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Title:

What role do Death Doulas play in end of life care? A Systematic Review

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Abstract

Current health and social care systems don't always meet the needs of the dying in our communities. As a result, consumers are choosing to place their trust in those who can advocate for them or fill the gaps in care. Birth Doulas have been working with women during pregnancy and after birth for many years, and we are now seeing a new role, that of a Death Doula emerging in the end of life care space. How Death Doulas work within health and social care systems is not understood and we conducted a systematic review to explore the published literature to explore the role and potential implications for models of care delivery. Following the PRISMA recommendations, we searched the literature in January 2018 via bibliographic databases and the grey literature. We looked for articles that describe the role / work of a death doula or a death midwife in the context of end of life care, or death and dying. Our search retrieved 162 unique records of which 5 papers were included. We analysed the papers in relation to relationship to health service, funding source, number and demand for services, training, licensing and ongoing support and tasks undertaken. Death Doulas are working with people at the end of life in varied roles that are still little understood, and can be described as similar to that of 'an eldest daughter' or to a role that has similarities to specialist palliative care nurses. 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.

Key Words

End of Life, Death Doula, models of care

Introduction

The end of life care arena is changing globally, with an ageing population who are living longer with increasingly complex needs and who won't necessarily have cancer (Commisso et al., 2017), or be under the care of a palliative care team. Workforce changes, costs and an emphasis on medical intervention has led to healthcare systems that lack the infrastructure and capacity to support those who are caring for our dying in the community in terms of fundamental service delivery and time availability (Phelan, McCarthy & Adams, 2018). In their study of 450 community (district) nurses in Ireland, Phelan and colleagues (2018) reported on incidences of 'missed care' (where support was more likely to be left undone), finding that care had been reported as missed in the context of 'support to families' by 66.3% of respondents, and care had been reported as missed in the context of 'support to carers' by 67.5% of respondents. There was no discrimination by carer or family circumstance, but it can be assumed that these constitute some of the gaps in end of life care.

In addition to this, fewer people are available to take on caring roles (Lockett et al., 2014), as families nowadays are often geographically dispersed (such as with emigration from country of origin or adult children moving away for work), and with a greater economic need for women to play a role in the paid workforce (Williams et al., 2011, Ireson, Sethi & Williams., 2018). Low mortality and lower fertility may also mean that more people are living alone at the end of life (Pleschberger & Wosko., 2017) which brings its own care challenges. Changes in family structure arising from couples having fewer children, divorce and separation also affects the availability of care, all of which leads to more complex family interactions (Thomeer, Donnelly, Reczek, &

Umberson, 2017; Williams, Wang, & Kitchen, 2016). If there are available carers, then they need practical, emotional and social help and support in their caring role (Rosenberg et al., 2015), with many older carers equally unwell (McKechnie, MacLeod, and Jaye, 2011). Expectations of family members in caregiving roles at the end of life are high, with overwhelming financial, emotional and physical challenges (De Korte-Verhoe et al., 2014), albeit often counterbalanced with descriptions of life altering rewards (Anderson and White, 2018). Despite this, families are increasingly expected to take on this caring role (Thomas et al., 2018). Caring can then often fail in the community, with dying taken back into hospital, due to these considerations of overwhelming family carer burden, and the economic costs of being ill (Gardiner, McDermott & Hulme, 2016). The lack of access to services such as 24-hour nursing care, can also drive demand. Conversely, healthcare in the community is often facilitated by the use of private organisations and /or community groups (Mills et al., 2015).

There are also indications that baby boomers may have different expectations and practices around their health than their parents (Bradley, Tieman, Woodman, & Phillips, 2017), and this could extend to their preferences and arrangements for care at the end of their lives. As well as changing social patterns, contemporary community models of care and palliative care models of care in many countries are often disparate and fragmented (Brereton et al., 2017), struggling to cope with demands, and while not all of those at the end of life require intervention from palliative care services, most if not all, will require support at home. With healthcare systems now increasingly overwhelmed, there appears to be a move back to its roots in the community (Gott et

al., 2018), albeit a changed community, and one that may no longer necessarily adequately support its members at the end of life (Guilbeau, 2018).

Dying has been increasingly medicalised over the years (Mills et al., 2015), seen as far back as the late 18th century (Walter, 1994) with “*Doctors appearing more and more beside the deathbeds of more and more people*” (Kellehear, 2007: p144). This has seen a shift of the deathbed into hospital (Walter, 1994), with futile treatments often continued until death (Clark, 2002). Death is a personal, emotive and complex experience that we cannot approach simplistically. It cannot be seen solely as a medical issue to be managed through a health system (Walshe et al., 2016), (although there is an important and continuing contribution of the healthcare system to the quality of death, dying and care at the end of life), but rather a humanistic one where dying is accepted as a normal part of life with a balance between the two approaches (Stringer, 2007).

We need to consider that if the healthcare system is not meeting their needs, patients, carers and families will choose and place trust in those who can advocate for them or fill the gaps in care (Rosenberg, 2011) although arguably it is not the responsibility of the health system to provide this care at home. A recent thesis (Doyle, 2015) has highlighted the dynamic environment in which care at the end of life is being delivered and saw palliative care and hospices as bridges between the hospital environment and a “more wholesome community experience” (pg. 21). This author noted that changing family traditions and structures could promote development of new services such as death doulas.

Background

The term 'Doula' is *"of Greek origin that roughly translates as a "woman caregiver"* (Campbell, Lake, Falk, & Backstrand, 2006, p. 456). A doula has been defined as *"a woman who provides social, emotional and practical support to other women during pregnancy, birth and the postnatal period. She is not a health professional and does not provide any clinical care"* (Spiby, McLeish, Green, & Darwin, 2016, P.1). Birth doulas have been described as paraprofessionals usually working in a fee-for-service model (Low, Moffatt, & Brennan, 2006). The 'Doula' role has been adapted into contemporary midwifery models of care including: abortion doulas (Chora, Lymana, Tuskenb, Patelc, & Gilliama, 2016) and doulas for individuals with specific care needs such as women with an intellectual disability (McGarry, Stenfert, Kroese, & Cox, 2016). With birth doulas now well established, we are seeing innovative hospital and community models in both the UK (Darwin, Green, McLeish, Willmot, &, Spiby, 2017) and the US (Kozhimannil, Vogelsang, Hardeman, & Prasad, 2016) including doulas addressing inequity for women giving birth in lower socio-economic circumstances. Alternatively, within the literature there are also descriptions of Illness Doulas (Robinson, Spencer, & Lewis, 2017) and delirium doulas (Balas, Gale, & Kagan, 2004). These specialist roles demonstrate the possibilities in care that complements that of healthcare professionals.

Existing models of care

There is a need to recognise and acknowledge these potential deficits and gaps in care, and to acknowledge the evolution of new roles and models in end of life care to address these deficits (Poulos, Harkin, Poulos, Cole, & McLeod, 2018). This is not without precedent, both within and outside formal healthcare systems, to help

address not only deficits in systems, but also to support those who are ill and those who are caring for them. Below we describe examples of existing roles that can inform our understanding of new roles and models in end of life care.

For example, within the Australian context, Indigenous Aboriginal and Torres Strait Islander health workers, often have ties to the community, understanding what is needed culturally at a grassroots level (Mitchell & Hussey, 2006, McGrath et al., 2007), improving access to services, and facilitating care and important end of life discussions for individuals, families and community groups (O'Brien., et al 2013, Aboriginal Health Council of SA, 2018). There is a recognised need for Aboriginal and Torres Strait Islander Health Workers and Health Practitioners to play a role in end of life care (Palliative Care Australia, 2015).

