Wiley
European Journal of Cancer Care
Volume 2025, Article ID 6654399, 5 pages
https://doi.org/10.1155/ecc/6654399

WILEY

Research Article

'Death Doulas' are not yet an Issue in German Palliative Care—A National Survey of Palliative Care Providers

Christian Volberg,[1,2] **Aboud Makdsi**,[1] **Jannis Eersink**,[1] **Juliana Kushner**,[3] **Astrid Morin**,[1] **and Martin Gschnell**[4]

[1]*Department of Anesthesiology & Intensive Care Medicine, Faculty of Medicine, Philipps University of Marburg, Marburg, Germany*
[2]*Research Group Medical Ethics, Faculty of Medicine, Philipps University of Marburg, Marburg, Germany*
[3]*Doula Jules, Birth Space, Cologne, Germany*
[4]*Department of Dermatology and Allergology, Faculty of Medicine, Philipps University of Marburg, Marburg, Germany*

Correspondence should be addressed to Christian Volberg; christian.volberg@staff.uni-marburg.de

Received 17 September 2024; Accepted 17 January 2025

Academic Editor: Bowen Lin

Background: The support of 'Death Doulas' (DD) in the last phase of life is becoming more and more present in the individual care of the dying. This trend is slowly being brought to Germany from other countries. However, the extent to which this possibility of end-of-life care is offered in Germany or requested by patients is still unclear.
Aim: With this nationwide survey, we want to show to what extent DD support palliative care in Germany and whether a need for this activity is seen.
Design: Germany-wide cross-sectional study among palliative care institutions.
Setting/Respondents: All German hospices, palliative care units and specialized outpatient palliative care services were contacted by post and asked to participate in this anonymous survey.
Results: In total, we received 338 (36.4%) responses. A total of 27% of the respondents state that they are familiar with the term DD but only 18 institutions (5.3%) use the support. Patients' satisfaction is recognized as overall satisfied. A total of 95% of the institutions who work with DD would recommend other palliative care institutions to work with DD as well. More information about this topic is wished by 61%.
Conclusion: DD is not yet an issue in German palliative care. There seems to be little need as the support of the dying is carried out by other professional groups and volunteers. Since DD have another approach in their work, it would be interesting to see if a broader knowledge about their work and offer could improve quality in the dying process.

Keywords: Death Doula; end-of-life-care; German palliative medicine; hospice; palliative care

1. Introduction

Our current healthcare system does not always meet the needs of the dying in our society [1]. This was particularly evident during the COVID-19 pandemic and will be even more so in the coming years as skilled workers become scarcer [2]. As a result, patients and families rely on people who can advocate for them or fill in the gaps in care. 'Death Doulas' (DD) take on this role, providing emotional, spiritual and social support to the dying and their families throughout the palliative care situation and the dying process [3]. The activity of 'DD' is relatively new and has emerged in the United States of America in the last 20 years [4]. The role is derived from 'Birth Doulas' who support pregnant women before, during and after childbirth. It is not about taking over midwifery duties but about caring and being there for the woman giving birth (see section 1.1). There are very positive aspects to this, both for the mother

and the newborn baby, which have already been scientifically analysed [5, 6]. The beginning and end of life are often compared with each other as crucial experiences in the life cycle. The aspects of care and support are also important components in the field of palliative care, so it is obvious to offer the support of 'Doulas' at this stage of life as well [7]. Although there are now private organizations that train and certify 'DD,' many 'DD' continue to work on a private basis without certification. As the term 'DD' is not yet protected in Germany, there are, to our knowledge, no prescribed training programmes to become a 'DD' which maybe leads to a low level of acceptance among official palliative care providers. Even in an international comparison, the role and scope of practice of 'DD' remains unclear, as Deb Rawlings and colleagues explain in their review [1]. Marian Krawczyk and Merilynne Rush also focus on the definition of 'end-of-life doulas' in their work but concentrate on the Anglo-American area [8]. As there is no comprehensive data on the work of 'DD' in Germany, the aim of this nationwide survey is to fill a gap and provide a first overview of the work of 'DD' in palliative care for people at the end of life in Germany.

