

Palliative Care for Indigenous Peoples

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-
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Culture-centred Palliative Care

Indigenous peoples make-up approximately 2.4% of the Australian population, and comprise two distinct cultural groups – Aboriginal peoples and Torres Strait Islanders. The term ‘peoples’ is used to denote the heterogeneity of Australian Indigenous populations, which today comprises 200-300 different language groups or tribes.

It is understood that Indigenous peoples have a life expectancy at birth of 17-20 years less than other Australians, suffer higher morbidity from preventable diseases and a disproportionate mortality associated with treatable conditions such as cancer, cardiovascular diseases and renal diseases (Australian Bureau of Statistics, 2006). Paradoxically, Indigenous peoples have been under-represented in the palliative care patient population (Sullivan et al., 2003). Factors inhibiting Indigenous peoples’ access to palliative care include racism (institutional and personal), cultural blindness or ignorance of differences, and different perspectives of health, illness, dying and death (Sullivan et al., 2003; McGrath & Holewa, 2006; Prior, 2005).

Compatibility of core values

Indigenous Australians embrace the spirit and intent of palliative care because at first glance the values of compassion, caring and holism that define the palliative approach resonate with Indigenous cultural values.

Palliative care philosophy values the ‘total human experience’ as the essence of service provision and acknowledges the spiritual dimension of dying and death. Furthermore, the approach of palliative care is family centred and flexible to differences. From an Indigenous perspective, serious illness and death are essentially spiritual and social events (Rosas, 1995 cited in Indigenous Palliative Care Resource Kit, p.16) and culture and family are always paramount in health and illness care.

In Indigenous communities the ‘sorry business’ of terminal illness, dying, premature death, funerals and grieving are part of everyday life. Yet studies have demonstrated that Indigenous patients and families remain ambivalent about accessing palliative care because they fear losing control to the authority of *whiteman’s* medicine and dying away from

their country. Richard Trudgen in his important book ‘Why Warriors Lie Down and Die’ (2000, p.154) wrote of his experience when working with the Aboriginal communities in Arnhem Land:

Many Yolngu families are traumatised because the dominant culture lacks understanding of death and dying as the Yolngu see it. This happens when – as Yolngu see it - the health system “steals” their elders and sick countrymen from them at the point of death. Of course , these incidents are never intentional. But they are usually the direct result of hospital and nursing personnel making decisions in a vacuum of knowledge.

It is the responsibility of all palliative care services to find better ways to serve their local Indigenous communities and assure them of a culturally safe environment.

This edition of Centre Line presents the approaches used by two different palliative care services to provide culture centred care for Indigenous people. One service is based in a metropolitan hospital, and the other is in a rural Queensland community.

A culture-centred approach

The mantra of a culture-centred approach is that health care services... ‘should address what is rather than what ought to be’ (Airhihenbuwa, 1995, p.34).

A culture-centred approach in palliative care includes:

- A meaningful partnership with the local Aboriginal community and health services
- Palliative care staff cognisant of the fundamentals of Indigenous culture and the history since colonisation
- Respect of cultural differences
- A glossary of cultural mores, traditions and values relevant to the context of palliative care
- Culturally meaningful information about services, resources and palliative care staff
- Evidence of a culturally safe environment in the décor, and culture-friendly facilities.

Deborah Prior

Director of Learning and Development CPCRE

References

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Developing a culture-centred model in Goondiwindi

The Indigenous community of South Central Queensland district and the adjoining NSW region make up a significant proportion of the population. As Goondiwindi is situated on the border of NSW, a good percentage of our clients are from Boggabilla and Toomelah Indigenous communities, and the Indigenous population is increasing in Goondiwindi with new housing developments.

Goondiwindi Hospital was fortunate enough to receive Indigenous Health funding several years ago to complete major capital works in our palliative care unit. The wider local community donated equipment to furnish the family oriented area. The community also planted a beautiful garden area as a quiet reflective space for patients and families. The palliative care unit is used by all the Goondiwindi and Boggabilla community.

Although the health care facilities in Goondiwindi work closely with the local Indigenous community, I realised that often staff are uncertain about how best to communicate about palliative care issues with Indigenous clients. In addition Indigenous Health Workers reported that there are many myths and misunderstandings about palliative care among the local Indigenous community.

Concerns about cultural and communication difference are often the subject of discussion among the nursing team particularly after a death of an Indigenous client.

