Palliative Care and COVID-19

Grief, Bereavement and Mental Health

Outcomes paper from two Palliative Care Australia strategic forums held in 2020 with experts in palliative care, grief, bereavement and mental health with recommendations for policy makers, health and aged care leaders and professionals, and carers and consumers.

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> **“Reach out not just in the short term, but for the weeks and months to come.”** [1]

Grief, Bereavement and Mental Health – Palliative Care Expertise

Supporting people who are dealing with death, whether patients preparing for their own death or their family, friends and loved ones both before and after a death, is central to health professionals working in palliative care.

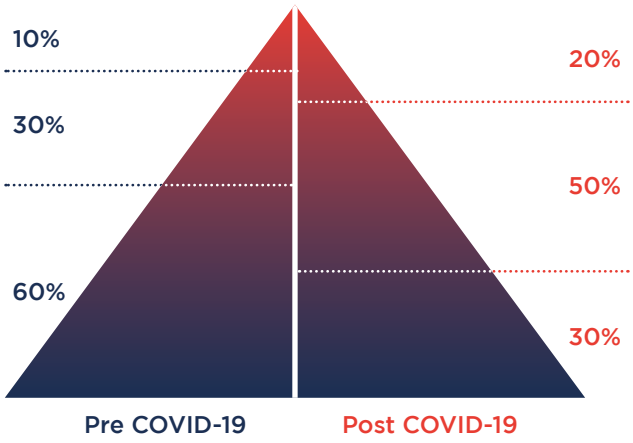
> *Everyone at some point will experience the death of someone close to them. Grief is the normal emotional reaction to loss, but the course and consequences of bereavement will vary for each individual. Palliative care integrates the psychological, spiritual and cultural aspects of care, and offers a support system to help carers and families cope during the person's illness and in bereavement.*[2]

The grief and bereavement support provided by palliative care professionals delivers a substantial, positive impact on the wellbeing of people affected by loss. On the other hand, a lack of sufficient support after the death of a loved one has a significantly negative impact on self-reported wellbeing, physical health, mental health and financial security. Those who report not receiving enough support report the greatest deterioration in wellbeing.[3]

The ability to support people through grief, bereavement and mental health distress by palliative care professionals in normal times is a vital community resource that can be harnessed to support patients, the broader community and health and aged care professionals both during and after the COVID-19 pandemic.

The public health model of bereavement support shows the predicted proportions of the level of grief risk for people experiencing bereavement pre-COVID-19 and post-COVID-19: low, moderate risk and high risk.

Figure 1: The predicted change of the three levels of grief risk pre and post COVID-19



HIGH RISK
At risk of complex grief issues. May need referral to mental health professionals

MODERATE RISK
In need of some additional support e.g. peer support/voluteer led group

LOW RISK
Majority of infividuals deal with grief with support of family & friends

From Professor Samar Aoun, Keynote presentation entitled: *Public Health Approaches to Bereavement Care – through the lens of the pandemic*, at the second international research seminar on public health research in palliative care: Towards Solutions for Global challenges, 17-18 November 2020.

In normal times, approximately 10% of bereaved people are at high risk of complex grief issues and this is predicted to rise to 20% of bereaved people post COVID-19. Further, the group in the moderate risk category is expected to increase from 30% to 50% following on from COVID-19. These figures are based on recent research on Motor Neurone Disease, a disease that is terminal, traumatic and fast progressing. The bereaved who are most likely to be in the 20% high risk group are those with depression, anxiety, poor family functioning, with insufficient support and a short period of caring, the latter two were the situation during the pandemic, in addition to other risk factors.[4]

This change in risk levels will have serious implications for the health and wellbeing of the population, increased use of health services and reduced productivity in the workforce and community activities.

Services would benefit from improved risk screening protocols and adequately resourced systems to identify those at greater risk of developing prolonged grief disorder.

Governments and service providers will be managing the grief, bereavement and mental health consequences of the COVID-19 pandemic for many years to come. These issues are not short-term and they will not resolve themselves without considerable strategic planning and investment followed by effective clinical treatment.

Consideration of these issues will support better patient outcomes in both the current pandemic and preparation for future pandemics or disasters. The issues of grief, bereavement and mental health distress as they relate to palliative care and dying patients during the COVID-19 pandemic is explored further on the following page.

