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Accessing an assisted death from the UK: Navigating the legal 'grey' area

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ABSTRACT

Assisted dying is available in many countries globally but remains illegal in the UK, where there are ongoing debates about its legal status. Britons seeking an assisted death must travel to Switzerland. This article explores the experiences of UK-based individuals considering an assisted death and family members of those who have completed an assisted death. We recruited 11 participants across two qualitative studies, analyzing data using Interpretative Phenomenological Analysis. These results indicated four themes: the "*burden*" of illness; the value of autonomy and control over death; the difficulties of talking about assisted dying; and the barriers associated with pursuing an assisted death. The findings suggest there are individuals in the UK who will seek an assisted death, despite its illegality. Those involved in these journeys are not currently able to access support and more needs to be done to ensure their needs are met.

Assisted dying, facilitated end-of-life, is an umbrella term that describes both euthanasia and Physician-Assisted Suicide (PAS; Fontalis et al., 2018; Mroz et al., 2021). Euthanasia refers to the act of a medical professional administering a lethal dose of a drug and PAS is the act of a medical professional prescribing the lethal drug for the individual to administer themselves (Fontalis et al., 2018).

One motive often identified by those requesting an assisted death has been described as 'unbearable suffering': *"a profoundly personal experience of an actual or perceived impending threat to the integrity or life of the person, which has a significant duration and a central place in the person's mind"* (Dees et al., 2010). This suffering may be related to a life threatening or degenerative medical condition, a mental health diagnosis, and/or a multitude of aging symptoms (Chambaere & Cohen 2017). Whilst the specific eligibility criteria for access to these services is country dependent, cross-culturally there are substantive protocols in place to safeguard these services and avoid misuse (Cohen & Chambaere, 2021).

Presently, 200 million people worldwide live in jurisdictions with access to some form of assisted dying (Mroz et al., 2021); many others, including those living in the United Kingdom (UK), live in jurisdictions where it is illegal. Therefore, UK-based individuals, who want an assisted death, must go to Switzerland, the only country to allow foreign nationals access to these services (Goh et al., 2022). The Swiss Penal Code (Fedlex, 2024) permits PAS (for which they use the term 'assisted suicide'; Dignitas, 2024) but not euthanasia. Swiss law requires that the individual has *"control over their death"* and decision-making capacity, and that the person 'assisting' is doing so in an altruistic capacity (Pegasos, n.d.). In Switzerland, assisted dying is coordinated by non-government 'right-to-die' organizations (Hodel et al., 2019), such as *Dignitas - To live with dignity - To die with dignity.* The Federal Court of Switzerland has imposed standardized process rules, which require these organizations to gather and review substantive documentation about each individual to aid decision making about permitting the assisted death, and to prevent misuse of services (Bartsch et al., 2019).

The first reported Briton completed an assisted death at Dignitas in 2003 (Revill, 2002). Current statistics indicate that 33 British people had an assisted death with Dignitas in 2022, and that the organization currently has 1,528 British members (Dignity in Dying, 2023). Whilst it is legal for a UK-citizen to access these services for themselves, anyone in the UK found guilty of 'assisting' a person to access such services may be liable for prosecution and face the

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possibility of up to 14 years imprisonment (Crown Prosecution Service; CPS, 2014).

Nevertheless, there is some evidence to suggest that the UK's position on legalizing assisted dying may be changing. In 2019, a large public poll, commissioned by campaign group Dignity in Dying, put UK public support for a change in law around assisted dying at 82% (Populus, 2019). Over half (53%) of respondents reported that they would consider an assisted death if they were terminally ill; 66% reported that they would break the law to accompany a loved one to Switzerland; and, 82% reported that people considering an assisted death should be able to discuss the possibility with their doctor. Furthermore, the British Medical Association (BMA), the trade union and professional body for doctors and medical students in the UK, recently shifted its 2006 position opposing assisted deaths to now being neutral on it (BMA, 2021). However, the UK government's Health and Social Care Committee has recently completed a national inquiry to understand the UK public's perspectives on assisted dying (UK Parliament, 2024) to inform decision making on legalization. Responses included a range of perspectives from those who both agree and disagree with a change in law. This data suggests that this topic continues to evoke polarized opinions within the UK.

Although there has been significant research conducted on stakeholders' perspectives on assisted dying in countries where it is legal (e.g., Dees et al., 2011; Ganzini et al., 2008), there have only been a few studies on the perspectives of individuals considering an assisted death in countries where it is illegal (e.g., Leboul et al., 2022; Sperling, 2022). To the best of the researchers' knowledge, only one study of this type has been based in the UK (Richards, 2017). Furthermore, only one other study has researched UK-based family members in relation to assisted dying (Fish, 2023), which examined grief experiences following a loved one's assisted death. This limited research base suggests that there are significant gaps in the knowledge base of UK-based stakeholders' perspectives on assisted dying. We examined the experiences and perspectives of those from the UK considering an assisted death for themselves as well as family members whose loved one had an assisted death.

