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Title: End of life doulas: A qualitative analysis of interviews with Australian and International death doulas on their role.

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Ethics

Ethical approval was obtained from the Flinders University Research Ethics Committee (Project: 7933).

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Conflict of Interest Statement

The authors declare no conflict of interest

Title: End of life doulas: A qualitative analysis of interviews with Australian and International death doulas on their role.

Abstract

Death doulas (DD) are working with people at the end of life in varied roles with more clarity needed around their role and place within the health and social care systems. The aim of this work is to explore the DD role in end-of-life care from the perspective of DDs. A subgroup of 20 DDs from a larger quantitative survey participated in semi-structured telephone Skype or Zoom interviews. Interview data was analysed using thematic analysis. Seven themes emerged from the qualitative analysis: what a DD offers, what a DD does, challenges and barriers, occupational preferences, family support, contract of service/fee, and regulation. There is a general perception that health care professionals (HCP) do not understand what it is that DDs do, thus the current study has helped to demystify the DD role and potentially reduce suspicion. The lack of a DD business model sees inconsistencies in what services each DD offers and what patients and families can expect. End-of-life is complex and confusing for patients and families and there is a need to further explore the DD role and how it can work when there are many inconsistencies in working practice. More research is required to look at the interplay between DDs, HCPs and palliative care volunteers in addressing the gaps in care provision and how these relationships might be more seamlessly managed.

Key words: death doula, end-of-life care, qualitative research, models of care delivery, health care, social care

What is known about this topic?

- HCPs will often work with someone who is at the end of life, and DDs are also increasingly working in this space
- HCPs offer defined services within clinical disciplines and multidisciplinary teams
- There are some similarities between HCPs and DDs in the tasks they undertake

What this paper adds

- DDs and HCPs will increasingly work with the same clients with discrete differences in role enactment, but also some overlap
- DDs could potentially complement the HCP role in end-of-life care models, although DDs may prefer to remain independent
- The DD role challenges what is a health system responsibility and what is personal arrangements in the complex business of dying
- A lack of a DD business model sees vast differences in what is offered and what a patient or family member can expect including care options and fees

Introduction

Current health/social care systems are experiencing increasing demand arising from more prevalent chronic diseases (Martin-Lesende et al., 2016) and an ageing population for whom death will be an inevitable part of a foreseeable future (ABS, 2019; AIHW, 2019 Commisso et al., 2017). There are concerns about a lack of infrastructure and capacity to fully support the increasing number of people approaching their end of life (Etkind et al., 2017). Moreover, access to end-of-life care is inequitable and sometimes supports are not available to families who provide care for the dying person (Rawlings et al., 2018).

Taking on the role of caring can be rewarding, but also be challenging, complex and demanding (Rosenberg et al., 2015). Care of the dying asks a lot of informal carers, and with fewer carers available (perhaps due to geographic dispersion of family members or more people living alone), a lack of coordination of health service provision, and the move from dying in hospital to dying in the community, there are gaps in what can be offered in health and social care support (Rawlings et al., 2018). With an increased reliance on social care in end of life (Brown and Walter, 2014), in tandem with a palliative care workforce shortage (Kamal et al., 2017), people who are dying and their families may seek the services of those in non-medical support roles, such as a Death Doula (DD) to support them in their care and advise on place of care choices (Rawlings et al., 2019).

DDs are described as a companion and advocate for the dying (Elliot, 2014). It is a role that is not well articulated, with a lack of clarity in the literature (Rawlings et al., 2018) and from DDs themselves as to what the role entails (Rawlings et al., 2019). A lack of consistency has been found in terms of the education/training DDs receive, how they enact the role, discretion in the elements of care provided/negotiated, and views on whether the role should be subject to registration and certification (Rawlings et al., 2019).

With differences in what is offered by each DD, there are subsequently differences in what a patient or family member can expect, including care options and fees (Rawlings et al., 2019).

While many role variations are related to the skills and experiences of each DD, some could be consumer-directed (e.g., in response to a stated need). To address the emerging role of the DD, we have embarked on a research program relating to the DD role in end-of-life care. A systematic review (Rawlings et al., 2018) found few studies on the DD role in the literature, however it did raise a series of questions, such as the DD relationship with health providers, and the needs of, and services provided to, clients. A subsequent survey of DDs was carried out (Rawlings et al., 2019), and while this provided greater detail on many aspects of work undertaken, there remained a lack of clarity about the nature of this role and inconsistencies in reported activities of DDs in the literature (Fukuzawa & Kondo, 2017).

The aim of this study was to provide a more detailed exploration of the activities, practices and interactions of DDs with clients and their families at the end of life and provide insights into the points of interface with Health Care Professionals (HCPs).

Methods

This exploratory study involved semi-structured qualitative interviews undertaken with DDs about their role.

Sampling and recruitment

One hundred and ninety people who self-identified as working in a DD role completed or partially completed an online survey about the different aspects of DD work. These survey data have been reported elsewhere (Rawlings et al., 2019), detailing recruitment via: email distribution lists, newsletter, a community partner, four Australian DD training organisations and via snowballing (with resulting international participants). Upon completion of the survey, participants were asked to provide their contact details (in a separate online form) if they were interested in participating in an interview to explore in more depth their roles within end-of-life care. In total 25 individuals provided their contact details and constitute a subsample of the original 190 who took part in the online survey. One researcher (CL)

159 contacted these individuals via email to confirm their consent to participate and arrange a
160 time for an interview. Four were not contactable and one declined to participate due to time
161 constraints.

163 Interview Procedure

164 All in-depth, semi-structured interviews with DDs were undertaken by CL between July and
165 September 2018. A participant information sheet and consent form providing further details
166 about the study was supplied to those volunteering to be interviewed via email. Those
167 agreeing to take part were required to fill out the consent form and email it back prior to the
168 interview.

