

Experiences of engaging a death doula: qualitative interviews with bereaved family members

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Abstract

Background: There has been an emerging trend of adopting a death doula, a non-medical advocate and guide for people at the end of life and their families. While there has been growing empirical research regarding the work of death doulas, no studies have been undertaken with the families who have engaged them.

Objectives: To understand the experiences of families who used a death doula in terms of what they did for the patient and family; to understand the benefits and drawbacks of using a death doula; and to use family insight to determine cultural shifts towards death and dying, and what the death doula phenomenon tells us around our attitudes towards death and dying.

Methods: We recruited and interviewed 10 bereaved family members to learn about their experiences using a death doula. This qualitative research took an interpretive phenomenological approach, and thematic analysis was used to analyse the data.

Results: The most valuable attribute the families gained from death doulas was an increase in death literacy resulting in personal empowerment. Empowerment enabled positive end-of-life experiences for the family and personalised deaths for the patient. A novel finding was that the connections and knowledge shared between the death doula and family had a resonant effect, resulting in families being more comfortable with death and keen to share their knowledge with others. Therefore, family engagement of a death doula led to an increase in community awareness around death and dying.

Conclusion: Family members' experience with a death doula was overwhelmingly positive, empowering them practically and emotionally to deliver the best end-of-life care. Empathy and sharing of knowledge by death doulas were valued by families and resulted in an increase in death literacy which provided families with opportunities to 'pay it forward'. Furthermore, the relationships formed between doulas and families have the potential for a lasting, resonant effect.

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Plain language summary

What are bereaved family members experience of using a death doula?

To date, there are no research studies with a focus on family experiences using death doulas for end-of-life care.

We interviewed 10 family members from Australia and the United States to understand what benefits death doulas provided, what complicating factors might be involved when engaging them and what value and impact they had on end-of-life care for families.

The most valuable attribute the families' gained from death doulas was an increase in death literacy. There was a direct connection between this and a sense of empowerment for patients and families. Empowerment enabled positive end of life experiences for the family and personalised deaths for the patient.

Keywords: bereavement, death doula, end of life, palliative care

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Introduction

It is becoming increasingly common for people to choose to die at home where possible¹; however, this requires both formal care provision and informal care; the latter often provided by family and friends and other social networks.^{2,3} Family members undertake many tasks and experience physical, emotional and financial burdens in the process,^{4,5} often trying to manage alone with services that are inconsistent and with health providers with limited time to provide the help and support required.⁶ Increasingly, there are also those with no family support at all.²

There has been an emerging trend of engaging a death doula (DD), a non-medical advocate and guide for people who are at the end of life (EoL) and their families.^{7,8} A DD provides guidance and support in the time leading up to death and in the period after providing many and varied services including helping with advance care planning, providing respite, helping with practical tasks and physical care, and providing companionship.^{9,10} The DD role has its roots in the fundamental belief that the medicalisation of death has removed much in the way of death awareness and death literacy, including the ability to talk openly about death.¹¹ In more practical terms, the movement reflects what some have identified as a shift in health services back into the community.¹² Parallels to the DD role can be found within Australian Indigenous communities, where support in dying (e.g. spiritual care) is provided at a grassroots and culturally appropriate level within the community, a role formalised in more recent years as that of Aboriginal and Torres Strait Islander health workers.⁸

The DD role has been under scrutiny in the literature as one, that while regulated in Australia, remains unregistered with no standardised education requirements.^{10,13,14} This is also true in the United States with no state or federal oversight or agency overseeing the DD certification process.¹⁵

While the topic of DDs has been popular in the media,¹⁶ it is only in the past 5 years that there has been a growing number of descriptive articles, followed by some empirical research. This has included literature reviews,^{8,10} surveys and interviews with DDs,^{7,14,17–20} a survey with DD training organisations²¹ and two studies on DD models of care.^{22,23} While this relatively new phenomenon is gaining more focused attention and

research, it has consistently focused on the DDs perspective, without to date, any research privileging the voices of families who have engaged a DD. Given the ultimate arbiter of the usefulness of any service role is the end user, in this case family members, it is therefore vital that an examination of their experiences be undertaken as the most appropriate way to investigate perceived value and family satisfaction with the care provided by DDs.^{10,24} The aims of this qualitative research were therefore threefold:

- (1) to understand the experiences of families who used a DD in terms of what they did for the patient and the family.
- (2) to understand both the benefits and drawbacks of using a DD from the families' perspective.
- (3) to use family insight to inform understandings of cultural shifts towards death and dying more broadly and what the DD phenomenon tells us culturally around our attitudes towards death and dying more broadly.

Methods

This qualitative research took an interpretive phenomenological approach²⁵ to understand the lived experience of families who engaged in the services of a DD *via* an in-depth inquiry.

Study recruitment

Names that have been included are pseudonyms. When recruitment stalled, a modification request was submitted to the ethics committee, and approval was received, to recruit more broadly *via* the international DD training organisations that we had previously reached out to.

We began by approaching those who had assisted with recruitment for our previous studies across Australia. We also approached carer organisations, funeral directors, death café networks and community centres. After a limited response over 6 months, we increased our scope internationally approaching independent EoL groups, national DD organisations and larger international DD organisations. All organisations were provided with a description of our research for circulation. We were also contacted by a colleague in the United States with a special interest, who was a DD herself and who offered to help with recruitment.

