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University**

Research Centre for
Palliative Care, Death & Dying

National Death Doula Roundtable

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About this White Paper

This publication is a RePaDD White Paper and Research Report.

The RePaDD White Paper and Research Report Series provides researchers and policy makers with evidence-based data and recommendations. By organising, summarising, and disseminating previous and current studies, the series aims to inform ongoing and future research in palliative care, death, and dying.

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Acknowledgement of Country

Flinders University was established on the lands of the Kurna nation, with the first University campus, Bedford Park, located on the ancestral body of Ngannu near Warriparinga.

Warriparinga is a significant site in the complex and multi-layered Dreaming of the Kurna ancestor, Tjilbruke. For the Kurna nation, Tjilbruke was a keeper of the fire and a peace maker/law maker. Tjilbruke is part of the living culture and traditions of the Kurna people. His spirit lives in the Land and Waters, in the Kurna people and in the glossy ibis (known as Tjilbruke for the Kurna). Through Tjilbruke, the Kurna people continue their creative relationship with their Country, its spirituality, and its stories.

Flinders University acknowledges the Traditional Owners and Custodians, both past and present, of the various locations the University operates on, and recognises their continued relationship and responsibility to these Lands and waters.

About the RePaDD

Death and dying will affect all of us. The Research Centre for Palliative Care, Death, and Dying or RePaDD works to make a difference to the care of persons at the end of life.

We examine the universal experience of dying and create innovative solutions for people living with a life-limiting illness, their carers, and the clinicians caring for them. Our members lead major national palliative care projects in Australia. Our team of multidisciplinary researchers and experts work collaboratively with various organisations and funding agencies to deliver impact. We also strengthen research capacity by offering evidence-based resources, researcher education, and training and scholarships.

Our research

We focus on the following research areas:

Palliative care across the health system: We conduct clinical and service studies and develop online palliative care resources and applications. Our work in this area contributes towards ensuring that quality palliative care can be delivered in all healthcare settings - whether in hospitals, aged care, homes, hospices, clinics, or the community.

Death and dying across the community: We examine and respond to community and consumer attitudes, views, and needs with respect to death and dying and palliative care. Our research in this area empowers the wider community to make informed decisions by raising awareness and building death literacy.

Online evidence and practice translation: We build, synthesise, and disseminate the evidence for palliative care. We also create innovative digital solutions to improve evidence translation and use. Our research in this area builds palliative care capacity of the health and aged care workforce, access and use of information by health consumers and the community.

Further information can be found at [Flinders.edu.au/repadd](https://flinders.edu.au/repadd)

Table of Contents

EXECUTIVE SUMMARY	6
INTRODUCTION	7
METHODS	8
RESULTS	10
DISCUSSION	20
CONCLUSIONS	24
REFERENCES	25
APPENDICES	27

List of Tables

TABLE 1: Participants	9
TABLE 2: Themes	10

Acronyms

Acronym	
AHPRA	Australian Health Practitioner Regulation Agency
ANMF	Australian Nursing and Midwifery Federation
ANZSPM	Australian and New Zealand Society of Palliative Medicine
CALD	Culturally and Linguistically Diverse
CEO	Chief Executive Officer
DD	Death Doula
EOL	End of Life
PCA	Palliative Care Australia
PCNA	Palliative Care Nurses Australia
RePaDD	Research Centre for Palliative Care, Death and Dying
SW	Social Worker
VAD	Voluntary Assisted Dying
WWC	Working with Children Check

Executive Summary

The death doula (DD) role has emerged over the past few years and has established itself in the end-of-life care arena.¹ While consensus has not been reached on an agreed definition of a DD, it is understood to be a non-medical role whereby support, comfort, advocacy and guidance is provided to someone who is dying and/or their family /friends.¹ With the role growing in popularity and in numbers, the Palliative Care Australia Peaks CEO Network identified a need for increased understanding of the Death Doula role and its intersection with palliative care service delivery and patient support. This was discussed at the Australian Palliative Care Peaks CEO Network meeting, where it was agreed that Flinders University researchers who have been studying the role should be involved and that a roundtable should be held.

The aim of the round table from the Australian Palliative Care Peaks CEO Network perspective was to find common ground between stakeholders, and to ultimately consider the development of a position statement around the role of DD, and guidance documents for consumers wanting to engage a DD.

The roundtable was held via Zoom on 7th December 2021 and lasted for 2 hours. It was facilitated by a strategic health consultant. The roundtable was recorded, and each participant signed a consent form agreeing to the researchers obtaining a copy for this

study. The participants were stakeholders identified by the Australian Palliative Care Peaks CEO Network and included representation from:

- Death Doulas
- Palliative care nursing
- Palliative care medicine
- Palliative care social work
- The Health Complaints Commission (responsible for the regulation of doulas)
- AHPRA and ANMF responsible for the registration and regulation of nurses
- Consumers
- Funeral directors
- The CALD community

Outcome

From the analysis of the roundtable proceedings, seven major themes were extracted from the analysis: *awareness and understanding, descriptions of the death doula role, interaction and collaboration between sectors, blurring of boundaries, variation in role/practice, safeguarding and quality of care, and registration and regulation.* Five minor themes were also detailed: *the role of palliative care volunteers, equity of access, Voluntary Assisted Dying, training and certification; acceptance of the role.*

Following the roundtable, the Australian Palliative Care Peaks CEO Network has met and drafted a policy position statement and community information flyer. These are expected to be available in late 2022.

Introduction

The Death Doula (DD) role has been increasing in visibility over the last 5 years, with the numbers of those training DDs and those working in this role growing exponentially.^{1,2,3} Death doulas (also known by 'End-of-Lie Doula, Death Midwife) work in a non-medical way with clients and families at the end of life. They provide support and advocacy such as the provision of information and options, liaison with services, companionship / respite.²

Palliative Care Australia peak bodies are receiving queries from their constituents (palliative care services and the general public) regarding the role and services offered by DDs. As a consequence, there was a need for a consistent and informed approach to the provision of guidance in response to DD queries (See Table 1). The Palliative Care Australia Peaks CEO Network (comprising the CEOs of the state jurisdictions and Palliative Care Australia) convened a roundtable of stakeholders to conduct preliminary discussions and find common ground. The aim of the round table from the palliative care peak bodies' perspective was to consider the development of a position statement around the role of DD, and to develop guidance documents for consumers wanting to engage a DD. As palliative care peak bodies also work alongside specialist palliative care service providers developing information resources will assist clinicians who

may see a patient who has engaged a DD.