Summary of key issues experienced during the COVID-19 pandemic

There are likely to be a number of long-term impacts relating to grief, bereavement and mental health distress for residents, patients, family and staff in health and aged care as a consequence of the pandemic.

> *We are experiencing much change and multiple losses. These losses might be obvious, such as jobs, income and physical connectedness. Less obvious losses include the losses of routine, freedom, trust in others, future plans, even a loss of how we thought the world works or should be.*[5]

The needs of palliative care patients and their families and carers

Grief, bereavement and mental health distress can be particularly pronounced for palliative care patients and their families. Normal visitation arrangements and close physical contact with someone close to death together with rituals and religious or spiritual practices have been minimised and restricted. Due to infection control requirements, families may experience compounded grief resulting from being unable to see their family member before they die, to view the body after the person has died and/or restrictions on attending a funeral.

> *As time passes and the pandemic eventually wanes, we will be left with a vast burden of loss, grief, guilt, anger, resentment and stress.*[6]

While COVID-19 has brought the focus more acutely on grief, bereavement and mental health, it also appears that the restrictions placed upon many familiar memorialisation practices have made room for creative new expressions of innovative memorialisation and made these new expressions more widely available to serve individuals, families and communities in a post-pandemic future.[7]

So while there may be some learnings about innovative practices that have been able to meet need, it is clear that the experiences of family members and friends accessing health and aged care facilities during the pandemic has varied greatly depending on differing visitation policies around the country, border restrictions and service and facility specific policies and guidelines. These are contributing to immediate or delayed anger, frustration, loneliness and despair, as well as disrupted and prolonged grieving.

> *In the next few months, many of the people we will be called upon to provide care to, will be shocked, frightened and alone. Many will deteriorate rapidly and will need the best support and care that we can provide professionally. Due to the necessities of isolation they will also need us on a deeper human level, especially those dying with significant distress. We will also be providing support to their carers and families as they deal with their shock, grief and bereavement. We understand that bereavement will be significantly impacted in nuanced ways and will need to be responsive to this both before and after the person's death. To meet this challenge, many of us will provide care beyond our usual standards, either in the frontline fight against COVID-19 or at our patients' bedside.*[8]

Guidelines do exist which can assist services to meet the grief and bereavement needs of palliative care patients and their families and loved ones. *Bereavement Support Standards for Specialist Palliative Care Services*[9] have been developed by the Centre for Palliative Care in partnership with the Australian Centre for Grief and Bereavement both based in Victoria.

Palliative Care Australia (PCA) is pleased to note that in the Federal Budget (October 2020), the Australian Government has committed over $12.5m to increase availability of grief and trauma support services for aged care residents and their families. This demonstrates recognition by the Government of this critical need[10] and while greater investment will be needed to make a sufficient impact, it is an important step.

The needs of health and aged care staff must be addressed

Health and aged are staff experience an increased burden of fear and anxiety when they or their colleagues become infected with COVID-19 or are required to enter isolation. Their employer's duty to ensure a safe workplace means that they must manage staffing capacity and ensure staff are supported when feeling overwhelmed and stressed. Additionally, many staff have experienced significant stress when they are required to restrict the visits of family members and carers to their loved ones in hospitals wards and aged care facilities. Palliative care staff who understand the vital importance of person-centred care face significant moral distress when their expectation that they should provide such care and support is obstructed by rules, regulations and infection control procedures which limit contact with the care team and loved ones.

> *Many people, including healthcare professionals, find it difficult to communicate with people who are grieving. As clinicians, we are not immune to the grief and suffering of others. Sometimes a death can have more of an impact than others, and it is important we look after ourselves.*[11]

To meet physical distancing requirements, many grief, bereavement and mental health services have offered their services through telehealth arrangements. While this has been a solution that provides at least some degree of much-needed support, for many practitioners/counsellors/ mental health workers, the inability to offer a personal connection is highly unsatisfactory, and should be seen only as a short-term necessity.

