

# Grief After Euthanasia and Physician-Assisted Suicide

### A Systematic Review

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Abstract. Background: Several countries have regulated euthanasia and physician-assisted suicide (PAS). Research has looked at the experiences of patients, family, and professionals. However, little is known of the effects on bereaved individuals. Aims: We aimed to assess (a) what is known about the grief and mental health of people bereaved by euthanasia or PAS and (b) the quality of the research. Method: Systematic review according to PRISMA guidelines with searches in Cinahl, Embase, PsycINFO, Pubmed, and Scopus. Results: The searches identified 10 articles (eight studies), and the study quality was fair. People bereaved by euthanasia/PAS generally had similar or lower scores on measures of disordered grief, mental health, and posttraumatic stress compared with those who died naturally. Lack of social support and secrecy may compound their grief. Being involved in the decision-making process and having the feeling of honoring the deceased's will may facilitate their grief. Limitations: Studies used self-reports from non-random self-selected participants, were retrospective, and were conducted in only three countries. Conclusion: There is little evidence of increased risk of adverse grief or mental health outcomes in people bereaved by euthanasia/PAS. As more countries legalize assisted dying, high-quality studies of the factors that may hinder or facilitate the grief process are needed.

Keywords: assisted suicide, bereavement, euthanasia, grief, medical assistance in dying, mental health, systematic review

Over the past decades several countries and states have passed legislation to legalize euthanasia and physician-assisted suicide (PAS; Dyer, White, & Rada, 2015; Emanuel, Onwuteaka-Philipsen, Urwin, & Cohen, 2016). Both types of assistance in dying hasten an individual's death. In the case of euthanasia, a physician intentionally ends the life of a patient at his/her request, usually by the administration of a lethal drug. In the case of PAS, the physician prescribes or supplies the lethal drug to the patient, at his/her request, with the patient performing the action that will cause his/her own death (Emanuel et al., 2016).

Euthanasia and PAS were already practiced in Antiquity in the context of a "good death" and the first attempts to create a legal framework occurred about 100 years ago, in 1906 in the US states of Ohio and Iowa (Dowbiggin, 2005; Emanuel, 1994). Advocacy groups within the general population and the judiciary have driven legal changes, and currently, euthanasia and/or PAS can be legally practiced in The Netherlands, Belgium, Luxembourg, Colombia, and Canada (Dyer et al., 2015; Kelleher, Chambers, Corcoran, Keeley, & Williamson, 1998; Kelleher et al., 1995).

PAS is allowed in eight US states (California, Colorado, District of Columbia, Hawaii, Montana, Oregon, Vermont, and Washington; https://www.deathwithdignity.org/), as well as in Switzerland, and most recently, in the Australian state of Victoria (Victoria State Government, 2019).

There is variety in the number of medically assisted deaths across countries. For example, PAS accounted for approximately 0.4% of deaths in Oregon and Washington in 2015 (Emanuel et al., 2016), and 1.4% in Switzerland (most recent data, year 2016; Bundesamt für Statistik, 2019). Euthanasia accounted for approximately 2.1% of deaths in Belgium (in 2018), and 4.4% in The Netherlands (in 2017) (Federale Overheidsdienst Volksgezondheid, 2019; Rijksoverheid, 2019). While eligibility criteria and application procedures vary across countries (for overviews, see: Dyer et al., 2015; Mishara & Kerkhof, 2018), access is usually limited to mentally competent patients whose suffering is considered to be unbearable.

Research in this field has focused on various aspects, such as the moral and ethical aspects (Bélanger et al., 2019; Kouwenhoven, van Thiel, van der Heide, Rietjens,

& van Delden, 2019; Mishara & Weisstub, 2013; Speijer & Diekstra, 1980), public acceptance (Cohen et al., 2006; Frey & Hans, 2016; Marcoux, Mishara, & Durand, 2007; Poma et al., 2015), and the legal status and epidemiology of euthanasia and PAS (Cohen, Dierickx, Penders, Deliens, & Chambaere, 2018; Steck, Egger, Maessen, Reisch, & Zwahlen, 2013). Studies have also looked at the views of individuals requesting medical assistance in dying (Dees, Vernooij-Dassen, Dekkers, Vissers, & Van Weel, 2011; Hendry et al., 2013; Lapierre et al., 2018), family involvement in end-of-life decision-making (Gamondi, 2017; Gamondi, Pott, Preston, & Payne, 2018; Kimsma & Van Leeuwen, 2007; Pott, Dubois, Currat, & Gamondi, 2011), and the perceptions of physicians (Emanuel et al., 2016; Ganzini, Dobscha, Heintz, & Press, 2003) and other professional caregivers (Castelli Dransart, Scozzari, & Voélin, 2017).

While scholars, clinicians, and ethicists have argued that a good death would require avoidance of preventable harm to others (Kuitert, 1994; Leenaars et al., 2001; Speijer & Diekstra, 1980), there are several reasons why a death through euthanasia or PAS may be thought to have the potential of compounding the grief of bereaved individuals (Beder, 1998). Providing long-term care for a chronically ill family member may involve many responsibilities regarding practical, social, emotional, and legal support, and may exhaust the family caregiver (Carr, 2003). Euthanasia and PAS are usually considered unnatural deaths, as such they may be associated with increased risk of social isolation, stigma, disordered grief, depression, posttraumatic stress disorder (PTSD), and suicidal behavior (Dyregrov, Cimitan, & De Leo, 2014; Kristensen, Weisæth, & Heir, 2012; Pitman, Rantell, Marston, King, & Osborn, 2017). Investigations by police, medical examiners, or coroners, as well as dealing with the media may add to the psychosocial stress of the loss (Chapple, Ziebland, Simkin, & Hawton, 2013; Spillane, Matvienko-Sikar, Larkin, Corcoran, & Arensman, 2019). By contrast, being involved in endof-life care, having the opportunity to say goodbye and to prepare for the loss, which are possible with euthanasia and PAS, have been associated with better bereavement adjustment (Wright et al., 2008).

