PALLIATIVE CARE
Professional Issues Forum
28 July 2006
WFOT 2006 Congress

Forum facilitated by Jenny Kashyap and Deidre Burgess.

Approximately 28 participants attended this forum.

Issues raised by participants

Experience

- Experience ranging from occasional input through to primary caseload
- Increasing numbers of referrals – no formalised training
- Generalist caseload including pall patients, pall funding access - ? how to develop
- Acute hospital, clinical background in Pall
- Manager of OT, Onc, haematology - end of life discharges
- Paediatric hospital with children/families from diagnosis to ESC
- Generalist but seeing increasing numbers of cancer patients/ALS
- Acute oncology facility, chemo day unit, radiotherapy
- Specialist cancer centre, interested in undergrad/post grad education
- 10 years experience, oncology /Palliative mix, specialist cancer centre
- 50 bed IP unit, Sacred Heart
- Palliative wards – community service, progressive neuro, MND, Huntington's
- Palliative Care Ward – 12 beds, linked with hospital
- Palliative Care in England – multidisciplinary clinical care pathways, return to Aus, service design and delivery, Palliative =services centred around city hospitals rather than suburban, non malignant Palliative care – ESC for dementia, respiratory, etc
- New to Palliative Care – part time position, validating need for OT a challenge, community work, caseload of ~300

Students

- Entry level masters, wanting to know what issues are
- Undergrad final year, interest in issues associated with palliative, to rural – will potentially come across
- Student – gather knowledge
- Student,
- Student – wanting to take ideas back to Singapore

Education

- Family experience of care and decreased support, spirituality, holistic care
- Networking/outcome measures,
- Head of school Curtin Uni - WA– population based palliative care research

Other

- Medico legal Axs with mesothelioma clients, cost of care

1. AREAS OF INTEREST

Service Delivery issues

- How are other services run?
- Role of OT – community, acute, specialist cancer centre, pall
- Educating medical staff re issues
- Population based planning needed - Those who miss out on the service – only 2/3 of those with cancer in WA were able to access Palliative Care, % of other conditions accessed Palliative Care
- Attitude of other team members towards cancer, care, ESC care, allocation of caseload influences access to OT
- Multidisciplinary teams including patient, care givers
- Outcome measures – QOL measure – Vic Onc/Palliative SIG exploring QOL measures, ?range of tools to be used throughout disease trajectory, process of having Ax is therapeutic as a prompt to raising issues not traditionally addressed by OT, ? develop guidelines for IAx to include QOL questions

Patient and Family/carer issues

- Palliative Care in different countries and cultures – aware of imminent death but family/patient may not be, when to come forward/move back, where are patients in disease process, ?denial/other coping mechanisms and impact on OT intervention, role of breaking bad news – what do we say?
- Patient consent for Palliative care involvement, planning for future…
  Helpful phrases "As things get difficult, when it gets harder, good days"
  What is your understanding of what is happening? What have the Drs told you?
- Being aware of the language we use with patients/families
- Paeds – child knowing they are dying and parents saying they don't want the child to know, role of advocate for child, individually negotiated process, family focused, siblings involved and what are their needs?
- Collusion associated with family differences, differences of opinions from team members, ask patient 'What do you want to know?' Empower the patient!
- Illness journey is unique – no set formula – brining therapeutic self

Self Care/professional boundary issues

- Coping
- Support system for OT – care of self, SIGS, hospice team ? rather than own discipline, clinical support from professional group – OT/other disciplines, find what supports you can access, formalized multidisciplinary supervision – developing strategies
- Personal reflective capacity – own needs v client needs, connecting v professional distance, not confusing a 'desire to rescue' with
- Be mindful of your motivation for working in Palliative
- Rope being tethered around waist and firm on shore, can go deep into the water but if you are not tethered firmly, it is not as safe to go deep into the water, imp to acknowledge that, self awareness

- Personal experience – impact on caring for others while grieving/facing loss of family member, -recognising it as an issue, getting support

2. CHALLENGES

Professional Role

- Other disciplines recognising value of OT
- NICE policies/recommendations in UK, EB document – primary care sector developed national framework for community palliative care – assuming positions are available for P
- Definition of Palliative Care/referral sources Definition can vary from place to place including definition of multidisciplinary teams – AH may not be included
- Funding needs – recognize need for OT but are these positions funded??

Gate keeping

- OT role in Changing policy and practice?
- Palliative Care is a national health priority, staffing standards in Palliative Care Aust
- Tumour groups – web based program so can access standardised care pathways
- Palliative Care Group now started in NSW – to develop similar – encouraging AH participation.
- Integrated Cancer Services (ICS) in Vic – developing pathways for different cancer diagnoses. (DHS funded)

Education

- Changing culture of wards – how do we change mindset? Example of a Hospital wide education system – 6 units, effective in shifting focus/study days/linked to professional development program in hospital, running focus groups and inviting strategic people (WA)
- *Multidisciplinary on line training package developed* – self paced, workshop format, training spiritual care for AH, nursing, med. GP, theologian, psychologist support – 3 trials on line in QLD – results to be published following 3 month trial Potential for this to go to Aged Care facilities? National/international

Rural/remote services

- Limited access to service/support.
- Mixed group of disciplines providing care
- Access to OT in rural community - ?getting lost in system - ++value of networking with key people – GP, team

Strategies

- *Mentoring/on line support*, calling for volunteers, good response – multidisciplinary training of volunteers, nature of HAxs may be different – short contacts, increasing frequency
- Self Care community supports – involve other members of community like massage,

- *PEPA funding* (Program of Experience in the Palliative Approach) is federally funded by the Department of Health and Ageing with the National Palliative Care program.
- Website: www.pepaeducation.com. Contact details below taken from website

State	PEPA State Website	Main Contact Email	
		For Nurses and Allied Health Staff	For GP's and Medical Practitioners
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3. FUTURE DIRECTIONS

- Chronic ESC conditions - Palliative Care Aust exploring role of Palliative Care in other end stage/life limiting illnesses

4. RESEARCH

- Future research - outcome measures