Lay (non-clinical) patient navigators are seen in the US cancer care system to “provide emotional support, information, opportunities for problem solving, and logistical assistance to mitigate or overcome obstacles to health” (Rocque et al., 2017 p 683). There are also Native Patient Navigators, described as working successfully with American Indians to improve health behaviours in the ‘Native Navigators and the Cancer Continuum study’ (Burhansstipanov et al., 2014). A similar program to that of native navigator is Apoyo con Cariño (support with affection): Patient Navigation to Improve Palliative Care Outcomes for Latinos with Advanced Cancer (Fischer, Min, Klein & Fink, 2015) with the authors highlighting its’ potential to improve palliative care outcomes in this population.

These examples highlight how patient / family advocates, can be incorporated into mainstream models of care, for both Indigenous people and those from culturally and linguistically diverse communities. Death doulas could be another type of patient / family advocate that could be incorporated into mainstream models of care. To explore this we need to develop a better understanding of what a death doula actually is.

Unsurprisingly, doulas are now emerging in end of life care arenas, with increasing reports on death doulas in the public media, as well as promotion of death doulas in a Massive Open Online Course on death and dying (XXX et al., 2018), where a number of participants described their involvement as a death doula or their use of a death doula. These death doulas were in Canada, North America and Australia, flagging that this role has now become a feature of end of life care in many countries. However, the role and functions of death doulas and their 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, an adjunct to an existing service or an unregulated form of care provision without oversight. We suggest that many of the problems highlighted here - the shift in family carers' ability to manage end of life (Martín Martín, Olano-Lizarraga, & Saracíbar-Razquin,2016), the gaps in community and health care (Lam et al., 2017) as well as fragmentation of palliative care provision (Phongtankuel et al., 2018) are global issues rather than just those affecting care at the end of life in Australia. The death doula role may provide a way of changing the way in which end of life care models are organised (Brereton et al., 2017).

Understanding what information about death doulas is held in the formal published literature provides an opportunity to assess the role and its potential impacts in care

provision. Published literature provides a more formal set of information than public media materials as it commonly involves a peer review process and compliance with editorial requirements. Systematic reviews (SR) are a research method that aims to identify, evaluate, and summarise the findings of individual studies relevant to a health or clinical issue.

AIM

This systematic review aims to explore within the published literature the role of death doulas working in end of life care, and potential implications for models of care delivery and health systems.

Methods

This systematic review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) recommendations (Moher, Liberati, Tetzlaff, & Altman, 2009). Given an anticipated paucity of literature on the topic, it was agreed not to limit the search retrieval by developing a PICO construction. The focus of the search strategy was on maximising the number of potentially relevant items for screening for inclusion or exclusion. A sensitive search based on the population of interest, that is, death doulas was therefore prioritised. The review process was built on a broad search for published articles held in bibliographic databases or on websites, defined inclusion and exclusion criteria, data management of retrieved items and quality appraisal of included articles to guide an assessment of the strength of the article materials. These elements are further described below.

Searches

A medical librarian constructed the search strategy, and conducted searches in PubMed, CINAHL, Medline, Proquest and Scopus on 11th January 2018. The search was informed by terms seen to be used in the media, and in discussion with the authors. Inconsistency in the nomenclature, (such as death doulas also being referred to as 'death midwives') along with a sway of terms that alluded to a similar role, such as 'psychopomp' (a guide of souls), 'Stervensbegeleiding' (a Dutch word for 'dying guidance'), 'lay navigator' (used in oncology), 'amicus mortis' and 'death sitter', saw a broad search conducted (See Supporting material, Appendix One). We did not use database search limits associated with study design, publication dates or geography nor did we restrict to English language only. This allowed us to capture the full scope of literature published internationally in the field over an extensive period of time.

A companion search of the grey literature was undertaken on 25th January 2018 (see Appendix two) via the following databases: Directory of Open Access Journals (DOAJ), Campbell Collaboration Library, and the CareSearch Grey Literature Collection. A Google Scholar search was also undertaken, limited to retrieval of pdf documents. A PDF delimiter was added to focus on potentially relevant inclusions, as PDFs are a common text form of publicly broadcast report. This would potentially limit irrelevant retrievals (eg promotion of death doula training), lower quality publications (eg personal blogs) and non-academic media pieces (eg news stories about death doulas). A supplementary study of other sources of grey literature (not included here) is underway (Rawlings et al., in preparation), providing a broader view of the death doula role as portrayed in the media.

We also searched within the websites of the National Council for Palliative Care (UK), the Canadian Hospice Palliative Care Association, and ehospice International, where we searched in the UK, US, Australia and International editions (limited to policy and research) (See Supporting Material Appendix Two).

Inclusion and Exclusion criteria

Articles were included if they met the following criterion:

- Describes the role / work of a death doula or a death midwife in the context of end of life care, or death and dying.

Articles were excluded if they were:

- Not written in English language (eg, Stervensbegeleiding),
- Not about dealing with human death (eg, psychopomps are mythical guides of souls to the place of the dead)
- Describing birthing or midwifery related doulas (eg, birth doula, abortion doula, stillbirth doula)
- Personal account of being a doula with no critical or reflective content or description of what the role entails.

Two authors were involved in the initial screening of titles and abstracts (xx,xx). Where there was disagreement about the inclusion of an item it was referred to the two remaining authors for consideration (xx,xx). All authors were involved in final decision for inclusion in the data analysis.

Data Management

All items were retrieved and loaded into an EndNote library for notetaking and record keeping. The information flow of study selection with reasons for exclusion is presented in Figure 1. Hand searching of references listed by all these papers was undertaken, with no further additions found.

Data handling and quality appraisal

As only descriptive articles met the inclusion criteria, the quality of the included articles was reviewed using the CASP qualitative appraisal tool (Critical Appraisal Skills Program, 2017). Quality appraisal was used to provide additional insights into the strengths and limitations of the individual studies rather than to eliminate items (Voss and Rehfuess, 2013). Two authors (xx,xx) completed quality appraisal and details of the assessment are included in Table 1.

Table 1: General Characteristics of studies included

Following final selection, one author (xx) worked with a Research Assistant (xx), with each independently deconstructing the death doula role from included papers.

Findings /Results

This review demonstrated a paucity of formal academic literature describing the role and effectiveness of death doulas. The five included articles were heterogeneous in nature – a mix of reports, published narrative pieces and a dissertation. Four out of

five are classified as grey literature according to the definition by Adams, Smart, & Sigismund Huf (2017), and the fifth was a literature review. However, all five studies are fit for purpose (Adams et al., 2017) in that they provide the information on the death doula role that helps to answer the research question. Many of the excluded articles described doula roles but not in the end of life context.

Role of death doulas

Death doulas have emerged as a care provider and companion in end of life care in Australia and other countries (Fukuzawa and Kondo, 2017) but none of these articles clearly articulated the underlying drivers for the emergence of this this type of role (eg, gaps in palliative care or community care provision). There was also a lack of a consistent articulation of the scope and functions of a death doula. To construct an understanding of what is being undertaken in the death doula role; we extracted the following information from each included paper: relationship to health service, funding source, number and demand for services, training, licensing and ongoing support and tasks undertaken.

Table 2: Included papers

Relationship to health service

We wanted to determine whether death doulas have any formalised working relationship with healthcare services, (such as receiving referrals from healthcare services, or doulas contacting healthcare services if a patient is symptomatic), or

whether they work completely independently, in order to understand if there is any overlap in care or services provided to those at the end of life.

