

# An international survey of Death Doula training organizations: the views of those driving Death Doula training and role enactment

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## Abstract

**Context:** Death Doulas are working globally to provide non-medical end-of-life care. They have different training experiences and views on the role and whether it should be standardised.

**Objective:** To seek the views of organisations responsible for training Death Doulas in order to determine what the drivers are behind this emerging role.

**Methods:** We conducted an online survey with Death Doula training organisations in five countries utilising both a targeted and snowball approach. Qualitative analysis was undertaken with themes pre-determined (apriori) due to the nature of the survey categories.

**Results:** In total, representatives from 13 organisations in Australia, New Zealand, Sweden, Canada, United Kingdom, and United States responded. The organisations had provided training for 0 to 20 years, with one just starting and another training birth doulas and now expanding. Owners and trainers hold an array of qualifications such as academic, medical, non-medical, and life experience. Curricula have usually been developed locally, and not always included pedagogical consideration, a strategic business model, nor mapping processes such as gap analysis. The organisations are run similarly, and curricula have several consistent topics but with distinctly different approaches. Trainers' views are also mixed about the way to proceed with registration of the Death Doula role.

**Conclusion:** The contrasting views of training organisations explain much of the ambiguity of Death Doulas themselves regarding standardisation of registration, education and role enactment. If heading towards the ultimate goal of professionalisation of the role then a challenging path lies ahead with little in the way of agreement in what this would require.

**Keywords:** Death Doula, Education, End of life, Training

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## Introduction

The role of Death Doula (DD) has emerged in recent years, described as a non-medical role and as a supporter/guide/advocate in end-of-life care.<sup>1</sup> Engaged for the most part by patients or families, working to empower them or provide some degree of autonomy,<sup>2</sup> DDs work in varying ways to provide information and support pre-death, during the dying process and after-death.<sup>3</sup> Anecdotally and via social media the role is growing in

popularity in Australia, the United Kingdom, the United States, and Canada in particular with a few formal studies undertaken involving DDs in these countries.<sup>4–6</sup> Examples of global initiatives that have been published include Indigenous doulas in Canada,<sup>7</sup> and Doulas for unrepresented patients in the United States.<sup>8</sup> The number of DDs working globally is unknown, with some working full-time, but with most more likely to be working part-time as a DD and part-time in

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another job.<sup>2,3</sup> It is only in the last few years that research into the DD role has started to emerge, with our systematic review and a scoping review undertaken more recently, finding little in the formal academic literature regarding the role.<sup>1,9</sup> The DD role is unregistered (although regulated in many States in Australia), with no standardised education or training in place or required, which is also true for birth doulas, a role which has been in place for decades.<sup>1,5,10</sup>

In a survey that we administered to those self-identifying as DDs to enquire about the role, respondents cited some Australian and International DD training organisations that they had studied with.<sup>3</sup> The respondents reported marked differences in the length and type of training and the number of courses undertaken, with 63.9% saying that they did not think that all DDs receive the same training.<sup>3</sup> The DDs also cited different ways in how they work, although arguably as an independent DD they take aspects of their training and use it to individualise their practice, tailored to client needs. It was also noted in the survey that word of mouth was a common way of receiving referrals, so services provided for one family (such as keeping the deceased at home after the death) may be something that they are then known for.<sup>3</sup> Anyone facing end of life, patient or family/carer can engage a DD if they have the means to do so, with a few DDs volunteering their services but for the most part charging a fee to clients.<sup>2,3</sup> There are no data to date that provide client satisfaction with DD services, and in our survey,<sup>3</sup> the DDs said that they evaluate their service via anecdotal feedback from clients, by how comfortable the dying person is, by fulfilling the client or families' wishes, and whether families refer their services to others (unpublished raw data). Our earlier work has provided the foundation for this study.

With the numbers of DDs growing globally DD training organisations are arguably part of the driving force in this evolving industry. Prior research indicates diversity in training experiences, so identifying the background and rationale for different training approaches is important. The aim of this descriptive study was to gather information and perspectives from representatives of DD training organisations across the world.

### Methodology

Study ethical approval was obtained from the Flinders University Research Ethics Committee

(Project: SBREC7933). The survey invitation was administered electronically via publicly available email addresses and consent was implied on completion of the online form. It was made implicit that organisations could be identified in the process on the Participant Information Sheet, and we asked for their organisations' name and web address.