Eighteen months ago the Palliative Care Clinical Network (PCCN) for Southern Area Health Service was formed and through this networking the development of the workshop from concept to implementation moved forward. Pauline Cleary, a passionate palliative care nurse in Goondiwindi, submitted a successful application to the Australian Palliative Care Fund to support education and service development for Goondiwindi palliative care. Thanks largely to Pauline's efforts and collaboration, part of the grant was used to fund a culture-centred workshop.

The workshop was intended for service providers, carers and interested community members involved in the care of the local Indigenous community. An important aspect of the workshop was that it should be held at a venue accessible and comfortable to the general community. It was also important that the workshop should be facilitated by an Indigenous person as well as others with experience in palliative care.

The workshop program was developed in collaboration with Deborah Prior, Centre for Palliative Care Research and Education (CPCRE) and Catherine Jacka Paroz from the Cancer Council Queensland (TCCQ). The broad aim of the workshop was to encourage interaction between the Indigenous community and the palliative care and general health care providers. Topics included:

- principles of a culture-centred approach in palliative care
- the myths of morphine and other palliative pharmacological interventions
- principles of clinical symptom management
- cultural traditions and values relevant to the palliative care context
- Indigenous social system and family structures
- Indigenous spirituality
- self-care and coping with 'sorry business'

Members of the local multidisciplinary team were encouraged to be involved and, in collaboration with the local Indigenous liaison officers, to promote the workshop to the general community.

The time and effort in terms of numerous phone calls and meeting with the Indigenous community members to promote the workshop paid off. People travelled from both sides of the border from up to two hours away to attend and all agreed that the workshop was an overwhelming success.

Deborah's introduction on the principles of a culture-centred approach and Catherine's presentation on traditional beliefs and cultural issues had the total attention of the audience. Charmaine Mullins, our local Indigenous mental health worker, gave an excellent overview of Indigenous social and family structures. The update on clinical practice presented by John Haberecht was also well received and provided an important trigger for open discussion about some of the concerns about palliative treatments that trouble the Indigenous community.

An outcome of the workshop was a resolve to implement early intervention case conferencing and also to trial meeting as a team with family members a few weeks after the death. Our rationale is that face-to-face meeting with the family would be more beneficial for both parties than a written survey, a viewpoint well accepted at the post workshop discussions.

Our next step in supporting a culture-centred approach in palliative care for the Indigenous community is to provide ongoing workshops and encourage attendance of the elders and local community members, and health care providers. Needless to say, funding is our limitation. The majority of health providers involved in this workshop are sole practitioners in a rural community with minimal or no administrative support, so we are very grateful for the support of organisations such as CPCRE, PCCN, and The Cancer Council Queensland in our endeavours to continue education in our local communities.

*Gerda Holcombe
CNC Community Health, Goondiwindi*

Indigenous Patients in a Metropolitan Cancer Centre.

There is an under-representation of Indigenous patients in our cancer service but those few we have cared for are remembered well. The Indigenous patient situations presented here impressed us with their unique cultural needs which we endeavoured to accommodate with respect.

The patient Mr Y, presented with a primary liver cancer and massive ascites. Mr Y challenged our usual approach of discussing his problem and treatment plan. He preferred to lie in his hospital bed with the sheet pulled up over his face as if trying to block us out. The Aboriginal liaison person was helpful in explaining that Mr Y may have had difficulty communicating with female staff or just wanted to keep his business private. It was important that we respected Mr Y's behaviour while doing our best to give comfort. Unfortunately, in a few days Mr Y discharged himself and chose not to return, but we hope he felt at liberty to be readmitted to our centre if necessary.

In contrast to Mr Y's response, Uncle A, an elderly Aboriginal man, had lung cancer that had failed to respond to chemo- or radiotherapy. He and his family accepted palliative care and the associated community support which enabled him to die sitting in his arm chair out in the back garden with his extended family in attendance.

A patient I remember particularly well is Aunty B. Aunty B had lived in an inner-city suburb for many years. Her medical history was extensive as evident by the three volumes of medical charts reflecting multiple visits to the hospital emergency department. Aunty B's medical history included a trail of problems relating to alcohol excess, trauma and infections. Her charts indicate her reluctance to be admitted to a hospital ward as she usually left after initial treatment.

In 2005 Aunty B presented with bleeding and was found to have locally advanced carcinoma of the breast. She agreed to palliative radiotherapy but it was clear that she hated the confines of being in hospital and refused admission on several occasions.