Method

Participants

Inclusion criteria were being over age 18, able to be interviewed, and currently UK-based. Hitchcock (2023) sought family members of someone that had an assisted death outside of the UK, at an established assisted dying organization, in the last five years, also requiring that the individual was not involved in any ongoing police investigations. Dean (2024) recruited UK-based individuals actively contemplating an assisted death outside of the UK with an established assisted dying organization.

A total of 11 people (7 women, 4 men) participated (6 individuals and 5 family members). In Dean (2024), all individuals who approached the researcher were eligible to take part. In Hitchcock (2023), the researcher received 166 expressions of interest, however only 9 met inclusion criteria. Those not eligible did not meet recruitment criteria (e.g., they were considering an assisted death for themselves, or their family member died in an assisted death outside of the stipulated timeframe). Many contacted researchers to show their support for the research. The demographics of the final participants are described in Table 1 (see supplementary materials). The medical conditions associated with the motivations for an assisted death included a variety of neurological conditions, cancers, and dementias, amongst others. All participants identified as having little to no religious beliefs.

Procedure

Ethical approval was obtained from the University of Hertfordshire's Health, Science, Engineering and Technology Ethics Committee with Delegated Authority (ECDA): LMS/PGT/UH/04982 (Hitchcock, 2023) and LMS/PGT/UH/04015 (Dean, 2024). Participants were recruited using purposive sampling, through several channels, including UK-based charities, online support groups for individuals considering an assisted death, and Dignitas. These channels shared overviews of the research including participant information sheets, and researchers followed up with telephone calls and/or emails once potential participants contacted the researchers.

The researchers ensured that participants understood the purpose of the research and boundaries of what could be discussed considering the current legal status in the UK. Researchers asked participants not to share details related to any involvement in an assisted death during their participation in the research. The researchers shared the protocol they would follow before commencing interviews. This protocol clarified what the researcher defined as 'illegal activity' and acknowledged that they were expected to share knowledge of such illegal activity with the police should it be disclosed during interviews. It

was noted that such a disclosure would be an example of when the researchers would be required to break the agreement around confidentiality. However, confidentiality was not required to be broken by the researchers during data collection. In Hitchcock's (2023) study, individuals with lived experience of the topic reviewed study materials.

Interviews lasted approximately 90 minutes and involved a combination of two face-to-face, three video-call and six telephone interviews, based on participant preference (Heath et al., 2018). Face-to-face interviews were conducted at participants' homes. Interviews were semi-structured and guided by interview guides relevant to the individual pieces of research. For Dean's (2024) study, questions focused on participants' reasons for considering assisted dying, how they were impacted by the current UK legal status, and their experiences of discussing assisted dying with their healthcare professionals. For Hitchcock's (2023) study, questions focused around ascertaining participants perspectives on assisted dying, the contextual factors that informed these perspectives, how their experiences might fit with their prior views on death and dying, and the resources that they drew on for support during this time. Interviews were audio-recorded using a Dictaphone and then transcribed verbatim for analysis.

Qualitative analysis

Interpretative Phenomenological Analysis (IPA) was used to analyze the data collected (Smith & Nizza, 2022). Initially, that study's primary researcher analyzed each interview transcript. This analysis involved reading it multiple times, making exploratory notes, then formulating experiential statements and clustering these statements into personal experiential themes (PETs) for that participant. After developing a set of PETs for each participant, the researcher undertook a cross-case analysis to develop an overall set of Group Experiential Themes (GETs), then consulted the supervisory team to ensure the themes were rooted in the data set. These discussions, alongside the researcher's own reflections on the process of 'double hermeneutic' (Smith et al., 2009, p. 3), supported a reflexive interpretative process. For the current paper, both primary researchers reviewed the GETs from each study and clustered them to describe overall themes from both data sets.

Results

The perspectives of these stakeholder groups are presented as four overarching themes (see Table 2 in supplementary materials) each illustrated with quotes ('I' represents an individual considering an assisted death and 'F' represents a family member of someone who has completed an assisted death). These themes are; 'The *"burden"* of illness', 'The value of autonomy and control over death', 'The difficulties of talking about assisted dying' and 'The barriers associated with pursuing an assisted death'.

Theme 1: The "burden" of illness

The *"burden"* of illness, for the individual themselves and those around them, was a motivating factor for considering and/or completing an assisted death. For individuals considering an assisted death, the *"burden"* of living with their severe and/or degenerative illness was experienced as a disintegration of self, no longer being able to enjoy things they used to do, combined with an anticipated fear about the illness course and possible impacts on those around them. One participant reflected on how she believed her motor neurone disease would likely develop and that there be no viable treatment options:

> …people…will sort of say, 'oh but you know, you can manage end of life symptoms…you can have pain relief'…that's very often the only thing they think about…They don't think about the distress of not being able to swallow…choking…and not being able to…communicate. There is…no solution…to a lot of these problems. (I2)

Another described a sense of loss toward the things they could no longer do:

> I can't do what I used to do…I'd enter a wood and just wander through it and…push my way through brambles and things and trip over roots and pick myself up and, I can't do any of that now. (I3)

A husband spoke of how his wife described her life prior to her assisted death as *"in-valid"*:

> I think she felt…she was getting to stage where she couldn't see anything other than her role being as a full-time invalid. And…as she put it, being a full-time invalid, in her mind, meant in-valid, it was no…life worth living. (F3)

One participant first began considering assisted dying as an option for himself when witnessing his father suffer with dementia:

> I was watching my dad…I thought that [an assisted death] was an…extremely goodand humane alternative. (I1)

The desire to avoid others having to witness their dying was also deemed important to other participants:

> I wouldn't want to see my death in their eyes…it was inevitable. Seeing their sorrows…their sadness…I wouldn't want to see that mirroring…I wouldn't resent…them being there. But I would resent being in that position of utter helplessness. (I6)

Family members reflected on their loved ones' medical diagnosis joining their relationship and the impact that this new information had on their own lives. Couples identified that care requirements can interfere in the romantic relationship:

> …the biggest difficulty is…how can you be a carer and be a partner as well?…If you're healthy in a relationship, then the relationship can…exist at an…emotional and physical level, but when it gets down to, a situation that requires so much care, you drop down to…it does become a grind…it made me, frustrated at times, bad tempered…[my wife] was full of frustrations…so. It was difficult then to have…the partner relationship. (F3)

Perceived quality of life was also identified as being negatively impacted by chronic illness for the individual and those around them:

> …one of the reasons why my wife took the decision was that she had no quality of life…But one has to remember…that if she had no quality of life, it wasn't doing my quality of life any good either. (F2)

Mirroring the fears of individuals considering an assisted death for themselves, family members identified that their loved one did not want to become a *"burden"* on others as their illness progressed:

> …part of her decision was, she never wanted to be an….burden is a strong word…for somebody else to have to take the responsibility. She was never a parent who wanted in her old age for the child to look after her…"I had you, to have your life. (F5)

These extracts highlight the negative impact(s) that severe and/or degenerative illness can have on multiple aspects of living, and how these struggles can place people in a position where death appears to be the only way to relieve this suffering.

Theme 2: The value of autonomy and control over death

All participants strongly valued individual autonomy. Individuals described the importance of having control over their bodies and decision making, and family members reported the importance of respecting their loved ones' autonomy regarding this decision, regardless of their own feelings. It was clear that beliefs about autonomy were privileged by participants over other emotional responses toward end of life. Autonomy was described as a *"human right"* (F5), or as a *"human law"* (I4) that is different to laws of a country:

> …when people…do not live in my body, whose completely different bodies are covered with different faith, different place…are trying to tell me what to do with my body…they are breaking, something that's more…than just the law of the country. It's…a sort of…It's a human law, it's a law of the jungle. (I4)

This autonomy was felt by both individuals and family members to be important in all aspects of life, and participants expressed that it should be extended to being able to be in control of their own death:

> Being in control of…my life…and my death. Being in control of that, not having someone else in control, not having someone else telling me, 'I can't die, because we don't like it'. (I4)

> …somebody having that control over me, is wrong. (F5)

Participants also considered the relevance of autonomy in the context of an 'ideal' death, should assisted dying become legal in the UK:

> I thought that is how it should be for everybody…in their own bed with the family and the pets around, it shouldn't be having to go off to a clinic abroad and… hope that the police don't stop you. (I3)

Family members shared different perspectives on their sense of duty to support the autonomy of their loved one in their decision to pursue an assisted death. For some, the decision was expected and easy to support:

> …it was for her…I only wanted for her what she wanted for herself. And we both knew what she wanted. (F5)

For others, despite being *"pro-choice"* (F3), the emotional experience of a loved one executing this choice was harder to reconcile:

> …in principle I would say, I'm…pro-choice…it should be an option for people to be in control of their own life…it's…a humane belief, almost…But there's a difference in principle, and you know how it affects you and how you feel about it. (F3)

The decision can also be a *"big shock"* (F1) but, for one father, the shock was quickly overridden by a strong sense of duty to support his son, however that was needed:

> …we were all sat together and [my son] said he had something he wanted to say, which was that he wanted to depart this world…obviously it was a big shock…we both felt that he…needed to be supported in every single way possible… (F1)

Assisted dying was viewed as a peaceful alternative to the anticipated extended and/or painful death. For some, knowing that they had the choice of an assisted death provided them with a sense of peace and comfort, and an opportunity to enjoy their current life more:

> I knew if I stayed on the bus to the Terminus, then it was going to be incredibly bloody painful…And I was enormously relieved that I could get off the bus because of Dignitas at an earlier stop…before I show up to the really nasty bit. (I6)

> …you haven't got a crystal ball. You don't know, and I still don't know, how it's going to end for me, but I think it would be nice to know that there is, a safety net if you like, that you can go, 'actually, you know, I don't want to do this anymore'. (I2)

And one husband identified that the comfort found in having the option of an assisted death allowed his wife to fully embrace the time she had left:

> She said…I've witnessed…women of her age group who've ended up in hospitals or hospices on endless cycles of chemotherapy, still with catheters and wires and drips and having a pretty awful death…and her thing was, I'd rather just live my life, continue painting, continue sculpting…and when I feel really bad then off I'll go to Switzerland… (F4)

Other family members supported the notion that having the option for an assisted death can provide comfort to those who are suffering in identifying that assisted dying offered their loved one the opportunity for a "*happy*" death (F3). Knowing that their loved ones had been able to choose the manner of their death appeared to be comforting to family members in the aftermath:

> …it is important to feel that she did die happy. I don't think she was putting it on, I think she was genuinely…had made a decision and was happy with the decision. (F3)

> …the more I think about my wife's death and the choice and her way of death, I become more and more enamoured with it. (F4)

These perspectives suggest that, for some, in certain contexts, and/or within the limitations of other medical alternatives, an assisted death may be seen as therapeutic and a better alternative to a painful and protracted death.

Theme 3: The difficulties of talking about assisted dying

Fear of legal repercussions, negative responses from others, and having conversations shut down by medical professionals prevented participants feeling able to discuss assisted dying with those around them, despite believing in the importance of such conversations.

Many participants described the impacts of not being able to discuss assisted dying with healthcare professionals caring for them:

> People need to be able to trust the doctor. They need to be able to go to the doctor and say what they feel about themselves, their illness, their body, their lives and not have someone sitting there all wimpy who does not want to talk about it… (I3)

Participants described feeling that there is a "*taboo*" (I4) around death and assisted dying within medical professions:

> It's viewed negatively [by healthcare professionals] because we have this awful taboo about death…this compulsion to keep living…to deny…what should be quite a gentle natural act. We want to surround it with intubation and emergency rooms and despairing stupid attempts to keep bodies that are absolutely worn out alive. For what! The sentiment of their remaining relatives… (I4)

One participant identified that the limited options to openly discuss assisted dying left him feeling that he was unable to access information when supporting his wife in her decision:

> …no organisations or groups will…really talk to you about it. They will explain what the legal situation is, and they may be a campaigning group who has a… belief that that the law ought to be changed. That's very different from anybody actually…providing information or…certainly advice…as soon as you get to the word advice, as opposed to information, then it becomes very tricky. (F3)

The taboo and current legal status meant that another participant hid their decision for an assisted death from friends:

> I've sometimes talked about it to friends and had them look a little bit ensconced with me. 'Oh well, or erm'. One friend I mentioned it to, she said, 'Oh, I don't agree with that at all. I think we should just wait for God to take us'. (I3)

Others had more positive experiences when being open with friends and family:

> …I've got quite used, in the past few months since [my wife] died of a) thinking a lot and b) talking a lot in a way that…doesn't come naturally to me. But a lot of friends and family have spent a lot of time listening to me ramble on…and sometimes that rambling is…a process of me trying to understand what I'm feeling… (F3)

And others identified personal reasons why someone might choose not to openly discuss their decision with loved ones:

> She tried it out with a brother, and one or two close friends, and then decided that it was, complicated because she would have to deal with their emotional reaction…and it would affect that relationship from then on. (F3)

> …she was a very private person and didn't discuss it with any of her friends…she didn't want to tell anybody. (F5)

This theme highlights the challenges of navigating an end-of-life process that is not readily accepted or openly discussed within UK society. These challenges lead people to having to carefully consider, amid the illegal context, who they discuss their decision with.

Theme 4: The barriers associated with pursuing an assisted death

Participants described unique experiences related to the illegality of assisted dying in the UK, and the impacts of the current legal status on individuals considering an assisted death and the family members supporting them. Participants shared difficult experiences of discussing assisted dying with their GP within the current legal context, illustrating how, for many, these conversations may pose barriers to feeling that assisted dying is an option open to them:

> My GP, was restricted, I guess he supported it, but understand why he won't speak about it any further…'[Acting out the voice of his GP] I'll make sure…all the bases are covered, and I'll sign it for you and put it on your record'…'…but…I can't discuss your assisted death, any further with you. What I am able to say, is that I genuinely believe that you and everybody else should have that right. (I1)

Family members identified practical challenges, including accessing necessary paperwork from medical staff, that is made difficult due to the legal status:

> …extraordinary getting medical records, getting various things, feeling like a…cheat. I'm putting on for this, and we mustn't quite say why…because everybody else will be scared that they've assisted her. (F5)

> …if they carry out a consultation with a person that is intending to have an assisted suicide, they're breaking the law really, or it could be construed as they're breaking the law, writing…a report, that allows him or her, to go off to Switzerland to have an assisted suicide…I think it's totally wrong. Giving a medical opinion for anything, shouldn't be wrong… (F4)

One participant shared that his wife's GP had been implicated, even when continuing to provide 'treatment as usual':