Flinders University RePaDD researchers were invited to attend and to conduct research on this roundtable event in order to capture the views of the stakeholders involved. This RePaDD report details the proceedings.

Aims of the Roundtable

One Jurisdictional Peak CEO outlined the aims of this roundtable:

“This roundtable we see as a first step in increasing our understanding in, as palliative care peak bodies, around the role of Death Doulas. [...] and the palliative care peak CEOs working with Palliative Care Australia will also be looking at developing some information sheets for consumers and also for service providers. Particularly looking at the role of death doulas, scope of practice, if I'm a consumer, how do I choose a death doula that is right for my needs in my jurisdiction? So, like I said, this is a first step. We want to increase our understanding, really look at how our sector can work together cohesively”
(Jurisdictional Palliative Care Peak)

Methods

Participants were invited to attend this roundtable event by the Australian Palliative Care Peak Body CEO Network. Participants were stakeholders in the intersect between the DD role and palliative care, which might be role enactment, role overlap and dual roles (Table 1). Participants represented the members of the Australian Palliative Care Peaks CEOs Network, major palliative care health professional peak bodies (medicine, nursing, social work), the health practitioner regulator (AHPRA) and the Health and Community Services Complaints Commission (who take carriage of implementation of the national code of conduct for unregistered health care workers including DDs in those states and territories that have passed relevant laws). There was also representation from DDs, consumers and community / CALD (who may engage a DD), funeral directors (some DDs also conduct funerals) and DDs themselves.

The roundtable event was held via Zoom on 7th December 2021 and lasted for 2 hours. An agenda was circulated prior to the meeting with a briefing on the DD role, as well as the research participant information sheet / consent form (APPENDICES A, B). A strategic health consultant facilitated the roundtable discussion, with items for discussion proposed in advance by the Australian Palliative Care Peak Body CEO Network, the facilitator and the Flinders researcher.

Research Study

All participants were presented with information on the research study, and all provided consent to be recorded and were aware that they would potentially be identified (not by name but by role or organisation). Ethics approval was received from the Flinders University Research Ethics Committee (No.7933). Data was recorded and automatically transcribed by 'otter.ai' (an automated meeting notes app), with this transcript provided to the researchers with full knowledge of the participants. The researchers also provided participants a copy of the draft report for verification that their contribution was fairly represented.

Data analysis

Data were thematically analysed using both a deductive approach and an inductive approach, guided by the concept of grounded theory.⁴ The transcript was coded using NVivo software version 12 by a research assistant who was not present at the roundtable event. The research assistant first engaged in a viewing of the original roundtable recording, followed by a detailed reading of the transcript, before coding the data line by line using open coding.^{4,5} This involved conceptually grouping similar words and sections of text and adding new codes when new concepts emerged.⁴ Coding of data was inherently inductive, however codes

tended to be grouped according to the specific questions asked in the roundtable (deductive).⁴ Axial coding was used to refine and group themes into overarching categories.^{4,5} To enhance rigour, the lead researcher (present at the roundtable discussion)

reviewed and then discussed the data coding and themes with another author (JT). This feedback was then given to the Research Assistant who reviewed the coding scheme and made some minor modifications.

Table 1. Participants

Participants	Location
CEO, Palliative Care Tasmania	TAS
CEO, Palliative Care Queensland	QLD
Strategic Health Consultant [External Facilitator]	NSW
Consumer Representative Palliative Care Australia & Death Doula	NSW
Social Work representative, Palliative Care Social Work Australia	NSW
Palliative Care Nurse Practitioner representative, Palliative Care Nurses Australia (PCNA)	NSW
CEO, Palliative Care New South Wales	NSW
Policy and Strategy Manager, Palliative Care Australia (Palliative Care Australia)	ACT
CEO, Palliative Care Australian Capital Territory	ACT
CEO, Australian and New Zealand Society of Palliative Medicine (ANZSPM)	ACT
Managing Director, "Preparing the Way" End of Life (EOL) Doula Training Organisation	VIC
CEO, Palliative Care Victoria	VIC
Managing Director, Natural Grace Holistic Funeral Directors & Death Doula	VIC
Community Engagement Manager, Palliative Care Victoria	VIC
Professional Officer, Australian Nursing and Midwifery Federation (ANMF)	VIC
Health and Community Services Complaints Commission South Australia	SA
CEO, Palliative Care South Australia	SA
SA State Manager, Australian Health Practitioner Regulation Agency (AHPRA)	SA
End-of-Life Doula	SA
Death Doula and Lead Educator, "Preparing the Way"	SA
Researcher, RePaDD Flinders University	SA

Results

A total of seven major themes emerged from the analysis: *awareness and understanding, descriptions of the death doula role, interaction and collaboration between sectors, blurring of boundaries, variation in role/practice, safeguarding and quality of care, and registration and regulation.*

Five minor themes also emerged: *the role of palliative care volunteers, equity of access, Voluntary Assisted Dying, training and certification and acceptance of the role.* Some quotes were used to illustrate each theme, in order to privilege the voices of participants.⁴ Major and minor themes are summarised in Table 2.

Table 2. Themes

Major Themes	
1	Awareness and understanding,
2	Descriptions of the death doula role
3	Interaction and collaboration between sectors
4	Blurring of boundaries
5	Variation in role/practice
6	Safeguarding and quality of care
7	Registration and regulation
Minor Themes	
1	The role of palliative care volunteers
2	Equity of access
3	Voluntary Assisted Dying,
4	Training and certification
5	Acceptance of the role

Major themes

1. Awareness and understanding

Roundtable participants who were not DDs expressed a need to gain a better understanding of what the death doula role involves from varying perspectives. This was also a specific need of the Australian Palliative Care Peaks CEO Network, who needed a deeper knowledge of the current status and implications of the role and contribution of DDs to palliative care in Australia to be able to meaningfully engage with queries from constituents who may be health professionals or consumers. Clarity on this could support a more consistent description of their role within the palliative care environment that could support both palliative care practitioners and community members.