169
170 A total of 20 interviews were undertaken via telephone ($n = 12$) or through Skype or Zoom
171 ($n = 8$) and used a semi-structured interview guide to allow the interviewer to explore the
172 ambiguity around the role. Interviews were developed, with questions drawn from the
173 systematic review, the researchers' previous work, and the preliminary survey findings
174 (Authors, 2019). The guide included questions about participants' roles as a DD, their
175 experiences working with clients, and the barriers and challenges to the role. The interviews
176 lasted an average of 58 minutes and were audio-recorded. All interviews were transcribed
177 verbatim by a professional transcription service, and all participants were provided with the
178 opportunity to verify transcripts as a true and accurate record of the interview. Seven
179 participants made minor amendments to their transcript.

180 Data Analysis

181 Two transcriptions were independently analysed by two researchers (KS, CL) who
182 developed the initial 'open codes' (Saldaña, 2016, p. 115) by searching each component of
183 every sentence. Three researchers (DR, CL, KS) merged the codes and developed a set of
184 coding themes. Using Nvivo 12 software (QSR International Pty Ltd, Victoria, Australia), CL
185 analysed all 20 transcripts and a visiting physician (AF) coded all transcripts manually
186 against the same themes. Twenty-three initial themes were identified, however upon

discussion within the research team, this was condensed to 17, and then two researchers (DR, JT) initially, and in agreement with all researchers, identified 7 themes to be the focus for this paper: 1) What a DD offers, 2) What a DD does, 3) Challenges and barriers, 4) Occupational preferences, 5) Family support, 6) Contract of service/fee, and 7) Regulation.

The themes from interviews were found to be similar to those from the survey, so further analysis/ a separate approach was undertaken on the interview transcripts to characterise the points of difference in care between what each DD said they offer, as opposed to what HCPs and/or specialist palliative care services (SPCS) offer. The aim was to discriminate from the survey findings and shine a light on the areas of interface and of unique contribution as described by DDs. Two researchers (DR, CL) separately reviewed the themes developed in the first round of coding and deconstructed each transcript to draw out examples of where the DD was describing what was a point of difference from HCPs. The extracted comments were then circulated to all researchers and agreement was reached (DR and KS are experienced palliative care nurses). This approach was informed by an interpretive description approach (Thorne et al., 2004) which enables representations of the data captured to potentially inform clinical practice.

Ethics

Ethical approval was obtained from the Flinders University Research Ethics Committee (Project: 7933) on 13 April 2018, with approval obtained specific to the interviews.

Findings

Demographics

Participants ($n = 20$) were predominantly female ($n = 18$; 90%). Eleven females and one male were from Australia, with participants from New Zealand ($n = 4$), the USA ($n = 4$), and one each from Canada and Singapore. Prior to the interview taking place, participants completed a short demographic questionnaire (Table 1). Participants were aged between 39

and 70 years and were on average 55 years of age. All participants were educated to trade / certificate level and above; 35% had a bachelor's degree, and 35% had a masters or above.

Of the 20 interviewees, 70% stated that they held one or more HCP qualifications (Table 2), however there appeared to be confusion as to what constituted a "health care professional". For example, HCP representation included five nurses, two allied health practitioners, and one aged care worker. Of those who said "yes" to HCP and who responded "other"; two held qualifications in massage therapy; two in counselling, two in clinical pastoral care; and one of each in epidemiology, psychotherapy and nutrition (free-text field allowed more than one qualification to be provided). These respondents may have considered that they work in health and so answered in this way. Conversely, of the 30% who stated that they did not have any HCP qualifications, one (social work) could be considered an allied health profession (Allied Health Professions Australia, 2020). There were also two who identified as massage therapists and one as a psychotherapist. More clarity in what a HCP is would have helped here.

Seven themes were drawn from the qualitative interviews:

1) What a DD offers: Representative of DDs speaking conceptually about the role (raison d'être) and that they provide a more open and flexible contribution to the person and family around death.

"Ongoing support, not just a 9 to 5 deal..." DD Participant #5

2) What a DD does: Acknowledges that DDs provide services that relate to what is needed by the family and the person in preparing for dying, dying itself and post death.

"Supporting families to create any sort of rituals" DD Participant #7

3) Occupational preferences: Demonstrates a significant aspect of the DD role relating to their control of the services they provide and how they choose to enact their role.

"There's a little bit more focus on the home funerals for me" DD Participant #6

242

243 4) Challenges and barriers: Reflects how DDs think HCP perceive the DD role, and the
244 implications for how DDs provide care and relate to HCP and services providers

245 *"They're all very keen but I found they're very reluctant because it's the unknown"*

246 **DD Participant #11**

247 5) Family support: Identifies that DDs have the flexibility and capacity to provide direct
248 support to families within occupational preferences.

249 *"I've cooked meals. Absolutely happy to do whatever is required"* **DD Participant #4**

250

251 6) Contract of service/fee: Articulates that DDs negotiate and receive payment (or choose
252 not to).

253 *"I guess part of me is like, making it a business. I mean that shouldn't be a problem in*

254 *a way. Why not. But there was a part of me that – I don't know"* **DD Participant #13**

255 7) Regulation: Identifies that the issue of regulation is a consideration of individual DDs and
256 the DD industry.

257 *"...if there is a way to have us registered and maintain the heart of what we do, then I*

258 *probably wouldn't have any issues with it"* **DD Participant #10**

259

260 These are summarised in Table 3, outlining: what DDs articulated about their role (extracted
261 from the interviews in the initial formal qualitative process), and what it is that HCPs do that
262 is conceptually different (derived from the experience of two palliative care nurse
263 researchers in the second analysis). DDs provided examples of how they enact the role and
264 we have extracted quotes to exemplify this, drawing out differences.

