

Relocation for specialist treatment for Indigenous people: escort issues

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Abstract

To date, although there is some literature on the experience of relocation, there are no research papers that focus exclusively on the Indigenous relocation experience. As a first step to address this hiatus, the present article provides findings from an Australian National Health and Medical Research Council two year study on Indigenous palliative care conducted in the Northern Territory that focus on escort issues. The methodology was qualitative, based on open-ended interviews, audio-recorded, transcribed verbatim, thematically analysed. There were a total of seventy-two (n=72) interviews completed with Indigenous patients (n=10), Indigenous caregivers (n=19), Indigenous and non-Indigenous health care workers (n=41), and Interpreters (n=2). The findings indicate that relocation for special treatment is a process fraught with difficulties and challenges for Australian Aboriginal people. Many of these problems such as loneliness, the emotional distress of separation from family, financial distress and the practical problems associated with travel and accommodation resonate with previous research on the tribulations of relocation. However, in addition to these issues, the findings indicate that there are many other specific problems associated with Aboriginal culture that negatively impact on the relocation experience. In view of the quite serious problems associated with relocation for Aboriginal people, there are strong indications from the findings that relocation for Indigenous people should not only be carried out in a culturally appropriate way, but, should be avoided whenever possible.

Key words: Relocation, Aboriginal, Indigenous, Health, Psychosocial, Qualitative Research.

Introduction

In Australia health care services are disproportionately concentrated in major urban areas (AIHW 1996; Humphreys and Murray 1994; Keleher and Ellis 1996). In addition, rural and remote patients are often isolated geographically due to dispersed population patterns, and are therefore often required to travel long distances to access services, especially services of a specialist nature (AIHW 1996; McGrath et al. 1999). Even patients in urbanized areas are required to relocate for prolonged specialist treatments not available locally (McGrath 1998). The process of relocation for specialist treatment is associated with significant emotional, social and financial stresses (Andrykowski 1994; Eyles and Smith 1995; McGrath 1999; 2000; McGrath and Rogers, 2003). Research indicates that relocating is difficult for both patients and their families as the experience disrupts all aspects of the family's lives, with severe stresses placed on both the family unit and individual members. These stresses are exacerbated by alteration in roles and financial problems caused by lost employment income, along with additional travel, food, telephone and lodging expenses (Andrykowski 1994; McGrath 1999, 2000).

Case studies reported by Atkins and Patenaude (1987) demonstrate that relocation can be associated with feelings of abandonment, and a heightened sense of helplessness as patients are removed from the family environment and located in an alien hospital setting during a time when they are experiencing fears about their physical integrity. The process is intensified for patients with a life threatening illness who have to deal with issues of mortality outside of the comfort of the usual network of family and friends (McGrath 1999). All of the relocation issues are magnified for many Aboriginal Australians who have additional cultural concerns. The Western clinical system is recorded as being threatening and alienating places for many traditional Indigenous people (Morgan et al. 1997). In addition, Aboriginal people have strong ties to their land and the notion of community and family relationships are very important cultural characteristics (Mogan et al. 1997; Mountford and Roberts 1965; Bennett 1988). Thus, for many Aboriginal people who have to relocate there are the additional stresses of dealing with the emotional distress of their illness away from the traditional comfort of land, family and community. As a consequence, it is essential for Aboriginal people who have to relocate to the major metropolitan area for specialist treatment to be accompanied by an escort. In the Northern Territory (NT), where the study presented in this article is located, escorts are funded by the government's Department of Health and Community Services to accompany patients relocating to the city for specialist treatment.

