

Family care giving for Aboriginal peoples during end-of-life: Findings from the Northern Territory.

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Abstract

Although there is an extensive literature on the needs and experience of family caregivers for seriously ill people, there is a distinct lack of research articles on the specific topic of Aboriginal family caregivers. The lack of available information is a particular concern in view of the fact that a national survey on the social impact of caring for terminally ill people in Australia indicates that the experience for Indigenous Australian carers is fraught with challenges of distance, social isolation, poverty, and overcrowding, as well as different cultural needs. Thus, in order to begin to address the gap in knowledge the present article provides findings on family care giving for Aboriginal peoples from an Australian National Health and Medical Research Council two year study conducted in the Northern Territory.

Keywords: Care giving; Indigenous; Qualitative Research, Service Delivery; Culture.

Introduction

Although there is an extensive literature on the needs and experience of family caregivers for seriously ill people, there is a distinct lack of research articles on the specific topic of Aboriginal family caregivers. The lack of available information is a particular concern in view of the fact that a national survey on the social impact of caring for terminally ill people in Australia indicates that the experience for Indigenous Australian carers is fraught with challenges of distance, social isolation, poverty, and overcrowding, as well as different cultural needs (PCA, 2004:59). Thus, in order to begin to address the gap in knowledge the present article provides findings on family care giving for Aboriginal peoples from an Australian National Health and Medical Research Council two year study conducted in the Northern Territory.

An important assumption underpinning the following discussion is the different notion of family for Aboriginal peoples as compared to the Western European concept. As Gray and associates (1991) explains the notion of family has a much wider meaning in Aboriginal culture than can be understood by applying the Western notion of the nuclear family. For this reason, the National Palliative Care Program (2004:5) definition of the term 'family' for Aboriginal peoples will be used for this discussion which is - 'blood relatives' and 'significant others' as defined by the person. Significant others may be Elders and/or community leaders. Kinship rules which define whole classes of people (not necessarily biologically related) throughout the community within family relationships govern almost all social situations for Aboriginal peoples (Gray et al., 1991). The plural term "Aboriginal peoples" as used within this article infers a respect for cultural diversity of Australian culture, which comprises a broad range of distinct groups with distinct cultural practices, traditions and laws (NPCP, 2004).

THE RESEARCH PROJECT

The aim of the two year research project, funded by the National Health and Medical Research Council (NH&MRC), was to develop an innovative model for Aboriginal palliative care. This objective was achieved and the model is available in a final report (McGrath et al, 2004). The project was initiated by a request from the Aboriginal community, the data collected by a well respected Aboriginal Health Worker (AHW), the Aboriginal community extensively consulted and involved, and the outcomes which have strong practical implications has been returned directly to the Aboriginal peoples as well as a diverse range of service providers and policy makers throughout the Northern Territory and Australia who can assist to translate the findings into action.

The data for the model development was collected through open-ended, qualitative interviews with a cross section of participants throughout the Northern Territory. The model was assessed by a national panel of experts in Aboriginal health and a meeting of Northern Territory Aboriginal Reference group. The data from the study is extensive and rich and thus is being published in many separate articles which in combination provide the full context for the model. The specific findings under discussion in this article refer to the data in relation to the experience of being an Aboriginal family caregiver.

ETHICS CLEARANCE

This project was conducted in compliance with the NH&MRC guidelines on ethical matters in Aboriginal and Torres Strait Islander Health Research (NHMRC, 2004), and the Australian Institute of Aboriginal and Torres Strait Islander Studies guidelines for ethical research in Indigenous Studies (AIATSI, 2004). Permission and authorisation was obtained from a number of research ethics committees: The Human Research Ethics Committee of Department of Health and Community Services (previously Territory Health Services) and Menzies School of Health Research in Darwin; The Central Australian Human Research Ethics Committee in Alice Springs; the Human Research Ethics Committee of Charles Darwin University (previously Northern Territory University); and the Human Research Ethics Committee of Central Queensland University. Approval was sought from relevant Community Council's (Chairs/Elders as appropriate) participating in the project. Free and informed consent (written and verbal as appropriate) was sought from all individuals prior to participating in the project, and a guarantee of anonymity for the individual and the community was assured.

RESEARCH FOCUS

The research questions informing the broader data collection for the model development included:

1. What Palliative Care services are provided and are they meeting the clients' needs?
2. How can services be modified to deliver a culturally appropriate, innovative and exemplary model?
3. What strategies are needed to develop and apply the model developed?