Inclusion criteria for our participants were members of the public aged between 18 and 80 years who had used a DD to assist them with the EoL care of the patient and who were now bereaved. Initially, we sought those whose experience was between 3 and 6 months prior to interview. However, due to the difficulty in recruitment, we allowed participants who had used a DD up to 3 years prior. Only one participant did not fall in this range, her experience being 6 years prior. A study by DiBiasio *et al.*²⁶ found stable responses from participants between 3 and 9 months following the death of hospice patients, with Bentley and O'Connor²⁷ describing bereaved family members feeling most comfortable being interviewed within the first 5 months of bereavement and that the timing of such interviews should be at their discretion. It was also felt to be important to not only have some distance between the death but also (we thought) distance from the DD, with any current caregiving experience and reliance on the DD for support and guidance, potentially colouring the experience.

The research assistant (an experienced female PhD qualified qualitative researcher) contacted prospective participants in the United States and Australia, providing study information sheets detailing the purpose of the research and conducting interviews with 10 family members who had engaged the services of a DD for a loved one. Five family members were from Australia and five from the United States and all but one was female. All participants contacted the researcher if interested in participating and none subsequently dropped out. Those being cared for were predominantly spouses (6), parents (3) and one great-aunt (see Table 1).

We conducted nine semi-structured interviews online *via* Teams or Zoom, and one *via* telephone, with the interviewer not known to the participants beforehand. All participants were interviewed alone, with each interview of approximately 1-h duration. Field notes were not taken, as each interview was audio and visually recorded and transcribed verbatim *via* a third party with a non-disclosure agreement in place. All participants were provided with a consent form and information sheet prior to the interview. The information that we were interested in came in the form of question prompts, based on the researchers' previous work. The questions were not piloted. Questions were posed about the person who had died, the bereaved family members'

relationship with them, any family support available and how they came to engage a DD. From there, we were interested in how the DD supported both the dying person and the family member (i.e. what they helped with). Other areas of interest included payment, other family members' feelings towards the DD and any positive or negative aspects related to engaging a DD. Interviews lasted approximately 1 h and were digitally recorded and transcribed verbatim by an independent company. No interviews were repeated or followed up.

Participants were offered the opportunity to view the transcriptions for verification, and some participants expressed interest in learning about our findings. Participants were provided with a \$30 gift card to thank them for their time. Unfortunately, though, this attracted over 200 scam emails that required verification screening, such as for duplicate responses and similar IP addresses. This is not an isolated incident as a result of online recruitment,^{28,29} but it does add to the complexity and the timelines.

Data analysis

We used a combination of both deductive and inductive coding to organise and analyse the qualitative data. As this research supplemented all our previous studies on DDs, we had very specific aims as noted above. Although deductive analysis usually begins with theoretical propositions or is guided by one theory, this was not in the design. Furthermore, it could be described as 'theoretical thematic analysis' only in terms of providing a more detailed analysis of some aspects of the data.³⁰ However, the researchers remained reflexive and mindful of this, recognising transparency is important when conducting inductive analysis with presuppositions.³⁰ In specifically addressing reflexivity, as four of the authors have a track record in DD research, the second author conducted the interviews and led the data analysis with no previous history in DD research and therefore no preconceptions. All participants checked the transcripts with no changes made, and verbatim exemplar quotes were provided.

We began with a coding table (or code book) before commencing analysis based on the research questions and aims.³¹ This table was assessed by all the researchers for coherence. Once agreed upon, 10 descriptive codes were tabulated to capture the aims of the three research aims and were

Table 1. Family members.

Family member	Country	Person being caring for	How heard of DD?	Who was at home to help?	Other supports	What did DD do	Place of death	Financial arrangement
One (female)	Australia	Her husband	She read about this particular DD in a magazine	Some family members and a neighbour were around	Community services were involved. The DD had no contact with them	Provided advice and support	Cared for at home for 18 months but actually died in hospital. His body was brought home after his death	DD was primarily voluntary, a minimal fee was paid for some things
Two (female)	Australia	Her mother	Rang around about finding support. Did a Google search to actually find the DD	The family member was the only carer	Community services were involved. The DD had no contact with them	Only dealt with the daughter in an advisory role	Nursing home (daughter could no longer manage). Brought home after death	DD was paid
Three (female)	United States	Her husband	Found out that her neighbour is DD so engaged here	Family was around	Hospice home care	Provided physical care, respite as well as advice	Home	Volunteer (DDs are provided free with hospice home care)
Four (male)	United States	His wife	The wife read about DDs in <i>The New York Times</i> and established contact for her own care	Mother (of the family carer)	Hospice involved. DD met some of the HCPs	Worked with the wife (patient) and then the husband and sons (family members) to provide mainly emotional support	Home	DD volunteered
Five (female)	Australia	Her mother	Another family member had engaged a DD, so they knew about it that way	The family was around and helped a bit	Nursing home staff	Provided phone support – advice and reassurance. Did not meet patient or family member in person	Went to a nursing home for respite and died there	Paid 'basic amount' that covered a period of time
Six (female)	Australia	Her partner	Google search undertaken. Four family members then did a workshop with DD	Family not geographically close enough to help	Nursing home staff	Phone/zoom support – advice and reassurance. Did not meet patient (COVID)	Cared for at home initially but later went into a nursing home where he died	DD was paid, and charged by the hour
Seven (female)	United States	Her mother	DD is known to family members as she worked in the nursing home. Engaged as companion and completed DD training at the same time	Big extended family not always around or could not be (COVID-19)	Hospice is also involved. DD and hospice staff talked as professionals together	The DD was hired to talk to their mother, keep her company, and do activities with her in the aged care facility. Advice and support were provided when mum was dying	Nursing home	DD charged by the hour
Eight (female)	United States	Her great-aunt	Home hospice facilitated the DD	Family around	Home hospice. DD worked with hospice staff and told family members when to call them in	DD spent time with the aunt and supported the family member as the aunt deteriorated	Home	Volunteer role (free with home hospice care)
Nine (female)	United States	Her husband	Knew of the DD personally (is also a massage therapist)	Family around	Hospice involved. Family members felt DD supplemented hospice who were not supportive	DD was an advocate for the patient and family. Emotional support for both of them. Post-death support is also provided	Home	DD was paid by the hour (his parents helped with payment)
Ten (female)	Australia	Her husband	DD organiser of the aged care package. Then did the DD course	Extended family but not around	Cared for at home with an aged care package and respite. Palliative care ward at the hospital	DD was engaged for moral and emotional support. Also conducted funeral	Husband in respite care (nursing home) but fell and was admitted to hospital where he died	DD was paid (family member was on an aged pension)
DD, death doula; HPC, Health Care Professionals.								

