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Title: “It’s like a wedding planner”: Dying2Learn Massive Open Online Course participants views of the Death Doula 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

The authors declare no conflict of interest.

Data availability statement.

Data are available from the authors on request

“It’s like a wedding planner”’: Dying2Learn Massive Open Online Course participants’ views of the Death Doula role

Abstract

A Dying2learn Massive Open Online Course (MOOC) was held in 2020 with the aim of bringing the community together to talk about death and dying, with participants undertaking activities, contributing comments, and sharing thoughts and feelings. An activity was posed for participants within a compassionate communities’ framework related to the Death Doula role. As we were interested in the views regarding the Death Doula role by those without a professional background in healthcare. We extracted comments from this cohort of course participants (n=147) and analysed them in NVivo. Eight themes were subsequently generated: 1) It is new to me, and I have no experience with one, 2) I have heard of it, and I have met one, 3) There is a place for it, but what about the role of family and friends, 4) Death doula training, finding the role interesting and wanting to know more, 5) Creating community, supporting the dying and helping loved ones, 6) I am one, I do this informally, or I want to be one, 7) The name, the industry, paying someone 8) Providing an alternative and recognising similar roles. The Dying2Learn community MOOC participants felt that there was value in having a supportive role such as a Death Doula and that it had importance for individuals and society. It was also apparent that the Death Doula role generated considerable interest from participants.

Key words

Death doula, compassionate communities, death, dying, MOOC

Introduction

A non-medical support role, that of Death Doula (DD), has emerged and become established in the palliative and end-of-life care space even though there is a lack of mandated training, registration requirements or commonality within role enactment [1]. DDs are working globally, undertaking a variety of non-medical roles and tasks at the direction of patients and families, that could include providing education, companionship, emotional or spiritual support, advocacy, advance care planning, vigiling, death bed rituals and funerals [2].

Community engagement has become important in end-of-life care, with the recognition that formal health care services are finite and that there are substantial gaps in what patients and their informal carers need when someone is dying [3]. ‘Compassionate communities’ is a term coined to describe the mobilisation of support networks (such as churches, local councils, workplaces) around people with the understanding that it is everyone’s’ business to care and to contribute when someone is dying [4]. There is a dichotomy in how or whether the DD role sits within the compassionate communities’ remit as while some DDs are volunteering in the role, which would add to the community contribution to care, other DDs are paid (or transitioning into paid work).. Negotiating the space between the person, family and friends, compassionate community support, DD and health professionals can be complex and perhaps unclear [5].

Also worthy of consideration, is that while described as a non-medical role, many DDs have a healthcare background, as it appears to be a role that resonates [2], evidenced in a survey of DDs in 2019, whereby a question regarding whether participants had a professional

background in healthcare saw over half (61.9%) of respondents report a health qualification with nearly half of those again were nurses (47.9%) [2].

The role of DD was initially raised with the authors via participant comments in a Massive Open Online Course (MOOC) at its' first offering in 2016 [6]. In the 2020 'Dying2Learn' MOOC the role of DD was highlighted specifically, and presented within a compassionate communities' framework, with questions posed to MOOC participants regarding their awareness of the role. While empirical evidence is accumulating on understanding the DD role from the perspectives of health professionals and DDs themselves [2], very little is known about the thoughts around this type of care held by those without a professional background in healthcare . Thus, the aim of this study was to give voice to non-health community member perspectives through a convenience sample of participants in this MOOC on Death and Dying, recognising that all MOOC participants were likely to be death aware.

Methods

Participants and Procedure

Ethical approval related to the Dying2Learn MOOC was obtained from the XX XX Research Ethics Committee (Project: 7933). In week 1 of the MOOC, participants were provided with information on the 'Compassionate Communities' movement, with links to online information and resources from Australia, the UK and the Public Health Palliative Care International website (<https://www.phpci.org/>). From there the DD role was posed within a Compassionate Communities framework as that of a support person who provides death and dying education and social support. After providing a description of the DD role, participants

were asked a question: *'Have you had an experience with a death doula? Please share your experience/knowledge on death doulas in the comments below'*.

Demographic data was collected at enrolment. In the 2020 MOOC a total of 1400 participants enrolled and $n=671$ respondents then participated in this activity. Of the $n=671$, $n=142$ self-identified as not having a health care professional (HCP) background. Responses from this sub-sample of non-HCPs were included in this study.

Data Handling and Analysis

It is important to acknowledge that the three researchers were authors, developers and moderators of the Dying2Learn MOOC, had constructed the activity and watched as comments were made, participating in course delivery. They had also authored three published papers on DD's. Therefore, with a focus on reflexivity and researcher subjectivity (to avoid potential bias and influence) [7], a research assistant with no prior knowledge of the MOOC or of the DD role was responsible for data analysis and generation of initial themes arising from the dataset of comments.

