The experiences of families who support a patient who dies from assisted suicide in Switzerland

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

Claudia Gamondi, November 2021, Agno (Switzerland)

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ABSTRACT

Background

Permissive legislation about assisted dying is increasing internationally. While patients' and health care professionals' rights, duties, and needs are considered in guidelines, the experience of patients' families remains under-researched.

Aim

To investigate the experience of family members with patients, health care professionals and right to die associations when the patient is in the process of seeking assisted suicide.

Methods

(i) A systematic literature review was performed about families' experiences with a family member who died with assisted dying, in jurisdictions where it is it is legally permissible using thematic synthesis.

(ii) An empirical qualitative interview study to investigate Swiss families' reflections of their experiences when a family member is considering assisted suicide analysed deductively framework analysis. A secondary data analysis was performed using framework analysis to depict Swiss family members' reflections on their interactions with health care professionals and right to die associations during the time their family members were considering assisted suicide.

(iii) An empirical qualitative interview study with palliative care physicians to explore Swiss palliative care physicians' accounts of interactions with patients and their families when they are considering assisted suicide analysed inductively with thematic analysis.

Results

The *literature review* (19 articles) showed that families across all jurisdictions are involved in assisted suicide decision and enactment, where open communication is maintained, and that family needs in this context are under-researched.

The *interview studies* (28 relatives and 23 physicians) showed that Swiss family carers are often involved in the preparation of assisted suicide along with patients, irrespective of their personal values. Swiss palliative care physicians struggle to reconcile their ethical principles with the patients' wishes to exercise their autonomy, and deplore the lack of legal and professional guidelines. The *secondary analysis* revealed that, in Switzerland, there is limited interaction about assisted suicide between families and health care professionals, where families report more open interactions with right-to-die associations.

Conclusion

It is argued that this thesis extends existing understanding of the role of family carers during assisted dying by (i) highlighting their active supporting role in many instances of this practice, (ii) describing the multiple moral and social tensions that result from this support, and (iii) drawing attention to the unmet needs of family caregivers, as well as treating physicians, in the context of assisted suicide.

CHAPTER ONE

INTRODUCTION

1.1 Personal statement

I have for many years been interested in assisted dying as experienced by family members, both in clinical practice and in research. Having worked in palliative care for more than 20 years in Switzerland, both as a physician and as a member of the board of the Swiss Society of Palliative Care (*palliative ch*), I have seen how the growth of assisted dying has impacted upon my daily practice and that of my colleagues. As a practitioner, every time I meet a patient and their family asking for assisted dying, it tests my own willingness and capacity to accompany them during one of the most challenging decisions a human being can make. I have observed many heated debates in national and international meetings, expert panels, the media and international peer reviewed journals. I have noticed how most of the debates centre on the rightness or wrongness of assisted dying from an ethical and theoretical point of view and how views can be polarised, and the discussion focused on general principles, often dissociating the discussion from patients and family needs (Borasio, Jox, Taupitz, & Wiesing, 2021; Radbruch & Jaspers, 2021). I have come to observe that family members' needs can differ in nature to those ofthe patient but are often disregarded and not sufficiently considered in daily clinical practice or institutional recommendations. For these reasons, I wanted to conduct research to investigate family experiences of assisted dying to provide new evidence that may contribute to recommendations for practice based on my research findings.

Given my interest in the topic, in 2012 I undertook a master's dissertation at Bristol University, conducting a qualitative study exploring family members' experiences of assisted dying, with a small Italian-speaking sample (Gamondi, Pott, Forbes, & Payne, 2015; Gamondi, Pott, & Payne, 2013). While carrying out the study and writing the results, I developed a deeper understanding of the challenges of conducting research on assisted dying. At that time, there were very few jurisdictions where assisted dying was legally permitted and only a limited number of specialised and related research was available to use to expand my background knowledge and to help develop the research design.

Since I started this thesis in March 2013, there has been an important increase in the public awareness of assisted dying, with more and more countries now permitting assisted dying and with changes ongoing in various other countries. Whilst the published articles which form the central systematic review includes research data and literature up to December 2019, in the thesis I have drawn upon literature that was published until March 2021. Further developments may have occurred since then.

1.2 Why should research on family members in the context of assisted dying be conducted?

As *The Lancet* editors pointed out a few years ago, referring to biomedical research and its impact on economics and medicine, "*we should ask ourselves: what does this research mean, and what does it add?*" (Lancet (2013), p. 374). Some authors claim that 85% of research is wasteful or inefficient, and identified deficiencies in four main areas.

1. Is the research question relevant for clinicians or patients?
2. Are design and methods appropriate?
3. Is the full report accessible?
4. Is it unbiased and clinically meaningful? (Chalmers & Glasziou, 2009).

If we apply these questions to assisted suicide research of the last 20 years, we can derive several conclusions. Most of the literature concerning assisted dying has focussed on patients and professionals, with much of the data concerning professionals', patients' and the public's attitudes towards euthanasia and assisted dying in different countries. There is a plethora of data regarding assisted dying epidemiology, patients' reasons for choosing assisted dying, laws and practices. Much of the evidence has used quantitative methods very often starting from a positivist approach, gathering relevant data with surveys on professionals and patients and using large epidemiological studies exploring frequencies and practices across different countries. Another important part of the literature consists of editorials and opinion papers exploring ethical and legal points of view, the pro and cons of assisted dying implementation, and legalisation in different countries. Researchers have also focussed on the reasons motivating patients and a lot has been written about the concept of unbearable suffering, its components, the concept of autonomy and its limitations, safeguards, the concept of vulnerability and the precautions that should be considered and taken.

Behind a patient there is often at least one carer, a family member, a friend, or someone involved in their care, and it is unlikely that a decision about assisted dying will not impact them at some level. A Delphi study conducted in 2016 with experts and interested bodies, aimed to identify the principal areas of uncertainty and subsequent research priorities to inform the ongoing debate around assisted dying (Rodgers, Booth, Norman, & Sowden, 2016). In this Delphi study, experts, including patients and stakeholders, identified a list of ten priority research areas with the primary research question asking, what effect requests for assisted dying have on carer burden. It is questionable if such a research question is potentially impactful to families and professionals or is this question trying to answer a more political and controversial question regarding the rightfulness of assisted dying itself. When Chalmers advises us of the imperative of an unbiased and clinically meaningful research question (Chalmers & Glasziou, 2009), what are the priorities we should look at,what are the biases in assisted dying research that should be taken into account and what are meaningful gaps in the knowledge that should be addressed? How should this research be conducted?

Families' experiences in assisted dying are of crucial importance for many reasons while remaining an under researched area. Assisted dying can represent a complex experience and may be one of the most difficult decisions a family ever makes. This decision is the result of the complex interplay between personal and family values. Families are important in assisted dying because they can influence the patients' decision and influence assisted dying outcomes. Assisted dying conveys to the family an additional role to that of caregiver, and their bereavement experience may differ to one where an assisted dying decision was not made. Families, after having had an experience of assisted dying, may have memories of this death and may recall this experience as positive, challenging or difficult. To support the process of effective family decision-making, it is important to recognise and understand the roles that individual family members may play and how the family system reacts to the complexities and the challenges that assisted dying may create. In a family, every unit is both a whole and a part, and every part is influenced by the others and the wider family. For these reasons research should consider these relationships and functioning in the specific context of assisted dying.

Since assisted dying cannot be pursued completely outside the health care system, it is relevant to understand how families interact with health care professionals, how clinicians perceive family functioning and how these interactions potentially influence the patient's decision and the family's experience. It is arguable that the way in which clinicians engage with families and how clinicians understand the family's function during a crisis may influence the family's experience of the process. Through this research their experiences will be shared with others and may help forge a greater understanding of assisted dying in future years.

1.3 Format and structure of the thesis

This PhD thesis is presented in alternative format. It incorporates four original articles published in peer-reviewed journals. In addition to these scholarly papers two letters (Borasio, Jox, & Gamondi, 2019; Gamondi, Borasio, Limoni, Preston, & Payne, 2014) have also been published in *The Lancet* that support the thesis.

This first chapter includes a personal statement on why I chose to write a thesis on families' experiences when a family member is considering assisted suicide in Switzerland. It provides a justification for why research in the area of assisted dying and family experiences is needed. It concludes with an overview of the format of this thesis, providing a brief outline of each chapter.

In the second chapter the scene is set for this research with a literature review providing a global overview of assisted dying in countries where it is allowed, addressing the controversial issue of terminology and providing a special focus on Swiss practice. A reflection is provided, in chapter three, on how families can be defined in modern times, how they function and how they are structured. Since, in most cases, assisted dying happens in patients with a life threatening disease, this background chapter also offers an understanding of how families deal with life crises, face the life-threatening disease of their family member and how they adjust during this experience.

The fourth chapter begins with a statement of the research question and specific research aims. A comprehensive appraisal of the systematic review and qualitative methodologies used is detailed with a discussion of what methods were eventually chosen and how they were applied. Table 1 displays the research question and aims along with the methodology used and how the articles' addressed each research aim.

Chapters five to eight contain the original articles which have been published in peer reviewed journals and are included in this thesis in the form of journal articles, including abstracts and bibliography sections (according to the alternative format PhD thesis: Guidance Notes). The first paper consists of a systematic literature review using thematic synthesis to explore family members' experiences of assisted dying. The second paper describes a qualitative interview study which explored family caregivers' reflections on experiences of assisted suicide in Switzerland. The third paper details Swiss families' experiences of interactions with providers during assisted suicide using a secondary data analysis of the principal interview study. The final paper is an interview study about physicians' responses to assisted suicide requests.

Each of these four article chapters starts with an overview of how the article addresses the overarching main research question of this thesis and provides a summary of the methods used followed by a reflexive account for each article.

The discussion chapter includes a critical exploration on how the results address the research questions and is set in the context of the existing literature (reviewed in chapters two, three and four). The research strengths and limitations are then described in chapter ten, along with the implications of the findings for clinical practice and policy.

Table 1: Research question, aims and methodology.

Research question	**The experiences of families who support a patient who dies from assisted suicide in Switzerland**			
	Paper 1	**Paper 2**	**Paper 3**	**Paper 4**
Research article	Family members' experiences of assisted dying: a systematic literature review with thematic synthesis.	Family caregivers' reflections on experiences of assisted suicide in Switzerland: a qualitative interview study.	Swiss families' experiences of interactions with providers during assisted suicide: a secondary data analysis of an interview study.	Responses to assisted suicide requests: an interview study with Swiss palliative care physicians.
Published in peer reviewed journal	Palliative Medicine.	Journal of Pain and Symptom Management.	Journal of PalliativeMedicine.	BMJ Supportive and Palliative Care.
Topic.	Methodological.	In depth interview study.	Secondary data analysis.	In depth interview study.
Perspective	Scientific methods and reporting.	Families' accounts.	Families' accounts.	Palliative care physicians' accounts.
Design	Systematic literature review.	Cross sectional interview study.	Secondary data analysis of primary qualitative data.	Cross sectional interview study.
Aim of article	To explore what are family members' experiences with patients who died with assisted dyingin jurisdictions where it is legally permissible.	To investigate how Swiss family members are involved in the decision for assisted suicide.	To understand how families in Switzerland interact with physicians and right to die associations about assisted suicide and what are their choices around disclosure.	To depict Swiss palliative care physicians' perspectives and involvement in assisted suicide practices and what are their experiences interacting with families.

CHAPTER TWO

SETTING THE SCENE: GLOBAL PERSPECTIVES ON ASSISTED DYING

In this chapter, the context in which Swiss family members' experiences of assisted suicide is introduced. A global overview of assisted dying is provided, outlining the terminological challenges, describing which countries permit assisted dying and detailing the principal features of the different models of assisted dying implemented across jurisdictions. Following this, the specificities of the Swiss context of assisted suicide are described. The characteristics of families' experiences of caring for a person with advanced disease are then discussed.

2.1 Global definitions and status of assisted dying

There are different terminologies used to describe assisted dying practices which are detailed in the next section. For the purpose of this thesis, when referring to the international situation, the term assisted dying is used and when referring to the Swiss situation the term used is assisted suicide. The decision to use the word *suicide* for the Swiss practices is because it is a term that is currently used in Switzerland, by health care practitioners, professionals, institutions and the public. It is also mentioned in the law.

2.1.1 Global overview of definitions and terminology

The terminology concerning assisted dying is confused and contested both in professional, academic and public contexts. Many terms have been used in different countries and at various times to define the practice of helping someone to hasten their death. Terminology is diverse in the media, medical and legal fields. When assisted dying is discussed in social media and in public, viewpoints are often extreme and radical. It is reported that in the US, there is higher public support for euthanasia than assisted suicide and in most Western European countries, support for euthanasia and assisted suicide has increased over recent years but remained stable in Central and Eastern European countries (Emanuel, Onwuteaka-Philipsen, Urwin, & Cohen, 2016). On the other hand, within the media terminology is often confused and terms are misused. For example, in nearly a quarter of the Dutch newspaper articles the term euthanasia was used to refer to practices that were outside the scope of the Dutch euthanasia law (Rietjens et al., 2013). This confusion in the terminology can have important consequences, for example evidence shows that a lack of clarity over the various terms may influence opinion polls on assisted dying (Jaye, Lomax-Sawyers, Young, & Egan, 2019).

In medical, legal and academic use, many terminologies have been used and many of them are still contested and ignite heated debates. The different terms used to name assisted dying practices include assisted suicide, physician-assisted suicide, medical aid in dying, assisted dying, physician assisted dying, voluntary euthanasia, direct euthanasia and death with dignity (Diehl-Schmid et al., 2017; Emanuel et al., 2016). In table 2 an overview of the different terms and definitions used in the medical literature across countries is provided. It is worth noting that the European Association of Palliative Care (EAPC) could not reach full consensus upon definitions in its White Paper (Radbruch et al., 2016). The main controversial point revolved around the term killing, mainly objected to by Low Countries' professionals.

Table 2: Terms used to define assisted dying across countries

Term	Country	Definition
Euthanasia	Belgium Luxembourg The Netherlands Colombia Italy Spain Portugal	A physician or nurse practitioner (or other person) intentionally killing a person by the administration of drugs, at that person's voluntary and competent request (Radbruch et al., 2016)
Assisted Suicide	Switzerland Spain Portugal	A person intentionally helping another person to terminate his or her life, at that person's voluntary and competent request (Radbruch et al., 2016).
Physician Assisted Suicide (PAS)	Luxembourg The Netherlands Belgium Germany	A physician intentionally helping a person to terminate his or her life by providing drugs for self-administration, at that person's voluntary and competent request. (Radbruch et al., 2016).
Medical Aid in Dying (MAiD) Medical Assistance in Dying	Canada	Term used to describe both the direct administration of a lethal medication by a physician or nurse practitioner, and a prescribed substance that a mentally capable individual self-administers (Tucker & Steele, 2007).
Aid in Dying (AiD) Medical Aid in Dying for the Terminally Ill Assisted Dying (AD) Death with Dignity (DWD) Physician-Assisted Dying (PAD)	Some US territories	Term used to describe both the direct administration of a lethal medication by a physician or nurse practitioner, and a prescribed substance that a mentally capable individual self-administers (Tucker & Steele, 2007).
Voluntary Assisted Dying (VAD)	Victoria, Australia	The person must administer the medication themselves, unless they are physically unable to do so, in which case their doctor may assist (Victoria, 2017).
End of Life Choice Act	New Zealand	Term used to describe both the direct administration of a lethal medication by a physician or nurse practitioner, and a prescribed substance that a mentally capable individual self-administers (Tucker & Steele, 2007).

2.1.2 Medical versus legal terminology

A crucial point in assisted dying medical terminology is related to the intention to provide precise terms that describe how the medication is administered and whether to use the term suicide. In euthanasia, the medication is administered by a physician, or as in Canada, a nurse practitioner. In assisted suicide, the person should ingest the medication by their own means, but they can receive some assistance (Radbruch et al., 2016).

In some of these definitions, the word physician is used, with the intent to clarify the physician's professional role in assisting with the patient-centred decision. The role of the physician and other professionals in self-administration differs across countries and legislation. For example, physicians in Switzerland and in the United States are not required to be present when the patient ingests the medication; consequently, in very few self-administrations are Oregonian physicians present (Bosshard et al., 2008). More recently, assisted deaths in Canada can be assisted by nurse practitioners, whilst in other countries where euthanasia is practiced, it remains within the physicians' responsibility (Pesut, Thorne, Schiller, Greig, & Roussel, 2020). Figure 1 provides a visual description of what type of assistance the health professionals can provide when assisting their patient.

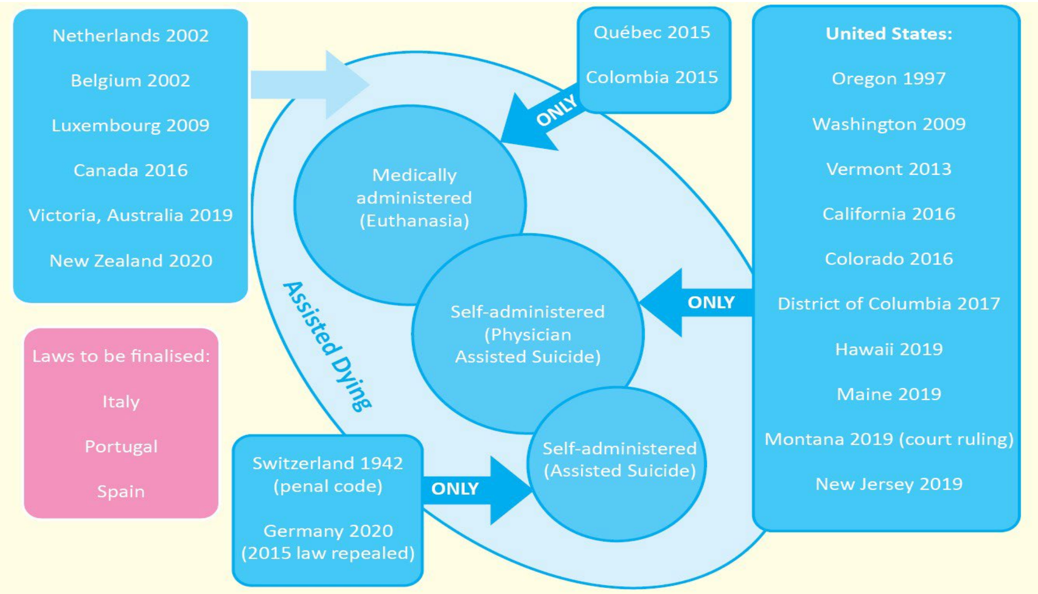

Figure 1: Types of assistance allowed from health professionals during assisted dying across countries.

Since 2006, in Oregon the term, physician assisted suicide, was used to define self-administration practices authorised by law. From 2006, Oregon State decided to describe the conduct under the Dignity Act, with the term 'Death with Dignity', taking the name explicitly from the law itself. While the Dutch law that passed in 2001 is called 'Termination of Life on Request and Assisted Suicide', the Canadian law regulating assisted dying was named 'medical aid in dying' (MAiD). The California law enacted in 2016 was called the 'End of Life Option Act'. The most recent states that regulated assisted dying were Victoria in Australia in 2017 and New Jersey in April 2019. The law in Australia was named the 'Voluntary Assisted Dying Act' and in New Jersey 'Medical Aidin Dying for the Terminally Ill Act'.

In September 2019, Italy's constitutional court ruled that euthanasia should be permitted by law under certain circumstances, including those in which a patient's irreversible condition was causing physical and psychological suffering that he or she considers as intolerable (Costituzionale, 2019) . The law is still under discussion and is not yet finally enacted. In 2020 Portugal's parliament voted in favour of allowing euthanasia and physician-assisted suicide for terminally ill people, the constitutional court blocked this law in March, 2021 and an amended proposal was passed in November 2021. The lower house of Spain's parliament approved a similar bill that will allow people to lawfully end their lives if they suffer from serious or incurable diseases. At the time of writing, the bill is awaiting Senate approval. Similarly, in early 2020, Germany overturned a five-year-old ban on medically assisted suicide. The country's top court ruled that the ban was incompatible with the constitution, making assisted suicide once more possible in Germany, as it previously was. The verdict has opened a door to legislation that would allow doctors to counsel patients about this option and provide them with lethal drugs, that the patient self-administers. In Switzerland, there is no national law, but two Cantons in 2012 enacted a law regulating assisted suicide practices. In contrast with other countries, in the Swiss case, the law refers specifically to the term assisted suicide.

Table 3: Terminology of the laws regulating assisted dying

Country	Name of the law
The Netherlands	Termination of Life on Request and Assisted Suicide
Belgium	The Belgian Act on Euthanasia of May 28th, 2002
Luxemburg	Law on the Right to Die with Dignity.
Switzerland	La santé publique sur l'assistance au suicide en établissement sanitaire reconnu d'intérêt public
Canada	Medical Assistance in Dying (MAiD)
Oregon	Death with Dignity Act (DWDA)
Washington	Death with Dignity Act
Vermont	Patient Choice and Control at End-of-Life Act
California	End of Life Option Act
New Jersey	Medical Aid in Dying for the Terminally Ill Act
Montana	Rights of the Terminally Ill Act
Hawaii	Our Care, Our Choice Act
District of Columbia	Death with Dignity Act
Colorado	End-of-Life Options Act
Victoria (AU)	Voluntary Assisted Dying Act
New Zealand	End of Life Choice Act
Portugal, Spain, Italy	Law expected to be finalised in 2021

2.1.3 Shifts in terminology due to stigma, society and the concept of death

Recently it appears that medical language is shifting to more neutral terms, abandoning the use of the term suicide in favour of a different terminology such as assisted dying or medical aid in dying (Tucker & Steele, 2007). There are many reasons why the term suicide appears to be abandoned. One of the reasons may be related to the decision to distinguish a dying patient hastening their impending death from the historical mental health perspective of suicide (Leeman, 2009; Tucker & Steele, 2007). Many authors distinguish classical suicide from assisted dying, based upon important differences between these two acts (Dallner & Manning, 2004; Lieberman, 2006; McKhann, 2000; Spoerri, Zwahlen, Bopp, Gutzwiller, & Egger, 2010; Tucker & Steele, 2007). In assisted dying the patient often has a terminal illness. The family is frequently informed of the choice and in some cases is supportive of it and the death is carefully planned and organised. Differences between suicide and assisted dying can also be distinguished in terms of the framing within the social milieu. Using the example of deaths occurring among patients with chronic kidney disease Bostwich and Cohen (2009) distinguish between what authors define as true suicide from behaviours that include patient's self-harm without a clear intention to end their life. The authors suggest that a death that takes place with the collaboration and support of others can be considered in the frame of assisted dying, whilst one that takes place in isolation and without social support can be considered in the frame of suicide (Bostwich & Cohen, 2009). An important distinguishing feature is also related to the differences in the social acceptability of assisted dying and classical suicide. Whereas the social acceptability of classical suicide appears to be more related to religious background (Stack & Kposowa, 2011), the growing social acceptability of assisted dying that is observed in US and European countries appears to be related to different factors, such as underlying terminal illness and related suffering, ethical acceptability and legalisation (Emanuel et al., 2016). Other reasons for the shift in terminology refer to the idea that assisted dying is believed to be related to a form of autonomy and empowerment of the patient, whereas classical suicide is considered to be an expression of despair, futility and compulsive behaviour (Leeman, 2009).

An important reason for minimising the use of the term suicide in assisted dying can also be linked to the stigma and guilt that the word carries in society. Stigma and guilt are almost inevitable legacies of classical suicide (Hanschmidt, Lehnig, Riedel-Heller, & Kersting, 2016). Stigma is a term commonly linked to psychiatric or neurological illnesses but is also well-described in relation to people who have experienced bereavement, particularly after suicide and other unnatural losses (Hanschmidt et al., 2016; Pitman, Osborn, King, & Erlangsen, 2014; Pitman, Osborn, Rantell, & King, 2016; Pitman, Stevenson, Osborn, & King, 2018). Stigma includes different features, such as public or personal stigma, perceived stigma, and self-stigma. Stigma can be manifested with stereotyping of the bereaved, distrust, negative predispositions, fears, and social embarrassment. Avoidance of social interactions is also a common characteristic of stigma. Surveys have demonstrated higher stigma and shame scores in people bereaved by suicide when compared with people grieving a death by natural causes (Pitman et al., 2016). Beder anticipated the mourning experiences following an assisted death using theories of bereavement (Beder, 1998). She highlighted the possibility that feelings such as anger and guilt, or ambivalent feelings towards the deceased, could be part of the experience. Although this hypothesis has not been tested in clinical studies on bereavement after assisted dying, some data suggests that assisted dying can be characterised by feelings of shame and isolation (Buchbinder, Ojo, Knio, & Brassfield, 2018; Gamondi et al., 2015; Gamondi et al., 2013; Gamondi, Pott, Preston, & Payne, 2018; Starks et al., 2007; Starks, Pearlman, Hsu, et al., 2005; Wagner, Boucsein, & Maercker, 2011; Wagner, Keller, Knaevelsrud, & Maercker, 2012; Wagner, Müller, & Maercker, 2012). It is possible that family perceptions of stigma may relate to the use of the word suicide to name the practices of assisted dying in some countries. Jurisdictions using the word suicide in assisted dying context should take into consideration the possible consequences of using this emotive term.

A further reason why the term suicide is disappearing may be related to the concept of natural death. In common language and medical terminology, suicide is often labelled as an unnatural death; assisted suicide is also often similarly labelled within the medical literature (Bradbury, 2016; Pitman et al., 2016; Pitman et al., 2018). Although these two types of dying have different features they can both eventually carry similar characteristics of the so called unnatural deaths (Lewis & Preston, 2019). For example, Seymour (1999) and Howarth (2007) theorised that natural death can be in opposition to an unnatural or medical death. Some authors criticise the so called medical death; suggesting the use of the term medicalised becomes a way of indicating a bad death, whereas by applying the label natural, death can be considered as good (Raus, Sterckx, & Mortier, 2012). In general, assisted dying is perceived as a medicalised death.

Nevertheless, assisted dying is also seen as the ultimate expression of patient autonomy and of their capacity to decide what they consider to be in their best interest. In this version, assisted dying terminology can have an implicit value in a good death, but sometimes it can be perceived as a medicalised, bad and stigmatised death. For these reasons, persons may feel less comfortable discussing assisted death compared with death by natural causes (Holmes et al., 2018). This uneasiness can also be related to the use of the term suicide with the terminology describing some forms of assisted deaths.

2.1.4 A geographical overview of legally assisted dying

In this section the different types of assisted dying legislation implemented worldwide are described. The number of US jurisdictions that have legalised assisted dying is increasing and one in five Americans now live in locations where assisted dying is an available option. Since 2016, all Canadian citizens have access to assisted dying. Of the 743 million EU citizens, only Dutch, Belgian, and Luxemburg citizens have access to assisted dying, representing three out of the 27 countries that are part of the EU. In 2017, more than 13,000 patients had an assisted death in countries where these practices are permitted, with important differences between euthanasia and self-administration (Borasio et al., 2019). Euthanasia is quickly approaching 5% of all deaths in the Netherlands, which is a higher proportion than in Belgium. In 2017, euthanasia already represented almost 1% of all deaths in Canada, whereas self-administration in Californians represented only 0.14% of deaths.

Belgium, Luxembourg, the Netherlands, and Canada allow both euthanasia and self-administration, while all other jurisdictions allow self- administration only. Figure 2 below depicts euthanasia and self-administration rates over the last 10 years (Borasio et al., 2019). As is visible from figure 2, the pattern of assisted dying shows a different trend over the years. It may be that assisted suicide, legalised with stringent procedural rules such as in Oregon, could limit the number of assisted deaths and keep the rates more constant over time. The rate at which euthanasia is changing in countries where it has been legalised could lead to the hypothesis that being helped to die at the final stage of a disease may pose less of an impediment than actively ingesting a lethal dose when still able and capable (Borasio et al., 2019). For a comprehensive list of countries where assisted dying is legal and a description of epidemiology, please see Appendix 1.

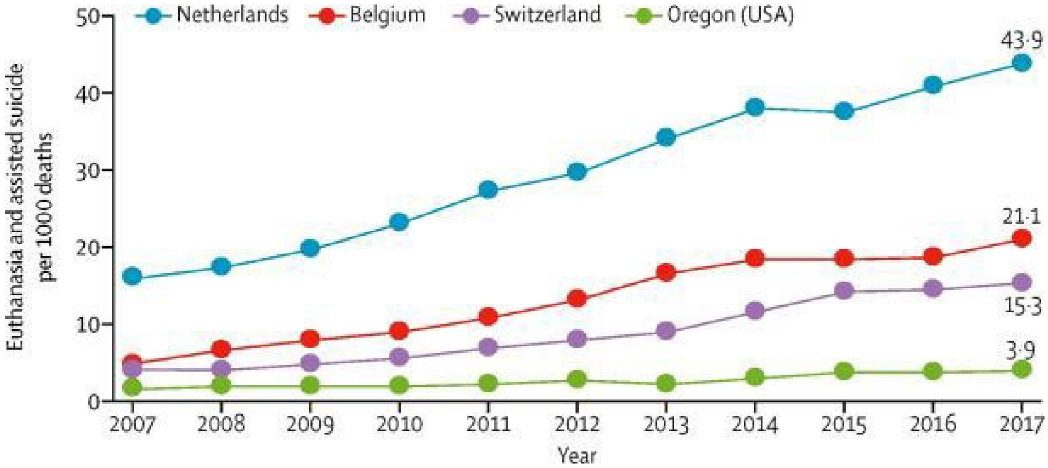

Figure 2: Euthanasia and assisted suicide rates over the last ten years across four countries (modified from Borasio, Jox, Gamondi, 2019)

The criteria for accessing assisted dying varies depending on different country legislations (Emanuel et al., 2016). In general, individuals requesting assisted dying must be older than 18 years of age and capable of making and communicating their decisions to the physicians involved. No jurisdiction requires a psychiatric evaluation, although patients may be referred for a psychiatric evaluation if there are concerns about their mental health or decision-making capacity. In most countries, criteria referring to the underlying illness mention that the patient's medical situation is without prospect of improvement, and that the individual's suffering is unbearable. Belgium specifically allows assisted dying in patients affected by unbearable physical or mental suffering; recipients do not need to have a terminal illness, but their illness must be incurable. In these cases of non-terminally ill patients, Belgium requires a one month waiting period from approval of the request to the provision of assisted dying. In US jurisdictions, on the contrary, the law requires specifically that the patient should have a maximum 6-month prognosis. Most of the US states permitting assisted dying require a 15-day period between two verbal requests being made to the attending physician. In most states the physician must wait 48 hours from the time of receiving the written request to write the prescription. Canadian law requires a 10-day waiting period between a written request and provision of assisted dying, whereas the Low Countries do not have mandatory waiting periods.

In the majority of countries, patients must be residents in the same state where they are applying for assisted dying, only Belgium and Switzerland allow non-permanent residents to access assisted dying and Belgium allows minors also.

2.2 Switzerland and assisted suicide

Switzerland is a small, peaceful, wealthy, and stable country, situated in the heart of Europe, with a per capita Gross Domestic Product among the highest in the world. Switzerland is second only to Japan for the average longest life expectancy; according to the World Health Organization, where in 2015 life expectancy was 81.3 years for Swiss men and 85.3 years for Swiss women. Its main cities have been ranked among the top ten cities in the world in terms of quality of life.

2.2.1 Government and laws

Switzerland is formally a confederation of 26 cantons but similar in structure to a federal republic. The Swiss Confederation was founded in 1291 as a defensive alliance between three cantons. In 1848, a constitution replaced the confederation with a centralised federal government. Over the past half century, the political and economic integration of Switzerland within Europe has developed. Switzerland is now highly active in many international organisations but retains a strong commitment to armed neutrality.

Following the principle of subsidiarity, the 26 cantons and 2800 municipalities have a high level of autonomy. Subsidiarity implies that Cantons have a robust local and regional arrangement, with a spread in responsibilities in conjunction with the corresponding authority. As a result, there is a principle of non-interference by the higher authority in the workings of the lower authority and a principle of the duty to help – that is help that encourages individual and cantonal autonomy.

Cantons and cities have their own political, health and economic systems, whereas the Swiss law is based on the solidarity of the Cantons. Four main linguistic and cultural regions characterise Switzerland: German, French, Italian and Romansh. Although most of the population is German speaking, a national identity encompassing languages and cultures is shared. Fundamental principles of Swiss society lie in federalism, neutrality and direct democracy. An important characteristic of the Swiss identity is that all citizens should take part in decision-making, made explicit through direct democracy coupled with a strong tradition of attention to diversity.

2.2.2 Demographics and health care characteristics

In 2018, Switzerland's population slightly exceeded 8.5 million, with a consistent annual growth projected up to 2035. Switzerland has an ageing population, almost one-fifth of the population is already 65 years old or more and expected to reach 30% by 2060. This is mostly due to a decrease in the rate of immigration and a fertility rate close to the replacement level (OECD, 2019). Switzerland is a country with a considerable number of first- and second-generation immigrants. It holds one of the largest proportions of foreigner residents in the developed world, of about 23% of the total population. Around 20% of the permanent resident population, have animmigrant background, with about a third of this population holding Swiss citizenship. Approximately 39% of children in Switzerland were members of families of foreign origin with at least one foreign-born parent.

While Switzerland has no official state religion; Christianity is the predominant religion of Switzerland (75% of Swiss citizens) divided between the Roman Catholic Church and the Swiss Reformed Church. Further Protestant churches, Eastern Orthodox and other Christian denominations are also present. Islam is present in a sizeable minority of citizens, mostly in immigrants' groups.

The Swiss health care system is one of the most expensive in the world. It is based on the principle of promoting public health and reducing public costs while encouraging individual responsibility. Swiss healthcare is universal and is regulated by the Swiss

Federal Law on Health Insurances. There is no federal insurance. A basic private health insurance is compulsory for all persons residing in Switzerland and the insurance premium should not exceed 8% of annual personal income. Health insurance covers the costs of medical treatment and hospitalisation, and the insured person is asked to pay part of the cost generated by treatments (in general 10% of the total amount). The compulsory insurance can be supplemented by complementary insurance that allows for coverage of some of the treatment categories not covered by the basic insurance, such as complementary medicine, dental care and preventive medicine.

In Switzerland, every year, about 70,000 people die and most deaths are in people aged over 80 years (Bopp et al., 2009). Multimorbidity related to ageing, with all its complexities, is becoming a common feature in the Swiss aging population. Diseases of the circulatory system (ischemic heart disease, cerebrovascular diseases, etc.) are the most common single cause of death followed by cancer (Chammartin, Probst-Hensch, Utzinger, & Vounatsou, 2016). Epidemiological data show that only 9.9% of deaths have one diagnosis (Chammartin et al., 2016). In 38% of cases, four diagnoses are registered as a cause of death and the number of diagnoses increases with age, with the greatest number of diagnoses registered for 80 to 94-year-olds (Bopp et al., 2009).

2.2.3 Suicide and assisted suicide in Switzerland

Suicide in Switzerland represents an important cause of death (Canu, Bovio, Mediouni, Bochud, & Wild, 2019). It is one of the European countries with the highest suicide rates, coming after only the eastern European countries and France. For example, in 2014, 1029 people died of suicide in Switzerland, with a rate that has stabilised since 2010 (Canu et al., 2019).

Switzerland had a standardised suicide rate of 10.7 per 100,000 deaths. In 53% of cases, causes of suicide death registrations did not contain any information about concomitant diseases and 56% of entries cited depression as a cause. In the remaining 44% of entries, a physical disease was mentioned (Steck, Junker, & Zwahlen, 2018). Physical diseases mentioned in suicide reports were similar to those reported in assisted suicide cases.

Switzerland is the only country in the world where assisted suicide is performed without specific legislation, within the law, mostly without medical participation (Hamarat, 2021). It is important to understand the roots of this unique model of assisted dying. Assisted suicide practices, as they are today, are fundamentally based on two articles of the penal code: article 114 and 115 (Feuille fédérale, 1918). Article 115 of the Swiss penal code prohibits assisted suicide for self-serving reasons and article 114 allows the causing the death of a person for commendable motives, and in particular in compassion for the victim.

These articles date back to 1918. In 1918, while finalising the first federal penal code, the Swiss federal government wrote:

> *In modern penal law, suicide is not a crime ... Aiding and abetting suicide can themselves be inspired by altruistic motives. This is why the project incriminates them only if the author has been moved by selfish reasons.*
>
> *Feuille fédérale (1918) IV/I (36).*

The federal government recognised the attitudes of the Swiss public toward suicide; that they were shaped by honour and romance, and that these motivations were considered valid motives to end one's own life and allow someone to help. Legislators continue to view suicide as a possibly rational choice. Since Article 115 does not explicitly regulate assisted suicide for unselfish reasons, the Swiss Criminal Code does not require that a physician be the person to assist a suicide, nor does it require the involvement of any physician whatsoever, which is a significant departure from legislation in other countries where assisted suicide is permitted. This said, physicians are not given any special status in assisting it, and so physicians assist outside their medical role. At the federal level, the parliament (2008-2012) refused to legislate on more specific eligibility criteria or to further regulate the activities of assisted suicide associations. In conclusion, assisted suicide can be considered as legal and the word suicide has remained in common language, legal language, and medical terminology to describe assisted dying in Switzerland.

A federal law regulating assisted suicide is absent. Several attempts have been made in the last 25 years to submit a proposal for a law and none of them were successful. Out of the 26 cantons, only Neuchâtel and Vaud have a cantonal law regulating assisted suicide (see Appendix 2 for the criteria for assisted suicide in public health care facilities in Vaud and Neuchâtel Cantons). The law in Canton Vaud was enacted after Exit ADMD proposed a referendum asking for general legalisation on assisted suicides. Whereas 95% of assisted suicides happen in the patients' home, the two cantonal laws regulate assisted suicide requests and assisted deaths in public institutions. While assisted suicide is less commonly allowed in nursing care homes of Catholic cantons, increasing numbers of nursing care homes across the country permit assisted suicide (Castelli Dransart, Voelin, & Scozzari, 2015). In 2014, 60 out of 583 assisted suicides declared by Exit took place in nursing care homes. Assisted suicide is also allowed in some university hospitals such as Lausanne (Vaud Canton) and Geneva, exclusively if the patient cannot be discharged.

Unlike other countries, from a legal point of view, being affected by a terminal, degenerative or severely disabling disease is not a *sine qua non* criteria for eligibility for assisted suicide. The law enacted in Canton Vaud requires that the patient "*… presents with an illness, or consequences of an accident, which are severe and incurable*" (Directives (Janvier 2013- Janvier 2018), p.2. The recently produced guidelines of the Swiss Academy of Medical Sciences for assisted suicide cases states that "… the symptoms of disease and/or functional impairments are a source of intolerable suffering for the patient", confirming that the focus in the criteria is the intolerable suffering and not the illness itself (SAMW (2018) p. 23).