265

266 **Discussion**

267 These results build on a previous systematic review (Authors, 2018) looking at the DD
268 relationship to health services, their funding source, the numbers of DDs and demand for
269 services, training undertaken, licensing, ongoing support, and tasks undertaken. A

subsequent survey of DDs about their role (Rawlings et al., 2019) discussed training, experience and skills, registration and certification, reasons for becoming a DD, and the role of a DD. The findings from the qualitative interviews conducted for the present study enabled not only an identification of the role perceived by DDs themselves, but provided new insights into the points of similarities and differences perceived between the DD role and that of a HCP, and the interactions between the two groups. This is important as there are suggestions of overlap in purpose and activity, with concern about the work being undertaken by “unregulated” workers in the end-of-life space. The focus of this paper was therefore to look to points of difference drawn from the data on what can be provided by HCPs, community care services or SPCS and what DDs offer. The interviews in conjunction with previous work, contribute to the broader picture of the DD role in end-of-life care and may provide more of an understanding of how the HCP and non-medical DD role articulates.

Dying is a complex affair, with family, friends and neighbours of those at the end-of-life often facing prohibitive costs and often overwhelming caring responsibilities (Rosenberg et al., 2015). These patients and families will usually be supported by HCPs and services although often in a fragmented way that varies globally and may or may not include specialist palliative care (Hall, 2014). The intersect between patient/family, HCP and DD is not as yet fully realised or articulated, with the dichotomy of a paid and unpaid workforce and how this might play out on a case by case basis. With care provided in many settings there can be a complex interplay of people providing care, including general practitioners, SPCS, district (community) nurses, community allied health professionals, hospital staff, volunteers and family/neighbours/friends. Care provision then needs to be negotiated, demanding effective communication channels and role delineation, bringing its own challenges such as how costs are covered. Many of these structural considerations around palliative care, death and dying were also reflected in the perspectives and themes arising from the interviews.

The results of this study yielded seven themes from interviews where DDs describe and conceptualise their work:

1. What a DD offers

While individualised, flexible/adaptable care has been emphasised by DDs in the interviews as is the ability to be fully involved and to provide a spectrum of support/services, arguably though, these can be fulfilled by a number of HCPs within a multidisciplinary team or via different models of care (Sheinfeld, Gorin & Haggstrom, 2018). DDs are employed/engaged by the dying person and/or family, sometimes seeing only one client but maybe two or three. In contrast, most HCPs will see many patients/clients at any given time and each patient/client may be seen by a different HCP (e.g., nurse, doctor, physiotherapist). As a result, the DD as a companion to the dying person, may be able to circumvent some of the fragmentation, and concentrate on the individual and their situational needs. Given the increasing interest in what could be considered to be consumer-directed care (Kaambwa et al., 2015), DDs may reflect another avenue and service that enables consumer preferences to be enacted.

2. What a death doula does

A vast array of tasks was described, with each DD offering a unique service at various points in the dying trajectory with the person who is dying and their family. This flexibility makes it difficult to determine whether any one individual DD will meet the needs of any one individual patient and/or family member, whereas HCPs have clearly delineated roles and subsequent expectations of what will be delivered (Australian Health Practitioner Regulation Agency (AHPRA), 2020).

There is no one business model described by DDs that articulates the person for whom services will be provided, how revenue will be accrued, or the method of service delivery. This is reflected in the theme on contract of service/fee, and arguably contributes to inequity of access to DD services as not everyone will be able to afford the services available.

325

326 HCP may not wish or be able to provide care outside of the “confines” of their role, due to
327 potential medico-legal issues when considering working boundaries. The majority of HCPs
328 work in multidisciplinary teams (Liberati et al., 2015), each contributing to care, although with
329 some role overlap or blurring such as managing multiple roles if working in an isolated
330 setting (CareSearch, 2019). DDs do emphasise that they can provide continuity of care and
331 support (Rawlings et al., 2019), which HCP teams are not necessarily able to do in the same
332 way with multiple staff involved. Continuity and integration of care are viewed as important
333 aspects of the patient/consumer experience (Kaambwa et al., 2015).

334

335 HCPs working in palliative care see the patient and family as a whole (World Health
336 Organization, 2020), managing care in this way. Role overlap between the DD and HCP is
337 highlighted here as an area where confusion and misunderstanding may occur, with some
338 individual examples provided (Table 3). It is also worth noting that even within SPCS
339 models, there can be differences in scope of services, how they are provided, and what is
340 provided (e.g., a social worker, a bereavement counsellor, or a palliative care volunteer, may
341 enact similar roles). For example, some nurses offer “vigiling” (Fleming-Damon, 2016)
342 something that many DDs will also offer.

343

344 Palliative care volunteers can be aligned with health services, with hospitals and SPCS
345 working in various settings including the community (Vanderstichelen et al., 2019).
346 Volunteer coordinators or HCPs will provide initial and ongoing training and support
347 (Claxton-Oldfield, 2015). There also appears to be some overlap between palliative care
348 volunteers and what both paid and volunteer DDs do. For example, legacy work such as a
349 biography service may be offered by volunteers (Hesse et al., 2019), as well as a
350 “befriending” role (Dodd et al., 2018) and advocacy (Claxton-Oldfield & Blacklock, 2017). In
351 their study of Belgian palliative care volunteers, Vanderstichelen and colleagues (2018)
352 found volunteers “*occupying a unique space between professionals, family and patients and*

fulfilling a liaison function" (p. 1) as well as "focused on building a relationship with the dying person and providing psychological, social and existential care for them and those close to them" (p. 3). Along with the practical and social care also described in this study and the fact that palliative care volunteers have been described as under-utilised (Claxton-Oldfield, 2015), role overlap is apparent. It should be noted that not all palliative care volunteers or HCPs will offer all services required by a dying person, but then neither will a DD. Many of the services offered by DDs are arguably complementary and can help to address the fragmentation of healthcare provision.

