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ORIGINAL RESEARCH

Passing on wisdom: exploring the end-of-life wishes of Aboriginal people from the Midwest of Western Australia

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ABSTRACT:

Introduction: Indigenous patients with life-limiting conditions have complex needs, experience reduced access to and uptake of treatment, and have lower utilisation of palliative care services than the general population. Lack of understanding of the role of palliative care and poor availability of culturally safe specialist palliative care services impact on Indigenous people's end-of-life decision-making.

Methods: To understand Aboriginal people's perspectives and experiences at the end of life, an exploratory study using facilitated group discussions in community settings in a region of Western Australia was undertaken. Local Aboriginal people were engaged to talk frankly about their wishes and concerns around end of life. The community consultations included two meetings at the local Aboriginal corporation, an evening meeting for invited community members, a meeting at the local Aboriginal community controlled health service and two further meetings of community members at local gathering places. These were supplemented by the analysis of previous in-depth video-recorded interviews that were undertaken with Aboriginal people with cancer reporting on their concerns and wishes.

Results: The community consultations raised considerable discussion about wills, where to die, burial versus cremation, and the cost of funerals. Possibilities emerging from participants' reflections on the issue were public celebrations to honour someone's life, the potential use of sorting cards to help discussions about end-of-life personal wishes, and interest in making and decorating coffins. Aboriginal people with cancer raised similar issues, and focused on avoiding family disharmony by ensuring their family were aware of their end-of-life wishes.

Conclusion: Within a safe space, Aboriginal people were happy to talk about end-of-life wishes, although certain aspects of death remain contentious. Sorting cards, ceremonies, education and care roles involving Aboriginal people offer potential means for effectively engaging Aboriginal people in preparing for death and dealing with grief.

Keywords:

Aboriginal, Australia, cancer, community, end of life, Indigenous, palliative care.

FULL ARTICLE:

Introduction

Aboriginal and Torres Strait Islander (hereafter respectfully referred to as 'Aboriginal') people are well known as having premature mortality, with a substantial proportion of the life expectancy gap caused by chronic diseases. With the ageing of the population and the high burden of chronic and terminal diseases among Indigenous populations, the need for support at the end of life is increasing[1].

The palliative approach aims to reduce unnecessary suffering by treating, relieving and reducing adverse end-of-life symptoms including the provision of emotional support to patients and their families. Palliative care considers people's physical, emotional, psychological and spiritual needs and aims to achieve better quality of life for individual patients, carers and families who are dealing with terminal illnesses and end-of-life processes[2,3]. However, while existing data on service use is limited, palliative care is thought to be underutilised by Aboriginal families[4], with data from the Australian Institute of Health and Welfare (AIHW) indicating that the rate of palliative care separations (where palliative care was a substantial component of the care provided and the clinical intent was palliation during part or all of the hospitalisation) for Aboriginal Australians is higher than for non-Aboriginal Australians but that their length of stay is shorter[5]. Supportive and palliative care at the end of life can help alleviate stressors in caring for a terminally ill family member[6] and assist families to deal with some of the grief and stress associated with death[6,7].

Lack of understanding of the role of palliative care, poor availability of palliative care services, other serious health problems, family issues, cultural incongruity, geography and service distribution may all be reasons why end-of-life care is underutilised[6]. As identified in a recent systematic review on palliative care service delivery to Indigenous peoples in specified countries, there is little research on end-of-life issues for Aboriginal Australians other than that conducted in the Northern Territory[8]. The work of McGrath et al[9-12] and Carey et al[13,14] identified distinctive requirements, values and priorities of Aboriginal people in relation to end-of-life care and decision-making[4,11,15-19]. Much of the research around the end of life has focused on what health services need to do to meet the requirements. However, it is important that, when delivering services in a cross-cultural context, there is a deep understanding of people's underpinning beliefs and wishes as part of understanding how services could respond to those needs. Fundamental to effective palliative care service delivery is an informed health sector that understands the issues and concerns of patients and their families in their larger sociocultural context. This will enable provision of appropriate care that focuses on quality of life for people with a life-limiting illness, and their families.

