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**Department of Brain and Behavioral Sciences (DBBS)
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Needs of Informal Caregivers of Patients Seeking Assisted Suicide or Euthanasia: A Narrative Review

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ABSTRACT

Informal caregivers are individuals who provide unpaid practical, emotional and physical support to a person who is dependent on such care. In the context of Assisted Dying, these roles acquire additional characteristics, because caregivers must navigate not only illness and approaching death but also a deliberate and legally regulated process of dying. To address this, the aim of the narrative review is to synthesize the available evidence on how informal caregivers and relatives experience assisted dying across the trajectory from the patient's request or expressed wish to bereavement. Therefore, 11 empirical studies were included, selected through electronic searches in PubMed, Scopus, and Web of Science. The findings were organized according to three phases of the assisted-dying trajectory: pre-MAiD, during MAiD, and post-MAiD. Within each phase, emotional, relational, communicative, practical, ethical, legal, institutional, and bereavement-related experiences were identified and considered together rather than treated as separate themes. Informal caregivers' needs should be understood as longitudinal and relational rather than event-specific. The findings also revealed that informal caregivers' experiences depended on whether their needs were met or unmet. These needs should not be confined to a single phase.

Keywords: Informal caregivers, Assisted Dying, bereavement, narrative review, pre-MAiD, during MAiD, post-MAiD.

INTRODUCTION

Assisted dying has become an increasingly relevant legal, ethical, and clinical issue across several jurisdictions. The term is commonly used as an umbrella concept encompassing practices such as euthanasia, physician-assisted suicide, medical assistance in dying (MAiD), and voluntary assisted dying (VAD), although terminology, eligibility criteria, and procedures vary considerably between countries. In Europe, Switzerland has permitted assisted suicide under specific conditions since the mid-twentieth century, whereas the Netherlands and Belgium became among the first countries to establish comprehensive statutory frameworks regulating euthanasia in 2002. More recently, assisted-dying legislation has been introduced in other jurisdictions, including Canada in 2016, parts of Australia from 2017 onward, Spain in 2021, and Portugal in 2023. Legal frameworks have also emerged in Latin American countries, including Colombia and Ecuador. However, these contexts are not equally represented in the empirical literature, particularly in English-language studies examining the experiences of informal caregivers.

Although assisted dying ultimately concerns the decision and death of the patient, its consequences extend substantially to relatives and others who provide care. Informal caregivers are individuals who provide unpaid care to a person who depends on them for practical, emotional, or physical support and commonly include spouses, adult children, parents, other relatives, and close friends (Oyebode, 2003; Loi et al., 2014). This work is often largely invisible and socially unrecognized, is typically undertaken without professional healthcare training, and continues to be disproportionately performed by women (OECD, 2025). Caregivers may consequently place aspects of their own personal,

professional, and social lives on hold while attending to the needs of the person they support.

In assisted dying, this caregiving role acquires additional characteristics because caregivers must navigate not only illness and approaching death but also a deliberate and legally regulated process of dying. Their experiences therefore extend across the entire assisted-dying trajectory rather than being confined to the procedure or the moment of death. Once a patient expresses a wish for an assisted death, caregivers may become involved in obtaining information, identifying appropriate healthcare professionals, understanding eligibility requirements and legal procedures, attending appointments, advocating for the patient, communicating the decision to relatives, arranging farewells, preparing the physical environment, and organizing practical and funeral-related matters. Limited knowledge among healthcare professionals, unclear pathways, or institutional resistance may further require caregivers to advocate actively on behalf of the patient. The legal and healthcare systems within which assisted dying occurs can therefore either facilitate this process or substantially intensify caregiver burden (Hales et al., 2019).

These practical responsibilities coexist with substantial emotional and relational demands. Caregivers may experience anticipatory grief, uncertainty, moral ambivalence, distress, stigma, and disagreement within families while simultaneously attempting to support the patient's autonomous decision. Some have described the caregiving role as “all-consuming” or as requiring them to remain continuously “on call” (Smolej et al., 2023). Uncertainty can be particularly pronounced when information about assisted dying is difficult to locate or when caregivers do not know whom to approach. The absence of safe spaces in which assisted dying can be openly discussed may further reinforce secrecy, stigma, family conflict, and moral uncertainty. At the same time, caregiver

experiences are not uniformly negative. When the process is well supported, caregivers may also report preparedness, relief, meaning, and a sense of closure following the death (Michael et al., 2025).

