leading to an assisted suicide. They can play a pivotal role acting as advocates for the patients and providing practical help to obtain an assisted suicide, in addition to their role as caregivers. They can also be key persons in reflecting pro and contra arguments about assisted suicide with the patients and pondering with them the timing of the act. It is arguable that many factors such as the patient's capacities to pursue their intentions by themselves, the family member beliefs toward assisted dying, type of family relationships and interaction with right to die associations and health care professionals have played a role in how family members acted at different phases.

Assisted suicide appeared to be the result of numerous negotiations happening

within the family circle and outside. Patients and families discussed in depth before coming to an agreement. Their relationship enabled them in most cases, but not all, to share the responsibility of the decision.

Agreeing upon assisted suicide

Consistent with earlier research, assisted suicide appeared to be predominantly the result of a thoughtful, complex and negotiated decision based on personal values and characterized by intense and prolonged discussions^{5,6,7,28,29}. Our data suggest that the decision about assisted suicide required at least two levels of agreement: a preliminary acceptance within the family and a second agreement mainly with the right to die association.

A preliminary acceptance within the family of assisted suicide as an acceptable way to die seemed crucial. The acceptance of assisted suicide appeared to be discussed initially only within the family, marginally involving health care professionals, since assisted suicide was interpreted to belong to an intimate sphere of the person and their relationships. Discussing assisted dying options firstly within the family and not with physicians appears to happen also in The Netherlands, confirming the very private nature of this decision³⁰. Data showed that health care professionals when involved in an assisted suicide decision in Switzerland, tend to include families in extended discussions, mostly being unaware whether and to what extent the family already accepted assisted suicide as an option⁸. Swiss families seemed to play an important role in this early phase. The recognition of the patient's suffering as unbearable motivated some initially reluctant or ambivalent family members to accept assisted suicide as a reasonable option and support it. The majority of family members became, in effect, partners of the patients in helping them seek assisted suicide and providing emotional and practical support. Those participants holding beliefs against assisted dying did not prevented patients from obtaining assisted suicide but mostly voiced their dissent during decision making. It would be desirable

to conduct further research to explore the experiences and roles of family members when patients planning to pursue assisted suicide either changed their mind or died before assisted suicide could occur.³¹

A *further agreement* around the feasibility and organization of assisted suicide involved other actors, such as physicians and right to die associations. Consistent with previous literature, patients' awareness of approaching death and fears of imminent decline seemed to trigger the phase of active organization of assisted suicide^{5,28}. This phase involved families in different ways; many of them negotiated directly with health care professionals for certificates and with right to die associations. A few assumed a passive role in these negotiations, leaving the patients to negotiate directly. Most participants were ready to screen physicians to find one willing to prescribe the lethal drug, apparently avoiding those potentially in disagreement. In all cases, the families and the patients appeared to decide and obtain assisted suicide mostly with little medical support beyond the diagnostic certificates and prescription, as it is typical in the Swiss civil model of assisted suicide²².

Building a relationship to obtain assisted suicide

Our data illustrate the importance of building a relationship and of sharing the burden between patients and family members regarding the decision about assisted suicide. Consistent with the literature, the process towards assisted dying appeared to be as important as the event itself¹⁴. However, families in our study seemed to play a role that emerged as more incisive than that described elsewhere^{6,7,29}. Most of the family members interviewed had acted as advocates for the patient and in strong cohesion with them, while in The Netherlands the predominant relationship has been described to happen between patients and physicians, within a shared decision-making model^{6,7}. This can be explained by the fact that in The Netherlands there is a legalized medical model of assisted dying and there could be less need for

family members to advocate for it (*See Table 2*). With euthanasia as it occurs in the Benelux countries, patients and their physicians seem to have primary roles and the process is characterized by open communication, mutual trust and intense collaboration with health care professionals^{6,7}. Openness in dialogue was also valued by families in Oregon, while the absence of a clear legal framework seems to leave families isolated and facing various dilemmas^{5,19}. In contrast, Swiss families and patients seemed to decide by themselves, and only during the later phases do they involve right to die associations. These associations then appeared to take on roles such as verification of eligibility criteria and help at the moment of ingestion – roles that are assumed by physicians in other jurisdictions³².

