Families’ experiences with patients who died after assisted suicide: a retrospective interview study in southern Switzerland

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Background: In Switzerland, if certain conditions are met, assisted suicide is not prosecuted. International debate suggests that requests for hasten death are often altered by the provision of palliative care. Aims of the study were to explore patients’ reasons for choice of assisted suicide and family perceptions of the interactions with health care professionals.

Patients and methods: This is a qualitative study upon 11 relatives of 8 patients cared for by a palliative care team, deceased of assisted suicide.

Results: Pain and symptom burden were not regarded by patients as key reasons to seek assisted suicide: existential distress and fear of loss of control were the determinants. Most patients had made pre-illness decisions to use assisted suicide. A general need for perceived control and fear of dependency were reported as a common characteristic of these patients. Patients held misunderstandings about the nature and purpose of palliative care, and the interviewed indicated that patients did not regard provision of palliative care services as influential in preventing their decision.

Conclusions: Assisted suicide was preferred despite provision of palliative care. Better understanding of the importance placed on perceived control and anticipated dependency is needed. Further research is needed to develop appropriate support for patients contemplating assisted suicide.

Key words: assisted suicide, family, hasten death, interviews, palliative care, qualitative research
individuals making these requests should have access to comprehensive palliative care and therefore advices that physician-assisted suicide are often altered by the provision of palliative care in Switzerland. From the proxy accounts of family members in southern Switzerland, we investigated the interactions during the decision-making phase, using proxy accounts from family members as they are the only people able to provide a complete account. The right-to-die associations in Switzerland have played an important role in the diffusion of information among the population and thousands of members and their activities play an important role in the diffusion of information among the population and undertake political lobbying [7, 8].

**introduction**

The European Association for Palliative Care defined physician-assisted suicide as a ‘doctor intentionally helping a person to commit suicide by providing drugs for self-administration, at that person’s voluntary and competent request’ [1]. Moreover, it states that requests for euthanasia and physician-assisted suicide are often altered by the provision of comprehensive palliative care and therefore advices that individuals making these requests should have access to palliative care. This study aims to explore the patient’s reasons for seeking assisted suicide, and to investigate the interactions with the health care professionals during the decision making from the proxy accounts of family members in southern Switzerland.

In Switzerland, euthanasia is punished by law [2], but if certain conditions are met, assisted suicide is not prosecuted [3]. Article 115 of the Swiss penal code requires that the act must be selfless, and physicians must provide a certificate to verify that the patient is competent and that the illness is incurable [3]. The law considers suicide as a violent death, requiring a police investigation. For assisted suicide, the investigation usually leads to a judgment of dismissal [4–6]. Four main organizations provide assistance to patients who wish to die. The right-to-die associations in Switzerland have thousands of members and their activities play an important role in the diffusion of information among the population and undertake political lobbying [7, 8].

The typical annual death rate of the Home Palliative Care Team in Southern Switzerland is around 300 deaths/year. Between 2003 and 2010, a mean of two patients per year, cared by this team, died of assisted suicide (Figure 1). This represents <1% of all deaths, while euthanasia in Belgium represents 1.9% of all deaths, 1.8% in The Netherlands and <1% in Oregon [9].

Little is known about how patients undertake sensitive end-of-life choices that result in assisted suicide. Our study aimed to explore reasons underpinning this choice, and to examine interactions during the decision-making phase, using proxy accounts from family members as they are the only people able to provide a complete account.

**methods**

A more detailed section about the methodology of this study is available at Annals of Oncology online.

Cross-sectional qualitative interviews were conducted with bereaved family members of patients who had died from assisted suicide. Our study focused on the Canton of Ticino (Italian-speaking part of Switzerland), with a population of 330,000 in 2009. Data comparing assisted suicide and suicide in Ticino, provided by the Cantonal Police, are shown in Figure 2.