To date, although there is some literature on the experience of relocation, there are no research papers that focus exclusively on the Indigenous relocation experience. As a first step to address this hiatus, the present article provides findings from an Australian National Health and Medical Research Council two year study on Indigenous palliative care conducted in the Northern Territory that focus on escort issues. For the purpose of this discussion the definition of escort is taken from the Northern Territory Government regulations (DHCS 2003) for the government funded scheme to financially assist with travel and accommodation during relocation, titled the Patient Travel Scheme (PTS),

An escort is a person who is regarded by the requesting practitioner and/or the treating specialist, as being appropriate and responsible for the client's needs during the period of transport and /or accommodation and during treatment. Persons under the age of 18 years accompanying an eligible patient cannot be an approved escort. Exceptions: Where in the opinion of the delegated officer, the minor can meet the functional requirements of an escort, and, where the patient is able to provide normal adult supervision of the minor.'

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 Indigenous 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 Indigenous person, 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 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 Indigenous health and a meeting of Northern Territory Aboriginal Reference group. The findings under discussion in this article refer to the data in relation to the issues associated with Indigenous escorts who accompany Indigenous patients relocating for specialist treatment to major metropolitan hospitals.

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 2003), 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 data collection included:

- What Palliative Care services are provided and are they meeting the clients' needs?
- How can services be modified to deliver a culturally appropriate, innovative and exemplary model?
- 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 Indigenous people during the end-of-life trajectory.

Participant group

An Aboriginal Health Worker was a participating member of the research team, and co-ordinated 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 the following Australian Bureau of Statistics (ABS 2004) figures demonstrate (Table 1), the populations in these areas are small, and thus the seventy-two interviews completed for the research represents a meaningful consultation with key individuals in the area. Within these four geographical regions, Indigenous peoples comprised 15.2% of the population.

Table 1: Northern Territory populations by geographical area with aboriginal populations in parenthesis (ABS 2004).

Region/City	Town	Population (aboriginal population)
East Arnhem Land	Maningrida	1,645 (1,366)
	Millingimbi	992 (918)
	Elcho Island incorporated with Galuwinku	1,463 (1,346)
	Nhulunbuy	3,804 (275)
	Yirrkala	648 (493)
Katherine Region	Angurugu	822 (721)
	Borrooloola	824 (494)
	Ngukurr	933 (844)
Alice Springs	Katherine	8,610 (1,568)
		26,229 (3,474)
Darwin		68,516 (5,957)
Totals		114,486 (17,456)

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. Seventy-two interviews were completed with a wide range of participants in the above named geographical areas including 10 Indigenous patients, 19 Indigenous caregivers, 41 Indigenous and non-Indigenous health care workers and 2 Interpreters.

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 escorts relates to important concerns raised by various participants. Data was collected using taped interviews with Indigenous clients and service providers in the participating communities. All of the data collection was completed by a respected Indigenous palliative care health care worker 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. The interviewer also recorded notes at the end of each interview that detailed her immediate impressions of the interview process. 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 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 and 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 and Carpenter 1995; Crombie 1996; Greenhalgh and 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 and Atkinson 1996; Marshall and Rossman 1995).

For some interviews, an interpreter was used. Hence, many of the language texts were influenced by a combination of English and the Indigenous language. 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 Indigenous 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.

Results

The findings indicate that escorts encounter a range of accommodation situations once they reach their city destinations with patients. Those accompanying palliative care patients generally stay with patients in their hospital room. Escorts accompanying non-palliative care patients either stay with the patient, or, as will be expanded upon later, they are accommodated in hostels. Where the patient's gender makes it culturally inappropriate for the escort to sleep in the same room as the patient, they may be accommodated at a gender-specific hostel.

The findings on the experience of relocation for the escort will be presented in four sections:

1. The need for escorts
2. Factors affecting the suitability of escorts
3. Factors contributing to the phenomenon of escorts leaving patients rather than remaining to actively care for them
4. General funding issues

The Need for Escorts

Patients have a strong need for emotional support when relocating for specialist treatment. Further findings from the study, yet to be published, indicate fear of the unfamiliar 'high tech' hospital environment and treatments, cultural alienation, language barriers and loneliness due to separation from family. These factors cause patients so much distress that they are often too frightened to relocate on their own.

