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Title:

The voices of death doulas about their role in end of life care

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## **Abstract**

'Death Doulas' have emerged as a relatively new role supporting dying people and their family members, however there is a lack of clarity around how the role is enacted, and around the death doula role within health and social care systems. This study aimed to explore the ambiguity of the role of death doulas in end-of-life care including the skills, training, and experience of death doulas; how the role is communicated to the community; and the relationships to palliative care providers and other health professionals. People identifying as death doulas were invited to participate in an online survey between April and June 2018. Ethical approval was obtained. A descriptive cross-sectional study was conducted, and purposive sampling was used to survey death doulas registered with death doula training organisations, newsletters, and email distribution lists. Questions were based on the researchers' previous findings about the role. One hundred and ninety completed or partially completed surveys were received. Results showed diversity within, and some commonalities across the sample in terms of: training, experience and skills; Death doulas have emerged not only as a response to the overwhelming demands on families and carers, but also demands placed on health care professionals (including palliative care) at the end-of-life. They have identified gaps in health and social care provision, perhaps taking on tasks that health professionals don't have responsibility for. However, the roles and scope of practice of death doulas is not clear-cut even within their cohort, which can then make it hard for patients and families when choosing a death doula, especially as a lack of regulation and standardised training means that doulas are working without oversight, and often in isolation.

**Key words:** death doula, end-of-life, community, models of care, health and social care

What is known about this topic?

- Death doulas are working with people at the end-of-life
- Death doulas work in varied roles however there is a lack of clarity around the role and their place within the health and social care systems
- There is no regulation of doulas nor standardised education

What this paper adds

- There is diversity and some commonalities within death doulas, in terms of education undertaken and in the reasons for taking up this role
- How the role is enacted in end-of-life care is dependent upon the skills, knowledge and experience of individual death doulas, and arguably the wishes of their clients

## **Introduction**

The role of 'Doula' ('woman caregiver') has seen women (friends, family, community members) helping to birth babies in the community for many years (Wingate, 1998). The role of 'birth doula' has subsequently emerged in modern times, reflected in the midwifery literature since the 1970's (McLeish & Redshaw, 2018), with men and women now working mostly in non-medical roles, supporting women emotionally and physically in their birthing plans and often in the post-natal period (Meadow, 2015).

From these origins, 'death doulas' have appeared as a relatively new role (albeit with the same historical beginnings), with increasing reports of death doulas in the public media. Nomenclature to describe the role often reflects these origins, with terms such as 'midwife of the soul' and 'soul midwife' in use. More commonly though, terms such as 'death doula' and 'end-of-life doula' are used not only in the media but in how people working in these roles refer to themselves. The role has been described as one of companion, mentor and advocate for the dying (Elliott, 2014).

The majority of people spend most of their last year of life at home (Martin, Olano-Lizarraga, & Saracíbar-Razquin, 2016) with an increasing reliance on family, friends, neighbours and community members for support. Despite formal help such as nursing /community services both public and private, there are gaps in what can be provided and what carers have identified as needed (Lam et al., 2017). Globally in order for people to be able to achieve their desire to die at home, there is an increasing dependence on this informal social care (Brown & Walter, 2014). Thomas et al. (2018) describe the 'background worries' of family carers who could potentially benefit from people such as hospice volunteers, who could maybe listen and help identify these concerns. Arguably death doulas are starting to fulfil this role and have emerged in response to how much we ask of those caring informally for the dying. This may reflect both the lack of availability that people have to care in an increasingly economically driven society as well as the emotional and knowledge preparedness to

provide care for someone who is dying. Part of the 'Compassionate Communities' movement also looks to address the unmet social needs of family carers via 'resilient caring networks of support' (Abel, 2018).

