

# Why aren't rural family caregivers receiving appropriate bereavement support in Australia? *Practical considerations for palliative care settings*

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- Access to bereavement support is recognised as standard six of the national palliative care standards and an important benchmark of quality-of-care access throughout Australia.
- Poorer health outcomes are a well-established consequence of complex bereavement, making access to support in both urban and rural communities vital.
- A bereavement risk assessment tool is a validated and effective method of identifying and stratifying bereavement risk in both hospital and community settings.
- Families and carers of palliative care patients in rural hospital settings are at an increased risk of complex bereavement without a systemic approach to bereavement care.
- Transition of care in rural settings between the acute hospital and community setting for at-high-risk-of-complex-bereavement is a vital component of ongoing care.

## Abstract

Bereavement support for families and carers in rural Australian settings often fails to meet well-established and longstanding guidelines in key areas, subsequently causing undue mental distress for many individuals and potentially leading to the development of prolonged grief disorder (PGD), a debilitating psychiatric disorder of intensified grief and additional physical health detriments. In this paper, we consider the literature surrounding rural bereavement care in Australia and identify factors that contribute to poorer bereavement care in these locations, including issues of lacking policy elements to guide bereavement support and deficiencies in training and staffing which create difficulties between competing healthcare priorities. We synthesise recommendations of several guidelines to propose an individualised, multi-disciplinary, and pathway-based approach to rural bereavement care, and finally suggest several key areas that can be targeted and improved to help improve rural bereavement care in Australia without creating significant strain on the already thin resources of rural healthcare settings.

## Introduction

Bereavement support for grieving families and carers is important in palliative care. In Australia, the disparity between bereavement care guidelines and practice is evident in rural palliative care services, and the support issues family caregivers experience remain under-investigated (Aoun *et al*, 2017). This paper comments on bereavement assessment and management guidelines and identifies the gaps in bereavement support within hospitals in order to inform how to approach the psychosocial needs of families and carers of rural palliative patients.

## Bereavement and its assessment and management protocols in Australia

Bereavement is a process that most individuals experience; however, according to a meta-analysis conducted by Lundorff *et al* (2017), almost 10% of the family caregivers (in this paper the term family caregivers encompasses both families and carers) have a difficult and extended bereavement process and develop what is known as prolonged grief disorder (PGD), previously known as complicated grief or traumatic grief (American Psychiatric Association, 2013). This recognised psychiatric disorder causes an individual's thoughts to be pervasively intruded upon by grief, and leads to significant impairments in functioning and quality of life (Boelen & Prigerson, 2007; Hudson *et al*, 2018). PGD can furthermore lead to a risk of developing psychiatric issues (ie substance misuse, depression, anxiety and suicidality) and physical health detriments (ie hypertension, insomnia, cardiac problems, and cancer) potentially resulting in increased health service utilisation and hospitalisations (Boelen & Prigerson, 2007; Hudson *et al*, 2018; Prigerson *et al*, 1997; Latham & Prigerson, 2004; Prigerson, Vanderwerker & Maciejewski, 2008). Therefore, the national peak body of palliative care (Palliative Care Australia) places a large emphasis on the importance of bereavement care for family caregivers of palliative patients. In the protocol National Palliative Care Standards, Palliative Care Australia provides nine quality and safety standards, aiming to provide a holistic framework for supporting patients and their grieving family caregivers across Australia (Palliative Care Australia, 2018).

Standard six of the protocol targets the psychosocial and emotional responses of bereaved family caregivers (Palliative Care Australia, 2018). The standard addresses the need for the provision of information and support throughout the spectrum of the grieving process. It qualifies that palliative care services should perform a comprehensive assessment of distress and bereavement for family caregivers and ensure their appropriate access to and utilisation of counselling or health services when indicated. Standard six also advocates for the risk assessment of a caregivers' likelihood of developing PGD, and the implementation of guidelines for follow-up of those at an increased risk. Currently, there are no routinely recommended screening tools for risk assessment, however these tools may be helpful as part of the holistic assessment of the family caregiver's ability to cope with grief (Hudson *et al*, 2018; Palliative Care Australia, 2018; Kristjanson *et al*, 2005). Based on the holistic assessment of bereavement risk, various follow-up and referral pathways can be developed to address the family caregivers' support needs beyond the end-of-life stage (Kristjanson *et al*, 2005).

## Bereavement support gaps in in-hospital rural palliative care

There exists a range of bereavement support programs within health systems to meet palliative care quality and safety standards in Australia. In hospitals, these programs take the form of specialised teams who are responsible for the follow up of individuals at risk of complex bereavement. The members of such teams may include (but are not limited to) social workers, nurses, bereavement counsellors, and palliative care specialists. However, in rural Australian hospital settings, bereavement support policies and dedicated teams for approaching grieving family caregivers are frequently absent. Additionally, a majority (up to 60–70%) of patients who die in hospital have no contact with palliative care whatsoever, and without bereavement teams or governance policies, will receive no bereavement support throughout their grief journey (Australian Institute of Health and Welfare, 2021).

Policy elements are missing in rural hospital palliative care settings; for example there is often a lack of evidence-based programs, a diminished organisational culture, and inadequate health and

safety assessment guidelines. A study conducted by Kobel *et al* (2019) identified that about 9% of registered Australian palliative care centres had no protocols for bereavement follow-up, even in the common form of phone calls. Additionally, there was a large difference in the availability of specialised bereavement support staff in rural settings, with bereavement counsellors/coordinators being significantly less involved in rural hospital bereavement support systems (Hudson *et al*, 2018). Aoun *et al* (2017) identified in a survey-based study with the clients of Australian funeral providers in rural and metropolitan settings that 25% of the bereaved family caregivers who used palliative care services had not been contacted at all by bereavement staff after the patient's death. Furthermore, the majority of clients reported not being assessed for their psychosocial wellbeing before the patient's death. These aspects of bereavement support that are missed highlight the disparities between policy guidelines and the actual provision of care, resulting in decreased support mechanisms for grieving family caregivers.