When Aunty B became symptomatic from hypercalcaemia she agreed to be admitted for treatment as long as we promised to let her go home the following day. We respected her request and in so doing we were able to build up a rapport and a degree of trust. On this basis, Aunty B agreed to subsequent admissions for pain control and treatment of infection and other complications of her disease. As long as she attended clinic, we could supply her with pads and dressings; without this Aunty B was limited to using whatever was to hand.

Aunty B loved playing the 'pokies'; the activity seemed to be an important part of her social interaction. It was therefore vital to her 'quality of life' that we accommodated her social need by allowing her to visit the local venue at least once a week. There was one occasion of concern

when Aunty B announced she was leaving the ward for a 'smoke' but did not return as we expected. It was fortunate that Aunty B was known in her community and she was brought back to the ward some hours later. She had been found after collapsing at the 'pokies' venue, racked with pain. On another occasion when Aunty B didn't return from a shopping trip the Indigenous Liaison Officer was able to locate her in the local park which is a common meeting place for the local Aboriginal community.

Our primary concern for Aunty B's well being was to control her pain which was a major problem. Her compliance with the analgesic regimen was at the best patchy. Towards the end of her life, Aunty B had to be admitted for pain management. We had difficulty contacting Aunty B's family but fortunately our Indigenous Health Workers were able to collect various extended family members to bring them to visit Aunty in hospital. We were confronted by the reality that some of Aunty B's close family members couldn't be with her during the final days because they just didn't have the funds to travel.

The ward was respectful and accepting of Aunty B's particular needs and in return, she was able to accept our care. It may be easier to stick to the routines of our ordered services, but if we are to meet the uniqueness of Aboriginal people and others with diverse cultural backgrounds, respect and flexibility are vital. Furthermore it is essential that we work with the Indigenous Health Centre and liaison Health Workers to build a culture of trust between the cancer-palliative care centres and the local Aboriginal community.

*Professor Janet Hardy and Dr Deborah Prior
Centre for Palliative Care Research and Education*

Neonatal Palliative Care Part II

The majority of neonatal deaths occur in the NICU (or PICU) with the infant never having left the hospital after birth (Felid & Behrman 2003; Carter 2004; Leuthner et al. 2004) partly because the time to death is so short. An American study has shown that when a NICU made referrals to a paediatric palliative care service the trend changed from all deaths occurring in the NICU to 33% occurring at home (Leuthner & Pierucci 2001). Other research demonstrated that a positive relationship between parents and health care professionals at the time of the infant's death is more important than the physical setting, and influences the parent's evaluation of their experience (Brosig et al. 2007).

For Infants in the Mater Mothers Hospital the available settings for palliative care are:

- By the bedside with screening (commonly where palliative care begins, with cuddles while still on the ventilator, naming ceremony/baptism/prayers, visits by extended family members etc.)
- In the dedicated 'family room' next to intensive care which has home-like furnishings, dimmable lighting and is (just!) big enough to accommodate extended family

members, a baby bath etc. This is the most usual setting for infants who are expected to die very quickly after withdrawal of life-supporting technology.

- The mother's hospital room (single room). This option is often preferred by families if the mother is still an in-patient.
- One of the neonatal nursery 'rooming-in' rooms. (These are designed for parents to provide care for their infant prior to discharge home.) This option is preferred if the baby is expected to live for many hours to a few days, as the room has a double bed.
- At home. This option is used for babies expected to live for some weeks or months when there is sufficient time to organize community supports. However, we have been able to facilitate this for a few infants expected to take some days to die. This option has been limited by the difficulty in accessing community palliative care supports instantaneously '24/7'.

Follow-up is vitally important. Parents value contact from team members involved in their child's care as they feel their baby had an impact and is remembered. (Brosig et al. 2007). The social workers usually ring families in the weeks after baby's death to offer telephone support and advice. Medical follow-up may be important in helping parents to understand why their baby died. The change from 'cure' to 'care' can be quite sudden, and in their grief at the time parents may be confused as to what happened. There may also be further information available after death, from autopsy or complex tests sent prior to death. Parents often want to discuss implications for further pregnancies. We offer parents a medical follow-up visit about 6 weeks after the death. Unfortunately comprehensive after-care is limited by the in-patient care paradigm of hospital-based care, and would be enhanced by a paediatric palliative care service.