In short, the research was concerned with, What is? What works? What is needed? The outcome is a 'Living Model' which involves a generic model incorporating all important factors that is to be applied to the unique circumstances of each health care services working with Aboriginal peoples during the end-of-life trajectory. The insights for this article on family care giving were offered by participants during the interviews for the model development.

PARTICIPANT GROUP

An AHW was a participating member of the research team, and coordinated all communications with Aboriginal peoples and communities regarding introduction, progress and review of the project. Stories and sources of information were acknowledged and only used in publications with the permission of the person and the community involved. The interviews were conducted in four geographical areas in the Northern Territory including East Arnhem Land, Katherine Region, Alice Springs and Darwin. As Table 1 outlines and the Australian Bureau of Statistics (2004) figures demonstrate, the Aboriginal populations in these areas are small. Within these four geographical regions, Aboriginal peoples comprised 15.2% of the population.

Table 1: ABS Population Figures for locality of research (ABS 2004)

East Arnhem Land	Katherine Region
6 communities: 5,119	3 communities: 2,906
Alice Springs: 3,474	Darwin: 5,957

Because of the small population base for the areas from which participants were enrolled, full details of participants and communities cannot be provided as individuals may easily be identified. There were a total of seventy-two (n=72) interviews completed with a wide range of participants in the above named geographical areas including:

- Indigenous patients (n=10),
- Indigenous caregivers (n=19),
- Indigenous and non-Indigenous health care workers (n=41), and
- Interpreters (n=2).

DATA COLLECTION

The qualitative process used was exploratory, iterative and open-ended. The interviewer initiated the discussion with a generic focus question and then actively listened, with bracketed assumptions to the issues considered important by the participant. Thus, it is important to note that the discussion on family caregiving relates to important concerns raised by various participants. Data was collected using taped interviews with Aboriginal clients and service providers in the participating communities. All of the data collection was completed by a respected AHW who has over a decade experience as a nurse in palliative care working with Aboriginal people. The interviewer engaged in extensive preparatory discussions in qualitative interviewing with the principle investigator, engaged in pilot interviews which were then further discussed and engaged in follow-up reflective sessions on the interviews throughout the data collection. An interpreter was used if the participant spoke in their local language.

DATA ANALYSIS

The interviews were audio-recorded and transcribed verbatim. The language texts were then entered into the Qualitative Solutions Research N5, Non-numerical Unstructured Data Indexing Searching and Theorizing (QSR NUD*IST) computer program and analysed thematically. A descriptive phenomenological approach was used to analyse the data in that the aim of phenomenology is to describe particular phenomena or the appearance of things as lived experience (Streubert & Carpenter, 1995). The process was inductive and descriptive as experiences were recorded and analysed from the viewpoint of the individual who had them without imposing a specific theoretical or conceptual framework on the study prior to collecting data (Polit & Hungler, 1995). All of the participants' comments were coded into free nodes (files or codes in the NUD*IST computer program that are labelled and store similar language texts on one specific topic), which were then organised under thematic headings. The coding was established by an experienced qualitative researcher and completed by a number of research assistants for the project. There was complete team member agreement on the coding and emergent themes.

The reporting of findings was based on a commitment to the participants' point of view with the researcher playing the role of co-participant in the discovery and understanding of what the realities are of the phenomena studied (Streubert & Carpenter, 1995; Crombie, 1996; Greenhalgh & Taylor, 1997; Holloway, 1997). Thus, a narrative account dominates, with a clear separation between the presentation of the exact words of the participants in the findings section and the interpretation in the discussion section (Grbich, 1999). For economy of presentation the selected nodes have been organised under categories that, when juxtaposed, build an outline of the issues (Coffey & Atkinson, 1996; Marshall & Rossman, 1995).

For some interviews, an interpreter was used. As a compromise to readability, some of the texts required additional words in parenthesis to improve clarity. It was considered important not to change the texts further than this to stay true to the participant and so that the reader still has a sense of the original words.

It is also important to note that there is no identifying information associated with any quote from participants. Strict confidentiality was promised to participants in this study. A reassurance of strict confidentiality was an imperative for this study for two special reasons. Firstly, strict confidentiality is essential because of the sensitive Aboriginal cultural information given by participants. It was also important because of the small size of the communities from which data were collected where any information about a participant could potentially lead to identification.

