Committed to People

11th Congress of the European Association for Palliative Care
7th – 10th May 2009
Vienna, Austria

Abstracts
with careful planning can be addressed. There is considerable scope for extending the use of this powerful technique of serial qualitative interviews in palliative care. Such studies can be especially useful for planning improved services. We conclude by suggesting good practice guidelines.

FC 12.6

Interviewing older people about end of life issues: Engaging with ethical frameworks in four countries

Seymour LF, Fleischgreher S, Brown F, Fleischgreher R, Onwuteaka-Philipsen B, Payne S, Bengt M; Cancer Experience Collaborative: Perspectives of Older People Project

1University of Nottingham, School of Nursing, Midwifery and Physiotherapy, Nottingham, United Kingdom, 2University of Klaggenfurt, Department of Public and Occupational Health, EMGO Institute, Amsterdam, Netherlands, 3Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom

Background: There is an increasing emphasis on using qualitative research among older people to gain their perspectives on palliative and end of life care, but little debate about the ethical issues involved. This paper has arisen from a European study focusing on the secondary analysis of interview data from older people about end of life issues in the Netherlands, Germany, Belgium and England.

Aim: The aim of this project was to develop understanding of the methodological requirements and constraints in studies of ageing and end of life care.

Methods: Ethical and research practice issues were identified during workshops focusing on interviews with older people (n=880) from six projects which had broadly similar concerns and which had been conducted in four countries. To facilitate this, the team compared transcripts and field notes. Where necessary these were translated. Summary 'pen portraits' about interviews were also compared.

Results: We noted across the four countries that the structure and form of the formal documents and procedures for ethical committee review did not correspond well with the purposes of our qualitative studies.

Across the four countries we encountered problems in gaining written informed consent from older people which are not adequately acknowledged in the literature. Examples of this included: the social significance of ‘signing’ consent forms; interpretations of information, expectations about underlying motivations.

Researchers encountered ethical issues in the interview process with older people that were not embraced by the formal review procedure, for example, the role of support persons during the interviews.

Conclusions: This paper makes recommendations to inform researchers who seek to engage with older people in palliative and end of life studies. We conclude that formal ethical frameworks should be complemented by attention to the development of understanding of practical ethical issues.

FC 13 Children

A transition care pathway for young people with life-limiting conditions

Chamber J P* ACT; BS BT, United Kingdom

Aims: An estimated 6,000 to 10,000 young people live with a terminal illness or life-threatening condition, and many know that they will face a premature death and the challenges of adolescence into adulthood is compounded by facing a complex and often bewildering transition from children's to adult services.

The Association for Children’s Palliative Care have developed this resource to guide and support young people, families and professionals to adult services. ACT. The Association for Children’s Palliative Care have developed this resource to guide and support young people, families and professionals to adult services. ACT. The Association for Children’s Palliative Care have developed this resource to guide and support young people, families and professionals to adult services.

The number of children in palliative care programmes contributed to the first textbook on Children’s Palliative Care in Africa, relevant to the resources available in the developing world and relevant to the different cultures. By sharing the experiences of training, support and supervision, with a qualitative and quantitative assessment carried out at each site. The number of children in palliative care services increased from 3,200 at the beginning of the year to 7,000 by September 2008. Assessment of records and progress reports showed an improvement in assessment of children, including developmental and pain assessment, treatment of psycho-social problems and pain management and audit which showed the need for ongoing training and support of sites. In September 2008 a further 22 sites were identified for the roll-out of children’s palliative care with 3 sites identified for development as Centres of Excellence in children’s palliative care. These centres will be developed to provide clinical experience for medical practitioners and nurses in Africa through developing local resource centres linked to training with a piloted curriculum.

FC 13.2

Acupuncture to alleviate nausea and vomiting in pediatric cancer patients - A randomized multicenter crossover trial

Gruninger J†, Reindl T*, Meyer S*, Berang J*, Groher S*, Geis M*

1University Childrens Hospital Hamburg, Hamburg, Germany, 2Charite University, Berlin, Berlin, Germany, 3Gemeinschaftskrankenhaus Heide, Heide, Germany, 4Institute of Medical Biometry, Hamburg, Germany

Background: We investigated whether acupuncture as a supportive treatment approach reduces the need for antiemetic rescue medication during highly emetogenic chemotherapy in pediatric oncology. We report about a multicenter crossover study at 5 tertiary hospitals in Germany.

Patients and methods: Twenty-three children (13.6 ± 2.9) receiving highly emetogenic chemotherapy for treatment of solid malignant tumors were included. Patients were randomly allocated to receive acupuncture treatment either during the second or third identical chemotherapy course together with standard antiemetic medication. The main outcome measure was the amount of additional antiemetic medication during chemotherapy. Secondary outcome measure was the number of episodes of vomiting per course.

Results: Forty-six therapy courses with or without acupuncture were compared. The need for rescue antiemetic medication was significantly lower in acupuncture courses compared to control courses (p=0.001). Episodes of vomiting per course were also significantly lower in courses with acupuncture (p=0.007). Except for pain from needling (4/23) no side effects occurred. Patients acceptance of acupuncture was high.

Conclusion: Individualised needle acupuncture as applied in our trial seems to be a cheap and effective method for reducing both, the amount of antiemetic standard medication. The main outcome of the investigation was the reduction of additional antiemetic medication during chemotherapy. Secondary outcome measure was the number of episodes of vomiting per course.

FC 13.3

Developing children’s palliative care in South Africa through developing local resource centres in all provinces

Marston J M, Roberts MP, Boucher SF

1Hospice Palliative Care Association of South Africa, Management - Paediatrics, Bloemfontein, South Africa, 2Hospice Palliative Care Association of South Africa, Paediatrics, Pretoria, South Africa, ´International Children’s Palliative Care Network, Information Systems, Durban, South Africa

South Africa has the highest number of people living with HIV and AIDS. Whilst hospice services for adults are well-developed and effective, children receive few services. Children live almost half the highest mortality rate due to infectious diseases such as TB and pneumonia, and malnutrition. In 2007 there were only 6 children per million in South Africa with HIV/AIDS. Through donor funding, the Hospice Palliative Care Association of South Africa designed a model to identify 10 children’s palliative care resource centres. Children’s palliative care services in South Africa have increased from 3,200 to 23,000 between 2007 and 2010. A total of 1,187 deaths were included in the analyses, 534 (46.8%) died from cancer. The proportion of home deaths was 19.6% (IT), 20.9% (E), 20.6% (W), 21.0% (NO), 23.8% (BE) and 28.6% (NL). Home death was more likely for children dying from cancer in BE, NL, E and W, for children with high SES in BE, in areas with low number of hospital beds in IT, and for boys in NL.

Conclusion: The proportion of home deaths for children differs between studied countries. In most, but not all countries, children dying from cancer had better odds of dying at home than those not dying from cancer. Although acknowledging the influence of culture in the differences, studying care provisions in countries with higher proportions of home deaths, particularly in chronically ill children, can be helpful to identify factors facilitating terminal illness to die at home. Early involvement of palliative care and equal access to appropriate care can be important in this context.

Funding: IWT-Flanders.