Death doulas in end of life care: What does that look like? Surveys and Interviews with Death Doulas

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Background

- CareSearch Dying2Learn Massive Open Online Course (MOOC) held in 2016 [1]
- “I’m a Death Doula “

Birth Doula

- Midwifery literature since 1970’s
- Mostly working in non-medical roles, supporting women emotionally and physically in their birthing plans and often in the post-natal period
- Paraprofessionals
- Specialisation
  - Abortion doula [2]
  - Doula for women with specific needs or from own racial or ethnic group [3]
  - Bereavement (such as stillbirth) doula [4]

Research beginnings

- Death doulas (DD) –increasing reports in the media
- Not a new role, especially overseas – Canada, North America and the UK
- Nomenclature
  - Death Doula (DD), end of life doula, death midwife, midwife of the soul, death walker.

SYSTEMATIC REVIEW

- Dearth of published academic literature about DD in end-of-life care
- The DD role and place within the health and social care systems is not well understood.
- They may represent a new direction for personalised care directly controlled by the dying person, or an adjunct to existing services

Doulas do not replace medical or nursing expertise, but rather they add a missing layer, acting as an expert family member, a mentor or facilitator and a source of information and guidance" [5]

Survey

- To explore the role of DD
- Disseminated via 4 Australian DD training organisations, Groundswell, D2L emails
- April - June 2018 to those self-identifying as DD to describe their role, experience, and reasons for becoming a DD.
- 190 valid responses (complete and partial responses)
- Demographics collected at the end (attrition) (n=85)
  - Most aged between 50-59 (36.9%)
  - 96.5% female
  - **Majority have health qualification** (61.9%) (predominantly nursing 47.9% or 23/47).
  - Only 5.9% (n=5) were actively working solely as a death doula, with 32.9% (n=28) in a dual role.

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

Table 4: Common death doula tasks

Task	n=
Providing family and individual with education / information on choices / options	46
Facilitating funeral planning e.g., before death parties, assisting with memorial, burial or cremation planning and ceremony (including assistance writing eulogies, celebrancy), wake, assisting with memorial	37
Helping loved ones in caring for the dying person e.g. environment, music and art therapy, non-medical pain relief suggestions	36
Advocating / facilitating end-of-life wishes e.g. find someone whom the dying person wishes to make contact with	34
Being a companion / spending time with the person who is dying	28
Assisting with practical and personal tasks e.g. shopping, housework, general day to day tasks	24
Providing emotional support/counselling	23
Listening	22
Assisting with advance care planning/providing legal explanation e.g. Advanced Care Directive planning, Enduring Power of Attorney, Enduring Guardian and Will Preparation	22
Providing spiritual support	21
Vigiling	20
Supporting the dying person to find peace and acceptance, facilitate unresolved issues, reflection, regrets	18
Facilitating connection to local services and supports e.g. sourcing equipment for home deaths	16
Home funeral support e.g. washing and looking after a dead body at home	15
Providing physical care e.g. mouth care, massage	14
Opening up conversations about death and dying	12
Legacy projects e.g. writing letters, making photo albums, videos, biographies etc.	12
Attending medical appointments to translate ‘medicalese’(jargon)	11

Common Death Doula tasks	n=
Providing respite	10
Coordination of support teams / family and friends	10
Acting as a liaison between the dying person and family and support family relationships e.g. provide family mediation, support difficult conversations and fractured relationships	9
Supporting end-of-life decision-making	8
Liaise with health professionals / medical teams	7
Help establish compassionate community networks and promotion of death literacy	7
‘Hold Space’	6
Providing bereavement support/counselling to after death to carers, families, hospital/facility staff including text message or visit on birthdays or anniversaries	6
Holistic Support e.g. support from diagnosis to death, burial, cremation, and grief	5
Assessing needs / wishes	4
Other** (e.g. photography services, services for specific populations)	2

* Note: More than one response could be provided by participants.
** ‘Other’ includes less common doula tasks (all reported once each)