The data was extracted, cleaned and deidentified by an administration officer before being made available for analysis to the Research Assistant. Data were imported into the NVivo software package by the research assistant, with each statement an open-ended response. Thematic analysis was conducted via an inductive approach with findings arising directly from the data not via apriori expectations [8]. The analysis identified and collated codes into and 8 themes [9]. Each participants statement may have been assigned multiple coding labels when deconstructed. All researchers subsequently discussed the themes that had ben

generated from the data, with agreement reached that this was representative of their experience in the MOOC [10].

Results

Demographic Characteristics

Respondents to this activity ($n=142$) ranged in age from 24-81 years with an average age of 53.58 years ($SD=12.20$). They were mostly female (88.73%), from Australia (97.89%), and university educated (61.27%). Half of respondents had cared for someone with a terminal illness in their personal life (54.93%) and interestingly, despite excluding participants who have a professional background in health care, $n=12$ said that they had cared for someone in their professional life (8.45%) and $n=3$ were unsure (2.11%). As all 100% reported that they were not, nor had ever been a “health professional”, it is possible that these $n=15$ respondents are working for example, as a DD without a HCP background, or a funeral celebrant who consider their work as a professional role. These demographic characteristics were similar to those of previous Dying2Learn MOOC offerings [2, 11].

[Table 1 near here]

Themes

Overall, eight themes were generated by the qualitative analysis. Some participant responses included all parts of the theme and others did not, so numbers do not tally.

Theme 1: It is new to me, and I have no experience with one (n=77): Comments include individuals with no knowledge, awareness or experience of DDs and those who may have

heard about them but have little knowledge of, or no direct experience with one. The frequencies of the comments in these respective groups indicated that there was a lower level of prevalence of knowledge about the DD role in this community sample.

I had never heard of death doula before now (P112)

Have heard of doulas but never seen them at work so to speak (P12)

Theme 2: I have heard of it, and I have met one (n= 48): Comments here express knowing about DD at a basic level and some participants indicating having met a DD(s) or knowing one (or more).

I have read about Death Doulas in Islamic communities, but not in traditional western religions (P18)

I know a death doula who works for the organisation with which I volunteer (P122)

I have heard of death doulas and the relevance in the journey of death (P131)

Theme 3: There is a place for it, but what about the role of family and friends (n=43): In this theme participants underscored the general importance and value of the DD for individuals and society. There was also comparison with non-medical lifestyle roles such as wedding planner.

I've had no direct experience of a Death Doula, but this seems to be a very valuable role (P4)

I think this role is important to be carried out by a family friend rather than someone with no connection (P13)

This area really interests me, rather than a wedding planner you engage a death/farewell planner (P22)

I think it's a great idea - it's like a wedding planner (P41)

I think needing to have such a role is a very sad reflection on our society, and that it is something we should be able to do within our families and communities without having a paid (particularly) person (P60)

..am very aware and feel the role of a death doula is much needed in our community.

I would definitely engage one in a situation where a close family member was dying (P142)

Theme 4: Death doula training, finding the role interesting and wanting to know more

(n=30): Comments relate to wanting to know more about the role (whether through reading or training) and those who indicated already doing so.. The theme also captures comments which identify the role as interesting and those individuals who have expressed wanting to know more about it in a general sense.

I've done death doula training (also called death midwifery), but have not practiced as such (P118)

I'm really interested in training as a death doula, and would love to know of any good courses or training (P107)

Wasn't aware of Death Doula till today. I am very interested (P123)

Theme 5: Creating community, supporting the dying and helping loved ones (n=24): Death

Doulas were seen as performing three important functions: these were creating a sense of community, providing support throughout the dying process, and helping loved ones, whether this was through fostering a connection between loved ones and the dying individual or helping friends and family deal with grief.

I think that independent, supportive, informative role can assist all involved in the dying process cope more confidently and comfortably and bridge the gaps that often

exist between the person dying and their families and friends, particularly when death has not been an open topic (P129)

I had not heard of a death doula, but I think the role is very valuable, especially for people who do not have a large support network (p29)

Even if someone who is dying is surrounded by people who care about them, I imagine a death doula would help that support network feel slightly less pressure in knowing what to do as the doula would carry some of that burden and provide care for the patient + advice from the support network (p44)

Theme 6: I am one, I do this informally, or I want to be one (n=16): Comments in this theme related to individuals who are already practicing DD's (whether formally or informally) and those who would like to be one. The comments in this group suggest some interest in practicing in the area.

