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Bereavement support and prolonged grief: Issues for residential aged care

Issues Brief

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Key messages

- ❖ Bereavement – the loss of a loved one through death – is a normal, common human experience. Although it is associated with a period of acute suffering, most people adapt to their loss over time. For a few, however, grief can become extreme and persistent, leading to mental and physical ill health. Researchers have given this type of grief a variety of labels; here we refer to it as prolonged grief.
- ❖ Residential aged care provides a range of care options and accommodation on a permanent or respite basis for people who are unable to continue living independently in their own homes. As might be expected, outside of hospitals most deaths occur in residential aged care.
- ❖ There is an increased focus on end-of-life care and palliative care and there are wider options and considerations for residential aged care providers in terms of how they deal with death and dying (which is something they have always dealt with).
- ❖ Bereavement and its effects on staff and other residents is under-recognised and under-acknowledged. For many people in residential aged care (both staff and residents), it is a silent experience.
- ❖ There does not appear to be any particularly structured approach to bereavement support either through pastoral care programs or more broadly within the sector. There is a reliance on chaplaincy and volunteers rather than paid staff for bereavement support.
- ❖ When families and carers have unmet expectations about their loved one's death this can lead to challenges with bereavement. Ensuring carers felt supported in the immediate post bereavement phase was seen as an obvious way of mitigating future problems.
- ❖ One of the most frequently discussed unmet needs was providing people (residents, carers and staff) with the opportunity to talk about bereavement.
- ❖ There is also a need for more information about bereavement support and prolonged grief and there were several suggestions about how to target this appropriately to residents and carers.
- ❖ The role of Advance Care Planning was raised as was the importance of the wider community having conversations of this nature a lot earlier in the ageing process and well before people need to access home care packages or enter a residential aged care facility.
- ❖ One of the most consistently mentioned challenges was dealing with different cultural and spiritual beliefs about death when working with families and carers of residents. This was a particular issue for less highly trained staff working in residential aged care facilities.
- ❖ There is a high level of interest in palliative care working with residential aged care facilities as palliative care support makes it feasible for the resident to stay in their home (i.e. the facility).
- ❖ The provision of bereavement support in residential aged care is not a high priority, given the many competing demands for resources and attention.

Introduction

Bereavement – the loss of a loved one through death – is a normal, common human experience. Although it is associated with a period of acute suffering, most people adapt to their loss over time. For a few, however, grief can become extreme and persistent, leading to mental and physical ill health. Researchers have given this type of grief a variety of labels; here we refer to it as *prolonged grief*. An estimated 5-10% of bereaved individuals are at risk of developing prolonged grief: an extreme, debilitating grief that impairs functioning and mental and physical health.

In mid-2016, the Centre for Health Service Development (a multidisciplinary research centre based within the Australian Health Services Research Institute, University of Wollongong) was commissioned by the Australian Government Department of Health to undertake research into services and needs for people experiencing complicated or prolonged grief (Phase 1).¹ The Phase 2 research project has progressed several short term recommendations arising from the first phase of research with three sub-projects undertaken each responding to a separate recommendation.

This issues brief provides an overview of some of the factors that influence access to bereavement support and management of prolonged grief in the residential aged care setting. It addresses the research question:

What is the perceived need in the residential aged care sector for information about bereavement support and prolonged grief?

Residential aged care provides a range of care options and accommodation on a permanent or respite basis for people who are unable to continue living independently in their own homes.² As might be expected, outside of hospitals most deaths occur in residential aged care.

This issues brief explores how residents gain access to bereavement support, how staff and carers are supported and the relationship with primary care and palliative care in managing bereavement in residential aged care facilities. It concludes with a brief discussion of future policy considerations for bereavement and prolonged grief support in residential aged care.

Information about bereavement support and prolonged grief issues for residential aged care are likely to be of interest to the palliative care, aged care and primary care sectors.

Context

In 2013/2014 almost 37% of all deaths occurred for persons residing in a permanent residential aged care facility. With the number of people living in residential aged care rising so too will the number of deaths in residential aged care.^{1, p.112} An increasing number of residents have dementia. In 2013, 51.8% (or 87,074) of residents reportedly had dementia.³

Australia wide (not only in aged care) the number of people living with dementia was estimated to be 413,106 in 2017 and is expected to increase by 90% to 760,672 individuals over the next 20 years and 2.75 fold to 1,100,890 by 2056.⁴ In 2005, only 3.5% of all deaths (4,653 deaths) were recorded with the underlying cause / associated cause dementia, including Alzheimer's disease.⁵ Ten years later, in 2015, already 8% of all deaths

(12,625 deaths) were in this category.⁴ Consequently, deaths associated with dementia and Alzheimer's disease are predicted to increase further.

Of the 74,221 persons who died while admitted to hospital, 44% (32,686) had a palliative care-related hospitalisation⁶ and of the total number of persons who died (54,373) while in permanent residential aged care, 14.8% (8,047) were assessed as needing palliative care.⁷ In addition, there were 3,758 deaths of persons receiving palliative care by a Palliative Care Outcomes Collaboration (PCOC) participating service outside the hospital or residential aged care setting.⁸ While there is no data available on deaths of recipients of community-based aged care in 2013/14, the data for 2014/15 shows almost 5,600 deaths were recorded for recipients of Home Care packages, which are one form of community-based aged care.⁹

For residential aged care facilities the increasing incidence of dementia will have two main implications. Firstly, a larger proportion of persons with dementia will have lived in residential aged care facilities and subsequently die there. Secondly, more bereaved carers experiencing prolonged grief may turn to these facilities hoping to find support, thus generating additional demand for relevant information and/or bereavement support. Residential aged care providers should therefore be prepared to refer persons seeking help to suitable services, for example specialist bereavement counselling providers.^{1, p.111} It may also be appropriate for these service providers to review current practices to ensure that where possible staff and carers are provided relevant information about bereavement support.

