

# Impact of medical assistance in dying (MAiD) on family caregivers

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**Title:** The Impact of Medical Assistance in Dying (MAiD) on Family Caregivers

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**Abstract (232 words)**

Medical assistance in dying (MAiD) is a globally polarizing topic which often sparks debate surrounding the ethical and moral dilemmas that arise with a life-ending intervention. To gain a better understanding of this intervention, it is important to explore the experience of those most intimately affected by MAiD. Family caregivers of those with terminal illness are the backbone of the healthcare and support team, often providing a substantial amount of informal care while at the same time coping with their own distress and anticipatory grief. However, we know the least about how MAiD impacts the psychosocial wellbeing of these same individuals. The aim of this article is to explore the experience of MAiD from the family caregiver perspective, namely their beliefs and opinions about the intervention, how the process of MAiD impacts them, how the intervention shapes their view of their loved one's quality of death, and the psychosocial outcomes after the passing of their loved one. Beyond the literature, challenges within both the clinical and research realms will be discussed and future directions will be offered. While MAiD is currently legal in only a small number of countries, a better understanding of the impact of MAiD will help inform policy and legislation as they are developed in other jurisdictions. Further, this article will aim to inform future research and clinical interventions in order to better understand and support this underserved population.

**Keywords:** Medical Assistance in Dying (MAiD), medically-assisted death, physician-assisted suicide, voluntary euthanasia, family caregiver, end-of-life

Globally, medically-assisted death remains a controversial topic with various names and forms that differ based on the laws and customs of the countries where it is delivered. In Canada, where medically-assisted death became legal in 2016, Medical Assistance in Dying (MAiD) is a term that refers to both the direct administration of a lethal substance (i.e. injection of a drug) or providing/prescribing a lethal substance that the eligible patient administers themselves. In other jurisdictions, these may be referred to as voluntary euthanasia and medically assisted suicide, respectively. Regardless of the nomenclature used, ethical and political debate remains the focus of much discussion, with less emphasis in the lay press or health care literature on the personal perspectives and subjective experiences of those involved with the intervention.

Worldwide, MAiD is now legal in 10 countries and 8 states in the United States with many other countries soon to follow suit. With these rapid legislative and health care changes, there is a need to explore the experience and process of this intervention from the perspective of those most closely impacted by it. Much of the research literature to date has focused on the patient and healthcare-provider perspective of the MAiD experience, often excluding informal caregivers from the discussion. This is consistent with the patient-centered approach that is engrained as a standard of Western healthcare and the principle of individual autonomy which is often called upon to support the ethics of assisted dying. Given that family is so integral to the advanced disease experience, it is important to gain insight into how MAiD affects family caregivers in order to provide the best possible care not just to the patient, but to the family as a whole. While caregivers of those with advanced disease are seldom the focus of care or research, we know that their distress may in fact be higher than that of patients,[1] that they also need to be considered as a focus of end-of-life care,[2,3] and that attention to their needs during the dying process may be protective against later bereavement morbidity.[4]

The aim of this article is therefore to summarize what is currently known and understood about the experience and perspective of caregivers throughout the MAiD process. A comprehensive list of search terms (e.g., physician-assisted death, medically-assisted death, MAiD, family caregivers) was used to search both MEDLINE and EMBASE databases for relevant publications on the topic. A mix of both qualitative and quantitative research was found, with most literature to date being European (and more specifically, Swiss) or North American (and more specifically, Oregonian) in origin. In the majority of cases, the research focus was attitudes towards or provision of MAiD for patients with a variety of life-limiting illnesses, most commonly advanced cancer but also neurodegenerative diseases, dementia, heart failure, and in some cases frailty and advanced age. Not all papers had detailed information about how caregivers were identified (e.g. chart next of kin, patient identification etc.). In most studies only one patient caregiver, rather than multiple caregivers of an individual patient, were recruited and assessed. The majority of respondents in these studies were patient partners/spouses, but all studies included other patient-caregiver relationships including sons/daughters, parents, other family or friends. In our review of this available research, we focused on exploring caregiver beliefs about MAiD, how the process of MAiD impacts them and influences their perception of their loved one's quality of death, how MAiD impacts caregivers after the death of their loved one, and the challenges, limitations, and future directions for research and clinical care as it pertains to the caregiver experience with MAiD.