In contrast to the large number of research studies on bereavement following deaths by suicide or other causes, little is known of the effects of euthanasia and PAS on those who are bereaved, and to date no systematic review is available. The present review aims to fill this gap by reviewing studies on the grief and mental health of people bereaved by euthanasia or PAS, and to appraise the quality of the research in this field. This review does not entail a stance pro or contra euthanasia or PAS. Its findings may inform those involved in this field, including researchers, clinicians, family caregivers, and individuals considering euthanasia or PAS.

#### Method

The systematic review was conducted according to the PRISMA guidelines (http://www.prisma-statement.org/; Moher, Liberati, Tetzlaff, Altman, & Prisma Group, 2009), and comprised searches in five databases: Cinahl, Embase, PsycINFO, Pubmed, and Scopus. For example, PubMed ment[MH] OR (Griev\*[TW] OR "anticipatory grief"[TW] OR preparedness[TW] OR bereavement[TW] OR Bereave\*[TW] OR Griev\*[TW] OR Mourn\*[TW] OR grief[TW] OR "loss survivor" [TW]))) AND ((((((Euthanasi\*[TW] OR (Assisted[TW] AND Suicid\*[TW]) OR "death with dignity"[TW] OR "hasten death"[TW] OR "right to die"[TW] OR "Medical Assistance in Dying" [TW] OR "end of life"[TW])))))))))) NOT (veteri\* OR "animal euthana-the completeness and rigor of the approach. The number of keywords and the use of controlled vocabulary and natural language terms are in line with Cochrane recommendations (Higgins & Green, 2011). Similar searches were conducted in the other databases (search strings are available upon request). There was no restriction on language, location, or year of publication. The search was limited to peer-reviewed journals and conducted in February 2019.

#### **Inclusion and Exclusion Criteria**

Two researchers (KA, KK) independently assessed titles and abstracts for eligibility. Any disagreement was resolved through discussion. Original studies were included if: (a) the study population consisted of people bereaved by a death through euthanasia or PAS; (b) the study used quantitative, qualitative, or mixed methods; and (c) the study reported data on the grief or mental health of the study population. We excluded: (a) studies on other types of bereavement or not involving humans; (b) studies applying other methods such as case reports; and (c) studies without original data, such as reviews and opinion papers. The references of the selected and review papers were hand-searched to identify additional studies. Figure 1 depicts the search and selection process.

#### Data Extraction

Three researchers (KA, KK, DACD) independently extracted the following data from the selected papers: author, year and location (country), study design, eligibility criteria, sample size, participants' age and sex distribution, participants' time since the bereavement and relationship to the deceased, setting of the study, outcome measures,

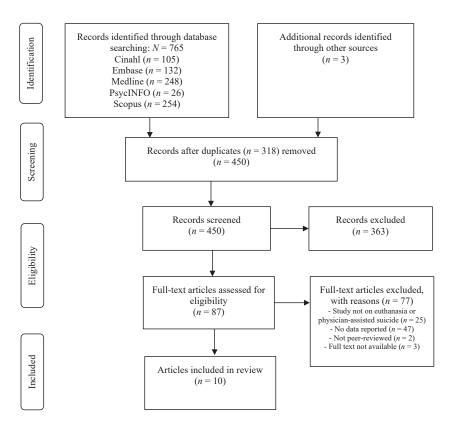


Figure 1. PRISMA flow diagram

names of the instruments used, and main results of the study. Any disagreement was resolved through discussion.

#### **Quality Assessment**

Two researchers (KA, DACD) independently assessed the quality of the included studies. Discussion with a third researcher (KK) settled any disagreement. The quantitative studies were assessed with the Newcastle-Ottawa Quality Assessment Form for Cohort Studies (Wells et al., n.d.). The instrument consists of three components: selection (four items), comparability (one item), and outcome (three items). The total quality of a study was categorized as good, fair, or poor depending on the number of "stars" allocated to each category. The qualitative studies were assessed with the Consolidated Criteria for Reporting Qualitative Research (COREQ; Tong, Sainsbury, & Craig, 2007). The instrument consists of 32 items structured in three domains: research team and reflexivity (eight items), study design (15 items), and analysis and findings (nine items). To compare the study quality, we totaled the number of reported items, in each domain, and for all items.

#### Results

#### **Study Characteristics**

The systematic review included 10 articles published between 1995 and 2018 and half of these were published in the last 5 years (Table A1 in the appendix). These 10 articles represented eight studies as three articles were based on one study sample (Wagner, Boucsein, & Maercker, 2011; Wagner, Keller, Knaevelsrud, & Maercker, 2012; Wagner, Müller, & Maercker, 2012). All research was conducted in three countries: five articles from two research teams in Switzerland (Gamondi, Pott, Forbes, & Payne, 2013; Gamondi et al., 2018; Wagner et al., 2011; Wagner, Keller, et al., 2012; Wagner, Müller, et al., 2012), three from the US (Ganzini, Goy, Dobscha, & Prigerson, 2009; Srinivasan, 2018; Starks et al., 2007), and two from The Netherlands (Swarte, Van Der Lee, Van Der Bom, Van Den Bout, & Heintz, 2003; van den Boom, 1995). All studies included bereaved family members, and half of them also included close friends. All studies focused on adult populations across the lifespan, although the mean age was about 60 in half of the studies. No study included children or adolescents. The percentage of females ranged from 54% to 69%. The time since bereavement varied across studies: Seven articles reported a mean between 11 and 24 months.