Importantly, caregivers' needs and experiences appear to change across different phases of the assisted-dying trajectory. Before or around the patient's decision, caregivers may require accessible information about the legal framework, available options, eligibility requirements, and how to initiate the process. Previous research suggests that some families would prefer such information to be available even before a formal request is made, allowing patients and relatives to understand assisted dying as a possible end-of-life option (Oczkowski et al., 2021). During the waiting and preparation phase, procedural barriers, delays, and perceived judgement from healthcare professionals may intensify distress. Mandatory waiting periods have, for example, been described by some caregivers in Canada as unnecessarily burdensome and emotionally difficult (Hales et al., 2019; Hashemi et al., 2021). During this period, caregivers may also assume responsibility for paperwork, funeral arrangements, communication with relatives, practical preparations, and the organization of the patient's final days (Gamondi et al., 2018). The procedure itself can generate intense and sometimes contradictory emotional responses, while bereavement experiences after the death may subsequently be influenced by the degree of preparedness, professional support, family communication, and overall experience of the assisted-dying process.

Despite the increasing body of research on assisted dying, evidence concerning informal caregivers remains fragmented. Existing studies have examined aspects such as communication, practical arrangements, moral dilemmas, procedural experiences, the final day, and bereavement, but these findings are dispersed across different countries,

legal frameworks, stages of the process, and methodological approaches. Research also frequently centers on patients or treats relatives collectively as part of the broader family unit, meaning that the specific responsibilities and experiences of those who assume an informal caregiving role may receive comparatively limited attention. This represents an important gap because informal caregivers are often directly involved in navigating both the demands of caregiving and the additional practical, relational, and ethical complexities associated with assisted dying.

Furthermore, caregiver experiences cannot be understood independently of their legal and institutional context. Procedural timelines, accessibility of information, involvement of healthcare professionals, regulatory requirements, and the extent to which assisted dying can be discussed openly may influence how caregivers experience and subsequently integrate the death. Research suggests that caregivers who encounter clear information, accessible pathways, responsive professionals, and opportunities for support may experience greater preparedness and more positive bereavement outcomes, whereas procedural difficulties, secrecy, conflict, and insufficient support can compound distress (Jeanneret et al., 2024; Boven et al., 2024). Examining the assisted-dying trajectory as a whole is therefore important for understanding how emotional, relational, practical, ethical, communicative, and institutional dimensions interact over time rather than operating as isolated experiences.

Accordingly, the aim of this narrative review is to synthesize the available evidence on how informal caregivers and relatives experience assisted dying across the trajectory from the patient's request or expressed wish to bereavement. Drawing on 11 primary studies conducted in Canada, Belgium, Switzerland, and Australia and representing 266 informal caregivers, including spouses, adult children, parents, other relatives, and close friends,

the review examines the emotional, relational, ethical, practical, communicative, and bereavement-related dimensions of these experiences. Particular attention is given to how caregiver needs and challenges change across different phases of the process and to the contextual factors that may facilitate or hinder their experience.

Where reported in the primary studies, the review also considers whether caregivers described their needs as adequately supported, unmet, or only partially addressed. By identifying recurrent challenges, facilitators, and gaps in support across the assisted-dying trajectory, the review seeks to clarify where clinical practice, policy, and future research could better respond to the needs of informal caregivers involved in assisted dying.

METHODS

The review was guided by the following primary question: *What is known about the experiences of family caregivers and relatives involved in assisted dying?* As previously noted, several initial dimensions were established a priori to guide the literature search. However, additional dimensions emerged inductively during data extraction, allowing the review to address gaps identified in the introduction. Accordingly, a secondary question was also considered: *What emotional, relational, ethical, practical, communication-related, and bereavement-related experiences are reported across the assisted-dying trajectory?*

This narrative review included empirical studies addressing the experiences of informal caregivers in the context of assisted dying. It was designed to provide an interpretive synthesis of the available literature rather than a formal systematic review or meta-synthesis. Electronic searches were conducted in PubMed, Scopus, and Web of Science between November 2025 and February 2026. Search terms included combinations of

keywords such as “assisted dying,” “euthanasia,” “assisted suicide,” “physician-assisted suicide,” “caregivers,” “informal caregivers,” “informal caregiver burden,” and “informal caregiver needs.”

The database searches identified 15 potentially relevant published articles. The reference lists of these articles were also manually searched to identify additional eligible studies. Each article was independently reviewed by another author against the predefined eligibility criteria. Following this process, 11 articles were retained for inclusion in the review. No restrictions were applied regarding publication date.

