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Aboriginal grief and loss: a review of the literature

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Abstract

This article is based on a literature review that was conducted in 2013 as part of the *NSW Aboriginal Grief and Loss Training Project* funded by the NSW Ministry of Health and delivered by the NSW Institute of Psychiatry (see Appendix, 1.). A series of workshops and resources in Aboriginal grief and loss has been developed and delivered for Aboriginal Mental Health and Wellbeing Workers across NSW, to support them with working with grief and loss in their communities.

The aim of the review was to examine the existing literature, training and resources on Australian Aboriginal grief and loss, identifying areas for further research, and to confirm the need for the project. Other Indigenous literature on grief and loss was not reviewed, due to limited resources.

Methods

The documentary analysis included published and unpublished books, articles, brochures, fact sheets and training material relevant to Australian Aboriginal grief and loss.

Results

Although there is significant research on the impact of trauma in Aboriginal communities, the review found little material, resources or research that focused on the complexities of Aboriginal grief, the main exception being Rosemary Wanganeen's work.

Conclusions

That there is a lack of theories, models and practices specifically related to Aboriginal grief, and a lack of training, resources and support for Aboriginal Mental Health and Social and Emotional Wellbeing Workers.

Implications

The magnitude of grief and loss experienced by Aboriginal people through loss of land, language, cultural practices, significantly higher mortality rates, suicide, incarceration and health related problems, has significantly impacted on their social and emotional well-being. As the NSW Aboriginal Mental Health and Wellbeing workforce are at the frontline in working with these issues, there is a need to support them through culturally appropriate specialist training.

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Grief and loss in Aboriginal communities

The centrality of grief and loss to social and emotional wellbeing in Aboriginal communities in Australia has been established in the literature, for example by Swan and Raphael in their extensive report on Aboriginal and Torres Strait Islander health [1]. They identified trauma and grief as being the most serious issue, both related to past history of loss and traumatisation, and to current frequent losses as a result of high mortality rates and ongoing losses through removal of children and incarceration. Traumatic loss was seen as a cause of mental health problems and as a major problem in its own right, fundamental to Aboriginal health and well-being. The report's recommendations included: education about and counselling for trauma and grief, including specialised culturally appropriate grief counselling, support for cultural requirements about death and dying, and an extension of funding and support to programs dealing with the impacts of Stolen Generations losses such as Linkup (http://linkupnsw.org.au). It also recommended that education and support be provided to Aboriginal workers.

Almost twenty years on however, it is acknowledged that grief and loss is still a fundamental issue that has not been given sufficient attention: 'Grief and loss remain at the heart of the life experience of Aboriginal people and communities, and we need to authentically acknowledge this' [2,p.3]. Raphael and Delaney cite the resources and programs that have been developed, noting that most have not been evaluated, and identifying that the ones likely to be most effective are those which have been developed by Aboriginal people, or in partnership with governments or other organisations where Aboriginal voices are predominant [3]. They note that although the health impacts of grief and loss have been broadly recognised, much stronger research support is needed in order to close the gap in the life expectancy difference between Aboriginal and non-Aboriginal people.

Grief and loss for Aboriginal Mental Health and Wellbeing Workers

The most recent National Report Card on Mental Health and Suicide Prevention confirms a general lack of training of Aboriginal people in mental health services and calls for increased and measurable action in this area [2, p.18]. This review found little evidence that Aboriginal workers have been supported through training and education, and specifically in grief and loss.

The Grief and Loss Training Project for which this literature review was conducted, seeks to address the important issue of supporting Aboriginal Mental Health and Wellbeing Workers to deal with not only the grief so prevalent in their communities, but also their own responses to loss, how they can support each other and strengthen community, and be supported by the mainstream system in which they work.

Grief and health

According to Caruana, Aboriginal people are the most disadvantaged group in Australia [4]. Life expectancy is estimated to be about 10 years lower than that for all Australians [5]. It is known that the experience of bereavement itself means a higher risk for a range of negative physical, mental and social outcomes [6]. Complicated grief or unresolved grief, which may ensue as a result of multiple traumatic losses, further heightens this risk, with links to increased rates of cancer, heart disease, high blood pressure and suicidal thoughts [6]. Unresolved grief as an underlying cause of health issues is also acknowledged in a palliative care resource produced by the Australian Government Department of Health and Ageing [7]. Hillin et al. point out that mainstream research and health services have largely failed to understand and address the complexities of grief and loss for Aboriginal people, and its connection with health and well-being [8]. This together with historical and ongoing racism, as well as lack of cultural safety and cultural competence in non-Aboriginal staff, has meant that Aboriginal people have largely been excluded from mainstream service provision.