## **WHAT ARE CAREGIVERS' BELIEFS AND OPINIONS ABOUT MAiD?**

Polling data can capture lay public opinions about assisted dying but these attitudes may differ from those held by individuals actually caring for a family member with a life-threatening illness. The opinions provided by caregivers regarding MAiD in research studies, however, may

be affected significantly by the legal status of MAiD in their setting. Three studies conducted by Ganzini and colleagues in Oregon, a jurisdiction where MAiD is legal, have explored the opinions of family caregivers about MAiD for their loved ones. In the first study, 98 individuals with advanced cancer and their family members were asked about their attitudes toward MAiD. Family members in this study were asked to indicate their overall position on the legalization of MAiD, predict their loved one's position, and predict their own position if their loved one decided to pursue MAiD.[5] Results indicated that 51% of family members supported legalization and would support the patient's request for MAiD, 30% opposed legalization and would oppose the patient's decision, and 19% were undecided. Family members' support for a potential MAiD request was predicted by low religiosity as well as the family members' concern for the impact of the patient's illness on their own health. Interestingly, a comparison between the patients' and family members' views demonstrated that although family members were able to accurately indicate the patients' overall views on the legalization of MAiD, family members were not accurate in predicting whether their loved one would pursue MAiD (Spearman's  $\rho=0.22$ ,  $p=0.03$ ), rating the patient's interest in receiving a lethal prescription higher (mean rating of 1.3 on a 10-point scale, with higher numbers indicating more interest) than the patient (mean rating of 1.1). Additionally, there was low agreement between patients and family members regarding whether the discussion had taken place, with 19 family members stating they had discussed MAiD while the patients disagreed, and 11 patients stating they had discussed MAiD while their family members disagreed.

Similar findings were reported in a study focusing on family caregivers of amyotrophic lateral sclerosis (ALS) patients [6]. In that study, out of 91 family caregivers, 62% noted that they would support their loved one's decision for assisted death, and 76% were able to predict

the patient's position on MAiD. Caregiver endorsement of MAiD for their loved ones in this study was found to be associated with their level of religiosity, but unrelated to the following variables: caregivers' level of social support, emotional distress, economic burden, and their perceptions of the patient's level of pain, suffering, and quality of life.

Lastly, in a study of 83 bereaved caregivers of patients with a variety of life-limiting illnesses who made explicit requests for MAiD, caregivers were asked to rate the importance of 28 potential reasons that their loved one requested this intervention.[7] The most important reasons that emerged from the caregiver perspective were: patient's wish to control the circumstances of death, and patient's fears about future loss of dignity, independence, quality of life, and self-care ability, as well as the wish to die at home. The least important reasons that emerged from the caregiver perspective were reasons related to patient's level of suffering, such as: lack of social support, depressed mood, or confusion.

Other studies have considered the opinions of family caregivers regarding MAiD for their loved ones in jurisdictions where MAiD is illegal. Emmanuel and colleagues [2] reported on a large study of 893 family caregivers of terminally ill patients in the United States which explored caregiver views regarding hypothetical MAiD scenarios for their loved ones. The study found that 58.7% of caregivers supported MAiD for patients in pain and almost 30% supported it in a scenario where the patients believed they were a burden. Similar to Ganzini et al.'s study in Oregon,[5] support for MAiD was predicted by low religiosity and by the perceived impact of the patient's illness on their wellbeing. However, less than 20% of those who supported MAiD indicated that they would be willing to personally help their loved one end their life.[2] While support for MAiD was relatively high among family caregivers, this attitude was not reflected in their willingness to be involved in the process. This difference may be understandable given that

the study was conducted in a settings where MAiD was not a legal option for their loved ones to pursue.