Some death doulas do work under the auspices of formal palliative care services (Corporon, 2011), or they are seen to augment palliative care and hospice services (Lentz 2014, Trzeciak-Kerr 2016) or to supplement palliative care (Fukuzawa and Kondo, 2017). In these models, death doulas are volunteers, seen to be undertaking roles that differ from those of health professionals. They are described as “*adding a missing layer.....the non-medical resources which could help bring death back home*” (Elliott, 2011, p.30), “*providing non-medical care*” (Fukuzawa and Kondo, 2017, p.612), or “*not medical – being, not fixing or doing*” (Trzeciak-Kerr 2016, p.8). However, in one model (Lentz, 2014), death doulas are experienced palliative care nurses, albeit still volunteers, although the role delineation is not described between the work undertaken by these doulas, more traditional volunteers and health professionals. It is easy to make the assumption, without further evidence, that independent death doulas may not have relationships with formal palliative care services or other healthcare professionals involved in the care of the dying person.

Funding Source

A fundamental question in the current economic climate is to ask how death doulas and other such roles are funded. The model described by Lentz (2014) is founded on an altruistic, voluntary, service to community basis, and those described by Corporon (2011), Trzeciak-Kerr (2016) and Fukuzawa and Kondo (2017) are also volunteer based, but it can be assumed that a proportion of death doulas work for payment. The

range of costs and charges was not reported and any differences in care provision between volunteer and paid death doula remains unknown.

Number and demand for services

In four out of five papers, no information is provided on the number and demand for death doula services. Corporon (2011) described that 80 people had been served at the time of writing the paper and presumably this number has continued to rise.

Training, licensing and ongoing support

There are mentions of training and ongoing support of death doula in the included papers. The Baylor death doula program (Corporon, 2011) sees death doula trained by health professionals with a program that covers many aspects of death and dying. There is also ongoing support provided by the program, with one supportive strategy seen in the matching of death doula to patient, as is often the case with palliative care volunteers. Fukuzawa and Kondo (2017) describe training that is also delivered by health professionals (nurses, palliative care teams, hospitals) although say that it could also be offered within national organisations, and describe support offered to the doula once trained. In the model described by Lentz (2014) the death doula is an experienced palliative care nurse, either working or semi-retired/retired. Training is not explained but is assumed, however no ongoing support mechanisms are described. Trzeciak-Kerr (2016) states that the death doula program has comprehensive and ongoing training and supervision for all end-of-life doula. None of the papers provides

information regarding the licensing of death doula and Elliott (2011) describes neither training nor ongoing support.

Tasks performed

Some descriptions of the tasks that death doula undertake can be seen as generalisations, such as 'communication strategies', 'relationship building' (Corporon, 2011), or 'advocate for the dying person' (Elliott 2011, Trzeciak-Kerr 2016), without a clear understanding of what this actually entails. Table 2 provides some of this information but on the whole, this care does not always include physical care but more psychological, emotional or existential care. This includes mentions of "*holding a compassionate space*" (Elliott, 2010, p.29) and "*unconditional positive regard and a loving presence*" (Trzeciak-Kerr, 2016, p.8). Fukuzawa and Kondo (2017) describe more practical tasks (such as :*cleaning eyeglasses, provide company for walks and listen to the concerns of the family*" p.613), while the palliative care doula (Lentz, 2014) takes a more nursing /leadership role starting with a formalised assessment, keeping records, staying informed about medical issues, concerns, questions and choices and anticipating medical issues yet to be experienced.

Discussion

Over the years, a palliative care philosophy has seen dying move from a model where arguably it has been historically rooted in the community,

"Dying is not an act you can easily undertake yourself. If being born amid those who will love you is the first best hope of life, dying within a community is the last" (Learn how to die 2017, Pg60)

to one whereby dying occurs in acute care settings, particularly in westernised countries. For example, although 54% of deaths occur in hospitals in Australia (Swerissen and Duckett, 2014), on the whole hospital staff “don’t do death well” (Elliott, 2011, pg.27) either in Australia (Virdun, Lockett, Davidson & Phillips, 2015) or elsewhere (Mayland, Mulholland, Gambles, Ellershaw, & Stewart, 2017, Novelli & Banargee, 2015). There has also been a paradigm shift in palliative care and hospice from a largely nursing domain (Fukuzawa and Kondo, 2017) to a medical led one with investigations and interventions not uncommon (Rosenberg, 2011), with arguably the focus lost on caring aspects. Subsequent to this has been a grassroots change to move dying back into local communities, seen in the work on compassionate communities (Kellehear, 2016). However, much of this has been nostalgia driven, with tendencies to romanticise the past or idealise it, in terms of care at home and dying at home (Randall, Rosenberg, & Reimer, 2017). With the changes in our social fabric, much of what is remembered in relation to a compassionate community with the knowledge, information and capacity to support dying outside of institutions has been lost (Abel et al., 2013) although starting to be reclaimed. The compassionate communities movement (rather than a compassionate community alluded to above) has started to address ways in which care at the end of life becomes everyone’s business (Kellehear, 2016) with the need for capacity building, the mobilisation of family networks, social networks (Gott et al., 2018), and wider community supports, and supporters (Horsfall et al., 2012). The rise of the death doula role may fall within this approach.

There is evidence that access to care and support in the community can be inequitable, with patients and families ineligible for care packages or domestic help

(Kunz and Atsus, 2013), resulting in costly care, and oftentimes private organisations and community groups (Mills, Rosenberg, & McInerney, 2015) contributing to the physical, psychological and social care needs of people at the end of life, which does not always involve symptom management and hospital admissions. As more people seek to plan for, and manage the treatment they receive at the end of their lives, it appears that they are being challenged by the support and services available to them (Duckett, 2018).

Anecdotally, death doulas may be working in a similar way to that of 'an eldest daughter'. We know that historically "*modern-day family caregiving responsibilities fall disproportionately on women*" (Washington et al., 2015 ,p.1049) (McChan, Loeb, Baney & Penrod, 2013) and death doulas may fulfil this role in the absence of a family member. It should be acknowledged though, that not all caregivers are women as not all death doulas are women. In family-oriented roles these individuals' may therefore not see the need to work with or alongside healthcare professionals, and indeed this may not be warranted. It should also be considered that there are roles that patients, carers and families do not want their health professionals to fill, or roles that they do not see as that undertaken by a health professional. They may also want to be in control of the services supporting them at home rather than having no part in the decision making as to what service is provided or when (McKechnie et al, 2011). If death doulas are indeed taking on roles that encompass social companionship (Corporon, 2011), providing a listening ear (Trzeciak-Kerr, 2016), discussing practical requirements (Fukuzawa and Kondo, 2017), or holding a compassionate space (Elliott, 2011), then regulation of the role seems contraindicated, as it is individualised to the person who is dying and their family.

While there are death doula training organisations in Australia, curricula content and duration appears to be individual to each, with no central register of death doulas nor regulatory body, which may mean that some death doulas lack adequate peer support or supervision (Trzeciak-Kerr, 2016). The Native Navigators referred to earlier received over 200 hours of training, with follow up sessions and debriefing through supervision that was included as part of the program (Rocque et al., 2017), although other authors have said that these navigators' qualifications and training also varies (Duggleby et al., 2018). 'Aboriginal and Torres Strait Islander health practitioners' while registering via a central regulatory body, also highlight the importance of ongoing professional training and regulation to support the role (Hill et al., 2018). These models of care delivery require attention to regulation, and to consistent training and education to ensure consistent care delivery, and expectations of, the role.

If however, death doulas are acting as a pseudo-professional, as in the work described by Lentz (2014) in recording the disease progression and patient information, staying informed about medical issues and anticipating medical issues yet to be experienced, then there is understandably an overlap with health professionals' roles, and more specifically that of specialist palliative care nurses (Howell et al., 2014). If the death doula role is more of a medicalised one, are they then replacing palliative care, and the support networks and mechanisms that come with specialist services? Poulos and Colleagues (2017) describe the role of the specialist supportive community care workers, who supplement care provided by the multidisciplinary palliative care team. They provide a free service that enables the provision of practical (non-clinical) care such as domestic tasks, respite and emotional support similar to those described in

our review of death doulas. This model incorporates a supportive role into mainstream palliative care, rather than a model where the support role is independent to palliative care and perhaps is one that could be considered a compromise in how people at the end of life are supported. With costs of care already high for individuals and families at the end of life (Rowland, Hanratty, Pilling, van den Berg, & Grande, 2017), a death doula, unless in a voluntary role, is thereby only a viable option for those who can afford them.