In the absence of a governing body for death doulas in Australia (and elsewhere), and of formal accreditation, no statistics are available on the number of death doulas working in Australia. Anecdotally however, it is a vocation gaining more awareness and traction. A recent systematic review, with five included papers (only one was a study that included doulas as participants) found that despite the fact that this is a growing and evolving role in end-of-life care there is a major gap of published academic literature about death doulas, (Rawlings, Tieman, Miller-Lewis & Swetenham, 2018). Grey areas were identified in what the role entails, the quality of education and training of death doulas, their relationship to health and palliative care services, the financial arrangements that are in place (if any), and the motivations behind those who are entering this growing industry.

The purpose of this study is to explore the death doula role from the perspective of death doulas. To this end we administered a survey to those self-identifying as death doulas to describe the doulas' role, experience, and reasons for becoming a death doula.

## **Methods**

### Study Design

People identifying as death doulas were invited to participate in a web-based survey (Regmi, Waithaka, Paudyal, Simkhada, & van Teijlingen, 2016), developed for this purpose. Criterion sampling (Palinkas et al., 2015) was used, with a specific cohort of individuals required to help answer the research question: 'What role do death doulas play in end-of-life care?' Survey questions were informed by previous findings from a Massive Open Online Course (MOOC) on death and dying (Dying2Learn) developed and offered by members of the

research team (Tieman, Miller-Lewis, Rawlings, Parker & Sanderson, 2018), and the systematic review on the role of death doula in end-of-life care (Rawlings, et al., 2018).

Using an online survey methodology facilitated accessibility, low cost, efficiency and reach (Leach, Butterworth, Poyser, Batterham, & Farrer, 2017). The survey consisted of questions relating to reasons for becoming a death doula, what the role entailed, the training associated with the role, and demographics. Responses to structured questions were either multiple choice, open-ended, or 1 to 5 Likert-type scales. Respondents used the general open-ended questions to expand on these issues. No responses were forced. Questions were piloted with colleagues, one of whom had undertaken death doula training (Regmi et al., 2016). The survey design and conduct has been reviewed against the CHERRIES checklist (Eysenbach, 2004).

### Recruitment

People who identified as death doula were invited to participate in the online survey via:

- a) the CareSearch Dying2Learn MOOC on death and dying email distribution list;
- b) the CareSearch newsletter;
- c) via a community partner (The Groundswell Project); and
- d) via Australian Death Doula training organisations: Preparing the Way, The Australian Doula College, The Natural Death Centre, and Death Doula Australia.

Organisations (advertised in the public domain) were asked to disseminate the survey electronically among their members. Potential participants were then asked to forward it to someone they know (Sedgwick, 2013). The participant information sheet was emailed with the link to the survey, which was open for a ten-week period (allowing dissemination via newsletters. With multiple avenues by which to invite death doula to participate, calculating a response rate is difficult.

## Data Analysis

Survey data was stored in the CareSearch Research Data Management System (CareSearch, 2019). Descriptive statistics were performed on the closed-ended questions to summarise and analyse the quantitative data and are reported as number of respondents (n=) and proportion (%) (IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp). Data from free-text answers were determined apriori due to the categorical nature of the survey questions, which captured what needed to be answered (Blair, 2015). As a result, the qualitative comments served to support and provide clarification of what had emerged in the survey, rather than being theory driven (Whitehead, Dilworth, & Higgins, 2016). These verbatim answers were coded into a relatively small and meaningful set of categories or themes. Coding and thematic analysis were undertaken using NVivo 12 (QSR International Pty Ltd. Version 12, 2018).

## Selection criteria

The introduction to the survey stated: “As we understand very little about the different aspects to death doula work, we are asking for **help from those who self-identify as working in this role**”. Therefore, anyone who self-identified as a death doula by completing the survey had their responses included. The survey comprised four main areas: training, reasons for becoming a death doula, role of a death doula, and lastly socio-demographics.

## Ethics

Study ethical approval was obtained from the Flinders University Research Ethics Committee (Project: 7933). An information sheet detailing what the survey involved was available prior to commencing the survey, and consent was implied upon electronic submission.