> It was frustrating as the GP had done nothing other than providing medical information. And yes, she knew…so she was aware of what [my wife] was planning, but…she would continue to be supportive you know, to any medical needs that [my wife] had. But it sounds like the legal situation has put her in a difficult situation… (F3)

Participants also shared concerns of the impacts of needing to go abroad for an assisted death, and how the requirement to go abroad and the inherent consequences of this, might mean that people go before they feel *"ready"* (I3):

> It shouldn't be having to go off to a clinic abroad and…hope that the police don't stop you…It's very true, that you have to go before you're ready. Because you have to be able to travel there. You have to be competent. You…have to have capacity…You have to be able to administer the medication yourself. (I3)

> … there's something unfair about being forced into the situation where you might have to go early or you might have to…protect your family members. When… the death could be…different at home. Could be… closer to the…death that you would want, perhaps? (I6)

Others shared concerns about those left behind after they had completed an assisted death and the reality that loved ones would not be able to have their preferred funeral for them in the UK as they would be cremated in Switzerland:

> …the funeral…If I outlive my mum, who is a… Catholic, she does support assisted dying. If she wants a full requiem mass with communion…After death, it is about those who are left behind. Not the person. If that helps mum get through the grief then that is fine. But, like I say, people are deprived of that. (I1)

Possible police involvement for themselves and/or family members put *"added pressure"* (F5) on an individual considering an assisted death:

> …that is an added pressure on the person who has decided upon an assisted death, and anybody who… might know of those wishes…I think that is an added cruelty…everybody is made to feel under hand…I have to do this secretively, because if [a stranger] down the road, hears about it, and they don't agree with it, they can go and tell a policeman, and the policeman will come and knock on your door. (F5)

Despite the identified *"pressure"* (F5) of assisted dying being illegal, there appear to be few

prosecutions related to assisted dying currently in the UK, indicative of a legal 'grey' area:

> I've been interviewed by the police, they're not going to take any action, I don't feel that I've done anything illegal. (F3)

> …fortunately, there are no prosecutions…But it's still illegal…again, that's a nonsense…either send us all to prison for 50 years hard labour or don't…don't hang that over people… (F5)

Participants also highlighted the financial barriers to pursuing an assisted death abroad:

> the financial aspect…you have to have a certain amount of money to be able to do this. So again, that is…not right, because it's restrictive. (F5)

> …the ridiculous thing about it at the moment, you know, t-to go to Dignitas is…12,000 pounds, something like that…almost like private medicine…isn't it? (F4)

This theme highlights the impact of what has been described as a legal 'grey' area around assisted dying currently in the UK, and the impacts on individuals and their families of having to navigate the systems within this legal context.

Discussion

This paper presents results from two studies that looked at the experiences of two groups of UK-based individuals: those considering an assisted death and family members of those who completed an assisted death abroad. We identified four overarching themes, representative of the participants experiences. These themes comprised of the identified "*burden*" for individuals and family members of living with severe and/or degenerative illness as a motivation for assisted dying; the importance of personal values such as autonomy and control that accompany this decision; the difficulties associated with discussing assisted dying; and, the barriers associated with pursuing an assisted death when living in a country where it is illegal.

The impact of severe/degenerative illness on the motivations of those considering assisted dying is well documented (Martin et al., 2023). Our findings identify the impact of present suffering and fear about the anticipated trajectory of illness progression. These considerations appeared to motivate individuals to consider an assisted death abroad, with the decision being supported by family members, despite the emotional impacts of this decision. In line with literature on the impacts of illness on family members (e.g. Golics et al., 2013), including the impacts of caring responsibilities (Gamondi et al., 2018), participants identified how the relevant illnesses not only affected the individuals, but also those caring for them.

The importance of individual autonomy has been well documented in literature from research conducted in countries where assisted dying is legal (e.g., Rodríguez-Prat et al., 2016). Being able to determine the location, time, and place of death (e.g., at home) allows individuals and their families to prepare for their death (Holmes et al., 2018; Srinivasan, 2019). Although individuals traveling abroad for an assisted death have some control over their death, they must go to an unfamiliar place, in a different country, with only one or two loved ones around them. Furthermore, loved ones who choose to accompany the individual must navigate the associated legal considerations when returning to the UK. If the individual's body is returned to the UK, a medical coroner must be involved, likely triggering a police investigation into the death, and anyone associated with 'assisting' this death. Therefore, following completion of an assisted death, the body is usually cremated, which can deny those left behind of a burial and their funeral preferences (Dignity in Dying, 2017). Participants also discussed needing to go abroad for an assisted death earlier than they would if it was legal in the UK due to the requirements associated with the application process (see: Dignitas, 2024), such as having capacity to consent to the decision and being able to take the fatal medication. Alongside these concerns, participants also identified that going abroad for an assisted death is costly. Despite these issues, participants viewed assisted deaths as a way of maintaining autonomy over life and death and had a sense of comfort knowing it was an option to them.