The present article reports information collected in two distinct ways. The first component was a scoping study based upon a series of workshops undertaken in community and professional settings in the Midwest region of Western Australia, at sites located more than 400 km north of Perth, the capital of Western Australia. The aim was to engage local Aboriginal adults who were living and working in community settings to talk frankly about their wishes and concerns around end-of-life issues, and to distil key themes and approaches that could inform wider discussions and interventions. These participants were a mixed age range and were 'healthy' – that is, not selected because of illness. Information from these community consultations was supplemented by analysis of video interviews undertaken with Aboriginal people with cancer, which often included discussion of their thoughts and wishes related to end of life. This approach enabled broader insights into end-of-life issues for Aboriginal people and included people with health conditions, which meant they were more directly confronted by their own mortality.

Methods

Component 1: Deliberative discussions on end-of-life care

Team: The team included a local Aboriginal woman who had grown up in the region and was widely known and respected. Her role was instrumental in the engagement of community members. She had been involved in the project described in component 2, in which local Aboriginal people with cancer were video-recorded as they spoke about their experience of cancer – conversations that included end-of-life care issues. Other team members included two researchers with many years of experience working with Aboriginal people and of Aboriginal people living with cancer. The team collaborated with two people with a background in performing arts, who helped to facilitate public forums. They had considerable individual and collaborative experience in using creative processes to facilitate conversations about end-of life and after-death care services, such as funerals; other ceremonial services; and providing guidance, counselling and support for a dying person, their family and the broader community.

Approach: Several team teleconference discussions were held prior to meeting with the local Midwest community. These enabled information sharing and identification of potential local sites suitable for discussion groups. Invitations were developed and distributed, inviting the community with an interest in death and dying to attend a forum to discuss issues around death and dying. Local service providers were identified by the local researchers. A local Aboriginal person with first-hand knowledge of the community was a key team member, with engagement of Aboriginal stakeholders and community elders largely driven by her. To encourage Aboriginal participants, meetings occurred in places that were convenient and safe for local Aboriginal people.

The external facilitators demonstrated sensitivity, competence and experience in dealing with what is often considered a difficult and challenging subject[20]. Their role assisted in instigating and facilitating difficult conversations. Underpinning the project was an understanding of the importance of conversation in exploring deep beliefs and possibilities for dealing with death and dying. The facilitators used an arts-based approach built on the concept of 'holding space' (a conscious act of being present, open, allowing and protective of what another needs in each moment – 'being there' for another person)[21]. This requires listening with awareness to participants and validating their experience without judgement, and without trying to 'make it all ok'. The facilitators' role was to be present, reflective, allow the free flow of ideas, knowledge, tensions and dissonances, and to be attentive to what was said and to the unspoken.

Settings and participants: All meetings were paced to allow opportunities for small and larger group discussions in a safe space, to enable those present to contribute to the extent that they chose. Formal and informal discussions occurred within larger meetings.

Community There were four meetings in community settings, three with high Aboriginal engagement, including one at a Men's Shed (a safe and friendly environment where men can meet and socialise) in a town 100 km from the regional city and two at an Aboriginal community resource centre. Because the fourth site did not include Aboriginal participants, it is not included in any further analysis.

In addition to the community meetings, facilitators and researchers had an informal lunch meeting with local Aboriginal artists in a large meeting room at the authors' workplace. This approach recognised the facilitators' experience of art-based approaches in ceremony and creating memories to honour ancestors, family and friends who are dead. Although attendees at meetings may have chronic diseases, they were not selected for any health condition or invited because of any particular interest expressed around end-of-life issues.

Public A group public forum was held for the broader community to engage in conversations about death and dying. Invitations were sent to key community members, and the event attracted interest from a diversity of people including those working in the funeral industry, palliative care volunteers, chaplaincy, community and arts sector, workers in palliative care and care for the aged, health science students and health professionals involved in service delivery and education. Two aspiring death doulas (who assist during the dying process) were among the attendees. Group work included use of Go Wish, a sorting card game to help users start a conversation about end of life in which they can express their wishes in life and at the end of life; paper and pencil activities; and discussion of some written material pertaining to emotional wills, in which a person expresses matters important to them regarding their legacy, beliefs and achievements.