They would be frightened [to go into hospital without family]. I mean I would be; would be lonely, frightened, no family around. Just going in this clinic I feel frightened, I got to have my aunty or someone with me.

Special mention is made of the need for escorts to accompany minors travelling to the city for treatment. It was noted that providing an escort for a minor was a legal requirement. However, it is seen to be culturally important for all Indigenous patients to have access to escorts no matter what their age.

Always somebody responsible for that person, eh, Aboriginal way? No matter how old they are....

Availability of Escorts

A number of participants noted that only some patients relocating for treatment were able to take an escort. There were regional differences in the availability of escorts.

. . . probably not as many as you'd get up in Darwin region.

Age restrictions also affected the availability of escorts for patients.

With the health department you can only go when – if they – you know, that kid is under what, 16, I think.

Another factor affecting escort availability is fear of *'blame'*. Indigenous people may be reluctant to nominate someone to be an escort if they feel that person will be at risk for being blamed for the patient's death.

Provided there's not that risk of – or vulnerability of being blamed, generally people are happy to nominate someone to go in with them and look after them.

An escort is more likely to be nominated in situations where death and dying has already been accepted for that patient as blame is less likely to occur.

Escorts haven't been so much of a problem from my experience provided that there is an understanding of death and dying and acceptance by the family.

Practical obstacles to the availability of escorts for patients were also noted, including issues with transport.

I couldn't fly out with him to Darwin... Yeah, because they didn't have any room on the plane.

When no escort is available, health workers are sometimes used.

I know on one occasion I sent one of our senior health workers because we couldn't get another escort.

Suitability of Escorts

It is noted that if escorts are chosen carefully they are likely to be able to sustain the process of caring long-term for patients while they are relocated. However there is an extensive list of requirements that must be met if escorts are to be chosen in a way that is culturally sensitive, which as the following findings indicate are either difficult to meet or are overlooked.

The importance of being in the 'right relationship'

As outlined elsewhere (McGrath et al. 2005), it is important in working with Indigenous people in health care to be aware of the importance of being respectful of relationship rules. For Aboriginal people, escorts must be in the 'right relationship' with the patient according to cultural tradition; however, this is not always appreciated by Western health care workers.

It wasn't until after the person's passed away that we've found out that, yeah, they were too close to family.

The escort accompanying the patient needs to be the 'right person' to make decisions about a patient's treatment, which often does not happen.

If a decision is to be made while they're there that that person is often not one who can make that decision.

Being in the 'right relationship' is a particularly important issue in relation to terminal care. It was noted that escorts were often the only people from a community to receive information about the patient's death.

When someone's in intensive care they pass away and because there's an escort there or relative, they talk to them and that's it.

However the strict cultural codes of practice governing who has the authority to receive this information and pass it on to families, means that the escort is often not entitled to do so.

So often that escort is not the most appropriate person.

Gender affects escort suitability

Escorts may find that they are unable to carry out their role as it involves tasks and situations that are only appropriate for a person the same gender as the patient.

There's some traditional things that they can't stay too. We had an old man that was dying, his wife actually come on the plane with him but she could not sleep at the hospital so we had to move her out ... Women's business is women's business and man's is man's, yeah.

Escort's ability to give consent for treatment

It is considered helpful if the escort is also legally able to give consent for the patient's treatment, especially in instances in which the patient is a child.

I would prefer a parent, somebody that is – that child has to go to theatre they're right there to sign, right, we don't have any hold ups in that area. Sometimes that's not always possible ...

Escorts must not be at risk for 'blaming'

As discussed in the section on availability, escorts are not considered suitable if they are seen to be at risk of being blamed for the patient's death.

I mean blame - comes back to the problem of blame. If people are afraid that they might be at risk of being blamed then yeah, they're reluctant to go in and out because if that person passes away – and certainly in East Arnhem there's still a big stigma with elders going to hospital and not coming back.