Many of the participants discussed the impact the legal grey area in the UK had on their ability to discuss assisted dying with loved ones and healthcare professionals. Several participants reported that healthcare professionals shut down discussion of assisted dying due to fears about possible legal repercussions. These experiences with healthcare professionals can leave individuals feeling as if they have not fully explored their considerations around assisted dying before needing to decide and plan, which has been shown to negatively impact mental state during the assisted dying assessment procedure in locations where it is legal (Verhofstadt et al., 2022). Family members similarly felt they had to be careful who they discussed their loved ones' assisted death with, due to fear of stigma from others and/or someone speaking to the police. They also identified the challenges of

talking with others given the taboo around assisted dying, alongside dying more generally, which has been identified even in countries where assisted dying is legal (Gamondi et al., 2015; Srinivasan, 2019). The possible legal implications for family members following the assisted death of a loved one were concerning for all participants, despite prosecutions in the UK being rare (Lipscombe et al., 2022). Nevertheless, participants still viewed assisted dying as the preferred option when compared to their current situation and/or anticipated course of a long and protracted illness. Individuals do not appear discouraged from seeking or accessing an assisted death, and family members were satisfied that this option was available to their loved one, to relieve their suffering, despite their own feelings.

These findings identify the need for clearer legal frameworks around assisted dying as it stands within the UK, so that individuals, their families, healthcare professionals, and researchers have a better understanding of what they can discuss on this topic, as well as having access to relevant information. The current law states that assisting suicide is a crime in the UK (Suicide Act, 1961), but does not stipulate what constitutes 'assisting'. The CPS advises that prosecution should not occur if, *"the victim had reached a voluntary, clear, settled and informed decision to commit suicide,"* and anybody seen to be assisting with this suicide was *"wholly motivated by compassion"* (CPS, 2014, p. 6). The fact that participants reported that healthcare professionals shut down conversations on this topic suggests that the current law, and professional guidelines, need to be further clarified. This clarity could help healthcare professionals feel better able to explore patients' consideration of an assisted death abroad for themselves, or the possible impact(s) on family members of someone who has completed an assisted death, without fear of reprisal. Clarity in the law will also aid family members' awareness of the options and limits of the law when supporting loved ones in their decision, as confusion around what is deemed 'assisting', as highlighted in this research, mirrors confusion shared in the recent national inquiry (UK Parliament, 2024, p. 6). Various healthcare professions should provide professional guidelines to enable individuals to talk with healthcare providers about assisted dying, and how it may/may not fit into their preferences for their ongoing care as part of advanced care planning.

This article demonstrates that it is possible to conduct legal, ethical, and meaningful research in the context of a country where assisted dying is illegal. It has identified that there are individuals, including those considering an assisted death and family members of people who have completed an assisted death, that find it difficult to talk about their experiences, face legal barriers, value autonomy, and are often not well supported by the current healthcare provision. The legal 'grey' area within the UK likely contributes to the challenges they face.

This article presents a range of perspectives on assisted dying, from those considering an assisted death for themselves and from family members who have had a loved one who has completed an assisted death. These perspectives offer insight into the motivations for an assisted death and the current barriers to accessing these services for UK-citizens.

We acknowledge that assisted dying being illegal in the UK may have impacted willingness to participate in this research and the openness of those who took part. The demographics of participants, although representative of those seeking assisted deaths globally (Emanuel et al., 2016), are unlikely to be representative of all stakeholder groups within the UK. Instead, the perspectives reported should be understood as part of the range of perspectives on this topic (both for and against) across the UK, identified by the UK Parliament's recent national inquiry (2024). The inquiry identified a range of perspectives aligning with those identified in this article, including that many are supportive of legalizing assisted dying; they feel it allows people to be able to avoid *"bad deaths"* and ongoing suffering (p. 19), and privileges the right to individual autonomy. The inquiry report acknowledged the need for clarity around the current law, concerns around the need to go to Switzerland and therefore people going before they are 'ready', and family members' experiences of being investigated by the police (UK Parliament, 2024).

For this research, researchers recruited participants through organizations and online support groups supportive of assisted dying, which may mean it was only the experiences of family members who were supportive of their loved ones assisted death that were included in Hitchcock's (2023) original study. For Dean's (2024) study, it is not possible to know whether the individuals considering assisted dying would go on to complete one. Therefore, these findings may not be generalizable to the group of individuals that complete an assisted death abroad. A further limitation of this study is the limited diversity in the participants recruited. Participants identified as 'White British' and most declared that they held no religious beliefs. The demographics of those in the UK pursuing or completing assisted dying abroad is not known, however globally it has been identified that people

accessing assisted dying are usually racialized as 'white', over 60 years' old and well educated (Emanuel, et al., 2016). It has also been shown that the relationship between assisted dying, race and ethnicity is complex (Cain et al., 2018; Periyakoil et al., 2016).

The findings from this research demonstrate that there are individuals who consider and pursue an assisted death abroad, despite the current legal context of the UK and the financial and potential legal repercussions. This conclusion highlights a need for UK-based people impacted by assisted dying to be able to access support, even while assisted dying is illegal. We suggest that clarity around the current law may enable healthcare professionals to feel more confident engaging in supportive conversations with patients and family members/loved ones, and for charities, such as campaign organizations within the UK already offering various forms of support, to be able to do so in a more open and accessible capacity.