The incidence of assisted suicide in Switzerland is different from other European countries where this practice, together with euthanasia, is legalised (Emanuel et al., 2016). In 2009, the Swiss Federal Office for Statistics published the first epidemiological data concerning assisted suicide over the last ten years (Statistik, 2009). The first reports indicate that from 1998 on assisted suicide has become available to Swiss citizens and foreign citizens travelling to Switzerland (Statistik, 2009). While there are no data for the period prior to 1998, in 2009 the number of deaths was nearly 300, which corresponds to

4.8 per 1000 deaths. The last report published by the Swiss Federal Office of Statistics, showed that in 2018, 1176 cases of assisted suicide were registered, confirming the data from the right to die associations that show a constant rise in cases over the last 10 years (Federal Statistics Office, 2018). The most represented cantons are those with a significant population growth, mostly industrialised and where large urban centres are present. The high prevalence of assisted suicide in the Zurich canton could relate to the right-to-die association, Dignitas, operating in this canton with foreign citizens.

The procedure to obtain assisted suicide is characterised by two crucial points. Patients should obtain a medical documentation and approval from a right to die association. Patients are required to provide their right to die association with a medical certificate stating their illness, their incurable situation, and their mental capacity. In addition, patients should get a prescription for the lethal drug. Any physician working in Switzerland can provide these certificates and prescription, and a refusal from one physician does not preclude others from prescribing. In some cases, patients refer to their general practitioner or consultant. In other cases, the right-to-die association have their own physicians that assess the case and provide the necessary documentation. If patients struggle to obtain a prescription for the lethal medication, many associations provide a list of physicians who do not morally object to assisted dying and are available to evaluate the patient and provide the prescription. When the patients are in possession of their documentation, the right-to-die association can help them with the next steps towards assisted suicide.

2.2.4 Right-to-die associations

The main associations active in Switzerland are Exit, Dignitas, Ex International, Exit ADMD, and Lifecircle in conjunction with The Eternal SPIRIT Foundation. In May 1998, interpreting the law and the context, Ludwig Minelli, a Swiss lawyer specialising in human rights law, founded Dignitas, the first right-to-die association in Switzerland. Right-to-die associations are operating in all Swiss cantons and Exit, Exit ADMD and Dignitas are the largest ones. Exit and Exit ADMD only help Swiss citizens or long-term residents, while Dignitas provides assisted suicide services to foreigners. For these organisations, people wishing to use their services must be members and should have regularly paid their membership. A median membership fee is about £80 per year. Dignitas states on their website there is no waiting period between becoming a member and applying for assisted suicide. Assisted suicide is not included in any insurance plan and the costs are paid by patients. Depending on the association, the costs for an assisted suicide can range from a few hundred pounds for Exit ADMD to about £8,000 for Dignitas.

When a patient is a member of one of these associations and in possession of their certificates and prescription, they can get help to proceed with assisted suicide. The association appoints a volunteer (usually a lay person) that meets with the patient, discusses motivation and alternatives and decides whether to help the patient with their suicide. In other words, this dyad is composed of two lay persons, one asking to be helped in suicide and the other willing to provide help without selfish motivation. This constitutes the core of the civil model of assisted suicide in Switzerland. It is not a professional person in their professional capacity that usually assists in suicide, but it is a private citizen that decides whether to help the other person. Of course, the patient should provide due documentation to the right-to-die association, but the essence of the decision to help remains between two lay persons.

The manner through which a patient dies is either by self-administration or intravenous self- administration (patients need to open the infusion without external help although the infusion can be prepared by others) of sodium pentobarbital, a sedative that in lethal doses causes a cardiac arrest. In most cases, when an intravenous administration is chosen, usually a nurse prepares the intravenous infusion, but it is the patient who opens the valve of the infusion. Dignitas customarily records a video showing the patient stating their name, date of birth and that they are sound of mind. The camera records when the patient opens the valve or ingests the lethal medication and then dies within a few minutes after self-administration. These videos are used to provide evidence to the police of the patient's autonomous decision to commit suicide. Since assisted suicide is considered a violent death, each assisted suicide must be announced to the local law enforcement. They are usually called by the attenders and come to where the assisted suicide took place. Police typically open an inquiry and prosecutors may take action if they find evidence that a crime has been committed. In general, the right-to-die association volunteer is interviewed by the police together with the people attending the assisted suicide. Most cases are closed within a few days after the death.

How right-to-die associations relate with families has never been specifically researched but some information can be found both in the public press and academic literature (Gamondi et al., 2015; Gamondi et al., 2013; Zala, 2005). Some associations require that the family should be informed and in agreement, others do not. In the Italian speaking part of Switzerland, Exit is the right-to-die association most active in the region. Exit in these cases asks the patient to inform the family and often the family is present when the right-to-die association volunteer meets the patients and explains the procedure. In other cantons, the contact between right-to-die associations and families can be different and sometimes conflictual (a real-life example of family conflict is presented in Appendix 3). It is known that when some Swiss patients are refused help from their family, they can threaten to commit a classical suicide (Gamondi et al., 2013). Likewise, some Dutch patients may continue to hold a wish to die and to desire assisted dying after the request is refused, although they may stop talking about it (Pasman, Willems, & Onwuteaka-Philipsen, 2013).

2.2.5 Health professional associations and assisted suicide

While there is public support for assisted suicide in Switzerland, some professional associations have issued guidelines and statements to their members mainly limiting their activities in assisted suicide practices. Exit, in 2018, reported having 110,391 members in German and Italian-speaking cantons of Switzerland, and 26,205 members in French-speaking ones. It should be noted that one of the most popular political partycounts about 100,000 in all Switzerland. These numbers show that a growing number of people are supportive of assisted suicide and choose to support these associations. The choice to become a member of these associations could be related to the wish to have future access to assisted suicide for themselves and for the desire to provide social and political support to these associations. A survey, conducted by Exit ADMD and published on their website, showed that among a thousand Swiss citizens 82% of participants agreed that *"a person suffering from an incurable disease and who is in intolerable physical and psychological suffering has the right to ask for death and to obtain help for this purpose."* (Hurst and Mauron (2003) p. 272). Of these, 68% considered that physicians should provide this help; 37% considered that the family, and 22% that right-to-die associations, should be able to fulfil such requests. The possibility to have specificlegislation allowing and regulating euthanasia was favoured by 71% of respondents.

Professional associations like the Swiss Academy of Medical Sciences (SAMW), the Swiss Nurses Association (ASI) and others have either newly published or revised their guidelines concerning professionals' participation in assisted suicide practices. The new revised guidelines published in 2018 by the SAMW brought some innovated changes compared to the previous version. They state that:

> *… physicians' responsibilities do not include offering assisted suicide, nor are they obliged to perform it. Assisted suicide is not a medical action to which patients could claim to be entitled; it is, however, a legally permissible activity. It can be performed by physicians if they are convinced that the requirements given below are met.*
>
> SAMW (2018) p.22

These new directives sparked an intense discussion at the Medical Chamber – which was seen by the parliament of the national medical federation, comprised of 200 delegates, finally deciding by a majority not to accept the new guidelines. The main point of controversy was the possibility that physicians could perform assisted suicide. In 2002 a more restrictive vision, situating assisted suicide outside the medical responsibility was shared also with the Swiss Nurses Association and a joint statement was prepared (Castelli Dransart et al., 2015; Hurst & Mauron, 2003). The old statement could have been interpreted in the sense that assisted suicide should be outside the field of professional oversight, and that physicians could only act as citizens. It should be noted that the Swiss Nursing Association position, dating back to 2005, has not yet been actualised and states that assisting a person to commit suicide is not part of the mission of nursing care. At the same time, it stresses the importance of the principle of non-abandonment in these situations.

In relation to Swiss physicians' attitudes, a national survey confirmed that most are willing to evaluate the patients, but only a small minority would consider performing assisted suicide as a medical responsibility (Brauer, Bolliger, & Strub, 2015). A 2002 survey of interdisciplinary members of *palliative ch* (Swiss society of palliative care) found that all palliative care professionals demonstrated wide variation in their positions concerning assisted dying (Bittel, Neuenschwander, & Stiefel, 2002). Whereas 69% of participants were opposed to the legalisation of euthanasia and 56% to that of assisted suicide, 19% stated that they would practice assisted suicide if it became legal. About 10% reported personal experiences with assisted dying.

In conclusion, assisted suicide in Switzerland represents a unique model of assisted dying. Input requested by physicians is limited and occurs mostly within the private sphere of the patient and their families. Right-to-die associations play an important role in evaluating a patient's eligibility, in providing the lethal drug, being present at the moment of self-administration and afterwards referring the case to the police for investigation.

CHAPTER THREE

THE CONTEXT OF END OF LIFE CARE FOR FAMILIES

This thesis is concerned with families and their individuals' experiences in relation to a family member's assisted suicide, starting from decision-making and continuing to death and bereavement. Even though assisted dying is a patient's personal choice, the decision is discussed with different people at different times (Dees et al., 2013; Gamondi et al., 2013). Families are known to be involved in this discussion and assisted suicide can represent one of the most challenging and complex conversations they can ever have (Beuthin, Bruce, Thompson, Andersen, & Lundy, 2021; Dees et al., 2013). Talking about and being involved in assisted suicide within a family can affect individual members of that family and the family as a whole. Family members are not passive bystanders, they do not only discuss but they also act and take operational decisions which may influence a patient's outcomes (Dees et al., 2013; Gamondi et al., 2013; Roest, Trappenburg, & Leget, 2019).

Families have been extensively studied since the 1800s across several disciplines and in order to explore and understand the Swiss family members' experiences of assisted suicide it is important to situate this research in the modern context of what a family is. This includes how a family functions and how families face such crises as life-threatening disease and end of life.

In this chapter the definitions of family are explored, and modern concepts of family are considered within the Swiss context. The complexities of care giving and the needs of family caregivers, particularly within the context of palliative care are described. A principal theory, Hudson's model on family caregiving in palliative care, is outlined and its application by Lowers, in the circumstances of hastened death, is reviewed and critiqued. An alternative approach, Walsh's family resilience framework, is presented as a model that could be used to explore the needs of families faced with a life crisis.

3.1 What is family?

Family is the fundamental basic unit of society. It represents one of the principal places for individual physical and mental development, and it affects the growth of every member playing a significant role in the normal operational process of social systems (Dai and Wang, 2015). Every member helps to constitute the family and is part of the social system in which their membership is based, which includes a combination of biological, legal, affectional, geographic and historical ties (Carr, 2012).

3.1.1 Defining family

Perceptions of what constitutes a family can vary across groups, societies and generations. Traditionally, entering a family was through marriage, birth or adoption. Widespread views of what defines a family have derived from common understandings of the usual tasks that people are expected to provide individually for one another and for society (e.g., reproduction, socio economic and emotional support, socialisation and education of children) (Naldini & Long, 2017). Marriage and family life in ancient societies could be viewed as a social construction emerging from the division of labour between men and women, their different but complementary roles, with the global aim of ensuring food and survival to individuals and the community (Coontz, 2005). In today's evolution of societies, the growing women's rights and feminist movements of Western societies and the frequent expectation of emotional and loving support in a relationship, have changed the expectations of individuals in respect of relationships, marriage and family. Consequently, the views, expectations and understanding of what a family is have evolved accordingly.

Every kind of kinship is fluid (Diderich, 2008). Today's families present a complex and multifaceted composition. Many households go beyond the traditional unit consisting of a heterosexual couple with children. New situations, such as single- parenthood, Lesbian, Gay, Bisexual, Transgender and Queer or Questioning (LGBTIQ+) couples, informal kinship adoptions, divorce and remarriage are common events. This implies that a narrow and traditional definition of the family is no longer possible because it would not be inclusive and comprehensive of the fluid modern society (Walsh, 2012).

For these reasons and for the purpose of this research, the following definition of family, drawn from the EAPC White Paper and derived from NICE (Payne, 2010) has been adopted:

> *A broad definition of "family" is used, including those related through committed heterosexual or same sex partnerships, birth and adoption, and others who have strongemotional and social bonds with a patient.*
>
> NICE (2004) p.155

With this definition in mind, it is important to situate families in the Swiss context. In Switzerland, the traditional middle-class single male breadwinner model is almost the exception with eight in ten mothers in coupled households being employed, mostly those living in urban areas (Feuille Fédérale, 2021). Nevertheless, it is still true that fathers tend to do more paid work and mothers remain mainly responsible for house and family work. The decision to get married and start a family is made increasingly later in life. The age at first marriage among women has risen from 24 (1970) to 30 (2016) and among men from 26 to 32 years; the average age of mothers at first birth has also risen from 25 to 31 years and the proportion of non-marital births has doubled between 2000 and 2016, from 11% to 24%. Divorce rates are high, the percentage was 41.5% in 2016, increasing by 44% since the 80s. Family characteristics have also changed in other ways: only 29% of private households belong to the classical type couple with children, while 27% of households are couples without children. Sixteen percent of the 1.1 million households with children under 25 years consist of single-parents, most often (83%) single mothers, and 5.5% are reconstituted families (Feuille Fédérale, 2021). The phenomenon of globalisation has led Swiss couples to be more intercultural and multilingual, especially in urban areas, although in rural areas couples tend to be less diverse (D'Amato, 2010; Linder, 2011).

For the purpose of this thesis, it is therefore important to take into consideration several aspects that can define a family. It is critical to maintain a broad and modern view of families as the research was conducted in recent times and within the Swiss social context where participants are living their experiences of assisted suicide. It is more realistic, and consistent within this research thesis to consider the family as a network of people, who, even if not related by blood, may play a significant role in a person's life, during the course of their illness, and in the assisted suicide related decisions and practicalities.

It has been described across many family theories (Doherty & Baptiste, 2009) that families strive to achieve success in their established goals and shared needs by maintaining family homeostasis. The common family values of loyalty, continuity and affection are instrumental to maintaining this family homeostasis, (Goldenberg & Goldenberg, 2012). Modern theories have identified common patterns of interaction within a family when aiming to maintain this status of equilibrium (Kreppner, 2005). Even when these key features are challenged, such as in crisis situations, families try to implement counteractive manoeuvres to re-establish positive relationships, maintain or restore homeostasis. Frequently, major stressors are a complex set of changing conditions in family life. Divorce, death, work changes, financial strains, and stepfamily formation are examples of family stressors that can occur as single events or, in some cases, as multiple events over a short period of time. To face the anxiety that derives from crisis, families develop different strategies. One of the resources that families can use to overcome crisis is fostering resilience, this possibility is explored further in section 3.7.

3.2 The complexities of caregiving

Caregiving is a universal experience. Many individuals in separate roles can provide care in a non-professional or unpaid relationship. These generally include family members, friends, neighbours and others, who have a meaningful relationship with a patient.

3.2.1 Future challenges: chronicity and caregiving

In the context of an aging population in the developed world, with more people living longer with chronic conditions, the overall percentage of adults involved as active caregivers is expected to increase (Kaschowitz, 2017). In the US in the early 2000s, nearly 11 million Medicare beneficiaries were receiving help with household tasks, self-care activities, or complex medical tasks from 17.7 million caregivers. In North America, in 2020, an estimated 48 million Americans provided unpaid care to an adult person, an increase from the estimated 40 million caregivers in 2015 (AARP & NAC, 2020). It is difficult to predict trends in terms of how many caregivers there will be in the future and what their needs will be in relation to the type of care they will provide. With the significant social, economic and demographic changes happening across Europe, it is likely that there will be fewer carers available in the future (Maguire, Hanly, & Maguire, 2019; Seale, 2000) yet with the increasing incidence of cancer, dementia and other chronic illnesses, the need for informal caregivers may increase proportionally (Heckel L, 2018).

3.2.2 Caregiving at home

Some caregiver needs that have been widely recognised as being of priority are related to the comfort of the dying person. They can vary from providing basic bodily care, managing complex symptoms and related medications and health technologies. Other important needs relate to the caregivers own physical exhaustion and the psychological distress they may experience. Issues related to financial, legal or work issues are known also to be important sources of worries in caregivers (Geng et al., 2018; Wang, Molassiotis, Chung, & Tan, 2018).

In the context of home deaths, researchers have shown that family carers may hold additional background worries on top of those priority needs (Thomas et al., 2018). These background worries may vary depending on individual issues such as personal significance and emotional intensity, and may be related to prognosis awareness, the dying episode itself, words left unsaid, experiences of previous deaths, and the patient's remaining capacity to interact and be present in the relationship.

The trend towards shortened hospital stays, with more outpatient/home care, raises important future challenges for caregivers. Home care enhances the burden on carers since it entails additional emotional and physical demands accompanied by economic consequences (Fisher et al., 2021; Hunt, Longacre, Kent, & Weber-Raley, 2016; Thomas et al., 2018). For example, caregivers of cancer patients are known to spend a median of 33 hours a week providing care to their patient (Geng et al., 2018). The international shift towards home care and home deaths has highlighted the necessity to investigate the specific needs that family carers may encounter (Geng et al., 2018) with tools such as the Carer Support Needs Assessment Tool (CSNAT) (Ewing, Brundle, Payne, Grande, & National Association for Hospice at Home, 2013) being used in community and hospice settings and more recently being tested in hospital settings (Hall, Ewing, Rowland, & Grande, 2020).

3.2.3 Caregivers' responsibilities in the provision of care

While the principal task of caregivers is to provide assistance in fulfilling a patient's daily needs, caregivers' responsibilities are multiple: they provide help and supervision for the daily activities upon which patients may be partially or totally dependent and they can be responsible for coordinating care, for facilitating communication with health care professionals, for acting on a patient's behalf with professionals, agencies and other bodies involved in the biopsychosocial and spiritual care of patients (Riffin, Wolff, Estill, Prabhu, & Pillemer, 2020; Talley & Crews, 2007). Caregivers are also involved in a patient's specific care; more than half of caregivers carry out complex medical and nursing tasks, such as injections, tube feedings, catheter and colostomy care (Lee, Ryoo, Campbell, Hollen, & Williams, 2019). In most cases these tasks are accomplished with insufficient information and training from healthcare professionals, generating more caregiver burden and challenges. The burden experienced by carers can be high and not only related to the patients' physical care but involves managing other aspects of their life such as jobs and families.

Figure 3: The heterogeneity of caregiving (Young et al., 2020)

In conclusion, providing care is a complex and burdensome task that can have an impact on carers' general wellbeing, mental health and emotional life (Bom, Bakx, Schut, & van Doorslaer; Morasso, Costantini, Di Leo, & al, 2008). This impacts personal and family finances and working life (Kamal et al., 2017; Lee & Cagle, 2021). The heterogeneity and complexities of caregiving have been summarised in figure 3 (Young et al., 2020), while acknowledging that the pattern of caregiving in end-of-life situations is more complex. The breadth and complexity of caregivers' needs are highly diverse and may depend on many elements, including: the context of care, the caregiving characteristics, the person receiving the care, and the person providing the care (Young et al., 2020). Since the nature and context of care may be highly diverse, assessment tools and interventions should not only reflect elements that might be broadly applicable to all caregivers but also consider elements that are relevant to the caregiver specificities and the context in which care is provided (Young et al., 2020).

3.3 The needs of families as caregivers in end of life

Caregivers, such as friends and families, are often involved from the initial diagnosis of a chronic illness to becoming heavily engaged when end-of-life approaches (Chi & Demiris, 2017; Ullgren, Tsitsi, Papastavrou, & Charalambous, 2018). Caring for a person at the end of life is a complex task, sometimes representing the first time in a person's life in which they are confronted with death and dying. The caregiver is called to deal with the patient's practical, psychological emotional and spiritual needs and at the same they are experiencing their own needs and emotions (McCabe, You, & Tatangelo, 2016).

A need refers to a condition that is important to the respondent and is not being currently satisfied by their environment (Hileman, Lackey, & Hassanein, 1992). A single definition of caregiver need is challenging as caregivers themselves may define 'need' differently, but within the literature, carer needs are generally discussed within six categories: informational, psychological, patient care, personal, spiritual and household. These categories are useful in informing supportive interventions developed for the carer (Milne & Quinn, 2008).

3.3.1 Breadth of tasks

Carers are required to accomplish many tasks during these last phases of life, such as illness and symptom management, participating in everyday life activities, life history review, and closure work, very often without having received training or detailed information (Levine & Zuckerman, 1999; Starks et al., 2007). The European Association for Palliative Care published a White Paper with the aim to analyse carers' activities, the context of care, and the needs and outcomes, while also exploring possible impacts of care on the medium- and long-term functioning of the family system (Payne, 2010). The White Paper identified challenges and possible adverse impacts on many aspects of carers' lives, such as health status, family communication, participation in social activities, and balancing work and finances. Together with these more challenging impacts, many authors have demonstrated that carers can also experience positive feelings, such as a sense of fulfilment, meaningfulness and closeness with the patient before death (Hudson, 2004; Maguire et al., 2019).

3.3.2 Caregivers' needs when death is close

Death and loss are painful, and these experiences can impact upon individuals and families at various levels (Große, Treml, & Kersting, 2018; McGoldrick & Walsh, 1991;

Nielsen, Neergaard, Jensen, Bro, & Guldin, 2016). Even when death is anticipated and happens after many years of chronic illness, family experiences can be shaped by dilemmas faced during the illness about quality of life, the nature of suffering, making decisions about the illness, treatments, and control over the dying process (Edwards, Olson, Koop, & Northcott, 2012; Elidor et al., 2020).

There have been a number of systematic reviews which have examined the needs and experiences of caregivers in end of life (Funk et al., 2010; Stajduhar, Funk, & Outcalt, 2013). Family carers can have specific needs during the illness of the patient. While some needs can be considered as more universal (Payne, 2010), others are specific to factors such as the nature of the illness, the socio-cultural context and the family structure (Bee, Barnes, & Luker, 2009; Fisher et al., 2021; McCabe et al., 2016; Plöthner, Schmidt, De Jong, Zeidler, & Damm, 2019).

Information and communication are crucial needs of families to enable them to get access to care, to obtain help and support. Psychological and emotional support is important to provide support for the distress that families may endure during the care. Most families request that professionals aim to ensure a patient’s best quality of life, and it is essential for them to be sure that the patient’s global suffering has been addressed. The care can become stressful and demanding and families need respite too (Mitchell, 2017) . Emergencies, crises and death, tend to happen in out of hours’ time periods, when the patient’s care is often the family’s responsibility (Munday, Dale, & Barnett, 2002; Papavasiliou, Hoare, Bowers, Kelly, & Barclay, 2021; Worth et al., 2006).

3.3.3 Cost and benefits of caregiving

Even if it is recognised that caring can be rewarding in emotional terms, the stress and the difficulties that families face are extensive and several models of intervention of palliative care have been developed and reviewed (Nelson & Goldstein, 2012). Families often do not have a previously learned competence in caring – rather their learning is very much related to lived experiences and from actively seeking information and guidance (Stajduhar et al., 2013). Family caregivers learn through many processes: trial and error, applying knowledge and skills from previous experience, and reflecting on their current experiences (Stajduhar et al., 2013). Research shows that family closeness and conflict resolution can help to alleviate the distress experienced by caregivers (Mitrani, 2005). Caregivers who described poor family functioning had higher ratings of strain and burden (Heru, Ryan, & Iqbal, 2004) depressive symptoms (Epstein-Lubow, 2014), and a lower quality of life (Rodríguez-Sánchez et al., 2011) than those caregivers who reported good functioning.

3.3.4 Family roles

Changes in established family roles in end-of-life situations and during complex decisions, such as assisted dying, are common. New and different roles may emerge, and people may behave differently from what it is usually expected (Quinn et al., 2012). In stressful situations, new roles may emerge to help fill the gaps in family members' responses to novel challenges (Anderson & White, 2018; Bartels & Faber-Langendoen, 2001; Gordon & Perrone, 2004). Patients' deciding to seek assisted dying may experience similar emotional challenges to that of families who decide to withdraw treatments in intensive care units or make decisions on organ donation (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001; Sque, Long, & Payne, 2005). In these situations, there is an intersection of both the health care domain and family domain, and it is important to identify the family roles that may be less prominent or less frequently portrayed, but which may be equally important in end-of-life decision-making (Quinn et al., 2012).

3.4 Conflicts and communication issues during caregiving

Even if the patient remains at the centre of decision-making during chronic illness and at the end-of-life, families must frequently face several decisions ranging from critical ones about medical treatments to decisions concerning the place of care (Hudson & Payne, 2011; Ullrich et al., 2020). Many choices that need to be made over the course of an illness may put significant pressure on individuals and on families as a system because the decision may often involve ethical and moral decisions that may generate dilemmas and conflicts (Petrillo, McMahan, Tang, Dohan, & Sudore, 2018). It is known that caring for cancer patients, for example, affects family functioning in many ways by altering dynamics, roles, and communication (Fisher et al., 2021).

Conflicts that may arise are rarely unidimensional, and very often they originate from multiple stressors and complex clinical situations (Lichtenthal & Kissane, 2008). Conflicts within the family can have direct consequences on patients' care, well-being and on families themselves, not only during the caring period but also in the bereavement phases (Kissane et al., 1996; Kramer, Boelk, & Auer, 2006). Competing needs or preferences for communication and truth-telling are common sources of conflict, sometimes exacerbated by pre-existing psychopathologies of the patients or a member of the family (Boelk & Kramer, 2012). Truth-telling to the patient about the nature of the illness or the prognosis is often a matter of debate (Vivian, 2006), while conflicts can arise from different perceptions of insufficient assistance within the family (Hancock et al., 2007). Gender and cultural related conflicts, such as the division of labour and the identification of the principal decision maker within the family are also frequent (Cohen, Sabik, Cook, Azzoli, & Mendez-Luck, 2019).

Many authors have proposed strategies to address family conflicts, with most of these based on open communication, reframing the conflict and agreeing common solutions (Back & Arnold, 2005). Kissane (2004) outlined three workable models in managing competing needs and conflicts in chronic illness including end of life care: a model centred on the patient's needs; one in which patients' and family members' needs are given equal attention; or a model that prioritises patients' and family members' needs based on their respective vulnerabilities at a given time. A commonality between these models is the need for open communication between professionals, patients and families to verbalise the conflict, analyse the communication and explore workable solutions based on priorities. It is known that patients and families value confidentiality and that secrets can be common (Galvin, Braithwaite, & Bylund, 2015). Secrets in families can assume different forms: taboos, rule violations and conventional secrets (Vangelisti, 1994). Considering that a secret is information hidden purposefully, families can hide information to non-members or to some family members or professionals, depending on family functioning and the nature of the secret. It is possible that a family prefers to keep some information as confidential due to fears of humiliation or rejection. In other cases, the presence of a secret facilitates more cohesiveness in the family (Kuhn, 2002). The open communication suggested by Kissane's model should balance the value of confidentiality with professionals with the value of respecting what families prefer to retain for themselves.

Changes in contemporary society, family structures and relationships influence how families care for their ill members. Thus, recognising caregiving cultures and differences within and across families is crucial to providing care that is culturally informed and related to the needs and strengths of modern families.

3.5 Supporting interventions to address family needs: the vision of palliative care

The World Health Organization, in its definition of palliative care, advocates that the patient and family should be considered a unit of care and identifies as one of the goals of palliative care *"that of improving the quality of life of families, as a unit and as individual member*s" (WHO (2011). There is an extensive literature on family carers involved in the care of a palliative care patient, showing that being a caregiver for a palliative cancer patient may negatively affect the carer's psychological, and physical health and may impact on bereavement and relations outcomes (Funk et al., 2010; Stajduhar et al., 2010) (Sanderson, Lobb, & Mowll, 2013). For this reason, many efforts have been devoted to the study of family needs and to identify conceptual and theoretical models of care which take into consideration the experience of caregiving at the end of life or in the context of life-threatening illness and to develop interventions aimed at improving their experiences during the patient's illness and afterwards in bereavement.

3.5.1 Palliative care family caregiving models in relation to assisted dying

Several family caregiving models have been specifically developed within palliative care (Andershed & Ternestedt, 2001; Hudson, 2003; Swanson, 1991; Waldrop, Kramer, Skretny, Milch, & Finn, 2005). One of the most frequently used, the stress and coping model is Hudson's (2003; 2004) family caregiving model for palliative care that draws on Lazarus and Folkman's (1984) seminal work on a transactional stress and coping framework, later revised by Folkman (Folkman, 1997). The revised model traces how caregivers appraise and respond to events in caregiving.

a. Hudson's model

Hudson's model (2003) for family caregivers in the context of palliative care is rooted in Lazarus and Folkman's stress-coping model (Folkman, 1984), further revised by Folkman (Folkman, 1997). Hudson's modified stress-coping model for family carers in palliative care consists of a complex framework that integrates the multiple needs and actions required to respond to family carer needs. The model aims to demonstrate the supportive strategies, which may influence the potentially stressful process that families can experience. It incorporates several concepts relevant to the family caregivers' coping process, with key building concepts such as preparedness for caregiving.

The model aims to provide a theoretical foundation to explain how families interpret their role over the course of an illness and after death. It has been used in palliative care settings, end of life care and curative cancer care for these reasons (Holm, Årestedt, & Alvariza, 2019; Hudson et al., 2020; Winterling, Kisch, Alvariza, Årestedt, & Bergkvist, 2021).

b. Utilising Hudson’s model in assisted dying

Lower’s (2020) thesis explored the experiences of informal caregivers who supported a patient through Voluntarily Stopping Eating and Drinking (VSED) and evaluated this VSED caregiving against theoretical models of end-of-life caregiving. Specifically Lowers used the Hudson’s modified stress-coping model (2003) to see if it could provide a framework of analysis in an empirical study investigating caregivers’ experiences of VSED (Lowers, Hughes, & Preston, 2021) along with a narrative review that compared caregiving experiences at the end of life and in a hastened death context (Lowers, Scardaville, Hughes, & Preston, 2020). Lowers explored the meanings created by family members during their caregiving experience in the light of the Hudson model, by which families’ strengths and challenges were systematically examined. Specifically, Lowers used the Hudson a priori themes (appraisal, coping, event outcome and emotion outcome) and the 18 influencing factors in assessing hastened deaths and end of life.

Both in her empirical work and the synthesis review, many of the themes identified in the analysis appeared to fit consistently with the Hudson model, such as the process of appraisal, coping, and resolution, with the specificity that events in hasten death followed a predictable pattern of planning, preparation, orchestrating the death, and tying up loose ends. Whereas Lowers concluded that Hudson’s model was an effective lens for interpreting caregivers’ experiences both at the end of life and in the context of hastened death, she suggested opportunities to refine the model which are discussed below.

c. A Critique of the Hudson Model

Although this well-known family caregiving model (Hudson (2003) has many advantages in informing the design of caregiver interventions it also has a number of limitations which dissuaded me from using it to interpret the findings of this thesis. Within the model itself the concepts of self-efficacy and competence are included without offering an explicit link between these concepts and the preparedness for caregiving, or it possibly assumes that if prepared they will be improved. The model does not integrate family functioning before the illness, or consider how usual functioning can affect present experiences and shape needs and stress over time and it focuses primarily on individual coping (Hudson & Payne, 2008). There are different types of dying across palliative care and in other critical illnesses. Which end of life decision the patient makes has a great impact on their family members, but at the time of collecting this thesis's data Hudson's model had only be tested with palliative care patients. The involvement of health care professionals is lacking in Hudson's model, and professionals input varies enormously depending on the type of death and the jurisdiction in which it takes place.

d. The Consideration of Social Processes

Families may be faced with numerous conflicts during the course of the illness of one of their members. Conflicts may arise between the family members and health care professionals, and the conflicts may relate, for example, to decisions about treatment goals, place of care, and extent of information provision. Despite having identified the development and improvement of family/caregiver-focused interventions as a research priority in palliative care, the general cohort of palliative care models of caregiving, including the Hudson model, only partially integrates the notion of conflict that families may experience during illness or considers the influence of the place of care and the length of the illness experience.

Hudson's model does highlight the stressors and burdens for individual caregivers, but has little focus on the positive self-gains associated with caregiving.-For example, positive experiences of caregivers of patients with heart failure (Bangerter, Griffin, & Dunlay, 2019), dementia (McCabe & al, 2016), cancer (Bee et al., 2009), blood cancer (Fisher et al., 2021) and eldercare (Plöthner et al., 2019) are now emerging. It is important that such positive gains are considered in caregiving models to avoid the pathologisation of the family carer role.

Specifically in Switzerland families have shown to believe that assisted suicide belongs to the private sphere of the family and it is interpreted as a civil right (Gamondi, 2013). This situates assisted suicide in Switzerland in more of a social than medical context.

e. Different Types of Dying and Professional Support

The model mainly focuses on end-of-life interventions in cancer care. In contrast, modern palliative care models describe the necessity and efficacy of earlier and integrated palliative care interventions in cancer care and in all life-threatening and life-limiting illnesses. The Hudson model has been mainly developed in the context of palliative care settings, whereas assisted dying worldwide usually now happens outside a system with integrated palliative care (Gerson, Koksvik, Richards, Materstvedt, & Clark, 2020; Gerson, Koksvik, Richards, Materstvedt, & Clark, 2021; Ward, Freeman, & Banner, 2021). Only a few countries, like Belgium and the Netherlands, use the integrated assisted dying model, where assisted dying happens in palliative care. Most of the other countries which have legalised assisted dying require a palliative care consultation but assisted dying occurs at home or in hospital settings.

As noted by Lowers (2020), the Hudson model lacks recognition of the input of health care professionals. Lowers reported that VSED caregivers placed similar emphasis on the importance of physicians, hospice nurses, and home care aides. In the context of assisted dying, a further challenge in the Hudson model is the diversity of medical input depending on the assisted dying model available to patients. In euthanasia, it is known that the dyadic patient-physician is recognised as the common centre of decision making (Dees et al., 2013; Gamondi, Fusi-Schmidhauser, Oriani, Payne, & Preston, 2019). At the same time, in assisted suicide, more responsibilities are concentrated on the dyad family member-patient. Different models of assisted dying present other medical inputs, considering that Swiss families feel assisted suicide decisions are a right and a private personal choice (Gamondi et al., 2019). At the same time, Dutch patients rely more heavily on medical professionals for decision making (Dees et al., 2013). A model where the relationship between patients, families, and health care professionals are considered is necessary to interpret participants' experiences and evidence needs. It also has to be considered how families’ experiences may be shaped by societal acceptance of assisted dying, an acceptancy that varies across countries and over time. For these reasons, the potential moral dilemmas and ethical issues with which families may be confronted should be considered when using a framework to guide the interpretation of their experiences, and such social processes are absent from Hudson's model.

f. Prior Planning of Death

Another concern for Hudson's systemic model in interpreting assisted dying data is that although it does take into consideration the critical variables that could influence families' experiences, the model is limited in integrating family functioning before the illness and lacks a description of how usual functioning can influence present experiences and shape needs and stress over time. The model does not integrate the notion of conflict experienced by families during illness and which can arise within families faced with a request for assisted dying.

Where a person lives in the world also influences the choices and discussions that they can make on future end of life decisions. Within this context, it is essential to recognise that in many families, assisted dying issues may be discussed long before experiencing life-limiting situations and that there is an increasing debate over assisted dying granted outside of classical palliative care situations such as for people with mental health illnesses, and that many patients and families requesting assisted dying may be cared for outside palliative care (Gerson et al., 2020; Gerson et al., 2021; Olié, 2020).

g. Changing Family Structures

The model needs to be adapted to consider the changes in diversity of the modern structure of families, and subsequent caregivers (older people caring for other older people – so often less fit/able people caring for ill people), women having additional demands, such as working outside the home (so less availability for caring duties), new types of families such as LGBTIQ+ and migrants with their specific cultural issues (Smietana, Thompson, & Twine, 2018). It focus primarily on individual caregiver coping (Hudson & Payne, 2008) versus the distribution of caregiving within a family is also limiting.

h. **Conclusion**

In conclusion, the Hudson model is a good starting point from which to guide understanding of the carer experience and to assist in the development of strategies to enhance support (Hudson and Payne, 2008) whereas recently tested in assisted dying (Lowers, 2020). While acknowledging the importance of taking the best of palliative care – such as seeing the family as a unit within the care context and including family needs into the care plan (Payne, 2010)– it may nevertheless be more innovative, for the purpose of this research, to look outside of the palliative care field at models that address the needs of families faced with a life crisis which take a non pathologising approach and considers the positive capacities of families to overcome difficulties and adversity.

3.6 Families confronted with life crisis

Caregiving is challenging, and caregiving for a family member who has a terminal diagnosis is considerably more challenging. This thesis goes beyond family caregiving experiences for palliative care or other end-of-life experiences, as the families interviewed for this thesis have the additional task of dealing with the discussion about the patient's decision for assisted dying.

Based on the family functioning literature, families faced with a life crisis will want to gain equilibrium and homeostasis. How well family caregivers cope with their carer burden depends on their level of resilience (Palacio, Krikorian, & Limonero, 2017).

There are a number of different strategies which can be used to face crisis depending on which type of illness is being confronted (Li, Cooper, Bradley, Shulman, & Livingston, 2012; Traa, De Vries, Bodenmann, & Den Oudsten, 2015). One of these strategies is to develop resilience, which was initially articulated in the 1980s, and more recently has been studied with research on its relation to coping and adaptation in the cancer experience (Deshields, Heiland, Kracen, & Dua, 2016; Higginson & Gao, 2008; Papastavrou, Charalambous, & Tsangari, 2012) and with caregivers of people with Alzheimer's (Harmell, Mausbach, & Roepke, 2011).

Resilience in families is an interesting point because it focuses on family capacity to overcome crisis and difficulties (Palacio, Krikorian, Gómez-Romero, & Limonero, 2020). As an assisted death can represent one of the most challenging crises a family may experience, both as individual members or as part of the family system, it is worthwhile reflecting on how family members can withstand and rebound from such disruptive life challenges, and even emerge from the experience with an increased sense of personal strength and resourcefulness.

A recent paper by Roen et al. (2018) based on carers' experiences explored factors that may promote family resilience by taking a multidimensional approach to resilience which examined personal, relation and environmental contributors (Stifoss-Hanssen & Danbolt, 2014). While medical, legal and societal dimensions have typically been considered in the assisted dying literature, approaches that may consider assisted dying as a family crisis and a life challenge that may not only carry dilemmas and difficulties, but may also foster their resilience and the resolve to overcome adversity have never been considered. An example of such an approach is Walsh's framework (Walsh, 2015) on family resilience.

3.7 Turning adversity into an opportunity: The Walsh framework

Walsh, one of the leading writers on family resilience, discards the models that focus on family deficits and survivors of dysfunctional families Walsh's framework focuses on strengthening families' resilience and is based on the concept of resilience, defined as *"the ability to withstand and rebound from serious life challenges"* (Walsh, 2015, p. 3) . It proposes that it is beneficial for families to turn adversity into a catalyst for the family's growth (Walsh, 2015). Difficulties and crises can be re-conceptualised as an opportunity to enrich relationships, offering family members a chance to become more competent if faced with crisis in the future (Patterson, 2002). One of the strengths of the Walsh framework is its focus on dealing with adversity at times of crisis; it could therefore bring an innovative lens through which to interpret the results of this thesis.

At the framework’s heart is a profound shift away from distress and deficit-based approach to family functioning to one that focuses on positive goals, resources, processes and outcomes that can facilitate healing and growth which can be forged under stress and across a life course. It assumes that no single model fits all families; it is a framework that does not pathologise families and considers the specificities that each family has in terms of values and beliefs. It is oriented toward human services which can be applied to multiple crises situations, disruptive transitions and multi-stress conditions. It is also motivating because of its practical application as an intervention.

