Palliative Care Social Work
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POSITION PAPER

A social work perspective on the Palliative Care Australia (2020) Outcomes Paper - Palliative Care & COVID-19: Grief, Bereavement and Mental Health

About PCSWA

Palliative Care Social Work Australia represents social workers who provide palliative and end of life care and bereavement support in Australia, regardless of the setting in which they work. PCSWA members work in specialist palliative care services, hospices and other settings such as hospitals, community and primary health, aged care facilities, correctional facilities, group homes and other government and non-government agencies. PCSWA is committed to enhancing the provision of high quality and holistic person centred, family focused and community-oriented care.

PCSWA aims to strengthen the voice of social work and to promote excellence in social work practice in the provision of psychological, social, cultural, emotional, spiritual, and practical support in palliative care and end of life care and bereavement. To this end, social workers consider an individuals' social determinants of health in the context of political and power structures and work to address issues of inequity that impact a person's structural vulnerability and disadvantage.

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Introduction

Palliative Care Social Work Australia (PCSWA) welcomes the outcomes paper ‘Palliative Care and COVID-19: Grief, Bereavement and Mental Health,’ published by Palliative Care Australia (2020).

PCSWA agrees that palliative care professionals are a “vital community resource that can be harnessed” (p2) to support patients, families, the community and health professionals during and beyond the pandemic. PCSWA recognises social workers who possess expertise in palliative care, grief and bereavement as particularly well placed to provide counselling, advocacy and support for people navigating the significant physical, psychological, social and economic challenges which may arise in the context of bereavement. (Stroebe et al., 2007, Hall et al., 2012)

In particular, PCSWA welcomes the call for the development of national standards for bereavement service provision in Australia, based on “best evidence of optimal bereavement interventions of the various populations at risk, considering longer term time points where these may be required post-death” and incorporating access to grief and bereavement services in the Aged Care Quality Standards (p 9). It is often assumed that mental health clinicians, psychologists or generalist counsellors have the expertise to deliver bereavement interventions, however they may not possess appropriate skills and expertise in contemporary grief and bereavement specific modalities to address poor bereavement outcomes. Medicare-funded psychological services available through the Better Access Initiative may therefore not be the most appropriate way in which to seek to provide meet complex grief and bereavement needs, nor the most equitable. PCSWA is also aware that a gap payment is typically involved in accessing psychological services through this initiative, which is a significant barrier, especially for those with limited economic resources. Specialist bereavement services must be differentiated from generalist support targeted toward mild to moderate mental health needs. A national framework such as the UK National Bereavement Alliance’s Bereavement Care Service Standards would provide criteria to inform expectations of a bereavement care service for clients, staff and volunteers. Such Standards would enable services to appraise, develop and improve their services to be both safe and effective in meeting the needs of bereaved people and provide a mechanism for closer oversight and regulation. Bereavement Care Service Standards would promote equity and governance across different services and lead to a more integrated approach to the delivery of bereavement counselling and support. Bereavement Standards would provide the Government with a framework to develop a minimum dataset to capture information on needs of the bereaved and the quality of service provided. When linked with other datasets (such as health and mental health service utilisation, bereaved carer payments, bereavement leave and productivity reports related to lost productivity as a result of bereavement and deaths by suicide related to bereavement), this would provide the Government with robust data on bereavement needs, service utilisation patterns and the economic costs of bereavement.

PCSWA wishes to highlight several issues:

a) **Broader understanding of the nature of complexity in grief and bereavement is essential in determining who needs and has access to support**