As described by Volberg et al., there is a two-tier system of palliative care provision in Germany. Primary care is provided by general practitioners, nursing services and hospital physicians at the general palliative care level. The second level includes palliative care units attached to a hospital where acute medical problems can be treated. In addition, there are specialized outpatient palliative care services (German abbreviation: SAPV), which provide palliative care at home, and hospices, where people with a low life expectancy can live and receive extensive palliative care until they die [9, 10]. In addition, there are many support organizations, such as volunteer hospice workers, who help seriously ill patients and their families to cope with the final stages of life. Civic engagement has a long tradition in German palliative care, with many volunteers supporting hospice work. Volunteers provide assistance with nursing care, conversation, outings, respite for family members, and necessary errands [11]. It is unclear to what extent the provision of 'DD,' therefore, plays a role in the German culture of palliative care, as no research has been carried out in this area to date.

1.1. What are 'Death Doulas'? 'Doula' is a Greek word that in ancient times referred to 'a woman who serves.' The term 'doula' began to be used again around the 1960s and often referred to a person who helped with childbirth. This person was often a woman who not only helped during childbirth, but also supported women before and after childbirth. Unlike midwives, 'doulas' are less responsible for medical support and more responsible for social and psychological support.

The term 'DD' or 'death midwife' was first used in the USA almost 20 years ago to describe people who provide assistance and emotional support to dying people and their families. Similar to birth doulas, 'DD' offer social, psychological and spiritual support. Above all, they listen carefully to the concerns, fears, hopes and life stories of the dying person and their loved ones in order to provide the support they need. Some doulas also offer spiritual ceremonies or help with practical tasks such as writing advance directives or making organizational and spiritual preparations for the funeral [1, 12].

2. Materials and Methods

After an extensive literature review on the topic, the study team developed a questionnaire with a total of 18 questions (see translated version in the supporting information files (available here)). This questionnaire was checked for comprehensibility by three uninvolved colleagues before the start of the study. After the positive vote of the local ethics board from October 7, 2022 (file number 136/22; ethics board of the Philipps University of Marburg, Germany), and the registration in the German register of clinical trials (DRKS-ID: DRKS00030426, registration date October 24, 2022), all German hospices, palliative care units and specialized outpatient palliative care services were contacted by post and asked to participate. The necessary addresses were generated via the homepage of the German Association for Palliative Medicine (DGP) [13]. In total, the questionnaire and a prepaid return envelope were sent to 259 hospices, 323 palliative care units and 347 specialized outpatient palliative care services in November 2022. The paper–pencil survey was anonymized, and the data analysis was purely descriptive. Each participant was informed in the invitation letter that taking part in the anonymous survey and returning the questionnaire to the study team included the consent for publication. According to German law, a signed declaration of consent is not required in this case. Due to the anonymous nature of the study, a reminder letter could not be sent to nonparticipating institutions. The research was conducted in accordance with the Declaration of Helsinki. The Checklist for Reporting of Survey Studies (CROSS) was used as a reporting checklist for manuscript preparation.

Not answering individual questions did not lead to the exclusion of the questionnaire. The questions were analysed individually, and the percentages were adjusted accordingly.

Data analysis was conducted using Microsoft Excel, Version 16.6.

3. Results

Over a period of four months (November 2022 to the end of March 2023), we received a total of 338 completed questionnaires (36.4%). A total of 120 hospices (46.3%), 112 palliative care units (34.7%) and 136 specialized outpatient palliative care services (39.2%) responded. The majority of responding organizations (90.6%) only care for adult patients, while 3.8% only care for children and 5.3% care for both adult and paediatric patients. The questionnaire was most often completed by the responsible physician (51.9%) or the nursing director (32.9%). Less frequently, it was completed by commercial or organizational management (13.1%) or another professional group (e.g., social workers) (7.4%). Further demographic data on the responding centres are shown in Table 1.

Table 1: Demographic data of the participating institutions.

Demographics		
	n	**%**
Responding care organisation	*338*	*100*
Hospice	120	46.3
Palliative care unit	112	34.7
Specialized outpatient palliative care services	136	39.2
Average number of patients cared for per year	*338*	*100*
1–100	49	14.5
101–200	107	31.7
201–300	70	20.7
301–400	39	11.5
> 400	73	21.6
Area of coverage	*337*	*99.7*
Metropolis (> 1 million inhabitants)	28	8.3
Large city (> 100,000 inhabitants)	109	32.3
Medium-sized city (< 100,000 inhabitants)	131	38.9
Small town, rural area (< 20,000 inhabitants)	69	20.5

The term 'DD' was recognized by 27% of the respondents, while 63% were not familiar with it and 10% were unsure. Only 18 organizations (5.3%) reported that they use the support of 'DD.' Most Doulas (67%) work in these settings on a voluntary basis, while 39% are employed and 11% work on a freelance basis. When asked about funding, several respondents reported that they were paid from the funds of the sponsoring organization, e.g., a hospice fund. Twelve organizations (66.7%) reported that 'DD' had received training. The areas of responsibility undertaken by 'DD' are shown in Table 2.