A study conducted in Japan by Okishiro and colleagues [8] demonstrated similar endorsement rates of MAiD in family caregivers. Of the 429 bereaved family members of palliative cancer patients who were asked about their beliefs surrounding MAiD, 45% supported legalization, 38% supported physicians' discretion of MAiD as an intervention, 6% would have liked it to remain illegal, and 12% did not respond. This may imply that over half of those who experienced death of a loved one with a terminal illness would have supported MAiD for their loved one. An analysis of demographic factors demonstrated that age under 60 of the caregiver, and a non-spouse status (e.g., child or child-in-law) predicted endorsement of MAiD. The relationship between younger age and MAiD endorsement may reflect the fact that younger individuals assign greater importance to patient autonomy relative to older individuals, or may be a by-product of the difference between the attitudes of spouse caregivers versus child caregivers.

Two qualitative studies provide deeper insight into the complexity of family caregiver views on MAiD. In the UK where MAiD is currently not legal, Tomlinson and colleagues[9] conducted semi-structured interviews regarding MAiD with 16 bereaved caregivers of dementia patients and found that 13/16 bereaved caregivers supported the right of these patients to access MAiD, however, conflicting themes emerged. The theme of *right to die* emerged, with some caregivers noting that it is a personal choice (“*I think it is always very much up to the individual themselves. It is their body*”) and that they would want the option of assisted dying for themselves if it got to that point (“*I would want the ability to end it because that would give me some relaxation that if I got to the stage where I can't bear it I can end it painlessly. You know say my goodbyes and go to sleep*”). In contrast, a theme of *problems with ending life* emerged, in



which bereaved caregivers discussed reasons that they would not consider MAiD for their loved one who suffered from dementia. Namely, that they were “*still a person*” and that the illness is “*not all bad*” and a minority endorsed that “*you don’t murder people*” and “*we can’t choose the way we die,*” which directly opposes the notion of medically-assisted death. One participant noted that “*it is not just the person that is killed, but their family and people that have witnessed it are affected.*” This quote encapsulates the notion that it is not just the individual that is impacted by this intervention, but rather the entire family, and that these multiple perspectives may be taken into consideration and weighted as decisions are made.

In a qualitative study by Gamondi and colleagues [10] in Switzerland, where assisted dying is legally available, 11 family caregivers of cancer patients who died by MAiD were interviewed. The study highlighted the moral dilemmas that the family caregivers faced before MAiD was performed and in the aftermath of bereavement. Most caregivers described feeling as though they were breaking a cultural taboo or the ‘*thou shall not kill*’ rule by helping their loved ones with assisted dying requests, and fearing consequent blame and social stigma. For a number of caregivers, these dilemmas were resolved through considering the value of respecting the patient’s autonomy, the degree of the patient’s suffering, the knowledge that the patient’s death was inevitable and imminent, the value of keeping their promise to the patient, and the idea that assisted suicide was a better alternative to unassisted suicide if the patient was not able to seek out the legal option. However, a few respondents reported continuing to be concerned with these issues years after the patient’s death.

It is evident that family caregivers of patients considering MAiD may be faced with ethical and moral dilemmas in the face of competing values, and that views regarding a hypothetical MAiD request for a loved one with a terminal illness may not align with opinions

once faced with the reality of MAiD. Their attitudes are likely informed by a complex interplay of individual, family, societal, and legal factors and further research should continue to explore the various determinants of caregiver beliefs and attitudes.

## **HOW DOES THE PROCESS OF MAiD AFFECT CAREGIVERS?**

The process of MAiD may be different depending on a variety of factors such as the disease experience, the support system, intervention eligibility criteria, process and setting, and other factors. During the MAiD decision-making process in the Swiss study conducted by Gamondi and colleagues [10], two types of caregiver involvement were noted: active and passive. In active involvement, caregivers shared common values with the patient and proposed assisted death or were active in helping the patient through the process of the intervention. In contrast, those with passive involvement often encountered a personal dilemma with MAiD, which could either foster better discussion of the pros/cons of the intervention or could isolate the caregivers from the decision-making process, and increase their emotional distress. The study suggests that the nature of caregiver involvement may play an integral role in how the caregiver perceives the MAiD process and perhaps impact their bereavement, as those with passive involvement tended to struggle more with moral dilemmas post-death.