There remains uncertainty about the scope and funding of the death doula role, the variable availability and quality of education and training, and their relationship to health and palliative care services. There are clearly areas of unmet need, but is this for death doulas or is it for palliative care services? Pertinent to this are the questions of how many clients death doulas see, and how the demand for death doulas is driven (how they receive referrals for example), with many unanswered questions as to what the death doula role is at the end of life.

Limitations

There are limitations due to the nature of the articles retrieved, and the low quality of included papers. This restricts the inferences that can be made and conclusions drawn, and highlights that more research is required. Our grey literature search was somewhat limited, in that we only searched for pdfs on google scholar and including other file types in this search may have found more articles about the death doula role.

Implications

Doulas are starting to emerge in the end of life space in Australia as they have done elsewhere, and an understanding of what they can offer is an imperative. This systematic review has revealed a dearth of published academic literature about death doulas in end of life care and therefore, has not provided the clarity that was sought into this role, but rather emphasised the disparities in how it is enacted. Further research into the role played by death doulas is sorely needed.

This literature review is but one part of our ongoing exploration in regards to the death doula role and we have recommendations drawn from this. It is recommended that future research should explore:

- the role of the media to better understand the role of death doulas as they are being discussed in society.
- the comments of MOOC participants self-identifying as death doulas about their role.
- death doulas perspectives of their role, as well as palliative care professionals who have worked with patients using a death doula
- what families who have engaged the services of a death doula report as important to them.

With a lack of evidence, we need to set the agenda in this arena. While we cannot determine what is currently in place without further investigation, we can suggest what could be explored. For example, the skills, training and support of death doulas could be examined and potentially determined, as well as how the role is communicated to the community. Relationships to palliative care providers and to other health professionals could be investigated and potentially formalised, with a view to

managing referrals and establishing guidelines regarding role delineation (if this is relevant). It is important to acknowledge that patient, carer and family views and experiences about death doulas have not yet been heard.

Conclusion

This systematic review has highlighted the paucity of formal investigations into death doulas, and a need to undertake further inquiry. Death doulas are working in end of life care, but their role and place within the health and social care systems is not well understood. 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.

Conflict of Interest

The authors declare no conflict of interest

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REFERENCES

Abel, J., Walter, T., Carey, L.B., Rosenberg, J., Noonan, K., Horsfall, D.....Morris, D. (2013) Circles of care: Should community development redefine the practice of palliative care? *BMJ Supportive & Palliative Care*, ;3:383–388. <http://dx.doi.org/10.1136/bmjspcare-2012-000359>

Aboriginal Health Council of SA. (2018). Aboriginal Health Worker Role. Retrieved from <http://ahcsa.org.au/our-programs/aboriginal-health-worker-role/>

Adams, R.J., Smart, P., & Sigismund Huf. A. (2017). Shades of Grey: Guidelines for Working with the Grey Literature in Systematic Reviews for Management and Organizational Studies. *International Journal of Management Reviews*, 19, 432–454.

Anderson, M.D., & White, K.M., (2018) “It Has Changed My Life”: An Exploration of Caregiver Experiences in Serious Illness. *American Journal of Hospice & Palliative Medicine*, 35, 2, 266-274.

Balas, M.C., Gale, M., & Kagan, S. (2004) Delirium Doulas: An Innovative Approach to Enhance Care for Critically Ill Older Adults. *Critical Care Nurse*, 24, 4, 36-46.

Bohren, M.A., Hofmeyer, G.J., Sakala, C., Fukuzawa, R.K., & Cuthbert, A. (2017). Continuous support for women during childbirth. *Cochrane Database of Systematic Reviews*. (70, 1-169 <http://dx.doi.org/10.1002/14651858.CD003766.pub6>

Bradley, S., Tieman, J., Woodman, R., & Phillips, P., 2017. Which online format is most effective for assisting Baby Boomers to complete advance directives? A randomised controlled trial of email prompting versus online education module. *BMC Palliative Care*, 16:43 <http://dx.doi.org/10.1186/s12904-017-0225-9>

Brereton, L., Clark, J., Ingleton, C., Gardiner, C., Preston, L., Ryan, T., & Goyder, E. (2017) What do we know about different models of providing palliative care? Findings from a systematic review of reviews. *Palliative Medicine*, 31, 9, 781– 797. <http://dx.doi.org/10.1177/0269216317701890>

Burhansstipanov, L., Krebs, L. U., Dignan, M. B., Jones, K., Harjo, L. D., Watanabe-Galloway, S., . . . Isham, D. 2014. Findings from the native navigators and the Cancer Continuum (NNACC) study. *Journal of Cancer Education*, 29(3), 420-427. <http://dx.doi.org/10.1007/s13187-014-0694-y>

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. <http://dx.doi.org/10.1111/j.1552-6909.2006.00067.x>

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.

Clark, D. (2002). Between hope and acceptance: the medicalisation of dying. *BMJ*, 324, 905-907.

Commisso, E., McGilton, K.S., Ayala, A.P., Andrew, M. Bergman, H. Beaudet, L.....Puts, M. (2017). Identifying and understanding the health and social care needs of older adults with multiple chronic conditions and their caregivers: a protocol for a scoping review. *BMJ Open*, 7 e01824 <http://dx.doi.org/10.1136/bmjopen-2017-018247>

Corporon, K. (2011). Comfort and caring at the end of life: Baylor's doula program. *Proc (Bayl Univ Med Cent)*, 24, 4, 318–319.
<http://dx.doi.org/10.1080/08998280.2011.11928748>

Critical Appraisal Skills Program. (2017). CASP Qualitative Research Checklist. (online). Retrieved from: <http://www.casp-uk.net/casp-tools-checklists>

Darwin, Z., Green, J., McLeish, J., Willmot, H., & Spiby, H. (2017). Evaluation of trained volunteer doula services for disadvantaged women in five areas in England: women's experiences. *Health Soc Care Community*. 25, 2, 466-477.
<http://dx.doi.org/10.1111/hsc.12331>.

De Korte-Verhoef, M. C., Pasman, H.R.W., Schweitzer, B.P.M., Francke, A.L., Onwuteaka-Philipsen, B.D., & Deliens, L., (2014). Burden for family carers at the end

of life; a mixed-method study of the perspectives of family carers and GPs. *BMC Palliative Care*, 13:16.

Doyle, C., 2015. Death Management: A cultural exploration in contemporary Canada. Submitted to OCAD University in partial fulfilment of the requirements for the degree of Master of Design in Strategic Foresight and Innovation Toronto, Ontario, Canada.

Duckett, S. (2018). Aligning policy objectives and payment design in palliative care. *BMC Palliative Care*, 17:42. <http://dx.doi.org/10.1186/s12904-018-0294-4>

Duggleby, W., Pesut, B., Cottrell, L., Friesen, L., Sullivan, K., & Warner, G., 2018. Development, Implementation, and Evaluation of a Curriculum to Prepare Volunteer Navigators to Support Older Persons Living With Serious Illness. *American Journal of Hospice & Palliative Medicine*, 35, 5, 780-787.
<http://dx.doi.org/10.1177/1049909117740122>

Elliott, H. (2011). Moving beyond the medical model. *Journal of holistic healthcare*, 8, 1, 27-30.