## **Results**

Two hundred and six respondents clicked into the survey, however 16 didn't answer any questions, therefore data is based on 190 valid responses and included complete and partial responses. As all questions were voluntary, there are varying levels of missing data, however all valid responses to each variable were included.

## **1.Sociodemographics**

Respondents (Table 1) did not fall into simple categories, with both considerable diversity within, and commonalities across the sample.

### **TABLE 1 HERE**

Of 85 responses, most were female aged between 50-59. Fifty-two respondents (61.2%) reported having a health qualification (predominantly nursing). Of those who responded to this question (n=85), only 5.9% (n=5) were actively practicing solely as a death doula, with 32.9% (n=28) in a dual role.

## **2.Training, experience and skills of death doulas**

Of those respondents (n=171) who replied to the question: 'Did you receive training as a death doula?', over half (58.1%) reported undertaking training although they classified a range of teaching and learning activities within this. This included face-to-face workshops, seminars, 'on the job' learning and completion of online learning (e.g. webinars and online learning modules), all perceived as relevant to the death doula role. Respondents acknowledged that, in many cases, their skills and knowledge were developed during work in other roles such as nursing and counselling with, for example, some classifying a University degree as training to become a death doula (while others did not). Three Australian death doula specific courses were frequently mentioned (70% had completed one of the three) when asked where they had received their training.



Of those providing a response to the question: 'Do all death doulas receive the same training?' (n=97), over half (63.9%) thought that death doulas did not receive the same training, although over 30% (n=31) did not know. With respect to the length of training described, there was a wide range of answers, with some examples being '1 day', to '1 year', to '200 hours theory' (n=93). Respondents identified a wide range of topics covered during their training (n= 67) (Table 2), providing detailed descriptions. Fourteen respondents did not provide descriptions, with some (n=8) providing general comments, such as the weblink to their training, and others (n= 6) commenting that the training was comprehensive, and it was too difficult to describe it. Some respondents (n=22) cited death doula training courses from overseas, presumably as they lived there, travelled there, or have undertaken online education. Some (n=19) had undertaken more than one course.

**TABLE 2 HERE**

### **3.Registration and certification**

Questions regarding registration and certification elicited the most survey responses (Table 3).

**TABLE 3 HERE**

In the registration responses, of interest is that nearly one third of respondents (n=51, 30.2%) "neither agreed nor disagreed" with the statement "death doulas should be registered". This indicates some ambiguity about this possible next step. In terms of training, the majority (n= 121, 72.9%) agreed or strongly agreed that there should be a minimal level of training to be a death doula. The views in the open-ended responses were also varied. Some were supportive of the role being formally recognised and certified, others were not:

*I believe developing a model of registration or certification would be very useful. Respondent #46*

*It would be a shame to make the death doula process too formalised as what I have seen is that we ALL need these skills as life skills, therefore it needs to be accessible to everyone..... If it becomes too formalise than (sic) it's creating more separation from the journey of death for the everyday person. ... Respondent #11*

#### **4.Reasons for becoming a death doula**

Many death doulas (n=33) came with a set of experiences, knowledge and beliefs that had developed over their professional lifespan (eg, nursing, social work). Some respondents reported being “drawn to the work”, and 11 used the word ‘called’ or ‘calling’:

*I realised that I had already done this, without even knowing what it was. When I heard about it, I knew that I would do this work. Respondent #69*

Twenty-six respondents included personal experiences in their commentary. Sometimes this informed their decision to become a death doula, including citing the need for the role because they had witnessed situations where dying was perceived as not being “done well”, or they considered there to be a lack of support and knowledge and wanted to be able to provide that to others.