> *Those of us who have experience in providing care for dying people will know that it is when we form a relationship with our patients based on our common humanity that we are of most help to them. While healthcare technology can make a huge difference to physical symptoms, it is the simple acts of communication – touch, conversation and the building of trust – that help our patients, their families and clinicians to find peace at the end of a person's life. The demands of infection control and a huge workload of COVID-19 can rob everyone of the opportunity of support to deal with their loss and grief, and to make some sense of what is happening.*[12]

Vulnerable groups

Aboriginal and Torres Strait Islander communities have experienced particular challenges during the pandemic because, in many cases, they have been unable to engage in traditional practices – close interpersonal contact is restricted, large gatherings have been banned, family and community members have not been able to return to their country communities, or state and territory borders have been closed. Palliative care professionals and other workers have reported mixed success with telehealth and online consults for Aboriginal and Torres Strait Islander people and there are additional challenges with technology in some remote communities.

The Australian Centre for Grief and Bereavement (ACGB) and PCA's ***Position Statement on Grief and Bereavement*** notes that grief and loss issues are often compounded by the inability for people to follow their traditions. These particularly include Aboriginal and Torres Strait Islander people, and also many others across Australia with our great cultural and linguistic diversity. The traditional large gatherings towards the end of life, smoking and other mortuary practices, and the practice of family remaining with a person at all times, including after death have, by necessity, been severely constrained.[13]

That such gatherings, rituals and behaviours have not been allowed – or have been restricted – during COVID-19, has the potential to compound and prolong the grief and loss issues for countless people across Australia.

Who provides Grief, Bereavement and Mental Health support?

One framework for identifying who provides grief and bereavement support is the *Public Health Model of Bereavement Support*. This model advocates for partnerships between formal and informal networks and classifies the support provided into three categories:

1. **Informal Support:** includes support offered by family, friends, funeral directors, financial or legal advisors, religious or spiritual advisors, the internet or literature.
2. **Community Support (which can be in generalist or specialist settings):** includes support offered by GPs, aged care facilities, hospitals, pharmacists, community-groups, palliative care providers or school-based advisors.
3. **Specialised Professional Bereavement Support:** includes support offered by trained counsellors, bereavement support groups, social workers, mental health case coordinators, psychologists and psychiatrists.[14]

All forms of support are important, and it is essential that there are mechanisms to ensure these are accessible, timely, evidence based, and of sufficient duration to achieve the desired outcomes. While policies commonly focus on the provision of specialised professional support, as Professor Samar Aoun has identified, it is also vitally important to build the capacity of the informal and community support networks where most help is provided, and most grieving is undertaken. It is important not to underestimate what family, friends and neighbours can provide.

For many people, General Practitioners (GPs) will be the first port of call to talk about their grief, bereavement or mental health concerns as the result of the loss of a loved one or to talk more broadly about loss during the pandemic. GPs should be provided with the resources they need to support their patients during this time, and particularly for patients experiencing prolonged grief disorder.

> *GPs can be supported through appropriate information and strong connections with services….GPs are often the first point of contact for people at risk of, or experiencing, prolonged grief and therefore have a crucial role in correctly identifying and referring patients requiring treatment.*[15]

Importantly, the Government announced in the 2020/21 Federal Budget that the number of Medicare-funded psychological services available to individual patients through the Better Access Initiative has doubled from 10 to 20. Anecdotally however, the sector has identified that this may be helpful for existing patients, but it may limit or even overwhelm the capacity for psychologists to take on new patients. While this concern may be resolved over time, the experience of the palliative care sector suggests that given the scale of the demand, there will need to be a significant increase in the number of qualified practitioners with the skills to meet the grief, bereavement and mental health needs of people during and following the COVID-19 pandemic.

Furthermore, while the focus is often directed to the important early months of bereavement, there are significant gaps for people who require longer-term support to manage their grief. There is a particular need for specialised treatment for people still struggling with grief two or more years after the death of a loved one and who may be suffering from prolonged grief disorder.

This will require innovative models and solutions to support people with access to the care they need in disaster situations.

> *We should collectively work toward improving accessibility of evidence based Prolonged Grief Disorder interventions, including cognitive-behavioural treatments in both face-to-face and online formats. It is particularly vital to stimulate the development and dissemination of internet-based Prolonged Grief Disorder treatments, as such interventions can be applied even if the pandemic persist for extended periods of time."*[16]

Further investment is needed to ensure workforce capacity and capability to meet the emerging need.

The need to improve grief literacy

For many people who have had little reason to think about death, dying, grief and loss, COVID-19 has brought into sharp focus the need for understanding, preparedness and support systems. Palliative care professionals know that literacy about death and dying does help people when they are facing death or are caring and supporting for someone who is dying.