Different types of losses

Of the multitude of ongoing and interconnected losses experienced by Aboriginal people, loss of land is seen as central by many. Professor Helen Milroy, an Aboriginal psychiatrist, describes its impact:

For Aboriginal people, Land is held in trust - you can't buy and sell land, it is selling your mother. Your 'country' is your home, identity, the basis of your knowledge, your law, it is where you will go when you die. It is an intensely intimate relationship. The profound grief of Aboriginal Australia comes from removal from land, from 'country'.... As the culture grieves for the many generations of loss and dispossession, the land also grieves for its people.... [9, p.13].

Another loss which has been endured by Aboriginal people relates to spirituality. Grieves describes this as the interconnectedness of all the elements of the earth and the universe, animate and inanimate, expressed through sacred stories describing the activities of powerful creator ancestors who established the Law – the ways in which all things should live so as to maintain order and sustainability [10, p.7]. According to Grieves, spirituality is the basis of Aboriginal social and emotional wellbeing and the ways of being implicit in it have been demeaned and devalued by colonisation, though not necessarily lost.



Loss of language is another aspect of cultural loss. Milroy points out that many attempts were made to wipe out languages through denigration, banning and punishment [9]. Bostock states that of the original estimated 500 Aboriginal languages, by the 1980s only 50 were considered viable [11].

Losses related to incarceration are also significant. The absence of male role models through incarceration and the associated distress and grief were commented on by Swan with the incarceration losses only increasing since then [12,p.9]. The most recent *National report card on mental health and suicide prevention* notes that Aboriginal people, both male and female, are hugely over-represented in Australian prisons: in 2012, while they comprised 3% of the population, they made up 27% of the adult prison population. Young Aboriginal people aged between 10 and 17 years were 24 times more likely to be in detention than non-Indigenous people that age [2]. Incarceration can bring particular fears and distress for Aboriginal communities due to the history of deaths in custody. The link between incarceration and mental health and wellbeing for Aboriginal people is an issue of serious concern.

High level of bereavement loss, often traumatic

The unusually high level of loss through bereavement for Aboriginal people has been noted by many. The Australian Institute of Health and Welfare found that 42% of respondents indicated they had experienced the death of a family member or close friend within the past year [13]. The term 'malignant grief' is used by Helen Milroy to describe the process of irresolvable, collective and cumulative grief over multiple generations that affects Aboriginal individuals and communities, causing them to lose function [14,p.6]. 'The grief has invasive properties, spreading throughout the body.... Many of Australia's Aboriginal people eventually die of this grief' [14,p.30].

Complicated grief

This cycle of continuous grieving alone, apart from the multitude of other losses experienced, and apart from the often traumatic nature of the losses, means that Aboriginal people may be a high risk group for 'complicated grief' [6]. No studies that address complicated grief in Indigenous populations have been identified. It is important to note, however, that the symptoms and timeframe of 'complicated grief' may vary according to individuals, cultural practices or expectations [6]. The expectation that grief will be integrated may not be in keeping with many cultures, including Aboriginal culture:

As a culture we don't believe it's the end of a life. They're moving on to a new life. That mourning period is there, for as long as a person wants, but whether they choose to move on quickly or not is not looked down upon. My mum's still mourning my grandfather, and he died 13 years ago. It could last a lifetime [15, p.22].

Suicide and grief

Grief associated with suicide adds to the complexity of Aboriginal grief and loss because of the traumatic nature of suicide and its relative frequency as a cause of death in Aboriginal communities [17]. Kristjanson et al. argue that people experiencing complicated grief have a substantially heightened risk of suicidality [6]. Suicide 'clusters' in communities sometimes develop as a result of this experience, particularly amongst young men:

Ripples of loss, grief and mourning after suicide can spread outwards through the community and to other communities, particularly where families are highly interconnected and there are strong cultural obligations with regard to funerals and observance of sorry business.... This 'bereavement stress' has overtaken the community's usual resources for coping with and containing suicidal behaviour, leading to clusters of 'copy-cat' suicides [17, p.100].