Methodology

The material included in this issues brief, draws on the final report from Phase 1¹ and new findings generated through the three sub-projects of Phase 2. For example the observations about carers included in the discussion about service gaps and unmet needs is drawn from the *Issues Paper: Stakeholder views and evidence relating to bereavement support for carers*, prepared for Sub-project 3.¹⁰

Several aspects of bereavement support, pertinent to the residential aged care sector, were explored with a small sample of key stakeholders (six in total). These respondents worked in a national role either through a peak aged care organisation ('PACO') or represented large residential aged care providers ('RACP'). Each interview was recorded by the taking of notes by two researchers and these interview records were imported into NVivo for analysis. The coding used a framework approach based on the research question and interview schedule.

Perceptions of bereavement in the residential aged care sector

Residential aged care providers have always dealt with death and dying. Recently there is an increased focus on end-of-life care and palliative care in residential aged care. Attention to these issues is largely being generated within the sector through policy and research interests. It may also be an unintended consequence of the debates and information presented in the media around end-of-life choices. This is stimulating residential aged care providers to have more open conversations around end-of-life issues and what they

need to do to consider these appropriately in aged care within the context of their overall ethos and priorities.

Projects in the last decade have increased our consciousness about how we support the person who is dying; the bereavement component is in a way the next logical step for us to focus on; what is the impact on everybody around them. (RACP 2)

Several respondents felt it was unclear whether there are significant gaps in access to bereavement support in the residential aged care sector. This uncertainty is partly attributable to the many and varied assumptions that are prevalent in the media and literature about grief and older people.

I think at the moment with all the current media etc. that there's much more focus on what is a premature death, which is a difficult conversation to have in aged care because when people are staying at home longer and longer, and then they are coming into residential aged care, so one has to ask the question: 'What actually is a premature death and at what point do we start the grieving process?' (PACO 2)

It is an area of grief that is often not well recognised in our society. As noted on the CareSearch website:

The evidence as to how the very old respond to bereavement is contradictory. Some evidence suggests that they have greater capacity to deal with grief, while other evidence that it is a cause of depression.¹¹

There are concerns about over medicalising bereavement. It is important to recognise that grief and loss is a normal part of life.

I wouldn't want to minimise a reflection that grief and loss is normal and there's a pathway to acceptance and most of us get through it and find our new normal. (PACO 1)

Bereavement and its effects on staff and other residents is under-recognised and under-acknowledged. For many people in residential aged care (both staff and residents), it is a silent experience with one respondent commenting:

There's no-one to tell and no-one to observe. (PACO 1)

For older residents the experience of loss is hugely common, as is the grief that comes with that. Staff and volunteers in residential aged care are dealing with this all the time. Bereavement may not only relate to death, however, for persons entering residential aged care it can be about loss of home and displacement, loss of control, loss of function and increasing disability.

Often the trigger for coming into residential aged care is the death of a spouse, so you're often dealing with people who are already experiencing grief when they walk through the door. Then you add the grief experienced from not being at home anymore. And you have the overlay of people with dementia, people with frailty etc. People are experiencing multiple different impacts on their life. (RACP 2)

Bereavement does not receive attention because death is expected in aged care; more than a third of all deaths occur in the residential aged care setting. It is seen as an area where death occurs. Providing bereavement support to frail or older people living with dementia was seen as a specialist role.

I'm not of the view that there is no intervention necessary – I do think we are light on in aged care in working out how we provide for people having more complex reactions to grief, I don't think we're very good in having access to more beyond the pastoral care level on the ground. I don't think it's an area we've really looked at working in with counselling, and I don't know that many counselling services are all that brilliant in knowing how to come in and work with an aged care facility, with people with frailty and dementia. It's an area we could do more without medicalising it. (RACP 2)

One respondent spoke about the cumulative impact of bereavement, explaining that even if a person is not very close to a resident who dies, the fact that people are constantly dying is a reminder of one's own mortality. This is compounded by the loss of the generation the resident grew up with. For this age group, issues of loneliness arise particularly when someone feels they are the 'last' of their generation.

Residents are also affected by deaths, particularly if they have been in the facility for an extended period. (PACO 3)

End-of-life care and bereavement support were seen as multilayered issues with the metaphor of an onion used to illustrate the varied factors that emerge and the many different ways that people individually respond to loss.

And then you layer over ethnicity, religion and cultural perspectives and you've got quite a mixing pot, which is why I suspect it is getting in the too hard basket because it really is like an onion. And everyone is different – some families are pragmatic and in a resigned position that they're at the end of the journey and want to make sure that the person in care doesn't have too much discomfort, and the other extreme is almost resisting anything to do with the dying process and preparing themselves, and they can be enormously distressed. Bereavement and grieving is just so personal. (RACP 1)

Supporting residents

Supporting residents who are experiencing bereavement is perceived as a complex issue. Several respondents referred to the responsibilities of residential aged care providers to consider the broader wellbeing and needs of residents and referred to the *Aged Care Act 1997*. An object of this Act is 'to protect the health and well-being of the recipients of aged care services'.¹² In addition the *Quality of Care Principles 2014* and *Accreditation Standards – Residential Aged Care* recognise the importance of emotional support for care recipients.¹³

In some cases providing holistic support and offering a broad range of care can attract residents. Most residents access broader support services provided by the aged care facility. This usually relies on a staff member noticing someone is not themselves and this may trigger requests for additional external or internal support. Usually the personal care worker / assistant would speak with their supervisor who might be a Certificate IV worker, Enrolled Nurse or Registered Nurse, depending on the staffing structure of the facility. It is usually anticipated that this issue would then be raised during case conferencing and be noted

in progress notes. At this point a referral may be made to pastoral care. If the resident does not relate to pastoral care then liaison may occur with the family or engagement with other services such as the Community Visitors Scheme (discussed further below). It appears to be rare to bring in external bereavement services.