Eligibility criteria

Empirical studies reporting the perspectives or experiences of informal caregivers were eligible for inclusion. Informal caregivers were defined as individuals who provided unpaid emotional, practical, or physical care to a person undergoing an assisted-dying process. Studies focusing exclusively on patients or healthcare professionals were excluded unless caregiver-specific data were reported separately and could be clearly identified.

Studies were eligible if they were conducted in jurisdictions where assisted dying was legally permitted and addressed practices such as medical assistance in dying (MAiD), euthanasia, physician-assisted suicide, or voluntary assisted dying (VAD). Studies examining assisted dying in illegal, underground, or otherwise non-regulated contexts were excluded.

Qualitative studies were included, as were mixed-methods studies when data specifically concerning caregivers’ experiences could be clearly extracted. Studies not available in English were excluded.

Data extraction

For each included study, information was extracted on the country, study design, legal context, participant characteristics, and the main findings related to caregivers' experiences. The data were then organized according to where these experiences occurred in the assisted-dying process: **before MAiD, during MAiD, and after MAiD**. This made it possible to follow how caregivers' experiences and needs changed over time rather than treating them as isolated issues.

Within each phase, attention was given to the main aspects described by caregivers, including emotional and psychological experiences, communication with family members and healthcare professionals, practical and logistical responsibilities, ethical or values-related concerns, legal and administrative issues, experiences of stigma or relational conflict, cultural or spiritual considerations, and bereavement.

The extraction also considered the needs reported by caregivers and, when this was clear in the original study, whether these needs had been met, remained unmet, or had only been partially addressed. Barriers and sources of support were also recorded. When available, short participant quotations This logic helped us understand not only what caregivers experienced, but also when these experiences emerged and what appeared to make the process easier or more difficult for them.

Synthesis strategy

The findings were synthesized narratively through an iterative process of organization, comparison, and interpretation (Sukhera, 2022). First, the descriptive characteristics of the included studies were summarized, including country, study design, legal context, and the phases of the assisted-dying trajectory addressed. Key findings were then extracted

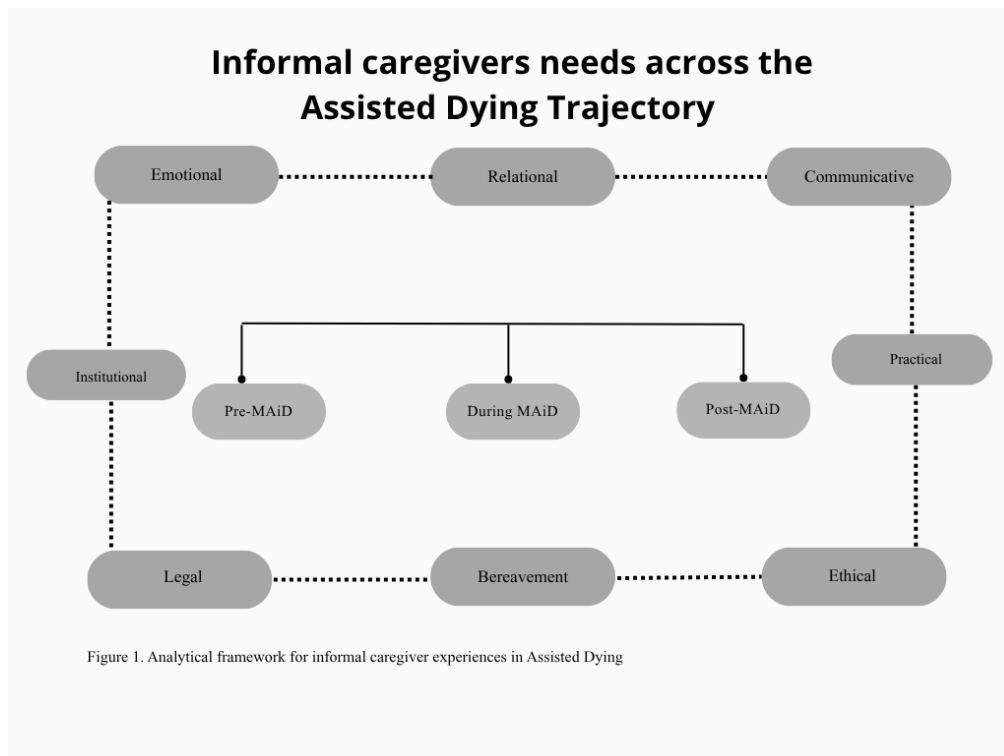
and organized according to the two review questions and the dimensions identified a priori. During repeated reading and comparison across studies, additional recurring patterns and areas of convergence or divergence were identified (Bourhis, 2017). These patterns were subsequently examined across different phases of the assisted-dying trajectory and legal jurisdictions. Attention was given to recurrent issues concerning caregiver burden, moral ambivalence, communication, the influence of legal and institutional contexts, and the need for relational and bereavement support.