Suicide rates of Aborigin1al and Torres Strait Islander people are twice that of non-Indigenous people, according to Australia's first *National Aboriginal and Torres Strait Islander Suicide Prevention Strategy* [17]. The *National report card on mental health and suicide prevention* reports that young men and women are between 4 and 5 times more likely to die by suicide than other young Australians.

'The heavy suicide burden carried by Aboriginal and Torres Strait Islander communities is a national shame, and one that impacts across generations' [2, p.85].

The *NSWSuicide Prevention Strategy* acknowledges that the complex factors involved include some disadvantage and risk factors shared by non-Indigenous people, but also many broader factors: intergenerational trauma and grief, dislocation and mistreatment, loss of cultural identity and social isolation, and current grief from the deaths of family and community members [18].

Many attempts are being made to address these high rates of suicide in Aboriginal communities and the ensuing grief. Silburn et al. provide an overview of recent trends in suicide, examining its meaning and impact and what is being done, including Henry's 3-level model for postvention response to suicide [16].

Trauma and grief

There is a growing body of work around the impact of trauma and the development of trauma-informed practice for Aboriginal people, for example the work of Judy Atkinson [19]. Whilst trauma, grief and loss are often used interchangeably in the Australian literature, according to her grief as distinct from trauma is not significantly addressed [19]. Atkinson identifies grief as an important but often unresolved issue in the many losses that are part of traumatisation. She asserts that although the concept of PTSD (Post Traumatic Stress Disorder) may be a starting point for working with Aboriginal grief, it doesn't include the trauma of

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colonisation, or cumulative traumatic stress whereby people lose the knowledge of who they are, and life is not seen as meaningful, which creates many greater losses. She also makes an important distinction between bereavement and the sense of victimisation that can occur as a result of the trauma of colonisation:

The bereaved feels loss. The victim feels like a loser. The bereaved feels sad. The victim feels humiliated. The bereaved may feel as though part of him/herself had been ripped away. The victim feels diminished, pushed down in a hierarchy of dominance, exploited and invaded [20, citing Ochberg, 1988, p.11].

Grief in children and young people

Children and young people make up the majority (57%) of the Aboriginal population [20]. Many of these children and young people know death at an early age, experience multiple losses and are more likely than non-Indigenous children to lose their primary attachment figure, especially if this is a grandparent, in childhood [21]. Limited grief-specific resources addressing the needs of Aboriginal children could be found in the literature search. One exception was a brochure entitled *What do we tell the children when someone dies* [22].

The over-burden of children's grief is echoed by several Aboriginal health workers in the video *Trauma, loss and grief for Aboriginal children* where the need for a change in social positioning is also stressed:

I know that our children have a heavy burden, a disproportionate burden of grief and loss in their lives. Children shouldn't have to live with grief and loss... but the social positioning of Aboriginal people in Australia today means that grief and loss is always going to be part (of their lives), until we change that.... While we are absent from the nation's consciousness of itself, we are not going to be able to offer kids that different view of the future that they should have [23, Dr Maggie Walter].

Hillin and McAlpine describe the broad range of losses experienced by Aboriginal young people, associated with high rates of incarceration, suicide, crime, violence, substance issues, injury and chronic disease [24]. Their comprehensive resource provides numerous practical tools for addressing the social, emotional and mental health needs of Aboriginal young people. For Aboriginal young people who are same-sex attracted, further research is needed into risk and protective factors affecting reactions to grief and loss. This is especially warranted given the elevated suicide rates and other indices of distress, including substance use and depression, experienced by both Aboriginal young people and same-sex attracted young people [24]. Cantor and Neulinger observe that same sex-attracted Aboriginal young people are perhaps the least researched and most neglected group in both same-sex attracted and Aboriginal focused work [25].

Grief in a palliative care context

There is a small body of literature around palliative care in an Aboriginal context, with references to grief both as a cause of illness, and a result of loss. Mainstream palliative services are generally not being accessed by Aboriginal people because of the lack of cultural awareness and culturally appropriate care. O'Brien et al. provide an overview of the issues in the development of end-of-life care for Aboriginal people [26]. They assert that the research is in its infancy and that only two models focusing on and developed in Aboriginal communities have been implemented. There is a need for further research and development of culturally specific and appropriate, locally accessible services delivered in a partnership between mainstream palliative care services and Aboriginal Controlled health services.