Seventeen out of the 18 organizations working with 'DD' say it makes sense to work with them, with only one person saying no. In addition, 66.7% would like to use more 'DD' in their care. Eleven percent of the survey respondents reported being asked by patients or relatives for the services of 'DD' frequently, 39% occasionally, 33% rarely and 17% never. The need is perceived to be high by most institutions (78%) that work with 'DD' and even very high by 11%. One institution sees little need, and another sees no need at all. Satisfaction of patients and families with the services of doulas is reported as very satisfied (47%) and mostly satisfied (53%). In addition, 94% of the institutions working with 'DD' would recommend them to other institutions. Only one was unsure.

Overall, 59% of the respondents expressed a need for more information on the topic (e.g., through articles). On the other hand, 28% disagreed and 14% were unsure if they want more information.

Eighty-nine percent of organizations that do not work with 'DD' state that the tasks and services provided by them are carried out by other professionals and volunteers. Free-text responses often described the role of 'DD' as being the core of palliative care and therefore there is no need for 'DD,' as their work is as well carried out by other professionals. Table 3 lists some verbatim quotes on why there is no collaboration with 'DD,' and Table 4 shows the professional groups involved in end-of-life care in the different institutions in Germany.

Table 2: 'Death Doulas' areas of responsibility.

'Death Doulas' areas of responsibility
Support during the dying phase
Talks with patients and families/psychosocial support
Occupation, activities, excursions, walks
Attendance/sitting watch
Helping to organise events (e.g., grief café)
Support for relatives
Household assistance
Help with final arrangements (e.g., paperwork and living wills)
Dog visiting service

Table 3: Direct quotes from the free text responses on why organizations do not work with 'Death Doulas.'

Why institutions do not work with 'Death Doulas'
"No additional professional group necessary"
"In my opinion, just a new name for an "old child""
"The range of tasks is covered in the organization"
"Hospice volunteers are already doing this job"
"Hospice assistants, therapists. This is the basis of palliative care"
"Spiritual support from all members of the palliative care team is much more meaningful"
"Since we have hospice counsellors. Superfluous, in my opinion"
"I see no difference to (well trained) hospice counsellors"
"Competition with outpatient hospice volunteers. Why another voluntary service? Organizational form? Added value?"
"Difference to 'Birth Doulas': Dying is not as time bound as a birth; therefore, frequent changes of caregiver are necessary"

Table 4: Professional groups in end-of-life care at institutions that do not work with 'Death Doulas.'

Other professional groups in end-of-life care
Bereavement counsellor
Nursing staff/palliative care specialists
Pastoral workers
Psychologists/psycho-oncologists
Medical doctors
(Spiritual) end-of-life counsellors
Hospice volunteers
Hospice outpatient service
Art and music therapists
Psychosocial service/social worker
Respiratory therapists

4. Discussion

Our findings show that 'DD' do not yet play a significant role in specialized palliative care in Germany. Even when searching for studies or specialist articles on German 'DD,' there are only a few popular science articles in magazines or online portals, and no scientific surveys on the topic [14–16]. Our results can, therefore, only be compared with studies from other countries, where palliative care is often organized differently than in Germany. Palliative care in Germany has developed at different levels over the last 40 years. In particular, volunteers have played an important role in palliative

care, both at home and in hospices and palliative care units [17]. The establishment and development of German hospice and palliative care is largely due to the commitment of volunteers. This volunteer work has made it possible to build up a nationwide network of care for people at the end of life. Currently, more than 120,000 volunteers are involved in over 1280 hospice and palliative care services [18]. These volunteers are usually trained as hospice counsellors according to the curriculum of the German Hospice and Palliative Care Association (German abbreviation: DHPV) and learn basic skills in dealing with the needs of the dying and their families. Hospice volunteers are not medically trained but look after the psychosocial needs of the patient and their relatives, organize excursions and provide bereavement support [11]. According to the curriculum, the training to become a volunteer hospice counsellor takes 100 teaching units of 45 min each and should include a practical placement in addition to the theoretical teaching units. The theoretical part of the training covers a variety of topics, including personal biographical reflection, spiritual and communicative learning areas and information about the palliative care movement and care in general [19]. As these volunteers play an important role in palliative care in Germany, the need for 'DD' may not be considered as great. This was also frequently mentioned in the free text responses of the questionnaire.