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References

Bartsch, C., Landolt, K., Ristic, A., Reisch, T., & Ajdacic-Gross, V. (2019). Assisted suicide in Switzerland: An analysis of death records from Swiss institutes of forensic medicine. *Deutsches Arzteblatt International*, *116*(33-34), 545–552. https://doi.org/10.3238/arztebl.2019.0545

British Medical Association (BMA). (2021). *Physician-assisted dying legislation around the world*. https://www.bma.org.uk/media/4402/bma-where-is-pad-permitted-internationally-aug-2021.pdf

Cain, C. L., Surbone, A., Elk, R., & Kagawa-Singer, M. (2018). Culture and palliative care: Preferences, communication, meaning, and mutual decision making. *Journal of Pain and Symptom Management*, *55*(5), 1408–1419. https://doi.org/10.1016/j.jpainsymman.2018.01.007

Chambaere, K., & Cohen, J. (2017). Euthanasia and public health. In *International encyclopedia of public health* (pp. 46–56). Academic Press.

Cohen, J., & Chambaere, K. (2021). *Euthanasia*. Access Science. https://doi.org/10.1036/1097-8542.246850

Crown Prosecution Service. (2014). *Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide*. https://www.cps.gov.uk/sites/default/files/documents/legal_guidance/assisted-suicide-policy.pdf

Dean, H. (2024). *Understanding the experiences of people who are considering ending their lives by assisted dying: An interpretative phenomenological analysis* [Doctoral thesis]. University of Hertfordshire]. University of Hertfordshire Research Archive.

Dees, M., Vernooij-Dassen, M., Dekkers, W., & Van Weel, C. (2010). Unbearable suffering of patients with a request for euthanasia or physician-assisted suicide: an integrative review. *Psycho-oncology*, *19*(4), 339–352. https://doi.org/10.1002/pon.1612

Dees, M. K., Vernooij-Dassen, M. J., Dekkers, W. J., Vissers, K. C., & Van Weel, C. (2011). 'Unbearable suffering': a qualitative study on the perspectives of patients who request assistance in dying. *Journal of Medical Ethics*, *37*(12), 727–734. https://doi.org/10.1136/jme.2011.045492

Dignitas. (2024). *Accompanied suicide*. http://www.dignitas.ch/index.php?option=com_content&view=article&id=20&Itemid=60&lang=en

Dignity in Dying. (2017). *The true cost. How the UK outsources death to dignitas*. https://cdn.dignityindying.org.uk/wpcontent/uploads/DiD_True_Cost_report_FINAL_WEB.pdf

Dignity in Dying. (2023). *Dignitas British membership at all-time high with 80% increase in last decade* [Press release]. https://www.dignityindying.org.uk/news/dignitas-assisted-dying-switzerland/#:~:text=Thirty%20three%20Brits%20had%20an,to%20die%20there%20in%202002

Emanuel, E. J., Onwuteaka-Philipsen, B. D., Urwin, J. W., & Cohen, J. (2016). Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. *JAMA*, *316*(1), 79–90. https://doi.org/10.1001/jama.2016.8499

Fedlex. (2024). *Swiss criminal code*. https://www.fedlex.admin.ch/eli/cc/54/757_781_799/en

Fish, J. (2023). *How does assisted dying affect the experience of the bereaved in the UK?* Lancaster University (United Kingdom).

Fontalis, A., Prousali, E., & Kulkarni, K. (2018). Euthanasia and assisted dying: what is the current position and what are the key arguments informing the debate? *Journal of the Royal Society of Medicine*, *111*(11), 407–413. https://doi.org/10.1177/0141076818803452

Gamondi, C., Pott, M., Forbes, K., & Payne, S. (2015). Exploring the experiences of bereaved families involved in assisted suicide in Southern Switzerland: a qualitative study. *BMJ Supportive & Palliative Care*, *5*(2), 146–152. https://doi.org/10.1136/bmjspcare-2013-000483

Gamondi, C., Pott, M., Preston, N., & Payne, S. (2018). Family caregivers' reflections on experiences of assisted suicide in Switzerland: a qualitative interview study.

Journal of Pain and Symptom Management, *55*(4), 1085–1094. https://doi.org/10.1016/j.jpainsymman.2017.12.482

Ganzini, L., Goy, E. R., & Dobscha, S. K. (2008). Why Oregon patients request assisted death: family members' views. *Journal of General Internal Medicine*, *23*(2), 154–157. https://doi.org/10.1007/s11606-007-0476-x

Goh, E., Wen, J., & Yu, C. E. (2022). Lessons from the departed: A planned behavior approach to understand travellers' actual physician-assisted suicide behavior. *Journal of Hospitality & Tourism Research*, *46*(8), 1675–1689. https://doi.org/10.1177/1096348020987626

Golics, C. J., Basra, M. K. A., Salek, M. S., & Finlay, A. Y. (2013). The impact of patients' chronic disease on family quality of life: an experience from 26 specialties. *International Journal of General Medicine*, *6*, 787–798. https://doi.org/10.2147/IJGM.S45156

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2018). It's just more personal": Using multiple methods of qualitative data collection to facilitate participation in research focusing on sensitive subjects. *Applied Nursing Research : ANR*, *43*, 30–35. 10.1016/j.apnr.2018.06.015 30220360

Hitchcock, M. (2023). *Understanding the perspectives of UK-based family members of people who have chosen to end their life by assisted dying* [Doctoral thesis]. University of Hertfordshire, University of Hertfordshire Research Archive.