*After my own personal experiences with death in my life and the lack of support and knowledge I and my family had, I wanted to be able to provide that support and information that was lacking to others so they never felt as lost as I did. Respondent#25*

One nurse reported seeing gaps in good quality care of the dying:

*My nursing skills give me an insight into the current services available and their limitations...One of my last nursing experience was with a gentlemen who wanted to die at*

*home but due to availability of Palliative team was transferred to hospital to then die 12 hrs later. This was my lightbulb moment to become a Death Doula. Respondent #51*

Doula's feedback that they recognise that the work of the professional healthcare team is essential and different to the services that a Doula provides. Doulas indicated that their point of difference is an ability to provide total person care throughout all aspects of dying and death. They reported having capacity to offer additional emotional and spiritual support alongside the care already being provided by the healthcare team. The question "What do you do that health professionals don't or can't?" elicited many responses, including:

*Provide time with the families as needed. It is not controlled by an agency/government funded etc. the family pay for the service you provide. Respondent #145*

*As a death midwife, I offer a continuum of care throughout the whole of the pan-death process -- which is not presently possible between hospital or hospice/palliative care and the funeral industry. Respondent #171*

*Health service providers are in and out within a set time limit. Basically, nurses are in for half an hour to an hour a day, changing pic lines, checking vitals, giving medication, etc. PSWs are in for maybe half an hour to an hour per day, washing or bathing, getting them dressed and up into a chair ...I do everything else. Respondent #174*

Many said that they felt comfortable with death and viewed it as a natural part of life. Not only did they say that they were comfortable with death, they also said that they were familiar with the dying process through previous life and work experience.

## **5.The role of a death doula**

### *Commonalities*

There were many similarities in the role tasks described by respondents (n=108) (Table 4). Likened to having a personal advocate and caregiver to accompany a person through the process, respondents (n=113) described the most important aspects of the death doula role as related to reducing fear/anxiety around death; providing holistic care; and empowering individuals/families/carers by providing information and choices. This often included providing education and guidance as well as physical, emotional, spiritual support and assistance with practical needs:

*To give informed information to individuals and family members for end-of-life care, Being available when the individual or family needs me (No time or shift clock). Advocating on their behalf if requested. Listening to their needs and requirements, managing and outsourcing to achieve the best of their lives until death and the immediate time after.* Respondent #51

*Emotional and spiritual support. Reassurance, practical support, interpreting medical speak into language others can understand, non-judgement, just being a calming presence.* Respondent #107

*Being a non-medical companion that can offer assistance when/if needed, from sitting and listening, to being present at appointments so that a second set of ears hears what is being said, to allowing a carer to have a break, and being there for the patient when needed to just be present, sometimes in silence and sometimes to talk.* Respondent #108

Eighty-four respondents provided 485 tasks in 29 categories (Table 4). Traits e.g. compassion, rather than tasks were excluded. Understandably there are similarities between tasks undertaken and the education provided

**TABLE 4 HERE**

Respondents initially described the types of things they do as a death doula. Following this the question was asked: “Do you think these things are common to all death doulas?” Of 108 respondents, just over one third of doulas thought the tasks they had described were common among their peers (n=42, 38.9%), although 21.3% (n=23) thought that there were differences in services that were offered, and 39.8% (n=43) didn’t know.

Death doulas reported being ‘*flexible, adaptive and responsive*’ to their client’s needs, appearing to recognise that more support is required as the health of a client deteriorates. They reported that symptom management becomes a priority, and that family members may require more emotional support as death draws near. When a client is no longer able to communicate, doulas, if involved earlier in the process, reported advocating for the client to achieve the type of care they wanted. Some respondents with a professional background in nursing, described being able to provide a holistic assessment of a dying person. Like other doulas, they described being able to identify symptoms as well as other needs, but they could also work with the healthcare professionals to manage symptoms:

*As a nurse working in Palliative care, I felt this integral role of Death Doula compliments and enhances my nursing practice. Respondent #88*

## **6. Working practice**

Of 88 respondents, around half (n=47, 53.4%) reported that they had a backup to take over duties if they could not be present for a client, implying that just below 50% do not, suggesting potential for isolation within the role. Indeed 67.1% of respondents (n=59) reported that they *do not* work with other death doulas when providing care.