Health service providers Team members visited a number of sites to discuss issues around death and end-of-life choices. These included the local Aboriginal community controlled health service, a regular professional development forum attended by a multidisciplinary health team, the regional palliative care team and the cancer centre at the regional hospital.

Synthesis of themes: Debriefing and extraction of key issues and themes followed each meeting. The findings reported consolidate distilled perspectives, representing the consensus of the facilitators and researchers (including the local Aboriginal researcher) based upon notes, observations, discussion and refinement of draft themes. Where there were discrepant views among participants, these are highlighted. The triangulation of data from both community and other professional meetings revealed considerable commonality in uncertainty, conflict and concerns that Aboriginal people face dealing with death.

Component 2: Analysis of videos of Aboriginal patients with cancer

As part of an earlier research translation activity, members of the team had, with signed consent from participants, made a series of videos of Aboriginal people with cancer, primarily for educational purposes. The interviews were free-flowing and loosely based on an interview guide that allowed for exploration of end-of-life issues. Participants were recruited by a local Aboriginal woman and team member. There were 10 Aboriginal participants in total: eight people with cancer and two with women who had played a major role in an Aboriginal cancer support group that had supported Aboriginal people as they approached death[22]. Only one participant was not a resident of the region where the community consultations occurred.

All videos were reviewed with respect to end-of-life wishes, with relevant comments identified and transcribed. Key themes were identified by familiarisation with the data, generating codes and identifying and refining themes based upon discussion among the team[23].

Ethics approval

The project was undertaken as part of a broader research project to examine the distinctive needs of Aboriginal people with cancer, including issues around end-of-life care, for which ethics approval was granted by the Western Australia Aboriginal Health Ethics Committee (WAAHEC Ref 483) and the University of Western Australia.

Results

Component 1: Discussions on end-of-life care with community and service providers

The format of each gathering was determined by the nature and make-up of the group, and the physical surroundings. The neutral outdoor meeting space at the Aboriginal community resource centre was hospitable and conducive for the conversation, with evident appreciation of taking the discussion to a site where people regularly gathered and talked. Generally, having informal and personal conversations while waiting for the full group to gather, before the start of the group conversation, gave time for the facilitators to land gently and gain their bearings. These informal exchanges provided insights as to how to introduce the conversation topic.

Talking about death: At the community meetings, the men were initially reluctant to speak about death because there was 'too much trouble' surrounding this issue. Aboriginal relationships and kin ties are complex and one death in a community was seen to affect many people. As there are many deaths, grieving can seem like a constant state. However, when questioned further, all agreed that deaths in the community often became the cause and focal point for feuding and arguments. Strong beliefs existed regarding what should occur after a person's death and many were concerned that the 'right thing' is not always abided by or even agreed on by everyone. Some expressed the strong belief that a person should be buried whole and at their rightful resting place, although where that rightful resting place might be was often a cause for dispute. Even when a person had made their wishes known as to their final resting place, arguments could still occur if others, who might claim a more 'respected' position in the community, deemed that those wishes were not culturally appropriate.

Another reason given for not speaking openly about death was the fear of 'jinxing' oneself or one's loved ones. The reluctance to talk about death was understandable if they believed that by avoiding talking about it they could keep death further away, concerns previously reported for Aboriginal people[24]. As one Aboriginal leader noted, 'people are closely connected in the Aboriginal community and one death affects many, and there are many deaths'. However, reluctance to speak about death was also often based on sensitivity to family troubles and feuding ('smashing up' (fighting)), which could be exacerbated by differences of opinion regarding financial responsibilities and level of care for the loved one before and after death.