Paediatric Palliative Care has developed through oncology services and hence is usually based in Children's Hospitals and often unavailable to Neonatal Units based in Maternity Hospitals. Palliative care within Neonatology, including at the Mater Hospital, is seen very much as an extension of the role of the neonatologist, neonatal nurses and social workers, with involvement, if appropriate, of the lactation consultant, pastoral care, chaplaincy, ethics, and patient advocate. We value fantastic community teams such as Xavier, Zoe's Place, BlueCare, St Luke's, and Karuna in being able to support some families at home (or in-hospice care at Zoe's Place) and on occasion when community supports have been unavailable we have involved the wonderful Complex Care team at the Mater Children's Hospital to assist us in providing home-based end-of-life care. However, there are no services providing a comprehensive service including medical support.

The new Queensland Childrens Hospital will have a Paediatric Palliative Care Service (centred around oncology services), and we hope that this service will be available to neonatal patients too. There is most certainly a need.

Even though death usually comes swiftly in the Neonatal Care setting, these hours or days will come to represent a lifetime of grief and memories for the family. We are very aware of the importance of everything we say and do in this time and are dedicated to 'getting it right' for families.

I will finish with the story of one family, who knew their baby had a severe brain abnormality from 18 weeks gestation, the family agreed to share their experience for this newsletter:

When our third child, Ava, was born we were euphoric. For a while we forgot Ava's prognosis and just enjoyed the moment of a new life entering the world.



Baby Ava

Ava slept most of the time and was very peaceful. We knew by her second day that her journey with us would be a short one. The doctors let us take her home on her 5th day telling us we probably had only a few days left. Whilst we were scared to take her from the hospital environment we desperately wanted to take her home for her final days. This transition was made easier by daily visits from Ava's neonatologist and support from the complex care nursing staff at the Mater (they are saints!!!).

Ava survived another 6 days. We like to think it was because she enjoyed her time with us at home. It sounds clichéd but it felt like we had an angel in the house. She heard her two sisters laughing, got lots of cuddles from her grandparents, we took lots of photos and we sang songs to her and told her how much we loved her. We also got a family photo with Santa at our local shopping centre (difficult, but worth



Baby Ava and family.

Continued on page 5

it!). Her father took her for a walk in the park by the river almost every day where she could hear the birds chirping and the dogs barking. She felt sunlight on her face and the wind in her hair. She felt life. Most importantly she felt the warmth and love of her family. We are so glad we got the opportunity to bring her home to be part of our family.

Dr Elizabeth Hurrion

Neonatologist, Mater Mothers Hospital, Brisbane

Elizabeth.hurrion@mater.org.au

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Carter BS. Providing palliative care for newborns. *Pediatr Ann* 2004; 33: 770-77.

Field MJ, Behrman RE, eds. *When Children Die: Improving Palliative Care and End-of-Life Care for Children and Their Families*. Washington DC. National Academic Press 2003.

Leuthner SR, Boldt AM, Kirby RS. Where infants die: examination of place of death and hospice/home health care options in the state of Wisconsin. *J Palliative Med* 2004; 7: 269-77.

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CPCRE ACTIVITY REPORT

Promoting access to high quality palliative care education

PEPA (Program of Experience in the Palliative Approach):

(Funded by the Australian Government Department of Health and Ageing)

CPCRE will offer 140 PEPA placements during 2007-2010 for GPs, nurses and allied health professionals. Additional placements for Indigenous Health Workers will also be offered. As at December 2007, a total of 15 placements will have been completed, with many more planned for early 2008. Applications for the program are now being received.

Indigenous Palliative Care Education (Activities supported by the PEPA Program, funded by the Australian Government Department of Health and Ageing).

Members of the CPCRE and PEPA team consulted with key representatives of Queensland Health Indigenous Health Workers, the Workforce Strategy and Change Unit, The Cancer Council Queensland, and the Queensland Aboriginal and Islander Health Council to assist with development of PEPA initiatives for Indigenous Health Workers.

A survey of Aboriginal and Torres Strait Islander Health Workers was undertaken to gather suggestions for topics that may be included in a PEPA course. The survey form was distributed by the Indigenous Health Worker Coordinators within Queensland Health, and the Aboriginal and Islander Health Services in Barambah, Brisbane, Mackay and Cunnamulla, with 44 surveys completed and returned. Information obtained has been used to develop a workshop program, to be implemented in collaboration with Indigenous communities in 2008.

A workshop on Indigenous Perspectives of Palliative Care attended by more than 25 participants was held in Brisbane in June 2007. A second workshop was held in Goondiwindi on Nov 28-29th. This workshop was attended by more than 36 participants and several members of the local Aboriginal community. Both workshops have been positively evaluated.