Traditional and contemporary Aboriginal healing

Two types of healing methods have been identified by the authors of a literature review of Indigenous traditional healing: 'traditional' healing, still practiced for example by Yolngu healers in East Arnhem Land and 'experientially informed' healers who have gained skills in dealing with their own trauma and now use Aboriginal ceremonial elements [27]. Atkinson's ceremonies of 'mutual care' are cited as examples of the latter. Programs of group healing and re-connecting to cultural traditions such as healing circles, are seen as vital to healing [27].

The Marumali Journey of Healing was developed by Lorraine Peeters in response to her own experience of removal from family and designed to support the Stolen Generations survivors: 'out of necessity, we were forced to become the experts of our own trauma and healing' [28]. The program is grounded in Aboriginal knowledge systems and spirituality, and provides a basis for understanding the symptoms of longstanding trauma and an overview of the healing journey. It has been endorsed as best practice and offers training workshops for Indigenous counsellors [28].

Painting and other creative arts may also be part of healing methods, but no published material could be found on the use of creative arts therapies in healing Aboriginal grief. The Dax Centre at the University of Melbourne facilitated a symposium and exhibition in September 2014 called *Healing ways: art with intent*, which explored the role of art in promoting healing and emotional wellbeing in Aboriginal communities. It included a two day art workshop that provided participants with the opportunity to learn about traditional Aboriginal grieving practices and facilitated the making of a traditional Aboriginal mourning cap (see http:// healingways.daxcentre.org/professional-development)

Aboriginal grieving practices

There is a large body of anthropological literature about death and dying in Aboriginal cultures. Most of this work does not examine the colonial context and assumptions in which it was developed. Aboriginal belief systems and spirituality, for example, were believed to be a lesser form of consciousness than science [7]. The usefulness and appropriateness of this anthropological material for contemporary Aboriginal people is debatable.

We've moved on in terms of ensuring that the processes that sit behind research and publication now are ethical, and that consideration and inclusion of us is paramount. Although it wasn't done ethically then, we can take the information that's useful to us today and by being inclusive of people, add value to what we're doing to address grief in our communities. Tom Brideson, personal communication.

The scarcity of Aboriginal voices is also noted in the literature with the exceptions being personal experiences of grief and loss in published auto-biographies, such as those by Langford Ginibi [29], and Morgan [30], and in documents associated with government enquiries, for example *Bringing them Home* [31].

Amongst the many ways of grieving practised today in Aboriginal communities, large numbers of people may gather when a person is dying:

It ranges from 80 to 100 people and.... they will be there out the front of the hospital sitting on the kiosk steps or down on the steps or just near, standing out the front.... It is marvellous to see them and you all know that they care. They are all affected by it [32, p.13].

The significance of attendance at funerals and for Sorry Business is important in many Aboriginal communities but is often poorly understood by mainstream services. This issue was identified in the extensive consultations conducted with Aboriginal Mental Health and Wellbeing Workers in NSW [33]. These workers are also community and family members within the community they work in, and within their home community. They are expected to attend and participate in funeral and Sorry Business in both a professional and personal capacity. This is often not understood by workplaces which have policies including limits on timeframes and specific information regarding relationships (direct family) when granting leave for attending funerals, both locally and where travel is involved. It is important that workplaces understand the need to demonstrate culturally safe and respectful ways of supporting Aboriginal staff in both professional and personal capacities [8].

Crying and wailing are common ways of grieving, in contrast to the 'silent grief' of mainstream Australian culture, identified by Barb Wingard, an Aboriginal woman who works with the Dulwich Centre in Adelaide, South Australia: If you go to a funeral service in an Aboriginal community you can wail and cry and grieve the way you want to grieve. But in mainstream funeral services there seems to be a lot of silence to grieving. I don't believe that this silence fits with Aboriginal culture. I don't believe that this silence is a good thing.... Silent cries can go on for years and be heard by no-one. They can eat away at a person's spirit. If only all those people who are silently crying could find ways to come together.... [34, p.2].