Within the patients cared for by the palliative care team who died in southern Switzerland between 2003 and 2009, 13 cases of assisted suicide were identified; 3 were excluded because lack of traceable relatives. Inclusion criteria were being a relative of a patient deceased following assisted suicide, being >18 years old, able to give informed consent and to complete an interview. Eleven relatives, five males and six females, associated with eight deceased patients were recruited. Four relatives declined participation. Relatives were interviewed with face-to-face semi-structured interviews between October 2010 and October 2011, and demographic data on themselves and the deceased patients were collected. The interview guide was developed from the literature, the first author’s clinical experience as a medical officer with training in oncology and palliative care and key informants’ advice and then modified during the process as recommended by qualitative approaches [9]. Themes explored during the interviews are shown in supplementary Figure S1, available at Annals of Oncology online.

The interviews were audio-taped and fully transcribed. Interpretation and analysis were carried out according to the principles of grounded theory [9]. The analysis started from the first interview and influenced the next one. The aim was also to ask questions derived from themes which emerged in the previous interviews to allow the generation of categories with explanatory power. Every interview was analysed at a micro-level and a pool of themes was obtained during the open coding. In the second phase of axial coding, all individual codes were sorted and resorted as concepts and common themes [10].

In the final step, overarching themes were grouped into defined categories and central concepts, using a selective coding process. An iterative process of discussion was engaged throughout the study which resulted in substantial agreement between the authors in terms of major themes identified.

**results**

Characteristics of the eight deceased patients and the relatives are presented in Tables 1 and 2.

**deceased patients’ characteristics**

Of the eight patients who undertook assisted suicide, six had completed high school or higher education and two primary or secondary school. All patients were diagnosed with cancer. Five...
were male and three were female, all but one Roman Catholic. Six patients were married, and those widowed were cared for by close family, usually a daughter. All patients were in contact with a community palliative care service for a mean of 199 days (range 9–420 days). Seven patients were assisted by a right-to-die association during the preparation, and actual assisted suicide; and in one case by his own general practitioner. It is very difficult to trace the timing between the first contact with the right-to-die association and the occurrence of death. In two cases, facilitated by a right-to-die association, relatives reported episodes described as delirium during the day when assisted suicide was performed. In another two cases, a physician (who was this patient’s relative) was present at the time of death. No complications were reported during the procedure resulting in death.

relatives’ characteristics
Eleven relatives with a mean age of 56 years (range 40–71 years) participated in the study (Table 2). All, except one, were principal caregivers and involved in the day-to-day care of the patients from the onset of cancer. Relatives comprised three nephews; three spouses, three daughters and two sisters were interviewed a mean of 36 months after the patient’s death (range 18–48 months).

perception of reasons for hastening death
Reasons for seeking a hasten death were attributed mostly to long-standing personal beliefs that patients held in favour of assisted suicide, if these circumstances arose. Some relatives reported that, long before the cancer diagnosis, the patients told them that they were contemplating a suicide or a hasten death in the case of a serious illness. This intention dated back a decade or more. An acceptance of assisted suicide within the family, across generations, is recognizable in two cases. In these two cases, the agreement between the patient and their relative to help with a potential assisted suicide dated back about 20 years.

The strongest message conveyed by the interviewees was that patients had a fear of the future, fear of loss of dignity, a lack of independence in daily activities and bodily functions. These were recalled as a strong motivation in the patients to enact their previously considered assisted suicide (Figure 3). While fear of future physical symptoms was frequently reported, actual intolerable physical pain was referred to as the main cause of the decision in one case. Feelings of anger, impotence, desperation and hopelessness were reported by the relatives as being present in the patients. The diagnosis of a life-threatening illness was referred to as a strong trigger to act. Patients’ concerns about living with a debilitating illness and a very short prognosis were reported as unbearable. The relatives generally recalled physical symptoms as being under control during the decision-making phase.

Most patients were described as sharing personality traits: being very independent, not prone to rely on others, little interested in others’ opinions regarding their decision about assisted suicide and unwilling to lose control. In some cases, the patients, in response to doubtful relatives, were reported to repetitively threaten to commit suicide. This kind of pressure from the patient was reported as strongly manipulative by relatives, and it forced the relatives to act in support of assisted suicide, which was regarded as qualitatively better than classical suicide.

professionals’ involvement in decision making
Many professionals were reported to be involved in the care of the patients: the general practitioner, the oncologist, the palliative care physician, district and palliative care nurses.

usually, the patients were referred to as being the main communicator with the health care professionals, mostly for symptom control and decision making concerning cancer treatments. A perception that some professionals lacked awareness of, and were unsupportive of, the patient’s existential suffering emerged. There was a tendency for some professionals whose personal beliefs were thought by relatives to be challenged by assisted suicide, to withdraw from the situation.