As the term or profession of 'DD' is not well defined or protected, and there is no standardized training, it is difficult to systematically record provision. In their systematic review from 2018, Deb Rawlings and colleagues also highlight the issue of nonstandardized training and a lack of understanding of the role. They were only able to include five papers in their analysis, indicating a lack of scientific investigation into the topic, and also describe the work of 'DD' as similar to that provided by multidisciplinary palliative care teams [1].

In their qualitative study, Marian Krawczyk and Merilynne Rush sought to describe the role of 'DD' in more concrete terms. They conducted 22 semistructured interviews with participants from four countries. They found that there is a wide variety of terms used to describe the same role. In addition to 'DD,' the term 'end-of-life Doula' or 'Death Midwife' is particularly common. This paper also refers to the different understandings of the role, as there is no single definition for the work of a 'Death Doula.' However, the primary descriptions include the terms 'support,' 'educate' and 'empower' [8]. Changing lifestyles and the increasing individualisation of society may lead to more personalised services for people at the end of life in the future. There is a growing trend for people to opt out of traditional medical care and to seek alternative forms of care. This is where 'DD' come in. As they do not provide traditional medical care but rather attend to the psychosocial and spiritual needs of the dying person, 'DD' can fill a gap that is currently not being satisfactorily addressed in traditional end-of-life care [1, 7]. As described in the review by Deb Rawlings, there are also no uniform standards of training for 'DD' in other countries, and no satisfactory overview of the areas in which they work. Most of their work is individual, without specific contact with palliative care services, so it is not surprising that the survey we conducted also found that 'DD' rarely work with palliative care providers in Germany [1]. So, perhaps the question is whether the work of 'DD' can be integrated into traditional hospice and palliative care at all, or whether it will remain an additional service for a particular group of people who are interested in individualised and alternative care.

4.1. Limitations. As this is the first nationwide survey on 'DD' in Germany, it is difficult to relate the results to other studies as there are no other studies from Germany on this subject and because of the different structure of palliative care in other countries. Due to the concept of the questionnaire, a systematic bias can be assumed, as the answers represent the attitude and knowledge of the person filling out the questionnaire and not the whole team. Responses may have been influenced by social desirability in some cases, and overall reflect a high level of uncertainty and heterogeneity about the role and profession of 'DD,' although we attempted to anticipate this issue with the info box in the questionnaire. A survey of the entire team would have been desirable but was not possible due to the concept of the survey in its paper–pencil form. The questionnaire focuses mainly on institutions already working with DD. Institutions that do not work with DD are only asked four questions. This imbalance might have missed critical insights from nonusers, such as their perceptions, reasons for not engaging or barriers to adopting DD services.

With a response rate of 36.4% in total, the data are not representative for all German hospices, palliative care units and specialized outpatient palliative care services. In addition to these three specialized forms of care, there is also other palliative care in Germany, which is organized by voluntary associations or the patients' family doctors. Our survey cannot show the extent to which 'DD' support them. To increase the overall response rate, it could be discussed whether follow-up reminders or other survey formats (e.g., digital surveys) could have been used. Another bias can be assumed that maybe more teams responded to the survey if they are familiar with the topic of 'DD' and think that they could play an important role. Furthermore, this study cannot make any assumptions about the quality of care through 'DD' as well as the benefits for the patients and their relatives. However, the purpose of the study presented here was to demonstrate if the work of 'DD' is available in Germany and in which way. The results can serve as a basis for upcoming studies.

5. Conclusion

Our results show that the use of 'DD' in German palliative care is rare. Assisting the dying and similar activities are often carried out by other professionals or volunteers. However, as the use of 'DD' has shown positive results in other countries, it would be desirable to implement these aspects in the German palliative care structure. This requires further research and training, so that, in addition to greater

public awareness, the benefits can also be secured on a scientific basis. The development and certification of formal training programmes could also increase the acceptance of 'DD' in end-of-life care by palliative care providers.

Data Availability Statement

The datasets used are available from the corresponding author upon reasonable request.

Ethics Statement

Positive vote of the local ethics board was given on October 7, 2022 (file number 136/22; ethics board of the Philipps University of Marburg, Germany), and registration in the German register of clinical trials (DRKS-ID: DRKS00030426, registration date October 24, 2022) were obtained before the start of the study. According to German law, a signed declaration is not required, as the data are collected anonymously. Participation and return of the questionnaire implies the willingness to process the data, about which participants were informed in the cover letter. Research was conducted in accordance with the Declaration of Helsinki.