“we really, as the peak body, didn't have a lot of understanding about the scope of practice of death doulas. How death doulas work in the palliative and end of life space? What is the interaction between doulas and other palliative care services? How do consumers choose a fantastic death doula to help support them?” (Jurisdictional Palliative Care Peak)

“As a peak body, people come to us asking questions, often in this space, looking at position statements from multiple players. So really understanding that” (Jurisdictional Palliative Care Peak)

“[...] a lot of people think palliative care is what doctors and nurses do, full stop. But palliative care is

actually an approach to care [...]” (Doula)

“So my role is national policy. But I am a registered nurse and I do a lot of work across all sectors, but I do a lot in aged care. So we do hear in the policy space about death doulas, particularly in aged care, but it's absolutely not very common” (ANMF)

2. Descriptions of the Death Doula role

Roundtable participants gave descriptions of what the role involves, from their personal experience. Descriptions of the role included:

Client advocates/support

Participants cited their own direct experiences with a DD as an advocate and when caring for a family member and/ or undertaking DD training themselves. Another DD spoke of an experience of being called in to help:

“Through my lived experience of caring for my mum after she died, I undertook Helen's training. So I've done Helen's training. And then have been working as much as I can to be an advocate to improve people's end of life experience” (Consumer rep & Doula)

“I arrived on a public holiday. Asked to see a social worker, no social worker, no palliative care services in this private hospital. And the family were having problems with pain management for their father. I spoke and advocated on behalf of the family to the doctor. And then a doctor went from that usual place of wanting to still keep that person

alive to realizing that we're doing palliative care and that we're on the same page just for one conversation and in front of the family. They asked me to be involved. Can you speak to the medical team?" (Doula)

Event coordinators

Death doulas spoke of the coordinating aspect of the role, the complexity of the situation that families are in and how the role of the DD is to fit everything together and assist the family and patient to navigate the health system at end of life.

"So to be most like an event coordinator, do you know what I mean, where you just bringing together all these pieces, and I think there's a very big role for doulas in there" (Doula)

Providing a 'holistic' package of end-of-life care

The concept of holistic care was highlighted in terms of an emotional, psycho-social, spiritual, integrated model of care that incorporates the time after death as well. It also recognises that this care occurs over a period of time.

"[...] the form of practice, which is holistic in nature, and inclusive of the whole person in their whole context on their whole journey. So it is, social, emotional, psycho-social, spiritual, deeply spiritually held scope, integrated model of care. It comes from an integration so that we all have a space of living well, end of life, maybe a diagnosis or aging, you're living with, maybe being actively palliative care, the time of death. The time after death is a very exquisite time, after death for families, leading into ritual and

ceremony, into the disposal of the body, and then of course into early and ongoing bereavement. So that's the integrated model of care that we work out of as holistic practitioners" (Holistic Funeral Director)

Providing information/options

A very apt description was provided by a DD of their point of difference by providing options not advice:

"we have four things that we say doulas do not do, end of life doulas, and we identify as end of life just so you know, is that we do not diagnose. We do not give advice or recommend starting or stopping medications or treatments. We do not administer medication, and we do not give advice. We provide options. So those are the very four basic, my world laws around end of life doulas" (Doula)

Working with different cultural groups

The concept of DDs working across cultural communities emerged. Representatives from the CALD community expressed excitement at the prospect of a DD who was culturally aligned being there to assist patients and families navigate end of life in a sensitive and supportive manner:

"[...] and I think it's about really looking at how we can walk in two worlds, whether it's working with First Nations people, people from different migrant backgrounds" (Consumer rep & Doula)

"I'd like to see acceptance and support from PC sector for accredited training for CALD doulas, affordable

and accessible to multicultural communities” (CALD)

3. Interaction and collaboration between sectors

Roundtable participants had varying views on how and where DDs fit in to the current palliative care health system/sector. Participants again expressed that a better understanding of the role would assist in enabling more seamless interaction and collaboration opportunities. What ultimately emerged from these discussions, was a potential need for the DD role to help fill certain gaps in the health system, and willingness from both health professionals and DDs to collaborate to improve understanding of each other’s roles. Discussions included the following topics:

Death doulas are ‘community business’

Comments were made about the DD role being community business rather than something found in specialist palliative care or in aged care facilities.

“In the home a different thing altogether and perhaps the more natural home of the death doula?”(PCNA)

Addressing system gaps

Participants spoke of the way in which DDs can and do address health care system gaps, such as connecting to palliative care services

“a lot of the people that she met with and engaged with have no connection with palliative care services, and were really out there

floundering.[...] Which just really highlighted to me that whole level of unmet need that we don't know about, and don't capture. And, you know, it struck me that there was some really good opportunities of partnership and collaboration, made sure that people got the whole support that they needed from all providers” (Jurisdictional Palliative Care Peak)

[...] “I've had palliative care nurses in a unit where they were on a ward [...] Two staff on, four people actively dying. And one of the pall care nurses came to me in tears saying, ‘thank God you are here for your person. I'm so sorry. We can't get to them.’ And that's true.” (Doula)

Meeting unmet need /demand

What was also apparent was that DD were responding to unmet needs within the health and social care system.