Other practices in some Aboriginal communities may include selfcutting, and prohibition of the use of the name, image, voice and possessions of the deceased person as a sign of respect [35].

Contemporary grief and loss resources

There are very few written resources developed by and for Aboriginal people specifically about grief and loss. A number of pamphlets and fact sheets are available from various sources which offer brief information and ways of helping: Australian Indigenous Health*InfoNet*: *What is grief and loss?* [36], *Grieving Aboriginal way* [37], Lifeline's self-help resource for Aboriginal people: *Coping with sorrow, loss and grief* [38], three brochures produced by the Aboriginal Drug and Alcohol Council of SA [22], and the *Guidelines for providing mental health first aid to an Aboriginal or Torres Strait Islander person* produced by ORYGEN and beyondblue [39].

The most in-depth model available is Rosemary Wanganeen's The Seven Phases to Integrating Loss and Grief, which she developed by drawing on her personal experience of grief and loss [40]. She proposes a way of working with the 'toxic' grief that evolves from long-term suppression across generations, compounding and complicating contemporary grief, causing disease. The key features of this complex model involve identifying the numerous and various levels of losses including the 'innate emotions' of childhood and adolescence. She identifies both ancient grieving ceremonies and contemporary loss and grief healing centres as important in the resolution of grief. Other distinctive features include the concepts of 'multiple inner children', 'grief anger', and 'grief-fear', and the importance of ancestral attachment in the healing process [40]. The Australian Institute for Loss and Grief in South Australia of which she is founder and director, conducts workshops and courses nationally in working with loss and grief.

Joyleen Koolmatrie's approach to working with grief and loss for Aboriginal people is also based on her own experience and her work with the *National Inquiry into the Stolen Generations* [32]. The removal of children she says 'left a powerful residue of unrecognised and unresolved grief that has pathological effects on Indigenous communities' [41, p.163]. The group work she facilitates is based on creating a safe environment through presence, respect and self-disclosure. At its core is the telling of stories,

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with validation and affirmation from the group. She describes the need to 'open the wound and unlock the repressed experience and feelings' for healing to begin [41, p.160]. 'Dependent grief', 'forbidden mourning', 'forbidden action' and 'inexpressible rage' are also identified by her as factors in Aboriginal grief [41].

Grief and loss work in collaboration with non-Aboriginal people

The dangers and limitations of using adapted mainstream models and practices in working with Aboriginal people have been outlined by several authors and practitioners. Grieves, for example, points out that the Western individualistic culture from which the therapies have developed, has a very different belief system and view of personhood from the Aboriginal worldview [10]. The long history of mistreatment by mainstream health and welfare services, including diagnoses of mental illness to support the removal of children, has led to mistrust and fear of contact. Psychology has played a significant role in contributing to cultural and institutionalised racism, through its alignment with mainstream Western scientific values, including testing, according to Adams, Drew and Walker [42].

However, there is an emerging literature and practice in the mainstream system which acknowledges and attempts to address the very different cultural needs of Aboriginal people, including practices and resources which relate to grief and loss.

The Dulwich Centre in Adelaide, South Australia has been working with Aboriginal communities since the early 1990s, facilitating the telling of stories about responses to difficulties, and then sharing these stories with other communities. It is also involved in training Aboriginal people in narrative approaches. One project based in Port Lincoln, South Australia produced a booklet and CD of songs, created from local community knowledge, describing how grief is affecting families and communities.

Too much grief brings divisions between families. It can break friendships. The anger, resentment and bitterness brought on by grief causes lateral violence around here.... It's like grief can make us lose respect for ourselves, and our families and our community.... [43, p.6].

What began with a community lunch and talk in groups about grief has developed into plans for healing grounds, a memorial park, and the recording of elders' stories, as well as counselling and the creation of artwork.

Another project in Narrandera New South Wales, involved sharing a range of stories and ideas about loss and healing, remembering old ways of honouring the deceased, and acknowledging current ways. 'When I think about what grief means, I think it means honour, integrity, a place to fall over and sit down' [44, p.8]. The listening team noted a 'precious combination' of grief, pain and humour: 'Aboriginal humour across this country remains so strong. It seems that this humour enables people to stand in a different place to grief. It seems very powerful to me' [44, p.8-9].

Other projects that have been conducted as a collaboration between Aboriginal and non-Aboriginal people include the NSW School-Link Training Program, and NALAG (see Appendix 2. and 3.).