Competing priorities among staff and resource allocation issues additionally contribute to inadequate bereavement care in rural palliative care settings. The role of providing bereavement support generally falls onto non-dedicated staff at opportunistic times who are required to provide a number of services in different roles (Kenny & Allenby, 2012). For example, healthcare providers are frequently unable to provide aspects of bereavement care, such as assessing the ongoing symptoms of bereavement and distress, engaging in supportive discussions with the family caregiver, and implementing the use of recovery resources, as a result of time constraints from their primary healthcare duties (Kenny & Allenby, 2012; Breen & O'Connor, 2013). Similarly, many rural patients rely on their GPs for support through grief, increasing the burden on GPs, who may be under-skilled or unprepared in managing bereavement. Nurses also report feeling vocationally under-prepared when balancing their primary duties with bereavement support, leading to bereavement care becoming a secondary priority (Kenny & Allenby, 2012; Breen & O'Connor, 2013). As specialised bereavement support is less available in rural hospital settings, psychosocial support is often provided by social workers who provide outreach to rural areas, or by community nurses with competing priorities (Kobel *et al*, 2019; Kenny & Allenby, 2012; Breen & O'Connor, 2013; Lynch,

2012). Consequently, co-ordinated bereavement support is not always present in rural hospital settings, which may compromise the mental health and wellbeing of rural family caregivers.

## Closing the gaps by personalised and multi-disciplinary interventions

The literature reveals that the quality and safety frameworks for bereavement support are not being consistently met in rural hospitals. There is a lack of relevant policy, assessment of bereavement risk factors, and competition between staff priorities. This inadequate support of family caregivers can potentially lead to a heavier physical and mental health burden, development of PGD, and a subsequent ongoing impairment of daily function (Boelen & Prigerson, 2007; Hudson *et al*, 2018; Prigerson *et al*, 2008).

Policies regarding the assessment of bereavement risk and follow-up would assist in optimising already strained health service resources to their best effect. If an assessment of bereavement risk is conducted, it allows a health service to individualise follow-up based upon their deemed risk of developing PGD. This subsequently lessens the psychological load on family caregivers and creates the opportunity for PGD to be identified and managed early. The optimisation of personalised delivery of health resources based on need can help to decrease health expenditure following on from PGD. A bereavement risk assessment can be performed by relevant health staff through a conversational and holistic exploration of the family caregiver's risk and resilience factors for bereavement, potentially aided by the use of structured bereavement risk assessment tools (Hudson *et al*, 2018; Kristjanson *et al*, 2005; Kobel *et al*, 2019). While there is great difficulty in definitively diagnosing those who will develop PGD, the identification of risk and resilience factors can aid risk stratification greatly.

Pathways for follow-up can be implemented based on the gauged risk of poor bereavement. An example is the stratification of a family caregiver's risk of PGD to low risk, intermediate risk, and high risk. Low-risk individuals may benefit from informal follow-up (eg phone call) and will probably rely on social networks for support throughout the grieving process. Intermediate risk individuals may benefit from more formal follow-up and referral to community support groups and

grief counselling. High-risk groups may warrant comprehensive follow-up and referral to professional psychological services (ie psychologist or psychiatrist) (Hudson *et al*, 2018; Kristjanson *et al*, 2005). Through risk stratification, health service resources may be directed to a pathway with the largest impact on beneficial outcomes.

Multi-disciplinary practice is integral to the comprehensive support of these patients. Optimal bereavement support relies on coordinated collaboration between community care nurses, social workers, and specialised palliative care staff. Additionally, use of community support groups and social networks warrants strong consideration, especially in rural areas where professional services for bereavement care are lacking. The literature strongly advocates the use of a multifaceted approach to bereavement care, which may be more relevant in rural areas where palliative care utilisation is generally lower, and individuals rely more heavily on the support of their peers (Auon *et al*, 2017; Hudson *et al*, 2018).

Education for relevant staff on how to support bereaved families is also essential. A common theme in the literature is that rural frontline staff in contact with palliative patients (often social workers or community nurses) feel under-prepared and overwhelmed when those under their care are requiring psychosocial support (Kenny & Allenby, 2012). While it is not expected for all staff to be experts on these matters, a measure of 'grief literacy,' – an understanding of different grieving processes and how to approach and discuss the topic with an individual – is essential for starting individuals on the pathway to ensure access to support and resources to manage grief (Breen *et al*, 2020).

## Practical considerations

We have identified several major gaps in the bereavement support for family caregivers of patients in rural hospitals. These gaps are even more pronounced in the context of Covid-19 with reduced hospital visitation access for family caregivers. While some of these issues may be alleviated through a dedicated bereavement workforce in rural hospitals, the following considerations are important to improve bereavement support during the pandemic:

- education of rural nursing staff about PGD, how to assess bereavement risk, and how to arrange follow up
- institution of standardised, easily accessible, and readily implementable bereavement pathways in rural hospital settings
- holistic assessment of a family caregiver's bereavement distress and risk and resilience factors, continuing throughout and beyond the patient's end-of-life journey
- increasing utilisation of community-based resources in the psychosocial care of grieving individuals.

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