We developed a survey based on previous research experience,<sup>3</sup> which we imported into Qualtrics. The online survey contained 20 questions in relation to the organisation's curriculum, how this was developed, the experience of trainers, and their views on standardised education and registration. Eighteen of these were open-ended questions and 2 were yes/no questions and an opportunity for a general comment was provided at the end. To establish background information, we asked respondents for the name and website address of their organisation, how long they had been providing DD training, how many DDs had they trained and about the qualifications of their trainers. We also asked their reasons for starting the organisation and the process they underwent to establish curriculum. From there we asked about the courses themselves, and how the DDs know they are ready to practice, and on to their thoughts about standardisation and the scope of the role.

From the earlier survey of DDs, participants identified 5 Australian DD training organisations and we included others in Australia and overseas following a Google search. Convenience sampling was employed (as organisations could be easily sourced and recruited), identifying specific organisations that met the inclusion criteria, with all arguably having a vested interest in the outcome.<sup>11</sup>

We administered the survey electronically on 4 August 2021 (via the lead researcher's email) to 15 DD organisations in 5 countries (Australia, New Zealand, Canada, United States and the United Kingdom). All contact details were found in the public domain. Anonymity was not assured as we were asking for organisations to provide identifiers (name of the organisation and URLs for training curriculum); however, we have chosen not to identify them as some organisations commented on others and are certainly identifiable within this small field. With training organisations in this arena potentially unknown, we asked these potential participants to disseminate the

survey to other training organisations that they were aware of via a snowballing approach.<sup>12</sup>

### *Study population*

Data were extracted from Qualtrics on 30 August 2021 with responses received from 13 organisations, based in Australia ( $n = 4$ ), United States ( $n = 4$ ), Canada ( $n = 2$ ), United Kingdom ( $n = 1$ ), Sweden ( $n = 1$ ), and New Zealand ( $n = 1$ ). From the 15 organisations that we identified and contacted initially,  $n = 6$  (40%) responded. The additional  $n = 7$  organisations were sourced via snowballing approach. There is no way of knowing with certainty who completed each survey, but from responses it appeared that it was the manager/owner.

### *Data analysis*

Due to the categorical nature of the survey questions some of the themes to emerge had been determined a priori.<sup>13</sup> Even so, qualitative data in the form of participant responses were thematically analysed by an independent research assistant using an inductive approach (with participant responses driving the analysis),<sup>13</sup> guided by the concept of grounded theory (theory grounded in the data).<sup>14,15</sup>

This involved first reading through all responses to a question in detail to derive themes.<sup>13</sup> From there similar words and sections of text were manually grouped under thematic headings using open coding<sup>11,16</sup> via a line-by-line analysis of responses, generating a list of concepts.<sup>11</sup> Axial coding was then used to refine the themes further, extending the initial open coding by looking in a more focused way for relationships between concepts.<sup>11,16</sup> Exemplar quotes from participant organisations were listed under each thematic heading, giving weight to the relevance of each theme.<sup>16</sup>

## **Results**

### *Background information*

Background information was provided on the establishment of the DD training organisation (See Table 1).

The DD organisations had been training DDs between 0 and 20 years, with one organisation (Org 4) having just commenced training in September 2021, and another (Org 10) having trained birth doulas and now training death

doulas. Organisations' report training between 0 and over 1,000 doulas per year although the latter figure could include birth doulas. With these organisations in existence for up to 20 years the numbers of DDs trained across the globe could be quite significant.

Trainers reported an array of different qualifications and work experiences. This includes academic qualifications (Masters/PhD) and /or health qualification (such as nurse), or a non-health qualification (such as lawyer). Others will have many different experiences, such as those undertaken by trainers (not owners necessarily) including energy work, dignity campaigner and life experience. Many DD training programmes have been established quite recently which again reflects that this is an emerging community response development.

The drivers of DD course development appear to have evolved from individual passion and attracting like-minded people rather than the professionalisation of a role. There was little indication of business model and gap analysis (or it was not reported). Programme development appeared based on personal knowledge in some cases, with very little report of the use of pedagogical frameworks or assessment or outcomes. Without a formal mapping process and contextual curriculum details, it is likely that each training programme is equivalent to Level 2 or Level 3 in the Australian Qualifications Framework (AQF), with level 7 a bachelor's (undergraduate) degree which HCP will usually study to gain their qualification (e.g. nursing).

## **Training**

### *Eligibility*

Some have no course entry eligibility criteria especially for the foundation or introductory course, one has an age limit (over 18), and others have criminal checks or pre-training surveys to discern the reason for joining. One mentioned postponing training if a recent close death had been experienced.