In a more recent study, also conducted in Switzerland, Gamondi and colleagues [11] interviewed 28 family caregivers of patients who died by MAiD about their involvement in the MAiD process. The study outlined five phases of the assisted-dying process including: contemplation, gaining acceptance, gaining permission, organization, and aftermath. The contemplation phase is defined by discussing assisted-suicide with family members, followed by gaining acceptance from family members and exploring professional opinions. After this,

individuals must gain permission from a medical professional and then organize the intervention (e.g. lethal injection, post death rituals, etc.). The aftermath phase involves disclosure of the assisted-suicide to close others after the loved one's passing. The study noted that family members may have either a passive or active involvement in all stages of this process, and that each type of involvement created unique burdens for family caregivers. This study highlights that clinicians must consider the involvement of caregivers in the process and this attention may help to reduce feelings of isolation and adverse outcomes after patient death.

The process of MAiD may also bring relational strain between those that are seeking MAiD and their family members. In a qualitative study conducted in the Netherlands by Snijdewind and colleagues,[12] 22 bereaved family caregivers and 28 physicians of patients with a variety of illnesses who died by assisted suicide were interviewed about the MAiD process and were asked about any complexities or challenges that they experienced throughout it. The authors identified two relational complexities, namely: the lack of time for all involved (the patient, the caregiver, and the physician) to mutually agree and process the decision to pursue MAiD, and situations where the caregivers were not able to appreciate the severity of the patient's suffering, and thus failed to empathize and accept the patients' assisted death requests. This analysis demonstrates the importance of open communication between patients, clinicians, and caregivers throughout the MAiD decision-making process. However, studies that compared patients' and caregivers' perceptions about such discussions are typically low in agreement on whether they occurred.[5, 10] This highlights the possible disconnect that may occur between caregivers and patients as they navigate the MAiD process, drawing attention to the need for open dialogue and the need for this to be instigated and facilitated by healthcare professionals involved.

Assisted-dying legislation differs between countries and more research is needed to explore how it may impact the dialogue with family caregivers. Notably, Snijdewind and colleagues'[12] interviews with Dutch physicians demonstrated that they included relatives in the process of physician-assisted suicide, and, in some cases, told patients they would not proceed if they did not feel as though their loved ones would be able to cope with the aftermath of the intervention. This may differ from the model of MAiD delivery in other countries (e.g., Canada) where there is no legislative requirement for caregivers to be included or considered in the formal MAiD process.

Differences in assisted-dying legislation between countries may also impact other elements of the caregiver experience. In Canada, for instance, current legislation does not allow consent for MAiD to be given as an advance directive, and individuals approved for MAiD must be suffering from an irremediable and grievous medical illness with a foreseeable natural death, and be capable of consent at the time MAiD is delivered. This may have the unintended consequence that patients are requesting MAiD earlier than they would wish, in order to ensure that they do not decline cognitively and cease to qualify for MAiD.[13] This may have an impact on caregivers who are having to face loss of a loved one earlier than anticipated and perhaps before there has been adequate time for death preparation. In contrast, in the Netherlands, it is legal for patients with neurocognitive impairment to create advance care directives for MAiD. Caregivers of these patients may be faced with a different kind of ethical and moral challenge if they do not agree with their loved one's decision by the time it is to be delivered, yet can no longer influence them due to the patient's cognitive decline.[14]. Indeed, even with an advanced directive in place, research has found that physicians and family members of dementia patients may be reluctant to provide assisted death in the context of the patient who is no longer capable

to provide informed consent. [15, 16] This further highlights the importance of a family-inclusive healthcare system that considers caregivers' perspectives and assists these individuals through the process alongside the patient, especially in ethically challenging cases with cognitively impaired patients.