Hodel, M. A., Hoff, P., Irwin, S. A., Biller-Andorno, N., Riese, F., & Trachsel, M. (2019). Attitudes toward assisted suicide requests in the context of severe and persistent mental illness: A survey of psychiatrists in Switzerland. *Palliative & Supportive Care*, *17*(6), 621–627. https://doi.org/10.1017/S1478951519000233

Holmes, S., Wiebe, E., Shaw, J., Nuhn, A., Just, A., & Kelly, M. (2018). Exploring the experience of supporting a loved one through a medically assisted death in Canada. *Canadian Family Physician*, *64*(9), 387–393.

Leboul, D., Bousquet, A., Chassagne, A., Mathieu-Nicot, F., Ridley, A., Cretin, E., Guirimand, F., & Aubry, R. (2022). Understanding why patients request euthanasia when it is illegal: A qualitative study in palliative care units on the personal and practical impact of euthanasia requests. *Palliative Care and Social Practice*, *16*, 26323524211066925. https://doi.org/10.1177/26323524211066925

Lipscombe et al. (2022). *The law on assisted suicide*. https://researchbriefings.files.parliament.uk/documents/SN04857/SN04857.pdf

Martin, T., Freeman, S., Lalani, N., & Banner, D. (2023). Qualities of the dying experience of persons who access medical assistance in dying: A scoping review. *Death Studies*, *47*(9), 1033–1043. https://doi.org/10.1080/07481187.2022.2160033

Mroz, S., Dierickx, S., Deliens, L., Cohen, J., & Chambaere, K. (2021). Assisted dying around the world: a status quaestionis. *Annals of Palliative Medicine*, *10*(3), 3540–3553. https://doi.org/10.21037/apm-20-637

Pegasos. (n.d). *Swiss law & requirements*. https://pegasos-association.com/requirements/

Periyakoil, V. S., Kraemer, H., & Neri, E. (2016). Multi-ethnic attitudes toward physician-assisted death in California and Hawaii. *Journal of Palliative Medicine*, *19*(10), 1060–1065. https://doi.org/10.1089/jpm.2016.0160

Populus. (2019). *Dignity in dying poll*. https://yonderconsulting.com/poll/dignity-in-dying-2/

Revill, J. (2002). First Briton helped to end life at 'death tourism' clinic. *The Guardian: UK Edition*. https://www.theguardian.com/uk/2002/nov/03/health.healthandwellbeing

Richards, N. (2017). Assisted suicide as a remedy for suffering? The end-of-life preferences of British "suicide tourists. *Medical Anthropology*, *36*(4), 348–362. https://doi.org/10.1080/01459740.2016.1255610

Rodríguez-Prat, A., Monforte-Royo, C., Porta-Sales, J., Escribano, X., & Balaguer, A. (2016). Patient perspectives of dignity, autonomy, and control at the end of life: systematic review and meta-ethnography. *PloS One*, *11*(3), e0151435. https://doi.org/10.1371/journal.pone.0151435

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. Sage. https://doi.org/10.1371/journal.pone.0151435

Smith, J. A., & Nizza, I. E. (2022). *Essentials of interpretative phenomenological analysis*. American Psychological Association. https://doi.org/10.1037/0000259-000

Sperling, D. (2022). Travelling to die: Views, attitudes and end-of-life preferences of Israelis considering receiving aid-in-dying in Switzerland. *BMC Medical Ethics*, *23*(1), 48. https://doi.org/10.1186/s12910-022-00785-w

Srinivasan, E. G. (2019). Bereavement and the Oregon Death with Dignity Act: How does assisted death impact grief? *Death Studies*, *43*(10), 647–655. https://doi.org/10.1080/07481187.2018.1511636

Suicide Act. (1961). *Section 2*. https://www.legislation.gov.uk/ukpga/Eliz2/9-10/60

UK Parliament. (2024). *Assisted dying/assisted suicide*. https://committees.parliament.uk/publications/43582/documents/216484/default/

Verhofstadt, M., Chambaere, K., Pardon, K., Mortier, F., Liégeois, A., Deliens, L., & Audenaert, K. (2022). The impact of the euthanasia assessment procedure: a qualitative interview study among adults with psychiatric conditions. *BMC Psychiatry*, *22*(1), 435. https://doi.org/10.1186/s12888-022-04039-2