Table 1. Principal characteristics of the deceased patients

<table>
<thead>
<tr>
<th>Case</th>
<th>Sex</th>
<th>Age at death</th>
<th>Marital status</th>
<th>Religion</th>
<th>Type of illness</th>
<th>Length of palliative care programme inclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID1</td>
<td>Female</td>
<td>85</td>
<td>Widow</td>
<td>Catholic</td>
<td>Pancreatic carcinoma</td>
<td>13 months</td>
</tr>
<tr>
<td>ID2</td>
<td>Male</td>
<td>63</td>
<td>Married</td>
<td>Catholic</td>
<td>Malignant schwannoma</td>
<td>2 months</td>
</tr>
<tr>
<td>ID3</td>
<td>Male</td>
<td>46</td>
<td>Single</td>
<td>Catholic</td>
<td>Hepatocarcinoma</td>
<td>8 months</td>
</tr>
<tr>
<td>ID4</td>
<td>Male</td>
<td>83</td>
<td>Married</td>
<td>Catholic</td>
<td>Renal carcinoma</td>
<td>5 months</td>
</tr>
<tr>
<td>ID5</td>
<td>Female</td>
<td>71</td>
<td>Married</td>
<td>Protestant</td>
<td>Rectal carcinoma</td>
<td>14 months</td>
</tr>
<tr>
<td>ID6</td>
<td>Female</td>
<td>57</td>
<td>Married</td>
<td>Catholic</td>
<td>Colon carcinoma</td>
<td>9 months</td>
</tr>
<tr>
<td>ID7</td>
<td>Male</td>
<td>93</td>
<td>Widow</td>
<td>Catholic</td>
<td>Carcinoma of unknown origin</td>
<td>10 days</td>
</tr>
<tr>
<td>ID8</td>
<td>Male</td>
<td>62</td>
<td>Single</td>
<td>Catholic</td>
<td>Oropharynx carcinoma</td>
<td>9 days</td>
</tr>
</tbody>
</table>

Table 2. Principal characteristics of interviewees, time since assisted suicide of family member

<table>
<thead>
<tr>
<th>Case</th>
<th>Relatives relationship</th>
<th>Age</th>
<th>Year of AS</th>
<th>Time elapsed between the AS and the interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID1</td>
<td>Nephew</td>
<td>43</td>
<td>2006</td>
<td>4 years</td>
</tr>
<tr>
<td>ID2</td>
<td>Wife</td>
<td>69</td>
<td>2006</td>
<td>4 years</td>
</tr>
<tr>
<td>ID3</td>
<td>Sister</td>
<td>51</td>
<td>2008</td>
<td>1.5 years</td>
</tr>
<tr>
<td>ID4</td>
<td>Daughter</td>
<td>55</td>
<td>2009</td>
<td>2 years</td>
</tr>
<tr>
<td>ID5</td>
<td>Husband</td>
<td>71</td>
<td>2004</td>
<td>6 years</td>
</tr>
<tr>
<td>ID6</td>
<td>Husband</td>
<td>66</td>
<td>2008</td>
<td>1 year</td>
</tr>
<tr>
<td>ID7G</td>
<td>Nephew</td>
<td>46</td>
<td>2009</td>
<td>1.5 years</td>
</tr>
<tr>
<td>ID7P</td>
<td>Daughter</td>
<td>56</td>
<td>2009</td>
<td>1.5 years</td>
</tr>
<tr>
<td>ID7R</td>
<td>Daughter</td>
<td>59</td>
<td>2009</td>
<td>1.5 years</td>
</tr>
<tr>
<td>ID8L</td>
<td>Sister</td>
<td>66</td>
<td>2007</td>
<td>2 years</td>
</tr>
<tr>
<td>ID8A</td>
<td>Nephew</td>
<td>40</td>
<td>2007</td>
<td>2 years</td>
</tr>
</tbody>
</table>
In most cases, a clear legal and moral responsibility concerning the management of the assisted suicide request by the health care professionals was difficult to identify. In the case where the general practitioner led the procedure, palliative care services were provided for almost a year. It was possible, in this case, to trace a clear and open discussion between all participants with a specific therapeutic contract about explicit roles around assisted suicide. In the other five cases where palliative care services were involved for >2 months, and in close alliance with the oncologist, there appeared to be openness about discussing assisted suicide. In three cases, the patient or the relative found a way to get the documents needed for assisted suicide, without the involvement of their doctors. According to relatives, patients held some negative preconceptions about the use of morphine and other drugs which were believed to reduce consciousness leading to incapacity in decision making. The relatives also reported that most of the patients were uninterested in involving palliative care staff in discussions concerning assisted suicide or their distress. They primarily wanted their help in physical symptom control. In many cases relatives reported that patients were sceptical about palliative care interventions because were seen as not curative. Families reported that some patients did not recognize the professionals as possible partners in discussing their existential and moral concerns. Some patients had a few discussions about their decision to undertake assisted suicide with their leading physician. Others were reported to be little interested in discussing assisted suicide outside the family. At some point during the decision-making process, some relatives recalled an urgency to undertake assisted suicide before the physical condition of the patient deteriorated too much (rendering them unable to actively take the medication), or a natural death could occur.