Allied Health Education

Two workshops have been held, funded through the PEPA program. The workshops were held in August and December in Brisbane, and were each attended by more than 30 Allied Health professionals. Further workshops are planned in 2008 as part of the PEPA program. Please check the CPCRE Calendar and website for further information.

Palliative Care Curriculum for Undergraduates (PCC4U) (A joint initiative between Queensland University of Technology, CPCRE, Flinders University, Charles Darwin University, and Curtin University with funding from the Australian Government Department of Health and Ageing).

A schedule for inviting all universities which offer undergraduate health courses to participate in the PCC4U project was developed early in 2007. Due to the strong uptake of the project we have decided to accelerate the targets so that all universities will be invited to participate in the uptake of PCC4U resources by the end of 2008.

This will allow the project team to use 2009 to consolidate the implementation of palliative care in undergraduate courses and focus on strategies for ensuring sustainability. To date, 101 course providers in 18 universities have been invited to participate in the implementation of PCC4U.

Queensland Health GP Education Program

Four projects were awarded for the 2007-2008 period to address priority issues identified by the CPCRE GP Advisory Committee. Projects funded are listed below.

Sunshine Coast Division of General Practice
PO Box 389, Cotton Tree Qld. 4558

Palliative Care Mentoring Program \$12,000

Brisbane South Division of General Practice
PO Box 211, Salisbury Qld. 4107

Palliative Aged Care Education \$15,000

South East Alliance of General Practice
2/27 Mt Cotton Road, Capalaba Qld. 4157

Palliative Care Mentorship Program for GPs \$14,980

Ipswich & West Moreton Division of General Practice
16 East Street, Ipswich Qld. 4305

GP Palliative Care Journal Club \$4,900

Applications for 2008-2009 GP Education Program will be on the CPCRE website soon — www.cpcre.com

Karuna-RBWH-CPCRE Specialist Palliative Care Nursing Education Program

CPCRE is continuing to work in partnership with Karuna and RBWH staff to develop a strategy for increasing the program's accessibility to a wider group of nurses. An application seeking eligibility for those who complete the course to seek credit towards university graduate certificate programs has been approved by QUT School of Nursing.

CARESOURCES and the Queensland Palliative Care Education Calendar

Information for the 2008 Education Calendar has been sought. The 2008 Education Calendar is expected to be distributed in early 2008. If you would like information about your course to be included, please contact cpcre@health.qld.gov.au

CPCRE Website

The CPCRE Website is currently being redeveloped, and will be migrated to be hosted on the Queensland Health Internet Site. The redeveloped website will provide a range of new resources and functions, including the Brisbane South Allied Health Directory, a new page on Indigenous palliative care, as well as copies of CPCRE developed guidelines.

CPCRE Annual Research Conference

Dr Josephine Clayton will be the keynote speaker for the 2008 CPCRE Annual Research Conference scheduled for 18th April 2008. A program will be distributed in early 2008.

Undertaking research

CPCRE Research Programs

Research programs involving Centre staff address areas including:

- Health services delivery
- Symptom management and supportive care
- Professional Practice Development
- Person centred palliative care

For further details of specific projects, publications, reports and conference presentations please visit www.cpcrc.com

New grants this quarter include:

Professor Janet Hardy: A double-blind, placebo-controlled cross-over study of the effect of corticosteroids on sleep quality – a pilot study in patients with advanced cancer. JP Kelly Research Fund.

Mitchell G, Hardy J, Currow D, Nikles J, Vora R, Schukter P, Yelland M. Using Single Patient Trials to determine the effectiveness of psychostimulants in fatigue in advanced cancer. National Health and Medical Research Council

Prior D, Haberecht J, Driver K, Podger M, Prentice L, Mannion S. Quality of life issues experienced by patients with advanced heart failure and their family, living at home. Queensland Nursing Council.

Palliative Care Clinical Studies Collaborative

The collaborative is a national initiative funded by the Australian Government Department of Health and Ageing, and led by a team from Flinders University. The collaborative was officially launched by Senator Brett Mason at the National Palliative Care Conference in September. Professor Janet Hardy is chairperson for the Trials Subcommittee, and is working with partners in the collaborative to develop protocols for trials. The first trial is expected to commence in Jan 2008.