### *Course information*

The foundation or introductory course could be 5 to 6 hours with most describing their main training course as lasting between 4 and 12 weeks, with one up to a year. It is unknown how many hours this entails as some will be full-time and others part-time. Nine out of 13 organisations

**Table 1.** Organisation information.

Country	Years providing training	No. of DDs trained over the last year (approx.)	Trainer qualifications	Why Establish the organisation?	Process to establish curriculum
1 Australia	1	12	Trainer 1: PhD, birth doula experience, 30 years of grief and trauma recovery psychotherapist experience. Trainer 2: Worked in compassionate communities for 25 years. Trainer 3: Not academically trained. Holds a Churchill Fellowship and worked as a funeral director. Trainer 4: National expert on cultural competence and safety.	"I had undertaken all of the current four Australian training programs and thought there were huge gaps in evidence-based delivery, inclusive content and language, and general social contexts. So I wrote one."	"[...] then I contacted relevant experts in fields that I consider both essential and highly relevant to my training course and asked if they would create content for my course. [...] worked with a graphic designer for some of the digital assets [...]"
2 Australia	20	150	Trainer 1: Owner/Director: Para Legal & 30 years of experience in the community	"The need for people and communities to have knowledge on their option for dying, death, ceremonies and bereavement [...]"	"In its latest format, we were approached by a philanthropic foundation to support us creating a project, our board had a planning day, and it became clear education was the best approach for us to take."
3 USA	5	400	Trainer 1: DONA International approved birth and postpartum doula trainer since 2002, trained over 2,000 doulas.	"I have been training birth and postpartum doulas since 1999; as I age myself, I find the end of life doula topics and issues more compelling"	"I have been an educator for 40 years. Process = identify topics that should be covered; create teaching objectives for each topic; develop outline to cover each objective; identify most effective blend of teaching methods to deliver content; identify best books and websites, as well as relevant articles related to content"
4 Sweden	<1 (approx. 3 months)	None yet	Trainer 1: Certified End of Life Doula (UK), funeral director. Other trainers: Certified grief counsellor, lawyer, body and transportation colleague, palliative care teams, head of burial in Gothenburg, Sweden, and fellow doula colleagues from UK organisation.	"I trained in the UK and saw the need to bring it to my home country, Sweden where the role is completely new."	"Not sure about the question but it's designed for Sweden and in Swedish plus my colleague who is a renowned grief counsellor, brings yet another view and depth to the courses."
5 New Zealand	2	10	Herbal medicine, energy work, psychology.	"I could see a need for it"	"I trained with a number of orgs and combined with my own experience, I scoped needs"
6 Canada	5	>1000	Expert knowledge in palliative care and End of Life Doula practice	"Need to quality end of life care"	"Douglas College protocol and peer review"
7 Canada	3	50	Trainer 1: Taken the course myself and practised. Has a Masters Degree with a focus in end of life care provision.	"I am a practicing death doula and death researcher"	"Group adaptation of an existing curriculum"

(Continued)

Table 1. (Continued)

	Country	Years providing training	No. of DDs trained over the last year (approx.)	Trainer qualifications	Why Establish the organisation?	Process to establish curriculum
8	UK	2	24	Msc. Pg dip education. Counselling. Teaching. Nursing in cancer and palliative care community nursing. Life coaching and one guest speaker is dignity campaigner and author of several books on providing care	"Identified need from nursing patients"	"Accreditation. Review of other orphanisations (sic). Piloted teaching. Linked competences to skills for health and curriculum to eol national standards"
9	USA	1	50	Varied, some life experience, some professional experience	"The absence of community deathcare training"	"10 years of training and hands-on experience
10	Australia	< 1 (just commenced)	None yet	Cert IV (TAE) and Cert IV in Doula Support Services	"We have been providing birth and post natal doula training since 2004."	The EOLD training we provide is a combination of decades of work amongst our team working as practicing birth, post natal and end of life doulas. We of our educators hold a Cert IV in Training and Assessment (sic)"
11	USA	16	200-300	Trainer 1: Hospice RN & Doula in Private Practice. Founding member of NEDA and present Chair of the End-of-Life Doula Advisory Council within the NHPCO for over the last 2 years.	"I started as a palliative educator and private end of life doula in private practice."	"a year long process of the last 10 years of my RN hospice nurse experience and 5 years as a private practice end of life doula."
12	USA	1	5	Bachelor's degree, advanced healthcare licence, experience.	"To make end of life doulas mainstream"	"Many years as a birth and postpartum doula, licensed nursing home administrator, read home health regulations, worked with lawyer"
13	Australia	5	160 (Foundation Workshop) 116 (4-day Intensive Course)	Cert IV in Training and Assessment (TAE 40110). All other current/future trainers are completing Cert IV in Training and Assessment. All trainers have extensive relevant EOL and EOL doula experience and a variety of other qualifications (eg: community services, management, nursing, other tertiary qualifications) and come to the training role with a range of diverse backgrounds and experiences including working in the caring role both privately and in the caring sectors and each has completed the organisation's 4 day intensive and Masterclasses and has undertaken other EOL specific training within their own professional development. We have a vocational training industry specialist consultant on our team.	"Requests for training creation from another organisation who trains birth doulas and were receiving requests for End of Life training. Gaps in service provision within the medical model experienced whilst doing this work. Significant feedback from nurses and other allied health practitioners, organisations and individuals have been received with requests for the EOL Doula Training"	"I undertook a Cert IV in Training and Assessment, debriefed and documented 30 years experience of supporting people at end of life and broke those down into experiences, researched end of life in Australia and overseas, created pilot training, ran pilots and got evaluation and feedback. Then I launched my training. I have continued getting evaluations and revisions on training over the past 5 years"