If the cultural factors outlined above are not taken into careful consideration in the escort selection process, it is likely that the escort will be unable to remain with the patient as their escort during the relocation period.

Escorts Not Remaining to Actively Care for the Patient

It is not uncommon for escorts to leave the patient after they have relocated to the city for specialist treatment.

We do get a few issues with escorts going over and taking off.

The escort's decision to leave may be influenced by the above-mentioned suitability factors and is also often influenced by a range of issues associated with health care practice, Indigenous cultural and personal concerns, and accommodation issues, and fear of separation, as listed below.

Health care practice issues

Careful selection of the escort at the outset is noted to be crucial.

I guess careful selection of the individual to start with is the key. If you've got someone – which unfortunately does happen – that seize the opportunity to get to town then, yeah, as soon as they hit town they're going to be disappearing off.

Where health care workers know the families well, it is seen as an important factor in facilitating the selection process.

If we know the family well it's not a big issue because we know who we think would be capable of doing what.

However this is not always possible because of lack of familiarity with families,

But if they're a family that's not well known to us it makes it very difficult to make adequate decisions on escorts.

Or because a suitable person is just not available,

We do have a little bit of trouble sometimes tracking down somebody that can be an escort. It's just we don't know where they are.

The escort decision may be made too quickly, leaving inadequate time for a thorough consideration of that person's appropriateness.

... stampeded them and found this girl, brought her up. And we'd only just turned our backs and went to get something from the kiosk and the escort bolted.

Indigenous cultural and personal issues

A major reason for escorts not remaining with patients is that the relocation experience is a frightening one for them.

Yeah, and there again it's simply quite a big scary experience for the escort as it was for the health workers that went down; she just wanted to come home...

The cultural importance of family and need for group relationships means that loneliness is felt acutely by escorts.

There are very few, if any (name location) that I know, who could actually – who would feel comfortable staying in my house as one or 2 people. It's too lonely ... there are no relatives. People want to be with their relatives.

Much stress is also felt due to the separation from the land which holds such strong ties for Indigenous people. Metropolitan hospitals are described as 'too distant'. Escorts also struggle with the emotional difficulty of caring for their clients.

... felt that they couldn't do it or it's just been too upsetting for them.

Many find that the responsibility placed on them is just too great.

At some point, once they realise that --what's involved or helping care for a client they've come back.

It was noted that it was not just informal carers who were affected by these factors, but also professional carers.

... one of our senior health workers ... said: I'm just looking after... at this great big hospital. And then she couldn't sleep on the hospital bed and in the end I said: take your mattress off and stick it on the floor. And that's what she did, but: oh, I want to come home. And, you know ... this is what happens when you get to Adelaide.

Escorts may feel overwhelmed by the responsibility of being the sole communicator of medical information to the patients they are caring for.

They get over there and they find out that they may actually have to ... translate, then they feel responsible because they – in charge of giving that information to that person.

They often feel intimidated when talking with doctors,

And some escorts going over and being so shy that they're not helpful because they are too frightened to talk to the doctors, too frightened to translate.

and fear that they will make errors when translating for the patient.

They get frightened they're going to get it wrong.

Exhaustion is common, especially in situations where a single person has been caring for a patient over a long period of time with no break or respite.

One person who's doing all the care and that's been nominated to be the carer for that family and they're given all that responsibility and they're not sort of given a break.

Accommodation issues

Limited space and bed availability in hospitals mean that escorts are sometimes unable to stay in hospital with patients.

'The escort's always an issue because of the room and bed space and all the rest of it and depending how heavy the patient is.

This leads many escorts to seek hostel accommodation which can result in a number of additional stressors. Lack of privacy is one common problem for escorts staying in hostels.

I found a couple of people complaining about... the lack of privacy... some of the hostels are actually big communal areas.

Lack of security is often another problem.