3. Occupational preferences

DDs offer a variety of different support options for their clients, with a lack of formalised role descriptions or business practices that are found in health organisations. HCPs work to clinical competencies and to role descriptions/responsibilities, are trained consistently, and enact their role according to their education, industry standards and scope of practice (AHPRA, 2020). They may not wish or be able to provide care outside of the "confines" of their role, due to potential medico-legal issues when considering working boundaries. The majority of HCPs work in multidisciplinary teams (Liberati et al., 2015), each contributing to care, although there can be some role overlap or blurring such as the need to manage multiple roles if working in an isolated setting (CareSearch, 2019). DDs emphasise that they can provide continuity of care and support (Authors., 2019) which HCP teams are not necessarily able to do in the same way, with multiple staff involved. Continuity and integration of care are viewed as very important aspects of the patient/consumer experience (Kaambwa et al., 2015).

For DDs there can also potentially be overlaps with roles such as nursing, palliative care volunteering, massage therapy and members of the funeral industry, although this is not as clear cut. One question raised in relation to the finding that many DDs had a HCP background was, how does a HCP who also works as a DD manage their role boundaries

and responsibilities in the face of something like a medical situation or crisis? Certainly, in a survey of DDs, while the majority of respondents said that they do not give medications, one respondent said: *“as a nurse I can administer medication”* (Authors, 2019, p. 8)

4. Challenges and barriers

One of the questions asked was: “How do you think that death doulas are perceived by health professionals?” There was some perception by DDs that HCPs feel threatened (especially palliative care nurses), and perhaps worried that DDs are taking over aspects of the nursing role. It could also be argued that not all DDs will understand what is offered by individual HCPs (who also do not always understand what is offered by other HCPs) nor what is offered by a Multidisciplinary Team (MDT), especially if they do not come from a health background. Clarification of roles, boundaries and collaborative working methods need to be communicated by all parties.

Despite an overarching agreement in what the DD role is, there is not always consensus (apart from it being a non-medical role) as to what is offered. It is difficult to know if the opinions or views of HCPs are of the DD conceptual role as a whole (its place in health or social care) or whether they are biased toward an individual DD, whose practices they are familiar with. The lack of a business model or even a care model (Boucher et al., 2018) as seen in organisations that employ HCPs, is a discerning difference between DDs and HCPs, and sees vast differences in what is offered and what a patient or family member can expect from a DD, including support options and fees.

5. Family Support

DDs say that they offer family support and the majority of HCPs would offer this as well, although in a different way. For example, some DDs provide “hands on” personal care pre- and sometimes post-death, as will some community personal support workers. Some DDs offer cleaning, housework and cooking, which HCPs won’t do, but some volunteers will. The

DD role is again more likely to offer many services that HCPs and/or community services cannot and also may offer a combination of services e.g., massage, cooking meals, or vigiling.

6. Contract of service/fee

Two divergent and often conflicting discourses emerged regarding payment. The main point of difference with HCPs is the inconsistency described around payment for DD services. It is known that costs related to healthcare rise towards the end of life (von Wyl et al., 2018), so a DD as an employee of the client (dying person and/or their family), brings an additional cost. It can therefore be posed that socioeconomic barriers exist for those who cannot pay, missing out on this individualised support unless they find a DD who works in a voluntary capacity. Also, for consideration is that a DD may be charging for a service that can theoretically be provided by a SPCS or local community services at no cost. This, however, speaks more to the failure of healthcare systems in that people are either unable to access services they need at the end of life, or that these services do not provide enough support for the dying person to remain at home (Boucher et al., 2018). It could be proposed that waiting lists for services may exist in some areas and that this could be a motivator for seeking out a DD.

Some DDs certainly seemed to be expressing some cognitive dissonance about charging money, with tensions between “doing good” and charging vulnerable people, and conflicted views on how much to charge. Some DDs wanted to transition into DD work but needed to be paid, so worked part-time as a DD. However, the sustainability of this as a career is unknown.

7. Regulation

435 *“Achieving an effective regulatory system is not just a matter of bureaucratic process and*
436 *government resources; it is ultimately a question of patients’ wellbeing, and of who bears the*
437 *responsibility for ensuring it” (Fleming, 2015, p. 170)*

438 Regulation, the lack of, or need for it, was a point of dissent among respondents. Loss of
439 autonomy and flexibility in how they enact their DD role (avoiding a “tick box” approach)
440 were they to be regulated, was a concern for some, versus the danger of lack of recognition
441 or not being taken seriously due to lack of regulation.

442
443 Within healthcare, certainly in Australia, there are registered professions (e.g., nursing,
444 physiotherapy) and unregistered professions (sometimes self-regulated with a registration
445 system or credentialing) such as massage therapists, and counsellors (AHPRA, 2020).
446 However, any profession whether registered or not is still held to account by a code of
447 conduct (e.g., The Code of Conduct for Certain Health Care Workers in Australia). Some
448 DDs acknowledged the issues in mitigating risk, such as public liability or professional
449 indemnity insurance, but with no governance it is important to find out locally what recourse
450 families have if a negative experience with a DD was deemed to cause harm, or if they had
451 poor ethical boundaries. Some steps have been made to address regulation of DD work in
452 Australia and overseas, but this has not yet occurred. There is also a consideration of the
453 need for a professional peak and/or regulatory body that is independent of DD training
454 organisations. One example is the Palliative Care Competence Framework (Ireland) which
455 articulates core competencies for all health and social care professionals with discipline-
456 specific supplements that education and training would need to address (Connolly et al.,
457 2016).