During the aftermath and bereavement phase, participants appeared to resort to their own resources, rarely discussing their experiences with other family members, friends and professionals. The present climate of relative secrecy surrounding assisted suicide, apparently characteristic of that choice in Switzerland, can have a negative influence on the bereavement process^{34,35}. Potential negative impacts of not discussing assisted suicide may be mitigated by a trend towards more open debate in society concerning assisted dying.

Strengths and limitations of the study

This study is one of few undertaking an in-depth analysis of families' negotiations with patients, health care professionals and right to die associations in relation to assisted suicide. We aimed to recruit participants with a diversity of involvement, but it is possible that family members in strong opposition with assisted suicide choose not to participate in this study. All data concerning the patients' wishes and behaviours derive from the families' accounts. It is unknown whether, and to what

extent, some patients could have hidden information from their families. Participants may have been influenced by a possible fear of stigma or being judged or a desire to represent the situation in a positive manner. Undertaking face to face interviews allowed ambiguities to emerge and preserved the very private context where assisted suicide happens. The qualitative design had important benefits. It permitted an in-depth exploration and a nuanced understanding of family dynamics regarding the process of assisted dying. It also required that the research team considered how their interactions with participants and data analysis might be influenced by their own professional backgrounds, experiences and prior assumptions. The researchers explored their subjectivity and reflected upon how to their professional's backgrounds and opinions regarding assisted dying and its regulation might have shaped the analysis and interpretation of the data.

The sample was drawn from Latin Switzerland, which covers about a third of the Swiss population but does not permit generalization of the results for the German-speaking cantons.

Clinical implications of this study

The nature of assisted suicide in Switzerland, as perceived by family members, was that of a personal right and a patient's choice made to avoid anticipated indignities, limit existential suffering and avoid a medically controlled death. Assisted suicide requests need to be understood by taking into consideration the life story of the patient and their family, and should be interpreted in the light of the various phases leading to the ultimate decision. Beyond patient autonomy, families should be recognized as deeply involved in assisted suicide and their specific needs should be identified and addressed. Our data demonstrate that involvement in assisted suicide created additional and demanding tasks for families, in addition to their role as caregivers, and they played a major role alongside the patient in achieving it. Despite diverse approaches to assisted dying across countries, there are important

implications of our data for all countries^{31,32}. It appears desirable that professionals including those within palliative care, when confronted with families contemplating assisted dying decisions should:

- Identify the possible roles that family members have in assisted dying
- Approach families involved in assisted dying acknowledging that patients and families have been probably considering assisted suicide for some time and that the acceptance of assisted dying within the family may vary.
- Use biographical approaches (such as life history) when discussing assisted dying to encourage person-centred practice and elicit values and life goals of those involved.
- Investigate if family members are required to undertake additional tasks concerning assisted dying and address potential needs.

CONCLUSIONS

Assisted suicide in Switzerland belongs predominately to the civil and private sphere and family members do not perceive it as belonging to the medical domain. Our findings indicate that families played a critical role in allowing patients to obtain assisted suicide, and it appears likely that assisted suicide in some cases may not have been possible if families had not provided crucial help. It is possible that the Swiss civil model of assisted suicide allows patients and families greater autonomy in decision-making and organization of assisted suicide. On the other hand, it requires families to assume a broader moral and practical responsibility of the whole process. In conclusion, clinical guidelines and legislators should pay greater attention to family involvement in decision-making and organization of assisted dying, whether obtained in the patient's own country or abroad.

- Acknowledgments: Thanks are due to all families who shared with us their personal opinions and experiences of such an intimate and private part of their lives.
- 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. The manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted.
- Data sharing: Additional data from the study are available from the corresponding author (claudia.gamondi@eoc.ch)

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Table1: Demographics and principal characteristics of participants