created as nodes using Nvivo v20 software (Lumivero, V13 (2020, R1)). As data were entered into the software, preliminary organising of the data was categorised under each descriptive node. Codes grouped in this way formed the key features of each participant's experience. Meaningful aspects of text matching these descriptive codes, such as 'benefits' or 'change and impact', were then identified and grouped under these codes.³¹

Transcripts were coded again, this time inductively to identify the main themes common across cases. We adopted Braun and Clarke's³⁰ approach to thematic analysis which they identify as phase IV of analysis. This is where the initial themes are refined, some collapse into each other and some may be eliminated and phase II, where we determine the validity of individual themes in relation to the data set.³⁰ Once this process was complete, three of the researchers met to discuss the themes and their significance with regard to the research objectives. All authors corresponded to discuss the main insights from the data and the main themes were discussed again to determine the 'essence' of what each theme was about in relation to the data.³⁰ Once there was agreement, three main themes (with subthemes) were identified.

Results

The results indicated that engaging a DD enabled an increase in death literacy which led to feeling prepared and empowered. As a broad concept, death literacy pertains to obtaining knowledge and skills that allow people to understand and act upon EoL care options.³² The concept of death literacy suggests that caring for someone at the EoL is not only a learning experience but strengthens the capacity for caregiving and encourages sharing that learning with others.³³ This was evident in a majority of cases in this study.

The amount of direct contact the DD had with the patient largely related to the context of the patient's condition and what assistance the family needed. In terms of fiscal arrangements, in four cases, there was no direct patient contact at all, with the families enlisting DDs for emotional and practical support for the family member. Six of the 10 paid a fee for their service, 3 were voluntary and 1 family member could not remember having paid or paid a minimal amount. It has been argued that since DDs are paid for their services, it is assistance that only those with a higher

socio-economic status can afford.¹⁷ However, in our study, none of the study participants considered the cost of their DD unaffordable, and one study participant said the cost was negotiable. Two participants from the United States were supplied DDs as part of their hospice package. One participating family member from Australia was on a pension and still managed to afford hiring a DD. DDs were, for the most part, on-call and responded to the needs of the family as they arose, and no conflicts were reported in their interactions with other healthcare professionals who were involved in the care of the patient.

Engaging a DD appears to serve both the practical and emotional support necessary for personalised and informed EoL care. The emphasis on the value of DDs from the families in this study was the empathy and knowledge they provide, the bonds they formed and their ability to enable a meaningful EoL care experience. These values were identified through three main themes: (1) preparedness, (2) empowerment and (3) connections. Each theme then had subthemes.

Theme 1: Preparedness (subthemes: physical, practical and emotional)

Preparedness around death and dying encompasses many elements. These can include medical, practical, psycho-social and spiritual preparedness.^{34,35} Family member's emphasis on feeling prepared came from the knowledge about death and dying processes, and about what pragmatic information they needed to care for the patient. One family member said, '*She supported me rather than him, so that I could keep my spirits up and keep supporting him. That's basically what I was wanting?*'

For those participating in our study, preparedness included knowing what to expect physically as the patient deteriorates and being prepared through knowledge of what pragmatic tasks would be required to enable a good death. For four of the participating families, their DD had a health background, which our previous research also indicated was common.²¹ Three had a nursing background and one had unspecified medical training through their career in the military. Those with health backgrounds usually explained this to the families in the first meeting or consultation. These consultations explained DD services but were also a way for the DD to understand the families. In the cases where participating

families had DDs with a health background, the difference seemed to be that they were more specific with the family members about what to expect from the dying trajectory and patient deterioration. None of the DDs administered medications.

Pragmatic aspects of preparedness were also highly valued. Families wanted to know the practicalities of what was possible, particularly for home deaths. However, sometimes they did not even know what questions to ask, but the DD would let them know what was possible in relation to what kind of death the family wanted within jurisdictional regulations and laws. Even for those who died in facilities, the pragmatic aspects of what happens after death were also highly valued (see Table 2).

Theme 2: Empowerment (subthemes knowledge and personhood)

In confronting death, there is a sense of loss of control.³⁶ For families in this study, knowledge was power. The knowledge provided by the DDs provided a sense of empowerment and control over the events for patients, but more significantly for the family members. Good deaths were achieved from the perspective of the families and a sense of empowerment was found through the preservation of the personhood of the patient. Indeed, empowerment for these families did not just come from knowledge and being informed, but in the family member being able to ensure the EoL of their loved one was carried out in a personalised way (Table 3).

Theme 3: Connection (Subthemes learning and sharing, paying it forward)

One of the most significant and novel findings from our research which could only have been garnered by speaking with families was the learnings that were shared between DDs and family members, and the depth of the connections that were made. In sharing openly about everything one needs to know about death and dying, the families felt that the experience left a resonant effect on their lives and a propensity to share that knowledge with others. In some cases, this led to helping other people at the EoL. Henceforth, although it is clear that DDs do not fit neatly into the compassionate communities' paradigm,^{24,37} as bereaved members of the community, the eagerness of the interviewed family members to

share and help others spreads compassion in the community around death and dying which we feel fits into the concept of 'pay it forward'.