458
459 While the DD role adds to what has traditionally existed in non-medical end of life care,
460 further clarification is required on how the DD role might be harnessed to address the
461 anticipated increased need for end-of-life services. There is enormous potential for the
462 development of innovative, fiscally responsible models to ensure safe, equitable care, that

support people to be cared for at home, potentially including a DD. These models could be developed within or outside of mainstream SPCS, community care packages, as an option for private healthcare funding, or healthcare agency provision. From the survey of DDs (Authors, 2019) we found that DDs ($n = 190$) received referrals from HCPs that included community nurses ($n = 18$), other community staff ($n = 31$), general practitioners ($n = 14$), hospital staff ($n = 22$), specialist palliative care staff ($n = 23$), residential aged care facilities ($n = 3$), and an ambulance paramedic ($n = 1$). The respondents provided more than one answer (Authors, 2019 unpublished raw data).

For DDs working alone, albeit potentially in isolation, there may be a wish to work within a MDT as indeed many of them (as HCPs) would be used to. However, there may be a preference to work autonomously and not lose the “integrity” of or diminish the role as it is currently enacted. Despite this, in other autonomous roles such as that of psychologist or social worker, clinical supervision is usually mandated to add quality controls to practice. If DDs were to be incorporated into mainstream health care models, there are examples of how this has been managed.

Lay navigators (Freeman, 2012) and palliative care volunteers (Claxton-Oldfield, 2015), other non-medical roles, are often managed under the auspices of an organisational umbrella. Patient (non-HCP) navigators have been in existence for many years and have seen lay people working to support clients in many areas, including obstetrics (Austad et al., 2017), primary care (Peart et al., 2018), women's health (McKenny et al., 2018) and oncology (Rocque et al., 2017). A systematic review (Carter et al., 2018) highlighted examples of teams comprising HCPs and lay navigators, with the authors of the view that the “*Fragmentation of the health care system is an antecedent for the creation of navigator roles and navigation service delivery models in primary care*” (p. 11) which arguably is a precedent of end-of-life care models.

Palliative care and hospice have utilised volunteers for decades and various models of care have been developed (Claxton-Oldfield, 2015). Consideration should be given however, as to whether the DD role being integrated into a palliative care model would lead to competition among volunteers for arguably very similar work. Studies from both Canada (Saari et al., 2018) and Australia (Poulos et al., 2017) describe the evolving roles of community care workers who work in tandem with HCPs to deliver care at the end of life. Arguably these are models that could incorporate a DD.

Strengths and Limitations

The participants were self-selected and likely to have also completed the DD survey, which may have influenced the way in which they responded to the interview questions. It is unknown how DDs who did not receive an invitation to interview (outside of the survey) are different to those who did, in terms of their views and experiences. The majority of those interviewed were from Australia and we cannot assume that the findings are applicable internationally.

Implications

The DD role could potentially complement that of HCPs and may be incorporated into models of end-of-life care, however DDs may prefer to remain independent providers rather than be part of mainstream care. Some HCPs are working as DDs and the reality of this should be considered in relation to roles and responsibilities, legal requirements, and codes of conduct.

The DD role appears to significantly overlap with that of palliative care volunteers who spend time with people at the end of life in many settings including their own home. Not all DDs receive payment for the work that they do, so the independence of the role as opposed to being under the auspices of a formal organisation (with direction and oversight) may be attractive to some. Consideration of how each DDs role has evolved determines their

working practices and how they work with HCPs. These differences may negate the ability to determine a replicable model of care, a business model or even guidelines on best practice.

Future Research

The results of this study support the need for further investigation, with several unanswered questions remaining, including: What are HCPs views of the DD role in end-of-life care? What are family's views of the DD role and why do families seek-out DD services? Is there a cost-benefit to the DD role? Is there a place for the role in end-of-life models of care?

Conclusion

There is a general perception that HCPs do not understand what it is that DDs do, thus the current study has helped to demystify the DD role and potentially reduce suspicion. Much of this confusion may arise from the lack of a DD business model that sees inconsistencies in what services each DD offers and what patients and families can expect. Possibly this deficit is related to an inability within the DD movement to agree on their role in end-of-life care and their determination to retain individualised practices.

If DDs can incorporate some of the hands-on care provided by families and help them to navigate the complexities of the needs and planning associated with end of life care, then they could represent an important opportunity to improve dying outcomes. More research is required to look at the interplay between DDs, HCPs and palliative care volunteers in addressing the gaps in care provision and how these relationships might be more seamlessly managed.

End of life can be complex and confusing for patients and families, so the DD role may provide a mechanism where needs outside of the scope of health professionals and health system can be met. However, there is a need to ensure that there is transparency in the role

546 and its relationship not only with the family but with health professionals and social care
547 practitioners.

548

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Table 1. Death doula interview participants' demographic information.