## **HOW DOES MAiD AFFECT CAREGIVER PERCEPTION OF QUALITY OF DEATH AND DYING?**

Overwhelmingly, in the research reviewed, caregivers of patients who sought MAiD viewed the dying experience more favourably than death they anticipated by natural causes. Multiple studies reported that caregivers had a favourable view of quality of death of patients who used physician-assisted suicide, namely by preventing unnecessary suffering of their loved one.[14, 17] In a study conducted in the Netherlands, Georges and colleagues[14] found that 92% of caregivers of patients with a variety of illnesses reported that medically assisted death was a favourable contributor to the quality of death experience. Further, in a broad systematic review of patient, caregiver, and the public attitudes towards assisted-death, conducted by Hendry and colleagues [17], they reported on 13 relevant studies (10 quantitative, 3 qualitative) that included caregivers of those who requested MAiD.[17] They reported that these bereaved caregivers viewed MAiD as humane, compassionate, and contributing positively to the death experience by preserving dignity, alleviating suffering, and respecting their loved one's wishes. From these studies, it is evident that bereaved caregivers of those who have been involved with the MAiD process retrospectively tend to view their loved one's death in a positive light.

In Oregon, using a standardized questionnaire developed for bereaved caregivers to assess quality of death and dying (the Quality of Dying and Death questionnaire; QODD), Smith

and colleagues [18] found that caregivers of patients with a variety of illness who requested assisted death felt more prepared for the death of their family member and rated overall quality of death more favourably compared to caregivers of those who did not request an assisted death. Similar research exploring caregiver after-death evaluations is needed in other settings where MAiD has been made legal. Further, there is a need to assess which quality of death assessment tools are most suitable for the assisted dying context. Lastly, we need to understand whether the perception of the death experience differ based on family being supportive of MAiD or not, and whether access to palliative care prior to the intervention makes a difference.

### **HOW DOES MAiD AFFECT GRIEF, BEREAVEMENT, AND MENTAL HEALTH IN CAREGIVERS AFTER DEATH OF THEIR LOVED ONE?**

A study in Oregon examining caregiver mental health outcomes after a loved one's MAiD request (in the context of cancer, ALS, or other illnesses) found that approximately 14 months after death, 11% of family members had a major depressive episode, 2% had prolonged grief, and 38% had received mental health care.[19] Interestingly, this study compared caregivers of those who requested MAiD with bereaved caregivers of cancer or ALS patients who did not request assisted death and did not find a difference between groups in terms of these mental health outcomes. Whether or not the patient went through with assisted death did not influence grief or mental health outcomes of their family members. Rather, caregivers of those who received MAiD expressed less regret since they believed that their loved one's decision was honoured.

In the Netherlands, Swarte and colleagues[4] found that bereaved caregivers of terminally ill cancer patients who died by euthanasia suffered less complicated grief when compared to

bereaved caregivers of terminally ill cancer patients who died of natural causes. In this circumstance, the authors posit that having the opportunity to say goodbye to their loved one mitigated the grief and post-traumatic stress reactions to follow. Of note, the recruitment methodology involved contacting the next-of-kin in the medical chart. These contacts were asked to participate and supply contact information for other relatives who were with the patient at the moment of death. There were differences in the caregiver groups recruited; family and friends of euthanasia patients consisted more of the subgroup defined as “other” (such as cousins, in-laws, or friends), whereas the family and friends of patients who died of natural causes consisted of more first and second-degree relatives (e.g. children and siblings). It is unclear if this reflects that euthanasia patients were less likely to have immediate family members involved in their end-of-life care, or that their immediate family members were less likely to participate in this kind of research.

Given that the process of medically-assisted death differs across jurisdictions, there may be different caregiver mental health outcomes based on country of MAiD delivery. In Switzerland, there is a forensic investigation that follows every assisted suicide which includes police, medical examiners, and the state attorney. In a Swiss study, Wagner and colleagues [20] assessed 85 bereaved family caregivers of patients who died of MAiD at 14-24 months post-death and found that 13% of participants qualified for a full diagnosis of post-traumatic stress disorder (PTSD), an additional 6.5% met criteria for sub-threshold PTSD, 4.9% experienced complicated grief, and 16% suffered from depression. Those with a diagnosis of PTSD reported experiencing more emotional difficulties with the forensic investigation. It is still unclear whether PTSD is related to witnessing the death of their loved one by assisted suicide or if it is mediated by the trauma of the forensic investigation.[21] Future research should assess PTSD

symptomatology in caregivers in different jurisdictions in which a forensic investigation is not routinely part of the MAiD process to determine if it is likely a consequence of the intervention itself. This study demonstrates that stigmatizing assisted death as a crime may promote caregiver ambivalence and distress about their loved one's decision regarding their death. One participant stated "*the fact that the police and medical examiner arrived after his death underlined the feeling of having done something wrong.*"[21] This highlights that the medical intervention and the legal process surrounding it are connected, and both may influence subsequent mental health outcomes in bereaved caregivers. Thus, there is a need to balance the medicolegal oversight with sensitivity to families who may be feeling vulnerable and bereft.