Many of the families in this study kept in touch with their DD after the death of their loved one. One family member said, *'It's hard for me to draw a line because I formed a relationship with her, and we still go out for coffee once a month'*. One husband, whose wife engaged a DD for her EoL care, still keeps in touch with the DD and still feels emotionally supported. They go out for lunch, and she shares support group information with him, and they speak on the phone. We asked if that means they are now friends, he said; *'Exactly, yes'* (see Table 4).

Discussion

DDs suggest that their role is for the benefit of both client and family, but there is an agreement that it is client centred (patient centred) first, to advocate for the wishes of the person who is dying.^{1,10} Death is not solely about the person who is dying. There are complexities and nuances around who is involved or affected, and therefore there are implications in designing any systems or models of care around individual needs.

In our previous research on the DD role, we have elicited the views of DDs themselves with positive aspects of the role and its benefits highlighted. In this study, we have described the experiences of families who have engaged a DD to assist in EoL care. In agreement with other research on the topic, the utility of DD's echoes other studies regarding their services and work structure.^{1,10,14} However, in this research, we were able to identify what values and benefits the families themselves experienced by engaging a DD. We discovered that variation in their services was not only influenced by family needs but determined by the stage of the trajectory that the patient was in when they were hired. In some cases, the DD had no patient contact at all; instead, the DD served to empower the family member to deliver the best EoL care.

What was surprising was that the relationships formed in the process of engaging a DD had a lasting, resonant effect. Two family members knew the DD personally before engaging them in the role (one as a massage therapist and one as a neighbour) however despite this, some of the others went on to develop strong bonds and even

Table 2. Preparedness: Physical, practical and emotional.

Preparedness: physical aspects	One family member whose husband was dying at home saw the benefits of being prepared this way:	‘Yeah, so I think, yeah, so many benefits. Yeah, understanding what was going to happen, not that it made it any easier in that moment, but it wasn’t a shock, it wasn’t . . . Things that would start to happen to his body were not as horrifying perhaps as they might have been, because I knew that these things would happen. That’s on that level. I think, understanding what was possible’. (Family member 1)
Practical aspects	One family member was not sure whether it would make a difference if she was there when her mother died in a care facility. Discussions with the DD, simply by phone, encouraged this family member to spend time with her mother in her final days:	‘And she was really good because she [DD] used her own mother as an example to me about what she did for her own mother and so, I don’t know, it just struck a chord that no one really should be left to die alone. I suppose I hadn’t really got that. The person can still hear you right up until the end, even if they don’t indicate that they can, and all these sorts of things. And it was really fascinating anyway’. (Family member 5)
Emotional aspects	This family member notes the benefits of the DDs knowledge of physical transitions in the dying trajectory:	‘As my Auntie was regressing, she [the DD] was sharing what was happening to her body. If she noticed something different like if something didn’t seem right from when she came the last time, she would mention it to me. She would try to coordinate her visit when the nurse came, but it never always worked out. So, she would just say, “Maybe when the nurse comes, you can share that I was here, and I noticed that this is going on and this is going on, and maybe they can check it.” So, that was helpful too because some of the things, I didn’t even take notice of what was happening to my Auntie’s body’. (Family member 8)
Practical aspects	Another family member who was caring for her husband at home had a DD who was strictly volunteer, but who had thirty years’ experience in hospice care. She explained how beneficial it was that she had such knowledge, particularly in knowing that her expertise would ensure her husband’s comfort:	‘My daughter and I got comfortable and then she would just listen to [husband’s] breathing and she’d say “Let me give him the morphine this time, let’s put this drug in, mash it up, and put it in.” She never gave the drug, she let me do it all, but she said that, “Let us try this because his breathing is changing,” or, “I hear a little bit of stress.”’ (Family member 3)
Emotional aspects	One family member who was caring for her husband at home experienced medical complications and he had to be admitted to hospital where he later died. However, she explained the benefits of having pragmatic knowledge provided by the DD which resulted in the family member being able to bring the body back home:	‘Because I found that out, because I learned through her, all these things that were possible, it’s just like, “Oh my gosh, that’s so amazing that I can do that.” I really felt that I did enable that end of life for him, the way we wanted, a slightly different way, but he came home’. (Family member 1)
Practical aspects	In a similar situation, a family member had comfort in the knowledge that she did not have to be rushed after her husband had died in a nursing home:	‘Prepared, I think I’ve said it. Yeah, prepared is . . . I mean, I do really appreciate the fact that she coached me in how to speak to specialists, doctors, and even carers. . . I did have, when he died, I really wanted to wash his body and wrap him. I didn’t want . . . They kept saying, “Have you rung the funeral place yet?” And [DD] had said, “Just tell them you’ll do it in your own time. Your own time.”’ (Family member 6)
Emotional aspects	Another family member who was religious was very specific that she wanted to keep her mother at home and prepare the body herself and allow for a home ritual. She appreciated the pragmatic information provided by the DD regarding what was possible:	‘So, I was particularly aware that I didn’t want my mother to go to an industrial shed and be in a situation with strangers handling her body. So [DD] organized the movement of mum’s body from where she was to home. Then she organized the cremation time. . . She sort of filled in the practicalities. I knew that I wanted to bring my mum home and have her lie home for at least three to four days. . . Because I wouldn’t have known about the legalities’. (Family member 2)
Practical aspects	Again, the pragmatic information that was most valued was about what was possible for EoL care at home, what would be required and what the family would need to do for the best possible outcomes:	‘Yeah. Actually, I wasn’t aware that we could do the end-of-life care at home. I mean, I knew he could do hospice, and I knew he could die at home, but I just assumed they’d come and take him away and do whatever we had decided, which was cremation. But she told me I could do the end-of-life care and help him one last time, and I didn’t know that was legal. And it is, it’s absolutely 1,000% legal in Montana anyway. She helped me with that and helped me know what to do. She couldn’t do any of it, but she could walk me through the process and gave me things to read, told me what supplies I would need, and basically how to do it, how to make him comfortable’. (Family member 9)
Emotional aspects	The following family member, whose husband was dying but had Parkinson’s disease and was blind and almost deaf, had to be placed in a facility. Her anxiety was immense as much of this time was during COVID-19 lockdowns. She could not visit him, and speaking over the phone was impossible. Her DD, who only communicated with her by phone or video link, gave her pragmatic advice. Here, you can see the link between how pragmatic preparedness allows for the feeling of being emotionally supported:	‘I’d say, for me, emotional support was huge. And also, legal knowledge. Legal support, and I suppose it comes under emotional support, just knowing, coaching me in how to speak to the medical staff so that I didn’t come across as hysterical. I’d ring them up and burst into tears, saying, “Sorry.” But then I’d collect myself, and say my little speech, and then they’d understand what I was talking about, which was really good, because I’d been coached’. (Family member 6)
Practical aspects	DD, death doula; EoL, end-of-life.	