Characteristic		<i>n</i> (%)
Gender		
	Female	18 (90%)
	Male	1 (5%)
	Other	1 (5%)
Age		
	30-39	1 (5%)
	40-49	3 (15%)
	50-59	10 (50%)
	60-69	5 (25%)
	70-79	1 (5%)
Location		
	VIC	6 (30%)
	NSW	3 (15%)
	QLD	1 (5%)
	WA	1 (5%)
	SA	1 (5%)
	New Zealand	4 (20%)
	USA	2 (10%)
	Singapore	1 (5%)
	Canada	1 (5%)
Level of education completed		
	Occupational training/Industry/trade or certificate	6 (30%)
	Bachelor degree	7 (35%)
	Master degree or above	7 (35%)

Table 2. Health care professional qualification and occupations

Health care professional (HCP) Qualification			Occupations
	Yes	14 (70%)	Nurse (5) Doctor (0) Midwife (0) Allied health professional (2) Aged care worker (1) Other† (6)
	No‡	6 (30%)	Spiritual/pastoral carer (3) Massage therapist (2) Lawyer (1) Hospitality (1) Administrative (1) Funeral celebrant (1) Construction (1) Epidemiologist (1) Psychotherapist (1) Social worker (1) Researcher (1)

† More than one qualification was provided

‡ Open-ended responses to those participants answering “no”. Note that some participants listed more than one occupation.

Table 3: Role differences

Theme	1) Description of DD role	2) Points of difference with a health professional or Multidisciplinary team (MDT)†	3) Exemplar DD quotes that articulate what DD can offer that HCP may not
What a death doula offers	<p>This theme is representative of DDs speaking conceptually about the role (raison d'être).</p> <ul style="list-style-type: none"> • Individualised care. This is emphasised as is the ability to be flexible /adaptable. • Time. This emerged often as something that can be offered. • A whole spectrum of support. This was described over what can be a substantial period of time (such as 1 year). It was mentioned in the context of continuity of care. • Non-medical support. • Advocacy. This is in the broader context of the general philosophy of the role. An advocate. • Traditional community support. Returning to this type of care/model. 	<p>Each HCP has a defined role, whereas a DD may often be perceived as a one-stop-shop fulfilling multiple care needs such as an event manager/coordinator facilitator to manage/liaise/advocate.</p> <p>SPCS offer information, care coordination and advocacy as can some HCPs, but there are variances between specialist and generalist service providers. The latter are often fragmented with little communication between professions and an overlap or alternatively gaps in information provided. Some specialities such as oncology can have delays in communication with other providers.</p> <p>A main differentiating factor is in that DDs can spend time with clients, staying on as needed. Specialist palliative care teams can discharge stable patients even though the life limiting illness remains.</p>	<p>I remember the nurse at the age of 17 umm sitting vigil next to a dying patient, which in today's fast-paced hospital world that can't be done anymore. DD Participant #1</p> <p>Ultimately I think it's a listening and helping to plan."This just feels like event planning." DD Participant #3</p> <p>So, one of the things I really liked about end of life doula work is going to medical appointments with people. I'm quite happy to translate medical speak into plain English. I'm quite happy to translate a client's questions and fears and wishes to a medical practitioner..... I think advocacy is really, really important. DD Participant #5</p> <p>Ongoing support, not just a 9 to 5 deal, having the time for people, you know, that I can offer the time for people to talk to that they're not getting from other professions, I guess. DD Participant #7</p> <p>... The other thing about being a death doula is it's non-denominational and it's non-medical and I think that that is very important to maintain. DD Participant #15</p> <p>The one thing a volunteer can offer is time. We can just sit there for as long as it takes. I mean if it's all night, I'll sit all night. (from a DD who doesn't charge money) DD Participant #16</p>
What a death doula does	<p>DDs described many and varied aspects of their role. These include:</p> <ul style="list-style-type: none"> • Funerals, funeral options. • Advocacy. • Normalising death and dying • Legacy work • Ongoing companion • Sitting vigil • Overnight respite. • Having a presence during the 	<p>HCPs working in palliative care see the patient and family as a whole and manage care in this way.</p> <p>Some of what DDs do can be provided elsewhere in various ways by different HCPs and palliative care volunteers (who work as part of the broader team) but not as part of a package.</p> <p>The point of difference here from a volunteer is the night-time option and length of time, however, in some countries overnight family respite can be arranged and paid for by specialist palliative care.</p>	<p>Can help people navigate through the funeral body disposal path DD Participant #2</p> <p>However, the people in palliative care don't know things like how to organise a funeral and all the options they can have and the law around that..... We can be involved in the whole process right through. DD Participant #2</p> <p>I quite often will do bedside singing with them. DD Participant #6</p> <p>The family and friends do the death care, which is washing and dressing the body and keeping it cool enough that it doesn't start to decompose.</p>

