



SUMMARY REPORT

Discussion Forum Summary and Recommendations

Part of the 3rd Annual End-of-Life Doula
International Research Symposium (2024)

End-of-Life Doula **International Research Group**



END OF LIFE DOULA UK
Doing Death Differently



University
of Glasgow



GLASGOW
END OF LIFE
STUDIES

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INTRODUCTION

On July 2nd, 2024, a small but diverse group of UK healthcare professionals, policymakers, researchers, and care organisations were invited to a Discussion Forum on the emergent role of end-of-life doulas in health and social care as part of the 3rd annual End-of-Life Doula International Research Symposium held in Glasgow, Scotland.

The forum aimed to explore the evolving role of end-of-life doulas in supporting community-led approaches to dying, death, and bereavement. In the first half, invited guests discussed their perspectives and questions about the future(s) of this role, and heard the ideas and insights of others. Attendees of the larger international Symposium participated in an open discussion in the second half of the Forum. With the field still relatively new, discussions centred around the following questions:

- Should end-of-life doulas be integrated into existing health and social care services?
- What specific outcomes or benefits would you like to see from incorporating end-of-life doulas into patient care?
- How should the success of end-of-life doulas be measured within the healthcare system?
- What additional information or evidence would you need to feel more comfortable working with end-of-life doulas?

The forum provided space for a wide range of topics which are summarised below. We are sharing our findings widely to guide collaborative policy, research, and practice development.

INTEGRATION ASPECTS

Integration Aspects

Participants emphasized the importance of clear communication between end-of-life doulas (EOLDs) and healthcare professionals, especially in coordinating messaging to families and establishing role clarity to avoid overlaps with other healthcare providers.

A key focus was how EOLDs can support person-centred care and addressing the individual needs of patients and their social networks, as well as having the potential to play an important part in broader policy discussions around the right to palliative care. A systems approach, including interprofessional collaboration with EOLDs, was deemed necessary to address structural challenges in healthcare systems.

However, there were concerns about the ability of already overwhelmed healthcare systems to integrate new roles. Others identified a knowledge gap among healthcare professionals regarding EOLDs, and some resistance to collaboration was noted. Participants also discussed tensions between the goals of traditional healthcare, which focus on clinical outcomes and resource management, and the broader death literacy and compassionate community movements. The cause of communication barriers was explored, acknowledging that while some healthcare professionals may be reluctant to engage with EOLDs, oversimplifying these barriers could needlessly polarize discussions.

COMMUNITY ASPECTS

Community Aspects

There was strong consensus that EOLDs can encourage and enable communities to engage more deeply in end-of-life care, helping to achieve the broader goals of death literacy and the development of compassionate communities. EOLDs were viewed as facilitators, helping communities access existing knowledge rather than “fixing” the dying process. While some felt that eventually communities may become self-sufficient in end-of-life care, others acknowledged that certain aspects of the EOLD role might always be needed, much like social work roles that were initially thought to become redundant but remain necessary.

The role of EOLDs within the Public Health Palliative Care model was emphasized, focusing on community-based support at the end of life rather than medicalized care which usually only comprises a small amount of care needed. However, defining what “community” means and how EOLDs connect with different communities sparked lively debate, with concerns raised about geographic and socio-economic inequalities influencing who is included and represented. Understanding and defining communities within EOLD practice, research, and policy development was considered important.

TRAINING, PROFESSIONALISATION, AND SCOPE OF PRACTICE

Training, Professionalisation, and Scope of Practice

Several considerations were raised about EOLD training, including the diversity and variable quality of training programs, role clarity, and scope of practice. Participants agreed on the need for research into why people pursue EOLD training and what happens after training completion. Concerns were voiced about the potential vulnerability of trainees entering an emotionally intense field, emphasizing the need for mentorship and practical training (practicums) to help trainees navigate these challenges.

There was also a focus on navigating power dynamics in the doula-client relationship and recognizing personal biases. Diversity in training was seen as crucial, with participants stressing that EOLDS should reflect a wide range of cultural and social perspectives to meet diverse community needs. The importance of supporting not only the dying individual but also caregivers and families was also emphasized. EOLDS were seen as having the potential to reduce harm by providing information on the dying process, with caution to avoid imposing their views on what dying should look like.

Participants were divided on the issue of professionalization: some advocated for standardized training and accreditation to ensure safety and scope of practice, while others cautioned against over-formalizing the role, which could undermine its flexibility and community-based nature.

EVALUATION

Evaluation Aspects

There was broad agreement for the need to evaluate EOLD practices to understand their impact, particularly regarding the experiences of families and communities. However, traditional clinical evaluation methods may not adequately capture the full scope of EOLD work. Participants called for more qualitative approaches, such as in-depth qualitative descriptions, sensory and emotional data, and process-based evaluations, which are better suited to the complexities of EOLD practice.

It was noted that evaluation frameworks should also include broader impacts like community engagement and social indicators, with a focus on continuous quality improvement rather than just outcome measures. There was recognition that while some outcome measures are needed for policy advocacy and integration potential, these should be balanced with social science approaches that capture the relational and community-building aspects of EOLD care.

POLICY, PRACTICE, AND RESEARCH RECOMMENDATIONS

Encourage Cross-Disciplinary Learning and Communication

There is a need to improve health and social care providers' understanding of the role of EOLDs. Promoting discussions to clarify roles and foster communication between disciplines will help integrate EOLDs into healthcare systems. We recommend creating opportunities for cross-disciplinary learning and collaboration to enhance person-centred care and support for those nearing the end of life, regardless of formal integration.

Enhance Training and Support Structures

There is strong interest in developing mentorship models and practical training for EOLDs. Training should also promote diversity to meet the varied needs of different communities, including those underserved by current systems. We recommend creating more collaborative training opportunities across health and social care services, especially in underserved areas.

Implement Holistic Evaluation Frameworks

There is a need for evaluation methods that use qualitative approaches to fully capture the impact of EOLDs, focusing on family and community experiences. Evaluation should include social indicators and community engagement, not just clinical outcomes. We recommend collaboration between EOLDs, healthcare professionals, and researchers to develop comprehensive methods that reflect the full scope of EOLD work.

POLICY, PRACTICE, AND RESEARCH RECOMMENDATIONS

Connect to Public Health Palliative Care Frameworks

End-of-life doulas are recognized as key contributors to public health approaches to end-of-life care, focusing on the social aspects of dying. We recommend that policy discussions highlight the role of EOLDs in building community capacity for managing end-of-life care, as well as providing direct support.

Support Ongoing Research

There is a strong interest in researching the background of EOLDs, the services they provide, and outcomes of EOLD care. We recommend using an interdisciplinary approach to better understand their impact across healthcare, social care, public health, and community development. Collaborative research can inform policies that support the broader adoption of EOLD practices across a range of care contexts.

Support Flexibility and Diversity

While policy development should provide structure, it is important to allow flexibility in how EOLDs operate, respecting different community needs and preferences. We recommend that policymakers ensure that support of regulatory processes, like accreditation, do not restrict the grassroots and diverse nature of EOLD work for those who do not wish to be formally integrated into health and social care.