FINDINGS

THE IMPORTANCE OF CARING FOR FAMILY

There were reports of Aboriginal peoples in some areas strongly identifying with their traditional culture and the traditional value of caring for their own family members.

- We all look after each other, sharing, helping, encouraging each other in the family...

The notion of the importance of family was stated clearly.

- I guess to people here what is more important than their relatives?

Participants pointed to the significance of caring for sick or dying family members. Being with the person was noted as essential during such a time of distress.

- If somebody's dying, I suppose, the main priority is to be with that person like all families, taking care of that person and all that,

Family closeness is reported to reduce the fear associated with dying.

- Oh, yeah, because at that stage some feeling frightened... and you need that family support there...

It was noted that involvement in caring is particularly likely in areas where there are strong kinship networks and traditional cultural practices.

- That's what we do in our (name location) way because we've got many extended family here. We've got a kinship here, (name location) mob. We are – we are looking after ourselves because we've got - we call ourselves the (name location) mob, (name location) people; we know our traditional way we can be living in our way and we can look to our culture way because we are black people, (name location) people, and we can look after ourselves.

In relation to traditional culture there are kinship rules which define who is in the right relationship to provide the care to the dying person.

- I could imagine again that there would be that many people wanting to be there, and having a right to be there and a responsibility to be there... (Interviewer: And that's through that kinship system know that responsibility of being involved with people and knowing their story?) Yeah, yeah.

Health professionals note the importance of such cultural rules in their work with families.

- But most of the issues we deal with are actually with family members and cultural issues regarding who can actually help us in that family, care for that person.

The full details from the study on the importance of kinship relationships are published elsewhere (McGrath et al., 2005). Closely linked to the notion of kinship is the fact that Aboriginal peoples have a broad extended network of relatives who will want to visit or be involved with caring for a dying person. Western health care facilities such as hospital rooms are usually only designed to accommodate a few visitors which creates problems for Aboriginal peoples.

- I could imagine there might want to be 100 people at a meeting in the case of a person who's dying, and there isn't room at the hospital to have such a meeting...

Again, the full findings from the study on this issue of family meetings is published elsewhere (McGrath et al., 2006a). Suffice here to point to the practice implications of this finding that the cultural fact of the number of visitors should be respected and supported. At hospitals, outside meeting places that accommodate large groups and folding beds to assist family members to stay are practical strategies that will foster support. As one participant explained,

- Provide folding bed so family members can stay when person is in hospital. If necessary another person could stay there as well because often if somebody is that sick and that low it is too scary for one person to be on their own and have a second person to support them. That is what we are pushing for, because family is just so important to someone who is dying.

FACTORS INFLUENCING INVOLVEMENT IN CARING

However, the participants' statements also indicated that involvement in caring is locality specific and not all Aboriginal families shared such traditional values.

- So it just depended on the group and the family...

Family and position in the community were also noted as factors influencing readiness to be involved in the role of caring.

- (Do you think with Aboriginal clients that family are really willing to be involved) Unfortunately probably not, they're probably not as – not as willing as some other families but it varies on the

family too, and I think it also varies on the client's structure in the community, you know, like the higher up in the community they are the more people they have that are concerned about them...

Fear was another factor noted as influencing involvement.

- And my other sister and cousin sort of ... they didn't – must have been illness... they were frightened and just pop in and say hello and that was it, they couldn't take it.

As outlined in full from further findings from the study (McGrath, 2006a), a significant part of the fear in relation to caring for a dying person is the worry about 'blame' and 'payback' for the person's death. Another fear in relation to cancer, dealt with in detail elsewhere (McGrath et al., 2006c), is the fear of contagion based on a lack of understanding of cancer.

- They thought it's catching, that cancer might jump to them but I used to tell them it's not like TB, it's different, you know. And I – I showed them that it wasn't because I said: look at me I'm a health worker, I stay with her, I do her dressing, I share the same cup with her to drink whatever, you know, I haven't got cancer.

Caring was also described as hard work not suited to some individuals.

- Like if they don't feel comfortable about looking after them, you know, you can't force it on them, even if it's the wishes of the person to go home, it's pretty hard...

The stark contrast in experience for Aboriginal patients who had a family who were prepared to be involved in the caring and those who do not is amply demonstrated with the following vignettes.