**discussion**

**principal findings**

This study has revealed that the predominant reasons for assisted suicide in patients diagnosed with cancer were associated with fear of losing control, dependency and existential concerns. Moreover, the majority of the patients had previously contemplated assisted suicide for many years, and the diagnosis of cancer represented a strong trigger to decide to undertake assisted suicide. Actual physical suffering was not reported as a main reason for assisted suicide, except in one case.

Relatives reported that health care professionals were perceived to be uncomfortable in addressing existential and moral issues, and most of the patients were believed to be reluctant to discuss their personal beliefs concerning reasons for assisted suicide with them. Relatives perceived that some health care professionals had difficulty in dealing with their own personal beliefs sufficiently well, to enable an open discussion. This potentially may explain the barriers in communication.

**comparison with other research**

There is growing evidence that the decision to undertake assisted suicide could be the result of the interaction between personality traits, moral beliefs, biography and external factors such as the diagnosis of a life-limiting diseases or its terminal phase. The contemplation of assisted suicide can mature during a patient’s lifetime, dating in some studies for >15 years [11]. Some specific personality traits have been postulated to play a role in those requesting assisted suicide [12]. Worries about the future, concerns about loss of control, loss of dignity and loss of sense of meaning in life are common concerns of patients requesting assisted suicide in countries where this practice is legal and countries where it is not [13–15]. There is evidence that fears of future distressing symptoms, such as unbearable pain or dyspnoea, play a more important role than present physical symptoms in those pondering assisted suicide [15, 16]. The impending death and a life perceived as useless and hopelessness contribute substantially to motivate the final actions [17].

The interaction of all these factors can result in what has been defined as ‘unbearable suffering’ and lead the patient to...
decide in favour of a hastened death [17]. The factors leading from an abstract idea to a concrete decision are related to the personal perception of the threshold for tolerating suffering and the patient’s capacities to cope and adapt to the evolving situation in relation with the impending fears of losing control of their own lives [11].

The skills needed to communicate with patients presenting this type of complex and multidimensional suffering can be challenging. Clinician openness in discussing assisted suicide issues has been judged of extreme importance, using the request as an opportunity for exploring fears and doubts beyond physical symptoms [11]. In this type of communication, physicians can feel unprepared, can experience psychological discomfort and may have difficulties in understanding patients’ preferences. These conversations can also be very time and energy consuming, morally challenging and physicians rarely seek support from other colleagues [18].

Evidence shows that the more religious doctors are, the less likely to feel they should disclose information about procedures to which they objected on moral grounds [19]. Ticino is mainly a Roman Catholic canton and it is possible that the medical teams involved in the care of the patients were morally challenged by the assisted suicide request. This can partially explain the perception of some relatives concerning the difficulty and hesitancy in communication.

In this study, the physician’s participation in assisted suicide seemed to be predominantly related to the prescription of the lethal drug and the provision of the necessary documentation rather than in active involvement in the administration of medication, as in physician-assisted suicide. This is not surprising. There is no specific law on assisted suicide in Switzerland. The right-to-die association volunteers predominantly manage assisted suicide deaths. The physician involvement is judged by the Swiss Academy of Medical Sciences as a personal decision, even if criteria for evaluating and managing these cases are strongly advised [20].