I have never heard of a death doula, or even the word/role of doula. Maybe I have been one for members of my extended family, but didn't know it had a name (P63)

I am a practising End of Life Doula more volunteer than paying service as anything around death is usually koha (donation) in my culture (P138)

I have not had personal experience of a death doula but would like to become one (P129)

Theme 7: The name, the industry, and paying someone (n=15): The name "Death Doula" elicited mixed reactions. The DD sector was seen as needing more regulation and guidelines around it. There were conflicting views as to whether this should be a paid position.

I have met some wonderful Death Doulas. I do think the terminology carries with it more than its fair share of immediate biases and unfair assumptions. That said, I

think it is a field that would probably benefit from some structure around it, in terms of quality and expectation setting (P125)

Very suspicious about the motivations of some death doulas - it's like a new opportunity to earn money for some (P134)

Theme 8: Providing an alternative and recognising similar roles (n=15): Comments in this theme highlight that the DD can be an alternative aid in dying, one different from clinical or medical/health-based supports or religiously affiliated assistance. Some participants identified other roles providing similar services to the dying and their family but were not DDs.

I had no knowledge of a Death Doula as such, but am very aware of the role of a non-denomination Chaplain who journey's with a dying person, supporting them on their final voyage which is a very similar role (P104)

I think death doulas are a wonderful and currently unfertilised resource both for those who are dying and their families. Having the additional support of a non-medical person would be invaluable (P72)

Do you think the role of the death doula has increased due to the decline of organised religion? Without religion, people are often at a loss about the rituals of death.

Whereas religion gives people within the family and community roles to play, without it, we have to outsource (P10)

Discussion

While there is growing recognition of the importance of understanding the value of models of palliative care and care at the end of life, consumer input into design, and effectiveness can be limited. As DD emerges as a new contributor within the end of life space, understanding

the experiences and attitudes of consumers of these services is needed. Rumbold and Aoun in their recent review noted that consumer perspectives are not well researched and involvement in service design is limited [12]. They also noted that palliative care guidelines reference communities and carers, models tend to be developed within the bounds of a health system [12]. More broadly, a recent scoping review identified different perspectives on the care quality between those delivering care and those receiving care [13].

The purpose of this study was to develop an understanding of the perspectives about the DD role held by the 2020 Dying2Learn MOOC participants who were general community members without a professional background in healthcare. There were many varied understandings of the DD role, with some having little awareness of the role, and others knowledgeable of what the role entails and who may or may not be a DD themselves. The results from this study have shown the diversity and range of community perspectives around the emerging role of the DD. As such it provides a unique perspective on the role and its relationship to end of life values and expectations of non-health professionals around care at the end of life. Such perspectives are important in assessing how care models can be assessed and framed. It was felt to be important to elicit the views of those without a professional background in healthcare because this group is perhaps more likely to be potential consumers of DD services and understand the appeal of this DD service from the point of view of a healthcare consumer rather than a health-care service provider.

We asked all 2020 MOOC participants at enrolment about caring for someone with a terminal illness personally, and more than half indicated that they had done so. This indicates a cohort who have a clear interest in death and dying, and who are likely to have been immersed personally in the caregiving experience providing a firsthand experience of what is required

to care for someone who is dying. Those who go on to become a DD will often have cared for someone in their immediate family who has died and then perhaps cared for family or friends before realising that this is what they want to do as an ongoing role [2]. However, as we have found in previous studies, participants who answered yes (or unsure) to caring for a terminally ill person “professionally” may be speaking of their DD role in this way, although this cannot be assumed. The majority of respondents answered that they had not cared for someone ‘professionally’, so for some this could just be the difference in perception of the DD role as a profession, or variations in the understanding of a role as a ‘profession’ versus a ‘health profession’. Death doulas aren’t always sure themselves where they ‘fit’, with perhaps an idea of what the role entails for them, but unsure where they ‘fit’ in terms of being a ‘profession’ or a ‘career’ or ‘job’ or a role for the ‘greater good’[2].

While there has been an increasing interest and awareness of the DD role there are those for whom this role is new, or there are those who have heard of it but know little more than that. Over half of our non-HCP activity respondents lacked awareness of the role, despite having a general interest in death and dying (as evidenced by their enrolment in a MOOC on the topic). This is an interesting finding, because if less than half of this sample of people with an interest in death have knowledge of the DD role, one can assume that awareness of DDs in the wider community would be considerably lower.