Facilities were perceived to have many responsibilities and operating with funding constraints. Consequently, several respondents felt that it may not be realistic to extend responsibilities even further. From a philosophical perspective, it is a reasonable expectation for aged care providers to consider the broader mental and psychological wellbeing of residents, however the challenge is ensuring they are properly resourced for that task.

From the point of view of who ought to be responsible, I think the challenge for aged care providers is they do have a lot of quite specific responsibilities under the Aged Care Act and they have to provide all of these things within a limited funding envelope. It is difficult to keep expanding the responsibilities of aged care providers with limited funding without exposing residents to the risk that care quality will diminish in order to meet this broader range of needs. (PACO 3)

Often admission to residential aged care is precipitated by a crisis and this can mean that both residents and carers are not well prepared for transitioning to care. Conversely people with a chronic illness, who have been steadily declining resulting in entry to residential aged care, may have started the grieving process some time previously.

Needing residential or home care is needs driven, it doesn't come on the wants and desires list. (RACP 1)

One respondent commented that when an older person entered a residential aged care facility there were two journeys underway:

... One for the older person themselves but also very importantly those people supporting the older person, namely their 'person responsible'. (RACP 1)

Several strategies are employed to assist residents. Some facilities conduct an emotional support assessment on admission to the facility. However for many residents transitioning into care has occurred because they are frail and unwell so other priorities overtake issues such as grief and loss.

The Community Visitors Scheme (CVS) uses volunteers to make regular visits to people who are socially isolated or at risk of social isolation or loneliness. According to the Australian Government Department of Health¹⁴ these visits can be one-on-one as well as group visits in aged care homes and one-on-one visits to home care package recipients. Referral to this scheme can be by the aged care provider, family or friends or self-referral. These volunteers are often able to assist with referral to other services, social engagement and pathways to access support if and when necessary.

Longer term residents may develop relationships with other residents and facilities try to manage this in various ways such as providing an opportunity for friends to say good-bye or ensuring that when a death occurs, other residents who may have been close to that particular person are sensitively informed about the situation.

... The thing you need to keep in the forefront of your mind is that it is very, very rare that there is an unexpected death in a residential aged care facility... It is mostly identified that there is a deterioration and this is what we are putting in place, which gives everyone time to be aware of what's going on. After the person has died, other services and support are offered. (PACO 2)

Historically, the residential aged care sector has included a large number of faith-based organisations and therefore chaplaincy services have been a primary source of pastoral care and bereavement support. These facilities provide weekly church services where it is customary to acknowledge the death of any residents. Many also hold memorial services on a six- or 12-monthly basis. It is not uncommon for pastoral care staff to be involved in funeral services for a resident. Some facilities have non-denominational pastoral care volunteers who come into the facility at certain times to interact with residents. There may be resident groups (sometimes organised by pastoral care staff or recreational staff) that provide a level of informal support to residents. Any staff within a facility can refer a resident to the chaplaincy service and residents can also self-refer if they have the cognitive capacity and desire to do so.

I would describe this as a very traditional approach or view of bereavement support as being a chaplaincy service. (PACO 4)

There is recognition of the range of services that can provide support with references particularly to palliative care services, primary care and specialist mental health services. For example, the resident's General Practitioner (GP) under the Medicare Benefits Schedule (MBS) can contribute to a multidisciplinary care plan for a patient in a residential aged care facility, prepared by that facility, or to a review of such a plan using the MBS item 731. In this case the resident may then be eligible for referral to allied health and dental care services, including for services by psychologists, mental health workers and occupational therapists. If a resident of an aged care facility is a private inpatient being discharged from hospital the resident may be eligible for a 'discharge' GP Mental Health Treatment Plan, if clinically appropriate.¹⁵

The first line of defence is counselling and chaplaincy. But there is also specialist mental health services. (PACO 3)

There does not appear to be a structured approach to bereavement support either through pastoral care programs or more broadly. Some providers have a policy that every resident and family are to be made aware of Advance Care Planning (ACP), however in practice the discussion is reportedly more often about 'death' than 'bereavement'. It is impacted by the stage the resident is in on admission, for example, a resident admitted with advanced dementia has limited capacity to be personally engaged in the conversation.

ACP is the process whereby a person's values, beliefs and preferences are made explicit so that they can guide decision making about their health and personal care at a time in the future when that person is unable to make or communicate their decisions.¹⁶ There is the potential for ACP to alleviate stresses related to caring in life-limiting illness by providing greater clarity about a person's wishes and aiding decision making at the end-of-life.

The concept of ACP is based on the assumption that when it comes time to enact a person's plan and make decisions about their care that their preferences, as stated in their advance care plan, will still be relevant. The evidence, from a systematic review, indicates that most patients' preferences 'are stable over time and after changes in health status'.^{17, p.1090} However, for a 'significant minority' of patients, their preferences

change over time, both away from and towards more aggressive treatment.¹⁷ There is an extensive research literature on ACP including individual studies investigating the impact of ACP on carers as well as ACP interventions for people with cognitive impairment and dementia.¹⁸ Martin et al.¹⁹ aimed to identify the effects of ACP interventions on nursing home residents. Studies of impacts on carers of recently placed nursing home residents were reviewed. Engaging in ACP was strongly associated with preparedness for death. Carers who reported feeling more prepared for death experienced lower levels of prolonged grief post bereavement.²⁰

Reactions from families to discussions about ACPs can be mixed. There are those who are happy to have the discussion and as a family may already have talked about this with their GP or during the course of a hospitalisation. However some families have never thought about it and find it a very difficult topic and one that they do not wish to engage in. Many providers support and promote the use of ACPs. However there can be difficulty if a resident is transferred to hospital and information from the ACP is not readily available.