- There was a lady there who was dying from (diagnosis) and she on the whole was cared for extremely well by the family. It was the warm time of the year, they'd set up little tents outside so I think they'd gotten around the housing problem by having a makeshift area away from the house. And yeah, basically they'd let us know if she seemed to be in more discomfort. And then contrasting that we've got a mob at (name location) who had an old lady who I think also had (diagnosis) and a few times I had very serious words with the family because this poor lady was riddled with (disease) and every time she seemed to get sick they'd bundle her in the car, causing extreme pain, and whiz her down to the health centre and just dump her and expect us to do something with her.

FAMILY WANT TO BE CARED FOR BY THEIR OWN

There were many descriptions of Aboriginal patients stating clearly their preference to be cared for by their own family members as can be seen by the following short examples,

- Because when I asked, you know – oh, you want to go to Katherine or you want to go somewhere have a rest, you know, said no, I'm staying with you.
- They always ask how long I was going... wanted me there all the time.
- Old people, real... real demanding and want you there...

DO NOT WANT TO RELOCATE

Participants reported that because of the strong bond with family Aboriginal peoples do not want to relocate for treatment and do not want to die away from home.

- We have lots of cultural issues regarding at home, well actually if we're trying to maintain them at home which we try to do for as long as we can because they're so – they belong so much to their community and they don't want to die away from their community.

There were vignettes of Aboriginal patients not wanting to leave for treatment,

- I took her aside and said, you know, in language, how serious it was. She said: no my girl, staying here, not going long way on big plane, I'm frightened.

And of others who wanted to return when relocated to city hospitals for treatment.

- ... because he was restrained because of health in Darwin always wanted to come home.

The full details of the findings from the study on this topic of the problems associated with relocation for both the patient and the carer are published elsewhere (McGrath, 2006b; McGrath & Paton, 2006).

DESCRIPTIONS OF FAMILY CARING

There were detailed cultural descriptions of Aboriginal people caring for their dying which involved the provision of constant emotional and spiritual support,

- There are relatives constantly there caring for them for months. Caring for them, doing whatever they can and it's an environment of great support I'm sure, emotional, spiritual support for that person; knowing that they are with their relatives.

Preparation of bush food,

- But like the general nursing and feeding the family took over that, they cooked the bush food for him and that...

Making music and singing.

- He had all his family around him, there was singing every night and afternoon music and they got sticks and bamboo and things and it was beautiful really. It was a very special time; it was very draining for us but it was a very special time.

Thus, the notion was expressed that the family could provide the best care.

- I didn't want anyone else to look after her, they wouldn't have looked after her the way we had her. ...with family members, the warmth and the compassion and the comfort that those people must feel can't be provided by a hospital.

This idea is substantiated by health workers with experience in the community.

- (Gave details of long experience as health worker with Aboriginal peoples) so I have seen a lot of it in communities and I have seen families that have been quite caring and capable and have managed to nurse their people, be it mother or father, you know, until such time as they do finish up. The families that I've known over the years they seem to be very caring towards the end and will do whatever they can, yeah.

The important practice implication of this finding is the need to respect the family connection for Aboriginal peoples.

- It was more or less just the family coming in and taking over and – you know, they somehow know to come in and look after their own... Yeah, and we don't interfere...

CARING IS DIFFICULT AND CHALLENGING WORK

The participant's statements indicated that although caring is spiritually important, it is also practically difficult and challenging work involving toileting, provision of food, driving the patient to clinical appointments, taking care of personal hygiene, obtaining needed equipment, maintaining fresh bedding, administration of medications and care of dressings. Toileting was recorded as a difficult practical challenge especially when the person was weak or had difficulty seeing at night. The problems with maintaining personal hygiene is particularly acute in many home situations because of the poor physical conditions of the buildings.

For many, the demands of caring can cause interruptions to work and study. Caring often involves full time demands and carers have to find ways of sharing day and night shifts. The pressure of full time caring can be frustrating.

- But it was really tiring for me and mum. Sometime I was frustrated because it was just ongoing thing .. I felt like having a break but I couldn't because I was more or less thinking of her.. you know, how she feel

In many cases Aboriginal patients had complex health needs.

- She is a person with very special health needs and her daughter is exhausted.

In some cases carer exhaustion contributed to patient placement in hospital.

- (‘ Mmm, but we - we've actually had some people who coming towards the end ... it's all too much for them (the family) and they wanted them to go into hospital because the family couldn't cope and that's happened on a couple of occasions. Not often, but just occasionally done

It was noted that towards the end of the patient's life the carers need emotional as well as practical support.

