Addressing spiritual needs in palliative care through conversations and stories

Elizabeth Summerfield

'GPS PLAY SUCH A HUGE ROLE IN THIS SPACE.'[1] These were the words of Dr Chloe Furst, dual-trained geriatrician and palliative care physician, referring to the pivotal role general practitioners (GPs) play in identifying the need for palliative care in their life-limited patients, whether physical, psychological, social or spiritual. As Furst explains, such care is now being offered earlier and for a much broader range of conditions. Because GPs truly know their patients' wishes and values, she says, they understand the ways in which the holistic approach of palliative care offers comprehensive support. This paper focuses on one existing program for spiritual care that GPs may be unaware of but that may support their work.

The Lancet Commission: Spiritual care at end of life

In 2022, Libby Sallnow et al released 'Report of the Lancet Commission on the Value of Death: Bringing death back into life'.[2] Commissioners argue that a problematic outcome of the wonderful scientific and technological advances in medicine has been the overtreatment of many at the end of life. Remedying this requires 'radically reimagining' end of life as a 'relational and spiritual' as well as 'physiological event'. They want to see 'conversations and stories' about ending a life become commonplace among patients, families and clinicians.[2]

Some researchers in geriatric medicine and palliative care echo the risks of overmedicalising end-of-life treatment. They see this as a social as well as medical problem. We have lost the language to articulate our spiritual dimension, they argue.[3] A broad cultural shift that includes medicine is needed to understand and appreciate the 'value of death'. GPs are often at the forefront of delivering diagnoses, so their role in patient and family education is critical in affecting medical and cultural change. One existing service, offered by some palliative care organisations, is the biography, or life-storytelling, program. It uses a narrative process based on the same premise as the *Lancet* report: that we all use stories, consciously or not, to create identity, meaning and purpose throughout our lives. Its innovation in the late 20th century was intended as a practical tool to elicit the conversations and stories the Commission now argues are a simple yet vital missing element of spiritual care.

Biography programs: 1980s' innovation for spiritual care

Biography programs were introduced to Australia from New Zealand in 2006 at Melbourne's Eastern Palliative Care (EPC).[4] In the late 1980s, Dr Ivan Lichter, a thoracic surgeon, then palliative care physician, identified the need for patient care, beyond the physical and psychological, that addressed spiritual need.[5] He conceived a service provided by trained volunteers. Each volunteer met with a patient over several weekly sessions to record the formative stories of the person's life. Volunteers transcribed, edited and reviewed drafts with patients to ensure accuracy and authenticity. A printed story was the end product, material evidence of the significance of an individual's life and legacy. More importantly, the process itself gave tacit permission to have conversations and tell the stories that captured patients' sense of identity, meaning and purpose. They could immerse themselves in an expansive life of the spirit even as their physical body declined. Rather than being locked entirely into the present reality of their ending, they could recreate the lived experience of their entire journey. (Narrative therapy is based on the same premise of living our lives through the stories we tell ourselves. However, it differs from the narrative

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process of life-storytelling in its focus on reshaping stories to reframe lives in order to address a problem. Biography programs aim to articulate and reaffirm the patient's sense of identity, meaning and purpose by reconstructing a whole life.)

Recent research: Reassessing impact

Between 2020 and 2022, research was conducted with patient participants in EPC's program.[6] Many noted the 'floodgate' of 'long forgotten memories' that emerged and the relief that came from their telling. One declared how 'wonderfully therapeutic' this simple yet powerful process of telling and listening had been. Many spent time between sessions reflecting on the elements of their lives they wanted to include to shape the 'type of story I wanted to tell'. Despite facing their ending, their focus was on reconstructing their lives, actively reflecting on issues such as 'just where to stop' and how to avoid 'too much boring detail'. Some worked hard to 'remember names and places', spending time between sessions searching for 'documentation which had dates' to aid the accuracy of their stories. Others found the work taxing but compelling. 'The review of completed units,' said one, 'was something of a chore, though a clear and necessary part of the whole process'. A sense of agency, control and productivity featured in the comments. Families often became involved, which decreased their sense of powerlessness. One man looked forward to working with his wife to 'record items that we may have forgotten about at the time' of the initial recording. Another was delighted at 'how easy it was to get my family involved'. Purpose was found in shaping their legacy for future readers. Physician-author Julie Kalanithi described the process as finding 'meaning in the striving'.[7]

Implications: Current practice and future research

Lichter envisaged biography programs as an integral feature of end-of-life care, a vital adjunct to the physical and psychological. Yet, while the programs are now offered by many palliative care services, they typically occupy a marginal role. And many patients may not be referred to palliative care at all, or they may be referred too late to benefit.

This reinforces Furst's declaration. Simply by being aware of the existence and potential of biography programs, GPs can introduce and offer referral at a time that best suits the patient. And even if a patient declines a referral, a trusted doctor will have acknowledged the spiritual dimension a life-limiting diagnosis presents and planted the seed of finding the 'value of death' in the spiritual relief that can come from conversations and stories.

Recent research on the positive potential of biography programs has two implications for GPs: (1) raising awareness and value of a well-established service to which GPs can refer their patients; and (2) the value of further research with GPs to determine how the narrative process may best be developed to support them in guiding their patients' spiritual care. GPs' 'huge role in this space' is the pivotal role as trusted educator and guide in the renewed focus on spiritual care at the end of life.

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Competing interests: None.

Funding: None.

Provenance and peer review: Not commissioned, externally peer reviewed.

AI declaration: The author confirms that there was no use of artificial intelligence (AI)-assisted technology for assisting in the writing or editing of the manuscript.

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