Unfortunately, research on post-MAiD outcomes in caregivers is relatively scant and it is unclear whether MAiD leads to better outcomes for caregivers in all cases. Either way, there is a need for implementation of support services and psychosocial interventions in this population prior to the passing of a loved one to ease in the transition and prevent undue psychological burden as well as a need for post-MAiD psychosocial support.

## **WHAT ARE THE CHALLENGES TO STUDYING THE CAREGIVER EXPERIENCE WITH MAiD?**

**The invisibility of the caregiver experience:** Caregivers of patients with advanced illness in general are understudied and underserved population and there are a number of challenges to researching their experience and needs. Without longitudinal research study designs, we cannot know the baseline psychological wellbeing of caregivers prior to their loved one's diagnosis of a terminal illness and/or MAiD request. The clinical emphasis on patient-centred care and individual autonomy often leads to exclusion of caregivers from clinical care until patients reach



the point of palliation, thus not allowing for caregiver research involvement at earlier stages. If they are approached for research, caregivers may be difficult to recruit if already stretched thin from their caregiving responsibilities. This does not allow for time point comparison or longitudinal follow-up of caregivers as they move through the different stages of advanced disease, possible MAiD consideration, and bereavement following death of a loved one. Future research should aim to follow the trajectory of well-being from advanced disease diagnosis through the MAiD process and into bereavement in order to identify critical points for psychosocial intervention delivery.

**Stigma around assisted dying and suicide:** Another challenge for both research and clinical program design is the stigma that continues to surround MAiD. Whether it be for political, ethical, religious, or personal reasons, individuals may feel less comfortable discussing assisted death compared to death by natural causes.[10] This is not unlike the stigma that currently surrounds discussing suicide in general. As MAiD becomes legalized in more countries around the world, this may encourage more open forums for discussion and may facilitate programs and interventions allowing caregivers to share their experiences and feelings about their loved one's MAiD decision and death. Findings that there are differences in caregiver attitudes related to age [8] highlight that this may be an area with rapidly shifting social attitudes. As MAiD legalization spreads, this may normalize the process, lessen stigma, and potentially shift attitudes further. For these reasons, this is likely a dynamic area in which research findings may not remain fixed over time.

## **AREAS FOR FUTURE RESEARCH**

As emphasized above, the research on the caregiver experience of MAiD is scant and from a variety of diverse settings and diverse populations preventing sweeping generalizations and conclusions. Limitations in the data currently available highlights numerous areas for further research and exploration.

**The need for better understanding of the determinants of caregiver attitudes and**

**experiences as they relate to MAiD:** As highlighted in this review, much more information is needed about how demographics, including the social determinants of health, culture, religiosity, setting, psychological wellbeing, past experiences and beliefs shape caregiver attitudes and decisions around MAiD. There may also be differences in caregiver experiences related to the nature of patient illness. Research to date usually has collapsed the patient populations under study most often grouping together patients with cancer and other life-threatening illnesses. While cancer diagnoses constitute over 70% of the MAiD requests and subsequent interventions in countries where MAiD is currently legalized [22], other illnesses that may qualify for MAiD include neurodegenerative diseases, dementia, and frailty. The natural trajectory of these conditions, their unique symptoms and challenges may impact the quality of life of patients and caregivers, and may impact the MAiD decisional process, quality of death and subsequent grief of caregivers in bereavement. Due to the complex interplay of factors that can influence caregiver experience and psychosocial outcomes, this could best be examined via prospective longitudinal studies of caregivers of patients with specific life-limiting illnesses assessed at set time points up until and after patient death.

