Shared bereavement care in western Adelaide

Final Report

A project funded

under

The Caring Communities Program

by the Australian Government Department of Health & Ageing

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31st March 2006

Project commencement date:	March 2003
Project completion date:	February 2006
Fund holder (auspice body):	The Queen Elizabeth Hospital, Adelaide.
Name of service conducting the project:	Western Adelaide Palliative Care (name changed in October 2005 from Western Palliative Care Services)

EXECUTIVE SUMMARY

Shared bereavement care in western Adelaide, *a Caring Communities Program project funded by Department Health & Ageing, based at Western Adelaide Palliative Care, Queen Elizabeth Hospital, Adelaide SA.*

1. Background

Setting: Western Adelaide Palliative Care is based in the Queen Elizabeth Hospital in the western metropolitan region of Adelaide and provides a consultancy service within QEH, to Philip Kennedy Hospice, aged care facilities and the community. The service has 12 in-patient beds, an outpatients clinic and interdisciplinary community outreach and bereavement programs.

The population of the western metropolitan region of Adelaide is culturally diverse and has a high concentration of Aboriginal people. The scope of the project was limited to three communities. The Italian community was targeted as the largest culturally and linguistically diverse group in the region while the Vietnamese community was chosen as a growing, newly emerging Asian community whose bereavement needs are poorly understood. The Aboriginal community was targeted due to low access rates (0.4% of referrals), characterised by late referrals with multiple psychosocial and grief issues facing families.

2. Project Objectives

- To collaborate with key stakeholders from Aboriginal and culturally and linguistically diverse communities to identify resources, barriers, needs and gaps in the access and provision of culturally appropriate palliative and bereavement support.
- To establish links and partnerships with key stakeholders from Aboriginal, Italian and Vietnamese communities in the western region concerning the provision of palliative and bereavement care.
- To promote palliative care to build the capacity of Aboriginal, Italian and Vietnamese communities to access bereavement and palliative care services.

3. *Methodology*

- *Literature review*
- Three steering committees were established representing peak bodies and key organisations from each community.
- Focus groups and interviews were held with health workers, community members, past carers and Aboriginal Elders. Semi-structured questions were used to collect qualitative data on people's experiences, views, local and cultural knowledge.
- Quantitative data collected - demographic information, referral numbers, cultural identity, country of birth, language spoken, diagnosis, age.
- Palliative care education sessions were conducted agencies and community / carers groups.
- Cultural competence training was conducted for mainstream staff.
- Community working groups developed culturally and linguistically diverse and Aboriginal cultural protocols

4. *Results*

- Major themes were identified in the data collection:

- Lack of knowledge of palliative and bereavement care was identified as a barrier to accessing services in Aboriginal, Italian and Vietnamese communities.
- The Aboriginal community lack of trust dealing with mainstream health services due to historical injustices and past negative experiences was identified as a critical factor to low access.
- The need for mainstream workers to be culturally competent and work in partnership with Aboriginal and multicultural services and workers were identified as significant factors in improving access to culturally appropriate services.

Unexpected outcomes

Additional funding from the Department of Health and Ageing for the local Aboriginal Elders group to design and produce a banner for the in-patient unit and promotional materials explaining palliative care in culturally appropriate ways.

The establishment of a Think Tank / working group compromising key palliative care and Aboriginal bodies to further develop initiatives for Aboriginal palliative care beyond the project.

Funding application submitted to second round of Department of Health and Ageing funding and Department of Health SA for Aboriginal grief and loss training and supervision program for Aboriginal and non-Aboriginal health workers.

5. *Discussion*

Major Achievements and sustainable outcomes

- Cultural protocols – Italian, Vietnamese, Aboriginal.
- Cultural competence training – culturally and linguistically diverse and Aboriginal. Participants from partner mainstream organisations, several areas within TQEH namely, palliative care, renal, cardiology, respiratory, the General Manager, Aboriginal Liaison Officers, Emergency Department, community mental health.
- Discussions with QEH management and Central Northern Adelaide Health Service re need for ongoing cultural competence training for clinical and non-clinical staff.
- The links made with peak Ethnic and Aboriginal organisations. Ongoing networking with key Aboriginal and multicultural agencies in the western region of Adelaide.
- Staff from Western Adelaide Palliative Care to attend staff meetings on six monthly basis to sustain links and partnerships between palliative care and Aboriginal and culturally and linguistically diverse workers.
- Aboriginal Banner for in-patient unit developed by local Aboriginal Elders group.
- Aboriginal palliative care posters and pamphlets developed by local Aboriginal community members.
- Working with Palliative Care Indigenous Resource Kit steering committee - Cultural protocols and process of engagement to be included in SA Companion Book for mainstream palliative care providers.
- Working group / Think Tank initiated by project bringing together key palliative care and Aboriginal peak bodies.
- Commitment from Department of Health SA to continue to facilitate the group to progress Aboriginal palliative care.
- Funding application for training and supervision for non-Aboriginal and Aboriginal workers focusing on loss and grief counselling. Discussions with Department of Health re funding opportunities.