The meeting with community artists provided the opportunity to show audio-visual and website material that enabled insights into celebrations around approaches to death that occur elsewhere in Australia. This promoted rich discussion. Based upon the work of the lead facilitator in a previous project, Honouring Our Dead, there was resonance with the ideas of creative, artistic and professional collaboration to honour loved ones in a place and manner appropriate for the person. The group recognised the need for an outdoor area, community cultural development and rituals that are appropriate and meaningful. The artists reviewed the Go Wish cards to help facilitate discussion about priorities and wishes. The cards encourage participants to talk about their end-of-life care and wishes, what is important and why, by sorting them into piles of three categories: 'very important to me', 'somewhat important to me' and 'not important to me'. This allowed participants to talk about their wishes and preferences for care at the end of life. The basis for this is the idea that talking can reduce stress at the time of a serious illness and help families understand a person's preferences. None of the participants had previously been introduced to the use of such card sorting in reflecting on priorities around values and dying. Areas that were trigger points for particularly lively discussion included wills, funerals and burial versus cremation.

Making a will: Emerging from all consultations was the issue of making of wills for Aboriginal people in Western Australia, which had been a matter for concern since the *Aboriginal Affairs Planning Authority Act 1972* ruled that the estates of those Aboriginal people dying intestate (without a will) be administered by the Public Trustee. To Aboriginal people, this ruling was seen as racist and demeaning when the rest of the Australian population was not bound by such a law. After much work in the mid-2000s and many submissions to the minister, the ruling was repealed in 2012.

A local agency whose role had included providing social and legal support for Aboriginal people had run a project for 2 years (2012–2014) called the Aboriginal Wills Project, with funding support from a large legal firm. The focus of the project had been to educate Aboriginal people on the importance of will making and to assist them to make a valid will. This was based upon the understanding that a valid will can proactively minimise conflict within the will-maker's family by making clear their wishes regarding issues such as place of burial, funeral arrangements and the passing on of special property such as artworks, music (and their associated copyright), artefacts and other unique personal items. Because the project was a free service, it had aimed to provide Aboriginal people with information on and assistance with things such as superannuation, life insurance and funeral plans. It also provided assistance with advanced health directives, enduring power of attorney and enduring power of guardianship.

According to the director of the agency, many Aboriginal people used the service during the time of its operation but unfortunately the project was discontinued due to lack of ongoing funding, rather than to lack of interest. The Aboriginal community and the agency were keen to re-launch the project if funding became available.

Where to die: Most of the participants seemed to assume that people would die in hospital rather than at home. Of note was that cancer care and palliative care were associated with imminent death. Those who knew about the local hospice held it in high regard and cited this as their preferred option. Dying supported by extended family and where they would feel free to do 'traditional stuff – playing music, singing' was important. 'Taking me back home to my own country' to be buried on country was noted by some as important.

Organ donation: Organ donation was not generally discussed but was raised in the professional development academic meeting. The topic proved to be confronting to an Aboriginal attendee at the meeting, who was horrified when asked if she would consider donating. Other participants reported having witnessed similar reactions. Some acknowledged the importance of raising awareness about organ donation in Aboriginal communities given the high numbers of Aboriginal people receiving renal dialysis who could benefit from an organ donation. Although the DonateLife (Australian Government Organ and Tissue Authority) website has a range of resources designed for Aboriginal communities, these were not known to the participants.

Cost of funerals, funeral plans, funeral directors: Funeral costs and culturally respectful funeral industry practices arose as significant concerns. There was concern regarding the cost of funerals. The local Aboriginal community controlled health service provided support to families following a death, and the CEO was a strong advocate for funeral insurance or pre-paid funeral plans. A local funeral parlour well known to the Aboriginal community facilitated loans to enable borrowing between $4000 and $25,000 to cover funeral costs, repayable over 18–60 months. It was difficult to see how many Aboriginal families could meet the criteria to obtain such loans or meet all the payments.

Another funeral service was criticised by some community members as the directors used Maori language and concepts in the funeral ceremony. Culturally focused Aboriginal community members reported that their approach clashed with their own Aboriginal values. However, this funeral service advertised helpful information and options for a full range of services including the least expensive funerals, funeral insurance and bonds.

A final resting place or scattering to the winds: People's wishes relating to being buried or cremated provoked the most discussion, with many participants stating emphatically that they wished to be buried. However, there seemed to be generational differences, with younger people being open to cremation and older people more emphatic in stating that the 'only way' is burial. Those with strong views on burial also had strong views regarding which cemetery to be buried in. Following discussion on cremation and the reasons for the distaste for cremation, it appeared that some people conflated cremation with 'scattering to the winds', a kind of dispersal of spirit as well as body. A recent incident of negligent and unlawful work practice at the regional crematorium regarding disposal of bone remains had been reported in the media and contributed to a lack of confidence regarding cremation.