It has to be acknowledged that there have been several limitations linked with studying this complex construct of resilience, such as: a lack of consistency in the definition and use of the concept, a focus on the individual, little intervention research specifically on resilience particularly within different populations and illness phases (Aburn, Gott, & Hoare, 2016; Faccio, Renzi, Giudice, & Pravettoni, 2018; Zanatta, Maffoni, & Giardini, 2020). Despite these challenges, research in this area has shown considerable value in the understanding of processes affecting at-risk individuals (Luthar, Cicchetti, & Becker, 2000) and it has been demonstrated to be a useful construct in caregiver research (Palacio et al., 2020; Petriwskyj, 2016).

Another limitation is that it has been conducted predominantly on white American, middle-class, intact families. At present, families are characterised by specific features in relation to their cultural, geographical and ethnographic context, thus the process that can be fostered over times of crisis, needs to be tailored to modern times and present challenges. While research conducted on a multicultural level has shown that how a family functions may be as important as the structure of a family in building resilience (Arditti, 2014), many challenges remain present. Walsh’s (2015) framework identifies and synthesises of key processes within three domains of family functioning: family belief systems, organisation patterns, and communication processes.

For Walsh the first key domain shows that a family’s belief system powerfully influences how members view adversity. Adversity can generate a crisis of meaning and cause potential disruption of integration within a family. Family resilience is fostered by shared facilitative beliefs that increase effective functioning and options for problem solving, recovery, and growth. For the second domain, resilience is strengthened when a family has an organisational pattern which has a flexible structure, connectedness, and social and economic resources. The third, communication domain, states that a family's resilience is facilitated by bringing informational clarity to crisis situations, encouraging open emotional sharing, and fostering collaborative problem solving and preparedness.

Following this framework, nine processes that characterise family resilience have been recognised, all involving beliefs, organisation, and communication within families (figure 4).

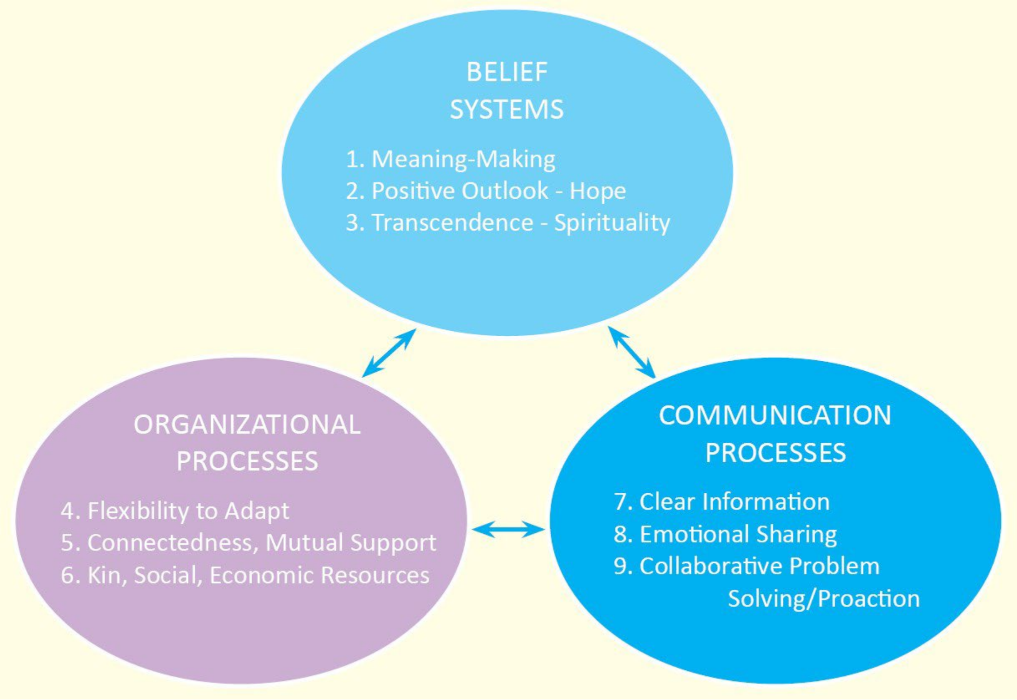

Figure 4: Adapted from domains of family functioning (Walsh, 2015)

This framework also offers several advantages. It focuses on strengths and family capacity and provides professionals with a resource-based model. It is flexible, adapting to changes that occur over time in the family system and composition and experiences of the families. It can become fragile when the relationships between individual, family and community are not known, or their interplay is multifaceted, it is based on a solid eco-systemic perspective which views the family as a functional unit. Given that there is evidence of the potential for post-traumatic growth following the experience of caring for a dying family member, a framework such as this with an intrinsic vision on positivity and non-pathologising approach to family crisis is worth exploring further in the assisted dying context.

The choice to use the Walsh model to interpret the results of this thesis was made at the end of the data collection and analysis. This model was chosen to discuss the results of the entire thesis in the attempt to provide an innovative interpretation of families' experiences in assisted dying.

In conclusion, over the years many theories and models on family functions have been developed which function both in palliative care, end of life and wider fields. The intent of this thesis was to describe and understand families' experiences of assisted suicide in Switzerland and interpret their experiences, with a non-pathologising approach to family functioning. The intention was seeing families' experiences of assisted suicide not only in the context of the difficulties and challenges that they faced, but by also observing the capacities and strengths that emerge in such situations.

CHAPTER FOUR
RESEARCH AIMS, DESIGN AND METHODOLOGY

In the initial part of this chapter, the research question is described with the specific aims and objectives of the overarching question. In the second section, the paradigm in which study is conducted is reviewed, with an illustration of how the paradigm of critical realism can serve as a foundation for investigating the complexity of assisted suicide in Switzerland. The methodological underpinnings of the framework and the analytic methods that have been used in the three studies are described and justified in the context of critical realism.

4.1 Research question and aims

The research question of this thesis is:

What are the experiences of families who support a patient who dies from assisted suicide in Switzerland?

4.1.1 Research aims

The aim is to investigate how family members experience their interactions with patients, health care professionals and right to die associations while the patient is in the process of seeking assisted suicide. This is addressed by four specific aims:

1. To systematically analyse the published literature on families' experiences with a family member who died with assisted dying, in jurisdictions where it is legally permissible.
2. To investigate Swiss families' reflections of their experiences when a family member is considering assisted suicide.
3. To depict Swiss families' reflections on their interactions with healthcare professionals and right to die associations during the time their family member is considering assisted suicide.
4. To analyse Swiss palliative care physicians' accounts of interactions with patients and their families when they are considering assisted suicide.

4.2 Methodology

A critical realist approach was selected to investigate family experiences of assisted suicide in the context of Swiss culture and reality. Selecting the paradigm with the most utility in enabling the research aims to be met is described below, followed by a consideration of the subsequent choices about methods.

4.2.1 Overview of the existing paradigms that are used in social research

A number of metatheories have been used in social research to look at reality and the three main (mutually exclusive) approaches are: positivism, interpretivism and realism (Bryman, 2016; Wainwright & Forbes, 2000). These different paradigms have distinct ontological (i.e. what exists), epistemological (how we can come to know about what exists) and methodological (the means of acquiring this knowledge) facets (Bryman, 2016).

In general positivists see the social world as a closed system where relations between cause and effect can be directly observed or experienced. Positivist ontological approaches are founded on the belief that the things we experience exist, but only if they are measurable and observable empirically. The positivist paradigm seeks to identify patterns and their causal effects. A positivist ontology assumes that the world is external and that there is a single objective reality to any research phenomenon or situation, regardless of the researcher's perspective or beliefs. Its epistemology requires the use deductive methodology of the scientific method (Park, Konge, & Artino, 2020; Wainwright, 1997; Wainwright & Forbes, 2000).

Positivism is a powerful and widely used paradigm, but is unable to capture social complexities, to locate events in complex contexts, and to confront emerging social challenges such as the study of vulnerable populations and health inequalities (Bergin, Wells, & Owen, 2008; Fletcher, 2017). Its reductive approach, with a focus on a single external and objective reality, is not congruent with this research study, with a focus on the experiential (Wainwright & Forbes, 2000).

In contrast to positivism, interpretivism argues that individuals shape society and this approach aims to recognise complex multiple understandings and acknowledges the subjective nature of meaning making. In this paradigm truth is seen as relative, resulting from multiple realities, agreements, negotiation, and collective consensus and thus is never absolute (Wainwright, 1997). Indeed, absolute truth (strenuously claimed by positivists) is seen as both meaningless and unachievable (Dickens & Fontana, 2015). Through the use of qualitative or mixed method research design it enables researchers to gain in-depth insight into the lives of individuals in order to construct knowledge.

Realism is a philosophical approach which takes more of a middle ground between the two extreme approaches of positivism and interpretivism and embraces a continuously developing set of philosophical positions intended to justify taking common-sense experiences of the world seriously (Julnes, 2015). Realism takes account of Kant's (1724) philosophy of realism and vision of science as a builder and not as a descriptor of worlds (Archer, Bhaskar, Collier, Lawson, & Norrie, 2013; Bhaskar, Collier, Lawson, & Norrie, 1998; Sayer, 1992). In essence, Kant underscores the importance of giving attention to the subject observing the object, and not only to the object itself, which has guided the fundamental attitudes of realist scientists. Kant's crucial insight was to argue that the experience of the world is only possible if the mind provides a systematic structuring of its representations. As such, the world is known insofar as we experience it and according to the *a priori* knowledge (certain knowledge that is derived from reason without experiencing it as an aspect of the world) and *a posteriori* knowledge (something existing and found in reality which is known by experiencing it as an aspect of the world) (Müller-Merbach, 2007). As such *a priori* judgments are known, but, since experiencing something as an aspect of the world is relative and variable, *a posteriori* knowledge is probable rather than certain or necessary.

Critical realism stems from the theories related to realism, and is a school founded in the late 1970s by Bhaskar, an English philosopher and developed further, such as by Sayer (1992) and Archer (2013a). Critical realism is positioned between the opposing paradigms of positivism and social constructivism, affirming that culture is ideological and that cultural differences cannot be studied without paying attention to the macro context in which culture arises. Having given an overview of these three paradigms, the following section will present a justification for the selection of critical realism as the preferred paradigm for this research, before giving a detailed consideration of critical realism and its implications on decisions about the conduct of this research.

4.3 Critical realism as the preferred paradigm for investigating family experiences of assisted suicide

In locating research within a paradigm, the question is not which of the metatheories is right or wrong, but which is more suitable to investigate family experiences of assisted suicide in the context of Swiss culture and reality. The object of this research is assisted suicide in Switzerland, from the point of view of family members who were involved throughout the process, and not only at the actual moment of death. Assisted dying, and in particular assisted suicide, is a complex phenomenon which is currently emerging as an end of life choice (both internationally and in Switzerland) and which has legal, ethical, medical and psychological implications. For the purposes of this thesis, rather than taking a controlled, theoretical standpoint, assisted suicide is investigated from a real world perspective, meeting and interviewing people, understanding where and how they came across assisted suicide issues and what those issues were.

During the PhD research I have continued to practice palliative medicine as my profession and I have met many patients and families asking for information about assisted suicide, with some of them pursuing it actively and finally dying from it. I chose to conduct this research whilst remaining immersed in matters associated with assisted suicide, and consciously influenced by these experiences both through my clinical daily practice and exchanges with colleagues and other researchers on this topic. My research was catalysed by the realisation that assisted suicide is not as a product already available to patients and families as an end of life option, pre-determined by the law, health professionals and right-to-die associations that families and patients passively chose. As such assisted suicide in Switzerland may be associated with multiple and complex factors, powers and mechanisms, that patients and their family members may both actively influence and passively endure.

The resulting aim of this research, to investigate how family members experience their interactions with patients, health care professionals and right to die associations while the patient is in the process of seeking assisted suicide, was driven by my interest in seeing assisted suicide through the eyes of family members. Within this I sought to see them both as family members experiencing the terminal illness of one of its members, and as members of Swiss society.

After having examined the existing paradigms, I decided to conduct my research from a critical realist approach. One of the main motivations was that critical realism is considered as a third way between positivism and postmodernism in the study of social sciences (Archer et al., 2013; Wainwright, 1997). I had chosen to be an active part of the research, a co-constructor of the data I was gathering and analysing. At the same time, I tried to value the strengths and potentialities of the methodology to come to an in-depth understanding of family experiences of assisted suicide as it exists in Switzerland, and its underlying invisible mechanisms.

Critical realism enables the researcher to get under the surface to understand and explain why things are as they are and to hypothesise the structures and mechanisms that shape observable events (Mingers, 2002).

Critical realists argue that understanding only represents a starting point from which to explore and explain phenomena. While both postmodernist and positivistic approaches to understanding aim to describe relationships between variables, critical realism results in in-depth explanations, understanding and interpreting phenomena more clearly (Wainwright & Forbes, 2000). More specifically in social sciences, critical realism posits that scientific theories provide descriptions of the world that are only approximately true. The laws we observe that regulate realities can be true, but they are not absolutely true, in part because social reality and its knowledge are considered multi-layered and multileveled and difficult to access (Banifatemeh, Shields, Golabi, Ghoreishi, & Bayani, 2018; Sayer, 2000). Critical realism argues that one has to move from the actual, superficial layer to deeper layers of reality and not confine observation to just the appearance of reality, but invite the researcher to a better and deeper, more intensive cognitive reflection, observing, interpreting and arguing in light of their previous experiences of realities and their values (Banifatemeh et al., 2018). In critical realism diverse interactions and mechanisms are seen to act at various times in complex open systems, such as the social world. For these reasons, a critical realist methodology can represent a valid instrument when the aim of research, as in this thesis, is to provide explanations of mechanisms that generate events rather than to make predictions about future events. The mechanism is believed to exist because they are not directly measurable or observable. The observability of mechanisms, which *per se* is not a necessary methodological requisite, should enhance our conviction that the mechanism exists, whereas the existence of the mechanism does not depend on its observability (Sayer, 2000).

Using a critical realist approach also has advantages when it comes to personal reflexivity. I am aware that I hold personal stances on assisted suicide which have evolved over years in clinical practice and personal development, and in turn have influenced the research I conduct on the topic. My background, typical of medical studies, in entrenched in positivism and I am conscious of what Bhaskar calls *"the inevitable fallibility of observation"* (Mingers (2002), p. 302). Using a critical realist approach facilitates my awareness of the assumptions I bring and the limitations of my research.

In the following section I provide an overview of critical realism, its leadings proponents and the implications for decisions about the conduct of this research.

4.3.1 Critical realism and the ontology of social reality

Within the field of critical realism, Bhaskar's school inspired other philosophers to further develop critical realist principles, to apply them in diverse settings, such as economy and technology, and to develop conceptualisations of social reality; two of which are Sayer (2013) and Archer (2013a).

Sayer's view of social ontology contends that human beings are able to change themselves and activities, such as understanding the meaning of symbols, images, rules and actions and that this self-changing is instrumental to transformation. As such only by integrating social interaction in the context where it happens can a social dimension of knowledge be assured. Social realities are seen as the outcome of the action of social actors, but they move aside after being created and for this reason they should be considered as independent phenomena (Banifatemeh et al., 2018; Sayer, 1999; Sayer, 1992). Finally, social structures endure only when people reproduce them, and people do not reproduce them intentionally or automatically, meaning that there is a sort of mutual nurturing that happens between social structures and people. Through the in-depth interaction between agencies and structure by which certain actions continue to be executed do social phenomena exist and this existence is dependent on their reproduction.

Archer offers the alternative view of methodological individualism, which affirms that that neither social class nor group dynamics are considered as illusory or artificial, but that subjective individual motivation explains social phenomena. Through analytical dualism people are seen to not act outside socio-cultural and structural contexts; rather that there is a continuous and ubiquitous interaction between individuals and society that exist in a sort of symbiosis (Archer et al., 2013). In Archer's critical realist ontology conflated theories evolve into a morphogenetic approach, which presents society as the result of a continuous happening of morphostasic and morphogenesic processes. Morphogenetic processes are characterised by internal changes made in the system which lead to both a change in the overall structure and in the ultimate product of the system. Morphostasis occurs when permanency and stability keep the system constant. Their happening, at all times and all places, determines changes in action, reaction and interaction, and results in structural complexities of society (Ryan, 2005).

Archer's morphogenetic perspective is positioned, in this research, as a fundamental ontology of social change; involving culture and influencing social actions. When new practices become available to people – such as assisted dying– society is subjected to an intense morphogenesis, intrinsically signifying that permanency and stability are not possible at the same time, given Archer's questioning about the possibility of establishing a new corpus of laws, norms and rules, under the pressure of new practices (Archer, 2020; Archer, 2013b).

During morphogenetic periods, it is highly likely that a crisis in normative regulation, social integration and social stability will happen. Archer argues that the proliferation of legislation at all levels could be the expression of a low level of system integration, underpinned by an escalation of morphogenesis in society. The adoption of normative bureaucratic rules enables tasks of increasingly complex social coordination to be performed (Archer, 2016). The emergence of normative rules may allow an increase in social coordination, solidarity and social order, which, at the same time may foster a further reduction of social integration. The present civil approach to assisted suicide in Switzerland is a good example of societal morphogenesis; different agents (right-to-die associations, professional societies, institutions) enact bureaucratic rules/ regulatory documents that may contribute to mobilising societal morphogenesis in a mutual dialectical way.

Within Archer's critical realism a necessary condition for an orderly society is that normativity, integration, and regulation must be mutually reinforcing (Archer, 2016; Archer et al., 2013; Banifatemeh et al., 2018). Societal morphostasis is required for this coherence to exist, and, in contrast, morphogenesis reduces this coherence. In emerging morphogenesis, normativity, integration, and regulation become unsupportive and norms and values may be recast by being newly generated, demolished or preserved. In Switzerland, normativity, integration, and regulation appear to exist in an uncoordinated manner. To cope with intensified morphogenesis, normative systems put in place different strategies, such as establishing technical regulative standards, which set prerequisites for individual or collective entities to respect (frequently about bureaucratic restrictions on action), such as those enacted by different regulatory bodies in Switzerland. Very often, technical regulatory standards lack any apparent normative content, which can lead to a collectivity of intrinsic ambiguity, for example, about their value, purpose, and utility. Technical regulatory standards may both indicate and foster a lack of trust among people concerned by these rules in the context of a social change and morphogenesis (Archer, 2016). The capacity of individuals to make decisions in coherence with both their material interests and idealistic convictions is also considered an explicit premise of the morphogenetic approach (Porpora, 2013).

In conclusion, critical realism provides an innovative and coherent framework to guide research in the field of assisted suicide, thanks to its realistic capacity to maintain a strong emphasis on ontology. Critical realism has been revealed to be, in many fields of research, a powerful instrument to gaining knowledge through intensive and rigorous research methods (Zachariadis, Scott, & Barrett, 2010). By providing a means for a systematic understanding of the relationships, structures and mechanisms of the social world, it provides a way to identify the complex interplay of multiple factors that contribute to shaping the motivations of family members to act in a certain way when facing assisted suicide issues, which is the aim of this research. It may also provide a foundation to help understand whether families contribute to shape assisted suicide practices in Swiss society.

4.4 Critical realism’s distinctive features

In this section critical realism is described in more depth, explaining key terms and characteristics of this methodology and how it was used to develop the research methods. Critical realism is not a single framework or set of beliefs, but it can be seen as a family of elements and paradigms that share common roots and characteristics. There are common features, similarities and resemblances that are shared by family members that make them all different but visibly belonging to the same family. This is the case for critical realism in that it consists of a family of ideas and philosophies that developed as a broad alliance against the dogmas of logical positivism and its imposition of terms and methodologies in research (Ab Kadir, 2007).

The three distinctive features that characterise critical realism can be summarised as follows (developed from Outhwaite (1987):

1. Stratified ontology: Reality is stratified into three domains: the empirical, the actual and the real. This stratified ontology permits explanation of causal mechanisms (Bhaskar et al., 1998)

2. Causality: Causal laws are not interpreted in the classical positivistic interpretation (e.g., universal constant conjunctions between observable events) but as tendencies which may or may not produce events which may or may not be observed (Outhwaite, 1987). The main task of research is to demonstrate the existence of the explanatory mechanisms in the real domain. The object of science is to discover agents and powers that define causal laws (Archer et al., 2013). These affirmations underpin the methodological principles typical of critical realist approaches.

3. Transitive versus intransitive knowledge dimensions: There are transitive objects (i.e., the concepts and models used to understand aspects of the world) and intransitive objects (i.e., the real entities and the relations between these real entities). Definitions of concepts affirmed in the real domain define the basic nature of an entity or structure.

Below I use these three features and two relevant epistemological assumptions to describe the basis of critical realism.

4.4.1 Stratified ontology

Critical realist ontology proposes the existence of a mind independent of the world. More specifically, almost all the world's entities and events and their relations exist independently of individual knowledge, and the laws we observe that regulate realities can be true, but they are not absolutely true (Bhaskar et al., 1998). Diverse entities and events coexist in the world, and they are not always confined to the realm of what is observable. In critical realism observability is not the only criteria that allows ontological claims to be made. Bhaskar believed that positivism committed an epistemic fallacy, collapsing together being and the knowledge of being, and suggests that research should take an antireductionist stance; avoiding merging ontology with epistemology and reducing the world to what is known via human senses (Bhaskar et al., 1998). To avoid the epistemic fallacy, the theory of being should be distinct from a theory of knowledge; with a resultant shift to focusing on questions concerning the creation of knowledge about that existence (Bhaskar et al., 1998; Frauley & Pearce, 2007). Since human knowledge can capture only a small part of a deep and vast reality, critical realism's aim is to uncover and describe the mechanisms that generate observable events. In contrast to the positivist view that reduces reality to those things that can be observed and measured under the conditions of experiment, Bhaskar theorised that reality was differentiated and stratified in three domains. These three domains (see figure 5) are out of phase in everyday experience, and scientific experiments should aim to put them into phase, being able to activate and isolate the powers of each domain (Gorski, 2013).

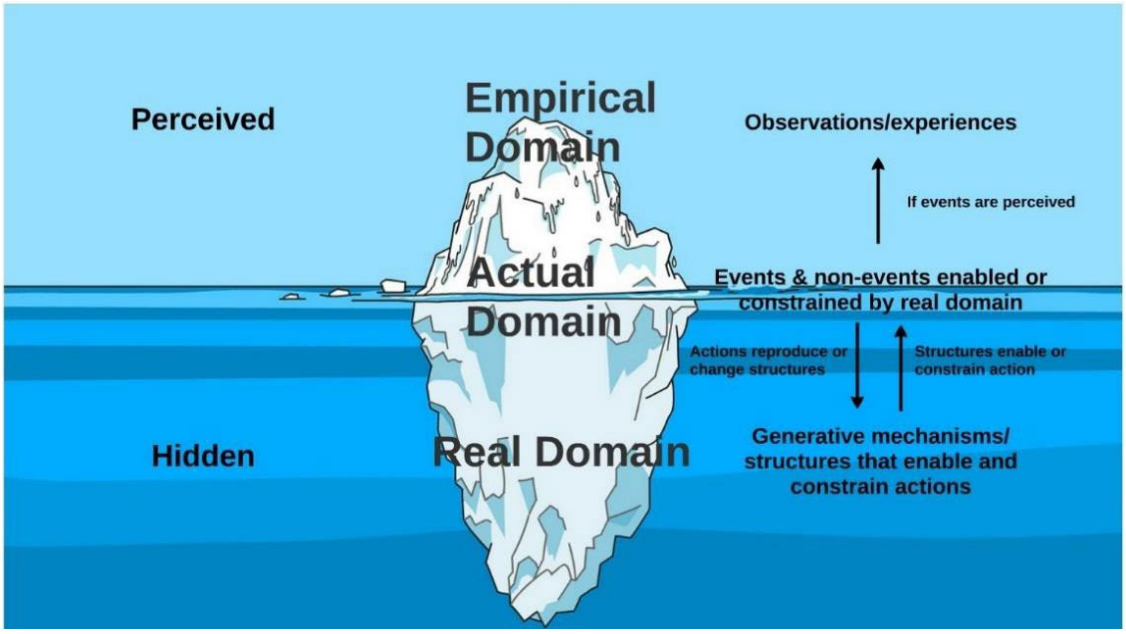

Figure 5: Critical realism's stratified reality (adapted from Brad C. Anderson, licensed under CCBY-NC-SA 4.0)

The most superficial domain is the empirical, which is constituted by what we can observe and experience. Mechanisms, events and experiences exist in this domain. It is where objects, their structures and powers are found. At this level we can measure events in an objective and empirical way and the objects (even if filtered by human experiences and interpretation) can be nevertheless explained with common sense. The empirical layer represents the transitive domain of reality, where actions and meanings are causal and occur.

Underneath the empirical, we find the actual layer formed of what is going on, which may or may not be observed but which is regulating the empirical. It is in the actual domain that things happen in reality, where powers and mechanisms are activated and events and experiences are produced (Danermark, 2002; Sayer, 2000). The domain of the actual considers phenomena that may or may not be experienced or interpreted but are less amenable to empirical study or measurement (Fletcher, 2017). When all the powers and mechanisms are activated in this layer, events and experiences happen and become observable.

The real layer or domain is formed by all mechanisms that exist in the world; it is where the generative mechanism contributes to the understanding of the actual. It is in the real domain, possibly being unreachable to human senses, that critical realist research identifies the entities and powers (or causal mechanisms and configurations) which are finally responsible for the occurrence of events.

In conclusion, a realist ontology allows us to explore a subject within the real domain and to determine the generative mechanisms that produce the events we can observe in the empirical and actual domain.

4.4.2 Causality

All social structures have causal powers and liabilities. These powers are intrinsic in objects and structures and allow or hinder them from acting in specific ways (Fletcher, 2017). Critical realism adopts a view of reality as an open system that is beyond our ability to control directly (Bhaskar et al., 1998). Realist epistemology affirms that events do not necessarily reveal the mechanisms which have caused them, therefore a realist methodology should involve the construction of theories which can explain these appearances (Wainwright, 1997; Wainwright and Forbes, 2000).

Based on the principle that researchers cannot observe nor derive causal mechanism or powers directly, researchers should infer their existence based on the observable experiences that might have caused them. How researchers come to know reality is a crucial point in critical realism. Researchers have two ways to identify mechanisms: perceptual or causal criteria. Researchers can perceive and directly observe mechanisms, or they can observe their effects (Bhaskar et al., 1998). The direct observability of mechanisms have important consequences on how researchers come to know the real domain. Bhaskar affirms that our knowledge of entities is the result of a blending of intellectual, practical, technical and perceptual skills (Bhaskar et al., 1998), thus, providing us with a vision of a fluid knowledge, interwoven with the time and circumstances and influenced by a wide variety of internal and external conditions.

Another important underlying concept in critical realism is how researchers may or may not have access to the causal mechanism without looking at observable experiences, and how research comes to know these mechanisms. For these reasons, critical realism advocates that the object of study of natural or social science should dictate the research method; so, researchers need to undertake qualitative structural and etiological analyses of the world, mainly using a process of abstraction and retroduction that occasionally can be enriched by the use of quantitative techniques (Wynn Jr & Williams, 2012).

Retroduction is a core explanatory model used in critical realism to identify and verify a set of mechanisms which researchers hypothesise generated the observed phenomena and to investigate how these causal mechanisms act in the world (Wynn Jr & Williams, 2012). In other words, retroduction is a type of inference that explains events by postulating and identifying mechanisms which are capable of producing phenomena and events. Retroduction is an imaginative process in which the researcher proposes multiple explanations that describe a causal mechanism, set within a social structure that must exist in order to produce the events that have been observed (Archer et al., 2013; Wynn Jr & Williams, 2012). When it comes to data analysis, retroduction allows researchers to use both inductive and deductive methods to confirm and justify the events or the phenomenon under study.

A complementary inference model that accompanies retroduction in causal analysis in critical realism is abstraction. Abstraction facilitates the movement needed to penetrate the depth of social structures, moving from appearances to real essences, allowing researchers to focus on certain aspects and shadow others (Brown et al., 2002). Abstraction and retroduction allow researchers to identify multiple possible explanations of mechanisms leading to effects and to identify the likely existing combinations of these mechanisms. But how do we decide which criteria we should use in any given situation for judging between different accounts? Bhaskar rejects the Baconian search for a “sure and certain method”; theorised as removing the need for human thought and thus human error (Bhaskar et al. (1998), p.62), and instead proposes judgmental rationality, which allows different positions to be evaluated as being better or worse. As such, the explanation and accurate representation of the real world is the result of weighing the most probable cause of the mechanisms’ interaction that generate a given phenomenon.

4.4.3 Transitive versus intransitive knowledge dimensions

Mediated knowledge is a further relevant epistemological assumption of critical realism. Critical realism defines scientific knowledge as having both transitive and intransitive dimensions (Bhaskar et al., 1998). The intransitive dimension of knowledge is constituted by elements of the world that we seek to explain; the real things and structures, mechanisms and events of the world, which are mainly independent from what is perceived and experienced. The transitive dimension represents scientific knowledge about reality, which is fallible (Bhaskar et al., 1998), includes researchers' observations and theories, resulting from scientific investigation, that explain the independent world.

Critical realism admits that there is no perfect match between reality and theory, thus resulting in a fallible knowledge. The knowledge a researcher possesses of intransitive entities is produced in the transitive dimension and for this reason it is mediated by the existing social interactions, the social structures to which researchers belong and researchers' sensory and conceptual interpretations. For this reason, all knowledge resulting from a critical realist perspective is value aware because it is derived from multiple value aware perceptions (Wynn Jr & Williams, 2012).

4.4.4 Additional assumptions: multiple methods and triangulation

In addition to the three critical features, there are other relevant epistemological assumptions related to critical realism. Two pertinent critical realist beliefs reflect the use of multiple methods and triangulation. First, there is the existence of an independent reality that individuals can only partially access and understand. Second, there is the belief in the ability of science to approach this reality in a progressive manner (Archer et al., 2013). Social reality is an open system and an epistemological approach based on mediated knowledge, observability, and the possibility of multiple underlying mechanisms is considered effective to enable the identification of the generative mechanisms of events. As such, it is important to approach reality from multiple viewpoints in order to overcome a researcher's limits in perceiving it, using mainly qualitative research but also multimethod and triangulation strategies.

These strategies can be accomplished by using a combination of data sources, different approaches to data analyses, theories, investigators, and methods (Brown et al., 2002; Wynn Jr & Williams, 2012,). Interviews, archival data, documentation, and observation can all be used in triangulation in order to achieve the final aim of explaining events. The use of alternative theoretical perspectives and multiple investigators permits the researcher to explore conflicting reasons and to reduce personal biases.

4.5 Critical realism's methodology and methods

According to Hughes and Sharrock (2007) the terms method and methodology refer to two separate but related elements of research practice. Method alludes to those techniques adopted to collect data about a research object. Methodology examines the logic and rationale which underpins the use of particular methods. Critical realism, thanks to it double inclusiveness to overcome positivist and constructivist methodological research boundaries, supports an ample variety of research methods (Sayer, 1992). The encompassing ontology typical of critical realism allows a methodological pluralism characterised by both intensive qualitative research and extensive quantitative research approaches (Danermark, 2002; Sayer, 2000). To answer this research question, a qualitative approach was chosen to study the real domain as this research was conducted in the real world, which can be considered an open system. In other words, the objective was to obtain a deeper insight into how families' experiences are produced by causal powers. A qualitative rather than a quantitative approach was considered an appropriate tool to explore the complex interplay between the Swiss approach to assisted suicide and families' experiences of it. The aim was to gain in-depth information of practices, principles, and experiences that contribute to an understanding of the real domain.

Critical realist researchers are interested in identifying the deeper causal processes at work in the world (Sayer, 2000). To do so, researchers are called upon to identify an object of observation to abstract the underlying causal powers, or causal mechanisms, and finally to think conceptually about how they operate. Qualitative methods are suitable for this task because they allow the construction of a model of a potential mechanism, which can then be used to explain a set of observable patterns (Bhaskar et al., 1998). After having created a theory that explains the mechanism, it is possible to test its robustness in an open system. As a final step, researchers come to know how a causal mechanism operates and under what conditions it is activated (Sayer, 2000). In other words, the methodology focuses on what makes things happen, or as Sayer says, focuses on what kind of universe of meaning exists in a particular situation (Sayer, 2000).

4.5.1 Critical realist methodologies as a tool for studying family members' experiences of assisted suicide

In this section a brief description of the qualitative methods used in this research (see table 4) is provided, including a reflection of how they link with the critical realism ontology that underpins this research.

Table 4: The methods used in each article

	Paper 1	**Paper 2**	**Paper 3**	**Paper 4**
Research article	Family members' experiences of assisted dying: a systematic literature review with thematic synthesis.	Family caregivers' reflections on experiences of assisted suicide in Switzerland: aqualitative interview study.	Swiss families' experiences of interactions with providers during assisted suicide: a secondary data analysis of an interview study.	Responses to assisted suicide requests: an interview study with Swiss palliative care physicians.
Methodology	Systematic review and thematic synthesis	Framework analysis	Secondary data analysis	Thematic analysis

4.5.2 The need for a systematic review to capture a global picture

For the purpose of this research, a systematic review of the literature available in the area of assisted dying in jurisdictions where it has been legislated for, was necessary to capture a global picture of the status of scientific studies in a relatively new and developing area of research. The aim is to search, identify, select, appraise, and synthesise evidence relevant to the research question using a methodology that is explicit, reproducible and which should lead to minimal bias. Systematic reviews are regarded as a reliable foundation for the development of research (Tranfield, Denyer, & Smart, 2003). There are various approaches to organising the body of a literature review. In qualitative reviews, the results of relevant studies are summarised but not statistically combined. Finally, meta-analyses use statistical methods to integrate estimates of effect from relevant studies that are independent but similar and summarise them (Murad & Wang, 2017; Tucker & Steele, 2007).

The literature concerning families and assisted dying was derived from different countries, different legislations of assisted dying and from studies conducted with different methodologies. To rigorously interpret the existing literature, synthesising similarities and differences, a qualitative systematic review with a thematic synthesis was selected. Thematic synthesis has three stages: 1. the coding of each line of text; 2. the development of descriptive themes; and 3. generating analytical themes (Thomas & Harden, 2008). While the development of descriptive themes remains close to the primary studies, the interpretative stage of analytical themes allows the reviewer to go beyond the primary studies and generate new interpretive constructs, explanations or hypotheses (Thomas & Harden, 2008). Thematic synthesis is a tried and tested method that preserves an explicit and transparent link between the conclusions and the text of primary studies. It allowed me to gain an in-depth knowledge of the literature which produced an original publication, which has proven useful for other researchers, being cited more than ten times within its first year of publication.

Reflection on undertaking the systematic review

There were a number of challenges and considerations in the timing and conduct of the systematic review. First, I was well informed with the published material as a result of my earlier MA, from working in this area, but the formal systematic review was at a later stage of the PhD, when a greater body of literature had become available. Second, having conducted data collection for some of the empirical studies, I already had in mind the previously observed results which presented a challenge to reading the articles identified in the systematic review as if they were new to me. The process was also facilitated, as recommended by good practice, by having the co-authors also critically appraise these articles. Third, at the final stage of generating new interpretive constructs and explanations I had to go beyond the results of my own studies, widening my outlook to other approaches to assisted dying, and in other cultures, in the different countries where these studies were conducted.

4.5.3 Using qualitative interviews to capture the complexities of family member's experiences

In health care research, the qualitative interview is a useful and frequently utilised data-collection tool. Interviewing participants provides insight of their views and experiences and allows researchers to analyse and understand the world views of these participants. The use of interviews maintains the focus of the research on the interviewees' point of view, and they are preferable when the aim of the research is to take an individual's subjective perspective rather than that of a large group. Interviews also enable minority groups to express their views and to talk about sensitive topics, such as that of assisted suicide. Interviews are an interactive method of conducting research, they can establish a dialogue where the meanings, explanations and emotions articulated by interviewees are taken seriously by researchers (McGrath, Palmgren, & Liljedahl, 2019). As the epistemological background of this thesis is based on a critical realist approach, interviews are a suitable method that could allow an appreciation of the interviewees' interpretations of the subject with the interviewees' perceived social contexts, constraints and resources (Fletcher, 2017; Smith & Elger, 2014). Interviews give the interviewer and interviewee the opportunity to engage in a fluid interactive process that may facilitate the emergence of perspectives, observations, and experiences in a protected context.

A range of interview formats can be conducted with both individuals and groups and are available to researchers. The choice of method needs be relevant to the research design and methodology. There are several different types of interviews, from structured, semi-structured to unstructured. For the purpose of this thesis semi-structured in-depth interviews were chosen. Semi-structured interviews use an interview grid (Appendix X) to help guide the researcher. This type of interview consists mostly of a guided conversation between the researcher and participant, while ensuring that the conversation goes in the direction defined by the aims of the research. It provides the researcher with the flexibility to keep the interview open to new and unexpected additional details that may arise from participants. The choice of this type of interview was also made because previous knowledge from research about family experiences of assisted suicide (Gamondi et al., 2015; Gamondi et al., 2013; Starks, Pearlman, & Hsu, 2005) allowed the identification of a series of themes that had been suggested as essential to further investigate.

Due to the sensitivity of the topic, the choice for face-to-face interviews (typical for in-depth interviews) was made to create a safe space for interviewees, and for the researcher to be aware of the participant's body language and any other nonverbal cues that could add a high level of understanding to the answers. In-depth interviews usually provide rich, descriptive data about how people think and behave, and give the opportunity to unpack complex processes.

4.5.4 Framework analysis to manage a large and rich database of interviews

Framework analysis was used to analyse the data collected in the qualitative study exploring family members’ experiences during the decision for assisted suicide. The framework analysis method, also termed qualitative content analysis, was firstly applied in social policy research in the 1980s and has been more widely used in medical and health research fields (Bryman, 2008). Framework analysis may be used inductively and deductively. When used as a deductive approach, the researcher needs to have identified a priori themes, in advance of data collection, that they expect to detect in the data. These themes can be derived from similar studies or a literature review. When used as an inductive approach, themes are identified in the collected data and form the second step of the framework analysis. There is also a combination approach that takes a deductive stance juxtaposed with theresearcher’s openness to observe new themes appearing in the data, adding these into the framework.

Whether using deductive, inductive or combined approaches the framework analysis method produces highly structured summarised data and it is appropriate for multidisciplinary teams and to manage large datasets when the aim is to offer a holistic, descriptive overview of the entire data set (Davda, Gallagher, & Radford, 2018). A disadvantage for the researcher is that the framework method can be very time consuming and resource-intensive (Gale, Heath, Cameron, Rashid, & Redwood, 2013). It also requires extensive, reflexive and critical dialogue about how the participants’ ideas that are being coded may relate to concepts and theories that are already known, and to the real problem that is under investigation.