Table 3. Empowerment: Knowledge and personhood.

Theme	Description	Exemplar quotes
Empowerment: Knowledge	Much of the knowledge gained by the families through the DD led to a sense of control and feeling empowered:	<p>"So, it's really quite extensive what services she [DD] can provide to the family. But it's always about information and options. It's never her saying, "You must do this. You must do that. You've got to do these things in this order. Now off you go." It's more about, "Well, here's this stuff that I know about. You digest it and then you decide what you want to do with it." It's really empowering, actually. It's very empowering". (Family member 5)</p>
Empowerment: Personhood	One family member who was looking after her husband seemed shocked at the direct manner in which the DD asked what kind of death the patient wanted:	<p>"I still remember her first question to [husband] was, "What is a good death"? What does a good death mean to you? I lost my bananas because, what? But we worked through all the things. Did he want music? Did he want videos when he wasn't coherent? Did he want me? Who did he want to help take care of him? (Family member 9)</p>
Empowerment: Personhood	A husband explained that his wife was very involved in the planning of her death. He did not know what a DD was until his wife explained and told him she wanted one to be involved. He said the DD went through the 'five wishes'. These were a personalised list of care options the patient wanted while they were dying:	<p>"I think [DD] gave her a lot of ideas about the five wishes and about, what do you want? How do you want to be treated? What do you want to be surrounded by? Because one of the things she came up with, this is the music I want played, and she came up with a Spotify list and that's what I played for a while she was in a coma basically. And she said I wanted nice scents, like essential oils rubbed on me, things like that. I want to be kept, comb my hair, do this, do that. There might be things that you'd normally say, oh, well, I'll do that anyway, but the essential oils, I wouldn't have thought of, I wouldn't have known the music that she wanted to play". (Family member 4)</p>
Empowerment: Personhood	Another family member who looked after her Auntie at home until her death talked about the personalisation of her care which was possible as the DD got to know her on a personal level. The family member was relieved, as there were some prior communication difficulties:	<p>"She had a personal connection, I think, is the main thing in having an end-of-life doula where she's not just coming in to do this, monitor you, and then say, "Okay, maybe you should take this medicine." She went beyond that. She found out the things that my auntie enjoyed and didn't enjoy. She worked on the things that my auntie enjoyed to make her end of life a more joyful and peaceful ending, not always . . . because at that stage too, they're always worried, always angry. She had given my auntie some peace to know that it was okay that she was going through this and just had her focus on happy things and good things, so that if she ever had to remember, "Oh yeah, I did this with [doula] today," or . . . because I remember [doula] was telling her, "Think about your happy place." (Family member 8)</p>
Empowerment: Personhood	One family member explained that discussing the personalisation of the process with the DD was very helpful as she wanted to carry out her husband's wishes the best that she could. She explained the value of those open conversations:	<p>"Yeah, whether we'd want a casket or a shroud, and she'd give an example of some ceremony she had conducted for somebody and what they had done. I liked the idea of it, and [husband] didn't, and he said so quite firmly, which was great. It's so helpful". (Family member 10)</p>
Empowerment: Personhood	Although the DDs provided emotional support for the families through knowledge and empowerment, there were also occasions where having a DD meant that the patient or family member could have conversations about death and dying that they would not otherwise have had. These private moments showed that a good level of trust was developed between the family member and the DD, and the patient and DD. Furthermore, it highlights the importance of patient autonomy in the dying process:	<p>"[Husband] actually at one point asked me if he could talk to her alone. I still don't know what they said. I don't need to know what they said. Obviously, it was something he didn't feel comfortable telling me about for whatever reason". (Family member 9)</p> <p>"The nurses didn't talk to her on that personal level. So, it was just like in and out, whereas [DD] actually took that time. She had that extra care, which emotionally, Auntie needed. It was a big comfort for her to where she could really connect. She looked forward to [DD] coming over". (Family member 8)</p>
Empowerment: Personhood	Another family member hired a DD for her mother who was in a nursing home. The family was concerned that she would be lonely. Although they all visited frequently, they felt reassured knowing there was a companion for their mother. The mother developed a trusting relationship with the DD:	<p>"[DD] told me about the experiences that . . . you know . . . "Your mum asked me today about . . . I don't remember what she asked, but it was conversations relating to death. So, while we didn't seek that out for my mum necessarily, it was provided if my mum wanted it . . . I think that was a positive". (Family member 7)</p>
Empowerment: Personhood	Finally, being able to personalise the death of their loved one made it into a beautiful experience:	<p>"Yeah, so I really struggled, but I think having her involved with us meant that things happened in a really beautiful way, and so I feel grateful and happy that we did that, because of her connection and yeah, it made such a big difference". (Family member 1)</p> <p>And, again: . . . We couldn't have done it without [DD]. And, we couldn't have. It was just so beautiful, the death, the experience, the care he received, he was just so comfortable. . . . (Family member 3)</p>
DD, death doula.		

