Improving Palliative Care Outcomes for Aboriginal Australians: Service Providers Experiences with Aboriginal People in Western Australia

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Palliative Care Issues in Western Australia

- Palliative Care services provided by private sector
- Two-thirds of the people who died of cancer received specialised palliative care (SPC) services
- Less than one in ten people who died of selected non-cancer conditions received SPC
- Disadvantaged group: single, widowed or divorced; Indigenous people; those aged over 85 years and others; living in an area other than a major city
- Aboriginal Medical Services does not have SPC
- No comprehensive data on the rates of Aboriginal access to SPC
- Aboriginal people mostly receive SPC in hospital

Rosenwax and McNamara, 2006; Sullivan and others, 2003
A BRIEF BACKGROUND

Three interlinked studies

Objectives of the service provider study

- Document the perspectives of service providers about Aboriginal cancer and palliative care patients in WA
- Identify service providers’ key experiences and concerns in managing treatments and care in Aboriginal people
- Explore opportunities to overcome gaps in communication between mainstream service providers and Aboriginal people
RESEARCH PROCESS AND METHODS

Ethics approval

Cancer Council Grant 2007 (supporting the PhD study)

- Data collection in Perth, Geraldton, Roebourne, Carnarvon
- Over 30 in-depth interviews with Aboriginal people affected by cancer and 20 interviews with service providers
- Thematic analysis

New Data Collection in 2011 – additional and current perspectives of HSPs

- In-depth interviews with HSPs
- A variety of service settings
RESEARCH FINDINGS

Few in numbers

“I suppose on a monthly basis we probably consulting on, we’ve got about thirty patients on average but about only two or three of them are Indigenous.” (Rural non-Aboriginal HSP)

“it’s difficult because clearly if we’re not seeing many then our skill set as a team is not fully developed and optimal.” (Urban non-Aboriginal HSP)

Key Themes

1. Barriers to utilisation of PC
2. Problems and issues in dealing with Aboriginal patients
3. Aboriginal people’s preferences at the end-of-life
BARRIERS TO UTILIZATION OF PC

• Lack of awareness of such services and lack of understanding

➢ Across the board

it’s my own family and they say, “Oh palliative care, what’s that?” And people just tend to assume it, it’s in the sort of like the last few hours before you die. And so I think there’s just barriers for everybody .... So I would be doing sort of more, well just educate the public in general I think really. (Rural non-Aboriginal participant)

➢ Lack of appropriate resources and information

• Late referral

• Lack of availability of local services
• Palliative care = ‘death and dying’

“you’re palliative and now you’re going to die and that’s that, there’s nothing else going to be happening.” (KD, rural non-Aboriginal participant)

“Whereas our approach is still very much active, care and treatment of a person to manage their pain and to make their end of life experience as comfortable as possible and support for the families. A lot of people still don’t know or probably appreciate that’s what our service is all about so I would imagine Aboriginal people are no different, perhaps even worse off in terms of understanding what it means to have our service involved and the benefits of it I guess. That to me is the obvious barrier” (Rural non-Aboriginal participant)
PROBLEMS AND ISSUES IN DEALING WITH ABORIGINAL PATIENTS

Communication around death and dying

“I find it very difficult to begin the conversation about the end of life with Aboriginal people. The process of talking with Aboriginal people about death is a very difficult one and I don’t think I’m doing it very well. There’s a strong sense, I feel of Aboriginal people avoiding the topic and I just really don’t know what to do about that strong sense of avoidance.” (Rural non-Aboriginal participant)

‘Non-specified’ anger

Silence and ‘non-communicative’
Family feuding over services/ will/ funeral

“Because he was sick we did, we were half way through our wills and then we got, he got flown to Perth and I thought, here we go, but yes, but I tell them well, every patient I see now, “Make sure your will, make sure you write a will, tell them where you want to get buried, write in the will where you want to get buried otherwise there are going to be arguments.” So I tell a lot of people that now. I advise them too. Because some of them say, “Oh I want to go get buried back over here,” and I say, “Well put it, in writing, don’t tell me, have it written up for you.” (Rural Aboriginal participant)
Cultural issues