Palliative Care Outcomes Collaboration (PCOC) (Funded by the Australian Government Department of Health and Ageing)

The northern zone of PCOC (Queensland and Northern NSW) are currently working with 34 service providers. In Queensland, 28 of the 32 services (88%) have agreed to join PCOC. Currently the northern zone of PCOC has service providers joined from all Queensland Health area health services, wide geographical spread including metropolitan/regional/rural & remote providers as well as private, public and non-government organisations. Since May 2007, 14 training sessions attended by 117 staff have been conducted. A benchmarking workshop was held in August 2007 for eight services who have received their first report.

Developing and promoting the use of evidence based resources

Practice Guidelines

The following guidelines and information resources continue to be distributed through CPCRE:

- The management of syringe drivers guidelines (with accompanying summary card and on line education package)
- Paediatric Loss and Grief Information Resources

Copies of these resources are available from the CPCRE website.

Following a priority setting activity earlier in 2007, guidelines for the management of dyspnoea are currently being developed. A draft of the non-pharmacological intervention component of these

guidelines has been prepared and is currently undergoing peer review.

Establishing and facilitating partnerships

Palliative Care Clinical Networks.

CPCRE is represented on Central and Southern Area Health Service Palliative Care Networks, and is actively supporting activities of the networks. CPCRE staff are advising on the mapping study currently being undertaken by Central Area Health Service Palliative Care Network.

The Prince Charles Hospital Heart Failure Palliative Care Nurse Project

CPCRE continues to participate as a key member of the group leading a project funded by the Commonwealth Local Palliative Care Grants Scheme.

Brisbane South Collaborative Supporting People at Home Project (Funded through the Australian Government Department of Health and Ageing)

CPCRE staff are collaborating with Brisbane South Palliative Care Collaborative on a recently funded project to support carers with medication administration in the home.

Syringe Drivers Project

CPCRE continues to work with Palliative Care Australia to develop information to guide services in reviewing devices for administering continuous subcutaneous medication. A report has been published by Palliative Care Australia in December 2007.

Identifying trends in palliative care service delivery and their implications for Queensland

CPCRE Staff Representative Activities:

Acting Director:

- Member, Palliative Care Australia Standards and Quality Committee
- Member, Palliative Care Australia Executive Committee
- Member, Reference Group, National Standards Assessment Project, Palliative Care Australia

Director of Learning and Development:

- Chairman, Palliative Care Queensland Education Committee
- Member, Palliative Care Working Committee for the Palliation for the Sick Heart project,
- Member, The Cancer Council Queensland Advisory Group for Indigenous Cancer Education and Cancer Resource Development Group
- Chairman, Karuna Hospice Services

Clinical Research Program Leader:

- Member, The Cancer Council Queensland Medical and Scientific Committee
- Member, Palliative Care Medications Working Group
- Chair, Trial Management Committee, PaCCSC
- Member, Scientific Committee, PaCCSC
- Member, Management Advisory Board, PaCCSC
- Member, Medical Advisory Board, Xenome Pharmaceuticals

PALLIATIVE PROFILE: THE CANCER COUNCIL QUEENSLAND

The Cancer Council Queensland (TCCQ) addressing cancer control in the Aboriginal and Torres Strait Islander population

To address cancer control in the Aboriginal and Torres Strait Islander community, TCCQ formed state-wide advisory groups (late 2004) to provide direction and support for the implementation of initiatives to increase knowledge about cancer - early detection, diagnosis, treatment and psychosocial issues for Queensland's Indigenous population.

The Cancer Care Course for Indigenous Health Workers (CCCIHWs) was developed in collaboration with the advisory group and the first course was delivered in Brisbane in 2005 and again in 2006.

Early in 2007 I was employed as the first Indigenous Education Coordinator at TCCQ. The position responsibilities include co-ordination of the Cancer Care Course for IHWs and development of other relevant courses; building networks with course participants; developing Indigenous resources; providing organisational cultural support and collaboration with other agencies.

In 2007 the Cancer Care Course IHW was delivered in Brisbane and Townsville. It was recognised that Brisbane & Townsville are major oncology treatment centres, and that diversity to deliver the course in these locations would allow better access for health workers. All participants were supported (transport, accommodation, meals and course materials) by the Maureen Kirk Bursary. The course is a 5 day intensive program and includes site visits to health facilities, lectures from specialists, and information about palliative care and support services and resources available



for clients. A joint project for National Breast Cancer Centre (NBCC) and TCCQ has also delivered a Breast Cancer Workshop for IHWs.