Footnote: DONA – Doulas of North America, Cert IV TAE – Certificate 4 in Training and Education (Australian Industry and Skills Committee endorsed), MSC PG–Master of Science, postgraduate university qualification, PG Dip – Postgraduate Diploma, NEDA – National End of Life Doula Alliance (US), EOL – End of Life, NHPCO–National Hospice and Palliative Care Organisation.

provided further training. Overall, organisations stated that foundation courses were a prerequisite to engage in additional training, however it varied as to whether people tended to participate only in the foundation courses or continued on to do further training. All organisations stated that they provided students with a certificate after completing the training which may be the foundation course alone or additional courses. For the most part those completing DD training could start practicing at any time, one respondent stating: ‘They work that out’ (org 2) and another ‘they need to feel ready in themselves’ (org 4), others actively mentor trainees, and two require volunteering in a hospice (orgs 8,9). One required insurance.

### Curricula

Each organisation’s curriculum was described, some in detail and others via a few overarching headings, with ( $n = 7$ ) providing links to their website. As one organization described curriculum as “commercial in confidence/copyrighted” details are subsequently not provided on specific course content but rather via overarching lists. These curriculum content lists show some commonalities such as communication, bereavement /after death care but also individual content such as specific to First Nations people, or about holistic therapies. Information in Table 2 has been sourced from either the organisations’ website (if it was provided in the survey) or from the information provided in the survey (see Table 2).

### Content

When asked about the similarity of their content to that provided by others, some participants said that they don’t know for sure what the other organisations teach, and one agreed that there is some overlap. What stood out were the points of difference between training content of organisations articulated by some:

*My point of difference is a very broad and deep cultural, historical and social set of contexts, evidence-based information, a social science background in combination with psychotherapy training and practice [...] As far as I know I am the only end of life trainer to discuss sex and sexuality at end of life and to be as comprehensive and inclusive as I am. (org 1)*

*Mine is an expanded concept of the role of the EOLD. Encouraged to be involved further upstream of active dying process, even with Advance Care Planning when*

*folks are well. I also include training in how to be self-employed and create a doula business. (org 3)*

*[...] but mine also reaches back into renaissance and ancient greek ways of caring for the whole person. Nature and connection to nature is also central to my approach’ (org 5)*

*‘We do have more practical business application. (org 7)*

*Additional validated certificates (sic). Grounded in national standards and competences but bkended (sic) with a non biomedical model. (org 8)*

*I do not teach deathcare with an emphasis on “professional” or how to make money at caring for the dying and dead. That is the major difference!. (org 9)*

*I dont (sic) know of any training that is comparable to mine. I’m not being an ass, just truthful. I have a unique perspective on palliative care, hospice care, private practice. (org 11)*

*No, we are training specifically for our company policy, procedures, trade secrets, team-based care and do things differently than a solo doula. (org 12)*

*We are wholly EOL focussed and dedicated. We now have a Government accredited Certificate IV in End of Life Doula Services [...] Our after death training was developed in collaboration and under the ongoing guidance of Natural Grace holistic funeral directors. (org 13)*

Points of difference in curricula were fiercely defended and ranged from the personal unique perspective to the professional, citing government accreditation and an evidence base.

### Standardisation

We asked participants’ thoughts on a standardised (National or International) education curriculum for Death Doula training, with themes in their responses shown (Table 3), reflecting various sub-themes: that current training varies widely, no room for specialization, in favor of standardised curricula, against standardised curricula, unsure, alternatives to standardisation, importance for insurance and reassurance for the community.

