

Improving end-of-life care for Indigenous Australians: the role of PEPA

Michele Holloway¹, Shaouli Shahid¹, Stuart Ekberg², Patsy Yates², Gail Garvey³, Catherine Jacka², Sandra Thompson¹

¹Western Australia Centre for Rural Health, University of Western Australia, ²Queensland University of Technology,

³Menzies School of Health Research

Introduction

Aboriginal and Torres Strait Islander patients (hereafter referred to as Indigenous) with life-limiting conditions have complex needs, experience reduced access to and uptake of treatment, and have lower utilisation of palliative care services than the general population. Many Aboriginal people wish to go home when they are very ill as they wish to die where they belong (McGrath, 2000). In many communities, the local health clinic and community nurse are the mainstays in terminal care. (Pam McGrath, 2007). Poor availability of culturally-safe specialist palliative care services, lack of understanding of the role of palliative care and lack of palliative care trained health workers particularly in rural and remote settings, has an impact on Indigenous people's end-of-life decision-making. Following her research in the Territory, Catherine McGrath identified that remote area nurses and Aboriginal health workers were ideally placed to contribute to the development of the palliative care services. In addition, recommendations made by Pam McGrath following her research in the Northern Territory include consideration of the importance of engaging in service delivery dialogue to clarify the role of Aboriginal health workers for palliative care service delivery so that they can be employed most effectively. (Pam D McGrath, 2007)

Since 2003, the Department of Health has funded Queensland University of Technology (QUT) to deliver the Program of Experience in the Palliative Approach (PEPA) project. The overall aim of PEPA is to improve the quality, availability and access to palliative care for people with life-limiting illness and their family members at the end stage of life. PEPA offers a range of flexible training models to better equip health staff with the skills to care for Indigenous patients in a culturally sensitive manner. Since 2007, one focus of PEPA has been to target Indigenous Health Workers (IHW) through the Indigenous PEPA program.

Aims

- To explore how PEPA has influenced Indigenous participants and contributed to their provision of culturally appropriate end-of-life care for Indigenous people.
- To make recommendations for how the Indigenous PEPA program could be strengthened

Methods

A qualitative approach was taken for the evaluation in which semi-structured in-depth interviews were undertaken in two phases. **Phase One** examined the history and processes of the implementation of Indigenous PEPA. **Phase Two** evaluated the impact of PEPA participation on Indigenous Health Workers (IHWs) and the communities within which they work. Interviews were transcribed and content analysed thematically, utilising key focus areas to explore differences and similarities across jurisdictions and the effect on participants' willingness and opportunities to engage in palliative care. Analysis had an explicit focus on satisfaction and opportunities for improvements in training and placements.

Outcomes

At the program level, having a dedicated Indigenous Project Officer (IPO) was a key ingredient for success. A high level of success was achieved when the IPO and PEPA Manager both played a pivotal role in liaising with the communities and co-delivering the education. The achievements in the Northern Territory, when there was both an Indigenous PEPA Manager and an Indigenous Educator, demonstrate the real strength of this level of Indigenous ownership and commitment.

Many factors impacted upon achievements at the service delivery level. Better outcomes were clearly evident where there was support from line managers for Indigenous workers to attend training and more than one participant from the service meant further discussion occurred around implementation

at a local level. The impact of the training within the service and the community improved when IHWs were well supported by their health team and they were able to make a significant contribution to providing culturally sensitive end-of-life care to patients and their families. Many interviewees commented on the need for additional education on Advanced Care Planning as this assisted patients and their families with end-of-life preparation.

Conclusions

There was diversity in the delivery of the Indigenous PEPA program across jurisdictions around Australia in part due to the different geographic, administrative, historical and funding arrangements, and in part due to the adaption of the program delivery to better suit the needs of the participants attending. However despite identifying possibilities for improvements, Indigenous PEPA provides a flexible, clinical learning experience for Indigenous health professionals and supports their learning and skill set development in providing culturally appropriate palliative care for Indigenous Australians within hospital, residential aged care and primary health care settings.

Recommendations

Include more direct engagement with primary health care and hospital managers to improve their understanding of PEPA and the role Indigenous staff can play in providing appropriate palliative care for Indigenous patients. Development of appropriate local resources to meet the differing education and literacy levels of the participants should continue to be a key focus area. Trialling longer workshops, including all members of the health team and incorporating a dedicated session on Advanced Care Planning could enhance end-of-life planning and care for Indigenous people.

Bibliography

- McGrath, C. L. (2000). Issues influencing the provision of palliative care services to remote Aboriginal Communities in the Northern Territory. *Aust. J. Rural Health* , 8, 47–51.
- Pam D McGrath, M. A. (2007). The case for Aboriginal Health Workers in palliative care. *Australian Health Review*, 430-439.
- Pam McGrath, H. H.-B. (2007). They Should Come Out Here ...": Research Findings on Lack of Local Palliative Care Services for Australian Aboriginal People. *American Journal of Hospice and Palliative Medicine*, 24(105), 107-113.

Presenter

Michele Holloway qualified as a general nurse and midwife in South Africa in 1983. She worked in a number of different roles in nursing and travel medicine before taking up the position of National Operations Manager of Netcare Travel Clinics, South Africa in 2001. This was a division of the larger Netcare Hospital Group and included 11 South African Travel clinics as well as 5 remote site clinics in Africa. In 2006 she moved to Australia where she took up a position as a remote area nurse in the Northern Territory specialising the area of chronic disease. In 2010 she moved to Darwin where she worked as a Nursing Coordinator for Top End Remote Health division before commencing as the Continuous Quality Improvement Facilitator for the East Arnhem Health Area. She later relocated to Karratha where she worked in the area of chronic disease under the Closing the Gap funding program. After completing a Master of Public Health and Tropical Medicine from James Cook University at the end of 2012, she commenced working at WACRH's Geraldton office where she took up the position of Research Associate on the national research project, Discovering Indigenous Strategies to Improve Cancer Outcomes Via Engagement, Research, Translation and Training (DISCOVER-TT). Michele has worked on a number of projects in the field of Indigenous cancer and palliative and in 2014 was part of the team that evaluated the Indigenous component of the Program of Experience in the Palliative Approach.