A number of providers have been having quite explicit conversations around end-of-life issues and what would they need to do to consider those appropriately in aged care within the context of their overall ethos and priorities. (PACO 3)

Several respondents referred to the many pre-conceived ideas that are held by carers and family members as well as residential aged care staff about older people and end-of-life choices. One respondent spoke specifically about the assumptions in managing grief and bereavement with older persons.

It highlights one of the challenges in aged care – sometimes people just assume this is what older people want. (PACO 3)

Another view was that conversations about death and dying and the sequelae of bereavement can only occur in residential aged care when a trusted relationship has been established; this is illustrated by the following comment:

In our ‘customer journey’ we try to start preparing people for the conversation from the beginning but it is a bit like a ‘slow waltz’ – you have to judge whether or not they are prepared to lean into you or whether or not you need to guide them, or whether they are going to resist you completely... It’s difficult to touch on the elephant in the room question, ‘Have you already pre prepared the funeral plans?’ (RACP 1)

Supporting carers

There are four key time periods in the life of a bereaved person, each with its own challenges. If the death is expected, the *end-of-life* period can be demanding and stressful. The *bereavement* itself may be disturbing, especially if the death is sudden or violent (even in the late stages of a terminal illness, the death of a loved one can come as a shock, especially if there is a history of relapse and remission). In the *immediate, post-bereavement* period, ‘normal’ grief can be intensely distressing, with adverse consequences for mental and physical health. Finally, if high levels of suffering and impairment persist *beyond six months post-bereavement*, the person may be considered to have prolonged grief.^{21, p.3}

In the case of expected deaths from chronic, life-limiting illness, there are actions that health and care professionals can take that may protect carers against prolonged grief.^{1, p.3} For some residents and carers it may be useful to create an opportunity for people to acknowledge and start dealing with anticipatory grief. Facilitated conversations or family meetings, if sensitively handled, can help prepare residents and carers for the death. Documenting the patient's wishes for end-of-life care in an Advance Care Plan may relieve carers of uncertainty and pressure to make difficult decisions quickly, promote communication within the patient's family, and alleviate guilt and doubts later on. Events occurring around the time of death are likely to be remembered by carers and influence grieving. Providing accurate information to the family about what happens when someone is dying, and ensuring that the patient is treated with dignity and respect at all times, can help protect them from distress and trauma.^{1, p.51}

The involvement of palliative care services can help ensure a more peaceful and dignified death. One respondent spoke about the importance of conversations around palliation as a way to improve carers' capacity to cope with subsequent bereavement.

... There is one cohort of people who are open and happy to have the conversation about a comfortable palliation, and there's others who are just completely in denial about the fact that it will happen and they don't want to be a part of it. And when you get to that point, dependent on the family, there are so many people facilities can involve – the Primary Health Network do an amazing job with palliation, there's a lot of palliative care... (PACO 2)

When families and carers have unmet expectations about their loved one's death this can lead to challenges with bereavement. Increasingly there is a tendency for carers to forget that the residential aged care facility is home for their loved one, and many people wish to die in their home with their family around them. This may manifest in an insistence that their relative is transferred to an Emergency Department.

And what we are finding in the residential aged care space is that we are not just caring for the resident; there is a lot of caring for the extended family. (PACO 2)

When long-term residents die and their family and friends have had a long association with the facility they may wish to share information with staff and other residents about the funeral.

I've experienced families of residents who have been in facilities for some years (which doesn't happen often these days) come in and give a slide show of the funeral, hand out leaflets from the funeral – that is very common place. (PACO 2)

Several respondents discussed the guilt that many carers expressed at allowing their relative to enter a residential aged care facility and that this was exacerbated if the resident died relatively soon after. When dysfunction exists within family units or role reversal occurs with children caring for parents, stress is exacerbated.

My experience tells me that along with the grieving process often comes a lot of guilt and a lot of unmet family expectation, making the prolonged grief much more difficult to manage. (PACO 2)

For some respondents who had a role in oversighting complaints there was a perceived association between these complaints and bereavement related issues with families. This could be mitigated by encouraging residents and their family members to discuss issues related to end-of-life care through

developing Advance Care Plans/Directives, encouraging attendance at a family orientation and providing opportunities for families to connect with other families to establish support networks.

It's kind of like this really interesting thing that bereavement shows in complaints, bereavement and loss shows itself in expectations or that guilt element of whether or not they've done enough for the older person, and they do need support. (RACP 1)

Ensuring carers felt supported in the immediate post-bereavement phase was seen as an obvious way of mitigating future problems and made good business sense as it potentially reduced carer dissatisfaction and reduced reputational risk for facilities.

Even at the very end – after the person in care passes – we add in a final phase which is post care support, and that's recognising that we can't stop caring because the care recipient has passed, because actually the relationship we have with that family, we're still providing support. But it's not recognised anywhere, it's not recognised really in the standards, it's not recognised in the funding, so that's for me where the gap is. (RACP 1)

In some cases carers are allowed to return to the facility if they wish. This may be for an occasional visit as they feel ongoing connections with the facility and personnel. Options to volunteer may be suggested if appropriate. Because of the resource constraints in aged care, it appears unlikely that providers would be able to support carers and families in any ongoing way. Referral to external sources of support or suggesting options such as talking to an appropriate service, for example Lifeline, is a more realistic expectation. In some environments, particularly smaller communities where carers have broader connections, it may be possible to get other organisations to provide follow-up and support. For example a local service club may call on carers of a former club member.