For workers in rural, remote and isolated settings the Health workers see clients from birth to death. It is therefore important that IHWs have access to information about what is cancer, issues related to the diagnosis, caring for a client after treatment, and providing supportive care for palliative patients and families.

The Centre for Palliative Care Research and Education is working with me as the Indigenous Education Coordinator of TCCQ to facilitate workshops on Culture Centred Palliative Care. These workshops are offered for IHWs, palliative care providers and other health care professionals. The workshops provide an opportunity for building relationships between the various organisations that aim to provide culturally appropriate services for the Indigenous community.

*Catherine Jacka Paroz
Indigenous Education Coordinator, Health Education Team,
Cancer Support Services, The Cancer Council Queensland*

PALLIATIVE CARE RESEARCH

Fenwick C 2006. Assessing pain across the cultural gap: Central Australian Indigenous people's pain assessment. *Contemporary Nurse* 22:218-227.

The article looks at how principles of cultural safety can be applied to the pain assessment of Indigenous people. Issues discussed include problems with numerical pain scales and the main patterns of nurses' pain assessment, and how to ensure cultural safety, including the importance of developing trust in the relationship between the nurse and the Indigenous person. The author acknowledges that while the paper has most significance for health professionals providing pain management to Central Australian Indigenous peoples, many aspects of the discussion can be applied to other Indigenous groups. Fenwick C 2006. Assessing pain across the cultural gap: Central Australian Indigenous people's pain assessment.

McGrath P 2007. 'I don't want to be in that big city; this is my country here': Research findings on Aboriginal

peoples' preferences to die at home. *Aust J Rural Health* 15:264-268.

This article presents the findings of a two-year qualitative study on Indigenous palliative care in the Northern Territory. The study explored rural and remote Aboriginal people's wishes regarding place of death. Open-ended interviews were conducted with Indigenous patients, Indigenous caregivers, Indigenous and non-Indigenous health care workers, and interpreters.

The findings clearly articulate the wish of Aboriginal people from rural and remote areas to die at home connected with land and family. Cultural reasons given for this preference include strong connection with land and community, the importance of passing on sacred knowledge to the appropriate family member, and the significance of ensuring that the dying individual's 'animal spirit' is able to return to the land. The author concludes that the strong wish to die at home reinforces the importance of strengthening local palliative care and health services and avoiding, if at all possible, the need to relocate for health care to major metropolitan hospitals during end-of-life care.

FORTHCOMING EVENTS

Queensland

28 March 2008

Clinical Skills Update
CPCRE-RBWH
Contact 07 3636 8197

18 April 2008

CPCRE 7th Annual Research Conference
CPCRE-RBWH
Contact 07 3636 1449

24 May 2008

Palliative Care Queensland Biennial State Conference
Creativity in Palliative Care
Sea World Resort, Gold Coast
Inquiries: 07 3633 0096

12-13 September 2008

31st Annual Oncology Nurses Group Conference
Cancer Council Queensland
Townsville

Contact: 07 3258 2200

National

5-8 March 2008

Involving People in Research
University of Western Australia School of Population Health
The University Club, Perth, Western Australia
www.sph.uwa.edu.au/go/sph/involvingpeopleinresearch

5-8 March 2008

13th Ottawa International Conference on Clinical Competence
Exhibition and Cultural Centre, Melbourne
www.ozzawa13.com/

10-12 March 2008

Diversity in Health 2008:
Strengths & Sustainable Solutions.
'A Landmark Conference on Multicultural Health and Wellbeing'.
Sydney Convention Centre, Darling Harbour, Sydney
www.dhi.gov.au/conference/

26-29 March 2008

World Congress of Health Professions
Perth
www.worldhealthcongress.org/

30 April-1 May 2008

Facilitating Knowledge Exchange & Transfer For a Dynamic Future – 13th Annual National Health Outcomes Conference
Canberra
<http://chsd.uow.edu.au/ahoc/upcomingconference.html>

4-6 June 2008

2008 GP and Primary Health Care Research Conference
Hobart
www.phcris.org.au/conference/2008/

15-18 July 2008

8th International Conference on Grief & Bereavement in Contemporary Society
Melbourne
www.grief.org.au/conference.html

25-26 July 2008

Sydney Cancer Conference 2008
Sydney
www.cancerresearch.med.usyd.edu.au/SCC2008/

27-30 August 2008

National Conference for Rural & Remote Allied Health Professionals
Yeppoon, Queensland
www.sarrah.org.au