Wishing to be buried on country was a strong incentive, but questions arose about what that meant in practice. Should their resting place be where they were born, where they grew up, where they live now or where their kin are buried? For some who had ties to a number of places, the idea of allocating ashes to separate places seemed to provide a possible way of resolving this particular issue.

Funeral services: Although it remains customary to have a church funeral service, some Aboriginal people are now opting for a civil funeral service. One young person, who claimed he was not churchgoing, reported he had such a connection with the Catholic Church (building) in his local community that he wanted his funeral to be held in that church. Given this tie to tradition with the Catholic Church, it is possible that resistance to cremation reflects church teachings that encourage burial of the body and forbid the scattering of ashes[25].

Some participants voiced dissatisfaction around the disrespectful manner in which a loved one's body was handled in transfer. Further concern was expressed about the speed at which graveside and chapel services were conducted in order to keep within the allocated time.

Volunteers: Neither the Aboriginal controlled community health service, regional palliative care nor the cancer centre has a formal volunteer scheme to provide support to families with a dying family member or who have recently been bereaved. A support group primarily directed at supporting patients with cancer had operated in the region in the past and had played a major role around end-of-life and bereavement support[22,26]. Its failure to be sustained reflected challenges with resourcing, status and intercultural and inter-organisational partnerships[27]. However, the key agencies listed all agreed that a well-trained volunteer corps would be beneficial if there was the infrastructure to support it. This raises the possibility of a coordinated approach to volunteer training that could foster closer links between the groups.

Emerging possibilities for the future: At two community sites, some participants were involved in the Work for the Dole scheme (an Australian Government program that is a form of work-based welfare). Following discussions at the Men's Shed about the expense of coffins, the possibility was raised that these could be offset by offering community-crafted ones. Following initial concern expressed by some, the discussion became more positive, with genuine willingness to consider the proposal. While relevant acts of Western Australian law have little mention of regulation regarding coffin construction, the Funeral Directors' Association also has requirements, which appear to make home coffin construction difficult but not impossible.

The second visit to the community resource centre highlighted that conversations had continued after the facilitated discussion had ended. The first visit had prompted discussion of the possibility of the centre taking a lead in creating a memorial space and a not-for-profit funeral service specifically for the local

Aboriginal community. Within 2 days, the centre management had identified a possible memorial site, incorporating a community garden, and was preparing to put the proposal before the organisation's board.

Given the reported and initial reluctance of the Aboriginal community to talk about death, considerable interest was shown in the potential for creative community memorial ceremonies in consultation with community members. One idea was to have community picnics or ceremonies to talk about death and celebrate the life of loved ones, to be held in places congruent with family and community values. Opportunities to partner with local Yamaji artists emerged through a number of possibilities, including working to customise the Go Wish cards for local people, support for a Dying to Know day (to celebrate conversations and community actions around death, dying and bereavement) and the involvement of the external expert facilitators in further death literacy conversations and training.

Component 2: Themes identified in the cancer videos

The community recognised that terminal illness has enormous impact on friends and family and that end-of-life issues are difficult for all people. Participants reported that people are concerned that if they die away from country, their spirit will not find its way back. Funeral issues were identified as sometimes contentious, with some participants highlighting the importance of families knowing what a person's wishes are and understanding the importance of carrying out those wishes. As one participant stated, 'families can have a feud over this, so it's important for your family to know your wishes'. Views were not uniform, despite one person commenting:

> *Not much decision making to be had. When you die you must be buried 'back home' and kids know this – it's an unspoken rule. All own their own burial plots. Message to others is to encourage people to 'have the conversation'. Lots of Aboriginal people don't like talking about death and many used to think that talking about death would put a curse on you.*

One woman was adamant about wanting to be cremated but several were equally clear that they wanted to be buried where their elders and family are. Another woman spoke of wanting to be buried where her brothers and her son are buried, 'so that people can go and see me and talk to me, just like I still go and talk to my mum'.