There were five quantitative, cross-sectional studies (Ganzini et al., 2009; Swarte et al., 2003; Wagner et al., 2011; Wagner, Keller, et al., 2012; Wagner, Müller, et al., 2012). Two studies involved a control group of family members and/or friends bereaved by natural, non-medically assisted deaths (Ganzini et al., 2009; Swarte et al., 2003). One study compared the findings against the general (not necessarily bereaved) population (Wagner, Müller, et al., 2012). All assessed disordered grief, for example, through the Inventory of Complicated Grief-Short Form (ICG-SF; Prigerson & Jacobs, 2001), and applied various mental health and trauma-related instruments such as the Impact of Event Scale (IES; Horowitz, Wilner, & Alvarez, 1979; Weiss & Marmar, 1997). No study specifically assessed nondisordered grief or suicidal behavior as an outcome. Five studies collected qualitative data through semistructured interviews (Gamondi et al., 2013; 2018; Srinivasan, 2018; Starks et al., 2007) or with a questionnaire and interview (van den Boom, 1995). These qualitative studies explored the involvement of bereaved individuals in the decision-making process and their grief experiences after the death of their family member or friend.

#### **Quality Assessment**

Overall the methodological quality of the quantitative studies was fair (Table 1). For all studies, the sample selection was rated as "somewhat representative," ascertainment of exposure was reliable, and studies controlled for basic confounders such as age and sex in their design or analysis. However, only two studies involved a control group (Ganzini et al., 2009; Swarte et al., 2003), and all studies relied on self-report measures only.

The qualitative studies reported about half of the COREQ items (Tong et al., 2007) (Table 2). Most items in Domain 3 (analysis and findings), and about half of the items in Domain 2 (study design) were reported. Items in Domain 1 (research team and reflexivity) were reported the least.

#### **Disordered Grief Outcomes**

Three studies compared grief scores of those bereaved by euthanasia or PAS against a control group, and reported similar scores (Ganzini et al., 2009; Wagner, Müller, et al., 2012) or lower scores in the groups bereaved by euthanasia or PAS (Swarte et al., 2003). Ganzini et al. (2009) found no difference between the two groups regarding prevalence of prolonged grief disorder (2%) or grief symptom severity, measured by the ICG-SF (Prigerson & Jacobs, 2001). Wagner, Müller, et al. (2012) found a prevalence

of 4.9% among the PAS bereaved, which was comparable to the Swiss general population. There was no correlation between duration of disease and complicated grief symptoms (Wagner, Müller, et al., 2012). The study by Swarte et al. (2003) found higher scores on the Texas Revised Inventory of Grief (Faschingbauer, Zisook, & DeVaul, 1987), indicating lower current grief feelings, and lower scores on the Inventory of Traumatic Grief (Boelen, Van den Bout, De Keijser, & Hoijtink, 2003), indicating lower symptoms of traumatic grief in the study group. More bereaved people in the control group met the criteria of traumatic grief than in the euthanasia/PAS group (5.7% vs. 2.1%), indicating a statistically and clinically significant difference (Swarte et al., 2003).

Some participants in qualitative studies attributed difficulties in their grief process to having experienced medical/technical complications in the dying process (Starks et al., 2007; van den Boom, 1995). Clinical complicated grief symptoms were found in 6% of participants, with symptoms lasting from 1 to 3 years (Starks et al., 2007). Some participants reported that being in conflict with the assisted dying decision, anxiety experienced with the scheduling of the death, or difficulties in dealing with the stigma associated with the death hindered their grief process (Gamondi et al., 2015; Srinivasan, 2018; Starks et al., 2007). However, agreement with the decision, having the opportunity to say goodbye, and the thought that the dying family member avoided prolonged suffering eased the grief (Gamondi et al., 2015; Srinivasan, 2018; Starks et al., 2007).

## Mental Health and Posttraumatic Stress Outcomes

Three studies reported similar or lower mental health scores in the bereaved study group compared with a control group (Ganzini et al., 2009; Swarte et al., 2003; Wagner, Müller, et al., 2012). Ganzini et al. (2009) found no differences between the PAS group and the control group regarding major depressive disorder (11% in PAS group), severity of current depressive symptoms (6% in PAS group, measured with the Beck Depression Inventory [BDI]; Beck, Steer, & Carbin, 1988), and having received mental health care after the death of their family member (38% in PAS group). Also, Swarte et al. (2003) found no difference between the two groups on the Symptom Checklist (SCL-90; Arrindell & Ettema, 1986) and no difference on the Depressive Adjective Checklist (DACL; Lubin, 1965). However, Wagner, Müller, et al. (2012) reported a higher prevalence of mental health problems in the PAS group compared with the general Swiss population. The prevalence of depression in the PAS group was 16%, and the