	<p>time between the death and the funeral.</p> <ul style="list-style-type: none"> • Some offer other services in tandem with what they are doing– e.g., massage, singing, meditation • Family mediation role • Run death cafés 	<p>After-death care sees a major point of difference as HCPs do not engage in Funeral preparation or conducting the post death rituals or ceremonies. Many SPCS would have social work staff that assist families prior to death in preparing for the death by providing information on legalities, and what to expect in the immediate post death phase</p>	<p>And all the visitation is then done in the home. So you're not booking time with a funeral home. DD Participant #6</p> <p>So a lot of my work is sort of augmenting and picking up on things that palliative care probably wouldn't do, like alternative therapists and legacy work, which is helping the person write the story of their family. DD Participant #6</p> <p>And I feel that in the role of a doula there is a special respect for silent companioning and this is something that other formal professions and roles around a palliative and dying person are less inclined to do, or just not structured in that way DD Participant #15</p> <p>I've done vigiling at the bedside for someone who's close to death DD Participant #15</p>
Challenges and Barriers	<p>This theme emerged from a question posed to DDs on their views on how they are perceived by HCPs, summarised as:</p> <ul style="list-style-type: none"> • The DD role is not valued, possibly because it is not understood • HCPs frown on the DD role as it holds no formal qualifications • HCPs are suspicious as the role is not regulated • HCPs (especially nurses) are territorial, and feel threatened by DD 	<p>As many HCPs do not understand what a DD offers, not all DD will understand what is offered by individual HCPs or by a MDT.</p> <p>HCPs are generally valued within the healthcare industry and by the general public. They usually have clear role descriptions, formal accredited training requirements, and professional regulatory requirements.</p> <p>DD have an unclear business model</p>	<p>I spoke to one GP and she was quite disgruntled about what I'm doing. She said, 'Well, I think what you're doing is all a load of crap. Palliative care manages all that. They don't need you guys.' DD Participant #1</p> <p>...But I think that the majority of them, they don't understand what it is and think it's some sort of spiritual heebie-jeebies stuff and it doesn't have formal qualifications. So most health professionals frown on anything that doesn't have nationally recognised qualifications DD Participant #3</p> <p>...But then I've had other professions who almost feel threatened like we're taking over their role, which yeah, I don't understand that..... that's sort of mostly sort of palliative care nursing professional in a way. It seems to be a bit of a thing there with them. Yeah, but then other professions are open to it. DD Participant #7</p> <p>There are probably two sides to that coin: some see it as a blessing, a godsend, and others see it as a threat. They think that we're maybe out to do what they already provide but we're not medical providers, that's not our role.... so I can't get through because they think, 'oh this woman's out to take my job'. DD Participant #9</p> <p>Yeah, most of the health professionals I've come across are pretty happy about it, and as long as they feel that the doulas aren't trying to do their work for them. That is probably the only thing: if you're not a nurse, you shouldn't be providing nursing advice, which to me makes total sense anyway. DD Participant #10</p>

			<p>....in fact I know that nurses are one of our biggest oppositions in the end of life doula space; so I'm cautious about that. I like 'consultant', or 'companion'. By opposition, I mean that they may not understand what a doula is or does, not that we are oppositional in our work or practices. In fact, I see nurses and doulas as entirely complementary in their practices.....My experience is that the nurses are not ready to accept this role because there is a real sense that the nurses do this work – that this is their space – and I think there's a fear that bringing this role into places like hospice, or medical hospitals and aged care and yada yada that that is going to create a delineation between the role of nurses and doulas and that it's going to take away, in some form, from the nurses' work. DD Participant #15</p> <p>I think there's a lot of suspicion, possibly a good deal of that is coming from the fact that we're not regulated and there's no one sort of accepted level of qualification or training around it. So they're coming from all sorts of backgrounds. DD Participant #19</p> <p>It's not about being a threat to health professionals, it's about being an addition (sic) contributing and supporting what they do, so that I can then do my role and vice versa. It's not about taking over or taking away from, it's about being in that mix. DD Participant #19</p>
Occupational preferences	<p>DDs enact their role in different ways, and often fall into the following categories with the DD working with:</p> <ul style="list-style-type: none"> • family only. They may never meet the dying person; • the dying person only. For example if the person is alone; • the dying person and their family; or • post death only. They are involved in funeral and bereavement rituals. 	<p>HCPs work to clinical competencies and to role descriptions / responsibilities. They are trained in the same way and enact their role according to their education, industry standards and scope of practice.</p> <p>There can also potentially be overlap with roles such as nurses, volunteers, massage therapists and members of the funeral industry. HCPs will potentially offer much of what the DD offers but within an MDT brought together according to the person's needs.</p>	<p>There's a couple of doulas that I'm working with at the moment, and she has instigated where we want to go out and offer free doulas for the disengaged and like low income and isolated people. DD Participant #1</p> <p>My focus is the person that's coming towards the end of their life DD Participant #8</p> <p>...the dying people that I've worked with more closely have also been people who haven't had a lot of family close by DD Participant #10</p> <p>I actually haven't been involved with anyone who's dying, but their carers. DD Participant #11</p> <p>The main role that I'm fulfilling at the moment is community education. So I run death cafés and I'll talk to community groups like Rotary and I run a couple of 'dying to know' days. DD Participant #19</p>

<p>Family support</p>	<p>DDs describe that they offer all or any of the following:</p> <ul style="list-style-type: none"> • a 24 hour presence and on-call availability • Sitting and keeping people company • care of the body pre and post death • cleaning, housework, cooking (some will offer this) 	<p>Some DDs offer 24-hour availability and while some community nurses in some parts of the world are available 24 hours a day, not all offer this, and if they do then visits are likely to be in response to a specific nursing need and are generally of short duration.</p> <p>Some DDs offer an on-call service, as do many community palliative care teams. The DD role is again more likely to offer many services that HCPs and/or community services cannot and also may offer a combination of services e.g. massage, cooking meals, vigiling.</p> <p>Post-death work offered by DD is not offered by HCP to the same extent and they will not be available for support and practical help during this time. A bereavement service, if available focus on post death counselling and adjustment to loss.</p>	<p>Sometimes family relief, so if family are exhausted and that I can sit and assist with their loved one, giving them a break. Just keeping them company DD Participant #1</p> <p>But I have provided care, for example, when a family doesn't want to touch the deceased person. Well, I've helped wash a body; I've helped dress a person, I've helped get them prepared for the funeral home DD Participant #9</p> <p>But as a Thanadoula, I do companioning, obviously. I can drive them to and from appointments. I do things like basic housekeeping, PSW work, meal preparation and that kind of thing. DD Participant #16</p>
<p>Contract of fee/ service</p>	<ul style="list-style-type: none"> • Some DDs only work in a voluntary capacity and cannot see how it could be considered paid work, and others charge money for the work that they do and earn a living (full or in part) this way. • Even so, some DDs were conflicted about charging a client money and never more so for those DDs who work voluntarily in the role but would like to transition to paid work. • This tension was present even with some DDs who already require payment, as seen in the negotiation of packages (such as for a prolonged period of time) or 'sliding scale' payments for those who are less able to pay. • Some DDs were comparing their 	<p>HCPs do not have the same tensions around the services they are offering. Their role is clear cut and does not vary. They also do not accept less pay than what they are awarded in their organisation, nor do they accept 'in-kind' services.</p> <p>Some organisations do offer volunteer services</p>	<p>The introduction is free, but after that it's this much..... because it's such an emotional space the money thing freaks people out a bit sometimes, but both of my proper clients have said to me, "You need to pay for this – we need to pay for this. This is valuable service." And so that's given me a lot of confidence now to be able to say this is how much it's going to cost. DD Participant #2</p> <p>So, my base rate at the moment is \$100 an hour and you can buy packages of 10, 20 and 30 hours or you can buy me by the hour if you just want information. DD Participant #5</p> <p>... my decision was to charge a flat fee. And you got me for as long as you need me. So, essentially when they sign up with me, I ask them to pay – what is it? Well, it's \$1,200 for me to be there all the way through the process. I agree to a set fee and then I essentially consider myself on 24/7 call after that.. DD Participant #6</p> <p>I haven't had a paying client yet... DD Participant #9</p> <p>We're talking about people that don't have a lot of money in a lot of cases and I have a sliding scale.. It's not about money. It is about people. DD</p>