Data collection is very important in a critical realism approach, so in keeping with critical realism ontology, this data analysis began with the search for demi-regularities at the empirical level of reality. As such, critical realism looks for tendencies, not laws (Danermark, 2002). As Fletcher (2017) has noted:

> *These tendencies can be seen, for example, in rough trends or broken patterns in empirical data. Critical realists call these "demi-regularities"' Demi-regularities can be effectively identified through qualitative data coding*
>
> Fletcher, 2017, p.11

A combined approach to analyse data derived from the interviews was used. First, to develop the results of the pilot study conducted as part of my master's studies (Gamondi, 2012; Gamondi et al., 2015; Gamondi et al., 2013). Second, to identify to any new themes emerging from the participants' experiences.

In critical realism the use of existing theory as a starting point for empirical research is permitted as,*"once a hypothesis about a generative structure has been produced in social science it can be tested quite empirically, although not necessarily quantitatively"* (Bhaskar et al. (1998), p.62). In light of the results derived as part of my master's studies, a higher level of interpretative analysis had identified a timeline of assisted suicide that was visible in the data but was also observed in data published in the Netherlands and the United States (Dees et al., 2013), as well as in my clinical experience. In the existing literature there was no proven theory around family involvement, therefore the framework analysis enabled the structuring of the coding framework by combining two different strategies (concept driven and data driven) without having available a pre-existing theory.

4.5.5 Secondary data analysis to analyse interactions with providers and choices around disclosure

The first study, *"Family caregivers' reflections on experiences of assisted suicide in Switzerland: a qualitative interview study"* produced a large, high quality and rich amount of data. Recruitment to the study was challenging due to the sensitivity of the topic and the secrecy with which families usually treat the topic of assisted suicide. New research questions had emerged within the literature, following the publication of the three studies, which warranted further exploration of the families' interview data. A secondary data analysis of the first study thereby enabled me to ask a different question when analysing the original dataset; in this case, what is enabling or deterring these practices.

Although secondary data analysis of quantitative primary data is a common practice, it is less widely used for qualitative primary data (Long-Sutehall, Sque, & Addington-Hall, 2011). In general, a critique of secondary data analysis is that the secondary researcher does not participate in the data collection process and does not know how exactly it was conducted. To overcome this limitation, an additional researcher checked my data analysis, and we discussed the results, to ensure full familiarity with the data and how it was collected.

This secondary data analysis gave an opportunity for the further investigation of the research through replication, re-analysis and re-interpretation of existing data (Long-Sutehall et al., 2011). It enabled me to test new ideas, theories, frameworks and models of research design. Overall, the use of the secondary data analysis acted as a support to the primary data collection and as the last research study of this PhD, it provided new information to help address the research question.

4.5.6 Thematic analysis to discover existing tensions in Swiss physicians' perspectives and involvement in assisted suicide.

Thematic analysis was used to analyse the data collected in the study exploring Swiss palliative care physicians' perspectives of and involvement in assisted suicide practices, as well as their experiences of interacting with families. Thematic analysis is an accessible and flexible method of qualitative data analysis. It is one of a cluster of methods that focus on identifying patterned meaning across a dataset (Braun & Clarke, 2006). Originally developed by Braun and Clarke, it is a method for systematically identifying, organising, and offering insight into patterns of meaning (themes) across a data set (Braun & Clarke, 2006). By finding a transversal meaning across a data set, it allows the researcher to make sense of collective or shared meanings and experiences. One of the advantages of thematic analysis is that it is theoretically flexible. This means it can be used within different frameworks, to answer quite different types of research questions. Thematic analysis has been applied in a number ofways: inductive versus deductive coding and analysis, an experiential versus critical orientation to data, and an essentialist versus constructionist theoretical perspective (Braun & Clarke, 2006; Vaismoradi, Jones, Turunen, & Snelgrove, 2016). Any of these ways can share a common basis that assumes a knowable world that gives a voice to experiences and meanings of that world.

Braun and Clark recently revised their thematic analysis method and named it the reflexive approach. Authors have also used thematic analysis approach within a critical realist ontology (Clarke, 2019) appreciating that knowledge and experiences are constructed with language and discourses, and phenomena are generated by social structures. Authors using a critical realist ontology and thematic analysis approach to data were able to show how and why some important life decisions were negotiated and altered within relationships with partners, friends, and family (Wiltshire & Ronkainen, 2021). At the same time, by using critical realism theories authors were able to capture the complexities of the interactions between the individual choice and contemporary (re)constructions of some debated entities in society such as gender issues, parenthood and medical decisions (Wiltshire & Ronkainen, 2021). As there was no literature on Swiss physician experiences of assisted suicide, I considered thematic analysis an appropriate approach to take when exploring an evolving and debated theme, such as assisted suicide. This inductive approach includes a strong reflexive element which allows the bringing together of all participants' voices, whilst also contextualising data, and incorporating the complex and unique Swiss reality into the analysis.

I do not claim to have provided a perfect example of a critical realist approach to the theme of assisted dying but hope to have provided sufficient evidence and motivation to stimulate future researchers to apply a critical realist perspective and employ qualitative methodologies when studying the area of assisted dying and its multiple facets.

In conclusion, applying a critical realist approach meant taking into account that family members' and physicians' experiences of assisted suicide are both socially constructed and are influenced by external factors that can be real and independent of any one person or social group. Figure 6 provides a visual depiction of this methodological approach.

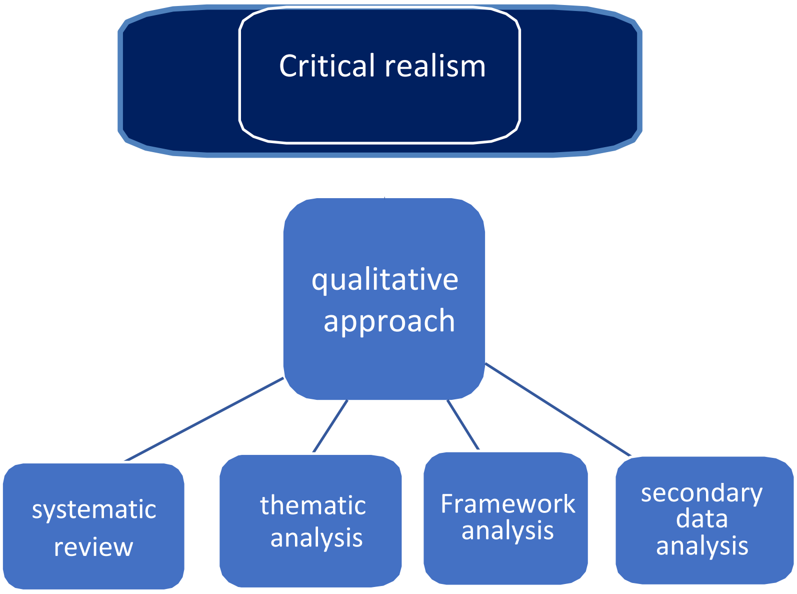

Figure 6: The methodological approach taken in this research

When considering how family members and physicians make sense of their involvement (cooperation) in assisted suicide, critical realism enables the consideration and incorporation of material (e.g., type of involvement), institutional (e.g., the availability of assisted suicide), embodied (e.g., system of belief), and other elements that may structure how the families make sense of their experience.

CHAPTER FIVE

FAMILY MEMBERS' EXPERIENCES OF ASSISTED DYING: A SYSTEMATIC LITERATURE REVIEW WITH THEMATIC SYNTHESIS

5.1 Overview

This paper (Gamondi et al., 2019) specifically addresses the first research aim of the thesis:

> *To systematically analyse the published literature on families' experiences with a family member who died with assisted dying, in jurisdictions where it is it is legally permissible.*

5.2 Data collection and analysis

I was supported by a professional librarian, Caroline Gibson, from the Lancaster University Library, who provided advice in designing the review's search strategy and in using databases. In all, 1390 results were retrieved, and following removal of duplicates, the remaining articles (n=1200) were screened. Good practice was adhered to by having more than one reviewer for the systematic reviews. These co-reviewers (acknowledged by co-authorship), Dr Tanja Fusi- Schmidhauser and Dr Anna Oriani, assisted by checking the inclusion of the articles I had selected and data extraction on a proportion of the papers. This included confirming the inclusion and coding of the three papers that had been written by me. Nineteen articles, representing 14 studies, met the inclusion criteria.

5.3 Reflexivity

This systematic review enabled me to explore the literature on families' experiences in both types of assisted dying (euthanasia and assisted suicide). It gave me the opportunity to reflect upon the different methodological approaches used worldwide to investigate family members' experiences. The main challenge was to be cognisant of how my pre-existing knowledge of the topic, and the emerging themes of the thematic synthesis, combined to shape the results and give foundation to the finding's clinical implications.

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Family members' experiences of assisted dying: A systematic literature review with thematic synthesis

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Abstract

Background: Families' experiences of assisted dying are under-investigated and families are rarely considered in clinical guidelines concerning assisted dying.

Aim: To systematically review family experiences of assisted dying.

Design: A systematic literature review using thematic synthesis.

Data sources: MEDLINE, Embase, CINAHL, AMED (Allied and Complementary Medicine) and PsycINFO databases (January 1992 to February 2019). Studies investigating families' experiences on the practice of legalised assisted dying were included. We excluded studies prior to legalisation within the jurisdiction, secondary data analysis and opinion papers.

Results: Nineteen articles met the inclusion criteria. Publications were derived from four countries: The Netherlands, United States (Oregon, Washington and Vermont), Canada and Switzerland. Dutch studies predominately investigated family involvement in euthanasia, while Swiss and American studies only reported on assisted suicide. Eleven studies had a qualitative design, using predominately in-depth interviews; seven were retrospective surveys. Five analytical themes represented families' experiences in assisted dying: (1) *context of the decision*, (2) *grounding the decision*, (3) *cognitive and emotional work*, (4) *experiencing the final farewell* and (5) *grief and bereavement*. The results showed that families can be very involved in supporting patients seeking assisted dying, where open communication is maintained. Family involvement appeared to be influenced by the type of legislation in their country and the families' perception of the social acceptability of assisted dying.

Conclusion: Our data confirm that families across all jurisdictions are involved in assisted suicide decision and enactment. Family needs are under-researched, and clinical guidelines should incorporate recommendations about how to consider family needs and how to provide them with evidence-based tailored interventions.

Keywords

Systematic review, thematic synthesis, assisted suicide, euthanasia, assisted dying, family experiences

What is already known about the topic?

- Families may play a role in facilitating patients to obtain assisted dying, and their opposition can impact the outcomes.
- Families are rarely mentioned in clinical guidelines and recommendations and their needs are mostly unknown.

What this paper adds?

- Family involvement may be influenced by many factors such as cultural aspects, the type of legislation in their country and their perception of the social acceptability of assisted dying.

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- Broader support from health care professionals and families seems to play a role in influencing families' experiences during and after assisted dying.
- Assisted suicide models appear to leave more tasks and responsibilities to family members, whereas the Dutch model of euthanasia seems to leave families with less responsibilities and tasks.

Implications for practice, theory or policy

- Families need to be recognised as participating in the decision and enactment of assisted dying. Assisted dying is a complex decision, mostly resulting from negotiations between the patient, the physician and the family members involved.
- Family members should be included in clinical consultations and their needs addressed, with the same care as for patients.
- Research should be conducted to understand family needs and interventions to support their needs in relation to the different models of assisted dying.

Introduction

The overall numbers of assisted deaths are rising, although few countries in the world permit assisted dying. In the last 20 years, assisted dying has been legalised in a growing number of countries.[1] At present, potentially about 176 million citizens worldwide have access to assisted dying. Assisted dying is a term that encompasses both assisted suicide and active euthanasia.[2] These end-of-life choices are characterised by competent patients having to self-administer (assisted suicide) or be injected (active euthanasia) with a drug to intentionally terminate their lives at their request.[3]

Assisted dying is a complex choice, which may be contemplated many decades before a patient chooses this end-of-life option.[4–6] The decision seems to be characterised by different phases leading to the final choice.[7] Families may play a critical role in facilitating patients to obtain assisted dying, and their opposition can influence the patient's possibility to obtain assisted dying. Depending on the model of assisted dying, it appears that family members may be required to take on extra responsibilities such as seeking practical information about assisted dying, approaching physicians and, in the case of assisted suicide, handling lethal medications and being present on the day of ingestion.[8,9] Conversely, dissenting members of the family can be stigmatised and accused of selfishness.[10,11] In jurisdictions where assisted dying was on the cusp of legalisation, data showed that some families helped patients to hasten their deaths in part to honour their intent, in part to be faithful to promises made in advance of their final illness, despite fearing and risking legal prosecution for their actions.[12]

It appears that ethicists, legislators and researchers' focus is predominately on patients and refers less to family members. For example, families are only marginally considered in clinical guidelines and recommendations internationally. Relatives are considered briefly by the Royal Dutch Medical Association position on euthanasia. They are mentioned as closely involved in the euthanasia requests and mostly in agreement with patients' wishes. The Dutch Medical Association states that family members' opinions are not decisive in principle; however, it is advisable that the physician should consider the possible dissent of family members and try to reconcile it as much as possible.[13]

To date, no published review could be found that identified studies concerning assisted suicide or euthanasia experiences among family members of patients who died of assisted dying in countries where it is legal. The purpose of this study was to review research critically and to describe the experiences of family members. In doing so, we aimed to identify implications for policy and practice and to recommend future research priorities.

Methods

The review question

What are family members' experiences of assisted dying? The aim was to provide a comprehensive understanding of family members' experiences with patients who died with assisted dying in jurisdictions where it is legally permissible.

The review design

Thematic synthesis was used because it is designed to address questions about people's perspectives and experiences and enables the synthesis of both qualitative and quantitative data.[14] This review was prepared using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocol (PRISMA-P) guidelines.[15]

The search strategy. Peer-reviewed and grey literature published from 1 January 1992 to 28 February 2019 was searched. For completeness, our search started 5 years prior to the implementation of the first law regarding

Suicide, Assisted or suicides, assisted or death, assisted or assisted death* or death*, assisted or assisted suicide* or physician-assisted suicide* or PAS or physician assisted suicide* or suicide*, physician assisted or medically assisted suicide* or suicide*, medically assisted or family assisted suicide* or FAM or patient-directed aid in dying or patient-directed dying or assistance in dying OR Euthanasia or voluntary Euthanasia or euthanasia, voluntary or active euthanasia or end-of-life decision making or hasten death or dying with dignity or aid in dying or bereavement euthanasia
AND
Family member* or carer* or caregiver* or relatives or prox* or famil* or friend (significant others)
AND
Experience* or perception* or attitude* or view* or opinion* or feeling* or bereavement* or attitude* or perspective* or reflection* or lived experience*

Figure 1. Search strategies and terms used in PubMed/MEDLINE (NLM): Keyword terms and medical subject headings (MeSH).

assisted dying in Oregon (enacted January 1997); however, no studies before legislation were included. A specialist health librarian was consulted regarding the search strategy. Five electronic databases were searched: MEDLINE, Embase, CINAHL, AMED (Allied and Complementary Medicine), and PsycINFO. The following keywords, along with synonyms and where available subject headings, were used: 'assisted suicide', 'assisted dying', 'euthanasia', 'caregiver' and 'experience' (see Figure 1).

The MEDLINE search was then adapted to also search the other databases. In addition to the electronic database search, the search strategy included a hand-search of the key journals, and selected articles were mined and citation tracked.

Study eligibility. In all, 1389 results were retrieved, and one further PhD thesis from other sources was identified ($n = 1390$). Following removal of duplicates ($n = 195$), the remaining articles ($n = 1200$) were screened in two phases. Three reviewers (C.G. and T.F.-S. or A.O.) screened titles and abstracts to identify studies that met the inclusion criteria (1155 articles excluded). Many studies were excluded because they were health care professionals' accounts of families' experiences or they were investigating opinions and attitudes about assisted dying in general, without evidence of having had a personal experience. With the aim to consider the participants' own words as generative of meaning and knowledge, only studies reporting about direct experiences of family members were included. In the second stage, two researchers (C.G. and T.F.-S.) reviewed the full texts of the remaining 45 studies to check adherence against inclusion and exclusion criteria (Table 1). Any disagreement was resolved by N.P. and S.P. Nineteen articles were included in the review. A flow diagram of the selection procedure and results (using the PRISMA tool) is presented in Figure 2. Informative qualitative studies about families' experiences in some US States were published before these States enacted laws regulating assisted dying; for this reason, these studies were not included.

Quality assessment and data extraction. The quality of included articles was appraised using a structured checklist designed for diverse data.[17] The tool was considered appropriate as it appraises the quality of both quantitative and qualitative studies. The quality assessment considered nine domains: abstract, introduction, method, sampling, analysis, ethics and bias, results, transferability and implications. Each domain was scored out of four, with higher scores indicating better quality, giving a maximum score of 36 and a minimum of 9. Two authors (C.G. and T.F.-S.) completed the appraisal form together. Equal weight was given to all papers included, independently from quality assessment scores. Data were extracted summarising the principal characteristics of the selected articles: data on the year of publication, study design, time, the country where research was conducted, recruitment methods, participants and analysis (Table 2). Furthermore, the aims of the included studies were carefully examined to identify those specific to our research question.

Data synthesis. The review followed a three-step process.[14] Articles were analysed, and the initial free coding, conducted line by line, was carried out with specific attention to the Results section of each article where the families' experiences were described. Codes were created freely without a hierarchical structure, created inductively to capture the meaning and content of each sentence. In the second step, descriptive themes were developed initially to group common issues. In this phase, the line-by-line coding enabled the *translation* of concepts from one study to another to start the synthesis. In the third step, analytical themes were generated *'going beyond' the primary codes and descriptive themes to generate new interpretative constructs. Reviewers i*nferred relatives' experiences from the content of the retrieved articles, reflecting upon the different aspects of assisted dying decision in terms of task, experiences and timeline. Reviewers also identified the different aspects of assisted dying and related them to families' experiences and compared them with the different model each

Table 1. Inclusion and exclusion criteria.

	Inclusion criteria	Exclusion criteria
Population or participants	Carers of adult patients (over 18 years old)	Studies reporting about proxy accounts of carers' experiences of assisted dying Research that does not include information about direct experiences Research upon classic suicide
Interventions or exposures	Involved in assisted dying	Studies on passive euthanasia (defined as withholding or withdrawing life-sustaining medical treatments from a patient to let the patient die), palliative sedation, LAWER (life-terminating act without explicit request) and ending of life without the patient's explicit request, and intensified alleviation of symptoms Studies exploring patient's wish to die, wish to hasten death or patients' or family members' opinions regarding assisted dying
Setting	Studies conducted in countries where assisted dying is legal or legally condoned	Studies conducted in jurisdictions where these practices are NOT legalised or legally condoned
Study designs	Primary research. Quantitative and qualitative studies	Non-empirical research, case reports, and opinion pieces and editorials
Language of the articles/time	Findings published in English, French, Italian, German and Spanish Studies conducted after implementation of law in allowing jurisdictions	Full text in English, French, Italian, German and Spanish not available or in other language Studies conducted before implementation of law in allowing jurisdictions

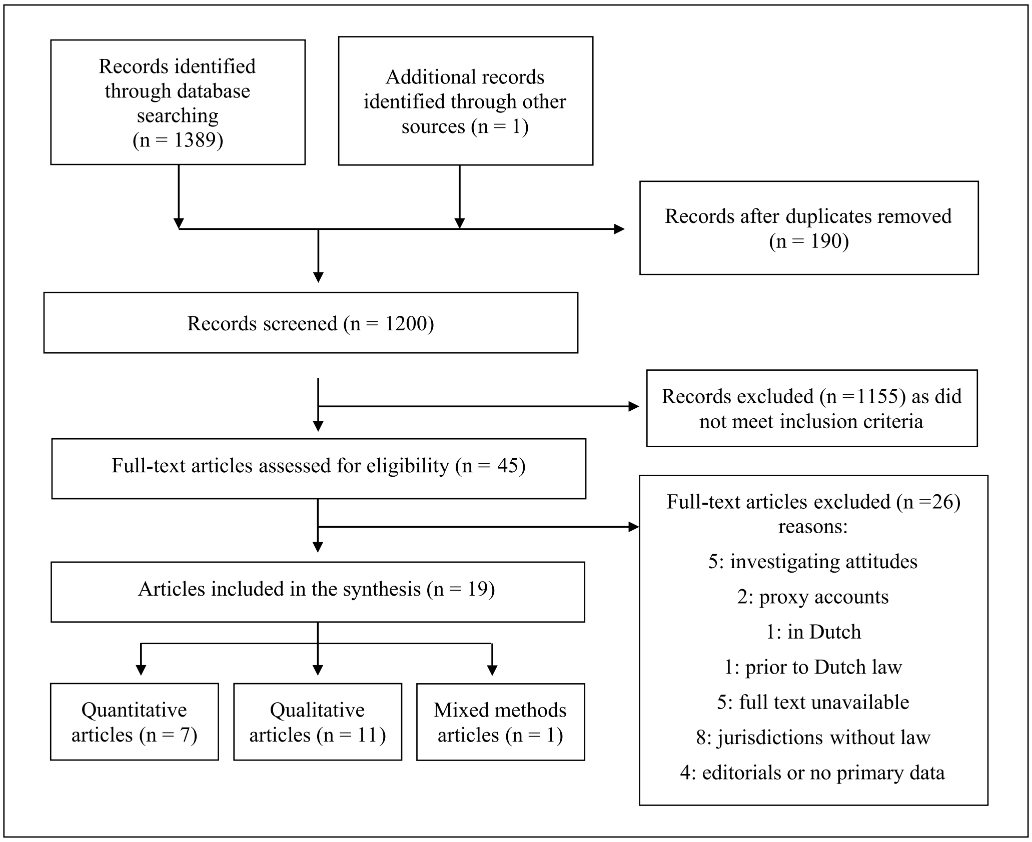

Figure 2. Search process flowchart (PRISMA flow diagram).[16]

Table 2. Principal characteristics of the selected articles.

Author, year of publication, country, quality rating (appraisal rating)	Study aims	Design	Recruitment method	Participants	Patients' main illness	Type of assisted dying discussed	Causes of patients' deaths
Buchbinder et al., 2018, Vermont, Hawker rating: 36	To explore the experiences of lay caregivers involved with AD	In-depth interview study	List of physicians in departments of oncology, neurology, and palliative care, hospice agency representatives, face-to-face meetings at medical conferences and advocacy events, snowball	19 bereaved family members	Cancer and ALS	AS	AS
Dees et al., 2013, The Netherlands, Hawker rating: 35	1. Explore the decision-making process of AD 2. Identify themes to optimise the process	Multiple perspective, serial interview study	Past treating physicians participating in previous studies, hospice organisations, right to die associations, hospitals and nursing homes	32 cases: 32 patients; 29 relatives and 28 treating physicians	Cancer, neurologic disease, psychiatric disease, chronic pain syndrome, heart failure, tired of living	Euthanasia	11 requests not granted
Dieltjens et al., 2014, The Netherlands, Hawker rating: 26	1. Explore the concept of unbearable suffering 2. Explore physicians' communication style	Interview study	Support and Consultation on Euthanasia in the Netherlands (SCEN network)	15 interviews with 5 patients, the closest relative and GP	Not mentioned	Not mentioned	Not mentioned
Gamondi et al., 2013, Switzerland, Hawker rating: 36	1. Explore patients' reasons for AD 2. Explore family perceptions of interactions with health care professionals	In-depth interview study	Palliative care home care services	11 bereaved family members	Cancer	AS	AS
Gamondi C et al., 2015, Switzerland, Hawker rating: 36	1. Explore family involvement in decision making of AS 2. Examine ways of coping in bereavement	In-depth interview study	Palliative care home care services	11 bereaved family members	Cancer	AS	AS
Gamondi et al., 2018, Switzerland, Hawker rating: 36	1. To explore family members' experiences of involvement in AS 2. To explore their reflections on involvement in AS	In-depth interview study	Palliative care organisations, right to die associations, hospitals and nursing homes, snowball, word of mouth	28 close relatives and family carers	Cancer, ALS, multimorbidity, tired of living.	AS	AS
Ganzini et al., 2002, Oregon and Washington, Hawker rating: 33	Understand factors associated with interest in AS	Survey	Neuromuscular clinic and veterans affairs Medical clinic	50 caregivers	ALS	AS	AS
Ganzini et al., 2008, Oregon, Hawker rating: 35	Understand patient' reasons for AS	Cross-sectional survey	Compassion and choices, two large medical centres and ALS association	83 AS requesters and their family members	Cancer (88%) ALS (7,2%) Cardiopulmonary (2.4%) Other (2%)	AS	AS and underlying illness

(Continued)

Table 2. (Continued)

Author, year of publication, country, quality rating (appraisal rating)	Study aims	Design	Recruitment method	Participants	Patients' main illness	Type of assisted dying discussed	Causes of patients' deaths
Ganzini et al., 2009, Oregon, Hawker rating: 36	1. How patients' choice for AS affected family caregivers 2. Measure grief symptoms, use of mental health services and depression after AS death 3. Compare it with a control group	Cross-sectional survey on bereaved family members	Compassion and choices, past treating physician, two large medical centres, hospices organisations, SLA Oregon association	95 bereaved family members	ALS		AS and underlying illness
Smith et al., 2011, Oregon, Hawker rating: 34	Explore differences in the quality of dying experience from the perspective o family members of three populations of Oregonians: who received a prescription for AS, who got a prescription refused, who did not pursue AS	Cross sectional survey with control group	Medical centres, hospices, ALS association, compassion and choices	147 family members	Cancer and ALS	AS	AS and underlying illness
Georges et al., 2007, The Netherland, Hawker rating: 25	1. Gain insight into background and history of request for AD 2. Gain insight into the influence of AD in need of a patient's life	Interview study	Past treating physicians	87 bereaved family members	Cancer (85%) Neurological condition (15%)	Euthanasia and AS	Euthanasia (97%) AS (3%)
Holmes et al., 2018, Canada, Hawker rating: 27	To examine the journey of family and close friends who supported a loved one through the process of AD	In-depth interviews	Clinic advising about AD in Vancouver	18 family members	Cancer, organ failure, neurological conditions		
Jansen-van der Weide et al., 2009, The Netherland, Hawker rating: 31	Investigate the impact of a visit from a consulting physician on the patient and relatives during euthanasia procedure	In-depth interviews and questionnaires with open-ended questions	Past treating physicians	86 bereaved family members	Cancer, other non-mentioned	Euthanasia	AD, refusal of euthanasia, and underlying illness
Pasman et al., 2013, The Netherlands, Hawker rating:34	Explore patients and family members' perspectives after a refusal of a request for euthanasia	In-depth interviews	Dutch associations that provide advance directives	9 patients, 3 bereaved relatives and 11 treating physicians	Stroke, rheumatism, multiple neurological conditions, dementia, autoimmune disease, heart failure, cancer	Euthanasia	underlying illness (EAS refused)
Snijdewind et al., 2014, The Netherlands, Hawker rating: 30	Identify and categorise the characteristics of euthanasia requests that are more complex than others	In-depth interviews	Past treating physicians participating in previous studies	28 physicians + 26 relatives	Cancer, psychiatric, neurological condition, heart failure, old age, COPD, dementia, ALS	Euthanasia	Euthanasia, AS, classical suicide and underlying illness

Table 2. (Continued)

Author, year of publication, country, quality rating (appraisal rating)	Study aims	Design	Recruitment method	Participants	Patients' main illness	Type of assisted dying discussed	Causes of patients' deaths
Srinivasan, 2018, Oregon, Hawker rating: 30	To explore grief following AD	In-depth interviews	Compassion and choices of Oregon	22 bereaved relatives	Not mentioned	AS	AS
Wagner et al., 2012, Switzerland, Hawker rating: 30	Examine effects of perceived social acknowledgement on symptoms of post-traumatic stress disorder and complicated grief in family members bereaved after AS	Cross-sectional survey	Right to die association	85 family members	Cancer (52%) Non-fatal disease (36%) Cardiac disease (14%) Dementia (6%) Mental disorder (3%)	AS	AS
Wagner et al., 2011, Switzerland, Hawker rating: 30	1. To evaluate the relationship between forensic investigation and mental health in family members bereaved after AS 2. Descriptively analyse the behaviour of the participating officials as perceived by a relative	Cross-sectional survey	Right to die association	85 family members	Cancer (52%) Non-fatal disease (36%) Cardiac disease (14%) Dementia (6%) Mental disorder (3%)	AS	AS
Wagner et al., 2012, Switzerland, Hawker rating: 30	Compare the psychological impact of AS on bereaved family members and friends with that described in the Swarte et al.[32] study	Cross-sectional survey	Right to die association	85 family members	Cancer (52%) Non-fatal disease (36%) Cardiac disease (14%) Dementia (6%) Mental disorder (3%)	AS	AS

AD: assisted dying; AS: assisted suicide; ALS: amyotrophic lateral sclerosis; COPD: chronic obstructive pulmonary disease.
Articles stemming from the same studies are grouped and appearing in different background colours in the table.

country legalised. Reviewers then considered the implications of their findings in terms of clinical practice and research priorities.

Results

Nineteen articles, representing 14 studies, met our inclusion criteria and were included in the review.[4,7,9–11,18–31] Ten studies (11 articles) used a qualitative design.[4,7,9–11,18,23,24,26–28] Three studies (seven articles), which were retrospective surveys, used a quantitative design.[19–22,29–31] Only one study (three articles) had a control group of patients dying of underlying illness.[20–22] One study had a mixed-methods design.[25] Included studies differed in the type of assisted dying, patient's underlying illness and time elapsed from death to participation in the study. Descriptive characteristics of the 19 articles are presented in Table 2.

Study characteristics

The 14 included studies (19 articles) provided information derived from four countries: The Netherlands (*n* = 6);[7,18,25–27] Oregon, Washington and Vermont in the United States (*n* = 4);[9,19–22,28,33] Canada (*n* = 1);[24] and Switzerland (*n* = 3).[4,10,11,29–31] Dutch studies investigated family involvement predominately in the context of euthanasia and refusal of euthanasia. Pasman et al.[26] reported on experiences when a euthanasia request was denied, resulting in deaths from underlying illness. Swiss and American studies focussed exclusively on deaths through assisted suicide.

All studies reported that patients had a variety of diseases such as cancer, neurodegenerative diseases or organ failure. Studies by Dees et al.[7] and Wagner et al.[29–31] also included a minority of patients who had 'non-fatal diseases', were 'tired of living' (the Netherlands) or had 'mental disorders' (Switzerland). Most of the family member participants were spouses or children of patients. A small amount of data concerned wider family members or friends.

Fourteen articles specifically investigated relatives' direct experiences. The remaining five articles' primary focus was on patients' or health care professionals' experiences or attitudes regarding assisted dying.[7,18–20,22] These articles used relatives as proxies. They were included in the review because there was additional information on relatives' experience that was relevant to the research question.

Five analytical themes were identified that represented families' experiences of assisted dying (Table 3): (1) *precursors and context of the relationship*, (2) *coming to and enacting the decision*, (3) *cognitive and emotional work*, (4) *experiencing the final farewell* and (5) *grief and bereavement*. It appeared that families reframe the decision over time, moving from the theoretical possibility of assisted dying to a practical option for the patients and its ultimate achievement.

A description of each analytical theme concerning the families' experiences is presented below.

1. Precursors and context of the relationship

Most of the data across countries indicate that family members involved in assisted dying had strong and close bonds based on open interactions with patients. These relationships were reported to be a positive help during assisted dying, offering families safety and comfort. Snijdewind et al.[27] also supported the hypothesis that relatives valued a time of contemplation in which they could play an important role and where patients and physicians '*grew together toward the final decision to perform euthanasia*'. In general, assisted dying was considered by relatives to be a personal right and a principle to be respected. This perception of assisted dying as a right was mostly evident in Switzerland and the United States in relation to assisted suicide.

The importance of family members in building an open relationship with patients and having the possibility to express their ideas about assisted dying emerged from all countries and independent of the type of assisted dying they experienced.[7,10,11,20,21,27] Gamondi et al. and Ganzini et al. indicated that being in support of assisted dying seemed conducive for families to discuss assisted dying as a theoretical possibility, long before it became an end-of-life possibility in own lives.[4,10,11,21] However, the very little data describing patterns of involvement of relatives who did not agree with assisted dying showed that consensual family members occasionally excluded and considered as selfish opposing family members.[10,11]

2. Coming to and enacting the decision

In general, witnessing patient's suffering becoming unbearable over the illness experience represented for family members a key motivator to agree with their request for assisted dying. Three components appear to interact and contribute to families' experiences at this stage: personal values, the respect of mutual values and the interaction with health care professionals.

Personal values and the respect of values of others played an essential role.[7,10,11,21] Agreeing on assisted dying appeared to play an important role in shaping families' experiences;[4,10,24] family members sharing with the patient the same values was more supportive on both moral and practical grounds during assisted dying preparation and lethal medication ingestion. Swiss, Oregon and Dutch studies indicated that families were previously aware or not surprised by the patient's wish for assisted dying. Assisted dying was perceived as the patient's

Table 3. Mapping of the themes in relation to the included studies.

Themes	Subthemes	Papers related to each category
Precursors and context of the relationship	Long-standing relationship Strong bonds within the family Medium/high level of education Agreement on assisted dying as a principle	Ganzini et al.[29] Dees et al.[7] Snijdewind et al.,[27] Wagner et al.,[29,30] Ganzini 2007 Gamondi et al.[10] Gamondi et al.[4] Srinivasan[28] Holmes et al.[24]
Coming to and enacting the decision	*In relation to personal values*: Legacy to respect Respect of patient autonomy Awareness of patient's wish for assisted dying Assisted dying as a component of quality of life and quality of death *In relation to illness experience*: Interpreting unbearable suffering Perception of care *In relation to the decision itself*: Sharing the decision Restriction in open dialogue within the family and with others Mutual respect for autonomy Clear and open communication/collaboration Pace of the decision Knowledge about the process of assisted dying *In relation to professionals*: Handling the responsibility of criteria verification and choice of the day to professionals Limited/ample sharing with physicians Openness and honesty of physicians	Ganzini et al.[29] Dees et al.[7] Georges et al.[23] Smith et al.[22] Ganzini et al.[19] Pasman et al.[26] Jansen-van de Weide et al.[25] Gamondi et al.,[10] Gamondi et al.[4] Buchbinder et al.[9] Holmes et al.[24]
Cognitive and emotional work	Acknowledging upcoming death Feelings of helplessness facing patient's suffering *Challenging aspects*: Regrets if assisted dying is not achieved Feelings of isolation during decision making Feelings of regret over how patient died Emotionally problematic 'Unnatural'/'Unfamiliarity' of the choice of the day Dealing with dissenting members of family Maintaining secrecy during decision Self-questioning concerning own selfishness Pondering the rightness of assisted dying and depth of involvement *Positive aspects*: Feeling at peace with the patient's choice Feeling involved in the choice Perception of advocating for the patient Peaceful death Assisted dying considered better than classical suicide *Legal concerns*: Fears of irregularities in the procedure (Switzerland) Fears of euthanasia rejection Safety if euthanasia responsibility stays with physicians Prudency in allowing euthanasia	Ganzini et al.[21] Dees et al.[7] Georges et al.[23] Wagner et al.[29,30] Smith et al.[22] Jansen-van de Weide et al.[25] Gamondi et al.[10] Gamondi et al.[4] Srinivasan[28] Buchbinder et al.[9] Holmes et al.[24]
Experiencing the final farewell	Navigating between 'limited time left' and postponing death Personal conflict between wish for more life and impotence facing inevitability of death Anticipating and controlling death Possibility and awareness of the final farewell	Ganzini et al.[21] Dees et al.[7] Georges et al.[23] Wagner et al.[29,30] Smith et al.[22]

(Continued)

Table 3. (Continued)

Themes	Subthemes	Papers related to each category
	Planning of the farewell considered as disturbing	Jansen-van de Weide et al.[25]
	Organisation of rituals	Gamondi et al.[10]
	Choice of the place of death	Gamondi et al.[4]
	Keeping communication open until death	Srinivasan[28]
	Dealing with authorities (Switzerland)	Buchbinder et al.[9]
	Privacy right after death (Switzerland)	Holmes et al.[24]
Experiencing grief and bereavement	A time for ‘re-thinking’, ‘coming to terms’, ‘solving dilemmas’	Ganzini et al.[21] Snijdewind et al.[27]
	Time as a healing instrument	
	Time makes things harder	Wagner et al.[31]
	Feelings of isolation during bereavement	Dieltjenset al.[18]
	Fears of being judged or disapproved	Jansen-van de Weide et al.[25]
	Concerns about potential stigma associated with assisted dying	Gamondi et al.[10]
	Unwillingness to share their experiences with others	Gamondi et al.[4]
	Gratitude for the natural death	Srinivasan[28]
	No access to bereavement services	Buchbinder et al.[9]
	Positive experience in participating in assisted dying research	Holmes et al.[24]

decision that they should honour, and when assisted dying was not achieved, some family members felt that this right was not respected.[21]

Most of the studies showed that families had contacts with professionals, during decision making and/or lethal medication delivery, depending on assisted dying models. Dutch families valued a shared decision-making model and valued mutual respect for autonomy between patients and family members.[7] Clear and open communication with health care professionals was valued by family members in the Netherlands, whereas Swiss families shared little or no information with their own physicians but actively looked for physicians who shared common values and were willing to provide them with the required legal documentation. Families in Vermont reported that physicians and nurses were sometimes present at the moment of death, and this gave them emotional support.[9]

3. Cognitive and emotional work

Families had to engage cognitively and emotionally in the experiences of assisted dying to come to a decision that could reflect their values and those of the patient. Families experienced mixed feelings, and they had to cognitively process many decisions that challenged their values, belief systems and their knowledge about legal issues and procedures.

Emotional work

Diverse emotions characterised families’ experiences. Families in Oregon indicated that they experienced positive emotions such as the feeling of being at peace, of accepting the patient’s choice and of having felt included in the choice.[21] Georges et al.[23] reported that 92% of participants in a survey stated that assisted dying had contributed to the quality of the patient’s end of life, leaving families with positive feelings. In general, assisted dying was perceived as a peaceful death.[9–11,22,24] Families appeared to consider assisted dying a better death than that of classic suicide.[10] Few families experienced feelings of regret over how the patient died.[21] However, when professionals refused euthanasia, some families expressed gratitude that the death did not occur.[18] Family members experienced some fears about assisted dying, such as being stigmatised by health care professionals or friends and being prevented from obtaining assisted dying.[4,10,11,25] In the Swiss civil model of assisted dying, families reported fears of being prosecuted after the patient’s death or fears concerning possible irregularities in the procedures.[10,31]

Cognitive work

Many family members, mostly in the United States, Canada and Switzerland, appeared to advocate for patients, to help them obtain assisted dying.[4,9,10,20,24] Nevertheless, the decision of supporting the patient’s wish for assisted dying exposed families to three main ethical dilemmas: the appropriateness of the patients’ choice of assisted dying, the depth of their involvement in it and their possible selfishness in wanting the patient not to die.[10] A significant contributor to these dilemmas was the perceived pace of decision making. In general, if a process was perceived as too fast, family members perceived it as problematic, whereas if families felt there was undue delay in obtaining assisted dying, this would cause more pain and suffering for patients. Some family members reported having hoped that death would be postponed.[11,21]

Legal issues and procedures

A contributor to the experience was the knowledge that families had concerning the legal and procedural aspects of assisted dying, and family members showed different levels of understanding concerning the legal aspects of assisted dying. Dutch families appeared to have a good understanding of eligibility criteria and how patients are assessed and thought euthanasia was a safe procedure if its responsibility remained in the hands of physicians.[7] Dutch families reported that they considered it important and a relief that the law leaves physicians with the final responsibility of evaluating eligibility criteria for euthanasia, while Swiss families demonstrated a limited understanding of legal aspect of assisted dying and mostly relied on right to die associations for evaluating eligibility criteria.[4,11] In Switzerland, some families reported specific concerns regarding the necessity of dealing with the routine procedures conducted by authorities after death.[10] Some data indicate that families expressed distress after death and police investigations and a relief when police assured them privacy by coming in plain clothes.[10,11,29,31]

4. Experiencing the final farewell

Two main experiences seem to characterise the final farewell. One experience relates to death anticipation and control over the circumstances of the death. A second experience was related to delegating the responsibility of the choice of the day when assisted dying should be performed to professionals or right to die associations. These two experiences have a complex interplay and can be identified in both experiences associated with euthanasia and assisted suicide.