RESULTS

Characteristics of the included studies

The included studies were conducted across several legal assisted-dying contexts and jurisdictions, including Canada, Belgium, Switzerland, Australia, and the Netherlands. The legal frameworks differed across countries, including differences in terminology and procedural processes. Most studies focused on informal caregivers, including spouses or partners, adult children, parents, and other close relations. Participants ranged in age from 19 to 81 years, and the majority were women. Caregivers supported patients diagnosed with terminal cancer, neurodegenerative diseases such as ALS and Parkinson's disease, and other chronic conditions.

The findings were organized according to three phases of the assisted-dying trajectory: pre-MAiD, during MAiD, and post-MAiD. Within each phase, emotional, relational, communicative, practical, ethical, legal, institutional, and bereavement-related experiences were considered together rather than treated as separate themes. Figure 1 provides further information.



Main Themes

Theme 1. Pre-MAiD

The pre-MAiD phase encompassed the period from the patient's expression of a wish for assisted dying through the waiting and preparation process. During this phase, informal caregivers experienced emotional, relational, practical, communicative, and legal challenges that often developed alongside the burden already associated with caring for someone with a serious illness.

Sub-theme: Caregiving burden and emotional responses

Informal caregivers described two forms of burden during this phase. The first was a background burden associated with providing care throughout the patient's illness. A second burden emerged when the assisted-dying process began and was described as emotionally intense, uncertain, and morally complex (Thangarasa et al., 2022).

Caregivers expressed a need to share responsibilities and have opportunities to engage in recreational and personal activities outside the caregiving role. However, this need was often unmet because caregiving substantially affected their identity, engagement in personal activities, and relationship with the person receiving care (Smolej et al., 2023).

A recurring experience involved trying to understand the patient's wish for assisted dying while simultaneously processing their own emotional reactions, doubts, and ambivalence. Informal caregivers therefore expressed a need for open communication within the family and greater clarity regarding the patient's wishes (Thangarasa et al., 2022).

Moral and spiritual considerations also influenced this process. In some cases, caregivers experienced tension between respecting the patient's decision and maintaining their own moral, spiritual, or relational positions (Michael et al., 2025). Family members could also hold different positions regarding assisted dying, generating disagreements and distress. These conflicts could continue beyond the assisted death and influence later bereavement experiences (Thangarasa et al., 2022).

Sub-theme: Information, communication, and professional support

The need for accessible and comprehensive information was recurrent across studies. Participants emphasized not only the need for better information but also greater organizational involvement in making information about assisted dying accessible (Jeanneret et al., 2024). According to Oczkowski et al. (2021), participants also addressed the need for early discussions and informed awareness of assisted dying

Informational uncertainty was associated with ambiguity and anxiety. Hales et al. (2019), for example, described situations in which caregivers were required to repeatedly contact

healthcare professionals while remaining uncertain about how long the assisted-dying process would take.

Informal caregivers also expressed a need for validation, guidance, and non-judgmental professional responses when assisted dying was first discussed. Participants described feelings of abandonment when healthcare professionals behaved inconsistently or appeared unwilling to engage with assisted dying (Michael et al., 2025).

In contrast, emotional support from nurses, psychologists, physicians, and priests was described as helpful. Boven et al. (2024) highlighted the importance of this support in helping caregivers manage their emotional needs and in contributing to a more adaptive grief process later in the trajectory.

Communication therefore involved several relationships simultaneously: between the caregiver and patient, among family members, and between caregivers and healthcare professionals. Clear, open, and empathic communication was associated with greater feelings of preparedness and support, whereas poor communication contributed to anxiety and distress.

Sub-theme: Waiting, legal requirements, and uncertainty

The waiting and preparation period emerged as one of the most burdensome aspects of the pre-MAiD phase. Informal caregivers often felt responsible for ensuring that the patient's decision could be carried out while simultaneously managing their own emotional reactions.

Caregivers reported that their personal needs were frequently neglected because of the amount of responsibility placed on them. They described difficulties associated with

having to manage practical responsibilities while also coping with uncertainty regarding the patient's choice and its timing (Thangarasa et al., 2022; Hashemi et al., 2021).

The waiting period could intensify emotional tension and ambivalence (Hashemi et al., 2021). Participants also described experiences of isolation and anticipatory grief and characterized the process as a "race to the end" (Thangarasa et al., 2022).

