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Research Centre for
Palliative Care, Death & Dying

Death Doulas in the News: A Media Scoping Study

A white paper published by the Flinders Research Centre for Palliative Care, Death and Dying

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CRICOS No. 0014A

How to Cite This Paper

Pimenta, JL, Pedroso, A, Tieman, J, Rawlings, D, Death Doulas in the News: A Media Scoping Study. RePaDD White Paper. Adelaide, South Australia: Flinders University Research Centre for Palliative Care, Death and Dying: 2022. Available at: flinders.edu.au. Doi: <https://doi.org/10.25957/4jev-sm25>

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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, & 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

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Executive Summary

Death Doulas (DD) have increasingly appeared in the media, normalising the non-medical advocate/guide role in the absence of formal academic literature.

This White paper reports on the retrospective, descriptive cross-sectional study of data analysed from international coverage of online media and Australian printed news published in English over a one year period from December 2016 to November 2017.

Study findings show that articles about DDs in the media were mainly in general news, blog format and events. The tone used in the articles was mainly emotional and supportive, lacking an objective perspective.

Analysing the content of the media stories provided insights into what DDs do, what influenced their decisions to become a DD, and why this role is emerging. Due to the subjectiveness around the question, feelings around DD work are difficult to classify. A strong and positive response to DD's work was reflected in all articles, except for four.

This emerging role appears to reflect a desire for different approaches and ways of caring at the end of life. They appear to be created by patients' and families' needs for promoting balance in their dying process: preventing/stopping the excessive medicalisation of end-of-life care and bringing meaning and spiritual comfort.

Introduction

End of life care provision is an expectation in the health system¹ but can be complex, and increasingly, health care professionals (HCP) find that they are unable to provide the depth and breadth of care that is needed. Family carers are also faced with what can be overwhelming demands with neither health nor social care systems able to fully meet their needs or those of the dying person.¹

Increasingly appearing in societies around the world, is a new movement of people who say that they prepare the way for the final journey, and they self-identify as Death Doulas (DD) or End of Life Doulas.² Better known for their work in birthing³, this informal role has been adapted into contemporary models of care such as illness doulas⁴, delirium doulas⁵, and abortion doulas⁶. The term 'Doula' has its origins in Ancient Greek and means the person (historically a woman) who serves other women (woman-caregiver)⁷. Following this trend in changing models of care, doulas are now emerging in the end-of-life domain. They are known by a range of names including death-midwife, and death-walker. Here we use the term death doula.

A DD can be considered as someone who provides non-medical integrated care that encompasses the dying person's physical, emotional, social, and spiritual facets.⁸ The role includes conversation and education about disease and end-of-life, discussion of

goals of care, companionship, advocating patient and family preferences and providence of psychological and spiritual resources. Family support is an important part of the DD's role, as is providing them with information to help navigate the healthcare system, the disease and death itself.

The arrival of a role such as a DD into the end-of-life space appears to have come from the need for empowerment during the dying process, giving alternatives to the current modern clinical approach, with a shift directed towards awareness and choice. It seems to have been created by the patients' need to promote balance in their dying process; preventing or stopping excessive medicalization of end-of-life care, thus bringing meaning and spiritual comfort. They also help to organise alternative funeral celebrations, personalizing them and giving them special significance.

This DD role though is mostly unknown within the scientific community and within health and social care systems, however, has been noted in the media for some years, with media communication and its impact on health being an area of increasing interest⁹, including the presence and impact of palliative care¹⁰. Agenda Setting Theory suggests that the salience and importance of a particular issue is

heavily influenced by media coverage of that topic¹¹. While we previously undertook a formal systematic review² to understand what has been documented in the academic literature regarding this role, it was apparent at that time that little had been written formally and that much of the rhetoric and commentary was in the media. To therefore understand how the DD role is portrayed there, we undertook a media analysis.