[...]”“But if a family is saying to their primary health carer, which often is community pall care, we need more help or we're looking for more support about this, or we need cultural guidance, or someone that understands how our death practices work, or whatever it is, it feels like there is this amazing opportunity for that gap to be shortened” (Holistic Funeral Director)

“it feels that this role is required because we've got significant gaps in the health system. [...] and as I said, alluded to before, registered nurses are moving into this space because they're seeing these gaps

every day and they're frustrated by it, and people aren't getting the care that they want and deserve" (ANMF)

Enabling continuity of care

The concept that DD's can provide the continuity of care that is not always possible within health and social care constraints emerged:

[...] "who are we here for? Are we actually authentically here for the person who has the diagnosis who's approaching end of life and those people around them? Because if we are that brings in continuity of care, and it's about not going, well I deliver palliative care medical and nursing, and then they have to go and find out all that other stuff themselves [...] So they've got someone that's bringing that continuity, because every other team including their pall team, drop off, the medical team. So I think you know that that to me is a crucial point" (Doula)

"We have a system that is overcomplex and we do need processes/roles in place to help people figure it out" (ANMF)

Working 'alongside' each other

Working in tandem to support clients and families was highlighted by more than one participant:

"So to me, it's about, we're not getting in the way of palliative care. You guys deliver specialist care, and I can't do my job without you. I just want to walk alongside you and collaborate with you so that together we can actually make a difference to the people that we're there to serve" (Doula)

"They were however, yes working alongside the palliative care team, but not part of that team [...] Whilst absolutely then can will (sic) walk side by side with a primary care physician, with a community wound care nurse, with a palliative care team, be it a social worker or nurse or a doctor. Absolutely. I can see how that would look" (PCNA)

As part of the Multi-Disciplinary Team

The DD as part of the multidisciplinary team (MDT) but not the palliative care team specifically was raised in this context:

"EOL Doulas are a valued member of the multi-disciplinary team but do not strive to become a member of the Palliative Team specifically" (Holistic Funeral Director)

Need to collaborate

The need for collaboration across the board was noted by members of the Australian Palliative Care Peaks CEO Network

"when we talk about the multidisciplinary team approach to care, we're not just talking about clinical teams, we are talking about everybody that is involved in providing palliative and end of life care. What is your role, everybody has a role to play. And how do we all work collectively to support the dying and their family?" (Jurisdictional Palliative Care Peak)

"Collaboration is critical and also to aim for best practice - setting high standards for how working together to support people with life-limiting illness and from our perspective palliative care services to show a

path forward” (National Palliative Care Peak)

4. Blurring of boundaries (between DD and nursing/ other clinical roles)

Participants who were health professionals or from peak Palliative Care bodies, expressed confusion and concern about the blurring of boundaries between the role of DDs, and clinical end-of-life care roles (e.g., nurses). Concerns mainly related to the administration of medications or other medical care. Participants who were DDs gave explanations of how this issue is managed in their experience.

“One of the big, some of the confusion for us as well is in terms of scope of practice. So in terms of we have registered nurses who also practice as death doulas. And as part of that scope of practice, they might administer medications, and other things. And so, for us, it's also looking at, you know, is there a boundary? A cut off between, when does the role of a death doula then become the role of a nurse or health professional?” (Jurisdictional Palliative Care Peak)

[...] “this is how we approach it at (their doula training organisation), I just want to declare that. I can't speak for any other doula trainers. So we are very, very clear in our training that a doula is a doula and a nurse as a nurse. And doulas are a non-medical, non-clinical role. Therefore, what we say to doulas is if you are a nurse, and you're going to be practicing as a nurse, and you're going to also be doula-ing, then you need to be uber clear with

your clients that you're, you know, talking to them about your services, that you have nursing services and you have doula services and that they need to be billed separately [...] So our doulas and our training, we absolutely do go through the code of conduct with them for unregistered medical or health practitioners” (Doula)

“And absolutely it is an issue, making sure that those lines aren't blurred. We have worked really closely with the NMBA to clarify this line. Identifying the line of where your registration could be affected whilst not being employed as a registered nurse is difficult. It's a very tricky space” (ANMF)

“I think the boundary issues are fairly complex and probably situation specific on some occasions. But I think the important thing to note is the code of conduct it doesn't just operate during business hours. It operates while you are a registered health practitioner. So nurses would still be bound by their code of conduct, regardless of the label that's worn at different times. And there's a whole complexity around that would need to be explored” (AHPRA)

“So I almost think, and I have tremendous admiration for death doulas, but really, this is family business [...] I'm so pleased someone said, let's take the term scope of practice away from this, because scope of practice implies a clinical role, and that's exactly what these people do not have” (PCNA)

5. Variation in role/practice

Participants discussed the challenges relating to the vast variation in the DD role as it is currently practiced and described.

“I think from our side as peaks, the challenge is around due diligence and ensuring when there is such a diverse group of people offering, using the same label. That's the challenge that we see we have in this space and, and so part of that I think the next steps would be us as peak bodies, understanding, looking at our stance around that, and understanding that there are going to be different groups in this space and how we manage that and how we support our members in those interesting times during the space” (Jurisdictional Palliative Care Peak)

6. Safeguarding and quality of care

Roundtable participants who were not DDs expressed concerns around ethical practice, ensuring quality care, mitigating risks, and safeguarding consumers against practicing DDs who may take advantage of people at their most vulnerable. Participants who were DDs outlined how these issues were managed from their experience.

“I think what xxxx (CEO) had talked about, with vulnerable populations, in particular some of the concerns around sort of safeguarding issues and things like that for if there's a monetary aspect of the business models, so there was concerns around exploiting that” (SW)

“We go through that. They do a whole piece on ethics, about the documentation required, about privacy of information [...] And so as such they have responsibilities as professional business people, even if they're just you know, starting little

baby business, you've still got responsibilities. And that's things like public liability insurance, professional indemnity, you know, first aid, making sure you've got all the documentation in place and client agreements and all those clear things. So we're very, you know, clear about that” (Doula)

“We've got a vulnerable population group. And that's how we ensure that they are not taken advantage of in this space” (Jurisdictional Palliative Care Peak)

“We tried to get a number of people in this room and it's been really lively and not everyone's agreeing. But I feel like we're amongst friends. I think we've got to pose the challenge, who's not here? You know, where are the Mavericks, who will stand out and actually do their own thing? Because in many ways they're the ones who will, maybe not tarnish, but taint the reputation of doulas, if they stay out of the tent. And so how do we bring them into the room? I think that's probably an ongoing conversation, but a really important one” (Jurisdictional Palliative Care Peak)

7. Registration and regulation

Roundtable participants who were not DDs expressed concern around the lack of formal registration of DDs, and how this might impact on quality of care. Participants who were DDs informed the other Roundtable members about a newly established peak body for DDs in Australia.