**Table 1.** Quality assessment<sup>a</sup> of included quantitative studies

Topic	Ganzini et al., 2009	Swarte et al., 2003	Wagner et al., 2011	Wagner, Keller et al., 2012	Wagner et al., 2012
Selection	et at., 2003	et at., 2003	et at., 2011	2012	et at., 2012
Representativeness of the exposed cohort					
a) Truly representative (one star)					
b) Somewhat representative (one star)	X	X	X	Χ	X
c) Selected group					
d) No description					
2) Selection of the non-exposed cohort					
a) Drawn from the same community as the exposed cohort (one star)	X	Χ			
b) Drawn from a different source					
c) No description			n/a	n/a	n/a
3) Ascertainment of exposure					
a) Secure record (e.g., surgical record) (one star)		Χ	X	Χ	X
b) Structured interview (one star)	Χ				
c) Written self-report					
d) No description					
e) Other					
4) Demonstration that outcome of interest was not present at start of st	udy				
a) Yes (one star)	X	Χ	Χ	Χ	Χ
b) No					
Comparability					
1) Comparability of cohorts on the basis of the design or analysis contro	lled for confou	nders			
a) The study controls for age, sex and marital status (one star)	Χ	Χ	X	Χ	X
b) Study controls for other factors (list) (one star)	Χ	Χ			
c) Controls are not comparable					
Outcome					
1) Assessment of outcome					
a) Independent blind assessment (one star)					
b) Record linkage (one star)					
c) Self-report	Χ	Χ	Χ	Χ	Χ
d) No description					
e) Other					
2) Was follow-up long enough for outcomes to occur?					
a) Yes (one star)	Χ	Χ	Χ		Χ
b) No					
c) Indicate the mean duration of follow-up and a brief rationale for the assessment above	14 months	1-9 years	19.7 months	19.7 months	19.7 months
3) Adequacy of follow-up of cohorts					
a) Complete follow-up, all subjects accounted for (one star)					
b) Subjects lost to follow-up unlikely to introduce bias, number lost less than or equal to 20% or description of those lost suggested no different from those followed (one star)					
c) Follow-up rate less than 80% and no description of those lost					
d) No statement	n/a	n/a	n/a	n/a	n/a

Table continued next page

Table 1. continued

Торіс	Ganzini et al., 2009	Swarte et al., 2003	Wagner et al., 2011	Wagner, Keller et al., 2012	Wagner et al., 2012
Stars					
Selection	4	4	3	3	3
Comparability	2	2	1	1	1
Outcome	1	1	1	1	1
Rating	fair	fair	fair	fair	fair

Note. <sup>a</sup>Newcastle-Ottawa Quality Assessment Form for Cohort Studies (Wells et al., n.d.).

A study can be given a maximum of one star for each numbered item within the selection and outcome categories. A maximum of two stars can be given for comparability. Thresholds for converting the Newcastle-Ottawa scales to AHRQ standards (good, fair, and poor): Good quality: 3 or 4 stars in selection domain AND 1 or 2 stars in comparability domain AND 2 or 3 stars in outcome/exposure domain. Fair quality: 2 stars in selection domain AND 1 or 2 stars in comparability domain AND 2 or 3 stars in outcome/exposure domain. Poor quality: 0 or 1 star in selection domain OR 0 stars in comparability domain OR 0 or 1 stars in outcome/exposure domain. n/a = not applicable

Table 2. Quality assessment a of included qualitative studies

Торіс	Gamondi et al., 2013	Gamondi et al., 2018	Srinivasan, 2018	Starks et al., 2007	Van Den Boom, 1995
Domain 1: Research team and reflexivity					
Personal characteristics					
1 Interviewer/facilitator			p. 2		
2 Credentials	p. 146	p. 1085			
3 Occupation	p. 146		p. 2		
4 Gender					
5 Experience and training					
Relationship with participants					
6 Relationship established					
7 Participant knowledge of the interviewer					
8 Interviewer characteristics					
Domain 2: Study design					
Theoretical framework					
9 Methodological orientation and theory	p. 147	p. 1087	p. 2		
Participant selection					
10 Sampling	p. 147	p. 1086	p. 2	p. 107	
11 Method of approach		p. 1086	p. 2	p. 107	
12 Sample size	p. 147	p. 1086	p. 2	p. 110	p. 177
13 Non-participation	p. 147		p. 2		
Setting					
14 Setting of data collection		p. 1086		p. 110	
15 Presence of non-participants					
16 Description of sample	p. 148	p. 1088		p. 110-11	p. 177
Data collection					
17 Interview guide	p. 147			p. 110	
18 Repeat interviews				p. 110	
19 Audio/visual recording	p. 147	p. 1086	p. 2	p. 110	
20 Field notes		p. 1087	p. 2		
21 Duration		p. 1086	p. 2		p. 177
22 Data saturation					
23 Transcripts returned		p. 1087			

Table continued next page

Table 2. continued

Topic	Gamondi et al., 2013	Gamondi et al., 2018	Srinivasan, 2018	Starks et al., 2007	Van Den Boom, 1995
Domain 3: Analysis and findings					
Data analysis					
24 Number of data coders	p. 147	p. 1087	p. 3	p. 111	
25 Description of the coding tree	p. 147	p. 1087	p. 3	p. 111	
26 Derivation of themes	p. 147	p. 1087	p. 3	p. 111	p. 178
27 Software			p. 3	p. 111	
28 Participant checking					
Reporting					
29 Quotations presented	pp. 149-150	p. 1089	pp. 3-7	pp. 112-24	
30 Data and findings consistent	pp. 149-150	pp. 1087-90	pp. 3-7	pp. 112-24	
31 Clarity of major themes	pp. 149-150	pp. 1087-90	pp. 3–7 pp. 112–24 pp. 181–		pp. 181-82
32 Clarity of minor themes		p. 1091	pp. 125		
Domain 1: Research team and reflexivity	2/8 (25%)	1/8 (12.5%)	2/8 (25%)	0/8 (0%)	0/8 (0%)
Domain 2: Study design	7/15 (47%)	10/15 (67%)	8/15 (53%)	8/15 (53%)	3/15 (20%)
Domain 3: Analysis and findings	6/9 (67%)	7/9 (78%)	7/9 (78%)	8/9 (89%)	2/9 (22%)
Total	15/32 (47%)	18/32 (56%)	17/32 (53%)	16/32 (50%)	5/32 (16%)

Note. <sup>a</sup>Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007)

prevalence of anxiety was 6%. Also, 8% of the participants reported impaired general mental health and 22% clinically relevant impaired physical health. There were no gender differences. By contrast, the prevalence of major depressive disorder and subsyndromal depression was 2.3% and 9.3%, respectively, in the Swiss population (Wagner, Müller, et al., 2012).