Of  $n = 13$  DD training organisations  $n = 4$  answered ‘No’ in regards to standardised training,  $n = 3$  had mixed feelings,  $n = 2$  did not answer and  $n = 3$  said ‘yes’, but had caveats to this occurring. One organisation did not provide an answer that addressed the question.

**Table 2.** Death Doula training organisation's curriculum.

Organisation	Details of curriculum
Org 1	<p>From the survey</p> <ul style="list-style-type: none"> <li>• All seven non-medical end of life roles, and the overlaps between them</li> <li>• Professional practice, language, cultural competence and safety</li> <li>• Supervision/mentoring, boundaries</li> <li>• Inclusive, respectful approaches to practice</li> <li>• First Nations (culturally approved Australian content)</li> <li>• Public health</li> <li>• Professional practice, working agreements, fees and payment methods/approaches,</li> <li>• Networking, accoutrement, identity, marketing</li> <li>• Self-care</li> </ul>
Org 2	<p>From the website</p> <ul style="list-style-type: none"> <li>• How to do Dying, death and bereavement well</li> <li>• Continual care</li> <li>• Know the stages of death and dying</li> <li>• Advocacy and legal considerations</li> <li>• Practice compassionate communication</li> <li>• Caring for a dying person at home</li> <li>• Recognize the signs of death</li> <li>• After death body care</li> <li>• Loss and bereavement</li> <li>• Charging for your services</li> </ul>
Org 3 (self-paced 35 + hours)	<p>From the website</p> <ul style="list-style-type: none"> <li>• Dying in America</li> <li>• The doula model of care</li> <li>• Accompanying the dying</li> <li>• Communication skills for doulas</li> <li>• Supporting the family</li> <li>• Case studies</li> <li>• After death care and informed choice</li> <li>• Grief and Bereavement support</li> <li>• Self-Care for Doulas &amp; B other caregivers</li> <li>• Establishing and End-of-life doula practice</li> </ul>
Org 4	<p>From the survey:</p> <ul style="list-style-type: none"> <li>• Anything from having deep death conversations, experiencing your own death as in trying out a coffin to being very practical, taking care of a body but also legal laws and regulations.</li> </ul>
Org 5	<p>From the website</p> <ul style="list-style-type: none"> <li>• The caregiver</li> <li>• Care of the soul</li> <li>• The power of nature inspired care</li> <li>• How to talk about death</li> <li>• The importance of paperwork</li> <li>• Working with energy</li> <li>• Creating ritual</li> <li>• Supporting grief</li> <li>• Sacredness of death care</li> </ul>

### Registration

We asked participants' thoughts on registration for Doulas via a peak body (a board for example) (See Table 4).

In terms of registration  $n = 5$  answered No,  $n = 2$  did not answer,  $n = 1$  was not sure that the sector is ready, and  $n = 5$  said yes with one of these adding a caveat.

**Table 3.** Views on standardised education.

Themes	Exemplar quotes
Current training varies widely (standardisation could help close training gaps)?	<i>"[. . .] I am concerned about the cults of personality that arise from many Australian training courses that are run by one person. This is further enhanced by closed FB groups, the blurring of lines between what is offered as doula work per se, and what is considered essential by individual trainers. Org 1</i>
Doesn't leave room for personal interests / 'specializations'	<i>"[. . .] standardisation does not leave room for personal interests and specialist investigations by students as they progress through the course, which in my experience is incredibly valuable. Also, I train pet doulas, and where might that fit into standardised training?" Org 1 "I think there could be some core competencies that are universal, but there also needs to be room for different approaches" Org 5</i>
In favor of a standardised curriculum	<i>"Welcome it but must consider country by country due to language, culture etc." Org 4 "Good idea much needed as long as those providing (sic) (sic) training already are included" Org 8 "Essential! A basic standard is required, i.e. Ethics and Legalities etc, Standard of Care. Org 13</i>
Against a standardised curriculum	<i>"After lots of thought and discussion I am against it" Org 2 "Absolutely terrible idea." Org 3 "NO thanks" Org 10 "No. We do not want to be aligned with hospice volunteers." Org 12</i>
Unsure/mixed opinion	<i>"Mixed. It depends on if it honours the original motivation for the role." Org 7 "mixed thoughts. I would prefer the standardization happen with trainers not practitioners." Org 11</i>
Alternatives to standardization	<i>"I like what we did here in the U.S. with the National End of Life Doula Alliance (NEDA). Trainers from many different programs came together to identify core competencies for EOLDs. Completely voluntary whether or not to comply with these." Org 3</i>
Important for insurance	<i>"Importantly, a standardised education curriculum for Australia Death Doula training is the gateway for insurance providers to recognize the End of Life Doula service and provide appropriate insurance coverage." Org 13</i>
Reassures community	<i>"It provides important assurances to the community and a more robust framework for doulas growing their capacity to make their unique contribution at the end of life." Org 13</i>