“So we have not seen any death doulas come across our desk in terms of the unregistered practitioner space, which kind of surprises me. I'm not sure that

there's actually an understanding in the sector that they do fall within the ambit of the code of conduct for certain health care workers" (Health and Community Services Complaints Commission)

"The ANMF are really clear if someone's not a regulated health practitioner then the term scope of practice does not apply to them, because scope of practice is a regulated clear delineation of a role and what you can do in that role. For example, an unregulated care worker who works in aged care or in a health service, doesn't have a scope, they have a job role or job description" (ANMF)

"[...] because the space is not regulated, death doulas are able to identify what their role involves. And as there is not consistency and clear boundaries for these roles it is difficult to create that quality of care" (ANMF)

"in terms of registering as a profession. Social work isn't even registered as a profession. So in terms of death doulas being registered with AHPRA, we're not. We do have mechanisms in place that regulate us as professionals, but that's only people who actually are members of the National Association of Social Workers. So the registering, registration issue is probably a long one way off" (SW)

"So it's just a matter of time and that we are, not only we're into providing professional support, myself, xxx, xxx, we are putting together an organisation in fact, it's registered, it's ready, we're going to be going public and for, it's a membership

organisation to provide professional support to our doulas. Businesses, how do they get their businesses up and going? There's support there. After death support, you know, via xxx. 24/7 on-call support for the doulas, ongoing professional development and training, that's all part of it" (Doula)

"I think that the use of a peak body would be great. However, a peak body only exists when everyone in that country, or majority of people are registered, and then they get momentum, that's going to take a long time" (Holistic Funeral Director)

"I think quite exciting to hear not only about a national peak body but also about a membership organisation that will support doulas to actually be responsible business owners and ensure that that is met. [...] Every single jurisdiction has different laws, different regulations, different ways we do things. [...] You know, we would not separate between clinicians and doulas, everybody is in the palliative care and end of life profession. But different jurisdictions do things differently" (Jurisdictional Palliative Care Peak)

Minor themes

Five minor themes also emerged from the analysis.

1. The role of palliative care volunteers

There are some DDs who do not charge a fee for their services and so work in a voluntary capacity. There are also palliative care volunteers, so

questions were raised regarding the two roles:

“So a big part of palliative care services are volunteers. [...]. So it was just to make sure that we factor in the role of palliative care volunteers and also, you know, the interactions that they have as well” (National Palliative Care Peak)

“Also keen to explore the intersection between pall care volunteers and doulas” (Jurisdictional Palliative Care Peak)

“But my role as a volunteer is very different to my role as a doula. And I think primarily because on (sic) a palliative care volunteer, so all the referrals come through palliative care, and I know that my role is just really friendship in a way. I don't mention dying to them unless they want to talk about it with me. The conversation is completely client driven. When I'm an end-of-life doula people will always approach me for whatever they're thinking to do. So they're the big distinctions for me” (Doula)

2. Equity of access

The equity of access to a DD was discussed, as not all people will be able to pay the fees that may be charged and would need a volunteer DD if available:

“Agreed xxx but everyone needs to be fairly compensated for their work. I'm confident everyone here is being paid as are pastoral carers, allied health practitioners, massage therapists, providers of household services etc” (Holistic Funeral Director)

“ xxx I'm not saying they should not be paid, I'm just saying that not everyone will have access - as they won't to massage et” (Researcher)

“Agreed - hence the need for more equity based funding!” (Holistic Funeral Director)

“I think it's very much there isn't equity across the board” (SW)

3. Voluntary Assisted Dying

The role (if any) of DDs relative to Voluntary Assisted Dying was raised in the meeting revealing that DDs are already working in this space with clients and families:

‘So now that voluntary assisted dying is part of end-of-life choices, options. So just understanding where that fits and how that would be a role in the doula space, and what's the provision of care that will be provided by a death doula in relation to voluntary assisted dying?’ (Jurisdictional Palliative Care Peak)

“I do think there's a role in assisted dying, it's another way of dying but again, it's supportive, not medical” (Doula)

“I've actually worked with a few clients now who have been accessing the voluntary assisted dying scheme here in xxxx” (Doula)

“We too often make the assumption that people have got family around them. And so those who are alone, I just want to keep reinforcing, because I think if you're alone and approaching voluntary assisted dying, maybe having a supportive hand there with you is fundamental. And so it's something to keep in our

mind” (Jurisdictional Palliative Care Peak)

4. Training and certification

Currently there is no accredited, recognised or even standardised DD training programs globally. One DD introduced the concept of a (now available) Certificate IV in End of Life Doula training:

“we've started the Cert IV that'll be going in the water, the first one will be going in the water in the first half of 2022” (Doula)

“Do you think the significance of the Certificate IV benchmark being put in the sand is... it hasn't actually been verbalised today, and I would like to talk about that. Because in some ways that starts to set the quality framework, the expectation. But it's almost like the other 3 or 4 trainers have run scared from that. Maybe I'm naming the elephant not in the room. And so, I do think there's something around that, that is critical to our conversation” (Jurisdictional Palliative Care Peak)

5. Acceptance of the role

While there was not always consensus in the room about concepts raised it was certainly accepted that the DD role has been established in Australia:

“I think we very much we're open to death doulas, which I think is a fabulous, really interesting model in the space” (Jurisdictional Palliative Care Peak)

“What I'm not hearing from any of you is these are not roles that should exist. There's a real

recognition in a number of things you are all thinking, you are all talking about, of the value of the role of doula” (Facilitator)

“I don't want anyone to think for a minute that I don't think death doulas can be terrific patient advocates. That's clear. That's the role I've seen” (PCNA)

Discussion

The roundtable meeting ensued with an atmosphere of collaboration and a general willingness to start a conversation.

Awareness and understanding

There was a fundamental unspoken acceptance that the role exists, that it is growing and that everyone present was there to understand more of each other's perspective and to establish common ground. The main purpose of the roundtable from the Australian Palliative Care Peaks CEO Network perspective was to increase their understanding of the DD work in order to develop information sheets for consumers and service providers and a policy position statement.

Descriptions of the DD role

It was acknowledged that there is no one accepted definition of a death doula, as has also been noted in the research literature.^{3,6} The DD role as described by participants was that of an advocate and an event coordinator who can provide holistic care. They can provide information and options for clients and can have a role working with different cultural groups (such as seen with birth doulas),⁷ and with Indigenous groups at the end of life.⁸ The variation in role enactment was also highlighted and the challenges relevant to this. It also became apparent that the role described during the roundtable of DD are closely aligned with that of a palliative care social worker.