| Case | Patient illness and age | Informal caregiver relationship, age | Time elapsed between the assisted suicide and interview | Type of involvement in assisted suicide |
|--------------------|-------------------------------------|--------------------------------------|---|---|
| ID 1 Peter | Cancer | Wife, 60-70 years old | 2 years | Active |
| ID 2 Thierry | Cancer | Wife, 40-50 years old | 1.5 years | Passive |
| ID 3 Stefanie | Arteriopathy | Son, 40-50 years old | 1 year | Active |
| | | Daughter in law, 50- 60 years old | | |
| ID 4 Antonio | Cancer | Daughter, 50-60 years old | 6 months | Passive |
| | | Partner, over 70 years old | | |
| ID 5 Giuseppina | Cancer | Daughter, 40-50 years old | 6 months | Passive |
| ID 6 Henry | ALS | Wife, 50-60 years old | 1.5 years | Active |
| | | Three friends, 60-70-years old | 1.5 years | |
| | | Power of attorney, 67 years old | 2 years | |
| ID 7 Richard | Cancer | Wife, 50-60 years old | 4 years | Passive |
| | | Friend, 50-60 years old | | |
| | | Son, 20-30 years old | | |
| ID 8 Patrick | Cancer | Sister, 60-70 years old | 4 years | Active |
| ID 9 Benedicte | Genetic Neurological disorder | Sister, 60-70 years old | 3 years | Passive |
| ID 10 Marie | Chronic back pain | Husband, over 70 years old | 6 months | Active |
| ID 11 Nadine | Cancer | Daughter, 30-40 years old | 1.5 years | Passive |
| ID 12 Valentine | Cancer | Husband, over 70 years old | 1 year | Active |
| ID 13 Veronica | Cancer | Daughter, 50-60 years old | 6 months | Passive |
| ID 14 Josephine | Tired of living | Daughter in law, 50-60 years old | 6 months | Active |
| | | Grand son, 20-30 years old | | Passive |
| ID 15 Gisele | Cancer | Stepdaughter, 40-50 years old | 6 months | Passive |
| ID 16 Angela | Cancer | Friend, 40-50 years old | 6 months | Passive |
| | | Volunteer, 60-70 years old | | |
| ID 17 Ernest | Multi-morbidity- Tired of living | Daughter, 60-70 years old | 1 year | Active |
| ID 18 Lisa | Cancer | Husband, over 70 years old | 1 year | Active |

Table 2: Differences in the experiences between active euthanasia in The Netherland and assisted suicide in Switzerland

ACCEPTED MANUSCRIPT

| Dutch situation (predominantly active euthanasia) | | Swiss situation (only assisted suicide) | |
|--|---|--|--|
| Initiation of sharing views and values about assisted suicide | Open sharing with relatives and general practitioner was reported. | Contemplation | Restricted disclosure, avoiding opponents of assisted suicide. Assisted suicide was perceived as a personal right. |
| Building the relationship as part of the negotiation | Effective relationships between physicians, patients and relatives, even if initial requests were declined. | Gaining acceptance | Negotiations happened within a restricted circle. Families experienced dilemmas in identifying the unbearable suffering and agreeing on assisted suicide. Families reported degrees of mistrust in health care professionals. |
| Fulfilling the legal requirements | Work towards an agreement about 'unbearable suffering' between the patient and the physician. The legislation offered clear guide of conduct. | Gaining permission | Overcoming dilemmas by acknowledging the patient unbearable suffering; families searched for medical certificates and lethal drug prescription. Experience or anticipation of stigma by professionals and lay people. |
| Preparation and performance of assisted suicide | Physicians step into their professional role and took control. Protocols were appreciated as they supported the physician's role at a time of high responsibility. Patients, relatives and physicians greatly valued the rituals that accompany active euthanasia. | Organisation | Families rely on the right to die associations' internal rules. Family members and patients discuss with right to die association the assisted suicide date and the last agreements. Health care professionals do not participate in assisted suicide preparation. |
| Aftercare and closure | A certain degree of burden on families and physicians was reported. Most relatives and physicians reported positive reflections. Relatives mentioned difficulties accepting the rapid process of decision that led to a choice that was often difficult for them to comprehend. | Aftermath | Families recalled the assisted suicide period as exhausting and very intense. There is no formal support in grief and bereavement. Some evidence of social stigma or fear of it. Positive reflections about having fulfilled patient's wishes. |