Table 4. Connection: Learning and sharing, paying it forward.

Themes	Description	Exemplar quotes
Connection	<p>The connection and trust that the DDs had with the families was very apparent. Paradoxically, it was their ability to be close and yet also 'detached' which was viewed as a great asset to have during EoL caring:</p>	<p>"Tremendous emotional support. Because it was one thing to be able to talk to my family, but when you talk to your family, I don't want to upset my mom, my sons by bawling, crying. And with her [DD], I mean, a lot of times when she came over, it was just my boys would be at work or whatever, so it was just the three of us. So, I could just let my emotions go, [wife] could let her emotions go. And you didn't feel like, well, what if it was my mom or my sons, they would be upset for the rest of the day. "Dad's really upset." And this way, I could just let it out. And she was kind of a benign person that it didn't affect as much". (Family member 4)</p>
Connection: Learning and sharing	<p>Another family member had difficulty with her Auntie's mood swings and she was reluctant to speak openly with the home hospice staff: Again, their value in being a step removed is reiterated:</p>	<p>"Then, I just told my Aunt and then I explained to [DD] that, "Maybe you can just spend time with her, and that'll be so she can have her privacy, and if she wants to open up, she can because she wasn't doing it with me." (Family member 8) "And you are also dealing with the emotion of it all, and so someone like her can come in with a little, not detached as much, but just a little separate so they can tell you the things". (Family member 5)</p>
Connection: Learning and sharing	<p>The learning and sharing which was part of the care provided by the DD was sometimes also shared with the extended family. Families felt this was beneficial as it enabled the facilitation of conversations and the following family member said that it helped the family understand what she was going through:</p>	<p>"Just like a day workshop to introduce us to the work that they do and what's available. My daughter, my son, so there's three of us. Yeah, I think there were four of us. And so, we just did a little day thing, each of us in our own homes on Zoom. It was really good. And so, two of my children were on board with what I was doing as well, which was lovely. And then, we so enjoyed it. . . But I was interested in it just from. . . I don't know, I loved becoming familiar with the language of death, because we don't talk about it very much. People aren't interested, or frightened". (Family member 6)</p>
Connection: Paying it forward	<p>Another family member who had engaged the services of a DD for herself when her mother was dying got so much from the support of the DD that she is engaging another, as unfortunately, her husband is now dying:</p>	<p>"Yeah. We've talked a lot actually, and well, not, and after the doula relationship finished, then I still would keep in touch with her, and then that now can come again with my husband. And where we've used [DD] even more perhaps with him, with our family, she's run a workshop for the extended family. . . She talked through the stuff about my husband. So even more extensive use than we did with my mom. My mom, it was just really me and her. So, she's become someone we know now. . . And then since that first one, she's run one with our three grandchildren, and the two daughters were on as well, but just were in the background, and it was specifically addressing the children and how they're feeling about losing their grandfather". (Family member 5)</p>
Connection: Paying it forward	<p>The knowledge and support the families gained from their experiences of using a DD in the care of their loved ones has a lasting impact. Understanding the process of death, and the increase in knowledge gained from the experience, led to a sense of empowerment for both the family member and the patient resulting in a more positive view of the dying process. Not only did they often recommend their DD to others who they knew were about to go through the same experience, but they also expressed their newfound comfort with death through their need to share knowledge and assistance with others going through the same thing. In some respects, paying it forward:</p>	<p>"Sadly, I've had three people in the last six months die, that I've been with as they die. My neighbour and a really good mate, she passed away. Yeah, that one, who actually lived in an apartment further down the hall, so I was there with her until a few hours before. Then strange things happen, but anyway, now I've got an elderly couple that also live on our floor, and she was aged, I think she was 91. They were a very reserved, independent English couple that I knew, definitely, and I would help out from time to time, but then she got very sick and then her husband had a stroke. . . Suddenly she was willing to connect with others. . . She wanted to die at home, and she had no-one, they've got no family, no friends, nothing. Myself and another neighbour we stayed with her for 10 days and 10 nights as she passed away. I think part of it is because of that experience I had with my husband, that's the worst person in the world to have died for me, so nothing else was just that bad. I think what I learnt from her is that it's a gift to be present". (Family member 1)</p>
Connection: Paying it forward	<p>The following two family members demonstrate the desire to share the knowledge and support they gained with others going through the same experience:</p>	<p>"I have a friend whose sister is a good friend of mine who's passing away. And she said, "How do you stay so organized?" And I said, "I'll just send you my notes and this is what you need to do." (Family member 3) "I know she was terrific with my husband's ex-wife's sister, if you can get that, who is also part of our extended family here, and she was somebody who had never married and was a prickly little person. When I first gave her the papers about [DD], she said she liked the sound of it. She was always a member of Exit and things like that. She was always wanting to control what happened to her because she lived on her own, I think. When I gave her all the papers, she said, "Don't, what you're giving me all this stuff for?" I said, "Look, I'm only giving it to you because I think somebody like this [DD] I'm talking about could be very, very helpful to you." They ended up being best friends, which is what Jackie needed. At the end, [DD] was all she wanted". (Family member 10)</p>
Connection: Paying it forward	<p>Finally, one family member expressed that due to what she had learned from using a DD and also the workshops the DD carried out with the family, she feels that she is now so prepared for death, there may not be the need to depend on a DD when she begins caring for her husband indicating an increase in death literacy leads to personal change:</p>	<p>"It's translating now into my current situation with my husband. So, we're bringing the whole family along now, the extended family, and my husband's mom's still with us. So, everyone in our family now knows about a doula. It's interesting. And as your knowledge and everything goes, your need to is lessened, but then that's them doing their job, I think. And you know that you can still talk to them at any time, but you maybe don't need to as much because you are gaining the skills yourself to cope with death and make death normal". (Family member 5)</p>