Some respondents reported that they are paid to undertake a doula role whilst others reported providing support in a voluntary capacity. Of 77 respondents, 49.4% (n=38) reported that they had *never been paid* as a death doula. Twenty-four (31.2%) reported

receiving monetary payments, and interestingly 5 (6.5%) reported receiving an 'in-kind' payment and 10 (13%) reported receiving monetary and 'in-kind' payments. Respondents who reported that they were not being paid, typically said that they planned to start charging a fee. In keeping with this, 43 out of 81 (53.1%) were in possession of an Australian Business Number (ABN) indicating a potential to start a payment process.

### Role after death

Some death doulas offer care extending past death, to bridge a gap between hospital or hospice/palliative care and the funeral industry. Over two thirds of respondents (68.1%) reported having a role immediately after death (usually 36.2%, or always 31.9%), e.g., funeral/wake/celebrations-of-life arrangements. A similar proportion (66.2%) reported having a role with the family following the death (usually 36.6% or always 29.6%), e.g., grief, loss and bereavement care.

Of those who provided free text comments at the end (n=54), nearly 30% (n=16) acknowledged the importance of this research, thanked the researchers, or were pleased that doulas were receiving recognition. Many wanted to ensure that medical professionals realised that death doulas should not be viewed as 'competition' in care of people at the end-of-life:

*Please make sure that medical teams don't see us as a threat-we are an additional support for a dying person. People need to be aware of our role and we should work as a community together to give people an informed choice and a holistic care* Respondent #74

*Please educate the community, medical and nursing staff, associations that death doulas are here to add another layer of support- not to replace anyone else's role* Respondent #76

## Discussion

The findings from this survey corroborate strongly with those from our systematic review (Rawlings et al., 2018). There are inconsistencies in how the death doula role is described and enacted, not only in the academic literature but through the voices of those working as death doulas. This is clear from the start with variations in terminology describing the role, with some not identifying with the title 'Death Doula', finding it '*diminishing and restrictive*' of the role.

The death doula role has emerged not only as a response to the overwhelming demands on families and carers, but also by demands placed on health care professionals (including palliative care professionals) at the end-of-life. In specialist palliative care, as disease trajectories become more prolonged in both the malignant and non-malignant patient groups and resources are stretched further to meet the early referral needs of those living with a life limiting illness, it is likely there is an unmet need as stabilised patients are discharged back to primary care providers. Death doulas have identified 'gaps' in health and social care and in our study reportedly see themselves as taking on tasks that health professionals have no time for, with time being a main differentiating feature from the perspective of death doulas. Death doulas may also provide care to those who live alone and may be isolated.

Those working in the 'caring' professions are maybe drawn to this role because they want to spend more time sitting, talking, listening than can be accommodated in the context of busy clinical work, or in the words of one doula "*Being a Death Doula allows me to practice the nursing of my heart*" (Respondent #68). There does appear to be some confusion though for some respondents who work as a death doula and in another health-related role or profession (32.9%, n=28 are in a dual role) with some viewing the roles as quite separate, while others see more of an overlap in tasks or a synergy in care intent. Some of the respondents who had a health professional role reported that they considered this

professional role to be the same as that of a death doula, and therefore saw themselves as a death doula.

*I am working as a Palliative Nurse in the community- I do night respite 8 hour shifts and believe I do doula work - but I am paid as an RN Respondent #99*

Such comments highlight a potential for duplication with existing roles and a potential for misunderstanding professional responsibilities. Health professionals feeling they are doing death doula work without the title, and unpaid doulas not recognised and managed within a volunteer framework, add to this role complexity. This can lead to confusion for health professionals and doulas as well as for families. As found in the midwifery literature, role definition and in this case, delineation is hard (Meadow, 2015). Such is the confusion that people who were clearly not a death doula were driven to complete this survey, even though it was not intended for them. Some respondents were confused as to whether it did apply to them while others were interested in the death doula role but had not yet taken this interest any further. Certainly, some respondents were transitioning from health care professional roles to that of a death doula, arguably creating tension between what is being paid for, and caring work that may previously have been undertaken by families or communities (Kellehear, 2013).