In the qualitative studies, van den Boom (1995) found no association between way of dying and depression. Some participants in the study by Starks et al. (2007) reported anxiety and exhaustion. While some participants in the study by Srinivasan (2018) reported anxiety in scheduling the death, the dying experience was deemed more comforting owing to a sense of control regarding the death.

Two studies reporting posttraumatic stress outcomes revealed mixed findings. In one study (Swarte et al., 2003), the family and friends bereaved by euthanasia or PAS had less posttraumatic stress reactions measured by the IES (Horowitz et al., 1979) than those bereaved by natural causes of death (Swarte et al., 2003). In the other study, Wagner, Müller, et al. (2012) found a prevalence of PTSD of 13% and subthreshold PTSD of 6.5%, while the prevalence of PTSD in the general Swiss population was 0.7% and subthreshold PTSD was 4.2%. There was a negative correlation between posttraumatic stress symptoms and the age of the deceased but not with duration of disease. Type of relationship (partner vs. parent) and gender of the bereaved person were not related to posttraumatic stress symptoms (Wagner, Müller, et al., 2012).

Those bereaved who met the diagnostic criteria of PTSD were more likely to have experienced emotional dif-

ficulties during the forensic examination than those who did not meet the diagnostic criteria (Wagner et al., 2011). Wagner, Keller, et al. (2012) found that perceived general disapproval, indicating having experienced low social acknowledgement as a bereaved individual, was strongly correlated with complicated grief and PTSD symptoms.

#### Other Psychosocial Outcomes

Those bereaved by euthanasia and PAS felt more prepared for and accepting of the death of their family member than those who were bereaved by natural causes, and they were more likely to believe that they had honored their family member's choices (Ganzini et al., 2009). There were no differences in their endorsement of the importance of caring for the ill family member or in the degree that they felt burdened by the care (Ganzini et al., 2009).

Similarly, participants in qualitative studies reported that their involvement in the decision-making process helped them to anticipate the death (Srinivasan, 2018) and to resolve moral dilemmas regarding their involvement in the decision-making process (Gamondi et al., 2013; Gamondi et al., 2018). Participants reported that honoring the patient's wish and autonomy facilitated an easier grief reaction

Ganzini et al. (2009) found no difference in social support after the loss between those bereaved by euthanasia or PAS and those bereaved by natural causes (Ganzini et al., 2009). Participants in qualitative studies reported feelings of isolation, selective disclosure, and fear of stigma

(Gamondi et al., 2013; Gamondi et al., 2018; Starks et al., 2007; Srinivasan, 2018). Some participants reported having little time for their own emotions after the death because of the police investigation, fear of being prosecuted, worrying about dealing with authorities, or feeling guilty for having violated a social rule (Gamondi et al., 2013). Some relatives questioned their own role in the death or wondered if they had contributed to killing their loved one (Srinivasan, 2018; Starks et al., 2007).

#### **Discussion**

This was the first systematic review of the grief and mental health outcomes of people bereaved by euthanasia or PAS. The review identified 10 research articles published over the past 25 years, all conducted in only three of the countries where euthanasia or PAS are permitted. While assisted dying is legal primarily in Western countries, it is unknown whether the study findings may apply to other countries. All studies involved bereaved adults, including older adults, but there have been no studies that included children or adolescents.

All studies reported on grief and/or mental health outcomes (Ganzini et al., 2009; Wagner, Müller, et al., 2012; Swarte et al., 2003). Although the number of studies involving a control group was limited, these studies reported that those bereaved by euthanasia or PAS had similar (Ganzini et al., 2009; Wagner, Müller, et al., 2012) or better (Swarte et al., 2003) scores on measures of disordered grief, grief symptom severity, depressive disorder, severity of current depressive symptoms, and PTSD. However, in the Swarte et al. (2003) study, there were more adult children and siblings in the control group than in the euthanasia group, although the impact of this difference on study findings is unknown. Only one study found a higher prevalence of depression and PTSD in the study group (Wagner, Müller, et al., 2012). However, the control group consisted of the general - not necessarily bereaved - population, whereas the control group in the two other studies comprised a "naturally" bereaved population (Ganzini et al., 2009; Swarte et al., 2003).

Some, mainly qualitative, studies reported specific issues faced by people bereaved by euthanasia/PAS. The main difficulties concerned moral or ethical conflicts, dealing with feelings of guilt and responsibility, dealing with authorities after the death, or coping with anticipated unfavorable social perceptions or judgment regarding the death. A sense of control both from the perspective of the bereaved and the dying family member, anticipating the death, the opportunity to "finish business," and the feeling of having honored the deceased's will were the main positive aspects reported.