And lack of security for their gear... they usually only take one bag but they've never got a lock or anything on the bag so... (they) are able to be accessed by any of the people in the actual hostel.

There are also practical issues such as the lack of cooking facilities in many hostels, and the fact that many hostels are located a significant distance from the hospital. Extra costs are incurred by escorts staying in hostels for the purchase of food.

It costs then an arm and a leg to eat if you don't get them into a hostel that supplies food. And it's very difficult to convince escorts ... to go to Darwin...when they have to pay for their food and everything...it's just too expensive.

Extra costs are also incurred by escorts who wish to travel to visit patients in hospital 'out of hours' when bus transport is not available.

If it's during hours we always organize the AIMS bus to go and pick them up and drop them off etc. but if it's outside of hours they're looking at cab fares through the roof, and of course they just can't afford it.

Fear of being separated from patient

Whilst there are problems with escorts leaving patients, there are also many escorts who fear being separated from their clients.

They get very worried about being separated from their clients – of course from their family member.

General funding issues

There are major funding issues affecting escorts in addition to the costs associated with hostel accommodation. The amount of funding available for escorts is described as generally insufficient.

I'm very supporting of escorts but of course the financial – you know, the budget isn't... (do you feel that they adequately support... when they do go) No.

Financial management is seen to be hampered by the fact that money was provided for escorts as lump sum payments. It is suggested that weekly payments could facilitate financial management.

Sometimes it's a lump sum is given when perhaps it would've been better to have a weekly amount of money to help people manage with.

There is no funding available for a second or subsequent escort even though lengthy treatments, cultural factors, and escorts leaving often necessitate a change in escort.

They might have even got all the way to Adelaide and then they want to change over. And then you go to the... system and they say no, we've taken one escort.

It is often extremely difficult or impossible for families to raise the money needed to fund a change in escort themselves.

It's a bit hard because the family got not enough money to pay for the plane and also for accommodation it's a bit hard sometime and it's the loving care that we love for our family'.

Discussion

As outlined in Figure 1, the findings indicate that relocation for special treatment is a process fraught with difficulties and challenges for Australian Aboriginal people. Many of these problems such as loneliness, the emotional distress of separation from family, financial distress and the practical problems associated with travel and accommodation resonate with previous research on the tribulations of relocation (Andrykowski 1994; Eyles and Smith 1995; McGrath 1999, 2000; McGrath and Rogers 2003). The NT Health Department guidelines for PTS affirm the participants' worries about age limits (as discussed in the introduction) and the practical concerns about travel as seen by the following statement with regards escorts,

The carriage of an escort at time of evacuation is subject to consultation with the pilot and flight nurse. (DHCS 2003:2.6)

