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## Abstracts



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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. Serial interview triads 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

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**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.

**Aims:** 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=80) 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 similar structures 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 project 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 supporting persons present in 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

#### FC 13.1

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

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**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 during their teenage years. Their journey through adolescence into adulthood is compounded by facing a complex and often bewildering transition from children's palliative care to adult services. ACT: The Association for Children's Palliative Care have developed this resource to guide and support young people, families and professionals through the transition maze and help services to better support young people to adjust to, prepare for, and move-on to adult services. It has been developed in response to the growing evidence of the unmet needs and growing

numbers of young people living with a life-limiting condition into adult years.

**Methods:** The session will cover the need for developing the pathway approach, the involvement of grassroots experts in the development of the pathway and will consider the need for multi-agency working and consideration of end of life issues. It will also discuss the progress of the implementation phase of the pathway across the UK.

**Results:** The first phase of the implementation of the Pathway will be to undertake an audit of service provision, based on the five standards of the Care Pathway. Results of this audit will be discussed.

**Conclusion:** The Transition Care Pathway provides a flexible framework for enabling children's and adult palliative care providers to work together to improve outcomes for young people with life-limiting conditions.

#### FC 13.2

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

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**Background:** We investigated whether acupuncture as a supportive antiemetic 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 y,  $\pm$  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 chemotherapy 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 rescue medication and the incidence of retching and vomiting in children and adolescents during highly emetogenic chemotherapy.

#### FC 13.3

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

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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 under 4 years have the highest mortality rate due to infections such as TB and pneumonia, and malnutrition. In 2007 there were only 6 children's hospice palliative care resources. Through donor funding, the Hospice Palliative Care Association of South Africa designed a model to identify 18 sites that could be developed through training and support, to provide palliative care to children, with at least one centre in each of the 9 provinces of South Africa. Training materials, policies and children's palliative care documents were developed, as well as a Toolkit for Developing Children's Palliative Care in Africa. Members of the Hospice Palliative Care Association of South Africa

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. The 18 hospice sites received training, support and supervision, with a qualitative and quantitative assessment carried out at each site. The number of children in palliative care programmes 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 in children. The assessment 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 sites will be developed to provide clinical experience for multi-disciplinary professionals from countries in sub-Saharan Africa linked to training with a piloted curriculum.

#### FC 13.4

##### Home death for children dying in six European countries

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**Aim:** Guidelines on pediatric palliative care underline that care at the end of life of chronically ill children should preferably be provided in the child's home situation. Till present, no European data at population level are available for place of death of children. The aim of this study was to compare proportions of home death for children in six European countries and investigate relation between place of death and sociodemographic and clinical factors.

**Method:** Data were collected from death certificates of all deceased children aged 1-17 in Belgium (BE), the Netherlands (NL), Norway (NO), England (E), Wales (W) (2003) and Italy (IT) (2002). Gender, cause (cancer, natural non-cancer and external) and place of death (home vs. outside home) and sociodemographic factors (socio-economic status (SES), degree of urbanization and number of hospital beds in the area) were included in the analyses. Data were analyzed using frequencies and multivariate logistic regression.

**Results:** A total of 3.187 deaths were included in the analyses, 534 (16,8%) died from cancer. The proportion of home deaths was 19,6% (IT), 20,5% (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 terminally ill children to die at home. Early involvement of palliative care and equal access to these services can be important in this context.

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