Legal and institutional frameworks directly influenced these experiences. Caregivers expressed a need for legal information from the beginning of the process, as well as clearer protocols and standardized guidance for navigating the clinical pathway.

Where mandatory waiting periods or procedural delays were present, caregivers described additional distress, particularly when they feared that the patient might lose capacity or become too unwell before the assisted death could occur (Hales et al., 2019).

In the Canadian context, the mandatory ten-day reflection period was associated with anxiety regarding the possible loss of the patient's capacity before the procedure.

Sub-theme: Practical preparation and family communication

The pre-MAiD phase also involved substantial practical and organizational work. Informal caregivers were involved in paperwork, planning, communication with clinicians, funeral-related arrangements, and preparation for the day of death.

Setting a date for the procedure could have both positive and negative consequences. On one hand, logistical responsibilities could be exhausting. On the other hand, knowing the date allowed families to organize visits, fulfil last wishes, complete financial planning, and prepare for the death. In these situations, caregivers described a greater sense of control (Thangarasa et al., 2022).

Informal caregivers also had to decide how openly the assisted-dying process should be discussed with others. Some participants were comfortable disclosing information and even considered themselves advocates for MAiD, whereas others were more reserved because of personal or religious concerns (Hashemi et al., 2021).

Where differences in disclosure or moral positioning existed within families, conflict could emerge. In Switzerland, secrecy surrounding assisted suicide was reported to negatively affect later bereavement experiences (Gamondi et al., 2018).

Taken together, the pre-MAiD phase was characterized by the interaction of caregiving burden, anticipatory grief, moral ambivalence, communication, practical preparation, family relationships, and the legal and institutional context in which assisted dying occurred.

Theme 2. During MAiD

The procedure day was described as a highly emotional, symbolically significant, and logistically delicate moment. Although having a predetermined date could provide a sense of control and allow caregivers and patients to plan the final moments, the experience of the procedure itself could generate both meaningful and distressing responses.

Sub-theme: Preparation and communication during the procedure

Caregivers valued receiving information about what would happen during the procedure and appreciated healthcare professionals who explained the process clearly.

Nissim et al. (2024) identified five aspects influencing caregiver experiences during the procedure day: attuned support from the clinical team, preparation for clinical details,

congruence between the physical setting and the significance of the event, opportunities for active participation and ceremony, and the pacing and timing of the procedure.

Compassionate, calm, and responsive healthcare professionals were described as important facilitators. Caregivers valued professionals who preserved dignity, communicated openly, and helped them understand what was happening. This support was particularly valuable when it was not possible to fulfil all of the patient's wishes (Nissim et al., 2024).

Clear communication with healthcare staff also helped caregivers remain calmer during the procedure, particularly when clinical information was presented in a way they could understand and process (Nissim et al., 2024).

Sub-theme: Emotional responses and unexpected aspects of death

Despite preparation, some caregivers experienced distress when confronted with unexpected aspects of the procedure. These included physical signs associated with death, medical details, delays, uncertainty regarding timing, or clinical environments perceived as inappropriate for such an important moment (Nissim et al., 2024).

Some participants reported being shocked by the number and size of the syringes used during the procedure or by physical changes such as pallor and the suddenness of death. Boven et al. (2024), for example, described an unpleasant experience reported by a parent when the patient's heartbeat increased after medication was administered.

These experiences reflected a need for preparation that balanced sufficient information about what caregivers might witness with sensitivity to the emotional significance of the event.

Sub-theme: Environment, participation, and dignity

The physical environment was also important to caregivers. Many expressed a desire to preserve the atmosphere of the moment, personalize the setting, participate actively in the farewell, and retain a meaningful final memory of the patient.

Some participants expressed a need for less clinical environments that could be decorated or adapted to make the experience more personal and comfortable. One caregiver, for example, changed the position of the patient's bed in relation to the window to provide a more pleasant view.

Caregivers also appreciated post-mortem actions performed by healthcare professionals, such as closing the patient's eyes and mouth, because these actions contributed to the dignity of the experience and influenced the final image retained by family members (Nissim et al., 2024).

The degree to which caregivers felt informed, included, and emotionally supported during the procedure appeared to influence how they subsequently experienced and remembered the death.

Theme 3. Post-MAiD

The post-MAiD phase encompassed bereavement, adjustment, continuing family and social relationships, disclosure, and support after the patient's death. Bereavement experiences were not described as uniformly positive or negative. Instead, they appeared to reflect what caregivers had experienced throughout earlier stages of the assisted-dying trajectory.