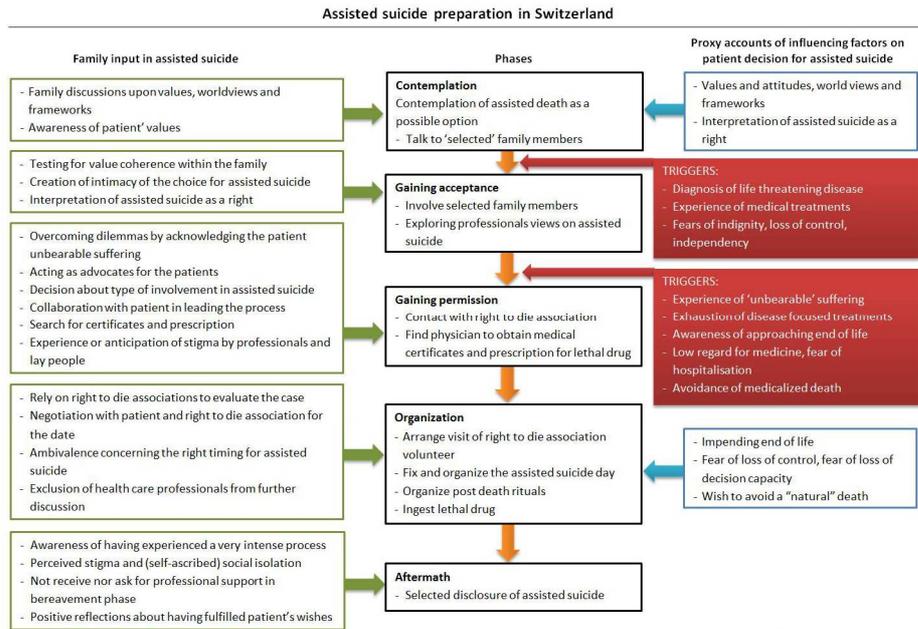


Figure 1: Assisted suicide preparation in Switzerland

Figure 2: Accounts of informal caregivers' reflections of the experiences in the different phases of assisted suicide in Switzerland