There are similarities and differences between euthanasia or PAS, and other modes of death, which may impact the grief of bereaved individuals (Srinivasan, 2018; Wagner, Müller, et al., 2012). Some features may be unique to euthanasia and PAS. People bereaved through euthanasia and PAS can say goodbye and prepare for the loss, for example, through family conversations, as with nonassisted deaths after chronic illnesses (Wright et al., 2008). However, this is different from sudden deaths, which may leave the bereaved individuals with "unfinished business" in their relationship with the deceased that may increase their risk of grief complications (Hui, 2015; Kristensen et al., 2012). With euthanasia and PAS, the bereaved people may have had the opportunity of being involved in the decision-making process and to accept the deceased's desires (Ganzini et al., 2009; Swarte et al., 2003). Nevertheless, being involved in the decision was also reported as confronting them with difficult moral and ethical dilemmas, relational issues prior to the death, as well as experiencing feelings of guilt and wondering about responsibility afterwards (Starks et al., 2007). However, most bereaved people experienced the moral dilemmas as beneficial for their grief, and they were aware that they had gone through a profound process (Gamondi et al, 2018).

As with a death by suicide, the bereaved person is confronted with the intentional death of a significant other. Most of the bereaved people did not consider PAS as a suicide or euthanasia as a murder, although some individuals in their social environment did (Srinivasan, 2018). Like bereavement by unnatural deaths, such as suicide, drug overdose, or accidents (Feigelman, Cerel, & Sanford, 2018), those bereaved by euthanasia and PAS anticipated negative reactions, for example, through selective sharing of information about the manner of death and self-chosen isolation (Gamondi et al., 2013), which can have an adverse effect on their grief and mental health.

Although there may be international differences (Gamondi et al., 2013), some bereaved people experienced a general lack of openness in society, so that they experienced disenfranchised grief (Srinivasan, 2018). Unresolved grief questions, lack of social support, and perceived stigma may increase their risk of disordered grief and negative mental health (Lobb et al., 2010; Oexle, Feigelman, & Sheehan, 2018; Pitman et al., 2017; Wagner, Keller, et al., 2012). Furthermore, depending on the legislation in a given country, there may be an investigation by police, medical examiners, or coroners (Biddle, 2003; Spillane et al., 2019). While such investigations can be an intrusive experience, sometimes resulting in greater mental health issues (Wagner et al., 2011), they can also provide opportunities to offer bereavement support through designated mental health and community services such as support groups (Mowll, Smith, & Fitzpatrick, 2017). Clinicians should be aware

that those bereaved by euthanasia or PAS may have gone through a long process of caring for their ill family member, struggled with moral dilemmas and feelings of guilt, and may find it difficult to share their experiences in their social environment. Moreover, one should consider that perceived general disapproval is a risk factor for PTSD and complicated grief symptoms (Wagner, Keller, et al., 2012). Reducing and avoiding discriminating or stigmatizing attitudes before and after the death may ease the aftermath of euthanasia or PAS (Wagner et al., 2011).

#### **Limitations and Implications**

The review included only 10 articles reporting on eight studies from three countries, and it is not known whether findings apply to other countries. All the studies are retrospective and mostly measure self-reported outcomes or elicit issues at one point in time. Longitudinal research from various countries is needed to shed light on the course of grief and mental health of people bereaved by PAS and euthanasia. Research should also examine social support, help-seeking, and factors that may hinder or facilitate beneficial or adverse grief outcomes. Future research could also investigate the pathology involved (somatic vs. mental illness) and whether outcomes regarding euthanasia and PAS cases would be different.

The response rate is known for only half of the studies and it varied from 23% to 75%. Moreover, very little is known about possible differences between responders and nonresponders regarding consequences of assisted dying in their life. In the Gamondi et al. (2013) study, the only study addressing this issue, four relatives refused to participate in the study because it would have been too distressing to recall the experience. This may suggest a possible bias of having more favorable outcomes being overrepresented. Similarly, the literature suggests that people with greater grief feelings have higher nonresponse rates (Stroebe & Stroebe, 1989), indicating that negative grief experiences might be underreported.

Most studies solicited relatives and friends witnessing the death. This seems appropriate when investigating traumatic symptoms but could result in a selection bias when considering bereavement or psychosocial, moral, or relational issues likely to influence the bereavement. People having opted for not witnessing the death might face specific challenges and have different grief reactions. Gamondi et al. (2013) also described the personal moral belief of the respondents and its possible influence on their bereavement (relatives with favourable beliefs possibly experienced less troubled bereavement). Further research should address these issues.

Research on grief in other circumstances suggests that some grief experiences may be more pronounced in younger age groups, for example, feelings of anxiety and self-harm (Andriessen, Hadzi-Pavlovic, Draper, Dudley, & Mitchell, 2018; Balk, 2014). Hence, children and adolescents may face specific challenges in coping with bereavement (Andriessen, Lobb, et al., 2018; Rosner, Kruse, & Hagl, 2010), and their omission from this field of research signifies a serious gap in our knowledge about how to best prepare or support them in the case of a death by euthanasia or PAS.

The overall quality of the included studies was rated as *fair*. To improve study quality, future studies should involve representative samples, include control groups of people bereaved by other modes of death, and apply standardized measures of grief and mental health-related outcomes.

#### Conclusion

Despite the many challenges associated with bereavement after euthanasia and PAS, the findings of this review suggest that the psychosocial aftermath of this type of death is not worse than that of other types of death. Nevertheless, those bereaved may have to cope with the social perception of assisted dying and with moral and relational issues within the family. Obviously, as more countries are regulating assisted dying, high-quality studies across the lifespan are needed to investigate the grief and the psychosocial aftermath of these deaths and the factors that may hinder or facilitate the grief trajectories of the bereaved. These studies should be based on representative samples and involve those who contested the deceased's will or opted for not witnessing the death.