### *Voluntary assisted dying (VAD)*

Participants were asked whether they see a role for Death Doulas in Voluntary Assisted Dying. The majority of participants ( $n = 11$ , 86.41%) said yes to this question citing it as a part of care of the dying. One participant had already experienced this type of care working in Victoria, Australia:

*The manifestation of that personal agency at end of life can be greatly enhanced by the presence of an end of life doula who is independent of the family, familiar with the process (increasingly so as VAD is taken up) and*

*providing instrumental practical and emotional support direct to the person in all settings. There is little difference from non VAD [. . .] I have worked with 2 families in this space that are from VIC and looking forward to supporting families in other states as their laws change. (org 13)*

However, there were some caveats:

*One of education and support for the dying person and their loved ones, yes. Direct involvement in the process, no, as that would be a violation of scope of practice.*



**Table 4.** Views on registration for DD.

Themes	Exemplar quotes
Support this idea	<p>"In theory yes" Org 5</p> <p>"I agree" Org 6</p> <p>"Excellent and something I'd like to see in Canada / nationally and provincially" Org 7</p> <p>"Welcomed as the vulnerable public need reassurance and a body to go to if doulas are in question (sic) but again a board representative of the industry" Org 8</p> <p>"Essential going forward!" Org 13</p>
Do not support	<p>"I am not in favour" Org 2</p> <p>"No; I'm American. Believe in freedom." Org 3</p> <p>"[...] when deathcare is kept small and intimate within a community there is no need for regulation.." Org 9</p> <p>"No thank you" Org 10</p> <p>"absolutely not. If you want to disempower the profession then do that" Org 11</p>
Unsure/undecided	<p>"I'm not sure we're there yet..." Org 1</p> <p>"Not sure about the question" Org 4</p>
Do not want government / bureaucratic involvement	<p>"I'm American. Believe in freedom. Doulas do not need to be regulated. We are talking about community based death care, not to be institutionalized or ruled by government." Org 3</p> <p>"Healthcare bureaucracy and insurance regs destroy everything. Doulas would be relegated to the bottom of the heap because they are not required to have higher education. Right now, doulas are advocates in essence and help families navigate for their highest good, not according to systems and they make a great paycheck." Org 11</p>
Regulator needs to be representative of the industry	<p>"a board representative of the industry . [...] clear direction and criteria" Org 8</p> <p>"Whether a 'peak' body is the most efficacious remains to be seen. Perhaps a 'professional' body would be most relevant. An independent, not for profit, professional body is currently being researched and worked and the vision is that it will be run by an independent trustee board. End of life doulas and allied EOL workers and practitioners must be represented by other doulas and like practitioners as well as other representatives. It would not work for a 'peak' body being managed by a medical/clinical framework." Org 13</p>

*Also, it will confuse consumers overall if the profession becomes conflated with assisted dying. (org 3)*

*Yes where this is legislated. (org 8)*

One organisation was not ready to answer yet and one (below) said no:

*I would not suggest it. I have had many conversations with leaders and it would be best to me if the people who companion through MAID be volunteers of the org that is supporting the family. and if that person is also a doula, they not mix it up in their services but rather state they volunteer with so and so. that they never charge for that support. (org 11)*

NB: MAiD is Medical Assistance in Dying – terminology used in United States and Canada

## Discussion

Results from this survey demonstrate diversity in the views of DD training organisation operators regarding training, education, regulation, and standardisation of the DD role. Despite being offered for some years, DD training is not accredited, standardised nor formalized in Australia nor overseas. There are an increasing number of DD training organisations,<sup>2</sup> each with their own unique view on what is to be included in the curriculum. We can see these training organisations in the media (such as those we found on a Google search), in tandem with a plethora of radio interviews, television appearances, podcasts and local directories with DD listings, all of which are helping to normalize this role in the public domain, albeit with a limited assessment of consumer need and understanding of the impact of different approaches and services.<sup>1,9</sup>