The importance of talking with family was reiterated many times. A woman with older children and grandchildren reported how challenging it was to get support from children who had difficulty in coping with the diagnosis. This made it difficult to talk to her children about death and dying and end-of-life wishes, yet she stressed the importance of discussing certain issues:

> *… finalise any outstanding business. Do your Will and let the family know where and how you want to be buried [and] where you want to be in your final days – at home or in hospital.*

Another participant commented on the need for support:

> *… it is important to have someone with you when the doctor tells you about what you can expect with regards to treatment and outcomes … don't be frightened to talk and don't be afraid to ask for help if you need it.*

Another person advised:

> *Take time for yourself, look after yourself. You are the cog in the wheel of your family.*

Interviews with those diagnosed with cancer indicated that while participants were keen to 'remain positive and think you can beat this' and trying not to think about the end of life, there was also considerable insight into the need to prepare their loved ones. As one woman whose family included young children stated:

> *Prepare kids for the worst-case scenario, especially when you still look well. Important to have your family with you (close) especially the little ones … Be prepared but carry on as normal when you can.*

Participants also noted the need for hospitals to be more accommodating for Aboriginal people who are dying, allowing their family to be around the person:

> *Service providers and others need to have adequate cultural understanding, understand where people are coming from, their limitations and language difficulties.*

The need for cultural respect, where people had options and were allowed to express their own preferences, was noted, rather than letting 'people … tell you what to do'. Those interviewed felt that increasing the numbers of Aboriginal people working in cancer and palliative care services could be a means of achieving this. An improvement in education for Aboriginal people to assist in overcoming barriers on denial and non-acceptance and to put an end to self-blame was recommended, and it was noted that Aboriginal primary healthcare services were well placed to provide good education and screening services.

One participant referred to 'difficulty in discussing what type of care you want when things get worse' and another talked about the important role palliative care could play in 'having the conversation … breaking the taboo – remaining respectful but modernising the conversation'. The local palliative care service was acknowledged for their help with development of a memory/eulogy book with messages and photographs for others to remember them by:

> *This allows people to say the things that are important to their loved ones.*

Most participants had an opportunity to view their own video. Some used the video to show their family, including one who had reported that her family was not coping with her illness. The grandchildren replayed the video to the family after her death as there were differences of opinion relating to funeral arrangements and arguments occurring with respect to implementing the person's wishes. Another participant had the video shown at her funeral.

Discussion

Despite premature loss of life experienced by Aboriginal people in Australia, little information is known regarding their attitudes to end-of-life discussions and their use of and experiences related to end-of-life care. The Australian literature related to palliative care and Aboriginal people is small, and to date been largely reported on the experiences of Aboriginal people in the Northern Territory[9,11,28,29], including issues such as dying on country, viewing and caring for the body post-death and ceremonial practices, and traditional post-death rituals such as smoking ceremonies and the wailing associated with sorry camps. A previous report from the Midwest of Western Australia reported that palliative care services are underutilised by Yamaji people, for reasons that included misperceptions about what palliative care entails, cultural and structural barriers to adequate service provision, and the inflexibility of death within institutions[30]. Yet Aboriginal health workers who have had opportunities to learn about palliative care through structured learning and an experiential program to improve their knowledge, skills and confidence in working with people who have chronic or advanced illness have usually embraced contributing to better end-of-life care for Aboriginal people[31].

The present article has approached learning about end-of life wishes by bringing together insights gained through two different types of discussion about dying and end-of-life wishes with Aboriginal people. The first is more theoretical, exploring wishes related to death and dying in community-based conversations where Aboriginal people were encouraged to talk with others about their views, experiences and own wishes in relation to dying.

Despite some initial reticence to opening up on these issues, reflecting that such conversations are not common, in the safe space within the community settings many participants warmed to the discussion. The experienced facilitators demonstrated that experiencing death is not only something that takes away from the affected family, but also that experiencing and talking about death can be life enhancing. Importantly, the approach occurred in a way that allowed for a diversity of views to be expressed. This was particularly so in the group of local artists where interest was shown in looking at how people elsewhere in Australia had creatively found ways to honour a person's memory after they had died as part of celebrating their life.