Fischer, S. M. D., Min, S.-J. P., Kline, D. M. S., & Fink, R. 2017. Apoyo con Cariño: Patient Navigation to Improve Palliative Care Outcomes for Latinos with Advanced Cancer (SA508B). *Journal of Pain and Symptom Management*, 53(2), 396

Fukuzawa, R., & Kondo, K. (2017). A holistic view from birth to the end of life: end-of-life doulas and new developments in end-of-life care in the West. *International Journal of Palliative Nursing*, 23, 1, 612- 619.

<http://dx.doi.org/10.12968/ijpn.2017.23.12.612>

Gardiner, C., McDermott, C., & Hulme, C. 2017. Costs of Family Caregiving in Palliative Care (COFAC) questionnaire: development and piloting of a new survey tool. *BMJ Supportive & Palliative Care*, 0:1–7. <http://dx.doi.org/10.1136/bmjspcare-2016-001202>

Gott, M., Wiles, J., Moeke-Maxwell, T., Black, S., Williams, L., Kerse, N., & Trussardi, G., (2018). What is the role of community at the end of life for people dying in advanced age? A qualitative study with bereaved family carers. *Palliative Medicine*, 32, 1, 268 –275.

Guilbeau, C. 2018. End-of-life care in the Western world: where are we now and how did we get here?. *BMJ Supportive & Palliative Care*. 0, 1-9

<http://dx.doi.org/10.1136/bmjspcare-2017-001424>

Gott, M., Wiles, J., Moeke-Maxwell, T., Black, S., Williams, L., Kerse, N. &, Trussardi, G. (2018). What is the role of community at the end of life for people dying in advanced age? A qualitative study with bereaved family carers. *Palliative Medicine*, 32, 1, 268– 275. <http://dx.doi.org/10.1177/0269216317735248>

Hill, K.L., Harvey, N., Felton-Busch, C.M., Hoskins, J., Rasalam, R., Malouf, P., & Knight, S. (2018). The road to registration: Aboriginal and Torres Strait Islander health practitioner training in north Queensland. *Rural and Remote Health*, 18, 3899. <http://dx.doi.org/10.22605/RRH3899>

Horsfall, D., Noonan, K., & Leonard, R., (2012). Bring our dying home: How caring for someone at end of life builds social capital and develops compassionate communities. *Health Sociology Review*, 21,4 373-382.

Howell, D. Hardy, B., Boyd, C., Ward, C., Roman, E, & Johnson, M. 2014, Community palliative care clinical nurse specialists: a descriptive study of nurse-patient interactions. *International Journal of Palliative Nursing*, 20, 5, 246-253

Kellehear, A., (2007). The rise and spread of cities, IN A social history of dying (ch.7), p125-146

Kozhimannil, K., Vogelsang, C., Hardeman, R., & Prasad, S. (2016). Disrupting the pathways of social determinants of health: doula support during pregnancy and childbirth. *J Am Board Fam Med*, 29, 3, 308-317.

Lam, M., Lam, H., Agarwal, A., Lam, H., Chow, R., Chow, S,..... Chow, E., (2017). [Barriers to home death for Canadian cancer patients: A literature review](#). *Journal of Pain Management*, 10, 1, 107-115.

"learn how to die; The West is too squeamish about death, says Kevin Toolis. After years of reporting on the Troubles, he finally came to terms with his own mortality at his father's wake." (2017, September 3). *Sunday Times* [London, England].

<http://link.galegroup.com.ezproxy.flinders.edu.au/apps/doc/A502876306/AONE?u=flinders&sid=AONE&xid=0e4c1c19>. Accessed 20 July 2018.

Lentz, J. (2014). Palliative Care Doula: An innovative model. *Journal of Christian Nursing*, 31, 4, 240-245. <http://dx.doi.org/10.1097/CNJ.0000000000000103>

Low, L.K., Moffatt, A., & Brennan, P. (2006). Doulas as Community Health Workers: Lessons Learned from a Volunteer Program. *Journal of Perinatal Education*, 15, 3, 25–33.

Luckett, T., Phillips, J., Agar, M., Virdun, C., Green, A., & Davidson, P.M. (2014).. Elements of effective palliative care models: a rapid review. *BMC Health Serv Res*, 26,14,136. <http://dx.doi.org/10.1186/1472-6963-14-136>

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? *J Appl Res Intellect Disabil* , 29, 1, 21-33. doi: 10.1111/jar.12155. <http://dx.doi.org/10.1111/jar.12155>

McGhan, G., Loeb, S.J., Baney, B., & Penrod, J., (2013). End-of-Life Caregiving: Challenges Faced by Older Adult Women. *J Gerontol Nurs.*, 39, 6, 45–5.

McGrath, P.D., Patton, M.A., Ogilvie, K.F., Rayner, R.D., McGrath, Z.M., & Holewa, H.A. 2007. The case for Aboriginal Health Workers in Palliative Care. *Aust Health Review*, 31,3, 430-439. <http://dx.doi.org/10.1071/AH070430>

McKechnie, R., MacLeod, R., & Jaye, C., 2011. The use of nurses in community palliative care. *Home healthcare nurse*, 29, 7, 408-415.

Mayland, C.R., Mulholland, H., Gambles, M., Ellershaw, J., & Stewart, K., (2017) How well do we currently care for our dying patients in acute hospitals: the views of the bereaved relatives. *BMJ Palliative & Supportive Care*, 7, 316-325.

Martín Martín, J., Olano-Lizarraga, M. ; Saracíbar-Razquin, M., (2016). [The experience of family caregivers caring for a terminal patient at home: A research review](#). *International Journal of Nursing Studies*, 64, 1-12.

Mills, J., Rosenberg, J., & McInerney, F. (2015). Building community capacity for end of life: an investigation of community capacity and its implications for health promoting palliative care in the Australian Capital Territory, *Critical Public Health*, 25, 2, 218-230. <http://dx.doi.org/10.1080/09581596.2014.945396>

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D.G. The PRISMA Group. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA statement. *PloS Med*, 6,7.

Murray, S. A., & Murray, I.R ., (2016). [End of life care still not living up to public and doctors' expectations](#). *BMJ*, 353.

Novelli, B., & Banerjee, R., (2015) Advanced Illness Care: We can do it better. *Journal of the American Society on Ageing*, 39,2, 106 – 111.

O'Brien, A.P., Bloomer, M.J., McGrath, P., Clark, C., Martin, T., Pidcock, T,O'Connor, M. 2013. Considering Aboriginal palliative care models: the challenges for mainstream services. *Rural Remote Health*, 13,2,2399

Palliative Care Australia. (2015). Improving access to quality care at the end of life for Aboriginal and Torres Strait Islander Australians: Position Statement. Retrieved from <http://palliativecare.org.au/wp-content/uploads/2015/08/PCA-Palliative-care-and-Indigenous-Australians-position-statement-updated-16-8-11.pdf>

Phelan, A., McCarthy, S., & Adams, E.,2017. Examining missed care in community nursing: A cross section survey design. *J Adv Nurs*. 74:626–636.
<http://dx.doi.org/10.1111/jan.13466>

Phongtankuel, V., Meador, L., Adelman, R.D., Roberts, J., Henderson, C.R. Jr., Mehta, S.S.,.....Reid, M.C., (2018). Multicomponent Palliative Care Interventions in Advanced Chronic Diseases: A Systematic Review. *Am J Hosp Palliat Care*. 35, 1, 173-183. doi: 10.1177/1049909116674669.