> *"There is a need for increased public awareness of prolonged grief to improve recognition and help-seeking by affected people."*[17]

As a nation, Australia and Australians would all benefit from improved grief literacy. Such knowledge would greatly enhance the ability of health and aged care workers supporting people as part of pandemic preparation and care during and after a pandemic.

Therefore, greater effort is needed to improve community understanding about loss and grief. Increased resources and support should be provided to the community to enhance grief literacy.

Strategic planning for Grief, Bereavement and Mental Health in disaster situations

The impact of COVID-19 will play out over many years and will require ongoing study. What is clear already from the grief, bereavement and mental health issues around death, dying and palliative care exacerbated during COVID-19, is that Australians have much to learn from this pandemic. Australia must take the opportunity to prepare more strategically for future pandemics or other disasters which may have similar implications.

Australian federal, state and territory governments should plan and prepare a more effective, strategic and considered response for the inevitable disasters that will emerge in the future. Within a National Framework, all jurisdictions need a grief, bereavement and mental health strategy to plan for events from which significantly increased numbers of deaths and associated social disruption can be expected. Each jurisdiction's strategy should incorporate a plan to support vulnerable groups including Aboriginal and Torres Strait Islander people and those in the community from culturally and linguistically diverse backgrounds. Ideally, each jurisdiction's plan will include the mapping of all available local grief, bereavement and counselling services.

Jurisdictional strategies should recognise that all people who die in Australia may have received any of a variety of services over the course of their illness (as have their loved ones). The provision of grief and bereavement services should be alert to the wide range of needs, referral routes, geographically based supports, which may or may not include ready access to specialist palliative care.

Currently, there are no national standards for bereavement service provision in Australia. As a result, bereavement care varies greatly across settings and locations. Service provision is more structured in some settings due to the introduction of standards or guidelines, including those of palliative care.[18]

The National Palliative Care Standards, developed by PCA, include Standard 6: on Bereavement. This requires that *'the service develop strategies and referral pathways in partnership with other providers in the community' and 'referrals to mental health specialists and counselling professions are made when clinically indicated.'*[19] This model could be used to expand to national standards for grief, bereavement and mental health service provision as it relates to the experience of palliative care patients and their loved ones during a pandemic or other disaster situations.

It will also mean that services across the country and in the various setting where higher than normal deaths can occur in a disaster situation are supported to proactively offer and provide essential grief, bereavement and mental health services, and not rely on the bereaved members of the community having to come forward to ask for support and services.

Bereavement risk screening is an area requiring further definition, research, education and training and should be included in national standards.

Conclusion

COVID-19 has had many negative impacts for people in Australia and around the world. The loss of control, the loss of physical contact between families and friends, the restrictions on gatherings and the burden of grief and loss when someone is ill or dies in such difficult circumstances will have an ongoing impact on many people for a long time.

All improvements in grief, bereavement and mental health services together with increased support for death and grief literacy in response to COVID-19 will enhance our community, well beyond the throes of the pandemic.

As a nation, we must consider what can be done to support the Australian community to cope with the added grief, bereavement and mental health distress that is affecting people now. We must also learn from what has happened and prepare and plan strategically for the future.

Recommendations

1 Policy makers

Recommendations for policy makers at the national and state and territory levels:

a. Within an overarching National Framework, each jurisdiction needs a Disaster Grief, Bereavement and Mental Health Strategy to plan for pandemics and other disasters where increased deaths are expected.
   - The National Framework and each jurisdiction's strategy needs to bring together currently siloed aspects of services in mental health, specialist palliative care, community health and primary care; to optimise integration and referral pathways and to minimise gaps.
   - Each jurisdiction's strategy should incorporate a plan to support vulnerable groups including Aboriginal and Torres Strait Islander people, prisoners and people from the full range of culturally and linguistically diverse backgrounds.
   - Each jurisdiction's strategy should map locally accessible grief counsellors and psychologists with grief expertise, continually updated to assist consumers and carers and health and aged care workers to know where services are support are available.
   - Each jurisdiction's strategy should support Primary Health Networks (PHNs) building better links and supports at the local level. PHNs are well placed to promote better care for prolonged grief through activities such as commissioning new services, coordinating (and facilitating access to) existing services and capacity building in the primary health workforce.[20]
   - Additional resources should be allocated for general grief and loss counselling services in all jurisdictions. The increased workload cannot simply be absorbed by palliative care services without additional funding.
   - State and territory governments should work with local government municipalities to coordinate services and build local capacity.
   - Greater financial and other capacity-building support is necessary for local community groups that offer grief, bereavement and mental health support to people during, and in the aftermath of, the pandemic and in preparation for future disasters with high death tolls.