The work of Sub-project 3 focused on the needs of carers and canvassed the views of peak carer organisations. The following information comes from the resulting issues paper and is based on findings from interviews with peak organisations that serve, or have regular contact with, carers of people with life-limiting illness.²¹

Provision of bereavement support in residential aged care facilities was seen by representatives of carer organisations as 'hit and miss', with no consistent approach across the sector. They acknowledged that some facilities do this very well, providing personal and compassionate care for the family as well as the client. However, the carer's relationship with residential aged care can be fraught. Carers often have complicated feelings about these institutions, especially at the point of the transition which can be a source of grief and guilt. The issues that carers raise are frequently around adjusting from having that person at home to having them in a residential aged care facility. There is a perception that there is limited support available for carers making this transition. For many carers there are feelings of guilt when a person enters residential aged care and concern that the care they experience will not be of the same quality as the care they received at home. Several respondents expressed concerns about the quality of care in general, and the capacity of residential aged care to provide any additional services, such as bereavement support.

According to respondents, one barrier to the expansion of bereavement support in residential aged care may be funding constraints and/or the business models of providers, who would need or want to 'attach a cost' to that role. There were also questions about who, within the facility, would be qualified to provide such care. With relatively few registered nurses on the staff, most day-to-day care was provided by people with

‘minimal’ training which was not likely to include dealing with family bereavement. Facilities may have a relationship with local churches, which could assist with pastoral care. There were, however, questions around whether such care would be suitable for people who do not have a religion or faith.

One respondent expressed concern that residential aged care facilities run by faith-based organisations may not recognise same-sex partners, involve them in decision making or offer bereavement support. This respondent pointed to research on the treatment of the LGBTI community in aged care, but also acknowledged some providers had set up systems to ensure quality care for people in this community.

In general, respondents believed that it was more difficult to recognise the role of the carer in a residential aged care environment. They saw a need for formal mechanisms to allow carers to be involved in the day-to-day care as much as they wished, and also to incorporate residents’ and carers’ views in quality assurance processes. One of the peak carer organisations had developed and implemented a good practice model for residential aged care incorporating policy and education around the importance of carers. This organisation provided training within facilities on how to ensure carers are kept informed and involved in service provision. This respondent saw scope to include bereavement support within this model of care in the future.

Most respondents said it was extremely important for residential aged care facilities to engage with issues around bereavement support for carers. They saw this as ‘best practice’ in residential care. Both residents and carers required access to psychosocial and spiritual support. Such access could be improved and promoted by ensuring these components of care are included in any funding models and mechanisms, so that facilities are enabled – and obliged – to offer a broad range of services including bereavement support.

Supporting staff

Any treatment for prolonged grief needs to target the distinctive symptoms and functional impairments associated with the condition. Specific attention is required to the person’s distress around loss, separation, identity and meaning in life.^{21, p.39} Specialist treatments are more effective than generic psychotherapy approaches.^{22, 23}

In Australia, the main providers of specialist treatment for grief-related issues are bereavement counsellors. They may be employed by palliative care services or community-based not-for-profit organisations or work in private practice, and typically have qualifications in social work, nursing, psychology or similar, with extra qualifications relating to grief counselling and intervention. Other important groups of providers involved in bereavement support are psychologists, social workers and nurses.

Staff do often find it challenging when residents pass on and staff do have issues with death, but there is an assumption they will move on. (PACO 3)

Helping staff to understand cultural differences in how people respond to death is challenging.

We could do better for staff (in terms of bereavement education) – some other providers may be more systematic than us, while others may not do to the level we do. However, I don’t think necessarily that we need a whole new infrastructure to make improvements, it’s partly about making sure staff are accessing the help when they need it. (RACP 2)

There is a reliance on chaplaincy and volunteers rather than paid staff for bereavement support. However several respondents recognise that there could be more training for staff in relation to bereavement. The Aged Care Channel was seen as a useful resource with some good programs. Although a commercial entity – some individual components are supported by government funding – use of the channel has not been mandatory for staff.

Personal care workers and staff may be supported by external providers. The example provided related to residents with cognitive impairment. Depending on how people respond to bereavement it could trigger interaction with services such as the Dementia Behaviour Management Advisory Service.

One respondent also spoke of the importance of allowing staff who had been close to a resident to have some time to process their death. Sometimes this might be simply by providing time and space for them to speak with their supervisor or an experienced member of the team. Some organisations permitted staff to attend the funeral of residents in work time.

Staff get to talk to each other, they get to talk to a good senior team, and if they feel that they need extra support that is always offered. Most places have counselling support which is provided by the facility or the local palliative care team would speak to the staff. And there is a lot of education that's done with staff throughout the year. (PACO 2)

Another perspective provided related to the 'balancing act' required to ensure effective staff/resident relationships.

If a resident is close to a staff member, the staff member may need some time off after death. It also raises the issue of how close staff should get to residents. This is a bit of a balancing act as quality care relies on effective staff/resident relationships however if staff and residents are too close this can adversely impact on the operations of the facility. (PACO 3)

Some providers use an Employee Assistance Program for provision of counselling support. This is a free and confidential service for any staff experiencing difficulties. In some cases staff support is provided by the pastoral care team.

We are conscious that we need to do things in more of a systematic fashion in the area of staff who are not coping with constant death. We're developing a new people and culture strategy – looking at support structures to make sure staff are doing okay, which may well be more than pastoral care, perhaps formal bereavement counselling or beef up information about dealing with loss and grief and more formal education. (RACP 2)

Service gaps and unmet needs

The evidence suggests that the lack of carer and community support for persons affected by prolonged grief is a significant unmet need – people in this situation appear to benefit from being able to speak with others going through a similar experience.^{1, p.70}

One of the most frequently discussed unmet needs was providing people (residents, carers and staff) with the opportunity to talk about bereavement. This was expressed as an issue at the level of residents, facilities

and more broadly for society as a whole. There was a general view that there are conversations that should happen in the community well before someone gets to residential aged care.