Interaction and collaboration between sectors

A question also emerged as to whether DDs are the solution to gaps in the current system, and while most participants acknowledged the gaps that exist in palliative care, a few questioned whether DDs were the solution to these gaps (as opposed to making the current system easier to navigate and more adequately funded). There was some tension about where the DD role sits. Participants who were DDs saw themselves as practicing and wanting / needing to collaborate, potentially as part of the MDT or working alongside palliative care. It was felt by the DD representatives that they were addressing system gaps, enabling continuity of care that cannot be achieved purely through health and /or social care teams. This also reflected findings from a recent review.¹ However, one participant questioned whether DDs belong in this space at all, or whether they are best to remain separate from 'health' altogether, sitting in the community arena. The questions remain then: Are DD an extension of a palliative care or health service, do they sit alongside, or do they remain as a standalone provider? Interestingly, there was also the description by one DD that it is not only doctors and nurses providing palliative care as it was an approach to care.

Blurring of boundaries

It should also be noted that the Social Worker (SW) representative highlighted SWs perform some of the same roles as described by DDs. Such as advocating for non-medical issues.⁹ From here the question is do DDs as part of the MDT refer clients /families to SWs or do they function in these roles themselves? Would this then

follow that with an increase in the numbers of SWs the number of DDs can be reduced?

It is also worth acknowledging here the aforementioned overlap with community nursing roles and palliative care volunteers and the implications for practice. Do DDs refer appropriately for clinical care or is it left to consumers to self-refer? Role overlap, role blurring, and role boundaries are important considerations in this space and arguably will be managed at an individual level on a case-by-case basis in the absence of formal DD job descriptions and the fact that there is no consistency in role enactment or approach to care.

Variations in role / practice

There was confirmation that DDs do not work in a consistent way, which has evolved as there is no overarching job description or even a common agreement on what the role entails, and no monitoring of work undertaken. There was also discussion about those that are both registered nurses and have training as a DD and what this looks like in practice. It has become clear that registered nurses are moving into the doula role, often as a result of becoming frustrated with the nursing model of care / gaps in care that they can provide (or would like to provide) in not having the time for patients.² Participants who were death doulas generally argued that to them the boundaries are clear cut (i.e. doulas are non-medical), whereas other participants were unsure of whether and how such boundaries are being maintained. It is complex and challenging to negotiate between the nurse role and the DD role, but it was

made clear that clients need to know who is providing care in order to clarify expectations or the service being provided. This is an area that needs more research.

Safeguarding quality of care

Ethical practice around the safeguarding of consumers who are considered to be particularly vulnerable was also highlighted as important, sentiments originating from a position of protecting those who are dying. This also speaks to concerns around registration and regulation and a lack of these safeguards in relation to the DD role, although noting that for DDs who are not registered health professionals that the code for unregulated health workers applies once enacted in all States and Territories (managed by State Health and Community Services Complaints Commission).¹⁰ Safeguarding with respect to equity of access and financial costs associated with DD appointment may affect both quality and capacity to benefit from the DD role.

Registration and regulation

Discussions covered the code of conduct for nurses which is overseen by AHPRA, and the question of 'when does being a DD affect your nursing registration?'. It was emphasised that the code of conduct for health professionals applies 24 hours a day and is applicable regardless of the job that the nurse is working in. It was apparent that this is perceived as somewhat of a grey area though, as it depends on whether a nurse is using their nursing knowledge and skills in a non-medical role such as that of DD and how in reality this can be

determined. It was reinforced that there is a national code of conduct for unregistered health workers that applies to DDs.¹⁰ To note is that some retired nurses take on the DD role and will arguably be held to account under the code of unregulated health care workers rather than AHPRA (if they are no longer registered).

Five minor themes also emerged from the data: *the role of palliative care volunteers, equity of access, DD role in relation to Voluntary Assisted Dying, DD training and certification and Acceptance of the role.*

The role of palliative care volunteers

The consideration of the role of palliative care volunteers was noted and some similarities with a volunteer DD (ie, those who do not charge money). This intersection of two different roles warrants further discussion, with conflation easily occurring in the absence of a full understanding of the uniqueness of each role. It then becomes important to distinguish between palliative care volunteers who are under the auspice of a hospice or hospital, and an independent doula. Vanderstichelen and colleagues (2022) in their survey of 2,273 palliative care volunteers found that provision of support for those who are dying can be provided, but that it requires training and consistent supervision.¹¹

Equity of access

Equity of access and consistency was raised in relation to the fact that some DD charge money for their services and that some do not. Also to note, is that there is no accepted pay scale and each DD may charge a different fee. This means that like many private services such as counselling or

massage therapy where there is a cost involved, only those who are financially secure are able to benefit from this service, unless there is a DD who volunteers. There were calls for equity-based funding but no indication of what that looks like.

Of note is that some DDs are working alongside marginalised, vulnerable and underrepresented groups to increase access and address equity (First Nations and CALD) although no information is available about the costs of this and who is funding the work.^{8,12} This has certainly been evident in the case of birth doulas with work undertaken for CALD women,⁷ disadvantaged women,¹³ Indigenous women,¹⁴ women with an Intellectual Disability,¹⁵ and incarcerated women.¹⁶ It will also need consideration of the interface between death doula and the existing support workforce such as translators and interpreters, Aboriginal Health workers and NDIS workers.

DD role in relation to Voluntary Assisted Dying

In terms of VAD, it was noted that DDs are already working in this space and supporting clients and families to navigate it. VAD has become legalised in many Australian jurisdictions, and it is likely that the rest will follow.¹⁷ It was proposed that someone without a family could be accompanied by a DD through VAD. However, yet to be determined is the difference between the DD role versus the patient VAD care navigator role.

DD training and certification

Inconsistencies with DD training methodology was discussed. Training via a Certificate IV in End-of-Life Doula training was brought to the discussion

highlighting moves on the part of DD training organisations to standardise training. It was acknowledged that only one DD training organisation is offering this course, and that not all current DD training organisations agree with this approach. Of interest are moves internationally to develop a European core curriculum for hospital end-of-life volunteer services.¹⁸

Acceptance of the role

Also noted was that some DDs are in the process of establishing an Australian DD peak body, to promote consistency and advocacy for DD. There was much interest in this from other participants, as well as concerns around how this would affect DDs sense of their own specific and unique contribution.