- ‘I guess when they're towards the end they get a little nervous and you'll get more calls at night when they think something's happening and they need that support so that they're not the only person there when it's happening.

ASSISTANCE PROVIDED

Participants spoke of the assistance provided to carers by various organisations. The local community clinics were mentioned as a source of assistance with toileting, provision of medication and clinical care. Meals-on-wheels were much appreciated for providing food when the carer was not available because of work commitments. Aged care was noted as providing assistance with washing and personal hygiene. In some areas the local women's centre was noted as a source of emotional support and referral to other organisations.

In view of the practical difficulties associated with caring, respite care was reported to be as a necessity. For participants in this study respite care usually required relocation of the patient to Darwin.

- We use respite care and that seems to help for a bit because it is quite tedious work and hard work. The respite care works quite well giving them some time off. (By respite care you mean someone coming in to give them time off?) No we send them to Darwin for two weeks.

As outlined in full elsewhere (McGrath et al., 2006b), there is a great need for, but lack of, local respite services.

Accompanying the description of services that were available is the concern that Aboriginal peoples either do not know what is available or can be reluctant at first to ask.

- Once they know that they can ask for things and they can ask for help they – they do which is good... that's the problem is sometimes they – the families don't feel that they should ask for more or they – they don't know whether they can or not and I try to encourage them.

DISCUSSION

The findings emphasise the importance for Aboriginal peoples of caring for their own sick and dying. The value of caring is reported to be strongly held in areas where there are well developed family networks and respect for traditional culture. Family involvement in caring is seen as providing closeness and reducing the fear associated with serious illness and death. Stoltz and associates (2006) refer to such closeness as 'sensing togetherness' and document it as a primary experience for family caregivers looking after a relative at home. As Sullivan and associates report (2003:117) it is seen as the 'Aboriginal way' to care for a family member who is dying, a tradition that has been established for generations.

Participants indicated that kinship rules determine which individuals in an Aboriginal family are in the correct relationship to provide the caring. According to the Central Australian Palliative Care Service the cultural restrictions on who is able to care for a family member and what types of care they can provide are factors that can impinge on the capacity to provide care to seriously ill Aboriginal patients (PCA 2004:59). Further findings from the present study highlight the importance of ensuring that full information is given to the 'right' people in kinship network with responsibility for caring (McGrath et al., 2005) and point to the cultural appropriateness of using 'family meetings' as a way of 'sharing the story' about the patient's illness with the appropriate family members (McGrath et al., 2006a).

The findings indicate that because of kinship obligations in relation to care of the dying, seriously ill Aboriginal patients are likely to have large numbers of visitors. As Winch (1989) explains, in

Aboriginal cultures it is important to pay last respects before death even if this requires travelling long distances, so there may be many people from the extensive family networks with an interest in the patient. In relation to the kinship rules, people who may be regarded by Western culture as a distant relative to the patient may in Aboriginal cultures have strong responsibilities to the patient or the patient's family (NPCP 2004). It can thus be very distressing for family members to be subject to policies that restrict the number of visitors (NPCP 2004:33). As Fried (2000) argues, culturally based considerations of lifestyle, beliefs and values assume increased significance during end-of-life care. Cultural respect for the importance of the Aboriginal family connection in relation to caring for sick members is reported to be at the core of appropriate health care practice. The findings from the present study point to the fact that such respect needs to be built on an appreciation of the strong motivation and ability that many Aboriginal people have for successfully caring for their own.

The findings posit health care service delivery strategies that can foster cultural respect in institutions such as hospitals, hospices and respite centres including provision of space for extended family visitors, development of outdoor areas for family meetings, and provision of folding beds for family members who wish to stay to support the patient or their carer. Where ever possible in the institutional setting relax the visitor number policies and consider room and bed placement near an entrance to the external environment to allow large numbers of visitors to come and go with minimum disruption (NPCP 2004: 33). If the Aboriginal patient is at home it would be of benefit to assist with finding accommodation for visitors and sourcing funding for travel (NPCP 2004:33).