Almost all doulas expressed the importance of having a medical team involved, and that they left the administration of medications to medical personnel. However, one doula reported that: *'as a nurse I can administer medication'* (Respondent #99), indicating again that role boundaries easily become blurred in dual roles. Generally, though, respondents reported contact with health professionals for symptom control needs and were comfortable with health professionals being involved with their clients. This may reflect an understanding of professional practice given the high number of respondents with health professional



qualifications, a belief that the death doula role is complementary to health professions (Elliott, 2014), or be particular to this cohort of survey respondents.

As with birth doulas (Meadow, 2015) there is no one single definition of a death doula, with each individual offering what they are comfortable with or what they envisage the role should be. As a result, each death doula can enact a slightly different role. For example, those who are multi-credentialed (i.e, they are also a teacher, nurse, social worker, pastoral care worker, or massage therapist) provided a blended skill set. The respondents themselves were not sure whether all death doulas offer the same services. This implies a generalised confusion within the industry, which does not then allow for ease of choice for patients and families when choosing a death doula. For example, some doulas reported supporting the dying person exclusively, some focused on supporting family and friends rather than the dying person, and some only offered support after death. Nonetheless, all were clear that it is a non-medical role.

There are a number of organisations in Australia and globally where individuals can undertake training to become a death doula. There is, however, a lack of common understanding regarding the training of death doulas, the skills they possess, and the role they play in end-of-life care. Training programs are well established, embedded long before role definition, which is arguably a symptom of an unregulated field. Death doula training varies considerably, and death doulas can and will do more than one training program (or none), before they establish themselves as a death doula. There was a small cohort that had attended as few as two days of training, most respondents however had undertaken more than one training course in addition to participating in self-directed learning. Those who have not undertaken death doula training may be health professionals who perhaps do not see that they need additional training and, here, included the experience related to that of a registered nurse, a Lifeline telephone counsellor, hospice work or hospice volunteering. Presumably this is due to the perceived transferability of skills and knowledge.

There was a high amount of variability in the duration and type of training undertaken by death doulas over a period of time. The training could be via face-to-face workshops, seminars, 'on the job' learning, online learning such as webinars and completion of learning modules perceived as relevant to the death doula role. There were some frequently reported doula colleges. Most of these were Australian, with a few from the United Kingdom, Canada, and the US. The doulas' motivation to undergo training also varied, and a study of birth doula training Gilliland (2016) found that apart from wanting to work as a birth doula, many were there for personal reasons (e.g., to understand own births past and future), some to establish a profession, others as a precursor to midwifery training. Interestingly the birth doula training is now part of early midwifery education (Gilliland, 2016).

In our study and also in Gilliland's (2016) birth doula study, there were those working in a voluntary capacity. In end-of-life care this then raises the question: How is a death doula different from a palliative care volunteer, which Claxton-Oldfield (2015) describe here: *"Volunteers provide a qualitatively different relationship from that of professional staff, that is, they provide support grounded in the everyday interpersonal experiences of non-professionals"* (p.39). There are similarities between volunteer death doulas and volunteer hospice roles in the tasks they perform, however, fundamental differences lie in the models of care. Volunteer coordinators are often linked to hospital/hospice teams, with a more consistent training program that, in Canada for example, is designed to be consistent nationally (Claxton-Oldfield, 2015).

Some death doulas are paid and others volunteer, such as with some birth doulas (McLeish & Redshaw, 2018) and some even take "payment in-kind" (typically goods or services in the place of cash payment). This begs the question: How can the death doula role evolve if they need to take paid work to support their unpaid work? They cannot then guarantee to be available for a client's needs, which seems a pragmatic realism that needs to be addressed.