### Training

The diverse views, training experience, and knowledge of what training other DDs receive that were seen in our first DD survey in 2019,<sup>3</sup> may reflect the diversity in views of the organisations that train them as seen in the current study. Krawczyk and Rush,<sup>5</sup> highlight this heterogeneity, saying their DD participants celebrated the diversity of the role, but arguably without consideration of the impact of multiple DDs practicing without accord or consensus, contributing to the complexity of potentially coming together via standardisation in practice. Mallon<sup>17</sup> says that approaches to practice and standardisation are in progress, which is starting to be seen in Australia, although with what Young (2021),<sup>18</sup> calls ‘professional ambivalence’. Young<sup>18</sup> uses birth doulas as an example, as they continue to ‘navigate uncertain terrain of their emerging occupation’ (p. 306), across several decades, and DDs may be destined to follow the same path.<sup>18</sup> The professionalisation of the DD role, while still controversial within the DD arena, can also be seen as a way in which to help define the DD role within healthcare, such as in hospital and hospice and to legitimize it.<sup>8</sup> However, not all DD see this integration in a positive light, asserting that their role is independent and should remain so.<sup>9</sup>

The professional ambivalence of DDs appears to be marked by their desire to avoid medicalization of death and dying with the emphasis on the non-medical ‘care work’,<sup>18</sup> in what Francis<sup>6</sup> has termed the ‘personal service industry’. However, this is countered by a drive to be acknowledged as worthy by health professionals in seeking authenticity via qualifications or professional legitimacy.<sup>6</sup> In our previous study, tensions were identified by DDs in interviews where they described that: Health Care Professionals (HCPs) don’t understand their work, that some feel threatened by them, that some are fundamentally opposed to the role, with a few HCP actually quite scathing in their views.<sup>4</sup> However, it should be noted that there are HCPs who do in fact refer patients to DDs.<sup>3</sup> Page and Husain<sup>2</sup> recognize that there are barriers to gaining recognition and acceptance, citing the birth doula movement as a forerunner in this area.

There is diversity in the qualifications of the trainers employed by organisations, and it is important to distinguish between qualifications which identify academic expertise and qualifications relating to relevance or life experience. Relative to this,

the drivers of DD course development appear to have evolved from individual passion such as noting a gap in what the owner felt was lacking, and attracting like-minded people, rather than the planned development and professionalisation of a role.<sup>18</sup> There was little indication of a business model in development of the organisations even as some organisations teach DDs about establishing their own business. Most curricula appear to be based on personal knowledge with some descriptions of evidence-based content but little report of the use of pedagogical frameworks, with a diversity in approaches and expectations.

Krawczyk and Rush<sup>5</sup> in their interviews with DDs found that the majority of their participants were able to outline different training models. However, in the current study of DD training organisations, we found that providers did not always know what other organisations offered but did think that commonalities occurred. In our previous survey of DDs,<sup>3</sup> nearly a fifth of respondents took more than one course and others took more than 3 courses which arguably would then allow them to see similarities and differences. This may also suggest that DDs take several courses as no single DD course meets all of their needs.

### Registration

When questioned on their views of DD registration and standardised training going forward, respondents had quite polarized views. It is unsurprising then that this mirrors our findings in the 2018 survey of DD themselves with respondents quite divided, and in that study also reflective of the general consensus of uncertainly or equivocation nearly a third were neutral.<sup>3</sup> A lack of core competencies for DDs and a lack of requirement for registration with a peak body remains a major gap when there is the expectation that people in the community will pay for this service; however, we note that both are currently being explored in Australia.

### Voluntary assisted dying

Voluntary assisted dying (VAD) is currently legislated in many, but not all, states and territories in Australia as well as in many countries overseas.<sup>19</sup> The majority of our respondents were in favor of being present with someone who was accessing VAD (or MAiD) and as DDs are engaged by the dying person and their family, this could foreseeably be within their remit. Maintaining the non-medical role throughout was emphasized by at

least one respondent though, and this distinction may be the difference between views of HCPs who are required to be more actively involved (such as medical specialists) and who may not be willing to take this role on.<sup>19,20</sup>

### *Strengths and limitations*

This is the first study internationally to source the views of organisations that train and support DDs, and we were successful in gaining input from DD organisations in 6 different countries. Nonetheless, we are aware of the possibility of social desirability in responses,<sup>21</sup> especially as anonymity was not guaranteed. This in itself could also speak to motivation in that while participants willingly contributed to the further development of DD training (i.e. self-selected), they would also be visible in their contributions. Alternatively, it could have prevented participation if organisations did not wish to be identified. It is also unknown how DD training organisations who did not respond or participate would differ from those who did.

### **Conclusion**

Independent organisations are driving the DD movement by laying foundations in terms of philosophies, approaches, knowledge and recommendations for practice. The development of each organisation appears to be based on personal perspectives, with variations in how the organisation evolved, the pedagogy or evidence base behind curricula development, the qualifications of trainers, and aspects of the curricula. The visibility of the death doula role in the media driven in part by the training organizations is normalizing the role, providing pseudo-legitimation in the absence of any formalized national or international processes for registration and standardisation of education delivery. Our empirical research has focused a spotlight on this lack of consensus on these requirements, highlighting the polarized views of those involved.