Methods

A retrospective, descriptive cross-sectional study was designed. This report details the quantitative and qualitative content analysis of media articles that included information about DDs. Ethics approval was not sought as all data was retrieved from freely available media sources.¹²

Search strategy

A media company searched using the terms “death doula” and “death midwife” in their database of print, television and radio (summaries) and online news archive. The search included international coverage of online media and Australian printed news published in English for one year (December 2016 to November 2017).

Data handling and analysis

A data set of the item was created in Excel. A total of 128 items were retrieved and their source is detailed below in Table 1.

Table 1. Characteristics of retrieved media items

| Sources | Number |
|------------------|---------------|
| Newspaper | 16 |
| AM Radio | 4 |
| Online News | 94 |
| Blogs | 1 |
| FM Radio | 1 |
| Magazine | 3 |
| Images and Video | 1 |
| Social Networks | 5 |
| TV | 3 |
| Total | 128 |

The 128 items were screened by one author (AP) and thirty-six articles were excluded. One article was excluded as not meeting the retrieval brief, content could not be retrieved for 11 items, 22 articles did not include a reference to DDs, and 2 articles were duplicates.

Of the remaining 92 articles, 46 could not be fully coded. Eighteen only had light referencing to DDs while 28 articles were syndicate-published, and hence duplicated. Forty-six items were included in the final analysis and then fully analysed and coded.

A qualitative content analysis was employed to describe the role of DDs and their characteristics, to help in understanding this new protagonist in end-of-life care. Due to a lack of a developed and validated schema to characterise news related to the DD role¹⁰, we developed one. The initial schema was developed (DR, JT) and tested against 25 random news items (sourced by AP). Following a collaborative review with discussion around added commentaries and new topics, an agreed set of codes based was established. Articles were first coded against their published format and audience, then the media content was analysed.

The information about DDs in each article is reported in the following way: Death doula characteristics: gender, location, background studies, other jobs, if they were paid or volunteers. The content of the media piece was coded against five death doula constructs:

- 1) Was the DD the author of the article;
- 2) What does a DD do;
- 3) Why the DD role has emerged;
- 4) Why did they become DDs;
- 5) Sentiments about DD work.

Results

Articles about DDs in the media were mainly in general news (26 articles), blog format (8 articles) and events (5 articles). The tone used in the articles was mainly emotional and supportive, lacking an objective perspective.

In 65% of the articles, the DDs were women, and many were still actively working. There was no standardized answer for background studies, but most were health care professionals or related occupations. Regarding payment, 15 DDs charged money for their services, and nine reported working as volunteers. The main reason for someone to become a DD as described in the articles included personal previous experiences followed by regarding it as their sense/mission of life. A less cited reason was modelling themselves on another DD. It is also worth noting that DDs were reported in stories across several countries.

Analysing the content of the media stories provided insights into what DDs do, what influenced their decisions to become a DD, and why this role is emerging. Due to the subjectiveness around the question, feelings around DD work are difficult to classify. A strong and positive response to DD's work was reflected in all but four articles.

Table 2. Understanding death doula perspectives

| | |
|-----------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>The author of the article (DD or not)</p> | <p>Only five of the articles were authored by DDs</p> |
| <p>What a DD does</p> | <p>The content reflected:</p> <ul style="list-style-type: none"> • psychological support/to be present around the end-of-life • understand peoples' needs and desires • provide information and resources • connect people • give meaning to the end-of-life • empower people to reclaim death as part of life • discuss advanced health plans and decisions about death, • help families cope with grief after the death of loved ones <p>Most articles mentioned all of those aspects (if not directly, they implied a similar meaning). Nonetheless, supporting and being present for the dying person and organizing the funeral were aspects which were almost always present.</p> |