The biggest issue we have in the sector is in beginning that whole conversation about what is an unexpected death, because you would've seen all the media about influenza etc. There's been no talk about what that person's comorbidities were (e.g. did they have emphysema, diabetes etc.). There is not enough 'real' conversation. I've had a call from a member recently who had a resident with end stage dementia (no longer walking, no longer feeding themselves, no longer continent) and a difficult family – the resident is passing away and the family has turned around and asked for the progress notes for the whole stay at the facility, because they want to know why their family member is passing. Many people don't understand dementia is a terminal disease. (PACO 2)

If you consider from a societal perspective, we have a very lacking conversation about the dying process. We put a lot more effort into helping mothers prepare for the birthing process and celebrate it, but we're not quite there yet in recognising that equally in how we help someone leave this world should be just as celebrated and supported. (RACP 1)

There appears to be a need for more information about bereavement support and prolonged grief and there were several suggestions about how to target this appropriately to residents and carers. On entry to a facility most residents are provided with a 'Welcome pack' that could include information about bereavement support. This was seen to be appropriate because for many new residents transitioning to a care facility triggers feelings of loss. This could be because loss of a partner has led to their admission or relate to loss of their home, former friends and community connections. Another way of presenting this could be through developing a toolkit or package of information for providers/facility managers which would assist with the management of bereavement. This might comprise reference materials to help train and educate staff as well as sections on bereavement for residents, families and staff. A toolkit or information package could also include management strategies, tools and approaches. It may be possible to work with peak aged care organisations to disseminate this resource to their members, however this would probably require early engagement from the outset of resource development. It was also suggested that the Australian Aged Care Quality Agency might also be able to support dissemination.

Considering the demands on facilities, a mix, a range of approaches is needed for a toolkit. A package should include self-education, an online component... training modules (for chaplains etc.). Adults have different learning styles / approaches, so a suite of written, online and face-to-face materials would be appropriate. (PACO 4)

The use of structured information that was developed particularly for the context of the residential aged care sector was suggested.

I'm always a believer that a formalising of an understanding that people may have gathered instinctively through their operations can assist in developing a systemic response. I mean I think if you talk to people in aged care they would know from observation and experience if nothing else, that some people struggle with bereavement and prolonged grief and it would be useful to have more structured information available to them which then assists in developing management and response strategies. (PACO 3)

Other suggestions were using email, flyers and brochures within the facility to increase resident and family awareness of bereavement support options. The important role of families and the value of residential aged care organisations building positive relationships with families so they felt informed about the care of their family members was raised by several respondents. A pertinent comment included:

It's about identifying your families. I would suggest the target group is the families, not the residents. (PACO 2)

The role of ACP has been previously discussed. This issue was raised on numerous occasions and the importance of the wider community having conversations of this nature a lot earlier in the ageing process and well before people need to access home care packages or enter an aged care home. The absence of nationally standardised documentation for ACPs or Advanced Care Directives (ACDs) was flagged as there is a perception that every state if not every facility uses something slightly different. A streamlined approach for residential aged care facilities wanting to support residents to develop an ACP / ACD would be valuable.

There were several references about increasing awareness of end-of-life issues in a variety of settings. This included access to bereavement and prolonged grief support. However, improved awareness is only useful if there is a means for people to act on this awareness or a referral pathway.

Raised awareness only works if there's something to go to. (PACO 1)

Historically, there has been limited access to counsellors and psychologists in residential aged care; however one respondent felt that this was changing. There has always been good access to chaplaincy services particularly in facilities that are run by faith-based organisations.

One of the most consistently mentioned challenges was dealing with different cultural and spiritual beliefs about death when working with families and carers of residents. This was a particular issue for the varying groups of staff, particularly those less highly trained and working in residential aged care facilities. One respondent advised that they had managed staff concerns about different cultural practices through referring to the *Residents' Charter of Rights and Responsibilities* which reinforced the right of residents to make choices that were appropriate for them, despite the values and views of other residents or personnel.

Indigenous residents were perceived to have special needs in terms of bereavement support. One organisation supported their facilities to engage with local community elders and through this established relationship they were better able to provide culturally appropriate support at the time of death. Through cultural awareness activities facilities were able to better understand why large numbers of family members and kin would visit after death to pay their respects to the deceased and could prepare for these increased numbers of visitors.

One of the most often reported unmet needs was information that could be used to support staff. The staff working within residential aged care facilities come from diverse backgrounds and many were unprepared for the reality of death or may not have the life experience, emotional intelligence or skill set to be able to cope with death. For the most part respondents reported that staff managed reasonably well; however improving the capacity for staff to understand cultural differences relating to how people respond to death would be of particular value.

Staff understanding is useful. If you give people structured understanding of what the issues may be and how to identify signs, then they can direct to specialist support. A basic understanding of bereavement would be useful, but not all staff need to be counsellors. (PACO 3)

Relationships with palliative and primary care

A recent literature review¹ did not identify any clinical guidelines specific to prolonged grief, but recognised the *Bereavement Support Standards for Specialist Palliative Care Services*²⁴ as the best source of current evidence about the management of bereavement-related health issues. These guidelines were based on a systematic review²⁵, consultation with experts, the results of a survey of Victorian palliative care services and adaptation of previous guidelines. They are targeted at palliative care services and consequently do not include information specific to primary care or residential aged care. However, they do recommend a multidisciplinary assessment process at intake into palliative care, including assessing the carer's risk of prolonged grief. Those at increased risk would be provided with greater support in the period immediately before the death, and follow-up at around six months after bereavement. At this point, people may be offered more comprehensive assessment and links to community-based supports or, if warranted, referral to specialist treatments.^{21, p. 7}

The role of carers as both providers and recipients of care is a guiding principle of the draft *National Palliative Care Strategy 2017*.²⁶ The National Strategy affirms palliative care is a person-centred approach provided in a range of settings by diverse service providers. The document notes that not all patients will require specialist palliative care and there is potential to increase the capacity of other health professionals, including those in primary care, to take a palliative approach. One priority is assessment of needs across all settings, including assessment of carer and family needs.²⁶ The Australian Commission on Safety and Quality in Health Care defines specialist palliative care as:

Services provided by clinicians who have advanced training in palliative care. The role of specialist palliative care services includes providing direct care to patients with complex palliative care needs, and providing consultation services to support, advise and educate non-specialist clinicians who are providing palliative care.^{27, p. 35}

According to the *National Palliative Care Standards*, primary care providers play a key role in delivering the palliative approach, which aims:

... to improve the quality of life for individuals with a life limiting illness, their caregiver/s and family. The palliative approach incorporates a concern for the holistic needs of patients and caregiver/s that is reflected in assessment and in the primary treatment of pain and in the provision of physical, psychological, social and spiritual care.^{28, p. 11}

These standards are under revision and the 5th edition is scheduled for release in 2018. The final draft, highlights the importance of caring for the carers (Standard 3) and grief support (Standard 6). Adhering to these standards may improve support for bereaved carers and/or facilitate early access to treatment.²¹

Grief and bereavement present specific challenges which are different from those associated with depression, anxiety and traumatic stress (although these may also be present as comorbidities). This means

that generic treatment models such as Cognitive Behavioural Therapy (CBT) are less suitable. It is highly desirable that people experiencing complicated grief / prolonged grief have access to specialist bereavement services wherever possible.^{1, p.124} For example, those who die in aged care settings may receive the palliative approach, but there is likely to be less 'institutional support' for carers as part of this service delivery model, compared with specialist palliative care.^{10, p.16}

For most respondents palliative care was perceived as an issue that generated much more interest than bereavement support. There was a view amongst respondents that the sector is more alert to palliative care issues.

There are often discussions about how links between aged care, primary care, palliative and acute care can be improved. It's quite variable; across different providers and different organisations - some aged care facilities do palliative care really well. (PACO 4)

Palliative care is often managed in the facility in consultation with GPs. Some residents will be transferred to hospital to die but this is usually not to palliative care. A recent study²⁹ has explored in depth GPs' experience and interest in palliative care. A key finding was that the majority of GPs are interested in learning more about palliative care; however, the different settings for palliative care, including residential aged care facilities, place very different demands on general practice, and have different ramifications for best practice palliative care.^{29, p.6} Better connections with local specialist palliative care teams are valued and often required for GPs to feel comfortable managing palliative patients.^{29, p.52}

There is a high level of interest in palliative care working with residential aged care facilities as palliative care support makes it feasible for the resident to stay in their home (i.e. the facility) until the end. Several respondents were well informed about the interaction facilities had with local palliative care teams. For example these palliative care teams would come out and meet with the family and talk to them about the dying process and what to expect. The relationship with the local palliative care team was seen as one of the most important relationships for the facility. Another respondent explained the importance of a really good clinical manager who is confident in themselves, and has the skill set to build up a relationship and rapport with the doctors visiting the facility but also with the palliative care outreach team from the local hospital. This person will also support carers and families through the palliative phase as they are able to sit down and explain what is occurring and why certain actions are (or are not) being undertaken.

If the palliative care team has got confidence in the fact that the clinical care coordinator (or whatever name you give that role within your facility) has a good approach to palliation and puts all reasonable measures in place and offers support, they will bend over backwards. I would have monthly or weekly contact with the palliative care team, dependent upon the circumstances. Again, it comes down to knowing the families – you instinctively know who is going to need more support. (PACO 2)

For many facilities there may not be a clinical manager with this expertise so there is high reliance on the palliative care team and GP to manage care. Issues in accessing appropriate pain relief for residents was also raised as facilities were reliant on medical officers to prescribe appropriate medications and having staff on duty with the appropriate training to administer them.

All of our homes are connected to community-based palliative care teams. We have a whole system or approach around supporting people because you've got this nexus from a quality standard / perspective which is quite important, and that is managing deterioration versus managing a palliative

care pathway. As a provider you would know that you can't mix those two things together. You have to be quite clear about actively supporting if that's the person's (and family's) wish. (RACP 1)

Staff in residential aged care facilities may not necessarily recognise when a resident is entering a palliative phase. For direct care staff who have limited training caring for someone at the end stage of life it can be challenging as they may not have any prior experience of palliative care or death. These personnel need to be supported by senior staff and some facilities allow them a choice about whether they feel ready to provide further end-stage care.

I think connections with the palliative care sector could be very helpful, the difference there of course is that I think everybody understands when you or a loved one enters a palliative care facility that you are rapidly approaching the end of your life. This isn't necessarily the case in residential aged care, that isn't the understanding of everybody. (PACO 3)

Reference was made to the Decision Assist project, an initiative to improve end-of-life care in residential aged care. This program will be superseded by the new End of Life Directions for Aged Care (ELDAC) project from 2018.³⁰

I think we are seeing more and more facilities available (e.g. allied health, primary care) that can help support the residential aged care facility. It's a matter of building on those networks. (PACO 2)

In summary, there are lessons to be learned from the palliative care sector to support staff with their own bereavement, and bereavement of families, as it is palliative care's core business.

Engagement with primary care was reported as variable. Some facilities have quite strong connections with general practice and others do not.

I think there is always a need to better improve the interactions and the connectivity between primary care and aged care...in some areas it works much better than others...opportunities to look to have a greater level of connectivity between these bodies can only be beneficial particularly for the outcomes for residents. (PACO 4)

For instance, in a recent survey of Australian palliative care services approximately 71% of these services indicated they work with residential aged care facilities generally (not specifically in terms of bereavement support). One respondent noted that within their community program, social workers work with residential aged care facilities to build capacity and assist them in setting up their own bereavement reviews and follow-ups. A little over half (55%) frequently work with primary care to provide support for bereaved persons. In addition, it is likely that some additional services may work with primary care regularly or as necessary.³¹

Discussion and conclusion

Future policy considerations for bereavement and prolonged grief support in residential aged care can be clustered into two major groups: issues for residential aged care providers and issues for the broader health and aged care system.