Pleschberger, S., & Wosko, P. (2017) From neighbour to carer: An exploratory study on the role of non-kin-carers in end-of-life care at home for older people living alone. *Palliative Medicine*, 31, 6, 559-565. <http://dx.doi.org/10.1177/0269216316666785>

Poulos, R., Harkin, D., Poulos, C., Cole, A., & McLeod, R. (2017) Can specially trained community care workers effectively support patients and their families in the home setting at the end of life? *Health and Social Care in the Community*, 26, 2, e270-e279. <http://dx.doi.org/10.1111/hsc.12515>

Randall, D., Rosenberg, J.P., & Reimer, S. (2017). Solid and liquid modernity: A comparison of the social geography of places to die in the UK and Australia, *Death Studies*, 41:2, 103-111. <https://doi.org/10.1080/07481187.2016.1225858>

Rocque, G., Dionne-Odom, N., Huang, C-H., Niranjani, S., Williams, C., Jackson B,..... Kvale E. Patient Care Connect Group. (2017). Implementation and Impact of Patient Lay Navigator-Led Advance Care Planning Conversations. *Journal of Pain and Symptom Management*, 53, 4, 682 – 692. <http://dx.doi.org/10.1016/j.jpainsymman.2016.11.012>

Robinson, A., Spencer, D., & Lewis, B. (2017) Illness Doula: Adding a New Role to Healthcare Practice *J Med Humanit* <http://dx.doi.org/10.1007/s10912-017-9438-4>

Rosenberg, J. (2011). Whose Business is Dying? Death, the Home and Palliative Care *Cultural Studies Review*, 17, 1, 15-30. <http://dx.doi.org/10.5130/csr.v17i1.1971>

Rowland, C., Hanratty, B., Pilling, M., van den Berg, B., & Grande, G. (2017). The contributions of family care-givers at end of life: A national post-bereavement census survey of cancer carers' hours of care and expenditures. *Palliat Med.* 2017 Apr;31(4):346-355. doi: 10.1177/0269216317690479. Epub 2017 Feb

Ireson, R., Sethi, B., Williams, A., (2018). Availability of caregiver-friendly workplace policies (CFWPs): an international scoping review. *Health and Social Care*, 26,1,:e1-e14

Spiby, H., McLeish, J., Green, J., & Darwin, Z. (2016). The greatest feeling you get, knowing you have made a big difference': survey findings on the motivation and experiences of trained volunteer doulas in England. *BMC Pregnancy and Childbirth.* 16:289

Swerissen, H., & Duckett, S. (2014) Dying Well. Grattan Institute. Retrieved from: <https://grattan.edu.au/report/dying-well/>

Stringer, S., (2007). Quality of death: humanisation versus medicalisation. *Cancer Nursing Practice.* 6,3, 23-28

Thomas, C., Turner, M., Payne, S., Milligan, C., Brearley, S., Seamark, D.,.....

Blake, S., (2018). Family carers' experiences of coping with the deaths of adults in home settings: A narrative analysis of carers' relevant background worries. *Palliative Medicine*, 32, 5, 950 –959.

Thomeer, M.B., Donnelly, R., Reczek, C., Umberson, D. (2017). Planning for Future Care and the End of Life: A Qualitative Analysis of Gay, Lesbian, and Heterosexual Couples *J Health Soc Behav*, 58, 4, 473-487. <http://dx.doi.org/10.1177/0022146517735524>

Trzeciak-Kerr, M. (2016). An existential-phenomenological exploration of an end-of-life doula. (Doctoral dissertation). Retrieved from: <https://pqdtopen.proquest.com/results.html?advisor=Drob,%20Sanford%20L>.

Virdun, C., Luckett, T., Davidson, P.M., & Phillips, J., (2015). Dying in the hospital setting: A systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. *Palliative Medicine*, 29, 9, 774-796

Voss, P. & Rehfues, A., 2013. Quality appraisal in systematic reviews of public health interventions: an empirical study on the impact of choice of tool on meta-analysis. *J Epidemiol Community Health*, 67:98–104. <http://dx.doi.org/10.1136/jech-2011-200940>

Walshe, C., Perez Algorta, G., Dodd, S., Hill, M., Ockenden, N., Payne, S., & Preston, N. 2016. Protocol for the End-of-Life Social Action Study (ELSA): a randomised wait-list controlled trial and embedded qualitative case study evaluation assessing the causal impact of social action befriending services on end of life experience. *BMC Palliative Care*, 15:60 <http://dx.doi.org/10.1186/s12904-016-0134-3>

Walter, T. (1994) *The Revival of Death*. Routledge. London

Washington, K.T., Pike, K.C., Demiris, G., Parker Oliver D., Albright, D.L., & Lewis, A.M., (2015). Gender differences in caregiving at end of life: Implications for hospice teams. *Journal of Palliative Medicine*, 18,12, 1048-1053.

Williams, A.M., Eby, J.A., Crooks, V.A., Stajduhar, K., Giesbrecht, M., Vuksan, M.,..... Allan.D., (2011). Canada's Compassionate Care Benefit: Is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care? *BMC Public Health*, 11:335.

Williams, A.M., Wang, L., & Kitchen, P. (2016). Impacts of care-giving and sources of support: a comparison of end-of-life and non-end-of-life caregivers in Canada. *Health Soc Care Community*, 24, 2, 214-24. <http://dx.doi.org/10.1111/hsc.12205>

What role do Death Doulas play in end of life care? A systematic review

Appendix one: Searches undertaken on 11th January, 2018.

Medline

N=46

#	Searches	Results
1	(Death or palliative or end of life).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	832566
2	(Doula* or transition guide* or Lay navigator* or patient navigator*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	757
3	1 and 2	35
4	(death midwi* or stervensbegeleiding or Psychopomp* or Midwife of the soul or thanadoulas or thanadoula or Death facilitator* or death cafe facilitator* or amicus mortis* or death sitter*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	12
5	3 or 4	46

Cinahl (EBSCOhost)

N=38

#	Query	Results
S1	(Doula* OR "transition guide*" OR "Lay navigator*" OR "patient navigator*") AND (Death OR palliative OR "end of life")	32
S2	"death midwi*" OR stervensbegeleiding OR Psychopomp* OR "Midwife of the soul" OR thanadoulas OR thanadoula OR "Death facilitator*" OR "death cafe facilitator*" OR "amicus mortis*" OR "death sitter"	6
S3	S1 OR S2	38

Pubmed

N=22

((Death[tiab] OR palliative[tiab] OR "end of life") AND ("Lay navigator*[tiab] OR "patient navigator*[tiab] OR doula*[tiab] OR Transition guide*[tiab])) OR "death midwi*[tiab] OR stervensbegeleiding[tiab] OR Psychopomp*[tiab] OR "Midwife of the soul"[tiab] OR thanadoula*[tiab] OR "Death facilitator*[tiab] OR "death cafe facilitator*[tiab] OR "amicus mortis*[tiab] OR "death sitter*[tiab]

Proquest

Limited to Scholarly Journals and Dissertations and Theses

N=66

(ab("death midwi*" OR stervensbegeleiding OR Psychopomp* OR "Midwife of the soul" OR thanadoulas OR thanadoula OR "Death facilitator*" OR "death cafe facilitator*" OR "amicus mortis*" OR "death sitter*") OR ti("death midwi*" OR stervensbegeleiding OR Psychopomp* OR "Midwife of the soul" OR thanadoulas OR thanadoula OR "Death facilitator*" OR "death cafe facilitator*" OR "amicus mortis*" OR "death sitter*")) OR (ab(((Death OR palliative OR "end of life") AND (doula* OR "Transition guide" OR "Lay navigator*" OR "patient navigator*")))) OR ti(((Death OR palliative OR "end of life") AND (doula* OR "Transition guide" OR "Lay navigator*" OR "patient navigator*"))))