In relation to anticipating death, data indicate that families experienced an inner conflict between their wish for more life for the patient and their impotence in confronting the inevitability of the patient's death. The patient's death appeared to be anticipated, and it appeared that the circumstances of the death such as the rituals and place of death were decided with considerable attention and care. Families appeared to navigate between the awareness of the limited time left with the patients and the organisation of the farewell which sometimes disturbed them.[7,9,24] Some families valued the possibility of being aware of the farewell date well in advance, whereas Dees et al.[7] reported that Dutch families might be unfamiliar with the emotional task of organising the final farewell for someone who has limited time left to live. An important issue for families was that assisted dying allowed them to keep communication open with the patient until death. Whereas data indicated that preparatory work in organising that day could be important, families in general reported some uneasiness when required to choose the day when assisted dying should be performed. Dutch families perceived it as '*unnatural*' to leave the choice of the day of assisted dying to them.[7,25,27] Dutch families seemed to rely on physicians to decide on the day of the death, whereas in Switzerland they relied on the right to die association.

5. Grief and bereavement

The possible influences that assisted dying could have on bereavement were uncertain and diverse. Most data showed that families perceived assisted dying as an important contributor to the patients' quality of life and death.[7,25] Social acknowledgement and family approval of assisted dying seemed to play a role in bereavement and complicated grief; nevertheless, families across countries do not systematically receive aftercare, and some data indicate that they could find it difficult to talk about this type of death and may hesitate to disclose the manner of death.[4,10,11,28–31]

Assisted dying seems to lead to preparedness and open communication, and these represented positive factors in bereavement.[21,28] For example, family members in Oregon felt more prepared and accepting of death in comparison with family members in other countries.[21] Data also showed that families had higher quality ratings on items measuring patients' symptom control and preparedness for death (saying goodbye to loved ones, and possession of a means to end life if desired) than those who did not die from assisted dying.[22] Data are controversial on the possible relationship between mental health outcomes and assisted dying. Eleven percent of Oregonian family members had a major depressive disorder, and 2% had prolonged grief; however, no difference was observed in depression, grief, or mental health services use when compared with a control group.[21] In Switzerland, 13% of Swiss bereaved family members after assisted dying met the inclusion criteria for post-traumatic stress disorder, 4.9% for complicated grief and 16% for depression, with a higher prevalence when compared with the Swiss populations in general.[29,31]

In Switzerland and Oregon, families experienced fears about assisted dying.[4,10,28] Swiss families reported some unwillingness to share their experiences with others and may experience feelings of isolation and fears of being stigmatised or being judged or disapproved of, and some disapproval was experienced in Switzerland and Oregon.[10,11,28] Wagner et al.[30] also reported that the perceived disapproval from their social environment and the family seemed to influence post-traumatic stress disorders and complicated grief symptoms. This contrasted with families who perceived high social support in bereavement in an earlier study.[21]

Across countries, access to bereavement services was limited. In Oregon, 38% of bereaved family members had received mental health care, and 15% had availed themselves of hospice bereavement services, while in Switzerland and the Netherlands none of the published data indicate that families had access to bereavement care.[21] Dutch and Swiss families generally valued their participation in assisted dying research, since it was perceived as a time to reflect on the process. On the other hand, some Swiss family members refused to participate in research due to the high stress caused by recalling the experience.[10,11]

Discussion

This systematic review described family experiences of assisted dying in jurisdictions where such practices are legalised. The results showed that families could be very involved in supporting patients seeking assisted dying and usually maintain an open relationship with patients and perceive assisted dying as an important contributor to the patient's quality of death. Families also experienced different types of interactions with health care professionals, which could vary from ample involvement and open discussion to avoidance and exclusion in decision and enactment of assisted dying. All these experiences were reported to be emotionally and cognitively demanding. Accounts of their experiences suggested that assisted dying may challenge family values. Nevertheless, they appeared to remain advocates for patient choice. Some accounts also suggested that social support and health care professionals' acknowledgement seemed to play a role in shaping family experiences and could influence grief and bereavement. This review suggests that making sense of an assisted death appeared to be a complex task for families, from accommodating the decision, through experiencing the final farewell and living after assisted dying.

It is supposed that family involvement in medical decision making could be an important cultural factor, but little attention has been given to the role of family members in medical decisions.[34] In general, it is known that, among different factors, family involvement can depend on cultural values.[35] For example, some cultures rely on the cultural concept of familism, characterised by strong ties of solidarity and interdependence in family networks.[36] Even if assisted dying has been legalised in Western European countries and North America, where family involvement in medical decisions is the norm, our data suggest that family involvement could have been influenced by many factors, such as cultural issues, moral background, the type of legislation of their country and their perception of social acceptability rather than cultural norms.

In general, our review seems to suggest that assisted suicide models appeared to leave more tasks and responsibilities to family members, whereas the model of euthanasia seemed to leave families with fewer responsibilities and tasks. In jurisdictions where assisted dying is legal and openly available, families reported to rely on health care professionals; they valued an open communication and decided to leave challenging decisions such as the eligibility assessment and the choice of the day to professionals. Where assisted dying is de-penalised, a legal framework is missing and health care professionals are marginally involved, families could have perceived more responsibilities such as offering patients all possibilities to obtain assisted dying. They could have also advocated for patients, taking on charges potentially causing them moral dilemmas and fears during both the decision making and the bereavement. These experiences appeared to be similar to those of family members helping patients to die in jurisdictions shortly before the enactment of the law.[8,12,37] Families in general were faithful to a promise made to the patients even if risking legal prosecution for their actions and assuming more substantial responsibilities of the patients' deaths.

Theorists have highlighted the importance of in-depth examination of the social framework within which an event occurs, and meta-analyses of risk factors for complicated grief and post-traumatic stress disorder have found lack of social support to be one of the strongest predictors of symptom severity.[38] Social acknowledgement seemed to play a role in influencing families' experiences during and after assisted dying.[24,28,30] Whereas the social acceptability of assisted dying is growing in many countries,[39] it seemed that families reported different accounts of their perception of social support. Data indicate that the large majority of Swiss citizens support assisted suicide as an end-of-life possibility and that families perceive assisted dying as a civil right and not a medical act. Nevertheless, the Swiss and Oregonian families reported experiences of isolation and fears of social stigma.[4,28] On the other hand, Dutch families appeared to be less influenced by fears of stigma and valued open relationships and open discussion about assisted dying.[7] The Dutch families' experiences could be explained by the fact that social acceptability of assisted dying in the Netherlands and Belgium is growing, and it is a well-known and trusted practice.[40] These differences in openness could also happen during bereavement. Although fewer data were available concerning bereavement, it seemed that Swiss families tend to feel isolated in comparison with the Oregonian or Dutch ones, possibly due to a different perception of social acknowledgement of their participation in assisted dying across these countries. Our data also indicated that systematic bereavement support was not described in the studies.

Strengths and limitations

As far as we are aware, this is the first review that has examined families' experiences of assisted dying. This review used a robust methodological approach with data extraction conducted by independent researchers, leading to a reduction in bias. This comprehensive review encompasses results deriving from studies conducted in different countries and included experiences of both euthanasia and assisted suicide. Unfortunately, insufficient high-quality articles are available, which permits us to discriminate families' experiences in relation to the type of assisted dying. Moreover, several potentially important studies were excluded from this review because the inclusion criteria restricted the search to articles published after the enactment of the law in the different countries.[8,12,37,39] As most participants were bereaved, their recall of the experiences may have been influenced by grief as has been acknowledged in the literature.[41] Three of the included studies were conducted by the first author of the systematic review.[4,10,11] Most identified studies were small qualitative studies, and we were unable to find trials testing psychosocial or educational interventions or large observational studies with comparison groups. The majority of included studies investigated close family members' experiences, so little is known about friends and other individuals closely involved in assisted dying.

Implications for policy and clinical practice

This review allows to draw some general recommendations for policy makers and clinicians, which may be summarised thus:

> In some countries, there is evidence that families and patients shared long-standing values and had conversations that included assisted dying as a possible end-of-life option.
>
> Families need to be recognised as participating in the decision and gaining of assisted dying. Assisted dying is a complex decision, mostly resulting from negotiations between the patient, the physician and the family members involved.
>
> Family members should be included in clinical consultations and their needs addressed, with the same care as for patients.

Future research priorities

An essential part of the published evidence concerns epidemiological data – patient's experiences and proxy accounts of patients and families and ethical-legal implications of these practices. Family members' experiences in assisted dying are under-researched. Future research should focus on understanding their needs during the decision and in the bereavement phases and in relation to the different existing models of assisted dying. More evidence should be collected directly from family members' voices, not using proxy accounts of their experiences. It will also be important to investigate the experiences of dissenting family members and the possible influences on patients' access to assisted dying. Investigating the accessibility to assisted dying of patients without families that support them will give further information about how families can influence assisted dying choices and availability.

Conclusion

In conclusion, our data confirm that families across all jurisdictions are involved in an assisted dying decision and its enactment and that their needs are under-researched. Guidelines concerning clinical decision making in assisted dying should incorporate recommendations about how to take family needs into account and how to provide them with evidence-based tailored interventions. Models of shared decision making should be more broadly implemented, with respect to social context and cultures of the different countries and citizens.

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Author contributions

C.G. designed the study, undertook the systematic review, carried out the thematic synthesis and wrote the manuscript. S.P. and N.P. participated in the design of the study and systematic review, provided guidance in the thematic synthesis, and reviewed the manuscript. T.F.-S. and A.O. participated in the systematic review and review of the manuscript. C.G. and N.P. are the guarantors.

Data sharing

Additional data from the study are available from the corresponding author (claudia.gamondi@eoc.ch).

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CHAPTER SIX

FAMILY CAREGIVERS' REFLECTIONS ON EXPERIENCES OF ASSISTED SUICIDE IN SWITZERLAND: A QUALITATIVE INTERVIEW STUDY

6.1 Overview

This second paper (Gamondi et al., 2018) presents the reflections of Swiss family members on their experiences of involvement in assisted suicide. It specifically addresses the following research aim:

> *To investigate Swiss families' reflections of their experiences when a family member is considering assisted suicide.*

6.2 Data collection and analysis

The data collection was led by myself with additional support from a co-interviewer, Murielle Pott. Interviews were conducted in the participant's native language (French or Italian). I transcribed and coded the interviews in their original languages. The French transcriptions were checked with my co-interviewer. Through an iterative process of discussion with the co-interviewer we reached a consensus on the coding.

6.3 Reflexivity

Since I am fluent in both Italian and French, I was able to transcribe and analyse the data in the original language of the interviews (Larkin, Dierckx de Casterlé, & Schotsmans, 2007; Santos Jr, Black, & Sandelowski, 2015). This enabled me to familiarise myself fully with all the data. Conducting the transcriptions and analysis in both languages allowed me to overcome some of the problems typically related to translation issues in qualitative research. I could minimise potential semantic loss or the difficulties inherent in translating the cultural meanings embedded in linguistic expression in both languages. I also had the opportunity to gain an in-depth understanding of how families, sometimes during many years of experience, mature their decision around their role in assisted suicide and how to overcome dilemmas. I acknowledge the final reporting of findings in English may introduce minor translational limitations.

Original Article

Family Caregivers' Reflections on Experiences of Assisted Suicide in Switzerland: A Qualitative Interview Study

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Abstract

Context. 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.

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

Methods. A cross-sectional qualitative interview study conducted in the Italian- and French-speaking regions of Switzerland. Interpretation and analysis were performed using qualitative content analysis.

Results. Twenty-eight close relatives and family carers of 18 patients who died by assisted suicide in Switzerland were interviewed. 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.

Conclusion. 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. J Pain Symptom Manage 2018;55:1085–1094. *© 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Assisted suicide, euthanasia, assisted dying, decision making, families' experiences, palliative care, family relations, qualitative research

Introduction

This study 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 euthanasia.[3]

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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 care.[4] 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.[7–10] Annually, several thousand families participate in assisted dying and the subsequent bereavement, including families supporting patients traveling from their own countries to have an 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 makes.[6] 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. Although family members may often support the patient's choice, family opposition is a common predictor of patients not achieving an assisted suicide.[19] 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 of 1000 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 institutions.[8] 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 before ingestion and assists during self-ingestion of the drug.[8] Crucial criteria to access assisted suicide involving right-to-die associations are 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 underrecognized and remain largely ignored in clinical guidelines and institutional policies.[14] 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 as follows: being a relative or a close friend of a patient known to be deceased after 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. Because 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, and semistructured 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 as follows:

- type of family involvement in assisted suicide and
- interactions that occurred before assisted suicide.

The interviews were audiotaped, fully transcribed, and coded in the original languages. To ensure

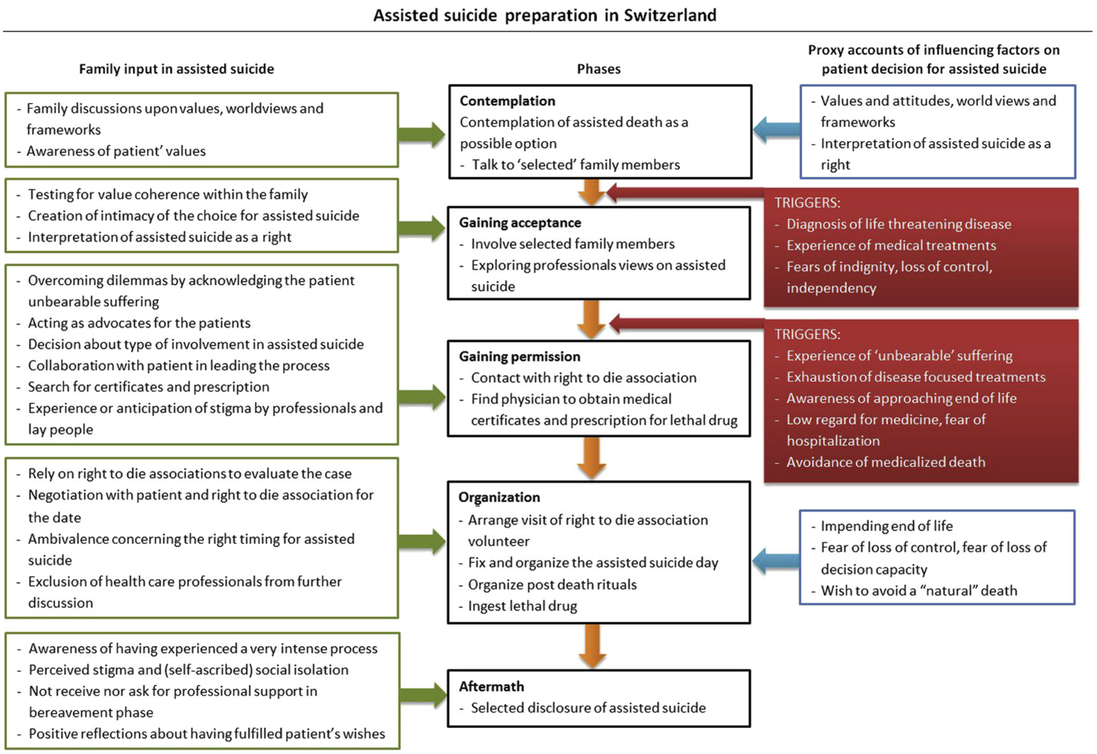


Fig. 1. Assisted suicide preparation in Switzerland.

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 analysis.[26] Researchers (C. G. and M. P.) 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 data set for analysis. In a first step, single interview transcripts were analyzed 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. Figure 1 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 (C. G. and M. P.). International COREQ guidelines for qualitative research were followed to assure credibility of the research.[27] 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.

Results

The demographic characteristics of the 28 participants are summarized in Table 1: 11 men and 17 women 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 categorized 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 Fig. 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

Table 1
Demographics and Principal Characteristics of Participants

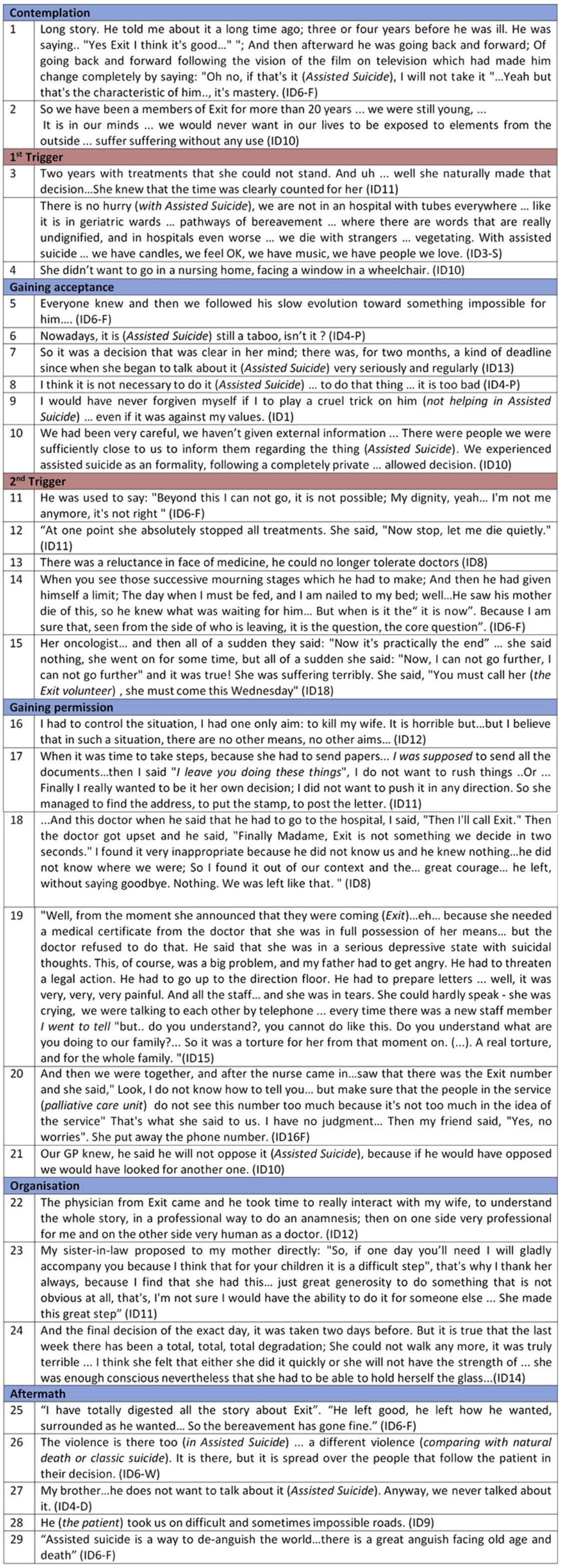
Case	Patient Illness and Age	Informal Caregiver Relationship, Age	Time Elapsed Between the Assisted Suicide and Interview	Type of Involvement in Assisted Suicide
ID 1 Peter	Cancer	Wife, 60–70 yrs old	Two yrs	Active
ID 2 Thierry	Cancer	Wife, 40–50 yrs old	One and a half yrs	Passive
ID 3 Stefanie	Arteriopathy	Son, 40–50 yrs old Daughter in law, 50–60 yrs old	One yr	Active
ID 4 Antonio	Cancer	Daughter, 50–60 yrs old Partner, over 70 yrs old	Six months	Passive
ID 5 Giuseppina	Cancer	Daughter, 40–50 yrs old	Six months	Passive
ID 6 Henry	ALS	Wife, 50–60 yrs old Three friends, 60–70 yrs old Power of attorney, 67 yrs old	One and a half yrs One and a half yrs Two yrs	Active
ID 7 Richard	Cancer	Wife, 50–60 yrs old Friend, 50–60 yrs old Son, 20–30 yrs old	Four yrs	Passive
ID 8 Patrick	Cancer	Sister, 60–70 yrs old	Four yrs	Active
ID 9 Benedicte	Genetic neurological disorder	Sister, 60–70 yrs old	Three yrs	Passive
ID 10 Marie	Chronic back pain	Husband, over 70 yrs old	Six months	Active
ID 11 Nadine	Cancer	Daughter, 30–40 yrs old	One and a half yrs	Passive
ID 12 Valentine	Cancer	Husband, over 70 yrs old	One yr	Active
ID 13 Veronica	Cancer	Daughter, 50–60 yrs old	Six months	Passive
ID 14 Josephine	Tired of living	Daughter in law, 50–60 yrs old Grand son, 20–30 yrs old	Six months	Active Passive
ID 15 Gisele	Cancer	Stepdaughter, 40–50 yrs old	Six months	Passive
ID 16 Angela	Cancer	Friend, 40–50 yrs old Volunteer, 60–70 yrs old	Six months	Passive
ID 17 Ernest	Multimorbidity—tired of living	Daughter, 60–70 yrs old	One yr	Active
ID 18 Lisa	Cancer	Husband, over 70 yrs old	One yr	Active

ALS = amyotrophic lateral sclerosis.

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 Fig. 2; Quotes 3–4; 11–15).

Contemplation (See Fig. 2; Quotes 1–2). Families reported that most of the patients contemplated assisted suicide for a long period. For some, this started long before their illness, whereas for others, this started 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, and 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).



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 afterward 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 (*Assisted Suicide*), 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)
1st 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)
	There is no hurry (*with Assisted Suicide*), 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-S)
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 toward something impossible for him.... (ID6-F)
6	Nowadays, it is (*Assisted Suicide*) 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 (*Assisted Suicide*) very seriously and regularly (ID13)
8	I think it is not necessary to do it (*Assisted Suicide*) ... 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 (*not helping in Assisted Suicide*) ... 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 (*Assisted Suicide*). We experienced assisted suicide as an formality, following a completely private ... allowed decision. (ID10)
2nd 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 (*the Exit volunteer*) , 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 (*Exit*)...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 (*palliative care unit*) 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 (*Assisted Suicide*), 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 (*in Assisted Suicide*) ... a different violence (*comparing with natural death or classic suicide*). 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 (*Assisted Suicide*). Anyway, we never talked about it. (ID4-D)
28	He (*the patient*) 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)

Fig. 2. Accounts of informal caregivers' reflections of the experiences in the different phases of assisted suicide in Switzerland.

Gaining Acceptance (See Fig. 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.

Gaining Permission (See Fig. 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 toward 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.

Organization (See Fig. 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 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.

Aftermath (See Fig. 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, whereas others spoke of retaining "intimacy" (ID1) when expressing their reasons for not disclosing at all. Although 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.[5–7,28] 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 because assisted suicide was interpreted to belong to an intimate sphere of the person and their relationships. Discussing assisted dying options first within the family and not with physicians appears to happen also in The Netherlands, confirming the very private nature of this decision.[29] 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 option.[8] 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 prevent 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 who were planning to pursue assisted suicide either changed their mind or died before assisted suicide could occur.[30]

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 suicide.[22]

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 toward assisted dying appeared to be as important as the event itself.[14] However, families in our study seemed to play a role that emerged as more incisive than that described elsewhere.[6,7,28] Most of the family

Table 2

Differences in the Experiences Between Active Euthanasia in The Netherlands and Assisted Suicide in Switzerland

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 toward 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.	Organization	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.

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] By contrast, Swiss families and patients seemed to decide by themselves, and only during the later phases, they do 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 jurisdictions.[31]

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.[32] Potential negative impacts of not discussing assisted suicide may be mitigated by a trend toward 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 behaviors were derived 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 on how 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 patients 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.[30,31] 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-centered 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.

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CHAPTER SEVEN

SWISS FAMILIES' EXPERIENCES OF INTERACTIONS WITH PROVIDERS DURING ASSISTED SUICIDE: A SECONDARY DATA ANALYSIS OF AN INTERVIEW STUDY

7.1 Overview

The first interview study had produced a large, high quality and rich amount of data to address the specific research aim on the reflections of Swiss family members on their experiences of involvement in assisted suicide. However there was considerable data, particularly with regard to families experiences with physicians and right to die associations, that was worthy of further investigation. Therefore a secondary data analysis was conducted which enabled the identification of new themes and resulted in the formulation of the following research aim (Gamondi, Pott, Preston, & Payne, 2020):

> *To depict Swiss family members' reflections on their interactions with health care professionals and right to die associations during the time their family members were considering assisted suicide.*

7.2 Data collection and analysis

For the secondary data analysis the example of secondary data analysis, as detailed by, Long-Sutehall, was followed to ensure high quality analysis and credibility to the methodology (Long-Sutehall et al., 2011).

7.3 Reflexivity

Although few methodological papers were available on secondary data analysis of qualitative data, the rigorous exploration of this specific topic provided interesting and innovative data, which contributed to understanding family dynamics. This secondary analysis allowed me to critically examine dilemmas and controversies that characterise families and to reflect again around the complex interplay existing between my clinical practice and experience and the position that I took during the original analysis.

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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 the 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.

Conclusions: In Switzerland, there is limited interaction between families and health care professionals concerning assisted suicide decisions, whereas 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.

Keywords: assisted dying; assisted suicide; decision making; euthanasia; families' experiences; palliative care

Introduction

Assisted dying encompasses both euthanasia and assisted suicide.[1] Terminology of these practices is often contested, as in the United States there is a tendency to avoid the use of the term suicide to keep a more neutral stance and avoid framing 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,

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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.* 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 published elsewhere, including a detailed account of sampling, data collection, and data analysis.[6] Little is known about families' experiences of interactions with professionals before 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 article 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 2 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 Dignitè*). 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 (C.G.) and supported by M.P. 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 rigor of the analytical processes.''[20,22]

Table 1. Summary of Topic Guide Used for Interviews

How were you involved in the process leading to assisted suicide?
- The process of the assisted suicide preparation
- What helped? What hindered?

How did you interact with health care professionals during the process of assisted suicide?
- 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?

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*Five main organizations, ''Exit Deutsche Schweiz,'' ''Exit ADMD'' (''Association pour le Droit de Mourir dans la Dignite''), ''Dignitas,'' ''LifeCircle'' and ''Exit International'' provide, in the different Cantons, practical and bureaucratic assistance to patients who wish to die.[12] Some of them offer help only to Swiss citizens, others are open to requests from foreigners.[12] 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.

Analysis was conducted in the original language of the transcripts and selective translation in to English was done for publication. Attention was paid to words and tone and paralinguistic features. C.G. and M.P. 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. C.G. analyzed each theme, noting any variation in perceptions within each type of interaction, and discussed findings with M.P. 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 $\sim$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] Ethics approval was obtained from the ethics committees of the Cantons involved in data collection (Ticino: ref 2424, Valais ref 004/11, Vaud ref 74/11).

Results

The sample included 48 men and 47 women, associated with 18 deceased patients. The average age of participants was 60 years, 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. 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, 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, talked to us and 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 hospitals 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 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 10 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 (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 the 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 toward 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 fulfill before assisted suicide. In 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 16-year-old son), *it is up to the grieving person to make the effort to move towards other*s.'' (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 health care system.[27,28] The system offers the patient different choices; choice whether to use private or public health care 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 United States 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 U.S. 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 basis 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 her personal and professional background as a palliative care physician, allowed her 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 toward 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 number 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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Data Sharing

Additional data from the study are available from the corresponding author (claudia.gamondi@eoc.ch).

Author Disclosure Statement

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CHAPTER EIGHT

RESPONSES TO ASSISTED SUICIDE REQUESTS: AN INTERVIEW STUDY WITH SWISS PALLIATIVE CARE PHYSICIANS

8.1 Overview

This paper (Gamondi, Borasio, Oliver, Preston, & Payne, 2017) was designed to specifically address the fourth research aim of the thesis:

> *To analyse Swiss palliative care physicians' accounts of interactions with patients and their families when they are considering assisted suicide.*

8.2 Data collection and analysis

I conceived and designed this study, and it was funded by a grant from Oncosuisse. This research project presented many challenges and complexities. Switzerland and the Swiss palliative care community are small, and I have been active in this community since 1999. I personally know most of the physicians and some are also good friends. It was therefore necessary that the interviews were conducted by an independent researcher. The data collection was performed by Pam Oliver, a research assistant with expertise in qualitative research. I designed the interview schedule and had regular discussions with Pam before and during data collection to monitor the quality and to avoid potential bias.

To ensure confidentiality and reduce the bias of recognising the participants, the transcription of the interviews was performed by professional transcribers. The transcribers all signed confidentiality agreements to ensure methodological standards were maintained and respected. All participants were assured that any potential ethical issues relating to confidentiality were therefore respected.

8.3 Reflexivity

Conducting this study was an intense experience because it raised my awareness of the challenges and dilemmas that other Swiss palliative care physicians also face, particularly with the gap of knowledge on this topic, which many referred to. It heightened my awareness of the diversity in moral beliefs and the struggle that some reported in conciliating their system of belief with their respect for patients’ and family members’ autonomy.

Responses to assisted suicide requests: an interview study with Swiss palliative care physicians

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ABSTRACT

Objectives Assisted suicide in Switzerland is mainly performed by right-to-die societies. Medical involvement is limited to the prescription of the drug and certification of eligibility. Palliative care has traditionally been perceived as generally opposed to assisted suicide, but little is known about palliative care physicians' involvement in assisted suicide practices. This paper aims to describe their perspectives and involvement in assisted suicide practices.

Methods A qualitative interview study was conducted with 23 palliative care physicians across Switzerland. Thematic analysis was used to interpret data.

Results Swiss palliative care physicians regularly receive assisted suicide requests while none reported having received specific training in managing these requests. Participants reported being involved in assisted suicide decision making most were not willing to prescribe the lethal drug. After advising patients of the limits on their involvement in assisted suicide, the majority explored the origins of the patient's request and offered alternatives. Many participants struggled to reconcile their understanding of palliative care principles with patients' wishes to exercise their autonomy. The majority of participants had no direct contact with right-to-die societies, many desired better collaboration. A desire was voiced for a more structured debate on assisted suicide availability in hospitals and clearer legal and institutional frameworks.

Conclusions The Swiss model of assisted suicide gives palliative care physicians opportunities to develop roles which are compatible with each practitioner's values, but may not correspond to patients' expectations. Specific education for all palliative care professionals and more structured ways to manage communication about assisted suicide are warranted.

INTRODUCTION

The European Association for Palliative Care (EAPC) edited a White Paper on euthanasia and physician-assisted suicide-explicitly affirming that

> *'Individuals requesting euthanasia or physician assisted suicide should have access to palliative care expertise.'*[1]

It also affirms that

> *'It is the responsibility of palliative care professionals to hear and explore the implicit or explicit requests for euthanasia and address the suffering underlying these requests.'*[1]

Even where a palliative care consultation is not legally required in countries where assisted dying is permitted, many international bodies suggested that such a consultation should occur.[2–8] The terminology describing assisted dying is controversial; for present purposes, the definitions in table 1 are used.[1] In this paper, we use the value-neutral term 'assisted dying' to encompass all forms of assisted suicide and euthanasia.[9]

Where assisted dying is legal, palliative care physicians are involved in up to 90% of cases from decision making to drug delivery.[10–12] The majority of patients who have died under the Death with Dignity Acts in Oregon and Washington were enrolled in hospice programmes, and in Belgium and The Netherlands, euthanasia and assisted suicide are practised commonly in inpatient hospices.[11 12] Historically palliative care and assisted dying have been considered incompatible by various palliative care bodies.[13–15] Whereas most of the 21 EAPC White Paper statements achieved high consensus in the Delphi process,[1] the authors acknowledged that

Table 1 Terminology describing practices that involve assisted dying[1]

Term	Definition
Euthanasia	A physician (or other person) intentionally killing a person by the administration of drugs, at that person's voluntary and competent request
Assisted suicide	A person intentionally helping another person to terminate his or her life, at that person's voluntary and competent request
Physician-assisted suicide	A physician intentionally helping another person to terminate his or her life, by providing drugs for self-administration, at that person's voluntary and competent request

> '*complete consensus on these topics seems to be unachievable due to incompatible normative frameworks that clash.*'[1]

The statement concerning the exclusion of assisted dying from palliative care practice did not reach consensus, with the Benelux countries in firm disagreement.[16]

European professional palliative care associations hold varying views about assisted dying,[1 2 17–19] with four positions proposed:

- 'Integral palliative care,' which views assisted dying as an integral part of palliative care[11];
- 'Euthanasia accompaniment,' which recommends assisted dying as part of good general care and provides it within palliative care consistent with the 'non-abandonment principle'[11];
- 'Studied neutrality,' defined as 'the careful or premeditated practice of being neutral in the dispute about euthanasia,' which embodies the principles of equality, individual autonomy and tolerance as core values of palliative care[20];
- A rejection of any integration between palliative care and assisted dying procedures.[1 21]

In Switzerland, assisted suicide is depenalised and socially accepted, although euthanasia remains illegal.[22 23] According to Article 115 of the Swiss Criminal Code, those involved in assisted suicide are not prosecuted provided they are without self-serving motives.[22 23] Assisted suicide represents approximately 1% of annual Swiss deaths, with a consistent increase over the last few years.[24] In most cases of assisted suicide, involvement of Swiss physicians consists predominantly of providing the patient with a prescription for a lethal dose of pentobarbital, which the persons must take by themselves and with full mental capacity.[25 26]

In 2012, the Swiss Academy of Medical Sciences (SAMS)—an institution bridging biomedical ethics, medical practice and society—developed guidelines largely opposing the involvement of the medical profession in assisted suicide.[27] The guidelines state that, if the physician is present at time of self-ingestion, this must be as a private citizen.[27] As a result, requests for assisted suicide are generally processed by right-to-die societies and assistance is provided by volunteers who may be physicians, other health practitioners or laypersons. 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 drug.[28] Thus, the involvement of Swiss physicians is mostly confined to the decision-making phase; medical certification of diagnosis and mental capacity.[28] Self-administration usually occurs in the patient's home, as few healthcare facilities allow it.[28] However, two French Swiss cantons (Vaud and Neuchâtel) recently enacted laws to regulate assisted suicide in public hospitals and nursing homes (see online supplementary appendix 1).[29] A survey conducted with a small sample of Swiss physicians confirmed that most were willing to evaluate eligibility, but only a small minority would consider performing assisted suicide as a medical responsibility.[30] A 2002 survey of interdisciplinary members of *palliative ch* (Swiss society of palliative care) found that all palliative care professionals demonstrated wide variation in their positions concerning assisted dying.[31] A significant minority endorsed the legalisation on assisted suicide and euthanasia, and about 10% reported personal experiences with assisted dying.[32]

In this paper, we focus on assisted dying among mentally competent people; we are not addressing separate issues such as suicide and its prevention in the mental health field. No studies have comprehensively investigated palliative care physicians' experiences of assisted suicide. This paper aims to describe their perspectives and involvement in assisted suicide practices.

METHODS

This cross-sectional interview study used a stratified purposive sample of Swiss palliative care physicians to capture the experiences of physicians working in specialised palliative care settings when dealing with assisted suicide requests. A qualitative methodology was chosen to enable diverse and culturally salient viewpoints to be elicited in a largely unexplored field. All 336 physician members of *palliative ch* were invited by email to register online their interest in participating in an interview. The inclusion criteria were: (A) working more than 0.7 Full Time Equivalent (FTE) in palliative care, for at least 3 years, and (B) working in an accredited facility and/or home care setting. Of the 64 doctors who registered (19% of those invited), 15 did not meet inclusion criteria such as working less than 0.7 FTE in palliative care. Of the remainder, 23 were purposively selected to represent a range of variables including gender, age, extent of experience and type of role and position, type of institution, and language group (approximately proportional to the distribution in the general Swiss population, ie, 65% German, 30% French and 5% Italian speaking). Participants were asked to describe their likely responses to a typical assisted suicide request scenario[31]; their actual experiences of responding to assisted suicide requests; their perspectives towards assisted suicide and the activities of the right-to-die societies; and the main influences on their views. Additional questions explored participants' philosophies of palliative care, their perception of their role as a palliative care physician, their training on responding to assisted suicide requests and their views on the relationship between assisted suicide and palliative care practices. Between January and March 2015, twenty-three semistructured interviews were conducted face-to-face at each participant's workplace (three by Skype). The interview questions were pilot tested with three participants and as no substantive changes were made, these were included in the data set. Interviews were conducted in English, with participants' agreement, to minimise translation bias. Their transcribed interview was provided to each participant for comment and to ensure accuracy. To enhance reliability and trustworthiness, the research team included a gender balance, various professions and researchers from four countries. Using thematic analysis,[33] categories were developed through an iterative process, then data were analysed to identify key emergent themes and variations in responses by age, gender and experience.[34] Verbatim quotes were selected to illustrate majority and minority viewpoints ('majority' refers to approximately 50%–75% of the sample and 'minority' less than 30%) (see figure 1). Approval for the study was obtained from the Local Ethical Committee (CE 2740) and Lancaster University Ethical Committee.

RESULTS

The characteristics of the 23 participants are shown in table 2.

Swiss palliative care physicians received assisted suicide requests regularly and tended to follow a common pattern in responding to them which involved (see figure 2):

- setting and communicating early on boundaries on their level of willingness to support a patient's assisted suicide request;
- playing an active role in the decision-making process by presuming a responsibility for exploring patients' reasons, offering alternatives and discussing assisted suicide risks, often iteratively over an extended period;
- engaging with families on the topic, without always explicitly obtaining the patient's consent.

The amount and focus of each participant's engagement appeared to be mostly determined by the individual's personal philosophies of assisted suicide. The majority of participants were not willing to prescribe a lethal drug and/or attend the death. A majority also wanted clearer and stronger state regulation of assisted suicide.