Factors contributing to success of project

- Time spent in building relationships with key bodies and stakeholders in each community was an important factor in the success of the project.
- The project goals evolved as new learnings were achieved about needs of the communities. For example, initial bereavement focus broadened to palliative and bereavement care.
- Advice, guidance and support from key people in targeted communities.
- The timing of this project was a contributing factor in its success as the aims and findings were congruent with other projects:
    - National research into Aboriginal palliative care.
    - Indigenous Palliative Care Resource Kit

Problems facing the project

The large number and diversity of communities in the western region of Adelaide. The scope of the project attempted to target Aboriginal and culturally and linguistically diverse communities which was too ambitious. This problem was addressed by focusing on two culturally and linguistically diverse (CALD) communities, with a view that the model could be adapted to other CALD communities in the future.

Dissemination of information about project

Presentations at state and national palliative care conferences, seminars and written information has been disseminated in a range of publications:

1. Aboriginal Palliative Care Workshop 2004
2. State palliative care update – 2004
3. Caring Communities National Workshop 2004
4. 8th National Palliative Care Conference – 2005
5. Palliative Care Focus Forum 2005
6. Palliative Care Community Forum 2005 – Jumping cultural hurdles
7. Lyell McEwin Palliative Care Service Education – 2005
8. Palliative Care Newsletter
9. QEH newsletter
10. QEH intranet
11. Adelaide Western Division of General Practice
12. Shared bereavement care in the west project newsletter sent to all partner organisations on regular basis.
13. Australian Medical Association Newsletter
14. Article on process of engagement with Aboriginal community
15. Aboriginal Health Council newsletter
16. Cultural protocols and process of engagement to be included in SA Companion Book for Indigenous Palliative Care Resource Kit
17. Network meetings - western Ethnic and Aboriginal organisations
18. Full Council of Aboriginal Elders
19. Western Aboriginal Elders group

Link with the National Palliative Care Strategy

The *National Strategy* respects the central importance of choice for patients, and families to meet cultural, linguistic and spiritual needs, understand nature of palliative care and can access service they need. A major goal of the strategy is to increasing community awareness and understanding of palliative care to build community capacity

This project has provided information and education to Aboriginal, Italian and Vietnamese community members, services and health workers about palliative care and bereavement to build the capacity of these communities to access culturally appropriate palliative and bereavement services.

The goal of the strategy to promote and support partnerships involving collaboration between palliative care and agencies, communities groups and individuals palliative care has been a significant focus of this project. It has developed links between the palliative care service and key workers and agencies in our region and ongoing networking arrangements.

Lessons for other regions / services

- Importance of building relationships with key bodies
- Develop partnerships with community organisations
- Need to build trust, particularly with Aboriginal communities and workers
- Outcomes generalisable to other services / region

Cultural protocols

- Cultural competency training
- Process of engagement with Aboriginal community
- Ongoing network meetings with key Aboriginal and ethnic services / workers in local region

6. Conclusion

The following are recommendations that rose from this project:

- That cultural awareness training is implemented on an ongoing basis for mainstream clinical and non-clinical staff to build cultural competency skills. Specific Aboriginal and culturally and linguistically diverse programs be conducted by experienced trainers from Aboriginal and ethnic backgrounds.

- That the cultural protocols developed by the project be adapted and further developed by mainstream health professions working with clients from Aboriginal or CALD backgrounds. That cultural protocols form part of the cultural awareness training.

- That the model of engagement developed in this project be widely disseminated to mainstream palliative care services as an example of how to engage with local Aboriginal communities.

- That mainstream palliative care peak bodies and services develop partnerships with key Aboriginal and multicultural stakeholders.

- That palliative care services establish ongoing networking with bilingual and Aboriginal health workers and services.

- That funding be made available for Aboriginal loss and grief counselling training program for Aboriginal health workers and non-Aboriginal mainstream workers.

- That the concept of employing Aboriginal workers in palliative care services be explored by palliative care and Aboriginal peak bodies.