The second group of participants each had a life-threatening diagnosis, so were closer to confronting their own mortality. Their thoughts related to end of life reflected having given serious consideration to the issue and recognition of the challenges in talking to others about their own wishes. These conversations were contained within longer reflections on their experience of cancer and cancer care, so it is unsurprising that thoughts related to provision of health services, talking with family and being clear about their own wishes emerged as central considerations. These were largely consistent with findings related to palliative care services reported for Indigenous peoples across other developed countries[8].

Within both groups, involvement of family was an important consideration, in terms of family being around, involved in decision-making and supporting their care. Family presence and involvement in decision making and care has been described for Australian and other Indigenous populations[8]. While not explicitly mentioned, this may reflect some element of recognising and deferring to the cultural knowledge and personal authority of family members and relevant others within the Aboriginal community that Fried referred to as necessary[32]. Concomitant with family involvement was the importance of family respecting an individual's preferences for their care and their preferred arrangements following death, issues that have been identified previously[33]. Areas where there were differences in personal beliefs and wishes leading to family tensions occurred around funerals and where there were strongly held views about burial versus cremation, including the appropriate place where a person should be buried, even when families agreed on burial. This reflects that in modern society many Aboriginal people are mobile, and often have lived much of their life away from 'their country', having moved for education, employment, relationship or family reasons. The notion of returning to one's country was evident in discussions, but because the discussions occurred in the Midwest of Western Australia with people from the Midwest region, this issue received relatively little attention. What surfaced as more of a potential issue occurred for people who had moved to the city for treatment and died away from home. The local Aboriginal community controlled health service provided assistance in repatriating bodies to the region for burial, which helped to overcome this problem. It is likely that, like other rural residents, preferences around place of death change with time, so that dying in a safe place becomes more important than dying at home[34]. A safe space includes familiarity and attention to physical, spiritual, family and cultural needs[8].

The cost of funerals emerged as a significant issue. Participants showed considerable interest in the possibility of a men's group making coffins as a way to reduce costs and indicated an interest in personalising the coffin by having family and friends decorate it. Opportunities to honour those who had died through appropriate and respectful events held at a place away from a church or graveyard, and where the community could come together to celebrate their lives, received considerable interest. Several practical challenges would need to be overcome for these ideas to be realised, yet with support and facilitation they are achievable and could enable opportunities for further conversations that help people deal with death and bereavement.

Most Aboriginal people are regularly dealing with grief and loss, exacerbated by Aboriginal people often dying prematurely[35], which adds to many other life stressors. Some of the loss relates to sudden death from injury (including suicide), yet many are dying from chronic diseases – cardiovascular disease, cancer, diabetes, renal failure and respiratory diseases – where expressed and supported preferences around end-of-life care can help improve a person's quality of life as they approach death. Opportunities to talk about grief and loss can be helpful in coming to terms with loss, whatever the cause[36]. Palliative Care Australia's Dying to Talk resources (workbook and cards) targeted at Aboriginal people offer opportunities to support individuals and communities to have discussions about end-of-life preferences. The extent to which these have been taken up and used with Aboriginal people is unknown, yet the authors' engagement with Aboriginal groups in the Midwest suggests they are likely to be useful as conversation starters and that, within a safe environment, opportunities to talk about end-of-life wishes and issues are welcomed.

Conclusion

While much has been written on the need to improve culturally appropriate end-of life services for Aboriginal people[8,28,29,37,38], many people remain reticent about conveying their death and dying wishes to those closest to them. Ceremonies around death play a pivotal role in the lives of Aboriginal people and finding acceptable ways for people to pass on their wishes to their loved ones is important to avoid the stress and family conflict that may occur following death. Use of sorting cards to promote discussions about end of life with experienced facilitators who are comfortable talking about life and death proved useful in encouraging conversations about end-of-life wishes in Aboriginal people. These brought up areas of tension where further group discussions are needed to create better understanding of the differences in personal views. The two projects both highlight the opportunities that exist to use the arts as a means of engaging with public discussions around end-of-life wishes, and honouring people as a means of helping those coping with the grief of bereavement.

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