Experiences of responding to assisted suicide requests

Participants reported receiving annually between 3 and 20 requests and estimated that only 5%–10% of them resulted in an assisted suicide. Most participants, especially those over 50 years, interpreted assisted suicide approaches as requests for information, rather than for help with obtaining assisted suicide (*see quotes 6 and 7*). Three participants acknowledged that their opposition/ambivalence about assisted suicide was probably a barrier to them recognising requests for help. More than half of the participants stated that they would not initiate a conversation about assisted suicide or discuss it unless the patient first raised the topic. However, several participants identified ethical dilemmas in determining what their role should be in assisted suicide, when their personal stance conflicted with explicit or implicit institutional policy (*see quotes 1 and 3*). Most participants required the patient to engage in extended, repeated discussions about the reasons for their request. The most frequently reported topics of discussion with these patients were: the reasons for requesting assisted suicide; offer of alternatives; consultation with families; provision of the required eligibility certificate; interaction with the right-to-die societies; and physician's unwillingness to prescribe the lethal drug (see box).

Alternatives to assisted suicide were presented as '*natural*' deaths (*see quotes 15, 11, 13*). These protracted discussions, sometimes over several weeks, and generally initiated by participants, meant that some patients died before assisted suicide could be arranged. Physicians also commonly reported engaging families in extended discussions, on the principle of including them in the care plan.

Most participants set boundaries early on with patients, clarifying that they would not participate in assisted suicide (such as prescribing or interacting with the right-to-die association), but would not interfere with the patient's choice (*see quotes 2, 4, 8*). Although participants saw it as their responsibility to write the medical certificates, if requested, four of them reported an organisational policy of sending the certificate to the general practitioner (GP). In general, participants did not liaise with GPs or other professionals outside of the patient's care team about assisted suicide requests.

All participants saw it as their responsibility to not create barriers to right-to-die societies visiting the patient, but most physicians regarded establishing contact with right-to-die societies as the patient's responsibility. While many physicians acknowledged that they might suggest that patients contact the right-to-die societies, only five had actively advised patients to do so (*see quotes 9, 10*). Four doctors reported having met with the right-to-die societies' personnel together with the patient; a further six would do this if asked by the patient, while two would recommend such a meeting to the patient. The four participants who had had direct personal contact with these societies'

1: This guy from The Netherlands said…"If you are not ready to talk about assisted suicide, nobody will ask you about it". And that's the thing. I'm not allowed to provide assisted suicide. But there were families who told me afterwards, … who would have liked to ask me [for assisted dying], and they didn't. Just to… uhm… not to bring me into difficulties. (Lucy, 50-65 years old)

2: I would give him the phone number of the association that is considered to be in charge of that. I would not prescribe it [lethal medication] myself in my doctor's position, okay? That is in line with the recommendations of our academy of medical sciences and the FMH, that's our professional association. … And this is something that goes back in medical history to the primum non nocere - first, do no harm. So I would not do harm to anyone. (George, 50-65 years old)

3: … an ugly situation I shared with a patient... So, the patient was not member of EXIT and requesting for medically assisted suicide for weeks. And because there is no law, people [health professionals] were just chit-chatting about the fact but not listening to the patient, I felt so uncomfortable … this situation where the patient was begging me at least to act as an advocate definitely impacted on my daily practice. (Brad, 40-50 years old)

4: We try to explain the situation to show him the other possibilities but if he wants to...ah, if he desires the assisted suicide, it's...at the end, it's his decision. But we will not help him to organise this way or the assisted suicide. It's not our wish to help him. And first he has to do it alone. And the second is it's not possible here or in the...in a hospital. He has to search another place. (Paul, 40-50 years old)

5: I'm sure that there are some very big common questions about values of society, about living styles, …about expectations in society and in each individual about end of life, and about having control. It raises big issues. So I think this debate [between palliative care and right-to die-societies] can be very fruitful for the whole development of society in regard of integrating end of life in everyday. (Frank, 50-60 years old)

6: As a request, I think...I don't get requests from patients. Patient talk about, 'I'm fed up. I don't want to live anymore. I'm tired. I don't want to live.' But I've never had the question, 'Please doctor give me medication.' Maybe these people know that for that they have to go to EXIT - I don't know. (Caroline, 40-55 years old)

7: Uhm well patients sometimes say, "Give me a drug to die." But I don't think that it's really what they want. It's perhaps a possibility or to talk about dying. And I never heard this wish directly for active suicide. No, never. (Paul, 40-50 years old)

8: So, okay, then I will ask him [person requesting assisted dying], do you suffer physically or psychologically from anything? Can I help you with this? And he then answers, no I'm fine. I've no pain. I have no dyspnoea. I have no … anything …Then I said okay. But I can't offer you assisted suicide. (Kristine, 50-65 years old)

9: And for me, it was special to call EXIT. They said, "Oh, it's rare that a doctor calls us, you know?" Because I thought the best is to call them and to ask for information, because that is what they do. … they were very happy that somebody was interested to know. (Lucy, 50-65 years old)

10: I even suggest to patients to talk [with EXIT] so they know what it is all about. … I say, "Well, then it's better you talk to them and you get information." … so for them, it's also important to have this door open … that's what they always tell me, you know, Exit means security. (Lucas, 50-65 years old)

11: I think it might not be necessary to have this tool if you start early in reflecting and also stopping, withdrawal of treatment. And also, voluntary stopping of eating and drinking, for instance, might be really another way to address or to take into consideration. (Jim, 50-65 years old)

12: I'm not one of the palliative care specialists who like to put them one against the other, the assisted suicide versus palliative care. I think both have their place in life and in dying. (Ernest, 40-55 years old)

13: So, I don't think that we should offer this (assisted suicide) to the patient. No. There's no place for it in palliative care. Because palliative sedation is a good possibility …yeah. To help the patient don't have their symptoms. But we shouldn't raise the dose of the drugs. (Paul, 40-50 years old)

14: I see my role is in giving him (the patient) best supportive care, and to do everything to reduce his suffering when I can. And when I have done this, I have to accept his decision, but I would tell him that I'm not...it's not my role to give him assisted suicide. (Francine, 40-50 years old)

15: And then I say [to patients], "With antibiotics you can prolong your disease, but it's also a chance to have a natural way to go". And to die with an infection is not the worst thing to do." (Sandra, 50-65 years old)

16: And I have to confess that I am supported here…at least in Neuchâtel state and the Vaud state – by the fact we have a legislation. To be honest, it's very helpful … I might have a personal opinion with regards to assisted suicide, but as a health professional, I hopefully have rules and I can follow the rules … At least for the physician, for the health professional, it's a step-by-step attitude. And maybe it's decreasing… or it lowers the pressure on our shoulder. I have to be honest, I feel far more comfortable in state of Vaud than in state of Geneva, where a patient 10 years ago were already requesting for assisted suicide and there is no bill in Geneva. And at that time, we were more or less all expressing our value system rather than listening to the patient value system. So I have to confess that with this bill or this guidance, definitely, it lowers the pressure on our shoulder because it's a step-by-step recipe. (Brad, 40-50 years old)

17: … the problem is … uhm, actually it's not regulated. There's no rule [about whether] people could go with assisted suicide in the hospital or not. Nowhere it's written yes or no. Actually, I would like to clarify that [rule], so I know what I can tell the patients if they ask". (Brad, 40-50 years old)

Figure 1 Selected quotes from the interviews.

Table 2 Characteristics of the participants

	Male	10
Sex	Female	13
Median age (range)	Median 50 years (35–67)	
Linguistic regions represented	German	10
	French	10
	Italian	3
Country of training	Switzerland	18
	Germany	3
	Italy	1
	France	1
Years of experience in palliative care	Median: 11 years (range 4–35 years)	

Box Identified topics of discussion between patients and palliative care physicians concerning assisted suicide

Topics of discussions

- The interaction with the right-to-die societies
- Being present at death
- The certification of medical condition and mental capacity
- Exploring reasons underpinning the patient's request for assisted suicide
- The offer of alternatives to assisted suicide
- Consultations with families

personnel were the most likely to regard them positively, view them as 'professional' and ethical and be willing to collaborate.

'Learning by doing'—how physicians deal with assisted suicide requests

No participants had received specific training in how to respond to assisted suicide requests. The majority based their approach on institutional policies, their senior colleagues' approaches, the SAMS policy guidelines or their personal perception of 'best practice' (*see quotes 12, 13, 14*). Three participants reported having attended an assisted suicide, and two experienced it as valuable learning. Most participants did not want to attend an assisted suicide, seeing it as unethical, voyeuristic or not useful. Nonetheless, all participants expressed confidence in their ability to describe the assisted suicide process accurately to patients and families. Of those participants who held strong religious beliefs, some said they would never consider assisted suicide for themselves, while many stated they would consider having assisted suicide in particular medical situations.

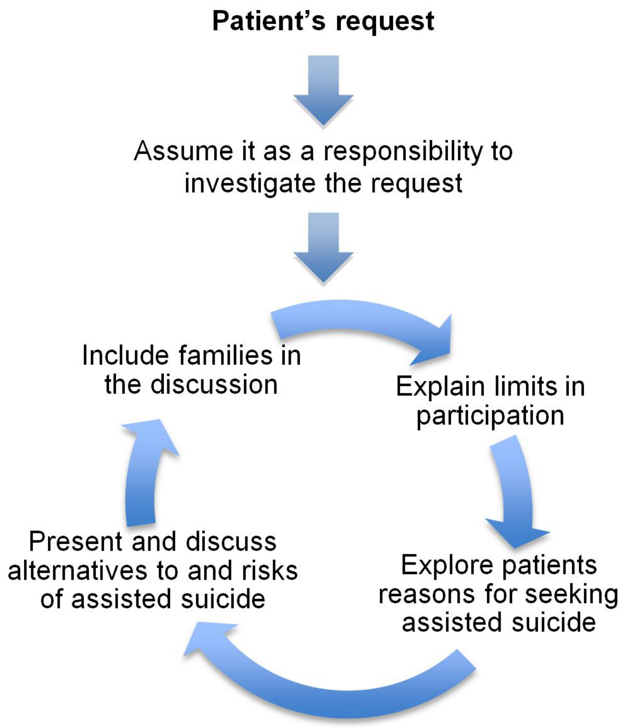

Figure 2 Typical pathway of palliative care physicians' involvement in assisted suicide.

Relationship of assisted suicide to palliative care

Participants' approaches to managing assisted suicide requests appeared to be aligned with each individual's conceptualisation of palliative care. Approximately a third of participants considered assisted suicide as actually or potentially a tool in palliative care. Another third were strongly opposed to assisted suicide, seeing it as having '*no place*' and '*no common ground*' with the goals of palliative care (*see quote 13*). The remaining third were ambivalent, seeing AS as having validity, acknowledging its legality and responsiveness to patient autonomy, but expressing concerns about participating in it, due to fears around professional stigma and lack of competence. Many participants described a fear of being stigmatised as physicians, palliative care practitioners or employees of a health institution. A majority of participants believed more collaboration is needed between palliative care physicians and right-to-die societies, being in the patient's best interests in terms of providing better coordinated information and services (*see quote 5*). However, individually, most physicians were reluctant to initiate or participate in such collaborations. Contact with right-to-die societies was considered as inappropriate by a minority of mostly older physicians opposing assisted suicide.

Improving responsiveness to assisted suicide requests

Around a third of participants wanted to see stronger state regulation of assisted suicide including specific laws like those in two Swiss cantons, to know what actions are required (*see quote 16*). Half of participants wanted assisted suicide to be available in all Swiss hospitals or wanted to discuss this option, viewing discharging very ill patients seeking this legally permitted procedure was contrary to palliative care principles (*see quote 17*). Such hospital discharges were perceived as stressful for patients and families, particularly when patients no longer have a home. Participants opposed to assisted suicide in hospitals identified their reasons as fear of hospitals gaining a bad reputation and losing patients' trust, or their belief that assisted suicide is not part of medical practice.

DISCUSSION

In our study, the role of Swiss palliative care physicians in assisted suicide appeared to be poorly defined, supporting the wider international literature on physicians' role in assisted dying.[35] Medicolegal professional bodies formulating policy and guidelines need to recognise that the desire for assisted dying goes beyond biomedical reasons.[34] Motives may also involve psychoexistential factors and the personal biography of the patient.[36] The Swiss civil model of assisted suicide permits palliative care physicians to develop individualised roles which reflect each practitioner's personal, ethical and professional belief systems. However, individually determined roles can be at odds with patients' expectations.[37 38] Participants reported undertaking extended discussions with patients, to address the underlying reasons for these requests, but not necessarily acting on the patient's request. Moreover, they rarely supported patient access to assisted suicide. They tended to avoid ethically challenging activities, such as prescription of the lethal drug and interactions with right-to-die societies, and focused on alternatives to assisted suicide and their perception of its disadvantages.

Participants had received little or no formal training on responding to assisted suicide requests and most preferred to avoid facilitating assisted suicide. Lack of training appeared to contribute to participants' uneasiness in responding to assisted suicide requests, reflecting research with Swiss GPs.[39] Responding to a specific request for assisted dying is complex and must comply with country-specific legislation.[37 40 41] It represents a significant responsibility for physicians and requires specific competencies that are not widely taught.[39 40] For example, Belgian physicians are offered training on end-of-life decisions, assisted dying and communication. They are encouraged to attend biannual 'intervision' groups to evaluate their practice.[42–44] Need for training was also stressed by the British Medical Association.[45] In our study, physicians were confronted with assisted suicide issues beyond certification and prescription. A lack of training and formal guidelines on how to respond to assisted suicide requests within a patient–physician relationship concerns many European countries, not only Switzerland.[46] Further research on how physicians respond to assisted suicide requests in diverse jurisdictions is warranted to understand cultural specificities in Europe and elsewhere.

The absence of clearly defined roles in assisted suicide for Swiss physicians means that their responses seemed to be largely shaped by personal/professional values and their own experiences of assisted suicide. Their typical reaction was to discuss alternatives to assisted suicide, while declining to prescribe the lethal drug. This input pattern, although done with good professional intention, could result in a disparate outcomes. First, extended discussions might create a barrier for deteriorating patients wishing to pursue assisted suicide which may lead to further fragmentation of the roles of professionals. Second, discussion may lead to patients being better informed and reviewing their decision.[47 48]

The physician's ambiguous role, apparently studied neutrality, can result in ethical dilemmas: while they believed in patient autonomy, many participants struggled to reconcile their understanding of palliative care principles with patients' wish for autonomy and assisted suicide. Therefore, patients commonly go directly to the right-to-die societies to obtain assisted suicide, or alternatively they may 'screen' physicians to determine their stance.[49] There is a resonance with physicians' limited role in Oregon and Washington hospices that prohibit staff from engaging in assisted suicide.[50] Our participants' preference for discussing risks and alternatives to assisted suicide may also reflect their need to feel comfortable and competent. However, the impact on patients means that they could remain trapped in a protracted decision making or have to pursue assisted suicide outside of palliative care. Research participants strongly opposed to assisted suicide did not generally refer patients to a non-objecting colleague or a right-to-die society, so that patients' autonomy may not have been respected.[42] The Ontario College of Physicians and Surgeons published guidelines requiring objecting physicians to declare a conflict of interest and refer to another non-objecting physician.[51]

The picture of Swiss-assisted suicide emerging from our study and previous data suggests a patient-initiated process, with diverse stakeholders involved who are typically not working in collaboration.[50 52] Right-to-die societies undertake a dual role, providing the means for patients to achieve assisted suicide and at the same time verifying the patient eligibility, which potentially poses a problem because there is limited external scrutiny.[47] Stakeholders can be unaware of patients and families about reasons for seeking assisted suicide, the nature of the patient's suffering, their plan of care and/or the options available.[50] Our research demonstrated a separate assisted suicide process, with unclear roles and ambiguous legal boundaries, which leaves many palliative care physicians walking a tightrope between fully respecting the patient's autonomy and upholding their personal and perceived professional ethical code.

Possible domains that professionals might explore when responding to patients' requests for assisted

Possible domains to explore when responding to requests for discussion about assisted dying.

- ❖ Be familiar and act in accordance with national and regional laws, professional codes and institutional policies and/or guidelines.
- ❖ Gain an understanding of the patient's unique situation in respect to their personal biography, illness trajectory and family relationships.
- ❖ Explore with the patient their expectations concerning professional input in relation to assisted dying.
- ❖ Recognise when it is appropriate to refer the patient to another physician.
- ❖ Explain national and regional laws to the patient, together with institutional guidelines and/or policies and how they pertain to the patient.
- ❖ Explore and address with patient agreement what 'unbearable suffering' means to the patient, bearing in mind the multidimensional components of suffering.
- ❖ Ensure that the patient has access to all relevant information. Refer where appropriate to external relevant sources (e.g. patient advocacy groups and/or right-to-die organizations).
- ❖ Explain the role palliative care can play including physical and psychosocial symptom management and palliative sedation.
- ❖ Explain death and dying processes, including available options potentially relevant to the patient situation, e.g. advance care planning (ACP), non-treatment decisions (NTDs), and Voluntary Stopping of Eating and Drinking (VSED).
- ❖ Explore with the patient agreement their sources of meaning, hope, dignity and healing.
- ❖ Include families and significant others in the discussion, with patient agreement.
- ❖ Respond to needs of families and significant others as appropriate, in respect of patients autonomy and confidentiality.
- ❖ Use communication skills appropriate to patient needs.

Figure 3 Possible domains to explore when responding to requests for discussion about assisted dying based on study findings.

dying are proposed in figure 3. These can be relevant to all professionals working in specialist palliative care and address the complexity underlying assisted dying.[53] Future research is needed to test these domains to seek professional consensus on ethical responses to assisted dying requests.

Strengths and limitations of the study

All the interviews were held in English with participants' agreement although this was their second language. Where necessary, the participant's meaning was checked during or after the interview.[54] The diversity of physicians' experiences and demographics enhanced the generalisability of the findings across Swiss palliative care physicians. It is unknown what proportion of patients described in the interviews went ahead with assisted suicide; thus the experiences described should be considered as interactions concerning patient requests for information about having assisted suicide, rather than a confirmed, definitive pursuit of assisted suicide. Since physicians were self-reporting data, social desirability may have played a role in their accounts.

CONCLUSION

Responding to assisted suicide requests remains a difficult task for Swiss palliative care physicians. To reduce the uncertainty evidenced in our interviews, the physicians' role in assisted suicide should be more clearly defined, based on valid competencies and respecting their ethical principles.[55] In Switzerland, as well as in other countries, patients, families and palliative care physicians can be actually acting in isolation and secrecy when confronted with assisted dying requests, resulting potentially in ethical dilemmas and possible collateral damage.[50] Isolation, lack of networking and lack of education may contribute to miscommunication and misunderstandings in the physician–patient relationship. Concerning palliative care physicians' future role in assisted suicide, questions about the required level of education and any personal objections to assisted suicide must be addressed, especially if assisted suicide becomes more widely available in Swiss healthcare facilities. All efforts should be done to preserve mutual respect, offer open team discussion, assure physician accountability, respect patients' autonomy and ensure appropriate support and counselling across the continuum of care.[56]

Contributors CG conceived the study. PO collected the data. CG and PO analysed the data and prepared the results. CG, GDB, PO, NP and SP participated in the design of the study and the discussion of the results, and CG wrote the manuscript with input from all other coauthors. NP and SP oversaw the research. CG and SP are the study guarantors. The manuscript is an honest, accurate and transparent account of the study being reported; no important aspects of the study have been omitted.

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Responses to assisted suicide requests: an interview study with Swiss palliative care physicians

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CHAPTER NINE

DISCUSSION

In this discussion chapter the responses to the overarching research question are presented and the key outcomes and contributions to new knowledge from the four articles are summarised. How well the empirical data, systematic literature review and new contributions fit a family functioning framework is considered. The possibility of future research on improving families' experiences of assisted suicide through interventions that are based on the framework is explored.

9.1 The research question

What are the experiences of families who support a patient who dies from assisted suicide in Switzerland?

The findings of this thesis provide original and new evidence on what a person experiences when a family member dies from assisted suicide. An experience that may be one of the most challenging and complex times that can occur in that person's life. Evidence from my research indicates that they are heavily involved and cooperate with the patient by providing several types of aid and support. In most cases, their decision to cooperate is made independently of their moral stance on assisted suicide. Although patients and their family members may have different or conflicting views about assisted suicide, emphasis is placed by the family on allowing the patient to achieve their requested assisted suicide. The core values underpinning family member's decisions were respect for the patient's freedom of choice and autonomy. The profound motivation pushing them to listen to the patients' request and to get involved in their assisted dying was altruistic in nature. Family members appeared to work hard toward accommodating the patient's wish within their system of values and to work to process that request with sincerity through communication and negotiation.

9.2 A summary of the published findings and specific research aims

A summary of the individual articles and how they address the specific research aims are presented below.

9.2.1 Summary of findings from article 1:

> *Aim I: To systematically analyse the published literature on families' experiences with a family member who died with assisted dying, in jurisdictions where it is legally permissible.*

The purpose of the systematic review was to critically appraise and to describe research on the experiences of family members of patients who had died of assisted dying in countries where it was legal. Thematic synthesis was prepared using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocol (PRISMA-P) guidelines (Moher et al., 2015). The search strategy included peer-reviewed and grey literature published from 1 January 1992 to 28 February 2019.

Table 3 of the systematic review (article 1) showed that families are an active part of the decision-making procedure for patients' seeking assisted dying and are usually present at their death. Family involvement may be influenced by many factors such as cultural aspects, the type of legislation in their country and their perception of the social acceptability of assisted dying.

The context in which the decision and action takes place influences the family members' tasks, responsibilities, and experiences (Buchbinder et al., 2018; Starks et al., 2007). In jurisdictions where only euthanasia is allowed, such as the Netherlands (Dieltjens, Heynderickx, Dees, & Vissers, 2014), the procedure is overseen and organised within the healthcare system, by physicians or nurses, whilst in jurisdictions where assisted suicide is allowed, such as Switzerland, the civil approach adds many tasks which are largely taken on by family members in the assisted suicide procedure that are not required in the euthanasia models (Gamondi et al., 2015).

It is confirmed by the empirical data in this review that assisted dying is the result of complex and sometimes long negotiations between multiple stakeholders. Broader support from health care professionals and families seems to play a role in influencing families' experiences during and after assisted dying.

9.2.2 Summary of findings from articles 2 and 3:

> *Aim II: To investigate Swiss families' reflections of their experiences when a family member is considering assisted suicide.*
>
> *Aim III: To depict Swiss family members' reflections on their interactions with health care professionals and right-to-die associations during the time their family members were considering assisted suicide.*

A cross-sectional qualitative interview study involving 28 close relatives and family carers of 18 patients who died by assisted suicide in Switzerland was conducted in the Italian- and French-speaking regions of Switzerland. Interpretation and analysis were performed using qualitative content analysis (article 2). This was followed by a secondary data analysis of the qualitative data using framework analysis (article 3).

Exploring individuals' experiences of assisted dying revealed the underlying mechanisms which had contributed to shaping these experiences. This data showed that in the context of the Swiss approach to assisted dying, a family member's involvement is characterised by five phases: contemplation, gaining acceptance, gaining permission, organisation, and aftermath.

Families can participate in these five phases at diverse levels and with varying degrees of involvement. These phases are not characterised by any set length of time and there can be fluctuation between them. Important triggers for families and patients for the transition between phases include patients' experiences of their life-threatening illnesses and related treatments, their increasing awareness (sense making) of approaching death, and family member recognition of the patient's unbearable suffering.

9.2.3 Summary of findings of article 4:

> *Aim IV: To analyse Swiss palliative care physicians' accounts of interactions with patients and their families when they are considering assisted suicide.*

A qualitative interview study was conducted with 23 palliative care physicians across Switzerland to describe their perspectives and involvement in assisted suicide practices. Thematic analysis was used to interpret the data which indicated that responding to assisted suicide requests remains a challenging task for Swiss palliative care physicians.

In Switzerland, as well as in other countries, patients, families and palliative care physicians may be acting in isolation when presented with assisted dying requests, potentially resulting in ethical dilemmas and unanswered questions. A physician's sense of isolation, the lack of established networks and a lack of education on assisted suicide may contribute to miscommunication and misunderstandings in the physician–patient relationship.

9.2.4 Conclusion

In conclusion, to adapt to assisted dying, the family members needed to develop their ability to cope and their capacity to surmount the crisis and endure the perceived stress initially and over time. This depends on the resilience that has been built within the family prior to and during this life event.

9.3 Theoretical perspectives to explain family involvement in assisted dying

Families involved with assisted dying are presented with competing complex issues as they are both caregivers and at the same time carry out tasks concerning assisted dying. Families, during a patient's chronic illness and in end-of-life phases, face numerous decisions, ranging from those about medical treatments to decisions concerning the choice of the place of care and death. Particularly relevant to this thesis and already explored in chapter 3, is that all families experience death as a significant challenge or threat and may react to this threat with varying degrees of avoidance (Geng et al., 2018).

Some families may be better able to recover their life functioning after a traumatic loss more easily than others and this observation raises the question as to whether families' coping skills can be developed and improved through supportive interventions (Palacio et al., 2020). In stressful situations, the anxiety that one person feels can expand and spread among family members, and the interdependence becomes emotionally demanding rather than comforting (Kershaw, 2015) which can lead to family conflict, that may be managed by an individual's emotional withdrawal. Frequently, major stressors are a complex set of changing conditions in family life, such as a request for assisted dying, which may ignite conflicts and dilemmas. According to Gamondi et al. (2013) and Gamondi et al. (2015), there is little data available to understand what the consequences of this are on the individual and the family system.

Whereas there are well known and widely applied palliative care caregiving models, as described in chapter 3, they present with some limitations if used to conceptualise families' experiences in assisted dying. The choice for this thesis was to take a positive and innovative approach to explore families' experiences of assisted suicide, with a specific focus on family capacity to overcome difficulties.

9.4 How appropriate is Walsh's Family Resilience Framework?

9.4.1 How the thesis findings were interpreted within the Walsh framework

The interview studies and the systematic literature review produced a wealth of data on family experiences. What follows is a discussion of how the empirical data may be interpreted in the light of the Walsh three domain framework, with the intention to understand to what extent it may explain family experiences in assisted suicide in Switzerland. As a secondary aspect, it was interesting to explore its potential use for future research to better understand key processes and to guide possible intervention studies. An overview of the supporting data is provided in figure 6 which includes the empirical data, systematic literature review and the more recent literature published after March 2019. At times, the decision on which process was better representing each experience, was a difficult choice. For example, the experience of isolation may be considered as part of communication, connectedness, and decision-making processes.

The final decision in these cases was based on a consideration of Walsh's in-depth description of the process and respecting the general coherence of the key process and its domain in relation to the assisted suicide experiences analysed in this thesis (figure 7). For some key processes there are limited data to provide relevant reflection. As the consideration of the Walsh framework came after the completion of the empirical studies the research design was not developed to capture all of the processes. Also, the methodology used, may have facilitated a more dyadic perspective rather than focussing on whole family relationships. Follow up interviews may have enabled further elaboration and verbalisation on what members may have felt were 'less important' processes.

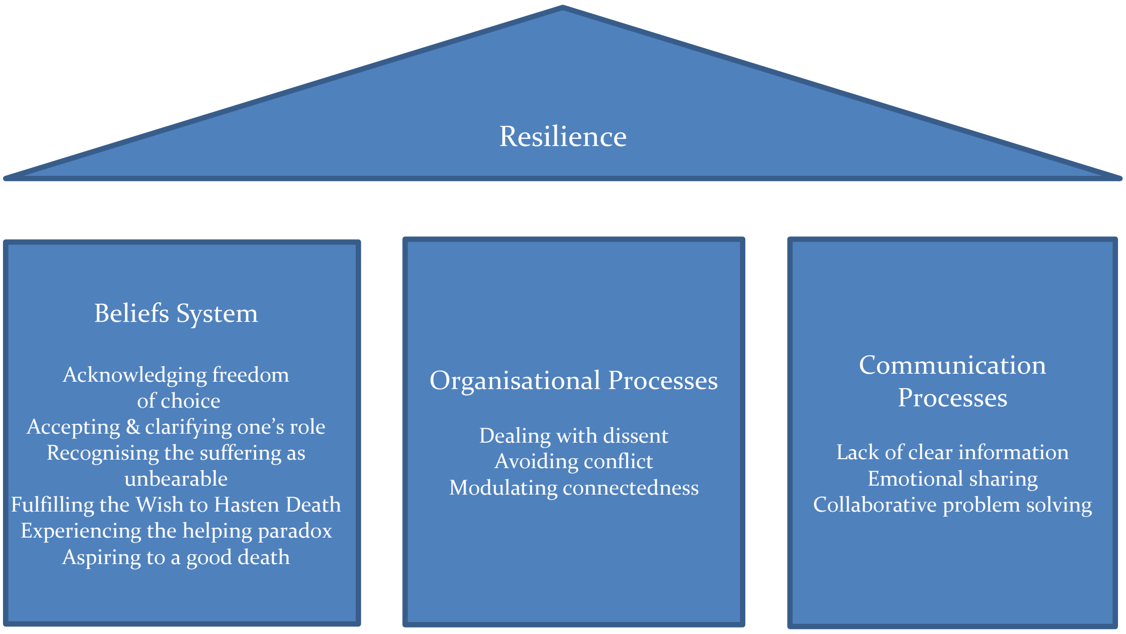


Figure 7: A visual representation of the experiences of families during assisted suicide organised within Walsh's key domains and the overarching concept of resilience.

9.4.2. Beliefs System Domain

The beliefs system domain includes systems which are central to family functioning and are powerful forces in resilience. The freedom to avail of assisted suicide is a belief observed within most of these families. Most of the families spoke about it as a civil right confirming that it was a part of their system of belief. For those families where assisted suicide was not part of their constitutional or family values, they appeared to have more challenges in fulfilling the patient's wish for assisted suicide (Gamondi et al., 2018). Often requests for assisted dying are not surprising to family members as most people expressed their interest earlier on in life, long before any diagnosis of life-threatening illness, as part of general discussion on assisted dying (Roest et al., 2019). Roest suggests that new qualitative studies with ethnographical narrative approaches could shed light on how requests develop over time, and mutual interaction between patients, their significant others and care givers. Roest concludes that future research in this field is needed to better understand the existential issues and views prior to becoming a patient. This thesis provides some interesting and innovative reflections which may address Roest's call for future research in this area.

In the Walsh framework, three key processes are described that contribute to the beliefs system domain. The meaning making and positive outlook processes contained the richest assisted dying data which is detailed below.

a. Meaning-Making

Throughout life people face and respond to moral challenges and demanding tasks and giving sense to one's actions – particularly with the complex involvement in assisted dying – may facilitate a positive outcome in grief and bereavement. Meaning-making is a complex core process that appeared in a discontinuous manner throughout the five phases of assisted suicide depicted in (Gamondi et al., 2018). To provide any sort of help, family members needed to make sense and provide a rationale for what they were doing. Making sense became crucial to these family members, not only in motivating themselves to respond to the patient's wish for a hastened death by facing all the difficulties and complexities that preparing an assisted suicide involved, but also in the bereavement phase when they anticipated being asked to explain their actions and feared being stigmatised. Family members' capacity for making sense in each phase differed and appeared to be influenced by several factors. A strong motivator that emerged from the empirical research in this thesis and other published literature is the fact that members sought to fulfil patient's wishes, independently of their own moral viewpoint (Beuthin et al., 2021; Hales, 2019). They appeared to act with the intent to balance their perceived duty to help the patient with their capacity to accept assisted suicide as a way to die.

Acknowledging the patient's freedom of choice

Freedom of choice represents a common ground across supporters and opponents of assisted dying and family members are no exception. Swiss family members reported that their most powerful motivation to support the assisted suicide decision was to respect patient's freedom of choice (Gamondi et al., 2018, 2020). Family members recalled the importance of respecting the patient's decision in all the phases of assisted suicide. Freedom of choice became a matter of discussion with dissenting family members, represented a point of reference for deciding to act and advocate for the patient and contributed to the acceptance of the action during the bereavement phase.

This finding was also observed across the systematic review (Gamondi et al., 2019) and in the international data, with (Dees et al., 2013) reporting that Dutch families valued a shared decision-making model which included a mutual respect for autonomy between patients and family members. Families in Oregon (Ganzini, Goy, Dobscha, & Prigerson, 2009) indicated that they experienced positive emotions such as the feeling of being at peace, of accepting the patient's choice and of having felt included in the choice.

Family members expressed the belief that the patient's access to assisted suicide was a civil right and a private decision to be made by the patient and not a medicalised decision for health professionals (Gamondi et al., 2018). Family members and healthcare professionals in Snijdewind, van Tol, Onwuteaka-Philipsen, and Willems (2014) review described patients who requested assisted dying as having a strong desire to control their death. This determination often clashed with the physicians' role in directing care and physicians often reported feeling pressured by family members to agree to assisted dying after their patient had lost the capacity to consent. In more recent literature (Beuthin et al., 2021) found that Canadian families also valued freedom of choice and chose to respect patient's wishes over other values they held.

Accepting and clarifying one's role within the assisted suicide

Deciding whether to participate in assisted dying and which type of involvement is a matter for family members. The decision to provide any sort of help to the patients requiring assisted suicide carries with it many burdens and responsibilities and may present as a challenge for some people's personal values. Initially observed in the Gamondi et al. (2013) study, the degree of passive or active involvement of family members within a patient's assisted suicide could be considered in terms of a continuous internal dialogue between a sense of commitment to their family member, their own personal beliefs and moral principles. Tension is created when these loyalties are split, which may influence the degree of involvement of the family members and their motivations to be involved. In the interview studies (Gamondi et al., 2018) there was some diversity between interviewees, with some who were in favour and a few who were against assisted suicide. This could be interpreted as family members who experience a more intense dilemma tend to withdraw and become passive in their assisted suicide support. Similar to what was observed in Swiss families, (Beuthin et al., 2021) found that some Canadian families perceived having provided help in assisted suicide as an honour, whereas for others it represented a burden. Canadian families showed that dissenting family members, while deciding to nevertheless provide help, perceived difficulties and challenges in going against their principles. Further research on commitment or allegiance is needed to understand how a family member's positioning on assisted suicide may influence the patient's capacity to achieve assisted dying.

Recognising the patient's suffering as unbearable

The families' recognition that the patient's suffering was unbearable is considered a key issue in assisted dying and was observed as a powerful motivator for families. A family member's decision to support an assisted suicide appeared to be shaped by two main values: their understanding of the patient's unbearable suffering and their views on freedom of choice (Gamondi et al., 2018, 2020). Families reported feeling powerless when faced with the patient's suffering. A family member's reaction to a patient's suffering seemed to play a significant role in motivating them to provide help and support, even if assisted suicide was contrary to their fundamental principles. The combination of feeling powerless when witnessing the patient's unbearable suffering and the willingness to help the person in obtaining what they desire may catalyse a family member's decision to provide help (in whatever form) to the patient and respond to their wish to hasten death (Gamondi et al., 2018, 2020).

Most of the documented reasons for supporting an assisted dying decision are related to core beliefs concerning the value of life, the sense of it and the components, that when lost, negate the purpose of being alive. It is known that contributing factors to unbearable suffering are a combination of physical determinants such as fatigue, pain and physical decline, and existential determinants – in particular hopelessness, physical dependency, loss of autonomy, futility, and loss of dignity (Bos, de Graaf, de Graeff, & Teunissen, 2019; Dees, Vernooij-Dassen, Dekkers, Vissers, & Van Weel, 2011). For example, in a Dutch study unbearable suffering did not appear as a discriminating factor as to whether euthanasia was requested or not (Pasman, Rurup, Willems, & Onwuteaka-Philipsen, 2009). This contrasts with an earlier study by Georges et al. (2007) who interviewed Dutch relatives of terminally ill patients that had chosen assisted dying. The most frequently mentioned reasons for the patients' decision were hopeless suffering, loss of dignity and no prospect of recovery.

Authors have argued that the inconsistency in the reporting of unbearable suffering between studies may be due to additional factors playing a role in its generation, or its interpretation, such as life history, social and cultural circumstances and personality characteristics (standards, values and existential motivations such as the will to live or not) (Dees et al., 2013; Ruijs, van der Wal, Kerkhof, & Onwuteaka-Philipsen, 2014).

Data from US and Dutch studies have shown that when suffering is not clearly visible, or is difficult to determine, an assisted dying decision can be harder to support by both families and physicians (Variath, Peter, Cranley, Godkin, & Just, 2020). They conclude that there should be a necessary agreement between patients and professionals regarding the degree of suffering.

b. Positive Outlook – Hope

In end of life and hastened death circumstances, it may be difficult to see where hope or optimism could be found as there is no possibility of the patient recovering. This was observed, with some Swiss family members reporting feeling hopeless in the context of the patient's suffering, with moments of disorientation and lack of hope also reported (Gamondi et al., 2013, 2018). Such feelings are common when a condition becomes incurable or when a treatment or the suffering appears unbearable, or overwhelming (Flaskas, 2007). Family members may be divided between holding on to hope and giving up (Flaskas, 2007).

Walsh (2015) argues that hope is essential to the spirit and helping families counter a sense of helplessness enables them to build capacity and search for solutions. In contrast to the reports of feeling helpless, families also perceived that the assisted suicide may become a release or a relief from suffering and illness, and they hoped for a non-medicalised death at home (Gamondi et al., 2018). Whilst hope was not specifically investigated within the scope of this research, families frequently reported positive reflections about their experiences. This was also confirmed by the systematic literature review. These points are grouped under positive outlook and hope using the headings: fulfilling the wish, the helping paradox and a good death.

Fulfilling the wish to hasten death

A major component of the positive outlook that families offered was the perception of having fulfilled the patient's wish. Their actions appeared to be guided by the principle, not only of respecting a person's wish, but also collaborating with this person to make their wish possible (Gamondi et al., 2018). Having fulfilled a patient's wish was also observed as a pillar in moral dilemma resolution observed in previous research (Gamondi et al., 2013). The systematic review, which included studies from other jurisdictions, also showed the importance for families in respecting their family member's wish, even though it may have created moral dilemmas for those family members (Gamondi et al., 2019). Further confirmation that respecting the patient's wish and autonomy are powerful underlying mechanisms in supporting an assisted dying request, can be seen in families operating in a context where it is not legal. Despite risking prosecution for their actions, families remained faithful to the patients and assumed substantial responsibility for the patients' assisted deaths (Starks, Pearlman, Hsu, et al., 2005). This desire to support the patient's wishes was also observed within Swiss families, who reported being unclear of the Swiss legal framework, but who nevertheless supported their family member in pursuing assisted suicide (Gamondi et al., 2013). In more recent research, both in the Netherlands and Canada, families appeared to value their intention to fulfil the wish expressed by the patient (Beuthin et al., 2021).

In general, it seems that this wish represents a pillar in giving families motivation to engage in assisted dying activities. The conviction of some that assisted suicide was what the patients strongly desired remained a motivation for their actions and one of the most frequent explanations reported during the bereavement phase. This conviction gave them purpose and a sense of hope in having fulfilled the patient's wishes.

Experiencing the helping paradox (when helping means helping to die)

In assisted suicide, family members appear to be motivated by a selfless concern for the well-being of the patient, even though the wellbeing of the patient at the end of the process is represented by their death. This altruistic support thereby creates a paradox that may contribute to the moral dilemmas often observed.

