

## **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; PsycINFO databases (Jan 1992-November 2017). Studies investigating families' experiences on the practice of legalized assisted dying were included. We excluded studies prior to legalization within the jurisdiction, secondary data analysis and opinion papers.

*Results:* 19 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*; (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.

*Conclusions:* 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.

### ***What is already known about the topic?***

- Families may play a role in facilitating patients obtaining assisted dying and their opposition can impact on 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.
- Broader support from healthcare professionals and families seem 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 recognized 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

Overall numbers of assisted deaths are rising, although few countries in the world permit assisted dying. In the last twenty 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 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 nor 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<sup>st</sup> January 1992 to 28<sup>th</sup> February 2019 was searched. For completeness, our search started five years prior to the implementation of the first law regarding 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).

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

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

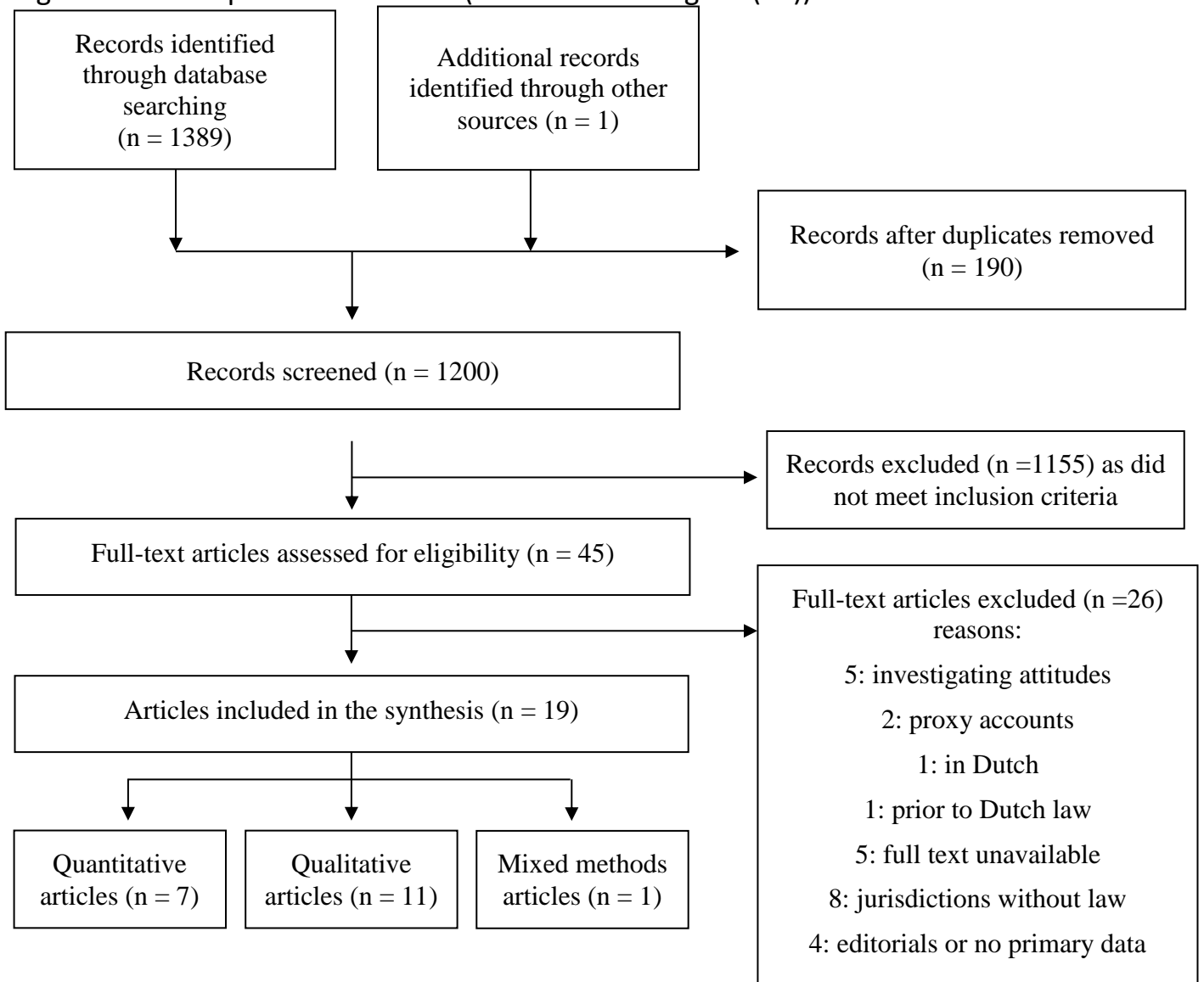
AND

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*

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 included articles were mined, and citation tracked.

**Study eligibility:** 1389 results were retrieved, and one further PhD thesis from other sources identified (n=1390). Following removal of duplicates (n=195) the remaining articles (n=1200) were screened in two phases. Three reviewers (CG & TFS or AO) 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 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 (CG and TFS) reviewed the full texts of the remaining 45 studies to check adherence against inclusion and exclusion criteria (Table 1). Any disagreement was resolved with NP and SP. Nineteen articles were included in the review. A flow diagram of the selection procedure and results (using the PRISMA tool) is presented in Fig. 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.

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



**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 (CG and TFS) completed the appraisal form together. Equal weight was given to all papers included, independently from quality assessments 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, analysis (Table 3). 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 inferred 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 with families' experiences and compared them with the different model each country legalised. Reviewers then considered the implications of their findings in terms of clinical practice and research priorities.

## Results

Nineteen articles, representing fourteen studies, met our inclusion criteria and were included in the review (4, 7, 9-11, 18-31). Ten studies (eleven 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-method 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 US (n=4) (9, 19-22, 28, 32) , 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. (2013) reported on



experiences when a euthanasia request was denied resulting in deaths from underlying illness (26). 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. and Wagner et al. also, included a minority of patients who had "non-fatal diseases", were "tired of living" (Netherlands) or had "mental disorders" (Switzerland) (7, 29-31). 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. The five themes generated were: (1) *Precursors and context of the relationship*; (2) *Coming to and enacting the decision*. (3) *Cognitive and emotional work*; (4) *Experiencing the final farewell*; (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 (2014) 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*"(27). 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 US in relation to assisted suicide.