b. Develop 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 timepoints where these may be required post-death. This includes incorporating access to grief and bereavement services in the Aged Care Quality Standards.
   - As part of this, national legislation should be developed around privacy and confidentiality that enables palliative care services to follow-up bereaved relatives of former patients and other clients of their services. Current regulation limits the ability of clinicians to exercise their common humanity by reaching out to provide comfort to the relatives and friends of those who have died and inhibits palliative care services providing ongoing support to people who would benefit from skilled bereavement support.
   - Bereavement risk screening is an area requiring further definition, research, education and training and should be detailed in national standards.

c. Work with general practice organisations to ensure GPs understand the impacts of COVID-19 and have the skills and resources to provide the mental health, grief and bereavement support and care to patients presenting because of issues relating to COVID-19.

d. Ensure improved education and understanding of grief and bereavement, including identification of prolonged grief disorder, by health and aged care professionals. This requires ongoing access to professional development and inclusion in undergraduate curricula and vocational training pathways.[21]

e. Further invest in research about the mental health, grief and bereavement impacts of COVID-19 and recommendations for better care and support of people affected by COVID-19.
   - This will include national Australian-based research together with supporting studies at more localised levels to identify local gaps, strategies and solutions.

f. Increase funding to ensure access to appropriate grief and bereavement services that meets the needs of residents, families and staff in residential aged care.

g. Ensure funding models for acute care include resources to deliver bereavement care to families and loved ones after the death of a patient. Currently funding models do not acknowledge this work which is often undertaken by doctors, nurses and social workers on acute wards.

2 Health and aged care leaders

Recommendations for health and aged care leaders managing hospitals and other health and aged care facilities:

a. Improve education and understanding of grief and bereavement, including identification of prolonged grief disorder, for health and aged care professionals. For relevant staff, ensure training is provided to recognise the specialised skills required to effectively treat individuals with prolonged grief disorder, and development of referral pathways to assist in timely access.[22]

b. Ensure there are risk screening protocols and systems in place in services to identify people at risk of prolonged grief disorder.

c. Engage more counsellors/psychologists with grief and loss expertise.

d. Ensure support is available for health and aged care staff – resources, counselling to deal with grief, moral distress and secondary trauma in the aftermath of the disaster.

e. Ensure services have appropriate telehealth capacity with the required technologies and upskill the workforce to use telehealth when appropriate.

f. Invest in contemporary telehealth technology and provide further training and skills that support health clinicians to undertake effective communication using telephone and video, including discussing prognosis, treatment options and planning for end-of-life care.

g. Ensure there are clear pathways for bereavement and mental health support, and referral for patients, residents and family members. This includes local community-based services through to specialist grief, bereavement and mental health support services for more complex cases.

3 Health and aged care professionals

Recommendations for health and aged care professionals:

a. Take opportunities for self-care. PCA's resources may be of assistance https://palliativecare.org.au/resources/self-care-matters.

b. Take opportunities for training or education in grief, bereavement and mental health distress.

c. Recognise that COVID-19 has created extremely difficult circumstances and most people are doing the best they can with more pressure and often reduced resources.

4 Consumers and carers

Recommendations for carers and consumers:

a. Recognise that as family and friends, they are the principal providers of grief and bereavement support which can be enhanced by a range of other primary and community services. Therefore they are encouraged to:

b. Seek additional information about grief, bereavement and mental health distress to be in a better position to support someone in the community who is grieving.

c. Stay proactive and find innovative ways to maintain contact and communication with people who have lost loved ones or are suffering from other losses during the pandemic.

> **Many people will carry the social, economic and psychological consequences of this pandemic for the rest of their lives. The sequelae of poverty, social disharmony and psychological stress will play out in the lives of those scarred by COVID-19. And when at some time in the future they find themselves interacting with palliative care services, their responses may well depend on how well they were supported in 2020.** [23]

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