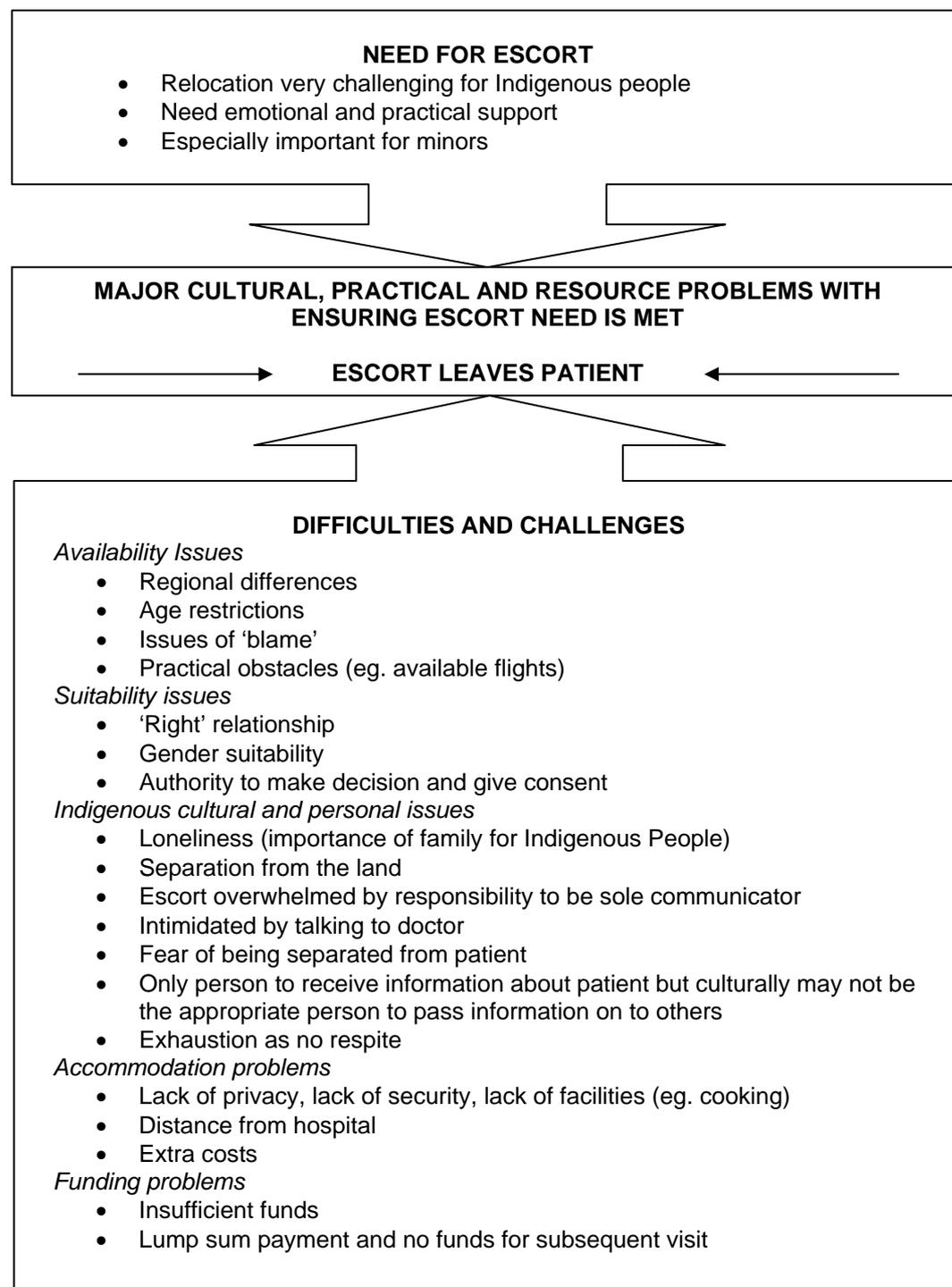


Figure 1: Overview of Issues

However, in addition to these issues, the findings indicate that there are many other specific problems associated with Aboriginal culture that negatively impact on the relocation experience such as the significance of the Indigenous tie to land, practices based on the importance of relationships and community and concerns about retribution and 'blame'. As demonstrated by the findings from this study, the serious difficulties can translate into the significant problem of Aboriginal escorts leaving the patient at the metropolitan centre.

Much has been written about the Aboriginal connection with the land (Bennett 1988) that affirms the present findings about the seriousness of the hardship imposed on Indigenous people when forced to relocate away from their homeland. Further published findings (McGrath et al. 2005) from the present study provide a detailed description of the need to engage with the 'right' person within the Aboriginal community in making any health care decision, particularly those associated with end-of-life care. The

full outline of the issues associated with the Aboriginal spiritual notion of 'blame' is also outlined in separate findings from the study (McGrath et al. 2005). Suffice here to indicate that in Aboriginal communities 'blame' is apportioned when death occurs (McGrath 2000; Weeramanthri and Plummer, 1994) and so involvement as an escort during the patient's dying trajectory can have serious repercussions for an Aboriginal person. This can add to the burden of caring and can lead, at times, to the escort leaving the patient during the hospital stay. For this reason it is essential that the choice of escort is made in full and close consultation with the Aboriginal community.