| | |
|-----------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Reasons for the emergence of DD</p> | <p>Reported reasons included:</p> <ul style="list-style-type: none"> • returning to traditional basics of death • providing alternatives to modern clinical approaches/rethinking death • after the empowerment about birth focus on death • a shift towards greater awareness and choice • filling the gap between the health system and funeral homes • the problems associated with dying alone. <p>The gaps in health care systems and funeral homes felt by patients and families were among the most common issues.</p> <p>Another commonly cited reason was searching for an alternative to modern clinical approaches, to rethink or reshape death.</p> <p>The problematic issue of dying alone did not seem to be driving this growing movement of DDs.</p> |
| <p>Why do they become DDs?</p> | <p>The main reason for someone to become a DD as described in the articles included:</p> <ul style="list-style-type: none"> • personal previous experiences • their sense/mission of life. <p>A less cited reason was modelling themselves on another DD.</p> |
| <p>Sentiments about DD work</p> | <p>Due to the subjectiveness around the question, sentiments around DD work are difficult to classify. Sentiments about DD work varied between:</p> <ul style="list-style-type: none"> • unreal expectations and disappointment, difficulties • as an opportunity for growth • awareness, gratefulness for life/life in absolute • feeling lucky to be a DD • gratefulness about death doula work • a wish to become a DD. <p>A strong and positive response to DD's work was reflected in every article except in 4 articles with a more skeptical perspective.</p> |

Discussion

In this study, we sought to understand the portrayal of DDs as they are featured in online media. On initial investigations into the literature, it was evident that there is little written evidence on the role², however the DD role appears well-profiled and supported in the media. Multiple publications of the same article through syndicate publication increase the dissemination and reach of media around this role. Moreover, the stories are generally uncritical and accepting, positively portraying those who choose this field and normalising its place in the end-of-life arena. Arguably though this is not restricted only to DDs and often accompanies stories on any role in end-of-life care. However, media reporting can provide a degree of legitimacy to the role and is often how families will learn about possible care options. They also promote the role of DDs and may increase interest in this role.

Death doulas can be seen to advocate for care for dying individuals. This analysis shows that the services DDs offer may not be consistent. What they do is currently unclear, because the meaning of “care” and the needs in death are so vast. Nonetheless, it is important to define boundaries because we are discussing a frail population paying for a service that is sometimes advertised as certified, which can be problematic.

Support and care for people at the end of their lives, in some form or other, is present in all societies.¹³ Caring for people across the last year of life as well as those who are actively dying is a growing demand for health systems and health policies. With full-time care rarely available, patients and families can and will seek out support in end-of-life care, and DDs are one way in which they can control and direct care. DDs aim to give much-needed support to the patient and their relatives during the end-of-life process, at the moment of death, and to the patients’ relatives after death in bereavement.²

Death doulas are therefore a growing movement, accompanied by the growth of official organisations supporting education and promotion of this role in the UK, USA, Canada, Australia and New Zealand.¹⁴ Death doulas are also noted in other countries in Europe, Latin America and Asia in facilitating Death Cafes’, so it is unsurprising that there is media interest and curiosity in the role.¹⁵

Despite the gap pointed out in the health care system, another possibility is whether there is a real gap in the health system or a gap in our society where the role of familial caregivers is being lost. Should the health care system fill this empty space, or recognise that this is a new era for those who are unwell and older in our communities?

Limitations

Our media data was based on the news articles provided by an external media agency, through its databases and represents a snapshot of what was available at the time. The search included international coverage of online media, but only Australian printed news, limiting our reach.

Nomenclature could be a limitation with so many variations in use, but this was early in our exploration into the role, and we were unaware of all nomenclature.

Conclusion

To conclude, in this snapshot of media reports on the emerging DD role, there is still much to learn. In the media, DDs are portrayed positively, but with a lack of objectivity and definition in most of the sourced articles. This emerging role appears to reflect a desire for different approaches and ways of caring at the end of life. Such new roles remind us as health professionals that our practice needs to reflect the patient's needs and desires.¹ Can the arrival of this new role in end-of-life care help health systems learn what dying people and their families want? The new role of DDs came to embrace some spare space in end-of-life care. They seem to be created by patients' needs for promoting balance in their dying process; prevent/stopping the excessive medicalisation of end-of-life care, bringing meaning and spiritual comfort.

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