“a high likelihood of payback for the family members who might have been perceived as being there at the point of death. So even, a person who’s giving care to an Aboriginal person, may well be accused of being a contributor to their death. And so many Aboriginal people and families are, will want to avoid that level of responsibility and retribution by having the family member in the hospital at the end stage.” (Rural non-Aboriginal participant)
Informed consent

“When a person is sick and nauseated and distressed and the family are stressed, getting a, informed consent is next to impossible whether you’re white or Aboriginal.” (Urban non-Aboriginal HSP)

Providers not flexible with time

“Number one was they felt that we weren’t flexible enough with time and I think that’s because they don’t understand that we’re not there just to look after that particular person. We’re there to look after that particular person at that particular time because after we’ve finished here we have to go somewhere else. So that’s taken a while for people to learn and that’s all, that’s always going to be an on-going issue so we are quite inflexible about times.” (Rural non-Aboriginal HSP)
ABORIGINAL PREFERENCES AT THE END-OF-LIFE

They want the best care

“They just want the care, they want the best treatment. … if the best treatment happens to be palliative care then it doesn’t matter what name you put to it….yes, but the non-Aboriginal patient is more, you know, puts people in you’re the oncology doctor, you’re the surgeon, you’re the palliative care doctor, they’ll put us in our boxes, whereas, maybe the Aboriginal one won’t.” (Urban non-Aboriginal HSP)

“then it’s sort of… the hospital sort of take care of all their needs or anything, it’s yes. If I know before it gets too bad we step in and give services at a home and do what we can. We go, take them to the doctors and do their shopping. Anything that they need, we can do while they’re at home.” (Rural Aboriginal participant)
The importance of place and the wish to die at home

“Nearly always the Aboriginal person, that they come into hospital and they die in hospital. It’s very unusual to, for an Aboriginal person to, to die at home here, even though there’s a lot of talk and rhetoric about dying you know, at home and in country, it often happens that, in fact it’s almost inevitable that a person will die in hospital rather than at home.” (Rural non-Aboriginal HSP)

“We need a palliative care centre here where the people can actually die here and that’s what they want and have their, the appropriate doctors or facilities and things for them to stay here where they want to be with their family and friends because Perth is a long, long way away to them. (Rural Aboriginal HSP)
People should have a choice

“you should have choice as well. There’s a common theme within the health profession that, you know people want to die at home but not all people want to die at home and not all, and it won’t it’s not maybe achievable for whatever reason, so people do have to have their choice, that’s what I feel and most certainly you know people can die at home around their family, that’s wonderful with support systems but it’s, it’s not, it’s not for everyone. It’s not for everyone so they have that option (RA, Rural non-Aboriginal participant).
Being with the family

“there’s a gentleman dying possibly today and there’s about fifty people at his house at the moment. The logistics of feeding and housing and looking after fifty people blows my mind but that’s just how they are.” (Rural non-Aboriginal HSP)

Care about the family oriented support services provided by palliative care providers

“She knew we would be there each day to shower her. She knew that we would be there to help her manage her medication. She knew that we would be there each day to help her family to understand what it is that they had to do to maintain her wellbeing when we were not there. She also knew that she could ring us after hours if she needed to or to see her doctor. (Rural non-Aboriginal HSP)”
Aboriginal staff/ Long-term relationship with non-Aboriginal HSPs

“if I see the family then I will liaise with the family and you know, how are you and how’s things…. Once they go from here, and I go, I don’t go to the funeral. Yes I haven’t been to any of the funerals. I don’t know why, I think in myself that if I go to the funeral that’s like the last stage of it, and then that’s the accepting. Like if they go from here from to their home, then they’re not dead to me. (SM, Urban Aboriginal participant)
SUMMARY OF KEY FINDINGS

• Aboriginal people have little understanding about palliative care
• Health professionals feel hesitant and challenged to discuss end-of-life and death
• Non-Aboriginal HSPs are unsure about spiritual issues
• Differences observed between rural/remote and urban health professionals
• Consent issues: Individual vs. communal
• Family is the key for most Aboriginal people at the end-of-life
• Mostly supportive family were observed by HSPs
• Most people prefer to die at home (?)
• Aboriginal staff preferable
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