DD, death doula; EoL, end-of-life.

friendships with the DD. The connection made between families and DDs and the knowledge gained by the families led to them being eager not just to recommend DDs to others, but to share their newfound knowledge around death and dying with others and in some cases, being compelled to help others going through the same experience. In this respect, DDs are contributing to the perpetuation of compassion in the community through an increase in death literacy and the concept of 'paying it forward'. This, in turn, is potentially contributing to a reshaping of the death system and enabling family members to become more compassionate community members. There was a decided connection between death literacy, empowerment and emotions, resulting in an increase in positive emotions while reflecting on their experience.

Preparedness (physical, practical and emotional) was found to be important for participants. However, preparedness for the patient and the family members differs. For example, a consequence of patient preparedness for pending death can manifest in having an EoL plan that allows for patient autonomy until death.³⁵ For family members, general unpreparedness when undertaking the challenging role of caring for someone at the EoL compounds the levels of stress and anxiety that they experience.^{38,39} Pragmatic aspects of being prepared were also highly valued. A recent study showed a categorical link between pragmatism and comfort; completing tasks that follow the wishes of the loved one has a two-pronged value.⁴⁰ In terms of knowing what to expect from the dying process, the DDs helped the families feel prepared for what physical transitions their loved ones would go through, especially if the DD had a health background.

The reason for the apparent rise in engaging DDs then cannot be viewed as simply filling gaps in the health system. The fact that families in our study still hired DDs when they had service provision means that their utility and value are much more complex. Perhaps some families engage in a DD not because they are necessarily incapable of providing care but because they require the extra support mechanisms (advice, guidance) that DDs provide for them in addition to community care services or hospices that are only able to provide fragmented care. Some of the DDs were also on-call or available around the clock. Roles such as navigators, Indigenous support workers, pastoral care services and compassionate communities

may provide similar support, as opposed to physical care tasks, recognising as our study does, that the needs of family members are often related to a lack of awareness and self-confidence. As previously stated, health and social support for EoL care, even when available, is likely to be inadequate and not necessarily offered to families, leaving it at the behest of families to request it.³⁸

The knowledge provided by the DDs provided a sense of empowerment and control over the events for patients, but more significantly for the family members. The process of dying and meaning-making in death are sociocultural; death embodies a permanent loss of personhood.⁴¹ In many respects, personhood is the preservation of autonomy. When it comes to EoL care, an empowered person is an autonomous person.⁴² Personal preservation permeated these stories, particularly for the home deaths. Personal preservation is couched in liberal ideas of individuality and rights as an ethics of care.⁴³ According to individualism and identity, to die well is to die in accordance with 'my' personal way of living, joyfully, beautifully, autonomously.⁴⁴ Indeed, beauty was mentioned now and again to describe the EoL that these families managed to arrange for their loved ones. The families in our study felt that the experience of engaging and working with a DD resonated so much with them, that they, in turn, went on to share that knowledge with others.

In our previous research, DDs claimed the most important aspects of their role were to reduce fear and anxiety around death, empower families, educate and inform and provide emotional and spiritual support.¹⁴ These aspects of their role were all echoed by the families in this study. The differences in emphasis in what families valued about DDs depended on the context of the situation, and their individual needs and wishes. Although previous research shows that what DDs provide depends on family needs and the DDs background,¹⁹ a more accurate observation would be, as another study has found, that this depends on the timing of when the DD is hired.¹⁷ For example, if a DD is engaged during the early stages of the dying trajectory, their role becomes more personalised to the patient's wishes around their death, whereas when they are hired much later, or in cases where the family just needs advice and support, then it is more about support for the carer.

What is particularly interesting to note regarding our recruitment process and in obtaining willing

participants for our study was that all the experiences that we documented were overwhelmingly positive, with no participants describing a negative experience using a DD. However, it is worth noting that one channel of enquiry of potential participants informed us that they did know of a family member who had used a DD, but that their experience was very traumatic, so it was unethical to reach out to them. Henceforth, no participants in our study could explicitly describe any drawbacks of using a DD. However, potential drawbacks or complicating factors of this movement can still be inferred from the data. Henceforth, the issue remains around potential conflicts with staff, how to regulate the industry and end-user protection. The question of potential conflicts between DDs and other healthcare staff could not be answered here as no overt conflicts were reported by the participating families. In two cases, however, families reported that they sensed an aloofness between the hospice nurse and the DD which for one person was simply referred to as a 'vibe'. As such, although potential conflict may be possible, for these families, there was no evidence of this.

The issue of payment of DDs may also be a source of contention. Indeed, some people may not be able to afford additional services in the care of their loved ones. However, all families in this study stated that it was affordable and well worth it although four family members engaged a DD who did not charge a fee. Many believed that the benefit outweighed the financial cost and many also stated that they would not have been able to provide, either practically or emotionally, the level of care they did had they not engaged the DD. Finally, there still remains the issue of lack of regulation and protection for families who may have a negative experience. Further research needs to consider what recourse families have in these circumstances and how this could be managed through regulation.

Based on our findings, the most positive benefit of using a DD appeared to be the sharing of knowledge with a decided link between death literacy, empowerment and positive emotions. Evidence suggests that a sense of preparedness does not just provide a sense of support for families, it leads to better post-bereavement outcomes.⁴⁵ Through this, families not only felt they had the means to cope with the death of a loved one but were able to provide the best death possible, a personalised death.