Families may gain a positive outlook from the knowledge that they are facilitating their loved one's request. Family members that agree with the principle of assisted suicide view it as a component of the quality of both life and death. For these family members, the collaboration and input given in assisted suicide preparation may be of great relief for them and they may experience less sense of hopelessness than those who do not fundamentally agree with assisted suicide. Many family members reported being in a personal conflict between the wish for more life for the patient and the powerlessness felt when facing the inevitability of death, be it a hastened or natural death (Gamondi et al., 2018). Wanting to keep the patient alive, despite their suffering, was mentioned by some family members, and caused them to reflect upon what they considered as their own selfishness.

Another source of positive outlook expressed by family members was that they had been of help to the patient. Family members who had confirmed their support for assisted suicide early in the process built a strong collaboration with the patient (Gamondi et al., 2018) and continued to support the patient through the difficult journey to achieving assisted suicide. In some exceptional cases family members had the sense that they were fighting against a system in which they needed to be strongly advocating for the patient.

Approaching end of life needs to be negotiated in all its forms and stages. This awareness brings great complexity and dilemmas for family members. The question of how far death should and can be managed is a running theme across the assisted suicide phases and appeared to govern family members' behaviours. The discourse concerning both the finality of the illness and the choice of assisted suicide has a common denominator in that families are confronted not only with death itself but with different deaths that may be chosen. Families become aware that they may negotiate, with the patient, the type, and the timing of death, which provides some sense of control over death. Nevertheless, the awareness of death being inevitable and governable brings both pros and cons.

Some families expressed the wish for death to be postponed allowing for more time with the patient. Others expressed a wish for a natural death to occur before the assisted suicide, possibly because the pressure resulting from the ability to control death had become a burden and a source of stress. Families were caught between their conscious perception of a limited time left, the wish to get the best from the time left and the additional tasks related to assisted suicide organisation.

Aspiring to a 'good' death

Fulfilling the patient's wish for assisted suicide was an important component for families of what a good death may be, but aspiring to provide a good death to the patient was also an important motivator for family members.

Perspectives of 'good ways to die' among the general public showed that euthanasia may be considered as a good death because it may let the person avoid being dependent on or a burden to others, to remain in control, and have a painless death (Rietjens et al., 2013). Although in the interview studies family members were not directly asked how they evaluated the death they had witnessed, families expressed an evaluation about the assisted suicide death. This happened mainly when they were asked whether assisted suicide should be comparable to a classical suicide, which was reported to be a matter of debate in family members in previous research (Gamondi et al., 2013). In general, Swiss families hold diverse views; some of them believe that assisted suicide is a form of suicide, since it is the result of a conscious choice made by the patient. Others perceived a stigma related to the use of this word. In general, assisted suicide was considered to be a better death if compared with suicide. This comes as no surprise. In Switzerland, the word, suicide, continues to be used; consequently, this choice of nomenclature may be forcing this type of comparison within families. To favour a more neutral and less stigmatising terminology, in other countries the term suicide has been abandoned (see Table 2: for the terms and definitions of assisted dying across countries). Future research is needed in Switzerland to allow an in-depth understanding of the implications of the use of the term suicide for professionals, patients and families and society in general.

The systematic review found that families in general tend to have a positive overview of assisted dying after they have participated in it (Gamondi et al., 2019). Some US data revealed that in some areas, according to family members, the quality of death for those who use physician-assisted death was better than those who do not. One of the highest ratings was related to preparedness for death and the ability to say goodbye to loved ones (Smith et al., 2010). Many factors may be related to the perception that a good death may have occurred, for example, preparedness, fulfilling a patient's wish, anticipation of the loss and a fast-dying phase were all characteristic features of a good death that may be identified.

What a 'good' hastened death should look like, for whom and according to whom, is a matter of debate due to the complexities related to this judgement (Roest et al., 2019).

There is limited international evidence about what families think about assisted dying and good death. The overall awareness that assisted dying provided a relief from suffering may also play a substantial role. More studies are needed to understand the complexities related to the perceptions of a ‘good’ hastened death by family members and what are the contributors to this experience.

9.4.3 Organisational Processes

Assisted suicide in Switzerland is characterised by many organisational aspects and the civil Swiss approach (Gamondi et al., 2019) adds more responsibilities to family members in comparison to other countries such as Canada or the Netherlands (Gamondi et al., 2019). These responsibilities are multiple, such as contacting Right To Die Association (RTDA), organising documentation and medical certificates and being part of rituals selected by the patient (Gamondi et al., 2019). Families appeared to be faced with a fragmented process where each stakeholder seemed to work in a dyadic manner with the patient and families. The RTDA and professionals did not appear to collaborate, leaving families negotiating with them separately to bridge the gap across all phases of preparation and organisation (Gamondi et al., 2018).

a. Flexibility to adapt

Walsh describes the flexibility to adapt as a key process of the organisational domain. Flexibility was one of the features that contributed to the capacity of family members to navigate the civil model. The Swiss civil model of assisted suicide is less straightforward or linear than the procedures in other countries, yet families still found their way – with whatever means available to them – to obtain what was necessary to assure assisted suicide for the patient. The capacity to adapt was never explored explicitly as a standalone theme when analysing the interview data (Gamondi et al., 2018), yet families' capacity to adapt may be indirectly derived from the data, in that this capacity was necessary to overcome the many obstacles and difficulties.

The next section more fully explores how flexibility aided family members in navigating dissent or opposition to assisted dying from others within their orbit

Dealing with dissent

Family members may be confronted with dissenting views from family members, their own social circle of friends and professionals. For family members with differing value systems the assisted suicide decision posed more problems, and dissenting members experienced several difficulties in adapting to the request. Some could not accept the patient's request at all and refused categorically to participate in any related activities, whilst other members were more passive in their dissent, by not actively helping in the process (Gamondi et al., 2018). A frequently declared reason was their moral disagreement (more or less firm) to assisted suicide. Some interviewees reported that other family members choose to remain faithful to their own principles (against assisted suicide) even in the context of a great amount of suffering, as it was expressed by the patient and echoed by other family members. These choices were reported to appear unusual and were sometimes recalled as selfish. These dissenting family members are reported to sometimes be excluded from the family (Gamondi et al., 2013). A common pattern of behaviour between opponents and promoters of assisted dying within families regarding polarised views was also reported in the scoping review of Variath (2020) who noted that it may put family connectedness in danger, affecting them negatively. When social cultural context such as religious background or professional values did not align with the request for assisted dying, there were reported instances of hostility or disinterest, which negatively affected patients and the family members (reported, for instance, in US, Dutch and Canadian cultural contexts). Whilst the Dutch and Belgian data (Variath et al., 2020) suggested that open communication and collaboration resulted in positive outcomes for families and professionals in the assisted dying process.

Avoiding conflict

The Swiss data concerning families' experiences and physicians' experiences showed that many conflicts may arise when assisted dying issues are discussed. Most of the described conflicts derived from a clash of values between families and physicians, each of them wishing to stick with their own values, in the context of no Federal law or clinical guidance. Conflict and discussion between families and physicians appeared to create obstacles and gatekeeping to the patient, slowing the process of gaining permission. The difficulties in communicating with physicians and the general perception of being judged or 'gate-kept' was a common theme in the interviews. When family members recalled their initial conversations with the patient on assisted suicide, they had the impression that patients were "testing" family members for a match in values and beliefs on the topic, possibly to avoid confrontations with those who might oppose it. They commented that the patient was also assessing health professionals in a similar way (Gamondi et al., 2018). Family disapproval or full dissent has been shown to influence professionals' views on whether to proceed with an assisted death request (Ganzini, Dobscha, Heintz, & Press, 2003). This shows that families can be considered part of, or may influence, the gatekeeping process. Further data reported that patients avoided conflict by not revealing their request to those dissenting members who objected to assisted dying (Variath et al., 2020).

In general, the conflict in values and intentions to help, when expressed or perceived, did not appear to provide a field for open and non-judgemental collaboration, rather it may have distracted families and professionals from the needs of the patient. Once more, polarised views may influence the discussion, possibly pushing people to a defensive position, lowering capacities and strengths on all sides.

b. Connectedness, Mutual support

Walsh's framework focuses on connectedness within the family which is vital not only for creating but also for maintaining family relationships (Walsh, 2015). Since assisted suicide needs the input of stakeholders outside the family, such as professionals and

RTDA, connectedness with these stakeholders was also considered in this thesis. In assisted suicide situations, relationships may be threatened by polarised views, irrespective of whether these views are between the family members or the patient or professionals. Dissent around assisted suicide may jeopardise connectedness and mutual support. Consequently interventions designed to foster family capacity to maintain a strong connectedness despite dissent may be advantageous.

Modulating connectedness

Reports of isolation and fragmentation of relationships were very prominent in earlier papers by Gamondi et al. (2013; 2014), while the empirical data examined in this work provided rich data that allowed further conceptualisation of families' experiences. Families reported more diverse experiences modulating between open disclosure, secrecy and isolation, and they seemed to have clear expectations from physicians and RTDA.

It should be noted that while Walsh (2015) refers to connectedness in the sense of having a close relationship, in the data gathered within the context of the Swiss model of assisted suicide, it was difficult to operationalise the concept of connectedness in its full sense. Families appeared to mostly manage relationships in terms of their needs, as well as their perception of being stigmatised or judged for their choices. In its higher interpretation, a general lack of connectedness emerged as a prominent experience within the empirical data. Consequences of this lack of connectedness within the family circle and supporting network may also have been the cause, or contributor to the reports of social isolation.

The literature review showed that in jurisdictions with other models of assisted dying, patient connectedness with professionals may be more stable. This was confirmed by more recent Canadian data, showing an open dialogue happening between stakeholders and patients (Beuthin et al, 2020).

In Switzerland it remains apparent that connectedness beyond the dyadic family members-patient bond is fragmented. The relationship that appeared most fragile was with physicians (Gamondi et al., 2020) due to reports that the main point of conflict evolves from a clash between personal values. A clash of values may be one factor, but not the only one, which may explain the isolation experienced by some health professionals. In the Northeast United States, physicians who seriously dealt with Physician Assisted Death requests were in relative isolation, speaking about it rarely with colleagues and only with personal contacts such as a spouse (Voorhees, Rietjens, van der Heide, & Drickamer, 2014). Families described more positive contact with RTDA, possibly due to a greater synergy in values concerning assisted suicide. Further research is needed to explore the nature of relations between families and RTDA.

The perception of being in conflict and/or the fear of judgment may have led to a deliberate limitation in interactions and a careful choice in disclosure at all levels, continuing into bereavement. Some participants report a certain sense of isolation persisting during bereavement (Gamondi et al., 2020). Although they did not have an explicit intention to avoid social contacts, there was uneasiness in others approaching them.

There is a complex interplay between stigma, isolation and secrecy and the difficulties that families may have to cope and reconcile with following the assisted suicide. Specific bereavement support, tailored for assisted dying experiences, appeared to be missing across cultures and countries both within the interview data and the literature. There appears to be dissonance between what a society expresses in terms of support for assisted dying and what its individuals and families experience or perceive.

9.4.4 Communication Processes

The three main communication processes needed for family resilience as stated by Walsh (2015) are clear information, open emotional expression, and collaborative problem solving. Unfortunately, these communication processes are rarely achieved within the Swiss civil model. Swiss families reported receiving fragmented and polarised information when seeking assisted suicide. This may be due to several factors, for example, difficulties in communication due to the number of stakeholders, or stakeholders not working in collaboration. Family members' fear of and experience of stigma may have made them cautious in what and to whom they communicated during all the assisted suicide phases, from initial discussion to bereavement.

a. Clear information

The sources of information for Swiss families appeared to be multiple and fragmented and, in many cases, polarised (Gamondi et al., 2018, 2019). Due to the Swiss civil model families do not tend to have a strong relationship with any one body (physician, RTD organisation). As there is no single professional to talk through the entire process, they seek information from various sources – media, society, professionals, and right-to-die associations – depending on which stage they are at. Most families described difficult relationships with the physician and were more likely to recall negative or judgemental experiences rather than positive experiences (Gamondi et al., 2018, 2019). They were also found to have misinformation about the palliative care treatments available (Gamondi et al., 2020).

In contrast, a recent study by (Roest et al., 2019) found that Dutch physicians were more likely to speak about end-of-life decisions with their patient's family members compared to their counterparts in other European countries. Family members, friends, and siblings were reported to be more frequently at the bedside of patients for these discussions.

b. Emotional sharing

This research did not focus specifically on investigating emotions, although during the interviews and in informal moments of exchange with participants their narratives were characterised by intense emotions. Many participants, even years after the assisted suicide, cried when recalling some moments and significant episodes. In general, in the Swiss data, it emerges that there may be challenges in sharing emotions with other family members and with professionals. Privacy, secrecy, and fear of stigma may play a role in shaping some family members freedom of expression.

Assisted suicide is a complex decision and can be emotionally demanding for all that are involved (Gamondi et al., 2019; Variath et al., 2020). The emotions family members may experience may derive from different challenges that participants may face at different stages of the decision (Gamondi et al., 2019). They may be triggered by the decision itself, when advocating for the patient, when faced with dissent, when preparing for the death, and afterwards. In general, a crucial point seems to be that family members are suffering at various levels. They perceive their own struggle for the patient, for the patient's condition and upcoming death. At the same time, they are exposed to the accounts of patients that expresses openly their suffering to justify their choice of assisted suicide.

The degree of disclosure around assisted suicide at different stages of decision-making are very variable in the Swiss data. Some family members reported that patients tended to look for the cooperation of individual family members – usually the daily caregivers – and were more open with them. It is arguable that patient hold long-standing views on assisted dying and what may be a good death in relation to their concept of dignity. Patient's views may also constitute a core family value, leading the patient to be more open with family members that may share their views. It is hypothesised that within families where these values were openly shared and agreed on, the request to collaborate in assisted suicide brought fewer challenges to their system of values. In general, it was observed that in the phase of acceptance and gaining permission, patients and their families tended to be very selective about to whom they spoke.

Some of the family members appeared to be solitary during the process, mostly relying upon a few other members or a small circle of friends for support. Some referred to psychological or spiritual support that had been offered but which was usually declined. They appeared to be cautious in seeking support, possibly because they feared being stopped or judged for their decision to provide help in assisted suicide (Gamondi et al., 2018).

c. Collaborative problem solving

Being able to address problems collectively as a family and to manage conflict enhances relational resilience (Walsh, 2015). In general, if family members are blocked from expressing their opinions, this can create conflict and impair effective problem solving. Gamondi's studies (Gamondi et al., 2017, 2018, 2019, 2020) showed that, in general, families did not benefit from a functional and supportive network. The Swiss civil model appeared to result in a dyadic support network between patient and family member, who turned to a medical practitioner for the necessary information and documentation and then approached RTD organisations to facilitate the final act (Gamondi et al., 2018).

The Dutch euthanasia model can also be viewed as a dyad, but one between patient and physician. Within the Dutch euthanasia model, Roest et al. (2019)recommends that it is adjusted to a triadic relationship which incorporates the family. Introducing the family in the complex tangle of needs that exist in the dyad between physicians and patients may be challenging and intuitive. There is, however, no empirical data supporting this intuition. Family needs in terms of type of network and support should be investigated across different cultures and models of assisted dying.

Would a more integrated collaborative system within the Swiss civil model work better for families? A more complex network of collaboration developed with families, physicians and RTDA may enhance the death experience for all involved, but how would this come and at what cost? Would this be a good response to family needs? A triadic model may also challenge the framework of autonomy of the patient. The discussion of the type of supportive network and its impact on the social fabric raises questions about social responsibilities, justice, and solidarity.

A medicalised triadic framework of support calls into questions the ethical duties of physicians: who to protect and who to support and whose autonomy to prioritise? On the other side, for example, GPs have traditionally focused on families and patients, so their knowledge of how to deal with sensitive topics in a triadic relationship may be of help in shaping a valid model for assisted dying. Adding the family may bring more complexity because it may shift power in the relationship and physicians should be cautious in interacting in these family decisions. For example, in cases of existential suffering (Snijdewind, van Tol, Onwuteaka-Philipsen, & Willems, 2018) reported that some physicians doubted whether they should have a role in the case of existential aspects of suffering, rather asserting that these problems mostly belonging in the societal field and not the medical one.

The Variath et al. (2020) scoping review examined health care professionals' experiences focused mostly on physicians, with reports on the unique role of nurse practitioners with assisted dying in Canada not yet being captured in the literature. A lack of interprofessional collaboration throughout the assisted dying process has been reported globally (Buchbinder, Brassfield, & Mishra, 2019; Denier, Gastmans, De Bal, & de Casterl, 2010; Dierckx de Casterlé, Denier, De Bal, & Gastmans, 2010; Van Bruchem-van de Scheur, Van der Arend, Spreeuwenberg, Abu-Saad, & Ter Meulen, 2007; van Delden, 2007).

In conclusion, the Walsh framework offers a way to interpret some of the findings, mostly via the belief and communication systems. A new and original finding from this thesis is that the international and Swiss evidence shows that a substantial amount of the work that families devote during assisted dying is concentrated in the belief domain. Although the other domains and processes have fewer supporting data, this may be due to the research design. It should be noted that the Walsh framework was introduced as an interpretative approach after the data had been collected, and therefore the research had not been designed with the theoretical intention to explore all three domains.

CHAPTER TEN
CONCLUSION

In this concluding chapter details of the key outcomes that have emerged from this thesis, with a discussion of their strengths and limitations and the implications for research and practice are presented. Future research that could inform and improve understanding and that results in support for family members of those seeking assisted dying is considered.

10.1 Personal reflection

Being conscious of our own role in conducting qualitative research is crucial (Dodgson, 2019; Palaganas, 2017). All through these 8 years of research with families and physicians over such a sensitive theme as that of assisted suicide I felt that I had to be aware of how this research was changing me in terms of values, ideas and conceptions around rightness or wrongness, goodness or badness, and possible or impossible. I think that being a PhD student has been one of the most rewarding, difficult and challenging opportunities that I have had in my adult life. In a broad sense it has allowed me to gain awareness about what reality is, how we see it and how we contribute to construct it with each act we perform.

As I recalled in my personal statement, I am a palliative care physician, with no religious background. I grew up in Italy in a family where freedom and logic were considered as prominent values. I moved to Switzerland when I was 26 and have lived in both the Italian and French speaking parts of Switzerland. Thanks to my residence in both these linguistic regions, I had the opportunity not only to become fluent in French, but also to come to know in depth the commonalities and differences between the French and Italian speaking parts of Switzerland in terms of culture and society. While I became naturalised two years ago, I am very much aware that to understand a country and its philosophy it takes a whole life. I am an emigrant, and I probably will always be considered as such.

When doing palliative care, I have always believed that the family is as important as the patient; this may be related to the education I had received in Italy and within my own family. Family in Latin cultures is quite an institution; it is difficult to go against their rules and there is a form of hierarchy to respect. This is possibly why conducting research on families in a Swiss context has so fascinated me from the beginning. I quickly realised that Ticino is a mixture of Italian, Swiss and international cultures, shaping the Ticino culture. In my clinical practice I see every day how families can play a crucial role in end-of-life care, how their decisions may influence the patient decisions and how as a physician I should have families involved to provide holistic care. I know that it may sound unfamiliar to many other cultures, but it is quite common in Ticino that patients take decisions that they believe may benefit their families more than themselves. This is frequently articulated by patients, and it is not uncommon to hear patients say: "*I'll do this because it is important for my daughte*r", or "*I will do chemotherapy because my family have asked me to try this last chance*".

The loyalties in some families are strong and some families expect from women different roles and responsibilities than from male members. In my interviews, I have met daughters and wives that overtly expressed to me the considerable expectations that the patient themselves and other family members had more or less openly expressed to them in terms of taking responsibilities over care and tasks concerning the organisation of the assisted suicide. This research has allowed me to reflect upon the education that I have received around gender related roles; it has improved my awareness about gender related issues in respect of duties in care, family dynamics and specifically of assisted suicide issues. I have also reflected upon how my being a woman may have impacted my relationship with participants during the interviews and the interpretation of the data.

Assisted suicide has interested me from many points of view: clinical, legal, ethical and sociological. As a palliative care physician, who has worked in the field for 25 years, my professional role brought the advantage that I was able to draw on a wealth of clinical experience to inform my research. With that comes one's professional baggage, which potentially could affect the qualitative data analysis, as I was looking with a palliative care professional's lens at the material. My interpretation, particularly of the data, may have differed to someone not working within this field.

I am a practical person, reflective and always interested in what "*lies beneath what is visible*". The choice of critical realism as the underpinning epistemology of my PhD research came as a natural choice. I had studied philosophy in my college years and retained an in-depth interest in clinical ethics and philosophy and how it is applied to social life. In palliative care I start from the reality as it appears to me, the reality as it appears to the team I work with, and the reality as it appears to patients and families. I am keen to believe that reality may be the puzzle resulting from the experiences and perceptions of those involved and that every voice should be listened to and should be taken into account before any decision is taken.

I wanted to listen to their experiences and opinions as individual persons, citizens, members of families and witnesses to the specific type of death of assisted suicide. My everyday experience in the clinical field is that patients and families have an initial idea of what assisted suicide may be and how they might obtain it. Then, over time, they meet professionals, other family members, friends and the right-to-die associations' volunteers and they negotiate rules, explain reasons, accept boundaries, experience stigma and provide support, adjust timelines and reflect repeatedly upon what they may or may not want to do. I have always had the impression that each assisted suicide is different in how it is negotiated, organised and perceived by all involved. In my research I wanted to explore these complexities and specificities thereby to better understand the experiences of families experiencing an assisted suicide in Switzerland.

I strongly believe that critical realism was a good approach to use to address the thesis research question and would recommend it for future researchers within this area. It was an extremely useful tool which helped me reflect on my findings as the research developed, allowed me to be more aware of the way I could be influencing the data and it gave me frequent opportunities to further the research through this replication, re-analysis and re-interpretation. A diagram showing how I have reflected in terms of the ontology of assisted suicide, the Swiss reality and the different layers of reality as described in critical realism is available in appendix 4.

My clinical experiences of assisted suicide and my previous master's research conducted on this topic has not always been a helpful tool. For example, it has been difficult to conduct the systematic review and to be adherent to the results whilst being aware of the knowledge and experiences that I already had on the topic. However, I was helped by a second researcher with whom I had long conversations and pondered the themes and our interpretation of the findings.

From working in palliative care, I have learnt to deal with distress from patients and families. This workplace experience and training helped enormously during the interview process where I saw first-hand the family's pain when recounting their experiences. I often was the first person they had been able to express these feelings and experiences to and it could sometimes become overwhelming.

The Covid-19 pandemic provided me with an overwhelming amount of clinical work which impacted on my research, networking at conferences and the writing of the thesis. Yet it allowed me to pause and provided a time of personal reflection, allowing time to look at my research from a distance. Seeing the importance that most families gave to being with a patient, despite the pandemic and the risk of personally being infected showed how important family legacies are. It demonstrated the extent to which families put themselves at risk, for the benefit of the patient but also for their personal need to be with the patient.

These are my reflections on my research process investigating families' experiences of assisted dying. I consider my personal experience enriches the findings of this thesis and the interpretation that I have drawn from the data. My aim was to give a prominent and proper voice to the families experiencing assisted dying and I hope this thesis proves to be an effective research tool which gives them a voice and makes them visible.

10.2 Key outcomes and contribution to new knowledge

The studies presented in this thesis are the first conducted in Switzerland and one of the few international studies exploring families' experiences in relation to assisted dying. At the time of writing there are no other papers on family experiences in assisted suicide currently coming from Switzerland. This thesis generated a wealth of evidence which revealed that family members are heavily involved in assisted dying from the beginning to the end, which is displayed across all the jurisdictions in which it is allowed. Even though there is a diversity of experiences across family members, assisted dying represents a major challenge to an individual's system of belief and family members devote many efforts to making sense of their emotions, decisions, and actions, with the aspiration to fulfil the patient's wishes. Most families appeared to be caught between witnessing the unbearable suffering of a family member, and the aspiration to fulfil the patient's request to hasten death. Most of the Swiss families had additional tasks and responsibilities related to assisted suicide preparation and emotional work to process what was happening. Swiss family members are an integral part of a complex and lengthy negotiation between multiple stakeholders in the assisted suicide continuum that leads from the initial contemplation to the moment of death. This experience increases their tasks beyond that of caregivers for other illnesses, or in different jurisdictions. The level of involvement can be considered a continuum of activities which can be passive (for example, listening) to more active (contacting right to die organisations, booking appointments for prescriptions).

In Switzerland, families in this study report a general opinion that assisted suicide represents a civil right (Gamondi et al., 2020) and the majority of steps leading to assisted suicide are taken outside the medical field. This viewpoint is not necessarily reflected across all international jurisdictions, as the role of physicians and health care professionals differ depending on the mode of assisted dying permitted (euthanasia or assisted dying). The diversity of family members' experiences may derive from the multiple interactions they encounter. The interaction with patients seems to be characterised by open discussions, while those with professionals or opponents to assisted suicide appeared to be more complex and charged with perceived stigma or fears of it especially in Switzerland. During these experiences, Swiss families were rarely offered professional support and in those few cases where they mentioned that they had been offered help, it had been declined. This is also a common finding in international studies (Biondo, Silva, & Secco, 2009; Gamondi et al., 2019; Roest et al., 2019). This decision may be due to fears that the support they receive will raise issues that may impede the patient's access to assisted suicide.

10.3 Strengths and limitations and future research implications

A particular strength of this thesis is that it comprises an in-depth investigation, via interviews exploring the real-world experiences of families who had witnessed assisted suicide in Switzerland. The interviews were reinforced by the overview provided by a systematic review conducted upon all jurisdictions allowing assisted dying. The specific limitations related to the published studies, with their recommendations, can be found in the original articles. A broader overview of the thesis strengths and limitations in terms of the transferability of findings to other cultures, professionals and models of assisted dying, as well as the influence families have on the final assisted suicide decision are explored below. A reflection on possible research priorities is also provided.

10.3.1 Values and limitations of using interview methodology in the Swiss context

The choice to conduct interview studies to answer the thesis research question presents with many challenges and advantages. The strengths and limitations of each study are presented in their related published articles. In the following section the most important challenges and complexities faced when conducting and evaluating qualitative studies in the Swiss context of assisted suicide experiences are considered in the light of Yardley (2000)'s criteria for validity: sensitivity to context; commitment and rigour; transparency and coherence; impact and importance.

There are a number of special cultural and contextual issues to consider when conducting qualitative interview studies in Switzerland, which are related to the different cultures that are present in the country. The studies upon families were conducted in the Italian and French speaking parts of Switzerland whilst the study investigating physicians' experiences was conducted across the three main linguistic regions. Within the family interviews, since the main researcher was fluent in both French and Italian, the in-depth interviews were conducted in the native language of the participants, allowing them to express themselves in their own words. The physician interviews were conducted in English, as physicians came from the four linguistic regions and the researcher could not conduct the interviews in all four native languages. I acknowledged the potential challenges of interviewing in a participants’ non-native language and ensured that the participants were competent in the interview language, allowed them to say phrases in their own language. This was an attempt to ensure rigour was achieved through the resulting completeness of the data collection and analysis. This also depends on the adequacy of the sample to supply all the information needed for a comprehensive analysis. The concept of commitment encompasses prolonged engagement with the topic (which has been clearly demonstrated by the researcher who has worked in this field for more than a decade) along with the development of proficiencies in the methods used (the author has six peer reviewed papers using qualitative data techniques), and data immersion (including secondary data analysis).

There are many benefits to using interview methodology which include the opportunity to establish rapport with participants to make them feel more comfortable, which in turn can generate more insightful responses. This is especially useful when exploring sensitive topics such as assisted dying. Interviewers have a greater opportunity to ask follow-up questions, probe for additional information, and circle back to key questions later in the interview, which generates a richer understanding of attitudes, perceptions and motivations. Interviewers can monitor changes in tone and word choice to gain a deeper understanding and, during face-to-face interviews, researchers can also focus on body language. Because in-depth interviews can potentially be so insightful, it is possible to identify highly valuable findings quickly. There are also none of the potential distractions or peer-pressure dynamics that can sometimes emerge in focus groups.

Disadvantages also exist in that in-depth interviews are quite time consuming, both in planning, implementation and transcribing. If the interviewer is not highly skilled and experienced, the entire process can be undermined, for example, with social desirability bias (Krumpal, 2013), or the tendency to present oneself and one's social context in a way that is perceived to be socially acceptable, but not wholly reflective of one's reality, (Bergen & Labonté, 2020) which is a particular concern when exploring sensitive topics.

A convincing transparency in the presentation of the analysis of the empirical data can be achieved by detailing every aspect of the data collection process and displaying the rules used to code data. This was described within all the articles as well as by presenting excerpts of the textual data which the readers can view and immerse themselves within. In addition, transparency refers to the degree to which all relevant aspects of the research process are disclosed.

The theoretical worth by which any piece of qualitative research can be judged is, debatably, its impact and utility. Such research can open new ways of understanding a topic and possibly provide some social purpose and having some societal effects.

10.3.2 The transferability of findings across diverse cultures

This thesis is one of the few international studies exploring families' experiences with physicians and right-to-die associations in relation to assisted dying. There are four main linguistic and cultural regions within Switzerland: German, French, Italian and Romansh. The sample for the interviews was drawn from two French- and Italian- speaking cultures, which covers about a third of the Swiss population. A particular strength was that the interviews with family members were conducted in the participant's native language and, as the researcher is bilingual, she was able to fully transcribe, code and conduct analysis in their original language. Some of the problems typically related to translation issues in qualitative research were thereby avoided, further strengthening the reliability of the interview findings.

It should be noted that assisted dying is conducted in various places across the world, which each have their own sociocultural and historical context. These complex sociocultural issues can only be understood in the context in which the data was collected, and researchers need to be aware of this when interpreting data. Although this study covered two cultural regions, generalisation of the results to the German-and Romansh speaking areas is limited. A further study, to explore families' experiences in other cantons and among immigrant groups, would assess the transferability of findings to these cultures within Switzerland, and internationally.

Another important cultural factor is related to the presence in some countries of right-to-die associations. In Switzerland, it would be relevant to investigate the right-to-die associations and their volunteers' experiences and roles in the overall assisted suicide process. This information would be relevant also in jurisdictions where these groups are present and active in providing any form of help in assisted dying procedures.

10.3.3 The international transferability of palliative care physicians' findings

The qualitative in-depth study exploring Swiss palliative care physicians' experiences of responding to assisted suicide requests is the only one conducted in Switzerland and one of few internationally (Khoshnood et al., 2018). Even though investigated in a unique model of assisted suicide, the conclusions highlight the needs of these physicians, including a need for in-depth education on the topic, specifically in how to respond to assisted dying requests. The need for further education is also confirmed by Gerson's systematic review (Gerson, 2019). A recent study that has explored Canadian physician experiences of assisted dying (Khoshnood et al., 2018) also confirmed this gap in physician education. Internationally physicians may often be the first port of call when patients are making initial enquiries on assisted dying. They have the potential to shape family and patients' early experience and they all need to develop communication capacities specific to this topic.

The civil model of assisted suicide in Switzerland is the only one in the world to allow physicians to develop roles compatible with each practitioner's values, specifically for those who may be conscientious objectors. Other jurisdictions have legal models which allow for conscientious objection, but more clearly defines conscientious objectors' roles, duties, and expectations. Further research is need in Switzerland to understand conscientious objectors' needs, and the experiences of physicians outside of palliative care.

10.3.4 The transferability of findings across different models of assisted dying

With the recent increase in jurisdictions legalising assisted dying there has been a positive shift in attention to families' needs, with recent studies emerging from Canada, Norway, and the US (Beuthin et al., 2021; Roest et al., 2019). Nevertheless, family experiences of assisted dying remain an under researched area.

The systematic review provided new evidence showing that different models of assisted dying provide a range of experiences for families. Across the jurisdictions that allow assisted suicide, this thesis has shown that there are still important contrasts that should be considered when comparing findings. For example, Oregon's assisted suicide model differs from the Swiss model in that it has a more defined role of physicians, which may have an impact on families' tasks and level of involvement in preparation.

While the literature review and interview studies have shown that the emotional work may be similar across different models, a striking finding is the level of family's responsibilities for the provision of certificates and medical documentation within the Swiss civil model. Another important contrast is that the physical location of the final act of assisted suicide differs across the various models. When a death occurs in an institution the family members can leave and return to their own homes. However, when the death has taken place in the family home – as is frequently the case in Switzerland – this could impact on those remaining in the home through having painful memories associated with the setting. It would be relevant for future research to explore what implications the place of assisted death has on a decision to have an assisted suicide as well as the bereaved household members.

10.3.5 Influence of family members on the outcome of assisted dying requests

The empirical data of this thesis included bereaved family members who had experienced the overall process of assisted suicide from initial consideration to assisted death. Since these family members had experienced the entire process from initial discussion to death and bereavement, they were able to describe the triggers that had facilitated the cascade of the events from one phase to another. This enabled the new identification and detailed description of five main phases that a family member experiences during this challenging time.

It is unknown what percentage of patients who have considered assisted dying then go onto enact their decision. Future research is needed to capture the needs and experiences of families, patients and professionals that may have stopped the procedure at different points. What influence, if any, do families have in the final patient's decision as to whether they proceed or not with an assisted death? This identified gap in the literature on the influence that families may have on the final decision for assisted dying may be further impacted by the type of assisted dying chosen (dependent on jurisdiction: euthanasia or assisted dying) and the place of death (institution or home).

There is also an important gap in the literature in that the interactions, and influence of family members with strong opposition to assisted suicide or any form of assisted dying have not yet been captured. In the Swiss model, which has less physician input, an opposing family member could potentially have a greater impact on the patient's final decision, compared to patients in other jurisdictions.

Since assisted suicide in Switzerland requires a police investigation conducted immediately afterwards, it is important to investigate the experiences, needs and impact such an investigation has on family members, right-to-die volunteers and the police officers involved.

10.3.6 Expanding from dyads to wider family networks

In this research key family members were interviewed, who were usually the nominated caregiver. Most of them had a strong and loyal bond with the patient, having been responsible for caregiving and supportive in the assisted suicide process. They therefore had an in-depth knowledge and personal exposure to the process for both themselves and the patient. This gave the researcher the opportunity for a private, intimate and privileged look at these experiences.

Families do not only function as dyads, involving a single caregiver and patient, they often have other members, differently bonded together and wider networks of support. Therefore, further longitudinal work, which involves all family members, including the patient, would be recommended. This could look at the dynamics of the family throughout the assisted suicide process independently from the outcome. This would enhance knowledge in this field and could further identify key triggers and phases of the decision-making process and their potential impact on the family.

10.4 Implications for clinical practice

10.4.1 Families as stakeholders

Implications for practice should include greater recognition that families are important stakeholders in assisted dying and they should be given specific attention. Assisted suicide represents a complex decision, in Switzerland mostly resulting from negotiations between the patient, family members, physician and the right-to-die associations. Across all jurisdictions, families need to be recognized as closely involved in the assisted suicide and recognised as participating in the decision and enactment of assisted dying. Clinical guidelines and policies concerning assisted dying should acknowledge, address and support family needs. Assisted dying needs to be understood by taking into consideration the life story of the patients and their family, and should be interpreted in the light of the various phases proposed by Gamondi et al. (2018), leading to the ultimate decision. Families should be included in conversations and provided with opportunities to expresses their needs and challenges. Space should be provided where they may have separate consultations with specifically trained professionals to facilitate open discussion. Families should be given the opportunity to voice their views without having to suppress them in front of the patient.

When countries are introducing assisted dying, they need to develop a structure to support, not only patients, but also families on this path which addresses their wellbeing throughout this complex life decision and experience. Since assisted dying remains a controversial issue, neutral or less polarised information should be provided to family members, aiming to address and respond to their needs, which may change across the process Future research is needed to pilot test intervention studies on their appropriateness and effectiveness to support families across different jurisdictions and cultures. The thesis studies were not designed as intervention studies but were explorative in their intention. Future investigations may test the Walsh framework within the Swiss context of assisted dying. This research has produced new knowledge about challenges and resources that these families had through the process of assisted suicide. It has emerged as new information that in many cases families believed that assisted suicide is a private issue and may be often a choice that the patent made to avoid a medicalised death. The Walsh framework may be a promising and innovative area for future research.

There is a need for nondirective counselling opportunities to talk things through in a supportive environment where family members do not feel judged. This may lead to helpful outcomes for people, enabling them to make choices based on their capacities, rather than fears, and in doing so receive support for themselves. All efforts should be made to preserve mutual respect, assure health care professionals' accountability, respect patients’ autonomy, and ensure appropriate support and counselling across the continuum of care.

10.4.2 Grief and bereavement after an assisted death

Even though this thesis did not look specifically at bereavement, it is a major area of interest in assisted dying, not only in exploring families' experiences and needs in this phase but also in understanding the long-term consequences of assisted dying for those who have witnessed and experienced it. The Swiss data showed that family members did not feel supported during their bereavement, nor had they received or were offered specific support. There is no bereavement service, not state, voluntary or charitable, at present in Switzerland. People of faith can turn to their own faith organisation for support at times of bereavement, but when it results from assisted suicide – a death contrary to most faiths' practices – family members may face or fear further stigma from such a source. As the numbers of patients choosing assisted dying are increasing due to changes in international legislation and changes in societal acceptance, further research on a larger scale may be possible. Future practice needs to consider the provision of bereavement services for this type of experience.

10.5 Concluding remarks

This research has offered new evidence that the Swiss civil model provides a unique degree of freedom of choice to families and palliative care physicians when a patient requests assisted suicide. Swiss families expressed a strong belief that assisted suicide is a personal and family decision and wished to keep medical involvement in the pursuit of assisted suicide to a minimum. Swiss palliative care physicians had the freedom to shape their role in assisted suicide discussions, having the choice to withdraw, refuse, or to support an assisted suicide request, as they were not swayed by any family commitment or stringent legal requirement. In this civil model, family members reported that they had carried many responsibilities throughout the process, as they appeared to be caught between different commitments such as personal beliefs, family loyalty, and love for the patient. However, supporting a family member comes at a price when the request for assisted suicide is contrary to their own moral principles. Nevertheless, independently of their own beliefs, most of the family members' actions were motivated by their desire to relieve the patient's unbearable suffering and to fulfil the patient's wish for a hastened death.

If enabling assisted dying is interpreted as a way to expand freedom of choice to people at the end of their lives, then the words of Jean Paul Sartre should be remembered: *"Man is condemned to be free; because once thrown into the world, he is responsible for everything he does."* If a society chooses to allow assisted dying, the community holds the responsibility to create an environment free of stigma and judgement that offers support to all those involved.