Sub-theme: Bereavement as an accumulation of previous experiences

Bereavement was influenced by previous preparation, relational conflict, professional support, perceived respect for the patient's wishes, the experience of witnessing the death, stigma, and decisions regarding disclosure.

The findings suggest that bereavement support should not begin only after the death. Caregivers reported that support during earlier stages of assisted dying could influence their later adjustment. Boven et al. (2024), for example, highlighted the importance of considering bereavement care preventively and beginning support before the assisted death takes place.

Some caregivers described feelings of relief, peace, or closure following the death, particularly when the procedure occurred in accordance with the patient's wishes and within a supportive context.

Having a predetermined date allowed some caregivers to fulfil their loved one's final wishes and contributed to a sense of control (Hashemi et al., 2021). It also allowed some families to avoid witnessing later stages of the illness and the loss of the patient's faculties (Thangarasa et al., 2022).

Sub-theme: Difficult experiences and continuing distress

Other caregivers reported more difficult bereavement experiences. Unresolved family conflicts, secrecy, stigma, insufficient preparation, disturbing final images, and limited post-death support could complicate the grieving process.

Discussing and preparing for the death was described as helpful for later bereavement and for maintaining a more favourable final image of the patient (Boven et al., 2024).

In Switzerland, secrecy surrounding assisted suicide was reported to have a negative effect on bereavement (Gamondi et al., 2018). Similarly, post-mortem care provided by healthcare professionals was important because some caregivers who did not receive this support were left with unfavourable final images of their loved ones.

Relational dynamics therefore continued to influence caregivers after the death. Family conflict and secrecy could contribute to more difficult experiences, whereas continuity of family and professional support could facilitate adjustment.

Sub-theme: Disclosure, stigma, and moral positioning after death

The social context surrounding assisted dying continued to influence caregivers after the procedure. Personal, religious, or moral objections could make disclosure difficult and contribute to continued ambivalence.

Caregivers who experienced stigma or moral conflict could find it more difficult to discuss the death openly. At the same time, some participants found support through priests, therapists, clinicians, or other supportive relationships.

When these forms of support were unavailable, caregivers could experience prolonged anxiety, ambivalence, and difficulties discussing the circumstances of the death.

Sub-theme: Continuing support

Post-MAiD support included bereavement counselling, support groups, professional care, and other forms of relational support. Some caregivers described bereavement counselling and support groups as helpful for later adjustment. In contrast, caregivers without these support systems reported persistent distress that negatively influenced their grief (Hashemi et al., 2021).

Overall, caregiver experiences after MAiD were closely related to experiences occurring before and during the procedure. Communication, legal and institutional conditions, family relationships, moral and spiritual positioning, professional support, and preparation did not operate independently within individual phases. Rather, their effects could continue throughout the trajectory and influence how caregivers experienced bereavement and adjustment after the patient's death.

Table 1. Characteristics, caregiver needs, and illustrative experiences in the included studies

Study	Country	Participants	Phase(s)	Main caregiver needs	Needs met/unmet & key experiences	Illustrative quote
Family caregivers' support needs in MAiD	Canada	11 family caregivers; spouses, parents, adult children	Pre-MAiD; During MAiD; Post-MAiD	Emotional support and self-care; transparent information; practical planning support; clearer communication from healthcare services.	Information/communication needs were often unmet. Counselling, peer support and self-care were valued when accessed. Caregiving was described as all-consuming, affecting identity, relationships and daily life.	<i>"How can I identify my needs right now? I need help." (P2, p. 4)</i>
Quality of bereavement after home MAiD	Canada	13 family caregivers; partners, children, other relative	Pre-MAiD; Post-MAiD	A set date to support planning; support from the MAiD team; bereavement counselling/support groups; ability to disclose the MAiD experience.	Needs were largely described as met. Planning increased a sense of control, and counselling/support groups were associated with better coping and positive bereavement experiences.	<i>"I was very grateful that this was all available to our family and for my dad..."</i>
Improving the MAiD process: family caregiver perspectives	Canada	11 participants; partners, children, siblings, friend	Pre-MAiD	Clarity about the process, medications and professional roles; support around the reflection period; non-judgmental professional care.	Mostly unmet. Caregivers reported uncertainty about the process, anxiety about loss of capacity, and perceived changes in care after the MAiD request.	<i>"Stressful not knowing if we would get a doctor or space for the day he wanted..."</i>