Registration, Certification, Training

What is your response to the following statements	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
Death Doulas Should be registered (n=169)	38 (22.5%)	53 (31.4%)	51 (30.2%)	19 (11.2%)	8 (4.7%)
There should be a minimal level of training to be a Death Doula (n=166)	61 (36.8%)	60 (36.1%)	24 (14.5%)	13 (7.8%)	8 (4.8%)

- Of those who answered the question (n=171) over half (58.1%) reported undertaking death doula training, although classified a range of teaching and learning activities within this.
- The length of training ranged from 1 day to 1 year, to 200 hours theory (n=93).
- Some (n=19) had undertaken more than one course.

Payment

Have you ever been paid as a death doula?		n=77	%
	No, I have never been paid	38	**49.4**
	Yes, with monetary payment	24	**31.2**
	Yes, with an 'in kind' payment	5	**6.5**
	Yes, with both monetary and 'in kind' payments	10	**13.0**
Do you have an ABN?		**n=81**	
	No	39	46.9
	Yes	43	**53.1**

Death Doula survey findings

- Confusion as to role
- Some are palliative care nurses who also work as DD
- The potential for duplication with existing roles and a potential for misunderstanding professional responsibilities.
- Health professionals feeling they are doing death doula work without the title, and unpaid doulas not recognised and managed within a volunteer framework, adds to this role complexity
- Inconsistencies in how the DD role is described and enacted
  - How does this relate to the need of the person and how is it negotiated?
- DD are working with families without oversight, and often without support

Commentary

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

At the end of the survey participants were invited to a one-on-one interview

Interviews

- Semi-structured in-depth interviews to explore the role of DD in end-of-life care.
- 20 participants from 5 countries (primarily Australia). Interviewed for an average of 58 minutes.
- Data analysis was undertaken to try and 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 offer.

Themes derived

- What a DD offers
- What a DD does
- Occupational Preferences
- Challenges and Barriers
- Family Support
- Contract of service / fee
- Regulation

Results/ What a DD offers (conceptual)

- **Flexibility / adaptiveness in individualised care**
- **Time**
- **Spectrum of support over a long period of time**
- **Non- medical / advocacy**

"Ultimately I think it's a listening and helping to plan. ……"This just feels like event planning." ***DD Participant #3***

"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***

"We can be fully involved, get right in there, be there from sitting with the dying patient to give the family some respite or to go off and do some things, to finding out and informing them about legal issues, through to running a funeral"
DD Participant #14

What a DD does

- **Funerals / funeral options. Present between death and the funeral**
- **Normalising death and dying**
- **Legacy work**
- **Ongoing companion**
- **Sitting vigil**
- **Other services e.g, massage**
- **Family mediation role**

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***

I quite often will do bedside singing with them. ***DD Participant #6***

Challenges and barriers

- **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 perceived as territorial, and feel threatened by DD**

"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***

"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***

Occupational Preferences

- **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**
- **Post-death only. They are involved in funeral and bereavement rituals**.

"My focus is the person that's coming towards the end of their life" ***DD Participant #8***

" actually haven't been involved with anyone who's dying, but their carers" ***DD Participant #11***

"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***

Family Support

- **A 24-hr 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)**

"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**

"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**

"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**

Contract of Fee /Service

- **Some DDs only work in a voluntary capacity and cannot see how it could be considered paid work**
- **Some DDs charge money for the work that they do and earn a living (full or in part) this way.**
- **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.**

"So, my base rate at the moment is $100 an hour and you can buy packages of 10, 20 and 30 hr or you can buy me by the hour if you just want information" ***DD Participant #5***

"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***

"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" ***DD Participant #19***

Regulation

- **Some DD indicated agreement as long as it is not deemed too onerous or restrictive**
- **Some DD suggested other similar models (e.g. art therapists in the UK).**
- **Others could not see how the regulatory process would work at all.**

"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***

"Oh it needs to be regulated. Definitely" ***DD Participant #8***

"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***

Discussion

- The role has emerged not only as a response to the overwhelming demands on families and carers, but also demands placed on health care professionals (and palliative care professionals) at the end-of-life
- DD have identified ‘gaps’ in health and social care and in our study reportedly see themselves as taking on tasks that health professionals have no time for, with **time** being a main differentiating feature from the perspective of death doulas.
- Those who have, or who are currently, working in the ‘caring’ professions are drawn to this role, perhaps because some nurses (for example) relish the more sitting, talking, listening part of the role that is no longer always able to be accommodated in busy clinical work
  - In the survey one respondent said: “*Being a Death Doula allows me to practice the nursing of my heart*” (Respondent #68).