Several issues are best addressed at the level of the provider, such as developing local policies to guide access to bereavement support; improving the capacity of staff to deal with bereavement through providing education and resources and enhancing cultural awareness; establishing clear referral pathways for residents requiring bereavement or prolonged grief support; and continuing efforts to ensure families and residents consider ACP.

We've talked about staff, volunteers, and consumers. I'd want the policy to bring them all together – it should have support for staff, allow for volunteer involvement and allow consumers to have a voice and be able to get support. (PACO 1)

There will be ongoing need for capacity development of the workforce as care for those with prolonged grief appears to require specialised skills and considerable experience of bereavement support.

Education is paramount. (PACO 2)

There is interest in managing behaviours in residential aged care primarily because of the immediacy and impact of these behaviours. Responding to emergent behaviours is likely to be the first response rather than thinking whether this is behaviour relating to bereavement. Similarly, for many facilities priority is given to physical care needs over psychological wellbeing.

This partly reflects instinct and partly reflects the regulatory environment, for example, care workers will tend to prioritise treating wounds or avoiding pressure sores over exploring a person's psychological wellbeing and I think that is actually reflective of the regulatory regime. (PACO 3)

Whilst you may have a model of care, it doesn't really matter because ultimately it's the journey of that one person and it's their experience. (RACP 1)

Respondents interviewed in relation to carer issues had mixed views on the potential for residential aged care facilities to serve as another pathway into bereavement support for carers. Although most felt it was an important service that facilities should provide to carers, they expressed doubts about the capacity of the sector to identify and respond to carers' bereavement needs.¹⁰

Everything comes back to relationships; being authentic, supporting. (RACP 1)

A greater shared understanding of how people access bereavement support can result from the documentation of referral pathways. Although bereavement support was considered an essential element of palliative care, other pathways into support are also required. Not all carers are in contact with palliative care, and some who are may not want to return to those services for bereavement support. Carers may self-refer into bereavement support or they may receive a referral via primary care. Respondents made a strong case for the need to strengthen these alternative pathways.^{10, p.23}

At a higher level, policy direction is best provided through existing mechanisms such as the *Accreditation Standards – Residential Aged Care* which are detailed in the *Quality of Care Principles 2014* and assessed by the Australian Aged Care Quality Agency. The Australian Government Department of Health is co-designing with the sector a draft single set of consumer-focused quality standards.³²

One respondent from a peak aged care organisation explained their policy advocacy role was about seeking the best outcomes (in terms of care and quality of life) for all older Australians and broadening the focus of care providers to encompass all aspects of quality of life.

For me, bereavement fits into quality of life. It's an individual thing so it is hard to make a system change approach. (PACO 1)

If bereavement support is couched in terms of quality of life it is more likely to be perceived as an important issue for peak aged care organisations. The reality for most respondents, however, was that provision of bereavement support in residential aged care is not a high priority, given the many competing demands for resources and attention. Certainly respondents could not recall any requests from members for assistance with bereavement support. On occasions members may ask for support in education and training or sector development in relation to priority issues, but this had not occurred in recent memory in relation to bereavement or prolonged grief. Providers indicated that they would more commonly look to chaplaincy services for help with bereavement issues rather than a peak aged care organisation.

At the outset I said it is not on top of the list of priorities. There are more immediate and obvious care needs. (PACO 3)

For most CEOs who are members this issue would be low on their radar... given the hectic pace of the reform agenda. (PACO 4)

It's down on the list because we're in a 'washing machine' at the moment, we've got a lot going on. Gearing this business for consumer direction, changing care models, building capability, leading through change. It is the most adverse environment for aged care I've seen in 25 years. (RACP 1)

There was recognition however that for residents themselves, bereavement and prolonged grief support may be perceived as a priority.

It's not as big an issue as dementia care, or palliative care more broadly, but certainly on the ground it's a real issue for people on a daily basis. (RACP 2)

Issues for the broader health and aged care system included the resource constraints upon providers (this was raised consistently) and the longer-term sustainability and capacity development of the workforce.

People are managing palliative care within facilities at the moment and there are resource implications as this is not included within the funding model. (PACO 3)

Overall a bit more awareness of the existence, impact and perhaps particularly important the prevalence of bereavement or prolonged grief would be useful. (PACO 3)

The conclusion from this synthesis of the respondents' feedback is that government policy can support appropriate care for older Australians living in residential aged care in several ways:

- Encouraging holistic care for residents through the existence of appropriate standards may ensure a common understanding of the needs of older people.
- Supporting a more systematic and coordinated approach to how providers work with families and residents to consider end-of-life choices.
- Strengthening the capability amongst residential aged care staff to appropriately refer residents requiring bereavement support through the development of resources, education and training.
- Recognising that residents who are experiencing prolonged grief require specialist expertise and care.
- Acknowledging the additional pressures for bereavement support arising from the increasing numbers of older Australians with dementia who are residing in residential aged care and families facing grief and loss potentially some time before bereavement actually occurs.
- Encouraging interested GPs, and providing appropriate incentives, to become more involved in palliative care within this environment. The relationships between providers and primary care are crucial to the ongoing welfare of all residents.
- Maintaining effective working relationships with local specialist palliative care services and strengthening the capacity of these palliative care services to inform, educate and assist their colleagues in residential aged care can only be of benefit to residents, carers and the residential aged care staff.
- Advocating for a more streamlined approach toward ACP and ACD may better assist residential aged care facilities wanting to support residents through this process.
- Reviewing funding models and mechanisms to ensure that residents and carers receive appropriate access to psychosocial and spiritual support so that facilities are enabled – and obliged – to offer a broad range of services including bereavement support.

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