Conclusion

In conclusion, this review of the literature on Aboriginal grief and loss finds a lack of well-articulated theories, models and practice specific to the cultural and historical context of grief (as distinct from trauma) for Australian Aboriginal people, whether by Aboriginal or non-Aboriginal authors.

It is recommended that Australian-Aboriginal specific research and practice is developed in several key areas to assist the process of ensuring that a legitimate voice is given to Aboriginal people. An approach that recognises the importance of Indigenous knowledge systems together with academic research and evidence is suggested as the most effective. The Gayaa Dhuwi (Proud Spirit) Declaration is an example of work that promotes this dual approach, as discussed in an article by Dudgeon, Calma, Brideson and Holland [45]. It was the product of a large consultative process and had broad support from many organisations. It outlines the many areas of work needed to ensure that the concept of Aboriginal mental health and social and emotional wellbeing has a greater legitimacy.

The key areas in which this research needs to be conducted are: complicated grief including anticipatory grief, factors contributing to poor social, emotional and mental health outcomes following grief and loss, bereavement by suicide, factors contributing to individual and community resilience in dealing with grief and loss, grief in children and young people, including young people in rural and remote areas and same-sex attracted young people, grief in the context of palliative care, the use of creative arts in working with grief, and the history of group mourning and protest. In addition the need for culturally appropriate evaluation of programs and methods is identified as being of central importance.

The review reinforces the need that has long been articulated for training, resources and support for NSW Aboriginal Mental Health and Wellbeing Workers in grief and loss. Addressing the high mortality rates and high rate of traumatic deaths in Aboriginal communities needs to underpin this support, in order to reduce the number of losses through bereavement. In addition, extensive systemic and policy change needs to be implemented, with particular reference to the development and practice of cultural competency in non-Aboriginal staff and managers. Attention needs to be focused on understanding the specific grief-related needs of workers for their own social and emotional wellbeing as well as building the resilience of the communities they live and work in. It is important that all organisations who employ Aboriginal staff provide or give access to support which may take different forms including supervision, self-care, or 'heal the healer' programs. The review highlights the importance of a long-term approach underpinned by culturally relevant research, evaluation and practice with a focus on self-determination.

Appendix

- The literature review on which this article is based was 1. conducted in 2013 and has been significantly condensed for publication. The review has not been updated since 2013. As a result, some valuable material has not been included in this article. The authors would like to acknowledge the significant work of the Healing Foundation in addressing grief and loss issues. One example is the Seasons to healing resource developed by the Aboriginal Family Support Services in SA in collaboration with Good Grief, which contains a training manual for facilitators and a model to support discussion between community members on how to cope with and resolve grief and loss experiences [46]. The Aboriginal and Torres Strait Islander Suicide Prevention Evaluation Project (ATSISPEP) based in WA has also recently produced fact sheets related to suicide, which make a valuable contribution to addressing grief and loss [47].
- Mental distress and well-being in Aboriginal young people 2 Strength in culture, a training module and resource package disseminated through the NSW School-Link Training Program and Queensland Ed-LinQ Cross-sectoral Workforce Development Program provides a range of resources for clinicians working with Aboriginal young people, including on issues of loss [48]. The resource notes that Interpersonal Psychotherapy (IPT) may be of particular relevance to some Aboriginal young people given that many experience depression driven by unresolved losses and complicated grief. It contains other material relating to grief and loss: practical information to help understand and work with the social and historical determinants and multiple nature of loss; guidance for assessing distress and suicidality, including postvention; and advice about interrupting racism and promoting inclusivity for Aboriginal people in organisational contexts. This resource is based on extensive consultations with Aboriginal elders, parents, young people and mental health workers [49].
- 3. NALAG

The National Association for Loss and Grief (NALAG) were invited by Aboriginal elders in Bourke, NSW to respond to grief issues in the community [50]. A plan of action was developed to address grief issues which included an annual Remembrance Day event, a Healing Ceremony and a Healing Camp to encourage the expression of grief in a safe environment. NALAG chapters have been established and regular healing days held for group education, sharing loss and expressing grief, for example through the making of 'love wraps' in memory of lost loved ones. Training in loss and grief support has also been provided by NALAG to members of the Aboriginal community.

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