Implications for nurses

- DD are working in EOL care in Australia perhaps more than we realise
- Nurses will increasingly work with /alongside DD in EOL care
- Some DD are palliative care nurses (currently working)
- There are some similarities between Nurses and DDs in the tasks they undertake
- There is potential for duplication with existing roles and for misunderstanding professional roles and responsibilities.
- The reality of this should be considered in relation to legal requirements, and codes of conduct.

Any person who is working in the health arena will have responsibilities either to AHPRA or under the National Code, and as such are subject to the mandates of these regulations.

- Nurses are accountable to AHPRA even if working in a DD role
- National code of conduct for unregistered health care workers applies to DD

Implications

- The DD role also appears to significantly overlap with that of palliative care volunteers
- The roles and scope of practice of DD's is not clear-cut even for them
- 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
- The DD role could potentially complement that of HCPs and may be incorporated into models of end-of-life care
- DDs may prefer to remain independent providers rather than be part of mainstream care.

Conclusion

- DD are a response to a system that is coping with unprecedented demand and changing expectations. It is highlighting that needs experienced by those at the EOL might be more than those identified by the health system.
- DD are unregulated without governing oversight.
- How the DD role is articulated and enacted is unclear, as are the training, scope of practice, business model
- Clarity is required to satisfy the consumer driven care that will be required in the future. End-of-life can be complex and confusing for patients and families.
- Roles such as the DD 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 and its relationship not only with the family but with health professionals and social care practitioners.

Publications

- Rawlings, Litster, Miller-Lewis, Tieman, Swetenham. End-of-Life Doulas: A qualitative analysis of interviews with Australian and International death doulas on their role. *Health Soc Care Community*. 2020;00:1–14. https://doi.org/10.1111/hsc.13120

- Rawlings, Litster, Miller-Lewis, Tieman, Swetenham. The voices of death doulas about their role in end of life care. Health and Social Care in the Community. Published Early View Aug 26, 2019. DOI: 10.1111/hsc.12833

- Rawlings D, Tieman J, Miller-Lewis L, Swetenham K. (2018) What role do Death Doulas play in end-of-life care? A systematic review. Health Soc. Care Community. 2018;00:1–13. https://doi.org/10.1111/hsc.12660

'Death doulas can fill the gaps in end of life care' was published in The Conversation (14/11/2018) https://theconversation.com/death-doulas-can-fill-care-gaps-at-the-end-of-life-105743 Viewed over 17,000 times

References

- [1] Campbell, D., Lake, M., Falk, M., & Backstrand, J. (2006). A randomized control trial of continuous support in labor by a Lay Doula. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, *35*(4), 456–464.
- [2] Chora, J., Lymana, P., Tuskenb, M., Patelc, A., & Gilliama, M. (2016).
- Women's experiences with doula support during first-trimester surgical
- abortion: A qualitative study. *Contraception*, *93*(3), 244–248.
- [3] McGarry, A., Stenfert Kroese, B., & Cox, R. (2016). How do women with
- an intellectual disability experience the support of a doula during
- their pregnancy, childbirth and after the birth of their child? *Journal*
- *of Applied Research in Intellectual Disabilities*, *29*(1), 21–33. [4] Kolb, K. The other side of doula work. Midwifery Today, Summer 2018,126:35
- [5] Elliot, H. (2014). Death doulas complement nursing care at the end of life.
- *Nursing Times*, *110*, 34–35