Scopus

N= 70

(((TITLE (death OR palliative OR "end of life") OR ABS (death OR palliative OR "end of life"))) AND ((TITLE (doula* OR "transition guide*" OR "Lay navigator*" OR "patient navigator*") OR ABS (doula* OR "transition guide*" OR "Lay navigator*" OR "patient navigator*")))) OR ((TITLE ("death midwi*" OR stervensbegeleiding OR psychopomp* OR "Midwife of the soul" OR thanadoulas OR thanadoula OR "Death facilitator*" OR "death cafe facilitator*" OR "amicus mortis*" OR "death sitter*") OR ABS ("death midwi*" OR stervensbegeleiding OR psychopomp* OR "Midwife of the soul" OR thanadoulas OR thanadoula OR "Death facilitator*" OR "death cafe facilitator*" OR "amicus mortis*" OR "death sitter*"))))

APPENDIX 2: Grey Literature search conducted on 25th January 2018

Directory of Open Access Journals (DOAJ) <https://doaj.org/>

(n=9)

“death doula” OR “death midwife” OR “midwife of the soul” OR “thanadoula” OR “death sitter” OR “amicus Mortis” OR “death facilitator” OR “Patient navigator” OR “Lay navigator”

Campbell Collaboration Library <https://www.campbellcollaboration.org/library.html>

(n=0)

“death doula” OR “death midwife” OR “midwife of the soul” OR “thanadoula” OR “death sitter” OR “amicus Mortis” OR “death facilitator” OR “Patient navigator” OR “Lay navigator”

CareSearch <http://www.caresearch.com.au/caresearch/tabid/82/Default.aspx>

(n=0) “death doula” OR “death midwife” OR “midwife of the soul” OR “thanadoula” OR “death sitter” OR “amicus Mortis” OR “death facilitator” OR “Patient navigator” OR “Lay navigator”

National Council for Palliative Care (UK) <http://www.ncpc.org.uk/>

(n=0) “death doula” OR “death midwife” OR “midwife of the soul” OR “thanadoula” OR “death sitter” OR “amicus Mortis” OR “death facilitator” OR “Patient navigator” OR “Lay navigator”

Canadian Hospice Palliative Care Association <http://www.chpca.net/>

(n=0) “death doula” OR “death midwife” OR “midwife of the soul” OR “thanadoula” OR “death sitter” OR “amicus Mortis” OR “death facilitator” OR “Patient navigator” OR “Lay navigator”

ehospice international – searched in UK, US, Australia and International editions (limited search to policy and research) <http://www.ehospice.com/en-gb/home.aspx>

(n=1)

“death doula” OR “death midwife” OR “midwife of the soul” OR “thanadoula” OR “death sitter” OR “amicus Mortis” OR “death facilitator” OR “Patient navigator” OR “Lay navigator”

Grey Literature search in Google Scholar

The following search was conducted in Google Scholar also on 25 Jan 2018 for pdf's:

(n=35)

“Death doula*” OR “death midwi*” OR “Midwife of the soul” OR thanadoulas OR thanadoula OR “Death facilitator*” OR “death cafe facilitator*” OR “amicus mortis*” OR “death sitter*”
filetype:pdf

Table 1: General Characteristics of studies included

Included Study	Description	Quality appraisal
Corporon 2011	<ul style="list-style-type: none"> • Published narrative piece (unreferenced) • Non-indexed journal* • Report of a Death Doula Program 	<ul style="list-style-type: none"> • Limited. Not designed as a formal study • Implied aim, program review only, no formal data analysis
Elliot 2011	<ul style="list-style-type: none"> • Published narrative piece • Non-indexed journal*. • Non-medical roles in end of life, including death doula 	<ul style="list-style-type: none"> • Limited. Not designed as a formal study. • No aim, commentary only, no data analysis
Fukuzawa and Kondo 2017	<ul style="list-style-type: none"> • Published peer-reviewed article • A review of the literature comparing birth doulas and end of life doulas 	<ul style="list-style-type: none"> • Limited. Not designed as a formal study. • No aim, commentary only, no data analysis
Lenz 2014	<ul style="list-style-type: none"> • Published narrative piece • Non-indexed journal* • Report of a death doula model. 	<ul style="list-style-type: none"> • Limited. Not designed as a formal study • No aim, commentary only, no data analysis
Trzeciak-Kerr 2016	<ul style="list-style-type: none"> • Unpublished PhD Thesis. • A qualitative study citing 15 interviews (including death doulas) analysed through existential-phenomenological thematic analysis generating 10 themes 	<ul style="list-style-type: none"> • Reasonable. Formal study design. • Aim, methods (including ethics approval), data analysis, findings included.

* According to International Scientific Indexing (ISI) <https://isindexing.com/isi/journals.php> and Science Citation Index (SCI) <http://mjl.clarivate.com/cgi-bin/jrnlst/jloptions.cgi?PC=K>

Table 2: Included papers

Author(s)	Overview	Relationship to health services	Funding for the death doula	Number and demand for services	Training, licensing and ongoing support	Tasks
Corporon 2011	<p>Introduction of the origin and development of Baylor's Doula to accompany and Comfort Program' (to serve those with limited support from family /friends)</p> <p>A description of how this programme is implemented</p>	<p>Referrals come from nurse, social workers and therapists</p> <p>Must be ordered by a physician</p> <p>Death doulas are assigned to 1 patient at a time.</p>	<p>Death doulas are volunteers and not funded by the organisation</p>	<p>To date, around 80 patients and families at Baylor Dallas have been served by the Program.</p> <p>Education to increase referrals is ongoing</p>	<p>Trained by health professionals in stages of death and dying, grief and grieving, advocating, comfort touch, compassionate presence, active listening, communication and spiritual and cultural beliefs</p> <p>No information provided about licensing</p> <p>Support for the death doula: Ensure the match between the assigned death doula and the particular patient and family</p> <p>Regular support groups are held for doulas to process their experiences, debrief, and</p>	<p>Death doulas visit the dying in different settings for comfort and social companionship (the frequency of visits is based on the agreement between both parties), such as: Listening and talking with the patient; rubbing the patient's hands, watching TV and praying together with the patient; praying for the patient).</p> <p>Provide respite</p> <p>Relationship building</p> <p>Providing emotional, spiritual support (Eg, accompanying the patient in music therapy)</p>

					provide and receive feedback	
Elliott 2011	<p>A death doula is a companion, someone who has been there before.</p> <p>The death doula acts as an expert family member, a mentor or facilitator and source of information and guidance</p>	<p>Death doulas do not replace medical or nursing expertise, but add a missing layer</p> <p>Doulas, mentors or trained volunteers are the non-medical resources which could help bring death back home.</p>	No information is provided on how death doulas are funded	No information is provided on the number of death doulas or the demand for their services	No information regarding the training, licensing and ongoing support is provided	<p>Death Doulas support the family, provide information, leave room for conversation, facilitate sharing</p> <p>Discuss practical requirements, liaise with professionals hold a compassionate space Be a guide into the next world</p> <p>“Holds” the situation with the family when families decide to look after their loved ones at home with an indeterminate period of time</p> <p>Provide companion for the dying</p> <p>Create an environment that is conducive</p> <p>Advocate for the dying person with respect of, and sensitivity to, the religious and spiritual beliefs of the family</p>
Fukuzawa and	This review provides an overview of birth	The roles of death doula and nursing	End-of-life doula activities are performed	No information is provided on the number of	Trainers for end-of-life doulas are Nurses, Palliative care teams at	Alleviate the physical and mental suffering of those who are dying as much as possible