A Race to the End: caregivers' experience of MAiD	Canada	22 caregivers; spouses, family members, siblings	Pre-MAiD; During MAiD	Support with anxiety and validation; open family communication; clarity about the patient's wishes; support with family conflict and logistical planning.	Mixed. Some caregivers felt honoured to support the patient's wishes, while others felt unheard or alone. Anxiety, guilt, family conflict and moral distress were reported.	<i>"My biggest fear is if [the patient] is not cognitive on the very last day..."</i>
Family caregivers' reflections on assisted suicide	Switzerland	26 family members and close relatives	Pre-MAiD; During MAiD; Post-MAiD	A care plan/professional assessment; support with funerals and rituals; clearer regulation and protocols; support with decisional dilemmas.	Important needs were unmet. Secrecy surrounding assisted suicide was described as negatively affecting bereavement. Distress, ambivalence, burden and decisional conflict were reported.	<i>"So it was a decision that was clear in her mind..."</i>
Suggestions for improving assisted dying regulation	Australia & Canada	65 caregivers; spouses, children, parents, friends, relatives	Post-MAiD	Better information and dissemination; more open discussion of assisted dying; peer and grief support; clearer institutional policies and responsibilities.	Unmet needs centred on unclear or absent institutional policies. Caregivers described discomfort, uncertainty and isolation, particularly when peer support was unavailable.	<i>"...there's a greater public understanding of what the process is, that it's not an easy process."</i>
"Walk me through the final day"	Canada	18 caregivers; spouses, children, close relatives	During MAiD; Post-MAiD	Attuned clinical support; preparation for the procedure; a less clinical environment; participation and ceremony; support to avoid shocking or unexpected details.	Mixed. Caring clinical support, procedural information and ceremonies were valued, but some caregivers were shocked by aspects of the procedure.	<i>"...it didn't feel strange. That's because of the types of people that they were. It was kind of calming."</i>
Caregiver accompaniment and non-abandonment in VAD	Australia	23 caregivers; spouses and parents	Pre-MAiD; During MAiD; Post-MAiD	Affirmation and validation; non-judgmental support for moral/religious conflict; ongoing medical support; a neutral professional perspective.	Mixed. Reframing concerns could help caregivers support the patient, while lack of support was associated with isolation, moral distress, burden and decisional conflict.	<i>"I'm not a nurse. I found I was very tense about looking after him..."</i>

Relatives' bereavement-care needs throughout euthanasia	Belgium	19 caregivers; spouses and other family members	Pre-MAiD; During MAiD; Post-MAiD	Empathic and involved healthcare professionals; emotional support; adequate information; support in processing the request; a positive final image of the deceased.	Mixed/partially met. Emotional support was comforting, but information was sometimes insufficient and some participants reported an unfavourable final image.	Verify that the selected quotation represents a caregiver before manuscript submission.
Improving experiences of patients and families requesting MAiD	Canada	17 caregivers; spouses, children, family friend	Pre-MAiD; During MAiD	Greater MAiD awareness; timely progression of requests; safe and comfortable assessment; trust; cultural/spiritual practices; choice of location, route and timing.	Mostly unmet due to unclear information, clinical delays and difficult assessments. Waiting was distressing, although it sometimes allowed families to incorporate personal traditions.	<i>"I don't think I saw any MAiD information over at the cancer centre... it needs to be there."</i>
Support needs of patients requesting MAiD and their relatives	Belgium	21 family participants	Pre-MAiD; Post-MAiD	Support for daily functioning, understanding the patient's wish, emotional regulation, meaningful activities, and social/family engagement.	Needs were more likely to be met when relatives were involved and could engage in meaningful rituals. Lack of involvement was associated with frustration or anger.	<i>"It would be useful to have someone as a backup, indeed."</i>

Note. All included studies were qualitative and were conducted in legal assisted-dying settings. For the Swiss study, the source table notes that assisted suicide was legal under specified conditions but without a federal protocol. Phases were standardized as Pre-MAiD, During MAiD, and Post-MAiD for consistency with the manuscript.

DISCUSSION

This review suggests that informal caregivers' experiences in assisted dying are multidimensional, evolving, and strongly shaped by the trajectory as a whole. Rather than involving only isolated support needs, their experiences encompass emotional strain, practical labor, ethical positioning, communication challenges, family negotiation, and bereavement adaptation. This adds to prior literature concerning informal caregivers' emotional experiences (Vissers et al., 2024) by proposing a multidimensional view of their needs.

Previous research addressed the assisted dying process in terms of “before and after” the procedure, rather than a series of determinate phases; neither does it consider the relation between the phases and the experiences or needs of the informal caregivers. The extent of these aspects is intrinsically interrelated. For example, more effective management in handling the pre-decision phase facilitated better outcomes in the next phases (Hashemi et al., 2021). Likewise, from a macro-level perspective, this dynamic is tied to external factors, such as legal statutes and support from medical staff.