The majority of research to date has examined the perspective of a single caregiver regarding MAiD. This ignores the multiple meaningful and differing relationships patients may have with immediate family, extended family, friend networks, etc. It is methodologically

challenging to study an entire support network and all of the individuals who may be affected by one MAiD decision or intervention, however, we need to understand how the nature of the patient-caregiver relationship (i.e. level of caregiving involvement, etc.) impacts their experience in order to educate and design interventions to meet potentially diverse needs. In addition, disagreement amongst caregivers about MAiD may lead to conflict causing more isolation and potential end-of-life strain for some which may also require clinical attention. Future research should aim to capture the diversity of caregivers and the complexity of patient-caregiver relationships and how these predictors impact the psychological consequences of those involved in the MAiD process.

**The need for better understanding of the impact of different MAiD processes on**

**caregivers:** As MAiD legislation is developed in different settings across the globe, it will be interesting to see how the field evolves. Currently, requesting MAiD as an advance directive is not legal in most countries where MAiD is delivered. Further research in the Netherlands, where MAiD is available as an advance directive, may inform policy changes in other jurisdictions. Research should aim to explore caregiver experiences as substitute decision-makers and how they are impacted by implementing their loved ones' wishes.

**The need to consider the impact of MAiD on caregivers of those with non-life threatening**

**illness:** There is much controversy over provision of MAiD for those suffering from psychiatric disorders leading to persistent and intractable suffering but without a life-limiting illness. Those in favour of expansion of MAiD into this area have argued that not providing MAiD to this population may ultimately cause more harm to patients and their loved ones. There are evidently negative psychological outcomes for family members who have had a loved one commit suicide and MAiD may offer these individuals and their families an opportunity for a more dignified and

meaningful death on their own terms. In contrast, many may oppose normalizing or sanctioning suicide in this population and argue that the desire for hastened death is a symptom of a psychiatric illness that can and should be treated. There will be ongoing ethical and legal debates about medically-assisted death and the different criteria that are required before one is eligible. Future research should assess family members of people who suffer from chronic refractory mental illness with suicidality and family members of those who have completed suicide to explore their attitudes towards the legality of MAiD for those with psychiatric illness. Caregiver beliefs surrounding MAiD for psychiatric illness could then be compared with the literature to date on MAiD for those with medical disorders. While results of from this type of research are not the only information important to consider in legislative and policy discussions around assisted dying beyond life-threatening illness, it is needed given that, as discussed in the introduction, much of the debate and decision-making around this controversial topic to date has been focused on opinion, values and beliefs and not on empirical data.

### **The need for development and study of clinical approaches to supporting caregivers**

**throughout the MAiD process:** From a clinical perspective, a shift away from a patient-centred approach towards a more inclusive family-centred approach is needed in end-of-life care in general and especially as it pertains to medically-assisted death. Including caregivers in end-of-life discussions and preparing them for the death of a loved one may yield better psychosocial outcomes and less psychological morbidity. Given what is known about the psychosocial impact on family caregivers,[4,19] inclusion of these individuals in discussions surrounding MAiD may be protective against adverse psychological outcomes. In addition, family support for MAiD is largely impacted by the caregivers' own ability to cope and wellbeing,[2,5] further emphasizing the need to support families through this process. Early psychosocial intervention aimed at the

family may allow caregivers to discuss their struggles with being a caregiver, how the process of MAiD impacts them, and how they see themselves coping after the potential loss of their loved one. Where caregivers are not supportive of MAiD, creating opportunities early on to discuss their ambivalence about their loved one's decision and explore their fears and worries about the future may insure there is time for appropriate support from healthcare providers and possibly better adjustment.

## **CONCLUSION**

Caregivers of those with advanced disease are an understudied and underserved population in the healthcare system as a whole, but particularly in the area of medically-assisted death. After the patients themselves, these individuals are the most impacted by the MAiD process and yet there is relatively little clinical attention or resources allocated to them at this time. Despite the challenges to conducting research with this population, there is a need for more rigorous study of the factors influencing caregiver opinions and experience of MAiD processes. Only then can we begin to design MAiD programs that are both patient and family-centred, as all good end-of-life care should be.

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