All patients in our study, despite being enrolled in a palliative care service, chose assisted suicide. Similarly, 78% of patients deceased with assisted suicide in Oregon were enrolled in a hospice programme [21]. A recent report showed that the provision of palliative care in countries where assisted suicide and euthanasia are carried out is well developed [22]. We therefore argue that palliative care is a necessary part of care, but not sufficient to prevent assisted suicide in all cases, contrary to the arguments presented by lobby groups.

In Switzerland, there are some inequalities in the access to palliative care, mostly due to the bottom-up growth of palliative care in the last 20 years. Depending on the region, age or type of illness, there remains some inequality of access [23]. In 2010, the Swiss Ministry of Health launched a national strategy to assure equal provision to palliative care. Nevertheless, the cantons where assisted suicide is more common are the most industrialized and densely populated, where the provision of palliative care services is well established.

The complex suffering of these patients, well beyond physical symptoms, and the lack of guidelines for how to handle assisted suicide requests contribute to the difficulty, even in palliative care, in managing these cases. Data show that nearly 60% of the requests for assisted dying made within a palliative care setting can persist or fluctuate until death, demonstrating the stability of these preferences [15, 24].

strengths and limitations of the study

We evaluated a complex issue, which is emotionally and ethically challenging, using retrospective accounts of relatives who participated in the decision making of those who died from assisted suicide. The rich data provided by well-informed witnesses to these unusual deaths provided important insights into an under-researched topic. Our study had a number of limitations. All data concerning the patients’ wishes and behaviour derive from the families’ accounts and recollections. It is unknown whether, and to what extent, some patients could have hidden information from their families. Interviewees may have felt the urge to justify or excuse some of their own acts or their family members’ behaviour, thus producing narratives that reflect only parts of what really happened. Our sample is small because Ticino is a small canton with few assisted suicide per year. Accounts may not fully represent the diversity of relatives experiencing assisted suicide in Switzerland, especially those not in contact with palliative care services.

We were aware that the researchers’ personal beliefs about assisted suicide could influence data collection and data analysis and we used research team discussions to ensure balanced interpretation of the data. The strength of our qualitative method lies in its potential to generate deeper insights about the decision-making process and to explore the reasons lying behind the actions. Our method generated exceptionally rich data. Further research is needed to explore health care professionals’ experiences in dealing with these complex situations.

Figure 4. Possible strategy to manage an assisted suicide request in countries where legislation is absent.
implications for clinicians and policy-makers
While research has explored professional and public views on euthanasia and assisted suicide, very little has explored the reasons that precipitate patients’ actions. Moral values that condone assisted suicide and a strong fear of lack of control appear to be important. Existential distress appears to be a critical reason for the patients’ willingness to hasten death in both countries where assisted suicide is legal or practised and where it is illegal. Addressing spiritual and existential concerns should be a crucial step in assessing patients’ expressing wishes for hastened death. Care for existential suffering is an essential part of palliative care, requiring interdisciplinary input [25]. We suggest professionals undertake general screening to explore the factors identified here. Clinical guidelines are needed to help professionals dealing with assisted suicide requests (Figure 4).

In conclusion, assisted suicide in southern Switzerland is the result of the interaction of complex multiple factors. As far as we are aware, this is the first qualitative study undertaken in Switzerland. Assisted suicide was still preferred by these patients, despite provision of community palliative care. Whether palliative care can prevent all assisted suicide cases is highly debatable and it is a matter of future research [25, 26]. Better understanding of the importance placed on perceived control and anticipated dependency is needed. Further research is needed to support professionals in dealing with moral concerns and existential distress in patients and families. While offering excellent symptom control is a necessary aspect of good palliative care, it is not sufficient to prevent a few patients seeking to hasten their own deaths.

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disclosure
The authors have declared no conflicts of interest.

references
2. 114. Swiss penal code of 21st December 1937 (revised 1 February 2009) RS 311.0 art.1142009.
3. 115. Swiss penal code of 21st December 1937 (revised 1 February 2009) RS 311.0 art.1152009.