PCSWA notes the use of the public health model of bereavement support in the outcomes paper, and recognises the potential value of this model. We also note the use of a recent research study on Motor Neurone Disease (Aoun et al., 2020) to underpin predicted proportions of the level of grief risk for people experiencing bereavement pre and post COVID-19 in the outcomes paper. We are aware that determinations of level of grief risk in similar research (e.g. Aoun et al., 2015) are based on criteria for Prolonged Grief Disorder (PGD). PCSWA is cautious about interpreting need and support primarily according to PGD criteria. Significant numbers of bereaved people may experience high distress and psychological complexity in their bereavement that does not meet diagnostic criteria for PGD, and yet may still require specialised intervention. PCSWA perceives complexity in bereavement as multifaceted. Evidence suggests bereavement may be accompanied by a host of complexities including financial disadvantage, strain and insecurity (Cordon et al., 2012, Roulston et al., 2018, Hudson et al., 2011), increased risk of depression, anxiety and other mental health concerns (Stroebe, Schut and Stroebe, 2007), experiences of trauma and PTSD (Ganzel, 2016, Stroebe, Schut and Stroebe, 2007), increased risk of mortality (Stroebe, Schut and Stroebe, 2007), or a combination of disorders with potential to complicate grief responses (Raphael et al, 2001). These consequences may be heightened for precariously positioned populations associated with gender, non-heterosexual identity, class, ethnicity and structural vulnerability (e.g. Corden et al., 2010, Williams et al., 2012, Spruyt, 1999, Bristowe et al., 2016, Glackin and Higgins, 2008, DiGiacomo et al., 2015, Bindley et al., 2019). An emphasis upon a singular tool or construct to identify complexity, and to target resources and intervention is therefore fraught. Further research on the practice implications of the public health model is needed. PCSWA agrees that there is a need to increase community death and grief literacy (p 6). However, we perceive the need for a holistic approach to public awareness raising that not only improves community understanding of PGD, but promotes understanding of the many ways in which bereavement can contribute to physical, psychological and spiritual complexity.

b) **A holistic, conversational, interdisciplinary approach must underpin assessment of bereavement risk**

PCSWA notes the suggestion that services would "benefit from improved risk screening protocols and adequately resourced systems to identify those at greater risk of developing prolonged grief disorder" (p3). PCSWA recognises the need for caution when exploring risk assessment, given that the National Palliative Care Standards (PCA, 2018) and Bereavement Support Standards for Specialist Palliative Care (Hall et al., 2012) do not promote the use of a specific risk assessment measure. While the National Palliative Care Standards promote "structured assessment of bereavement that addresses emotional, behavioural, social, spiritual and physical domains," (PCA, 2018), it is recognised that there is insufficient empirical evidence to support the validity of one specific tool to screen for risk of poor bereavement outcomes prior to death. In addition, it is acknowledged that "safe predictions" about the longer term outcomes for bereaved individuals less than 6 months post death are difficult to make (Hudson et al., 2017). Lack of knowledge about the components of assessment as well as contextual constraints also present barriers to appropriate utilisation of specific measures (Lawler et al., 2020). Due to the lack of empirical evidence to support one particular tool pre-death and prior to 6 months post death, "structured assessment" through "conversational exploration of risk factors and strength/resilience factors" is recommended (Hall et al., 2012). PCSWA calls for holistic approaches to assessment that consider the potential not only for PGD, but other mental health concerns (pre-existing or recent onset in the context of caring or bereavement), as well as interpersonal issues and socio-economic complexity (among other issues), alongside protective factors. Furthermore, each death is estimated to impact approximately eight to ten family members (Metropolitan Health and Aged Care Services Division, 2004), and the primary carer may not be the person at greatest risk. PCSWA asserts that the level of risk may fluctuate for individuals over time, and receptivity to support may change and be shaped by a range of factors (Blackburn and Bulsara, 2017). Additionally, there are concerns regarding appropriate documentation and storage of any psychological assessment for bereaved individuals. Thus the use a screening tool at a particular time point with a primary carer or other individual alone is problematic. PCSWA welcomes the call by PCA for further "definition, research, education and training" on approaches to bereavement assessment (p 7), and advocates that a holistic, interdisciplinary approach is indicated.

PCSWA suggests several further recommendations:

a) **We call for comprehensive and systematic profiling of the nature of existing specialist bereavement support across Australia.** While there is a need to build community capacity to provide grief support within informal and community support networks, PCSWA is aware that in many areas specialist bereavement support does not exist, or is limited to certain populations. There is often an implicit assumption that specialist services are broadly available, however from practice immersion, social workers who provide specialist bereavement counselling or other related support know that this is not the case. Systematic scoping of existing specialist grief and bereavement service provision is an essential action that would advance palliative and end of life care and an understanding of gaps in available support. Such scoping would also better guide determinations regarding PCA's recommended allocation of additional resources for specialist and generalist grief and loss counselling (p 9).