Consent

Not applicable due to the anonymous nature of the survey. Each participant was informed in the invitation letter that taking part in the anonymous survey and returning the questionnaire to the study team included the consent for publication.

Conflicts of Interest

The authors declare no conflicts of interest.

Funding

This study was funded by Philipps-University Marburg.

Acknowledgements

We would like to thank all participating institutions for taking the time to respond to the survey.

Supporting Information

Additional supporting information can be found online in the Supporting Information section. *(Supporting Information)*

Translated English version of the questionnaire. Questions 1–6 asked for demographic information about the palliative care organisation. Question 7 is a key question about whether the institution works with 'Death Doulas.' If so, questions 8–18 follow, whereas if the institution does not work with 'Death Doulas,' only questions 19–22 should be answered.

References

[1] D. Rawlings, J. Tieman, L. Miller-Lewis, and K. Swetenham, "What Role Do Death Doulas Play in End-of-Life Care? A Systematic Review," *Health & Social Care in the Community* 27, no. 3 (2019): e82–e94.

[2] J. Schwartz, M. C. Reuters, M. Schallenburger, et al., "Allgemeine Palliativversorgung in Pandemiezeiten," *Der Onkologe* 27, no. 7 (2021): 686–690.

[3] R. Browne, "The Rise of the Death Doula," https://macleans.ca/society/death-doulas/.

[4] K. Corporon, "Comfort and Caring at the End of Life: Baylor's Doula Program," *Proc (Bayl Univ Med Cent)* 24, no. 4 (2011): 318–319.

[5] N. L. Amram, M. C. Klein, H. Mok, P. Simkin, K. Lindstrom, and J. Grant, "How Birth Doulas Help Clients Adapt to Changes in Circumstances, Clinical Care, and Client Preferences During Labor," *The Journal of Perinatal Education* 23, no. 2 (2014): 96–103.

[6] K. J. Gruber, S. H. Cupito, and C. F. Dobson, "Impact of Doulas on Healthy Birth Outcomes," *The Journal of Perinatal Education* 22, no. 1 (2013): 49–58.

[7] R. K. Fukuzawa and K. T. Kondo, "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, no. 12 (2017): 612–619.

[8] M. Krawczyk and M. Rush, "Describing the End-of-Life Doula Role and Practices of Care: Perspectives From Four Countries," *Palliat-Care* 14 (2020).

[9] C. Volberg, H. Schmidt-Semisch, J. Maul, J. Nadig, and M. Gschnell, "Pain Management in German Hospices: A Cross-Sectional Study," *BMC Palliative Care* 23, no. 1 (2024): 7.

[10] E. Klaschik, F. Nauck, L. Radbruch, and R. Sabatowski, "Palliative Medicine-Definition and Principles," *Der Gynäkologe* 33, no. 10 (2000): 704–710.

[11] S. Fleckinger, *Hospizarbeit und Palliative Care: zum Wechselseitigen Arbeitsverhältnis von Haupt- und Ehrenamt* (Wiesbaden: Springer VS, 2018).

[12] K. Papagni and E. Buckner, "Doula Support and Attitudes of Intrapartum Nurses: A Qualitative Study from the Patient's Perspective," *The Journal of Perinatal Education* 15, no. 1 (2006): 11–18.

[13] "Deutsche Gesellschaft für Palliativmedizin-Wegweiser," (2022), https://www.wegweiser-hospiz-palliativmedizin.de/de.

[14] L. Csapo, "Charlotte Wiedemann ist eine der ersten Death Doulas in Deutschland," *Was Macht Ihren Job Aus?*.

[15] T. Spang, "Begleiten Menschen in Den Tod," (2021), https://www.domradio.de/artikel/doulas-begleiten-menschen-den-tod-hebammen-am-ende-des-lebens.

[16] P. Czienskowski, "Unser Umgang Mit Emotionen ist Definitiv Ausbaufähig," https://www.fluter.de/death-doula-interview.

[17] Deutsche Gesellschaft für Palliativmedizin, ""Das Ehrenamt in Der Hospiz-Und Palliativversorgung," (2019), https://www.dgpalliativmedizin.de/images/RZ_200630_Berichtsband_dt.pdf.

[18] (2024), https://www.dhpv.de/zahlen_daten_fakten.html.

[19] E. V. Dhpv, "Qualifizierte Vorbereitung Ehrenamtlicher in der Sterbebegleitung," *Eine Handreichung des DHPV. Berlin* (2021): https://www.dhpv.de/files/public/broschueren/2021_Brosch%FCre_RzQVEA.pdf.