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**Appendix** 

Table A1. Summary of studies

Author (year) Location	Eligibility criteria	Sample size	Age (years)	Male/ female	Time since bereave- ment	Relation- ship to deceased	Setting	Study design	Outcome measures	Main results
Quantitative studies	studies									
Ganzini et al. (2009) USA	Case: Family of deceased patient who had requested physician aid in dying or had sought information from aid-indying advocacy organization Control: Family of patient who died from ill-ness and never requested such aid or information	Case: N = 95 Control: N = 63	Case: $M = 60.9$ ( $SD = 13.1$ ) Control: $M = 60.1$ ( $SD = 14.2$ )	Case: Male  n = 29 (31%) Female  n = 66 (69%) Control: Male  n = 13 (21%) Female  n = 50 (79%)	Case: 13.8 months (SD = 8.6) Control: 14.7 months (SD = 6.9)	Spouse/ partner, child, other family	Partic-ipants' home	Cross-sectional study	Social support: Interpersonal Support Evaluation List (ISEL) Prolonged grief: Inventory of Complicated Grief-Revised (ICG-R) Mental health service use Depression: Beck Depression Inventory (BDI); and Structured Clinical Interview for Disorders-Revised (SCID-R) Study specific questions: preparation, regrets, acceptance of death; surprise, peacefulness, and sense of inclusion or rejection regarding deceased's choices at end of life	<ul> <li>No difference between the two groups in depression, prolonged grief, and mental health service use or social support. In cases this was 11%, 2%, and 38%, respectively.</li> <li>No difference between the two groups in endorsement of the importance of caring for the ill family member.</li> <li>The bereaved after physician-aided dying were more likely to believe that their loved one's choices were honored and less likely to have regrets about how the loved one died.</li> <li>The bereaved after physician-aided dying felt more prepared and less likely to have regrets about how the loved one died.</li> <li>The bereaved after physician-aided dying felt more prepared and accepting of the death than control participants.</li> </ul>

Table A1. continued

Author (year) Location	Eligibility criteria	Sample size	Age (years)	Male/ female	Time since bereave- ment	Relation- ship to deceased	Setting	Study design	Outcome measures	Main results
Swarte et al. (2003) The Neth- erlands	Case: Immediate family or friends; were with patient at death; informed about the cause of death; aged 18-85 years; fluent in Dutch; death occurred 1992-1999  Control: Family and friends of patients who died naturally during the same period	Case: N = 189 Control: N = 316	Case: $M = 48$ (SD = 14) Control: $M = 49$ (SD = 14)	Case: Male n = 87 (46%) Female n = 102 (54%) Control: Male n = 132 (42%) Female n = 184 (58%)	Approximately 1-9 years	Spouse, parent, child, sib-ling, other	University hospital	Cross-sectional study	Grief: Inventory of Traumatic Grief (ITG; Dutch) Grief: subscale of Texas Revised Inventory of Grief (ITRIG) Posttraumatic stress reactions: Impact of Event Scale (IES) General mental wellbe- ing: Symptom Checklist (SCL-90) Depressive mood: Dutch version Depressive Ad- jective Checklist (DACL) Personality: Generalised Self-Efficacy Scale (SES), and Eysenck Personality Questionnaire (EPQ-RRS) Study specific questions on the period of the patient's death	- The bereaved by euthanasia had less traumatic grief symptoms (adjusted difference -5.29 [95% CI -8.44 - 2.15]), less current feeling of grief (adjusted difference 2.93 [0.85-5.01]); and less posttraumatic stress reactions (adjusted difference -2.79 [-5.33 - 0.25]) than control group. These differences were independent of other risk factors cay goodbye was important for less grief symptoms and posttraumatic stress reactions
Wagner, Müller et al. (2012) Switzer- land	Family and friends, present at assisted sui- cide, between Oct, 2005 and Sep. 2006, in Canton Zurich	Case: N = 85 Control: N = 0	M = 60.1 (SD = 13.4; range 25-89)	Mate n = 37 (43.5%) Female n = 48 (56.5%)	M=19.7 months (SD = 3.83, range 14-24 months)	Parent, partner, child, sib- ling, friend	Right-to-die organization Exit Deutsche Schweiz, and at home	Cross- sectional study	PTSD: Impact of Event Scale-Revised (IES-R; German) Complicated Grief: In- ventory of Complicated Grief-Module SF short form (German) Depression: short form of the SCL-90: Brief Symptom Inventory (BSI) General physical and psychological function- ing: SF-12	- 13% met the criteria for full PTSD, 6.5% met the criteria for subthreshold PTSD - 4.9% met the criteria for complicated grief - Prevalence of depression was 16%; prevalence of anxiety 6% - Prevalence of PTSD and depression might be higher than in general population general population

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Author (year) Location	Eligibility criteria	Sample size	Age (years)	Male/ female	Time since bereave- ment	Relation- ship to deceased	Setting	Study design	Outcome measures	Main results
Wagner et al. (2011) Switzer- land	mepl	Idem	шер	mepl	mepl	mepl	mepl	Idem	PTSD: Impact of Event Scale-Revised (IES-R; German) Complicated Grief: In- ventory of Complicated Grief-Module SF short form (German) Depression: short form of the SCL-90: Brief Symptom Inventory (BSI) Forensic Investigation Experience Scale (FIES)	- The FIES total score correlated significantly with the diagnoses of PTSD, depression, and CG, with coefficients of r = -0.40, -0.28, and -0.27, respectively
Wagner, Keller et al. (2012) Switzer- land	Mem Jensey Jense Jensey Jensey Jensey Jensey Jensey Jensey Jensey Jensey Jense	mepl	mep)	m <sub>e</sub> m <sub>e</sub>	m <sub>e</sub> p <sub>l</sub>	ldem January 1980	шер	ш	PTSD: Impact of Event Scale-Revised (IES-R; German) Complicated Grief: In- ventory of Complicated Grief-Module SF short form (German) Social Acknowledge- mert as a Victim or Survivor Questionnaire (SAQ)	- Significant correlations between General Disapproval subscale and PTSD symptoms (rs = 0.50-0.56) - Significant correlations between Recognition and Family Disapproval subscales and IES Hyperarousal scale (rs = 0.33-0.34) - In multiple regression analysis, social acknowledgement factors explained 24% (adjusted R²) of the variance in IES scores. General Disapproval had strongest impact on both PTSD and CG - Many did not share experience with social relations