| Contemplation | |
|-------------------------|---|
| 1 | Long story. He told me about it a long time ago; three or four years before he was ill. He was saying.. "Yes Exit I think it's good..." ; And then afterwards he was going back and forward; Of going back and forward following the vision of the film on television which had made him change completely by saying: "Oh no, if that's it (<i>Assisted Suicide</i>), I will not take it "...Yeah but that's the characteristic of him., it's mastery. (ID6-F) |
| 2 | So we have been a members of Exit for more than 20 years ... we were still young, ... It is in our minds ... we would never want in our lives to be exposed to elements from the outside ... suffer suffering without any use (ID10) |
| 1 st Trigger | |
| 3 | Two years with treatments that she could not stand. And uh ... well she naturally made that decision...She knew that the time was clearly counted for her (ID11) |
| 4 | There is no hurry (<i>with Assisted Suicide</i>), we are not in an hospital with tubes everywhere ... like it is in geriatric wards ... pathways of bereavement ... where there are words that are really undignified, and in hospitals even worse ... we die with strangers ... vegetating. With assisted suicide ... we have candles, we feel OK, we have music, we have people we love. (ID3-5) |
| 4 | She didn't want to go in a nursing home, facing a window in a wheelchair. (ID10) |
| Gaining acceptance | |
| 5 | Everyone knew and then we followed his slow evolution towards something impossible for him.... (ID6-F) |
| 6 | Nowadays, it is (<i>Assisted Suicide</i>) still a taboo, isn't it ? (ID4-P) |
| 7 | So it was a decision that was clear in her mind; there was, for two months, a kind of deadline since when she began to talk about it (<i>Assisted Suicide</i>) very seriously and regularly (ID13) |
| 8 | I think it is not necessary to do it (<i>Assisted Suicide</i>) ... to do that thing ... it is too bad (ID4-P) |
| 9 | I would have never forgiven myself if I to play a cruel trick on him (<i>not helping in Assisted Suicide</i>) ... even if it was against my values. (ID1) |
| 10 | We had been very careful, we haven't given external information ... There were people we were sufficiently close to us to inform them regarding the thing (<i>Assisted Suicide</i>). We experienced assisted suicide as an formality, following a completely private ... allowed decision. (ID10) |
| 2 nd Trigger | |
| 11 | He was used to say: "Beyond this I can not go, it is not possible; My dignity, yeah... I'm not me anymore, it's not right " (ID6-F) |
| 12 | "At one point she absolutely stopped all treatments. She said, "Now stop, let me die quietly." (ID11) |
| 13 | There was a reluctance in face of medicine, he could no longer tolerate doctors (ID8) |
| 14 | When you see those successive mourning stages which he had to make; And then he had given himself a limit; The day when I must be fed, and I am nailed to my bed; well...He saw his mother die of this, so he knew what was waiting for him... But when is it the "it is now". Because I am sure that, seen from the side of who is leaving, it is the question, the core question". (ID6-F) |
| 15 | Her oncologist... and then all of a sudden they said: "Now it's practically the end" ... she said nothing, she went on for some time, but all of a sudden she said: "Now, I can not go further, I can not go further" and it was true! She was suffering terribly. She said, "You must call her (<i>the Exit volunteer</i>) , she must come this Wednesday" (ID18) |
| Gaining permission | |
| 16 | I had to control the situation, I had one only aim: to kill my wife. It is horrible but...but I believe that in such a situation, there are no other means, no other aims... (ID12) |
| 17 | When it was time to take steps, because she had to send papers... I was supposed to send all the documents...then I said "I leave you doing these things", I do not want to rush things ..Or ... Finally I really wanted to be it her own decision; I did not want to push it in any direction. So she managed to find the address, to put the stamp, to post the letter. (ID11) |
| 18 | ...And this doctor when he said that he had to go to the hospital, I said, "Then I'll call Exit." Then the doctor got upset and he said, "Finally Madame, Exit is not something we decide in two seconds." I found it very inappropriate because he did not know us and he knew nothing...he did not know where we were; So I found it out of our context and the... great courage... he left, without saying goodbye. Nothing. We was left like that. " (ID8) |
| 19 | "Well, from the moment she announced that they were coming (<i>Exit</i>)...eh... because she needed a medical certificate from the doctor that she was in full possession of her means... but the doctor refused to do that. He said that she was in a serious depressive state with suicidal thoughts. This, of course, was a big problem, and my father had to get angry. He had to threaten a legal action. He had to go up to the direction floor. He had to prepare letters ... well, it was very, very, very painful. And all the staff... and she was in tears. She could hardly speak - she was crying, we were talking to each other by telephone ... every time there was a new staff member I went to tell "but... do you understand?, you cannot do like this. Do you understand what are you doing to our family?... So it was a torture for her from that moment on. (...). A real torture, and for the whole family. "(ID15) |
| 20 | And then we were together, and after the nurse came in...saw that there was the Exit number and she said," Look, I do not know how to tell you... but make sure that the people in the service (<i>palliative care unit</i>) do not see this number too much because it's not too much in the idea of the service" That's what she said to us. I have no judgment... Then my friend said, "Yes, no worries". She put away the phone number. (ID16F) |
| 21 | Our GP knew, he said he will not oppose it (<i>Assisted Suicide</i>), because if he would have opposed we would have looked for another one. (ID10) |
| Organisation | |
| 22 | The physician from Exit came and he took time to really interact with my wife, to understand the whole story, in a professional way to do an anamnesis; then on one side very professional for me and on the other side very human as a doctor. (ID12) |
| 23 | My sister-in-law proposed to my mother directly: "So, if one day you'll need I will gladly accompany you because I think that for your children it is a difficult step", that's why I thank her always, because I find that she had this... just great generosity to do something that is not obvious at all, that's, I'm not sure I would have the ability to do it for someone else ... She made this great step" (ID11) |
| 24 | And the final decision of the exact day, it was taken two days before. But it is true that the last week there has been a total, total, total degradation; She could not walk any more, it was truly terrible ... I think she felt that either she did it quickly or she will not have the strength of ... she was enough conscious nevertheless that she had to be able to hold herself the glass...(ID14) |
| Aftermath | |
| 25 | "I have totally digested all the story about Exit". "He left good, he left how he wanted, surrounded as he wanted... So the bereavement has gone fine." (ID6-F) |
| 26 | The violence is there too (<i>in Assisted Suicide</i>) ... a different violence (<i>comparing with natural death or classic suicide</i>). It is there, but it is spread over the people that follow the patient in their decision. (ID6-W) |
| 27 | My brother...he does not want to talk about it (<i>Assisted Suicide</i>). Anyway, we never talked about it. (ID4-D) |
| 28 | He (<i>the patient</i>) took us on difficult and sometimes impossible roads. (ID9) |
| 29 | "Assisted suicide is a way to de-anguish the world...there is a great anguish facing old age and death" (ID6-F) |