APPENDICES

Appendix 1: List of countries where assisted dying is legal and epidemiology (type of legislation, criteria)

Appendix2: Criteria for assisted suicide in public health care facilities in Vaud and Neuchâtel Cantons

Appendix 3: Real life example of family conflict during decision making for assisted suicide

Appendix 4: Personal reflection in terms of the oncology of assisted suicide, the Swiss reality and the different layers of reality as described in critical realism

Appendix 5: Coding Example

Appendix 6: Interview schedule / questions (grid for the family interviews

Appendix 7: Interview schedule / questions (grid) for the physicians' experiences

Appendix 8: Lancet paper

Appendix 9: Lancet paper

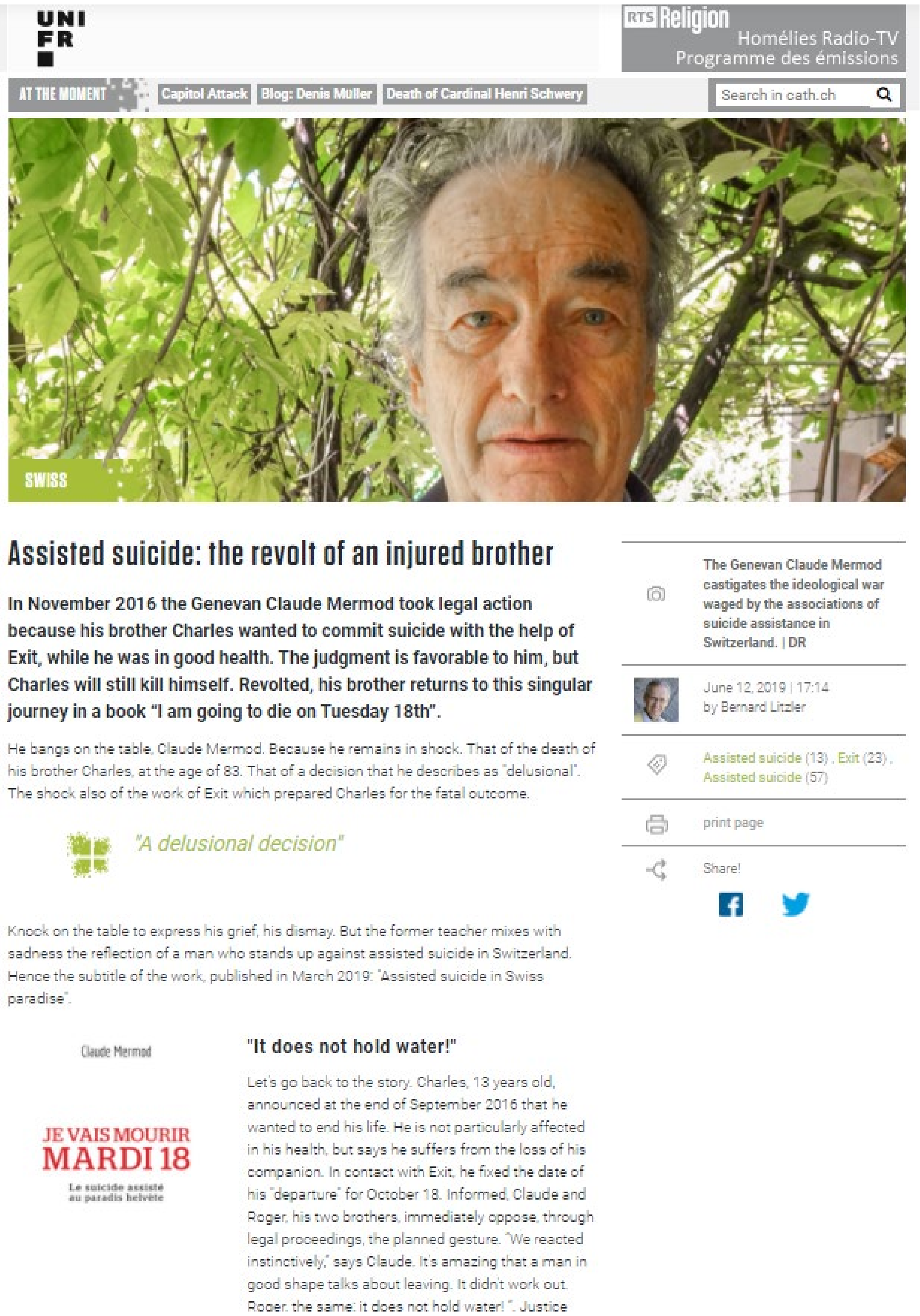
Appendix 1: List of countries where assisted dying is legal and epidemiology (type of legislation, criteria)

Nov. 1994	Oregon Death with Dignity Act Passed, Nov. 1997 - Oregon Voters Keep Death with Dignity Act.
2001	Netherlands Legalizes Euthanasia
May 2002	Belgian Act on Euthanasia
Feb 2008	Luxembourg Legalizes Physician-Assisted Suicide and Euthanasia
2008	Washington Death with Dignity Act Is Passed
Dec 2008	Montana does not have a death with dignity statute. However, the end-of-life option is legal in the state through the state Supreme Court ruling. The Montana Supreme Court ruled that nothing in the state law prohibited a physician from honouring a terminally ill, mentally competent patient’s request by prescribing medication for self-administration.
May 2013	Vermont legalize Act 39, Vermont Patient Choice and Control at the End-of-Life Act
Mar 2014	Belgium Legalizes Euthanasia for Terminally and Incurably Ill Children
Oct 2015	California Becomes Fifth State to Legalize the End-of-Life Option Act
June 2016	Bill C-14, medical assistance in dying (MAiD) Becomes Legal in Canada
Nov.2016	Colorado Legalizes Proposition 106, the End-of-Life Options Act
Feb 2017	DC Becomes Seventh Jurisdiction in United States to Legalize Death with Dignity Act
Nov 2017	Victoria Becomes First Australian State to Legalize Voluntary Assisted Dying Act
Apr 2018	Hawaii Legalizes Our Care, Our Choice Act
Apr 2019	New Jersey Legalizes Aid in Dying for the Terminally Ill Act.
2020	New Zealand

Appendix2: Criteria for assisted suicide in public health care facilities in Vaud and Neuchâtel Cantons

Steps	Requirements
Submission of the request	The patient should submit a written request to the Management of the Institution. The Manager informs the Medical Director and a meeting with the Medical Director, the patient and others involved in the request can be offered.
Medical evaluation of the request.	The physician in charge, after consultation with the care team, the general practitioner, a representative of nurses and (only if the patient agrees) with the family, verifies whether the following legal conditions are fulfilled: a. The patient: - has full mental capacity regarding the decision concerning assisted suicide - persists in his request for assisted suicide - presents with an illness, or consequences of an accident, which are severe and incurable b. Alternatives, specifically those related to palliative care, have been discussed with the patient. The medical director can ask for a second medical opinion or the advice of an internal committee of the Institution. If the medical director suspects any external coercion or underlying psychiatric condition, he should request a psychiatric evaluation.
Final medical decision	The physician in charge is asked to provide a written decision to the patient or a health care proxy, within four weeks. The written decision should be forwarded to the medical director and/or the Manager of the institution. The physician in charge should mention: - whether the legal conditions are fulfilled - whether a home discharge is possible (for hospitalised patients) - that there is a possibility for the patient to appeal the decision, in the case of disagreement
Notification to the caring team	The physician in charge, in agreement with the person responsible for the assisted suicide, should notify the caring team of any assisted suicide within the Institution.
Notification to the Cantonal physician	The person responsible for the assisted suicide, together with the physician in charge, should notify the cantonal physician of the patient's age, gender and underlying disease that justified the assisted suicide, in an anonymous fashion.
The Cantonal commission	The Cantonal commission can issue general recommendations; it does not have the mandate to evaluate assisted suicide requests.

Appendix 3: Real life example of family conflict during decision making for assisted suicide



Assisted suicide: the revolt of an injured brother

In November 2016 the Genevan Claude Mermod took legal action because his brother Charles wanted to commit suicide with the help of Exit, while he was in good health. The judgment is favorable to him, but Charles will still kill himself. Revolted, his brother returns to this singular journey in a book "I am going to die on Tuesday 18th".

The Genevan Claude Mermod castigates the ideological war waged by the associations of suicide assistance in Switzerland. | DR

June 12, 2019 | 17:14
by Bernard Litzler

Assisted suicide (13) , Exit (23) ,
Assisted suicide (57)

He bangs on the table, Claude Mermod. Because he remains in shock. That of the death of his brother Charles, at the age of 83. That of a decision that he describes as "delusional". The shock also of the work of Exit which prepared Charles for the fatal outcome.

"A delusional decision"

Knock on the table to express his grief, his dismay. But the former teacher mixes with sadness the reflection of a man who stands up against assisted suicide in Switzerland. Hence the subtitle of the work, published in March 2019: "Assisted suicide in Swiss paradise".

"It does not hold water!"

Let's go back to the story. Charles, 13 years old, announced at the end of September 2016 that he wanted to end his life. He is not particularly affected in his health, but says he suffers from the loss of his companion. In contact with Exit, he fixed the date of his "departure" for October 18. Informed, Claude and Roger, his two brothers, immediately oppose, through legal proceedings, the planned gesture. "We reacted instinctively," says Claude. It's amazing that a man in good shape talks about leaving. It didn't work out. Roger, the same: it does not hold water! ". Justice

'Assisted suicide: the revolt of an injured brother' has quickly become a famous case in Geneva and Switzerland.

https://www.cath.ch/newsf/suicide-assiste-la-revolte-dun-frere-blesse/ In November 2016, Claude Mermod sought legal intervention because his brother Charles wanted to obtain an assisted suicide helped by Exit ADMD. He was reported to be in good health but was tired of living, the brother assumed some degree of depression.

Claude told the press "I prefer to fight against a living brother, than being in harmony with a dead person". Even if the court had ruled in favour of Claude, Charles chose to die through classical suicide a few weeks before the court ruling. Claude has published a book about his experience titled "I'm going to die on Tuesday 18".

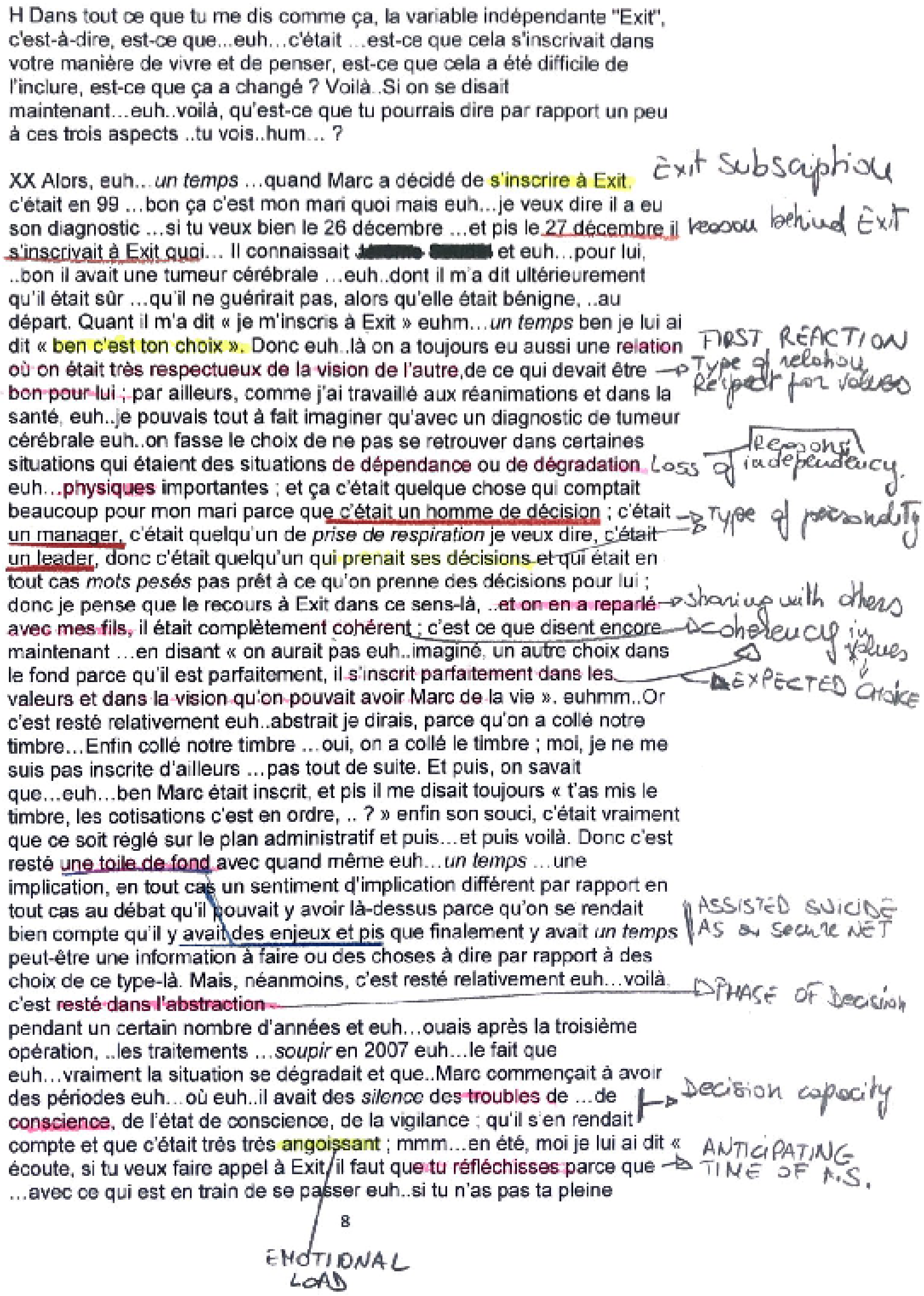
Appendix 4: Personal reflection in terms of the oncology of assisted suicide, the Swiss reality and the different layers of reality as described in critical realism

- precursors and context of the relationship
- coming to and enacting the decision
- cognitive and emotional work
- experieinced the final farewell
- experiencing grief and bereavement

- personal beliefs and values concerning AS
- family system
- relation with health care professionals
- relation with right to die associations
- need to advocate for the patient
- interactions with community

- missing federal law
- professional guidelines
- positive public opinion on AS
- internal rules of right to die organisations
- freedom as a core value
- privacy and intimacy

Appendix 5: Coding Example



H Dans tout ce que tu me dis comme ça, la variable indépendante "Exit", c'est-à-dire, est-ce que...euh…c'était …est-ce que cela s'inscrivait dans votre manière de vivre et de penser, est-ce que cela a été difficile de l'inclure, est-ce que ça a changé ? Voilà..Si on se disait maintenant…euh..voilà, qu'est-ce que tu pourrais dire par rapport un peu à ces trois aspects ..tu vois..hum… ?

XX Alors, euh…*un temps* …quand Marc a décidé de s'inscrire à Exit. c'était en 99 …bon ça c'est mon mari quoi mais euh…je veux dire il a eu son diagnostic …si tu veux bien le 26 décembre …et pis le 27 décembre il s'inscrivait à Exit quoi… Il connaissait [redacted] [redacted] et euh…pour lui, ..bon il avait une tumeur cérébrale …euh..dont il m'a dit ultérieurement qu'il était sûr …qu'il ne guérirait pas, alors qu'elle était bénigne, ..au départ. Quant il m'a dit « je m'inscris à Exit » euhm…*un temps* ben je lui ai dit « ben c'est ton choix ». Donc euh..là on a toujours eu aussi une relation où on était très respectueux de la vision de l'autre,de ce qui devait être bon pour lui ; par ailleurs, comme j'ai travaillé aux réanimations et dans la santé, euh..je pouvais tout à fait imaginer qu'avec un diagnostic de tumeur cérébrale euh..on fasse le choix de ne pas se retrouver dans certaines situations qui étaient des situations de dépendance ou de dégradation euh…physiques importantes ; et ça c'était quelque chose qui comptait beaucoup pour mon mari parce que c'était un homme de décision ; c'était un manager, c'était quelqu'un de *prise de respiration* je veux dire, c'était un leader, donc c'était quelqu'un qui prenait ses décisions et qui était en tout cas *mots pesés* pas prêt à ce qu'on prenne des décisions pour lui ; donc je pense que le recours à Exit dans ce sens-là, ..et on en a reparlé avec mes fils, il était complètement cohérent ; c'est ce que disent encore maintenant …en disant « on aurait pas euh..imaginé, un autre choix dans le fond parce qu'il est parfaitement, il s'inscrit parfaitement dans les valeurs et dans la vision qu'on pouvait avoir Marc de la vie ». euhmm..Or c'est resté relativement euh..abstrait je dirais, parce qu'on a collé notre timbre…Enfin collé notre timbre …oui, on a collé le timbre ; moi, je ne me suis pas inscrite d'ailleurs …pas tout de suite. Et puis, on savait que…euh…ben Marc était inscrit, et pis il me disait toujours « t'as mis le timbre, les cotisations c'est en ordre, .. ? » enfin son souci, c'était vraiment que ce soit réglé sur le plan administratif et puis…et puis voilà. Donc c'est resté une toile de fond avec quand même euh…*un temps* …une implication, en tout cas un sentiment d'implication différent par rapport en tout cas au débat qu'il pouvait y avoir là-dessus parce qu'on se rendait bien compte qu'il y avait des enjeux et pis que finalement y avait *un temps* peut-être une information à faire ou des choses à dire par rapport à des choix de ce type-là. Mais, néanmoins, c'est resté relativement euh…voilà. c'est resté dans l'abstraction pendant un certain nombre d'années et euh…ouais après la troisième opération, ..les traitements …*soupir* en 2007 euh…le fait que euh…vraiment la situation se dégradait et que..Marc commençait à avoir des périodes euh…où euh..il avait des *silence* des troubles de …de conscience, de l'état de conscience, de la vigilance ; qu'il s'en rendait compte et que c'était très très angoissant ; mmm…en été, moi je lui ai dit « écoute, si tu veux faire appel à Exit, il faut que tu réfléchisses parce que …avec ce qui est en train de se passer euh..si tu n'as pas ta pleine

8

Exit subscription
reason behind Exit
FIRST REACTION
Type of relation
Respect for values
Reasons
Loss of independency
Type of personality
sharing with others
coherency in values
EXPECTED choice
ASSISTED SUICIDE AS a SECURE NET
PHASE OF Decision
Decision capacity
ANTICIPATING TIME OF A.S.
EMOTIONAL LOAD

Appendix 6: Interview Schedule for Family Interviews

Introduction

- Clarify the purpose of the research, the purpose of the interview and how the information will be used. Ask whether they have any questions about the interview.
- Confirm the confidentiality of the interview

Decision making characteristics

- The patient's reasons
- Conditions for agreement on "unbearable suffering"
- Figures involved in the process
- Intercurrent negotiations
- Agreement on performance

Participants views on assisted suicide

- Comparison with classic suicide
- Who should be involved?
- Reasons why a figure should be involved
- General opinion about assisted suicide
- Views and experiences about natural death

Participants experiences of assisted suicide

- Dealing with gate keepers /opponents
- Dealing with incertitude about prognosis and illness trajectory
- Preparation of the day of assisted suicide performance
- Memories of the procedure

Managing the waiting for assisted suicide

- Living when the date of assisted suicide is decided
- Emotions and experiences

Dilemmas

- Dealing with doubts concerning the decision it self
- Dealing with patient ambivalence over the decision and timing of the procedure
- Dealing with doubts concerning the right timing of assisted suicide

Appendix 7: Interview Guide for Physicians

Introduction

- Clarify the purpose of the research, the purpose of the interview and how the information will be used. Ask whether they have any questions about the interview.
- Confirm the confidentiality of the interview

Participant's background

- Their current position and time specialising in palliative care medicine
- What they like or find challenging about this work.

Scenario

Eric Wallace is a 72-year-old man with metastatic pancreatic cancer. At time of diagnosis, the cancer was metastatic to his regional lymph nodes and liver. He has been treated with palliative chemotherapy, but the disease continued to progress. Recently he has become jaundiced, and he has very little appetite. He has been seeing a palliative care physician and a social worker on an ongoing basis. His abdominal pain is now well controlled with high-dose narcotics, and the narcotics have caused constipation. In addition to seeing the social worker, he has also been seeing a psychologist to help him to cope with his illness.

Mr. Wallace has been married to his wife, Catherine, for 51 years, and they have three children and six grandchildren. He and his wife have lived in Neuchatel, for the past 23 years, and most of his family lives nearby. He understands the prognosis of the disease, and he does not wish to spend his last days suffering or in an unresponsive state. He discusses his desire for assisted suicide with his wife and family members, and they offer him their support. The next day, he calls his physician (you) and asks for information about assisted suicide.

- Why do they think this patient is requesting a hastened death and what would they do in this situation?

Personal experience

- Have they ever worked with patients who have asked for an assisted suicide?
- As they understand it, what were their reasons for requesting hastened death?
- Their interactions with professionals and family members involved with this patient.
- What did they think about their role, their personal feelings, and the outcome?

Perspectives on assisted dying and palliative care

Values

- In their view, what are the core values in palliative care?

Palliative care and assisted suicide

- Is there a place for assisted suicide in palliative care?

Family

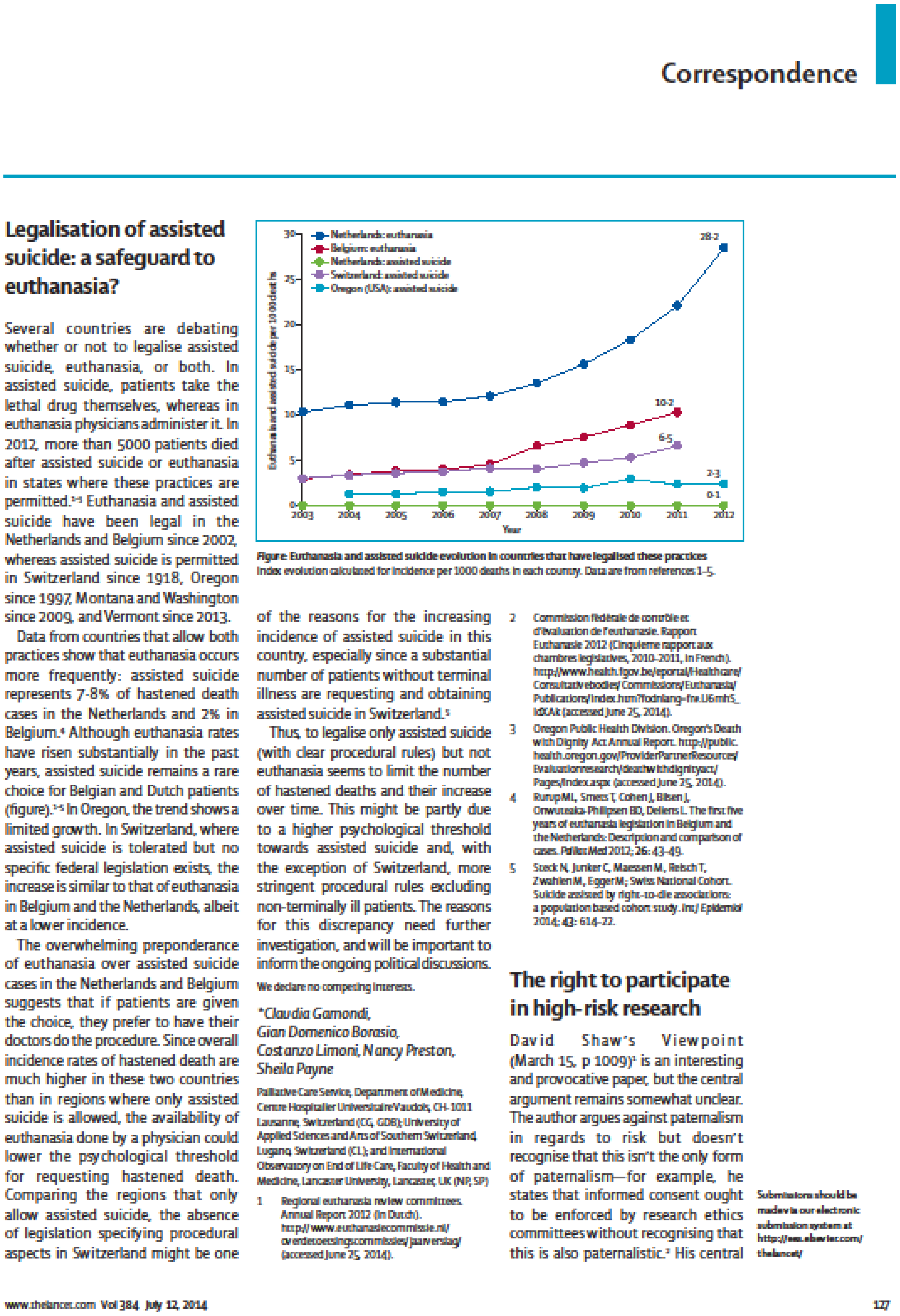
- What should be the family's role in end of life decision-making and what is the ideal relationship between the medical team and the patient's family in end of life care.

Factors influencing views on assisted suicide

- Where did they do their training in palliative care and did it involve learning about dealing with requests for assisted dying or hastened death? (If not), would they have liked training in that area.
- What have been the *main* influences on their views around assisted suicide and have they changed over time?

Appendix 8: Lancet Paper (Gamondi et al., 2014)

https://doi.org/10.1016/S0140-6736(14)61154-5



Legalisation of assisted suicide: a safeguard to euthanasia?

Several countries are debating whether or not to legalise assisted suicide, euthanasia, or both. In assisted suicide, patients take the lethal drug themselves, whereas in euthanasia physicians administer it. In 2012, more than 5000 patients died after assisted suicide or euthanasia in states where these practices are permitted.[1–5] Euthanasia and assisted suicide have been legal in the Netherlands and Belgium since 2002, whereas assisted suicide is permitted in Switzerland since 1918, Oregon since 1997, Montana and Washington since 2009, and Vermont since 2013.

Data from countries that allow both practices show that euthanasia occurs more frequently: assisted suicide represents 7·8% of hastened death cases in the Netherlands and 2% in Belgium.[4] Although euthanasia rates have risen substantially in the past years, assisted suicide remains a rare choice for Belgian and Dutch patients (figure).[1–5] In Oregon, the trend shows a limited growth. In Switzerland, where assisted suicide is tolerated but no specific federal legislation exists, the increase is similar to that of euthanasia in Belgium and the Netherlands, albeit at a lower incidence.

The overwhelming preponderance of euthanasia over assisted suicide cases in the Netherlands and Belgium suggests that if patients are given the choice, they prefer to have their doctors do the procedure. Since overall incidence rates of hastened death are much higher in these two countries than in regions where only assisted suicide is allowed, the availability of euthanasia done by a physician could lower the psychological threshold for requesting hastened death. Comparing the regions that only allow assisted suicide, the absence of legislation specifying procedural aspects in Switzerland might be one of the reasons for the increasing incidence of assisted suicide in this country, especially since a substantial number of patients without terminal illness are requesting and obtaining assisted suicide in Switzerland.[5]

Figure: Euthanasia and assisted suicide evolution in countries that have legalised these practices
Index evolution calculated for incidence per 1000 deaths in each country. Data are from references 1–5.

Thus, to legalise only assisted suicide (with clear procedural rules) but not euthanasia seems to limit the number of hastened deaths and their increase over time. This might be partly due to a higher psychological threshold towards assisted suicide and, with the exception of Switzerland, more stringent procedural rules excluding non-terminally ill patients. The reasons for this discrepancy need further investigation, and will be important to inform the ongoing political discussions.

We declare no competing interests.

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1 Regional euthanasia review committees. Annual Report 2012 (in Dutch). http://www.euthanasiecommissie.nl/overdetoetsingscommissies/jaarverslag/ (accessed June 25, 2014).
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The right to participate in high-risk research

David Shaw's Viewpoint (March 15, p 1009)[1] is an interesting and provocative paper, but the central argument remains somewhat unclear. The author argues against paternalism in regards to risk but doesn't recognise that this isn't the only form of paternalism—for example, he states that informed consent ought to be enforced by research ethics committees without recognising that this is also paternalistic.[2] His central

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Appendix 9: Lancet paper, (Borasio et al., 2019)

https://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(18)32554-6.pdf

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Archduke Franz Ferdinand and Sophie, Duchess of Hohenberg in Sarajevo in 1914, which sparked World War 1). Some analysts argue that access to weapons, or material for producing weapons, is an important factor. Others reason that man is evil by nature or that misunderstanding in communication or lack of understanding can lead to war.

War is often preceded by tensions, of which there are many potential sources.Tensions can arise from shortages of water, energy, and, not least, food. For example, as Torreon Creekmore,[3] of the Intelligence Advanced Research Projects Activity in the USA, reflected: "When crops fail and prices rise, people don't have the money to purchase food, which can lead to stealing, then riots, social unrest, and mass migrations."

Agricultural production in relation to need is a security factor, and future forecasts indicate challenges. The world's population is expected to increase to 9·6 billion by 2050,[4] and many people will also change their diet. According to the UN,[5] society needs to increase food production radically until 2050; this at a time when increasing food production will become more difficult. Soil degradation and climate change are two reasons. Therefore, to reduce the number of victims of conflict, society must ensure food production and the supply of water and energy. Innovation in agricultural methods is one approach that could be taken.

I declare no competing interests.

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Authors' reply

We appreciate the comment by Per Frankelius, in which he notes the role of agriculture in the origins of conflict.[1] We focus on the consequences of conflict, not its causes. Both are important issues worthy of investigation. We agree that evidence suggests that variations in the economy and climate, including those related to food production, could be important drivers of conflict.[2,3] Given the major consequences of conflict for child health documented in our work,[1] further inquiries into the causes of war, into understanding how to intervene to reduce conflict risk, and how to deliver health services in conflict situations are all urgent areas for future research.

We declare no competing interests.

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Regulation of assisted suicide limits the number of assisted deaths

Several countries and US states have recently legalised euthanasia, assisted suicide, or both, including Canada and California, USA. In 2017, more than 13 000 patients died through either method of assisted death in countries where these practices are permitted. Euthanasia and assisted suicide have been legal in the Netherlands and Belgium since 2002, whereas assisted suicide has been legal in Switzerland since 1918 and in Oregon, USA, since 1997.

See Online for appendix

In 2014, we presented aggregated data for 2003–12 comparing the frequency of assisted deaths in countries or states that allowed both euthanasia and assisted suicide (the Netherlands and Belgium) with the frequency of assisted deaths in countries or states that only allowed assisted suicide (Switzerland and Oregon).[1] Here, we present aggregated data for 2007–17 from the same jurisdictions (figure; appendix). Assisted deaths continue to rise substantially in Belgium and the Netherlands, with assisted suicide constituting 3·5% of assisted deaths in the Netherlands in 2016.[2] The frequency of assisted deaths in Oregon is increasing at a much more reduced rate than in the Netherlands and is currently at less than 10% of Dutch numbers (3·9 per 1000 deaths in Oregon vs 43·9 per 1000 deaths in the Netherlands in 2017). The rate of increase in assisted suicides in Switzerland, where this practice is tolerated without legal safeguards or monitoring, is similar to the rate of increase in Belgium and the Netherlands, with a frequency that is approaching that of Belgium.

In assisted suicide, patients take the lethal drug themselves, whereas doctors administer the drug in euthanasia. In 2012, this appeared to be a main reason for the higher frequency of assisted deaths in the Netherlands

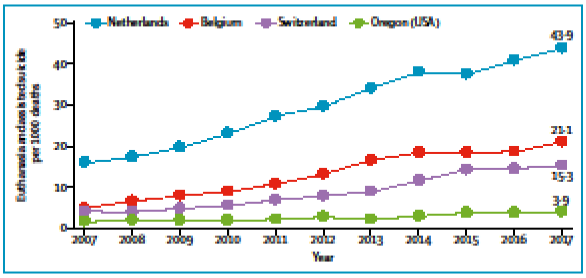

Figure: Change in number of assisted deaths in countries and US states that have legalised these practices
The Netherlands and Belgium allow both euthanasia and assisted suicide. Switzerland and Oregon, USA, allow assisted suicide only. Raw data and sources are available in the appendix.

and Belgium, compared with Oregon and Switzerland. Yet data from the past 5 years suggest that the lack of legislation in Switzerland could also explain the higher frequency of assisted suicide, particularly since an increasing number of patients without terminal illness obtain permission for assisted suicide in Switzerland. By contrast, the lower frequency in Oregon might be explained by the requirement of a maximum life expectancy of 6 months and by the requirement that patients obtain a lethal dose from the pharmacy for auto-administration. On average, 36% of these patients in Oregon end up not using the lethal drug and die of their illness.[3]

Euthanasia is quickly approaching 5% of all deaths in the Netherlands, which is a higher proportion than in Belgium (although underreporting is suspected in Belgium).[4] In 2016, Canada legalised euthanasia, and California regulated assisted suicide as in Oregon. In 2017, euthanasia already represented almost 1% of all deaths in Canada,[5] whereas only 374 Californians died by assisted suicide (0·14% of deaths).

Legalising only assisted suicide with stringent procedural rules that exclude patients who are not terminally ill, as has been the case in Oregon, therefore seems to limit the number of assisted deaths and their increase with time. This hypothesis will be validated further when assisted deaths are legalised in more countries in the future.

We declare no competing interests.

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Global health and cancer

Richard Horton (Sept 8, 2018, p 806)[1] hits the nail painfully hard on its head regarding the inexplicable indifference to cancer in low-income and lower middle-income countries (LLMICs). Non-communicable diseases, such as diabetes and hypertension, are easy to diagnose and low cost, effective treatments are available; primary prevention of non-communicable diseases does not require medical interventions. By contrast, cancer treatment requires adequate diagnostic, pathology, and imaging services and surgical, medical, and radiation oncology capability which are often only available in a rudimentary form (sometimes not at all) in LLMICs, particularly in rural areas where most people live. Long distances to oncology clinics, serious financial limitations, and scarcity of oncologists and oncology nurses pose further obstacles. These enormous constraints might explain why the global health community has neglected cancer care, but these problems cannot be an excuse to do little or nothing.

In high-income countries, oncology is increasingly focused on targeted therapies, molecular diagnostics, and advanced imaging methods, which are not achievable in LLMICs because of their high cost, need for sophisticated equipment, and other impediments. Therefore, LLMICs need to develop their own affordable and feasible approaches to cancer detection, diagnosis, and treatment. The challenge for the global health community is to help LLMICs to develop clinical trials that can identify the most effective, practical, and affordable drug treatments and schedules, simple imaging (ultrasound), pathology diagnostics, and palliative treatments in low-resource settings to reduce suffering of all patients with cancer.

I declare no competing interests.

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1. Horton R. Offline: Why has global health forgotten cancer? Lancet 2018; 392: 806.

Richard Horton[1] vividly points out the current and growing deficiency in global cancer care, and the relative inattention this problem receives compared with infectious diseases. Repeated

Appendix 10: Statements of Authorship

Statement of Authorship

Title: Responses to assisted suicide requests: an interview study with Swiss palliative care physicians

Publication status: Published

Journal: *BMJ Supportive and Palliative Care*

Publication details: Gamondi, C., Borasio, G., Oliver, P., Preston, N., & Payne, S. (2017). Responses to assisted suicide requests: an interview study with Swiss palliative care physicians. *BMJ Support Palliat Care, 9*(1), e7. doi:10.1136/bmjspcare-2016-001291

By signing the Statement of Authorship, each co- author certifies that:

a) Claudia Gamondi is the main author of this publication with substantial contribution to its conceptualisation, realisation and documentation; and that

b) Permission is granted for the publication to be included in the candidate's thesis.

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Name of co-author: Oliver, P.

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Name of co-author: Preston, N.

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Name of co-author: Payne, S.

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Statement of Authorship

Title: Family members' experiences of assisted dying: A systematic literature review with thematic synthesis.

Publication status: Published

Journal: *Palliative Medicine*

Publication details: Gamondi, C., Fusi-Schmidhauser, T., Oriani, A., Payne, S., & Preston, N. (2019). Family members' experiences of assisted dying: A systematic literature review with thematic synthesis. *Palliative Medicine, 33*(8), 1091-1105. doi:10.1177/0269216319857630

By signing the Statement of Authorship, each co- author certifies that:

a) Claudia Gamondi is the main author of this publication with substantial contribution to its conceptualisation, realisation and documentation; and that

b) Permission is granted for the publication to be included in the candidate's thesis.

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Name of co-author: Oriani, A.

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Name of co-author: Payne, S.

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Statement of Authorship

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

Publication status: Published

Journal: *.Journal of Pain And Symptom Management*

Publication details: Gamondi, C., Pott, M., Preston, N., & Payne, S. (2018). Family caregivers' reflections on experiences of assisted suicide in Switzerland: a qualitative interview study. *Journal of Pain And Symptom Management, 55*(4), 1085-1094, doi:https://doi.org/10.1016/j.jpainsymman.2017.12.482

By signing the Statement of Authorship, each co- author certifies that:

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b) Permission is granted for the publication to be included in the candidate's thesis.

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Statement of Authorship

Title: Swiss Families' Experiences of Interactions with Providers during Assisted Suicide: A Secondary Data Analysis of an Interview Study

Publication status: Published

Journal: *Journal of Palliative Medicine*

Publication details: Gamondi, C., Pott, M., Preston, N., & Payne, S. (2020). Swiss Families' Experiences of Interactions with Providers during Assisted Suicide: A Secondary Data Analysis of an Interview Study. *Journal of Palliative Medicine, 23*(4), 506-512. doi:10.1089/jpm.2019.0286

By signing the Statement of Authorship, each co- author certifies that:

a) Claudia Gamondi is the main author of this publication with substantial contribution to its conceptualisation, realisation and documentation; and that

b) Permission is granted for the publication to be included in the candidate's thesis.

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Name of co-author: Payne, S.

Signature S Payne

Appendix 11:

Doctoral Academy | Lancaster University

Statement for Submission with a Thesis Impacted by the COVID-19 Pandemic for PGR Students

The purpose of this form is to capture the impact of the pandemic on your research. We recommend you submit this form with your thesis to be sent to your examiners for consideration.

Student Name	Claudia Gamondi	ID No.	30966170
Department	Division of Health Research	Faculty	Health and Medicine
Research type eg Laboratory, field, desk	Field/desk	FT/PT	PT

1. **Stage of study when pandemic began (March 2020) e.g. were you planning your project, in the middle of data collection, writing up**

My final article had just been published and I was at the stage of writing up the dissertation.

2. **In what way did the pandemic affect your work? This might be both personal including additional caring responsibilities or your own health and wellbeing, or practical that you were unable to continue data collection, unable to access labs or office for essential reasons etc**

I am a physician working fulltime in palliative care and am the Head of the Division of Palliative and Supportive Care which has responsibility for 4000 patients annually, 2 palliative care units and 40 team members. Once Covid-19 struck the number of palliative care patients that were arriving to our wards massively increased. There was also the additional challenge of trying to manage distressed families who were no longer able to accompany their loved ones at their end of life. This had a practical effect in that my work hours far exceeded the usual fulltime workload, and resulted in a rise of 30-40% clinical devoted hours. There was also the effect of being emotionally and physically exhausted when out of the work setting.
I am a single mother of two teenage children and had the additional responsibility of managing home schooling and their emotional wellbeing. There simply was no personal time to spend on the writing up of my thesis.

3. **How did you try to address the impact of the pandemic on your thesis? You may have had to access alternative data, change aims and objectives, collected less data etc**

I requested, and was granted, a six month intercalation. Unfortunately the pandemic has been ongoing beyond this six month period and caused further delays in the final writing up stage.

4. **Are there any other comments you would like to make?**

Student signature	Claudia Gamondi	**Date**	12.11.21
Primary supervisor signature	SPayne	**Date**	12.11.21

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