The importance for family members of 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 to 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 were more supportive both on 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 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 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 (23). 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 US, 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 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 patients' 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 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 (7). An important issue for families was that assisted dying allowed them to keep communication open with the patient until the 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, rather than in Switzerland where 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 to family members in comparison with others (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. 11% of Oregonian family members had a major depressive disorder, 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 if 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, may experience feelings of isolation, 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 also reported that the perceived disapproval from their social environment and the family seemed to influence post-traumatic stress disorders and complicated grief symptoms (30). 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 indicates 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 patient's seeking assisted dying, and usually maintain an open relationship with patients and perceive assisted dying as an important contributor to the patients' quality of death. Families also experienced different types of interactions with health care professionals, that 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 (33). In general, it is known that, among different factors, family involvement can depend on cultural values (34). For example, some cultures, rely on the cultural concept of familism, characterised by strong ties of solidarity and interdependence in family networks (35). 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; valued an open communication and 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, 36). 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 (37). 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 (38), 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 (39). This differences in openness could be suggested also happens during bereavement. Although fewer data were available concerning bereavement, it seemed that Swiss families tend to feel isolated in comparison to 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 permit 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, 36, 40). 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 longstanding 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 be also 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.

**Declarations section:**

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**Authorship:** CG designed the study, undertook the systematic review, carried out the thematic synthesis, and wrote the manuscript. SP and NP participated in the design of the study and systematic review, provided guidance in the thematic synthesis, and reviewed the manuscript. TFS and AO participated in the systematic review and review of the manuscript. CG and NP are the guarantors.

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

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