31 August-6 September 2008

3rd ACORD Workshop - A workshop in Effective Clinical Trials Design
Sunshine Coast, Queensland
www.acordworkshop.org.au/

12-13 September 2008

Palliative Care Nurses Australia 2nd Biennial Conference
Adelaide
www.plevin.com.au/pcna2008/

24-27 September 2008

Australia and New Zealand Society of Palliative Medicine (ANZSPM) Conference
Darwin
www.willorganise.com.au/anzspm08

International

10-12 February 2008

Recovering Our Traditions III - A Journey of Transformation: Expanding the Horizons of Compassionate Care. Advancing the ministry of care across the continuum for those with chronic and life-threatening illness.

San Antonio, Texas, United States

www.supportivecarecoalition.org

28 February-2 March 2008

APOS 5th Annual Conference – Integrating Psychosocial Services in Quality Cancer Care
Irvine, California, United States
www.apos-society.org/apos2008

13-15 March 2008

Palliative Medicine 2008 – The 12th Annual International Symposium
Scottsdale, Arizona, United States
www.clevelandcliniced.com/live/promo/2008/PM2008

19-22 March 2008

The 2nd International Conference in Palliative Care:

Palliative Care in Different Cultures

Herods Hotel, Eilat, Israel

www.entersymposium.com/ofakim-pallcare2008

29 April-1 May 2008

7th Palliative Care Congress
The Glasgow Royal Concert Hall
Glasgow
www.pccongress.org.uk

28-31 May 2008

5th Research Forum of the European Association for Palliative Care
Trondheim, Norway
www.eapcnet.org/congresses/Research2008.html

11-12 June 2008

7th Annual Kaleidoscope Conference Pearls and Promises: The Changing Face of Palliative Care Practice. This conference will explore the pearls, or gems, of palliative care practice, and anticipate the promises they bring to future practice both in the hospice and wider health care setting.
St. Francis Hospice, Dublin
www.stfrancishospice.ie/education/kaleidoscope.htm

22-26 July 2008

XII World Congress of Music Therapy
Buenos Aires, Argentina
www.musictherapyworld.net

17-22 August 2008

12th World Congress on Pain – International Association for the Study of Pain
Glasgow

www.iasp-pain.org

29-30 August 2008

Singapore Palliative Care Conference
Singapore
www.singaporehospice.org.sg

GRASEBY SYRINGE DRIVER UPDATE

CPCRE has worked with Palliative Care Australia regarding guidelines for palliative care services needing to find replacement subcutaneous infusion devices following the withdrawal of the Graseby syringe driver from sale in Australia. Palliative Care Australia has a link to its report, which provides details of a number of alternative subcutaneous infusion devices, on its website at www.palliativecare.org.au.

As in the report, there are a number of possible options, and organisations seeking an alternative infusion device should discuss the issue first with their local specialist palliative care team, in an effort to avoid a multiplicity of devices.

CENTRE LINE

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Acting Centre Director/Director of Research

Professor Patsy Yates Ph: (07) 3636 1449

Director of Learning and Development

Deborah Prior, PhD Ph: (07) 3636 1337

Clinical Research Program Leader

Professor Janet Hardy Ph: (07) 3636 1449

Research Officer

John Haberecht Ph: (07) 3636 8197

Directors Secretary

Rosaleen Matters Ph: (07) 3636 1449

Project Manager National Co-ordination / Evaluation - PEPA

Nhu Tran Ph: (07) 3138 6121

PEPA Senior Project Officer

Dr Vinesh Oommen Ph: (07) 3138 6124

PEPA (QLD) Project Manager

Kathryn Laurent Ph: (07) 3636 6216

General Enquiries

Ph: (07) 3636 1449 Fax: (07) 3636 7942

Email: cpcre@health.qld.gov.au Website: www.cpcre.com

Postal Address

Centre for Palliative Care
Research and Education
Royal Brisbane & Women's Hospital
Post Office Herston QLD 4029

Street Address

Block 7/Level 7
Royal Brisbane & Women's Hospital
Herston Road
Herston QLD 4029

The Centre

The Centre for Palliative Care Research and Education is an initiative of Queensland Health and is a collaboration of the Royal Brisbane and Women's Hospital and Health Service District, The Prince Charles Hospital and Health Service, Queensland University of Technology, Karuna Hospice Inc., and the Queensland Divisions of General Practice.

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