However, not all Aboriginal peoples are recorded as wanting to care for ill family members. The findings indicate that there is considerable variation in relation to families or groups. Factors that can act as influences against Aboriginal peoples' involvement in caring for sick family members include a lack of commitment to traditional values, fear of 'blaming' or 'payback', position in the community, concerns about contagion with diseases such as cancer, and a reluctance to engage in the hard work of caring. It is recorded elsewhere that how Aboriginal families respond to illness of a member may be significantly influenced by their place in the family structure (NPCP 2004:33)

The study found that Aboriginal people coping with serious illness strongly want to be cared for by family members. For this, and other reasons, Aboriginal people do not want to relocate for respite or treatment during end-of-life care. Further findings from the study highlight serious concerns about the relocation experience from the perspective of the patient (McGrath 2006) and the escort or carer (McGrath & Patton, 2006) and raise significant questions about the cultural appropriateness of the Western biomedical rationale for relocation during end-of-life care. Separation from family through relocation for treatment is noted elsewhere as causing distress and confusion for Aboriginal people (Stamp et al., 2006). Indeed, the experience for Aboriginal peoples of 'coming down', that is leaving the comfort of family and community to attend hospital, is documented by Tanner and associates (2004) as a form of cultural shock leading to a sense of fear, isolation and powerlessness. Such findings point to the importance of building up local, community based palliative care and respite services to avoid the need for relocation (McGrath 2006; McGrath et al., 2006b).

A pride in the quality of care provided by Aboriginal families was expressed by participants accompanied by descriptions of the emotional and spiritual support they provide to their sick and dying family members. Such support can include preparing bush foods, engaging in music and singing, and activities such as fishing. The success of Aboriginal families in caring for their own is emphasised along with a call for health care professionals to respect the cultural importance of the Aboriginal family connection.

Participants also pointed to the significant stress that is associated with the process of providing care for an ill family member. Caring is seen as difficult and challenging work involving toileting, feeding, driving, taking care of personal hygiene, obtaining equipment, looking after bedding, medication giving, dressing care and liaison with clinical care. Results of a recent Australian survey (PCA 2004) affirm the difficulties pointing to particular problems for Aboriginal peoples caused by premature adult mortality resulting in less available Aboriginal people available to provide care and the fracturing of the networks which would have once supported those in need through dispossession of land (Dodson 1995; Fried 2003).

The lack of resources in the homes of many Aboriginal people was noted as a factor exacerbating the practical difficulties. Further findings from the present study also point to problems with power and obtaining equipment, especially for Aboriginal families in the rural and remote areas (McGrath et al., 2007). Sullivan and associates (2003:70) affirm these findings pointing out that often housing for Aboriginal people is substandard and may not contain a refrigerator for medication, storage to secure

dangerous drugs or washing machine to maintain clean clothing. The lack of income caused by high levels of welfare receipt of many Aboriginal peoples is also recorded as a factor contributing to limited financial and material resources to provide some aspects of care such as buying medications, hiring equipment or payment for medical or domiciliary nursing services (PCA 2004).

The commitment in time and the pressure to provide continuous care can interfere with work and study. Many Aboriginal people have complex health needs which can add to the burden of caring. One consequence of the difficulties with caring is that it can lead to admission of the patient to the hospital in the later stages of illness when the carer is experiencing burnout. End-of-life is thus seen as a time when carers require considerable emotional and practical support.

The findings indicate respite care is very important to give carers a break. At present, however, most respite care in the Northern Territory involves relocation by a trip to Darwin for two weeks as there are few local respite services. Many organisations such as the community clinics, Aged Care, Meals on Wheels, and the Women's Centre are recorded as providing much needed support and practical assistance. However, it was noted that Aboriginal people can be reluctant to ask for help and may not know of the services that are available. Sullivan and associates (2003:116) point out that many Aboriginal families look after their own without outside assistance. Research by Terry and associates (2006) indicates that problems with accessing services and practical support are generic to all dying patients and their caregivers.

CONCLUSION

The generous insight provided by participants throughout the Northern Territory go some way to highlighting the cultural importance for many Aboriginal people of being able *to care* and *be cared for* by family members. Not all Aboriginal people will want to accept the responsibility of caring for seriously ill relatives and some of the reasons for this are posited. The findings outline the many challenges associated with the difficult task of caring and celebrate the satisfaction that many carers experience through their successful efforts.

The key message from the findings for those who work with Aboriginal families during end-of-life care in the health care system is to show cultural respect for the strong family connection. Strategies are outlined for fostering this connection and for supporting carers during the very challenging time of caring for a family member who is dying. In essence the central notion from the findings is simply summed up by one participant, who stated that there is,

‘...a need to respect families’ need to be with and support dying members’.

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