The seriousness of the problems with regards escort provision for Aboriginal people echoes in the NT Coroner's Courts as seen by the following description from a recent case of the death of Lenie Pinawrut,

4.0 In any event, what occurred was that a demented, sick, old aboriginal man was returned to Katherine by bus, in his hospital pyjamas, possessing only his bus ticket. He had no-one to meet him, and was obviously incapable of contacting his family in Katherine, as evidenced by the circumstances of him being found in Katherine by family. He was found under a tree near the tourism centre. It beggars belief that no-one involved in his discharge, from the medical staff, nursing staff or Self Care Unit staff, would not have appreciated that they were sending a demented old man to Katherine without an escort. The lack of thought, and in particular communication, exhibited by the staff led to the deceased suffering considerable discomfort on the day of his discharge from RDH. It was only fortuitous that he was found by members of his family that afternoon, under a tree near the tourist information centre. Bearing in mind that the family had not been informed of his discharge, it was very fortuitous that they found the deceased after his arrival in Katherine, alone. (McDade DC, Coroner's Court, 17 July 2003, Darwin @ [4])

Recommendations

In view of the quite serious problems associated with relocation for Aboriginal people, there are strong indications from the findings that relocation for Indigenous people should not only be carried out in a culturally appropriate way, but, should be avoided whenever possible. To a large degree, from an Aboriginal cultural perspective the Western biomedical assumptions on which relocation are founded are inherently flawed. If the traditional Aboriginal connection with the land, the importance of family and community relationship, the need for communication based on 'right relationships' and the spiritual concerns in relation to sickness about 'blame', are taken into consideration there is a significant case for arguing that relocation is not a viable alternative. The findings affirm McMichael's (1989) notion of the 'profound cultural dissonances' between Aboriginal and non-Aboriginal beliefs about health and health care. The recommendation from this research is that the most appropriate response to end-of-life care for traditional Aboriginal people is to build up local community based services in order to deflect the need for relocation to the metropolitan hospital.

If, relocation is considered the only or essential step then the findings indicate the need for the following culturally sensitive process in relation to escorts for Aboriginal people:

- Ensure that all Aboriginal people, irrespective of age or circumstance, have an appropriate escort and that the escort is supported by the PTS program. This requires that western health professionals have a working knowledge of Aboriginal gender and relationship issues and awareness of the cultural practices associated with 'blaming'.
- Establish close and trusting relationships with the Aboriginal community so that when individuals need to relocate it is possible to know who the 'right' family members are to act as escorts, both in terms of the appropriate relationship to do the caring and to make decisions.
- Provide sufficient information to escorts about what is actually going to be required of them during the relocation experience.
- Provide reassurance that it is their role to stay with patients and so they will not be separated from them.
- Appreciate the importance of providing financial support to escorts who either need to return home or who find they are no longer the 'right' person to make decisions for the patient.
- Ensure that escorts are supported, preferably by Aboriginal Health Workers, during the relocation experience. Such support is both emotional and practical, including the need for appropriate accommodation that respects the individual's privacy, security for storing possessions, facilities for cooking and available transport to and from the hospital.
- Guidelines should be in place to facilitate culturally sensitive communication.

- Examine the desirability of providing ongoing payments of financial assistance rather than a one off lump sum.

Conclusion

The insights reported in this article, provided by a wide range of health professionals and consumers, are a sobering reminder that the process of relocating individuals for specialist treatment involves serious decision-making and should not be assumed to be an automatic or routine action. The findings indicate that at best relocation should be avoided for Aboriginal people. The alternative is to strengthen community based health services to deflect the need. If relocation cannot be avoided it is essential that this is approached with considerable cultural sensitivity.

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