

## Patient care

**P-75** 'COLD BEDROOMS, COOLING BLANKETS, AND CUDDLE COTS' PROVIDED BY CHILDREN'S HOSPICES: MAPPING PRACTICE

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**Background** The ways parents are supported at the end of their child's life and after death can profoundly affect the grieving process. Within children's hospices cold bedrooms, cooling blankets and cuddle cots are provided to enable families to be close and have unrestricted access to their child after death. Such facilities are thought to support parents in the initial stages of grief. However, there is wide variation in practice and almost no evidence to inform parents' decision-making during advance care planning.

**Aim** We aim to map current practice and explore parents' experiences of using cold bedrooms and/or cooling blankets and/or cuddle cots – either in the hospice or at home – and the perceived impact of this on immediate and long term bereavement.

**Methods** This study comprises two stages. First, a cross-sectional survey to gather data on previous and current practice, and reasons for inclusion of these facilities within the portfolio of care and support, collected via structured telephone interviews with heads of care in all UK children's hospices (n=52). Second, qualitative interviews with parents (n=30) exploring stories of the early days of bereavement and the support received from the hospice, their needs and desires in those early days and the perceived role of these facilities on early and subsequent experiences of bereavement. Survey data will be analysed using descriptive statistics and content analysis. Interviews will be analysed using narrative and thematic approaches.

**Results** We will not have data to report but hope presenting this work will alert others to this research and generate connections and meaningful conversations with others with an interest in this area.

**Conclusions** Findings will have implications for practice within children's hospices and also for statutory services which are beginning to offer this provision.

**P-76** ASKING SENSITIVE QUESTIONS ABOUT SEXUALITY ON AN UNCERTAIN LIFE COURSE

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**Background** The term 'sensitive research' first emerged in the 1960s. Since then there has been a growing acceptance that many topics are 'sensitive' in nature, including those that separately address sexuality and disability at the end of life but maybe further compounded when such topics are explored together.

**Aims** This presentation will focus on four intersecting 'sensitive' issues: sexuality, disability and young adults with life-limiting or life-threatening conditions on an uncertain life-course, who may or may not be approaching the end of life. The sensitivities of conducting research about

sexuality with young disabled adults and the dilemmas encountered for both researchers and practitioners will be addressed.

**Methods and results** This presentation draws on the in-depth, qualitative research interviews of the first author's doctoral thesis about intimacy, relationships, sexuality and the reproductive choices of 13 young adults with life-limiting conditions, two partners and the views of 10 parents and 10 practitioners (Blackburn, Earle & Komaromy, 2014). The findings highlight multiple taboos and 'sensitivities' when researching sex with young adults who may or may not be approaching death. These include addressing posthumous consent in advance of death, access to research participants and the implications for General Data Protection Regulations. Affective aspects for addressing the research findings and reflections on why research with young adults about sexuality, disability, dying and end of life is often regarded as taboo and sensitive will be explored.

**Conclusions** There is a delicate balance as to whether research about sex encroaches too sensitively on participants' lives, whilst recognising that there are important ethical considerations for the research relationship between participants and researchers.

**P-77** SEXUALITY AND RELATIONSHIP CHOICES IN PEOPLE WITH LIFE-LIMITING OR LIFE-THREATENING CONDITIONS

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Until recently, surviving into adulthood with a life-limiting or life-threatening condition (LLTC) was unusual (Beresford & Stuttard, 2014). Young adults with LLTCs are a growing population. It is therefore timely to explore their personal choices and considerations about sexuality, intimacy, and reproductive choices. This research aimed to understand and make the sexual knowledge and experiences of people with LLTCs more accessible and meaningful.

This presentation focuses on the first author's PhD thesis; centring upon 13 young adults, age 16+ and featuring some, but not all, life-limiting or life-threatening conditions, but including LLTCs, such as, Cystic Fibrosis and Duchenne Muscular Dystrophy. This research also sought the views and contributions of family supporters: two partners, ten parents and ten care practitioners, in order to gain their understanding about the sexual knowledge and experiences of people with LLTCs. This research used a qualitative approach, underpinned by a life course theoretical perspective. What has emerged is a picture of the transitions which occur from childhood to adulthood, from comparative wellness to progressive illness, uncertainty about the life course and most importantly, the sexuality of people with LLTCs.

The findings aim to influence policy and practice. They suggest that the voices of young adults are insufficiently heard, and that there is a gap in the provision of information particularly in relation to their sexuality and reproductive choices. As an increasing number of young adults strive for independence and sexual citizenship, efforts need to be congruent with and grounded in the views of those most personally involved; the young adults themselves.