Part of the issue is surely what death doulas are being paid for, and parallels to this can be drawn with work in home care (aged) where services are negotiated with the client, as consumer-directed care within a fee and management system.

Of our respondents who were not paid, they typically reported a plan to start charging a fee to care for people at the end-of-life, wanting it to be a profession and earn income from the service they provide. Currently there is no recognised professional body in Australia or overseas that certifies death doulas, nor are they regulated by any formal laws or standards which may also speak to some of the tension regarding payment, as presumably anything under a payment system without regulation is constrained. Despite decades of their existence, this is also still the case for the majority of birth doulas, certainly in the UK (McLeish & Redshaw, 2018) and in Australia (Rigg et al., 2018). Interestingly, the greatest number of responses were received to the questions about training and regulation, clearly an important issue for death doulas.

One argument within the birth doula literature to support the role, is that doulas can provide a continuous presence during the pregnancy and throughout labour, whereas a busy midwife might come and go (McLeish & Redshaw, 2018), and some mothers may only meet their midwife at delivery. In our study, however, nearly half receive referrals in the last days of life so any arguments about continuity throughout the end-of-life period do not necessarily hold true. Arguably though, the same can be said in some cases for referral to palliative care. For example, Hahn et al., (2017) describe 'standard cancer care' where: "*palliative measures generally are initiated when it is evident that disease-modifying treatments have been unsuccessful, no treatments can be offered, or death is anticipated*" (pg1).

### **Strengths and Limitations**

This study is the first to investigate the role of death doulas in detail, so no standardised questionnaire could be used. Doulas self-selected to participate in the study, and some were

not actually death doulas. It is unknown what difference might exist between doulas who chose to participate and those who chose not to. Around half of the surveys were partially completed. Participation dropped toward later sections of the survey which required specifics of the death doula role via open-ended questions. For those who were not yet working as a death doula this would represent their inability to respond to the question.

## **Implications**

Death doulas appear to be filling social care gaps not necessarily medical ones and this is how they describe their role. Death doulas are a response to a system that is coping with unprecedented demand and changing expectations. It is highlighting that needs experienced by those at the end-of-life might be more than those identified by the health system. Each doula offers services tailored to the client needs or to their own experiences and skills. Some doulas have additional professional training and credentials allowing them to offer specialised or blended services. However, families will need to find out more about services provided (perhaps from local health professionals) so that they can make informed decisions about care that they are potentially paying for, and before they bring someone in to their home to care for themselves or a loved one. This brings up the question of who are the death doulas serving?

In light of the lack of regulation and standardised training, which in itself requires further work, doulas are working with families without oversight, and often without support. Some doulas are working as, or have worked as, a health professional, and there may be some role blurring. Does this then mean that the palliative care nurses/hospice volunteers/pastoral care workers etc in their private lives are doing the work of the death doulas or are they including their work in paid roles as 'death doula' work? This speaks further to the lack of clarity around the role, as does the nature of the voluntary work that some doulas take on. Further investigation into many of these complexities is warranted.

## **Future Research**

The findings of this study raise further questions about the role of death doulas in end-of-life care. Future research underway includes hearing further from death doulas about their role via interviews. Similarly, we will conduct research with palliative care health professionals on their experiences of working with death doulas. Several unanswered questions remain, including: the experiences of families who have had a death doula involved in end-of-life care; are death doulas working only in the community or in other settings; how do palliative care nurses/hospice volunteers/pastoral care workers differ from death doulas; and most importantly, how does each group operate within and impact the wider palliative care system?

## **Conclusion**

With an ageing population, end-of-life is brought increasingly into focus. With changing population characteristics, the lack of funded resources, and the desire to receive care that is individualised for patients and family, the death doula role is evolving worldwide. How that role is articulated and enacted is unclear, as are the training requirements and scope of practice, however clarity is required to satisfy the consumer driven care that will be required in the future.

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