Table A1. continued

Author (year) Location	Eligibility criteria	Sample size	Age (years)	Male/ female	Time since bereave- ment	Relation- ship to deceased	Setting	Study design	Outcome measures	Main results
Qualitative studies	udies									
Gamondi et al. (2013) Switzer- land	Relative of a patient deceased following assisted suicide, in the years 2003–2009, older than 18 years, able to give informed consent and complete interview in Italian or French	N = 1 1	M = 56 (range = 40-71)	Males  n = 5 (45%)  Female  n = 6 (55%)	M = 24 months (range = 12-72)	Spouse, child, sibling, nephew, sister	interviews	Semi- structured interview study Grounded theory analysis	Exploration of families' experiences of assisted suicide deaths	- Themes regarding coping and bereavement:  • Secrecy management • Assisted suicide as a possible future option for themselves • Assisted suicide in comparison with nonassisted suicide - The relatives reported moral dilemmas, feelings of isolation because of fear of stigma or considered the death a private matter. None of the interviewees received formal psychological support.
Gamondi et al. (2018) Switzer- land	Family and close friends of a patient deceased following assisted suicide between Juny 2013, informed by the patient of their intention to seek AS, older than 18 years, able to give informed consent and complete interview in French or Italian	N = 28	M = 50-60 (range = 2-70+)	Male  n = 11 (39%) Female n = 17 (61%)	M = 12 months (range = 6-48)	Spouse, child, grandchild, sibling, friend, other	Individual interviews at a location chosen by the participant	Cross-sectional semistructured interview study; Qualitative content analysis	Type of family involvement in assisted suicide Interactions that occurred before assisted suicide	- Awareness of having experienced a very intense process - Careful and partial disclosure of assisted suicide by family members (anticipation of stigma) - Perceived stigma and self-ascribed social isolation - Not receive or ask for professional support in bereavement - Positive reflections about having fulfilled patient's wishes

Table A1. continued

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Author (year) Location	Eligibility criteria	Sample size	Age (years)	Male/ female	Time since bereave- ment	Relation- ship to deceased	Setting	Study design	Outcome measures	Main results
Srinivasan (2018) USA	Family members of someone who died an assisted death, aged 18+, able to communicate in English, bereaved within 3 years	N = 22	18+ 61-80 ( <i>n</i> = 13)	Male n = 7 (32%) Female n = 15 (68%)	Max. 3 years	Family members, spouses (n = 16)	Individual	Explorative interview-based study, Thematic analysis	Exploration of grief following assisted death	Five themes:  - General grief reactions  - Anticipating the death  - Sense of control  - Level of agreement with assisted death  - Grief expression and stigma
Starks et al. (2007) USA	Family of patients currently pursuing physician-assisted-suicide (1) (PAS), and family members of patient who had pursued PAS (2)	N = 48	M = 51 (range = 29-82)	Male  n = 20 (42%) Female  n = 28 (58%)	(1) M = 10.6 months (range = , 0.1–30.6) (2) M = 20.2 months (range = 2.4–49.5)	Spouse, child, in- laws, friend	Telephone or face-to-face interviews	Qualitative case study, involving multiple semi-semi-interviews (total 159 interviews)	Consequences experienced by family members as a result of participating in PAS	- Relief that the dying person's suffering ended as well as the caregiving duties - Dealing with loose ends such as financial management and last wishes - Dealing with regrets of what could have been different - Moving ahead by grieving the loss and continue life without the deceased. This was more challenging when families experienced difficulties during the dying

 Table A1.
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Main results	- Reactions in the bereaved: • sadness and sorrow n = 57 (95%), loneliness n = 40 (67%), sleeping problems n = 34 (57%), apathy n = 16 (27%), apathy n = 16 (27%), psychomotor agitation n = 1 (95%), depressive episoden n = 12 (20%), depressive episoden n = 12 (20%), depressive episoden n = 12 (20%), sleeping medication/other tranquillizers n = 19 (31%), alcohol abuse n = 8 (13%) - Qualitative findings: • Initially, death was abuse n = 8 (13%). • Qualitative findings: • Initially, death was abuse abuse abuse n = 8 (13%). • Qualitative findings: • Initially, death was abuse abuse abuse of the loss after 2 years. • Initially, death was alonger time others experienced little grief while others experienced associated with grief difficulties in the euthanasia process were associated with grief difficulties. • No association between way of dying and depression
Outcome measures	Impact of euthanasia on those bereaved
Study design	Mixed- method study with ques- tionnaire and face- to-face interview
Setting	Individual interviews
Relation- ship to deceased	Partners, family members, friends, buddies
Time since bereave- ment	Not reported
Male/ female	Not reported
Age (years)	Not reported
Sample size	09 = N
Eligibility criteria	Relatives of deceased AIDS patients, available between Oct. 1988 and May 1990
Author (year) Location	Van den Boom (1995) The Neth- erlands

Note. CG = complicated grief. PTSD = posttraumatic stress disorder.