Of note was the use of the term 'scope of practice'. Death doulas have used the words 'profession' and 'professional practice' in referring to their role, however the nursing organisations delineated between professional roles (meaning nursing) and the non-medical roles (DDs or perhaps pseudo-family) role arguing that the use of the term 'scope of practice' is only relevant to health care professionals' clinical roles. As DDs are not clinical scope of practice should not be applied.

Outcomes from the roundtable

Since the roundtable the Australian Palliative Care Peaks CEO Network has met and drafted a policy position statement and community information flyer. These are expected to be available in late 2022. There may not be quite the same clarity for the Peaks CEO Network relative to the other

aims of the roundtable such as DD factsheets for consumers aimed at helping vulnerable and potentially overwhelmed families navigate this system. Questions have arisen such as: what to tell the general community about DDs? If a family is looking to engage a DD to help a family-member in the end of life, what should they look for? What questions should they ask potential DDs? It is yet to be seen whether the roundtable was successful in achieving these particular aims.

To also note is that the themes identified during this roundtable could be utilised by palliative care agencies when other new roles emerge, in order to increase understanding of these roles.

It is also important to note that only one DD training organisation was represented at the roundtable. Their views cannot therefore be seen to represent all DD organisations as we note the disparity between them. There were individual DDs present and the holistic funeral director and consumer representative had also undertaken DD training however, it was again with the same DD training organisation. Only one DD had trained elsewhere.

Conclusion

The DD role is a relatively new one in relation to palliative care.

Communication and collaboration has occurred in a variety of ways, however, this is the first time in Australia that the Palliative Care Peaks CEO Network has formally engaged with DDs to increase their understanding about the role. The roundtable meeting was considered a first step in bringing together the major stakeholders in this space to discuss the DD role, and occurred amidst what is and continues to be, a rapidly changing health and social care sector. It should be recognised as a major initiative to promote improvement in end-of-life care in Australia.

The roundtable was a collegial discussion to establish a common understanding and to plan a way forward for jurisdictions in supporting consumers, community members and health professionals when understanding the DD role in the context of a person and their family experiencing a serious illness, dying, death or grief. What was clear though is that while collegial discussions and collaboration is occurring with some DDs, there are others who have chosen not to engage. This highlights that there is still a long way to go to achieve consensus on many issues.

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Appendices

Appendix 1. Briefing Paper



Research Centre
for Palliative Care,
Death & Dying

The role of the Death Doula in End-of-Life Care: A briefing paper for Round Table Discussion
Deb Rawlings, Lauren Miller-Lewis, Kate Swetenham, Jennifer Tieman

Background

The term “Doula” is “of Greek origin that roughly translates as a ‘woman caregiver’” or “woman slave”. Birth doulas have been recognised for many decades, cited in the Midwifery literature since the 1970’s. A birth doula has been described as a non-medical role that supports women emotionally and physically in their birthing plans (and often into the post-natal period). They are considered in midwifery as paraprofessionals, with specialist roles subsequently developed such as abortion doulas and stillbirth doulas.

The emergence of the Death Doula role was noted by our team in the Dying2Learn Massive Open Online MOOC, and subsequently via media coverage, including: local newsletters, National and International newspapers (e.g, Sydney morning Herald, the New York times), via individual Death Doula websites, advertisements for Death Doula training, and through television and radio interviews. Not a new role, Death Doulas are now working globally with a variety of names that describe the role such as Death Doula, End of Life doula, Death Midwife and so on. Death doulas are now established to the point where specialist roles are also being developed in the end-of-life space such as Dementia Doulas.

What we know from our research^{1,2,3,4,5}

Access to care and support in the community can be inequitable, with patients and families often ineligible for care packages or domestic help. This can result in costly care, and quite often the need for private organisations and community groups to contribute to the physical, psychological, and social care needs of people at the end of life. The care required of those dying at home makes great

demands on family (spouses / partners /parents /children / family/ friends) with no one health or social care service able to support them completely in this care. Death doulas appear to be filling social care gaps not necessarily medical ones and this is how they describe their role. Anecdotally, death doulas may be working in a similar way to that of “an eldest daughter’ albeit separate to family members. Many Death Doulas started working with the dying within their own immediate family circle and found their ‘calling’ as many would say.

There are fundamental differences in the way in which Death Doulas are trained and how they enact that training in supporting those at the end of life. There is no standardised Death Doula training, with a high amount of variability in the duration and type of training undertaken globally. Many organisations offer Death Doula training courses and provide certificate of attendance, some offer ongoing training and support. There is one Cert 4 currently available in Australia and while this will provide some standardisation it is not mandated training and is offered by one Death Doula training organisation with at least 3 others in Australia and some overseas organisations offering online training (even pre-COVID).

There is no requirement for Death Doula s to be registered anywhere centrally, although in Australia they are regulated in many (not all) state and territories via the Health Complaints Commissioners under the National Code of conduct for certain (unregistered) health care workers. Many Death Doulas are conflicted about the need for registration, with some seeing it as vital, and others worried about any associated loss of autonomy and flexibility in how they enact their role that may be a result of standardisation. As independent care providers, Death Doulas are then working without oversight, and often in isolation. To note, many Death Doula training organisations offer ongoing support, and additional training.

With the lack of a standardised business model there are inconsistencies in what services each Death Doula offers and what patients and families can expect. Some Death Doulas may work only with the dying person, only with their family or only after death (or all of the above). This may or may not be circumstantial or what the Death Doula has been required to provide to date, and if required, they can provide a full scope of Death Doula services. Some are likely to provide services according to their own experiences, skills or preferences as for example, many Death Doulas have a health qualification (predominantly nursing) so some can and do offer specialised or blended services. The result is that Death Doulas provide a multitude of tasks –education, guidance, physical /emotional /spiritual support, practical needs, companionship, rituals, funerals and so on.