The growing engagement with DDs for EoL care indicates an increase in families not only having control over the dying process, but in making deaths more personalised, taking suffering and death and making it more meaningful.⁴⁶ Having control over the manner of one's death reflects that liberal individualism around death. The death of their loved ones was in many respects transformed into something they could reflect on positively; and in some cases, even describing it as beautiful. To note is that the perception of a 'good' or here 'beautiful' death is in the eye of the participant, acknowledging that there is no single definition that exactly describes that experience.⁴⁷

Some have argued that DDs are operating as 'vanguards and ideological change agents' who challenge the biomedical framing of death as a medical event.¹⁹ Our view is that this approach to death and dying shifted long before DDs became popular. There is no supply of service without the need, and the increase in the number of people looking after their family members at EoL not only gives rise to a need for practical support, but emotional support. Indeed, death is relational, and families are diverse. The families in our study emphasised the emotional relief they experienced through engaging a DD. We agree with Broom and Kirby who argue that family involvement in death is an avenue that reflects the changing cultural ideas around the responsibility of care for the dying.⁴⁸ DDs are starting to be recognised perhaps because there is a gap not just in terms of capacity but in the type of needs that should be met by healthcare systems and the needs of living as you are dying. Public health, aged care, acute care, primary care and families and relationships must work together to seamlessly support those who are dying and their families.⁴⁹ This also speaks to the difference between care as a technical provision and care and caring in the familial context.

Interestingly, two participants (6, 7) alluded to their DDs working with the dying person who was in an aged care facility (nursing home), which we have found in a previous study,²³ and which could be an important step towards supporting those who are dying in facilities or perhaps in supported accommodation.⁵⁰ To also consider is that there are more people with no local family, friends or social networks (some of whom are in aged care facilities) and a DD can provide services that ensure nobody dies alone.²

Perhaps one key commonality within DD service provision along with their heterogeneity is their agreement that their role is strictly non-medical.^{8,10,15} However, this is complicated by the fact that DDs can have a background in health, which must continue to be recognised as a potential point of contention not just with role blurring, but with family expectations. It should be noted that one DD provided advice on the timing of providing morphine and as someone with 30 years of hospice experiences this would have come naturally to them. While this DD did not administer the medication themselves, they were providing advice to the family member about medical issues, a fine line undoubtedly for many DDs with a medical or nursing background.¹⁴

While our participants had overwhelmingly positive reports on the experience of engaging a DD, it needs to be acknowledged that most family members do not know what they do not know, and are grateful for any advice, support and guidance provided, but lack awareness of what else is available or what another DD can offer. It also should be noted that if a DD does not have a health background, then they are unlikely to have the same level of knowledge and experience in dying and what this entails, and consumers will be unaware if they are receiving accurate advice. This all speaks to a lack of standardised education programmes and mechanisms for registration that allow those with no experience (perhaps save for caring for their own family member) and/or a weekend DD course in setting up a business.

A broader conversation is required that includes death literacy, compassionate communities and bereavement care, with tensions between personal responsibilities, community functioning and formal systems. Where do these responsibilities lie within changing societal dynamics?

Strengths, limitations and future directions

The present study has generated valuable new knowledge about the lived experiences of families who engage in the services of DDs in Australia and the United States and is the first study of its kind to interview family members about the DD experience. Nonetheless, the findings should be considered within the context of its limitations. Our study, while providing unique and important data that have meaning, does have a lack of certainty about the potential for generalisability.

Recruitment was prolonged and problematic and conducted in phases as we extended our reach to capture potential participants. This may have led to a self-selection bias in only people with positive DD experiences agreeing to be interviewed, some having been recruited by the DD that they engaged. It is possible that family members who had a negative experience would have been less likely to feel comfortable talking about that experience, and they were also probably less likely to have seen the calls for study participants *via* the avenues we had available for participant recruitment.

For one participant, considerable time had lapsed since their DD experience, which may have resulted in recall bias with many details fading over time. Our initial thoughts for the bereaved family member to have distance from the dying experience and the DD were confounded by the fact that many participants were still in contact with the DD and considered them a positive influence and even friend, again a possible confounding factor. The experiences of using DD services may also be different in other countries with different health service provision models.

To gather richer information about the experiences of families engaging in DD services that can better account for recall and self-selection biases, future research needs to longitudinally follow families over time, recruiting them at the start of their DD consumer journey and learning how their experience unfolds. As the prevalence of DD services increases, this will be an important direction for future research to address.

Conclusion

For families in this study, DDs enabled the family member to be prepared for death which led to a sense of empowerment. This, in turn, made them feel emotionally supported and enabled the family member to provide personalised deaths and funerals for their loved ones. The increase in death literacy they gained from engaging in a DD left a resonant effect, whereby the families became more open to discussing death and sharing their knowledge with others. This has the potential to lead to an increase in community awareness and openness to engage with the fundamentals of death and dying.

Declarations

Ethics approval and consent to participate

Ethics approval for the study was granted by the Flinders University Research Ethics Committee (Project: SBREC7933). Informed consent was provided by the participants.

Consent for publication

Not applicable.

Author contributions

Deb Rawlings: Conceptualisation; Data curation; Funding acquisition; Investigation; Methodology; Project administration; Validation; Visualisation; Writing – original draft; Writing – review & editing.

Kristine Van Dinther: Investigation; Methodology; Validation; Writing – original draft; Writing – review & editing.

Lauren Miller-Lewis: Conceptualisation; Investigation; Methodology; Validation; Writing – review & editing.

Jenifer Tieman: Conceptualisation; Writing – review & editing.

Kate Swetenham: Conceptualisation; Writing – review & editing.

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Competing interests

The authors declare that there is no conflict of interest.

Availability of data and materials

The data that support the findings of this study are available from the corresponding author, upon reasonable request.

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