STORYTELLING AT END OF LIFE: EVALUATING THE ESTABLISHMENT OF VOLUNTEER-LED BIOGRAPHY PROGRAMS IN PALLIATIVE CARE

Dr Jessica Gereis[1], Prof Megan Best[1]

1. Institute for Ethics and Society, The University of Notre Dame, Broadway, NSW, Australia

KEYWORDS

Palliative care, volunteers, life review, narrative-based interventions, existential distress, meaning-making, service development and implementation

EXECUTIVE SUMMARY

Palliative care aims to support quality of life at the end of life, yet psychosocial and spiritual distress often remain under-addressed. Narrative and biography approaches offer non-pharmacological ways to mitigate existential suffering, foster meaning-making, and support legacy-building. Services are increasingly opting to train volunteers to deliver biography services, yet limited evidence exists regarding these programs' establishment. Using a qualitative case study approach, we examined volunteer-led biography services across Australian palliative care settings through document analysis and interviews with volunteer managers. Data collection and analysis is underway; preliminary findings encompass operational models, volunteer pathways, referral processes, and the biography journey.

INTRODUCTION

Palliative care services aim to enhance the quality of life of individuals with serious health-related suffering and have a life-limiting illness, through holistic consideration of their physical, psychosocial, or spiritual needs. Those facing an impending death are more prone to existential distress, demoralisation, and despair, all of which may constitute key barriers to a peaceful death.

The practice of storytelling is intrinsic to the human experience, spanning all times and cultures. Life review and biographical approaches constitute non-pharmacological tools for addressing patient's psychosocial and spiritual needs, often found to be under-addressed. Narrative-based programs aim to highlight the patient's personhood and whole of life beyond the immediate illness context. Their therapeutic potential lies in: the storytelling process itself, the experience of being listened to without judgement, the creation of the biographical product, and its subsequent use following completion. Narrative-based approaches can mitigate existential suffering, foster meaning-making, and produce a 'generativity' document that transmits a legacy of one's essence, values and beliefs. Reflecting on one's life story and generating a tangible biographical document may foster greater acceptance of one's journey and thus be more accepting of death. Such documents may even support caregivers in bereavement.

Given resourcing constraints of professional staff-facilitated approaches, services are increasingly turning to expand biography programs instead delivered by trained volunteers. Evidence supports volunteer involvement in palliative care as a means of providing compassionate companionship that can alleviate social isolation and loneliness of patients and caregivers, and improve client/patient satisfaction with care. An effective and sustainable biography service requires volunteers to meet the dual demands of the biography construction process and the emotional complexity of end-of-life care situations, thus require unique operational and ethical consideration. These programs therefore introduce operational and ethical considerations for services, including around adequate volunteer training and formation.

Although narrative and biography approaches are endorsed in palliative care policy frameworks, there is limited published guidance or evidence regarding their development and implementation. With growing

integration of volunteer-led biography programs into standard palliative care service offerings, it is timely to gather insights from the pioneers of these programs. The present study aims to examine and document the operation of volunteer-run biography services, including their development as volunteer services, volunteer selection and training, patient referral patterns, operations, and deliverables.

HIGHLIGHTS

Please be advised that data collection and analysis is presently underway, however will be ready by the time of the conference. Below are some ideas for what these highlights might be, pending full analysis.

- Managers play a central role in volunteer training, support, and oversight
- Volunteer selection and training critically impacts service quality
- Biography services are resource-intensive, yet widely considered highly impactful

METHODOLOGY/ PROCESS

We followed a Case Study approach to document the establishment and operation of volunteer-led biography services. This method facilitated comparison of services and their deliverables, and supported development of a practical blueprint for replicating similar services. Qualitative data were collected between December 2025 and March/April 2026 across several Australian palliative care services, including inpatient and community-based settings. We recruited volunteer managers responsible for coordinating and overseeing volunteers providing biography services, identified by investigators and through snowball sampling.

Archival research analysed policy and institutional documents relevant to the establishment of biography services and volunteer training. Semi-structured interviews were conducted with volunteer managers involved in establishing or coordinating services, either in person or via videoconferencing, audio-recorded and transcribed verbatim. Interviews explored volunteer training and support, the biography process, and patient or client participation. Participants completed a short demographic survey. Interview transcripts were analysed using constructivist grounded theory following Charmaz's approach, with quantitative data summarised descriptively. Ethics approval was obtained, and all participants provided written informed consent with assurances of confidentiality and deidentification.

RESULTS/ OUTCOMES

Data collection and analysis is presently underway, due for completion within the next three months. However, preliminary analyses of interview transcripts, all 13 of which are extensive and rich, show themes being constructed under the domains of: operational processes; the role of the volunteer manager; volunteer pathways (recruitment, screening, and training); client access to biography services (intake, consent, and matching to volunteer); and the biography journey and storytelling process.

CONCLUSION

Biography services are increasingly being incorporated as a key volunteer-led offering by palliative care services. Little has been published that explores their establishment, operations, and ongoing development. Our study offers key insights into the experiences of those founding and managing these services, especially with regards to the onboarding, training, and oversight of volunteers. Ultimately, volunteer managers consider biography services, even amidst the high demands and responsibilities of the role, to be worthwhile and highly impactful, almost universally reporting positive experiences for themselves and those who take part.