The theme ‘there is a place for it’ is one that sees participants place value on the role, and by likening it to a wedding planner, places the role firmly within the ‘life events’ cycle that sees formal planning of events such as weddings, christenings, bar mitzvah’s and funerals within a personal service industry framework [14]. However, there was the perception by some participants that this is a role that should be performed by family and friends, although others

saw that an outside person (ie, the DD) could act as a ‘surrogate’ family member or friend for someone with limited support [15], something we have proposed previously in that the DD may act in the role of ‘eldest daughter’ [1]. Throughout each offering of the Dying2Learn MOOC it has been apparent that the DD role has generated a lot of interest from participants. From this study there are respondents (n=46) who have made comments in relation to wanting to learn more about the role. There are those who are interested in training to be a DD, those who are currently doing the DD training or have done it (they may or may not be working as a DD), those who have questions about the role and want to know more and some who are already practicing as a DD or want to.

Death Doulas were seen to be performing three important roles: creating a sense of community, providing support throughout the dying process, and helping loved ones. The role was highlighted as an alternative source of help to clinical or religious affiliated roles, although as we found in our interviews with DD’s [16], some participants identified similarities with services provided by HCPs such as chaplains or bereavement services.

Participants felt that there was value in having a supportive role such as a DD and that it had importance for individuals and society.

The theme: “I am one, I do this informally, or I want to be one, sees one participant writing: *Maybe I have been one for members of my extended family but didn’t know it had a name*” (P63). Thus, by calling oneself a DD, perhaps there is some assumption that one has a level of existing knowledge that can be shared with others who are in the midst of ‘dying’. In the same way, we noted in the findings from our earlier survey of DDs that not all of those who were working as a DD had undertaken DD training, instead using their HCP role as assumed knowledge and experience. There was the dichotomy of having a paid DD position as well as a volunteer role, where the unpaid DD can be viewed through a public health or

compassionate communities' lens [17]. In contrast, paid DD work could be considered yet another cost to be factored in for families [18]. That the sector needs more regulation and guidelines was also noted.

Compassionate Communities

Kellehear (2020) has said that “*Compassionate Communities offer a social model of health*” (Page 116) also called a public health approach [4]. The non-medical DD role can be seen in some ways to fall within this remit as some DD's volunteer their services [3], evidenced in the provision of community education, or hosting 'Death Café's' bringing death and dying into the public domain [19]. The Dying2Learn MOOC and Bollig and colleagues 'Last Aid Course' are also exemplars of raising awareness and death literacy [20].

Many of these themes have re-iterated the complex environment in which end of life occurs where there is an intersect between health and aged care systems, families and the communities within which they live. Dying is generally not an acute event but occurs over time requiring broader supports for the individual [21]. These have traditionally been provided by the family but in a changing social circumstance, new models and initiatives are emerging. Public health approaches around compassionate communities are recognising the local support and social support that individuals need to enable families and carers to provide care and to meet care needs where family support is limited. These approaches also speak to building death literacy and grief literacy creating communities where the impacts of ageing, caring, dying and grieving are recognised [22,23]. DDs provide potential a different model that works at an individual level and interfaces primary with the dying individual and their family but situates in a broader range of community based and home-based initiatives. In all such care frameworks, the perspectives the consumer of these services needs to be heard to

assess the value and contribution of roles and intimates to improving care outcomes at the end of life.

Limitations and Future Directions

A key limitation of this study is that this cohort self-selected to participate in a MOOC on death and dying, and their views are therefore not representative of a general community. Also to consider is that many of these participants had personally cared for someone with a terminal illness, which will perhaps have informed their views of the need for the DD role. To also note is that their comments may have been informed by MOOC activity content and our general DD description. If they had enrolled in previous Dying2Learn MOOC's they may have heard of the DD role then or they may even be a DD themselves. We acknowledge that this continues to be a limitation in representativeness. Another potential limitation is that only one person was primarily responsible for data analysis, however, the importance of this being undertaken independently by someone unfamiliar with the work is emphasised. The authors discussed the themes generated from the data and agreed that they resonated with what they had experienced when immersed in the MOOC.

An important direction for future research is to investigate the awareness of and attitudes towards the DD role in the broader community. This further knowledge will help to better understand the potential broader appeal and possible uptake of DD services by people in wider society. We also recommend future research investigates the views and experiences of families who have used a DD, to understand why they utilised this service and its impact on the dying experience. It would also be worthwhile to understand the views of DD training organisations.

Conclusion

Death Doula's are working globally and the role is enduring, and for some people, this knowledge brings comfort. Participants in this study felt that there was value in having the DD role and that it was important for individuals and for society. This role is continuing to generate interest and while many HCPs are interested in taking up the role, this study shows that those without a professional background in healthcare are also interested in what the role has to offer.

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Conflict of Interest

The authors declare no conflict of interest.

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Data Availability

The data that support the findings of this study are available from the corresponding author, [DR], upon reasonable request

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