In these diverse roles, while filling gaps in care, there are also seen to be overlap with the roles of health professionals such as chaplains /pastoral care workers, palliative care volunteers, nurses, massage therapists. However, a main point of difference seen by Death Doulas is that they can provide time to be with people, something that health professionals cannot do.

There are inconsistencies in funding as some Death Doulas may be working in a voluntary role, while others charge fees for their services. However, even then, some who are not currently paid typically report a plan to start charging a fee to care for people at the end-of-life, wanting it to be a profession and to earn income from the service they provide. In this way there are those who are working in dual roles in an attempt to transition into full-time paid Death Doula work. This has seen the emergence of health professionals (mostly nurses) who work part-time as a Death Doula and part-time in their substantive role, with concerns over role overlap and professional boundaries. There is a need for awareness that health professionals, even when working as a Death Doula are held to account by their professional body.

There are existing models of care that can be viewed in a similar light to that of Death Doula. For example, in 2012 national registration was introduced for Aboriginal and Torres Strait Islander Health Practitioners. There are also roles such as lay (nonclinical) patient navigators in cancer care services, and specialist supportive community care workers, both of which are supported under umbrella organisations. However, the Death Doula role may also fall within the compassionate communities' approach with some Death Doulas volunteering in their local community for altruistic reasons. If the Death Doula role is not incorporated into an organisation (such as hospice) then they can potentially be seen as supplementary to palliative care multidisciplinary teams. However, there are many Death Doulas that prefer to remain independent and are not interested in working for or within an organisation.

Death doulas will often receive referrals via word of mouth and these referrals may be from health care professionals including General Practitioners, Hospital staff, palliative care teams. They also will often advertise locally about their services. We have seen over the past few years, a growing awareness of the role in the general community. From our Dying2Learn Massive Open Online Course participants, there is also an increasing interest in and demand for training and in providing services as a death doula.

Conclusion

In essence, the Death Doula role has emerged not only as a response to the overwhelming demands on, and expectations of families /carers, but also of health care professionals (and palliative care professionals) who cannot spend the time that they would like with people who are dying. End of life is complex and confusing for patients and families and with a healthcare system that cannot completely meet their needs patients, carers and families are choosing to place trust in those who can advocate for them or fill the gaps in care provision. For example, if Death Doulas 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.

However, there are implications in the growing numbers of Death Doulas who are working with people at the end of life, and we have seen both benefits and concerns raised. Transparency is needed in role scope and role delineation with perceived overlap with the role of volunteer and some health and social care professionals. Some health care professionals (mostly nurses) are working as Death Doulas, and the reality of this should be considered in relation to roles, responsibilities, legal requirements and codes of conduct.

Family expectations need to be considered in terms of the services that they are being offered, so that informed decisions can be made about care that they are potentially paying for, before they bring someone into their home to care for themselves or a loved one. This is especially true in light of the many inconsistencies in working practice.

The reality is that Death Doulas may represent a new direction for personalised care directly controlled by the dying person, an adjunct to existing services, or an unregulated form of care provision without governing oversight.

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Appendix 2: Roundtable Agenda

AGENDA

Palliative Care CEO's Network
National Death Doula Roundtable

Tuesday 7 December 2021
11.00am–1.00pm AEDT

Time	Agenda item	Inclusions / items to be covered	Notes on approach
11.00am 10 mins	Welcome and introductions	Welcome Acknowledgement of Country Housekeeping / guide to participation	Ask each participant to add into chat the land from which they are joining the meeting Ask each participant to introduce themselves – name and role Brief suggestions on making the most of zoom (mute, raise hand, use of chat function, cameras on if possible) Note that session will be recorded Facilitator to introduce CEO
11.10am 5 mins 5 mins	Aim of the Roundtable	Purpose of roundtable	Overview of purpose of the session Describe safe space for discussion – recognising range of perspectives represented Acknowledge session may not provide all answers but is the start of a conversation to increase awareness and strengthen interactions Expected output from the meeting (report, plan to develop short information sheets) CEO to introduce Researcher Overview of the Flinders research
11.20am 40 mins	The role of Death Doulas in palliative and end-of-life care	Brief insights from pre-workshop interviews with Death Doula training organisations	Facilitator to reflect on pre-workshop discussions with Death Doulas (including variation in role name and role description)

Time	Agenda item	Inclusions / items to be covered	Notes on approach
		<p>Reflections on variation within the role</p> <p>Reflections from stakeholders on the role and level of awareness and interaction with palliative care services</p>	<p>Facilitator to invite short comments from Death Doulas / palliative care peaks network</p> <p>Facilitate discussion on:</p> <ul style="list-style-type: none"> • what are the key benefits and challenges of the Death Doula role (from each stakeholder's perspective)? • what's common and what can vary in relation to the role? • what don't we know / what key questions do stakeholders have? • what needs to be considered from a consumer perspective? <p>Facilitator to invite Researcher to ask any additional questions related to research study</p>
12.00pm 40 mins	Future opportunities for consideration	<p>Explore areas for consideration to strengthen awareness and interactions:</p> <ul style="list-style-type: none"> • strengthening consumer awareness • cultural considerations • strengthening connections between palliative care services and Death Doulas • training and education • regulatory considerations 	<p>Facilitator to build on discussions about the current situation and ask participants for ideas about:</p> <ul style="list-style-type: none"> • what opportunities there are for improvement (improvement in awareness / improvement in role definition / improvement in consistency in approach)? • how can improvement be facilitated? • what can be done now / what needs more consideration? <p>Facilitator to invite Researcher to ask any additional questions related to research study</p>
12.40pm 15 mins	Reflections and next steps	Individual reflections: areas of agreement and actions needed	<p>Facilitator to invite each participant for an individual reflection on:</p> <ul style="list-style-type: none"> • priority issue needing action (immediate / longer term) • interest in involvement in ideas being suggested (e.g. review of fact sheet)
12.55pm 5 mins	Next steps	Summary of next steps	CEO to give final reflections on the discussions and suggested next steps

Time	Agenda item	Inclusions / items to be covered	Notes on approach
			Researcher to describe next steps with the Flinders paper Describe next steps: Roundtable report and Consumer and Health Professional fact sheets
1.00pm	Close	Thank everyone for attending	