<p>Kondo 2017</p>	<p>doulas and end-of-life doulas, in particular, in the context of Japan</p> <p>It compares the similarities and differences between birth and death and describes the characteristics of the doula approach and the implications for the healthcare system.</p> <p>The authors indicate the leadership role of nursing in the end-of-life doula initiatives</p>	<p>professional are complementary</p> <p>Non-medical care</p>	<p>primarily through volunteer-based programmes</p>	<p>death doulas or the demand for their services</p>	<p>hospitals, and Organisations such as “The International End of Life Doula Association” in the USA</p> <p>Support for doulas: Nurses and others who can provide counselling and guidance are close at hand; provide supportive care of the doulas themselves</p>	<p>and through any means available, such as:</p> <ul style="list-style-type: none"> • Cover them with blankets • Cool them with fans • Adjust and support their posture • Talk to them • Convey to medical personnel verbal and non-verbal complaints such as pain, needing to use the toilet • Clean eyeglasses • Tidy the hospital room • Adjust the lights • Provide company for walks • Listen to the concerns of the family • Introduce necessary resources
<p>Lenz 2014</p>	<p>This paper introduces a model for the Palliative Care Doula (PCD) for experienced and advanced practice palliative care nurses</p>	<p>Death doulas augment supportive and informational care provided by hospice and palliative care professionals</p>	<p>PCD is volunteerism</p>	<p>No information is provided on the number and demand for their services</p>	<p>The death doula is a highly experienced and educated palliative care nurse or advanced practice palliative care nurse</p>	<p>This is a nursing model -starts with an assessment and a conversation with the patient and family</p> <ul style="list-style-type: none"> • Record the disease progression and the pertinent information about the patient

	<ul style="list-style-type: none"> • A type of ministry for the expert palliative care nurse. • A strong spiritual base is essential for the role of PCD • The referral mechanism: word-of-mouth <p>It describes the process and evaluation of the PCD Model</p>					<ul style="list-style-type: none"> • Stay informed about medical issues, concerns, questions and choices. • anticipate medical issues yet to be experienced <p>Advocacy to ensure patient-stated goals of care are reflected and decision-making is less burdensome.</p> <ul style="list-style-type: none"> • E.g answer questions as they arise, encourage questions to be asked <p>Support psychological and spiritual needs of the patient and family as the unit of care</p> <p>Physical support is not the focus</p> <p>Build a trusting relationship, providing support and information.</p> <p>Have conversations with the patients and families regularly to determine their concerns and wishes (wishes and preferences are updated regularly as the situation changes)</p> <p>Establish a regular pattern of contacts(daily, weekly, monthly, on-call)</p>
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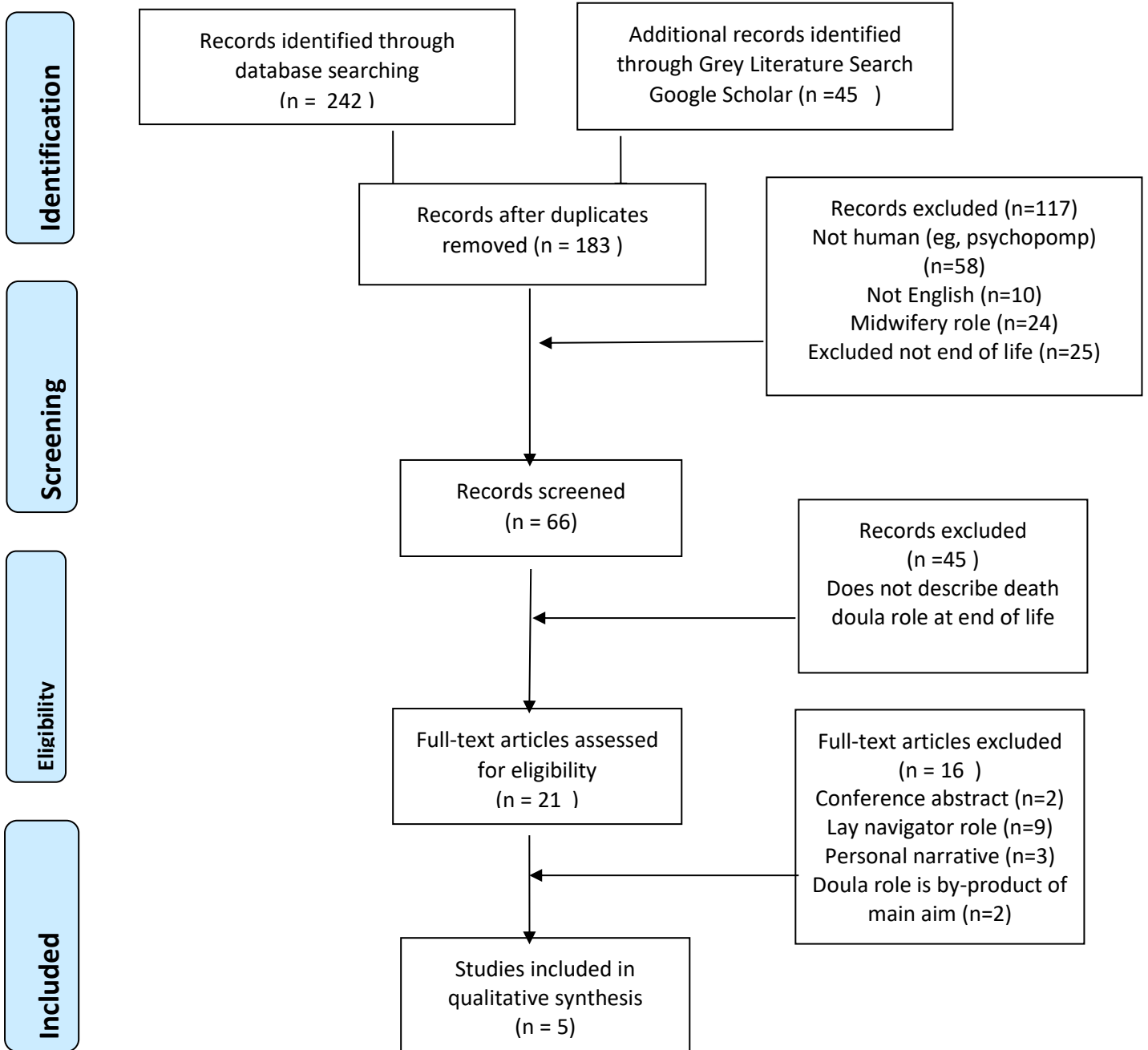
Trzeciak-Kerr 2016	This PhD project explores the lived experiences of end-of-life(EOL) doulas and EOL doula care recipients'(doulee's) family members while participating in the EOL doula program by using an existential-phenomenological approach.	Assessed by physician as life expectancy of 18 months or less but no medical referral required Volunteer role not medical – “being, not fixing or doing” EOL doula can augment current palliative and hospice care services	Death doulas are volunteers	No information is provided on the number and demand for services	Each volunteer participates in an initial 10-hour training program and ongoing training. All volunteers participate in an intensive training prior to visiting with an EOL doulee The topics of trainings include: <ul style="list-style-type: none"> • Preparing yourself • Self-care • The process of dying • The impact of culture • Finding meaning/ spirituality and religion • Advance directives • Active listening skills • Setting healthy limits and boundaries. Support for the doulas: <ul style="list-style-type: none"> • EOL doula group meetings • Support system of peers and supervisors • After the training, the volunteer may request to visit with EOL doulees who are 	Needs to have certain personality traits Compassionate companion and active listener An advocate Non-judgemental Unconditional positive regard and a loving presence Play major roles in providing emotional and spiritual support as needed Practical support <ul style="list-style-type: none"> • remain open to engage in activities wanted or needed by the EOL doulee, such as talking, listening to music, singing, art interventions, reading, sharing family photos and stories, taking the EOL doulee to activities within his or her ALF or nursing home • praying or participating in cultural traditions, • linking the EOL doulee to needed resources and referrals
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					<p>in the earlier phases of the illness as a friendly visitor or elect to volunteer in another program.</p>	<p>Provide support to the EOL doulee's family and loved ones and prevent not only the dying individual from being alone but also their loved ones</p> <p>Be able to work together with hospice</p> <p>May have teams of doulas in shifts</p>
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Figure 1

PRISMA 2009 Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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