The main contribution of this narrative review is to show that informal caregiver trajectory is processual and it can not be adequately understood by examining isolated “needs”; experiences accumulate and transform across phases. The meaning and intensity of these experiences shift across phases. This trajectory-based interpretation challenges and helps move beyond static descriptions of informal caregiver burden which are routinely found across the broader literature.

The findings also indicate that caregiver experience is inseparable from the legal and institutional context in which assisted dying occurs (Gamondi et al., 2018). Procedural requirements, access pathways, waiting periods, and the degree of professional coordination can either alleviate or intensify caregiver distress (Smolej et al., 2023). Although the legal dimension occupies a central place in much of the assisted dying literature, the direct impact on informal caregivers has not been studied to the same extent as the legal context itself, or as the impact on the patient.

However, law is not merely the background setting: it is an experiential determinant because it changes timing, responsibility, information access, professional involvement, secrecy/openness, and therefore the caregiver experience itself (Gamondi et al., 2018). It is important to underscore that the focus on the legal aspect must not be confined to the

legality per se, but rather extended to encompass deeper socio-normative considerations. Including: the willingness of countries to open the public dialogue around Assisted Dying as not being treated as a clandestine matter; the design of protocols that make the system more supportive for caregivers; and rules that prevent unnecessary delays in the process.

The review has practical implications for assisted dying services. Starting with early information. Informal caregivers appear to benefit from access to clear and timely information about the possibility of assisted dying and legal implications that could be provided at hospitals or medical settings Oczkowski et al. (2021). Followed by anticipatory support, especially outside the family. It is important to give informal caregivers a space to talk and process their emotions without being judged. Such as friends, psychologists, priests, or support groups (Smolej et al., 2023).

In the later stages of the process, informal caregivers need procedural preparation. Through explicit guidance about medical procedures, acknowledgment of emotional ambivalence, and preparation for what death may look like. Providing details, but not explicit information about the symptoms and physical reactions that the patient may experience (Nissim et al., 2024). Followed by support on the day, where it is important to offer a non-judgmental health care team and a good medical setting, because they need to know that their families will have a dignified and comfortable death, in a setting with pleasing features (Michael et al., 2025). Finally, a proactive bereavement follow-up. Support should not be offered only reactively; it should be integrated across the trajectory even after the patient's death (Boven et al., 2024).

Limitations

The findings should be interpreted in light of several limitations. Primarily, the evidence comes from a limited number of countries and legal systems, most of them from Canada. The inclusion criteria of only publications in English, excluded relevant studies published in other countries, particularly from European countries. Moreover, the review does not claim exhaustive identification of all available literature. In addition, the study selection and interpretation involved reviewer judgment, and no formal quality appraisal was undertaken.

Additionally, some studies included both patients and caregivers, requiring selective extraction of caregiver-specific findings. This limitation was mainly due to the difficulty in finding information about informal caregivers, because there is a limited number of publications addressing these populations. Most of them are about professional caregivers such as nurses or physicians. Furthermore, the corpus includes methodological heterogeneity, with qualitative, mixed-methods, and retrospective designs.

In addition, many studies emphasize caregiver needs and perspectives, but fewer explore differences by relationship type, cultural background, or long-term bereavement trajectory. Finally, there is a limitation of socioeconomic diversity. Evidence drawn predominantly from white, female, educated caregivers in Western legal systems may not transfer easily to culturally, religiously, socioeconomically, or legally different populations. Future research should focus on the inclusion of diverse populations.

CONCLUSION

Informal caregivers' experiences in assisted dying are complex, evolving, and shaped by emotional, relational, practical, ethical, and institutional factors. This narrative review

encompasses results from qualitative studies across countries. Showing that caregiver experience unfolds across the entire assisted dying trajectory. Therefore, informal caregiver support should be understood as longitudinal and relational rather than event-specific. Each of which entails: communication, legal/institutional context, relational dynamics, and moral/spiritual positioning. The findings also revealed that informal caregivers' experiences depended on whether their needs were met or unmet. These needs should not be confined to a single phase.

The context of informal caregivers of patients who requested Assisted Dying has not been extensively studied, largely because this population is often rendered invisible. Systems should recognize informal caregivers as participants affected throughout the assisted-dying trajectory rather than only as witnesses to the final procedure. Future research should further explore informal caregiver experience across different legal systems, family roles, and cultural contexts, with greater attention to how care systems can reduce avoidable distress while supporting meaningful involvement, addressing geographic, linguistic and legal gaps.

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