	<p>role with that of others who charge for their services such as a massage therapist, counsellor or life coach.</p>		<p>Participant #11</p> <p>So I've got an hourly rate for my counselling work and then I would look at some sort of package I think if it was going to be over a period of time, yeah. But look it is a tricky one, how do you charge for this work? But as one of my great supervisors said to me once, "well you know, people are paying for other professional services at end of life and you are one of those people, so you should feel okay about putting a price on it." DD Participant #14</p> <p>People are interested in my services, but not when they have to pay for them. PSWs, home nurses, etc. are all covered under insurance, I am pursuing the same thing. I believe that once my services will be recognized under insurance policies it will be a great boon to my business in providing necessary services to those in need. I tell people that I charge \$25 an hour,. DD Participant #16</p> <p>Always, always, always been voluntary. I don't know how - I mean obviously there are ways, but I don't know how you could charge for it professionally? I don't mean that in any judgement to anybody, I mean I just can't imagine any sort of formula that I would think appropriate that didn't somehow compromise the service. DD Participant #17</p> <p>The money, charging money for it. Yeah that's a huge discomfort that I'm still trying to come to terms with. I think the main thing is to put it in the context of any other kind of alternative or complimentary sort of therapies; like Reiki or massage or those sort of things, or even like a life coach. You know, some life coaches charge \$260 for an hour session. Most massage therapists are \$80 to \$100. If you're running your own business, you'd pay a plumber that much to come and fix your pipes. But yes, it is a bit uncomfortable because it could be hours and hours that you need. because there's only so much that the free health care services can offer. It's limited. And to get that personalised one-on-one care service, you know, people are used to paying for that. So I guess it's difficult because there is a level of it that is available for free from the healthcare system. So to say that I'm charging for this when people are used to getting it for free, is going to be an interesting sort of process.. DD Participant #19</p>
Regulation	<p>DDs who were interviewed were often also conflicted about role regulation:</p>	<p>Within healthcare, certainly in Australia, there are registered professions (e.g. nursing, physiotherapy) and unregistered professions (sometimes self-</p>	<p>.the problem is it's an uncertified kind of role and so people I think are a little bit wary of roles that don't have any certification and know they are</p>

	<ul style="list-style-type: none"> • Some DD indicated agreement as long as it is not deemed too onerous or restrictive • Some DD suggested other similar models (for example art therapists in the UK). • Others could not see how the regulatory process would work at all. 	<p>regulated with a registration system or credentialing) such as massage therapists, counsellors. These are a given and have been in place for some time.</p>	<p>working at a vulnerable life stage. DD Participant #2</p> <p>They want this to be an unregulated industry because it is so diverse and so different in different places, but I think I would just like to see a course that had some kind of – like a prerequisite course, but then I guess that's not really certification either. I don't know. Look, I'm a bit on the fence with it all. DD Participant #2</p> <p>I think it will have to come to that. Yes. But how that looks and how that is regulated, I don't know. But I think it will have to be - I am guessing it would look something like the massage therapists. You could become - you are part of the organization and you show your certificates and there is someone who looks at it. I mean to be with the Doula College you have got to have a police check and up-to-date First Aid certificate and public liability. DD Participant #3</p> <p>I would prefer it to stay unregistered, because I think it's going to be a lot of word of mouth in it anyway. So no. Not regulating works better, I feel. Somehow you are more likely to get the people who really want to do it from their heart and soul, from a sort of calling, rather than as a career. DD Participant #4</p> <p>I'm conflicted. I'll be really honest and say I can see both sides of the argument.....but regulation then may become too expensive. It may be prohibitive for people who are culturally and linguistically diverse who still have skillsets and knowledge to offer. But a peak body and real dialogue and action on - I'm talking myself into this now - is possible. It'd be work. It'd take a few years to get it established and working but that's viable and I also think there's a really good business case for it. DD Participant #5</p> <p>Double-edged sword, isn't it?... on some ways to have like code of conduct, professional membership to something, that professional support, yes. On the other hand, if it becomes too ruley and restrictive..... I can see the benefits of it but I can also see the downfall of it in some ways. DD Participant #7</p> <p>Oh it needs to be regulated. Definitely. DD Participant #8</p> <p>I think a great part of what end-of-life doulas do is sort of holistic and spiritual and a gift, I think it's a gift, and I don't know that there's a way, really, it would – how could you possibly regulate it? DD Participant #9</p>
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