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# Exploring the Perceived Met and Unmet Need of Life-Limited Children, Young People and Families



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Received 30 May 2014; revised 21 September 2014; accepted 24 September 2014

## Key words:

Life limiting/life threatening condition;  
Complex/palliative care;  
Children/young people/families;  
Met/unmet needs

This article presents an original study commissioned by the UK charity, Together for Short Lives which explored children and young people up to 25 years of age with life-threatening/limiting conditions and their families. Using Appreciative Inquiry and framework analysis, qualitative work sought to explore perceived met and unmet needs of services and care. Fifty-one families were interviewed from one UK area, 18 of which were children/young people up to 25 years old. Findings indicated that children and their families felt medical/nursing needs were well met but provision was needed for broader financial, social and emotional support alongside more responsive specialist therapies.

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IN CONTEMPORARY SOCIETY there is a strong movement towards the promotion of paediatric palliative care using the articles of the United Nations Convention (1989). A wide range of models of care has been established in both resource poor and resource rich countries (Dangel, 2002; Wright, Lynch, & Clark, 2008; Wright, Wood, Lynch, & Clark, 2008; Wright, Wood, Lynch, & Clark, 2008). Organisations such as The Worldwide Palliative Care Alliance (WPCA), The International Association of Palliative Care Networks and Human Rights Watch all include the United Nations Convention framework to underpin their work. In 2006, healthcare professionals with an interest in paediatric palliative care met in Trento, Italy to compare models of service provision, identify best practice and agree minimum standards for children's and young people's palliative care in Europe. The resulting guidelines are generally referred to using the acronym IMPaCCT (Interna-

tional Meeting for Palliative Care for Children, Trento). Drawing on the IMPaCCT agreed standards, in 2008 The Hospice Palliative Care Association of South Africa published a toolkit for children's palliative care programmes in Africa (Health Palliative Care Association of South Africa, 2008). This was followed in 2009 by a framework for children's palliative care in the USA by The National Hospice and Palliative Care Organization (Friebert & Huff, 2009). Rising numbers of children and young people with life-threatening and life-limiting conditions and changing expectations of healthcare staff and families have had substantial impact on care and services in the UK (Fraser et al., 2012; Goldman, Hain, & Liben, 2012; McNamara-Goodger & Feudtner, 2012). Consequently, in the UK, the national government has embarked on reforms aimed at improving and integrating health, education and social services for children and their families (Department of Health, 2008; Hunt et al., 2013).

This article will share a strand of work within a commissioned longitudinal project supported by the UK charity, Together for Short Lives in 2010

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[[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)]. The overall aim was to answer the question ‘How Well Are the Palliative Care Needs of Children with Life Limiting and Life Threatening Conditions and Their Families Met by Services?’ Within this aim, the study had a number of objectives (Table 1) that directly matched to five dedicated strands of work undertaken by five UK universities. Strand 2, which was the qualitative arm of the study, was commissioned to the authors’ team (Table 2) and focused on the perceived met and unmet needs of children and young people up to 25 years of age with long term, life-threatening and life-limiting conditions and their families.

## Context of Paediatric Palliative Care

Palliative care for children and young people is widely perceived as a multi-disciplinary total approach to care, from the point of diagnosis or recognition of life-threatening and life-limiting conditions (ACT & RCPCH, 2003; Goldman et al., 2012; McNamara-Goodger & Feudtner, 2012). Although each family is unique, many families have palliative care needs in common (Lenton, Stallard, Lewis, & Mastroiannopoulou, 2001). In 2011, a systematic review of children’s palliative care worldwide found that 65% of countries had no known children’s palliative care. However, 18% had building activities, 9% were able to cite examples of local provision but only 5% had existing children’s palliative care (Knapp et al., 2011). Therefore, the provision of high quality palliative care for children and young people remains a global concern (Downing, Marston, & Boucher, 2010). According to Marston and Chambers (2013 p. 458) even in ‘resource rich countries, the lack of sustainable funding and problems with co-ordination of services means that care remains patchy and inequitable’.

There is limited research regarding holistic care for families with a long term, life-threatened or life-limited child or young person. Some individual service-providers have undertaken internal evaluations and, although findings may be insightful for the organisations concerned, in general, there is no robust evidence on which to base care in the

**Table 1** Strands of the study (bold: Strand 2 reported here).

Strand 1. To identify the prevalence of need for palliative and supportive care within the West Midlands area.
<b>Strand 2. To identify the extent to which services were perceived as family centred and the extent to which perceived needs were met both quantitatively and qualitatively.</b>
Strand 3. To understand how professional networks both formally and informally supported the coordination, co-operation and collaboration of services.
Strand 4. To explore the costs of care to providers and families.
Strand 5. To facilitate involvement of parents, carers and young people in underpinning, advising and supporting the research

**Table 2** Inclusion and exclusion of Strand 2 (study reported).

<i>Inclusion criteria:</i>	<ul style="list-style-type: none"> <li>• Children and young people up to 25 years with a diagnosis of a life-limiting/life-threatening condition</li> <li>• Children and young people up to 25 years with a diagnosis of a life-limiting/life-threatening condition and their families living in the study defined study area</li> <li>• Children and young people up to 25 years with a diagnosis of a life-limiting/life-threatening condition in receipt of paediatric/children’s health services and their families</li> <li>• Children and young people up to 25 years with a diagnosis of a life-limiting/life-threatening condition in receipt of education at schools serving needs up to age 18 years</li> </ul>
<i>Exclusion criteria</i>	<ul style="list-style-type: none"> <li>• Children and families outside the study defined area and not using the services</li> <li>• Young adults not in receipt of paediatric/children’s health services</li> <li>• College and universities serving needs of young people/adults above aged 18 to 25 years of age</li> </ul>

community (Knapp & Contro, 2009). Never-the-less much of the literature focuses on the care of children and young people with palliative care needs and cancers (Huijjer, Sagherian, & Tamin, 2013; Knapp et al., 2011).

The importance of assessing children within the context of the family has however been highlighted in the international literature (Friebert & Huff, 2009; Hunt et al., 2013). Sloper and Beresford (2006) found that, although needs were often recognised by service providers, they were often unmet. The needs of children and young people with long term, life-threatening and life-limiting conditions are on a constant cycle of change through periods of remission from the condition to medical crisis and at each trajectory of the condition family members will have to develop coping strategies (Brown, 2007; Coad, Patel, & Murray, 2014). Most families do succeed at adapting, but this is dependent on well co-ordinated service provision that is easily accessible (Danvers, Freshwater, Cheater, & Wilson, 2003).

Furthermore, figures for the numbers of children and young people who have complex health needs, including those who have a diagnosis of a life-threatening or life-limiting condition, vary enormously resulting in limited confidence being expressed in the figures available (Noyes, 2006; SPRU, 2010). In 2014 The International Palliative Care Network (ICPC) held its first conference on children’s palliative care in India. The resulting action from the conference was the signing by delegates of the ICPCN Mumbai Declaration which calls upon governments worldwide to improve access to quality children’s palliative care services. The estimated global number of children in need of palliative care has been estimated by WPCA as 1.2 million with a slightly higher proportion of boys than girls. Over

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