There remain implications for those working alongside a DD and those who engage them, as transparency in what a DD offers is vital for potential clients/consumers and health care professionals alike. The DD training organisations will drive the professionalisation of the role, although this is likely to happen in the background to a sector where the number of DD

training organisations and indeed DDs are growing significantly.

### **Declarations**

#### *Ethics approval and consent to participate*

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

#### *Consent for publication*

Not applicable.

#### *Author contributions*

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

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

**Jennifer Tieman:** Conceptualisation; Writing – review & editing.

**Kate Swetenham:** Conceptualisation; Writing – review & editing.

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#### *Competing interests*

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

#### *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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## References

1. Rawlings D, Tieman J, Miller-Lewis L, *et al.* What role do Death Doulas play in end-of-life care? A systematic review. *Health Soc Care Community* 2018; 27: e82–e94.
2. Page AD and Husain JH. End-of-life Doulas: documenting their backgrounds and services. *OMEGA*. Epub ahead of print 22 September 2021. DOI: 10.1177/00302228211047097.
3. Rawlings D, Litster C, Miller-Lewis L, *et al.* The voices of death doulas about their role in end of life care. *Health Soc Care Community* 2019; 28: 12–21.
4. Rawlings D, Litster C, Miller-Lewis L, *et al.* End-of-Life Doulas: a qualitative analysis of interviews with Australian and International death doulas on their role. *Health Soc Care Community* 2020; 29: 574–587.
5. Krawczyk M and Rush M. Describing the end-of-life doula role and practices of care: perspectives from four countries. *Palliat Care Soc Pract* 2020; 14: 1–15.
6. Francis AA. Gender and legitimacy in personal service occupations: the case of End-of-Life Doulas and Death Midwives. *J Contemp Ethnogr* 2021; 51: 376–406.
7. Gaspard G, Gadsby C and Mallmes J. Indigenous end-of-life Doula course: bringing the culture home. *Int J Indig Health* 2021; 16: 151–165.
8. Flaherty A and Meurer A. Unbefriended, uninvited: how end-of-life Doulas can address ethical and procedural gaps for unrepresented patients and ensure equal access to the ‘good death’. *Clin Ethics*. Epub ahead of print 11 November 2021. DOI: 10.1177/14777509211057250.
9. Yoong SQ, Goh HS and Zhang H. Death doulas as supportive companions in end-of-life care: a scoping review. *Palliat Med* 2022; 36(5): 795–809.
10. Rawlings D, Davies G and Tieman J. Compassionate communities: what does this mean for roles such as a death doula in end of life care. *Public Health* 2021; 194: 167–169.
11. Green J and Thorogood N. *Qualitative methods for health research*. London: SAGE, 2018.
12. Naderifar M, Goli H and Ghaljaie F. Snowball sampling: a purposeful method of sampling in qualitative research. *Strides Dev Med Educ* 2017; 14: e67670.
13. Azungah T. Qualitative research: deductive and inductive approaches to data analysis. *Qual Res J* 2018; 18: 383–400.
14. Blair E. A reflexive exploration of two qualitative data coding techniques. *J Methods and Meas Soc Sci* 2015; 6: 14–29.
15. Noble H and Mitchell G. What is grounded theory? *Evid Based Nurs* 2016; 19(2): 34–35.
16. Saldana J. *The coding manual for qualitative researchers*. 3rd ed. London: SAGE, 2016.
17. Mallon A. Compassionate community structure and function: a standardised micro-model for end-of-life doula and community members supporting those who wish to die at home. *Palliat Care Soc Pract* 2021; 15: 1052569.
18. Young C. Professional ambivalence among care workers: the case of doula practice. *Health* 2021; 25(3): 306–321.
19. Booth S, Eleftheriou P and Moody C. Implementing voluntary assisted dying in a major public health service. *Med J Aust* 2021; 214(8): 343–346.
20. Sellars M, Tacey M, McDougall R, *et al.* Support for and willingness to be involved in voluntary assisted dying: a multisite, cross-sectional survey study of clinicians in Victoria, Australia. *Intern Med J* 2021; 51: 1619–1628.
21. Bergen N and Labonté R. ‘Everything is perfect, and we have no problems’: detecting and limiting social desirability in qualitative research. *Qual Health Res* 2020; 30: 783–792.