b) **We advocate for definitional clarification regarding "post-death care" and "bereavement counselling and support**". PCSWA acknowledges the call by PCA to ensure funding models for acute care include resources to deliver "bereavement care to families and loved ones after the death of a patient," which is often undertaken by "doctors, nurses and social workers on acute wards" (p 10). However, there is a need to differentiate "bereavement care" from "post-death care". We suggest this work undertaken by doctors, nurses and social workers in acute settings after a death is better described as "post-death care." This work is often oriented around organisational requirements (for example, care of the body according to hospital policy), brief or immediate support, and the provision of bereavement information (for example, a bereavement pack at the time of death). This does not constitute comprehensive bereavement support. Characterising this work as "bereavement care" may be misleading and fuel assumptions that support is available for longer term needs. Bereaved family members have reported a sense of "abandonment" by health services following a death (Holstlander et al., 2017, Stajduhar et al., 2010), and complex needs can arise well after a period of acute care has concluded. Given recognition of a focus often upon early bereavement, with "significant gaps for people who require longer-term support to manage their grief" (p 6), the identification of early support as "post-death care" may provide clarity and more appropriate direction of resources to ensure the availability of longer term bereavement counselling and support.

c) **We call for scoping of and investment in loss, grief and bereavement education in undergraduate curricula.** The World Health Assembly (2018) recommends education on palliative care should be integrated in undergraduate medical and nursing programs, including social work – which includes training on grief and bereavement (PCA, 2018). With the Australian Centre for Grief and Bereavement, PCA launched a joint policy statement (2018) advocating for "improved education and understanding of grief and bereavement", again with a problematic focus on the "identification of prolonged grief disorder, for health and aged care professionals." Whilst incorporating palliative care education (with the inclusion of grief and bereavement), into medical and allied health undergraduate programs is gaining momentum, it has not been implemented broadly (Pastrana, Wenk & De Lima, 2016). Despite universities increasingly offering post-graduate courses on loss and grief, undergraduate courses on the topic are notably scant. In Australia, the Department of Health funds the Palliative Care Curriculum for Undergraduate (PCC4U) resources and education packages, which includes modules on loss and grief. However, whilst the resources are readily available, universities are under no obligation to implement them. For example, out of the 30 universities that offer social work programs at both an undergraduate and postgraduate level, only nine universities are actively implementing the resources (PCC4U, 2019). Furthermore, the ACGB (2020) offers short courses on effective bereavement care for both health practitioners, and students. However, the courses incur a fee which may deter students. Additionally, the completion of short courses does not necessarily involve formal assessment of practice or the receipt of feedback – thus attendance does not necessarily indicate competence, nor does it equate to specialisation. A scoping review of worldwide grief training in undergraduate medical schools, postgraduate programs and professional development options found only one Australian article which explored loss and grief in undergraduate programs (Sikstrom et al., 2019). Training and education in loss and grief is predominantly a voluntary component of undergraduate medical school training and generally not integrated in core curricula. Physicians themselves report feeling ill-trained to address grief (Soklaridis et al., 2018, Sikstrom et al., 2019). This paucity is not limited to medical programs, but also other health disciplines (PCC4U, 2019). In a contemporary environment, where natural disasters occur often, education and training on how to address grief after such an event, or a pandemic, is ever pressing. The World Health Organization (WHO) estimates up to 10% persons affected by a disaster will require a therapeutic intervention to navigate their grief and trauma (as cited in Ekanayake et al., 2013). Harrop et al. (2020) suggest bereavement skillsets during a pandemic need to be "above and beyond" (p. 1179). The cultivation of capacity to attend to grief and bereavement support and complexity broadly within health and social care workforces requires further understanding and investment.

PCSWA recognises the critical nature of this particular period, in terms of implications for grief and bereavement support.

Bereavement, isolation, loss of income and fear have been identified as triggers of mental health conditions worldwide (WHO, 2020). The psychological consequences of COVID-19 have been recognised, alongside additional impacts of secondary losses such as loss of employment and social connections (Eisma et al., 2020; Mayland et al., 2020).

However, PCSWA argues that the pandemic has actually highlighted existing unmet needs and gaps with regard to grief and bereavement support that pre-dated COVID-19, and will persist long after the pandemic is resolved.

While we welcome increased government investment in mental health services, in the absence of scoping of existing specialist bereavement services and clear standards for bereavement service provision, equitable access to specialist bereavement support cannot be assured. The pandemic constitutes a catalyst for urgent and much needed change within Australia and beyond. PCSWA concurs that the identified issues regarding bereavement needs "will not resolve themselves", and necessitate strategic planning, investment, and effective interventions (p 3).

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