

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

Coad, J. , Kaur, J. , Ashley, N. , Owens, Christopher , Hunt, Anne , Chambers, Lizzie and Brown E.

Corrected proof deposited in [Curve](#) December 2014

Original citation:

Coad, J. , Kaur, J. , Ashley, N. , Owens, Christopher , Hunt, Anne , Chambers, Lizzie and Brown E. (2014) Exploring the Perceived Met and Unmet Need of Life-Limited Children, Young People and Families. Journal of Pediatric Nursing, volume (In press), DOI 10.1016/j.pedn.2014.09.007

<http://dx.doi.org/10.1016/j.pedn.2014.09.007>

Publisher

WB Saunders

"NOTICE: this is the author's version of a work that was accepted for publication in Journal of Pediatric Nursing. Changes resulting from the publishing process, such as peer review, editing, corrections, structural formatting, and other quality control mechanisms may not be reflected in this document. Changes may have been made to this work since it was submitted for publication. A definitive version was subsequently published in Journal of Pediatric Nursing [in press] DOI 10.1016/j.pedn.2014.09.007"

Copyright © and Moral Rights are retained by the author(s) and/ or other copyright owners. A copy can be downloaded for personal non-commercial research or study, without prior permission or charge. This item cannot be reproduced or quoted extensively from without first obtaining permission in writing from the copyright holder(s). The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the copyright holders.

CURVE is the Institutional Repository for Coventry University

<http://curve.coventry.ac.uk/open>



ELSEVIER

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

Jane Coad BSc, MA, PhD^{a,*}, Jasveer Kaur BSc^a, Nicky Ashley BSc^a,
Christopher Owens PhD^b, Anne Hunt PhD^b, Lizzie Chambers^c, Erica Brown MEd, MA^a

^aCentre of Children and Families Applied Research, CCFAR, Faculty of Health & Life Sciences, Richard Crossman Building, Coventry University, Coventry, UK

^bBrook Building, School of Health, University of Central Lancashire, Preston, UK

^cTogether for Short Lives, Bristol, UK

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.

© 2014 Elsevier Inc. All rights reserved.

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 (International 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

* Corresponding author: Jane Coad, BSc, MA, PhD.
E-mail address: jane.coad@coventry.ac.uk.

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 [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’.

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

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 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 (Huijer, 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 25% of children have a diagnosis of congenital abnormality (Worldwide Palliative Care Alliance, 2014). Downing et al. (2010) cite figures in relation to the diagnosis of life-limiting conditions, the majority of which are non-malignant.

Ensuring that the family is at the centre of care demands that all those involved in supporting the child or young person and the family work with, and on their behalf (Hunt et al., 2013). Professional carers are likely to come from a wide range of services and each will have their preferred way of working, organisational structures, salary scales and professional development programmes (Jassal & Sims, 2006). Thus, professionals have a pivotal role in meeting holistic family needs in order to provide a seamless service where joint working by professionals leads to better standards of care, lower levels of stress for families, improved communication and the pooling of skills and resources (Hunt et al., 2013).

Children, Young People and Family Perspectives

For many families bringing up children and young people with life-threatening or life-limiting conditions is a life-long responsibility. Craig (2006) and Coad et al. (2014) have highlighted that caring for a child or young person with a long term, life-threatening and life-limiting condition places an immense burden on families. Radriguez and King's (2009) small-scale study of the impact on parental mental health highlights the continuous adjustment by families throughout the trajectory of a child's illness. Although the affected child or young person is often referred to as 'the victim of illness' (Brown, 2012), brothers, sisters and entire families are partners in the same experience. Often the impact of a life-threatening and life-limiting condition is greatest for families with the lowest income. To obtain benefits, families need to be proactive in discovering what is available to them. According to research by Simons (2002) parents frequently glean information in a piecemeal way from voluntary organisations or well-informed friends and peers.

The need for good communication that prepares parents or legal guardians for the eventuality that their child might or will die has been identified as an important factor in coping with the situation (Avis & Reardon, 2008; Coad et al., 2014; Midson & Carter, 2010). The importance of good communication within families has also been highlighted as a significant factor in how well they cope with a life-threatened or life-limited child (Coad et al., 2014). Therefore it is important to assess the needs of family members both individually and as a unit.

The rights of children and young people to be involved in decisions made on their behalf have been recognised (UNESCO, 1989). Further, the need to involve young people and their carers in an assessment of their needs has attracted international debate (Lobchuk, 2007; Morris, Gibbons, & Fitzpatrick, 2009). Adults may however wish to protect their child from information about their illness although Brown's study (2007) revealed that children may be very knowledgeable about their illness and, providing they are supported by understanding adults, they are likely to voice preferences about the care they receive. The lack of evidence about what children, young people and families felt and understood about met and unmet needs informed this study.

Methods

Appreciative Inquiry (AI) was chosen as the approach to underpin the strand of the study. AI is an emerging research methodology that has theoretical and philosophical underpinnings in action research, organisational learning, and organisational change (Cooperrider and Whitney 1999; Trajkovski, Schmied, Vickers, & Jackson, 2013). AI has been used effectively within a variety of complex, structures including health and social care settings and lends itself well to a pragmatic discovery of information. Fundamental to this approach is the desire to discover 'what works well' and 'why it works well' and frequently uses participatory and/or action research based data collection approaches (Carter et al., 2012). It thus starts from the belief of positives not problems. Whilst we did have concerns about whether this would enable children and families to talk on sensitive, in-depth issues, the team felt that it was a good fit to explore perceptions of met and unmet needs (Cooperrider & Whitney, 2005).

Recruitment and Sampling

The study took place from 2010 to 2013 across a large area, 1/6th of England, UK. Inclusion and exclusion criteria were set as per Table 2.

Potential participants (affected children and young people up to 25 years old and families including parents, legal guardians, family carers and siblings) were invited via letter/recruitment posters distributed through the charity, Together for Short Lives website and medical practitioners/care teams. The team also approached all health services such as hospitals and hospices and local schools (junior and high up to 18 years) with the information. Potential participants returned consent forms voluntarily.

In total, 59 adult individuals who were part of fifty one families were interviewed. The included 74% mothers; 13% fathers and remainder (13%) were key family members (birth grandparents, foster grandparents and adoptive parents) who play a primary care role for the child or young person. Two

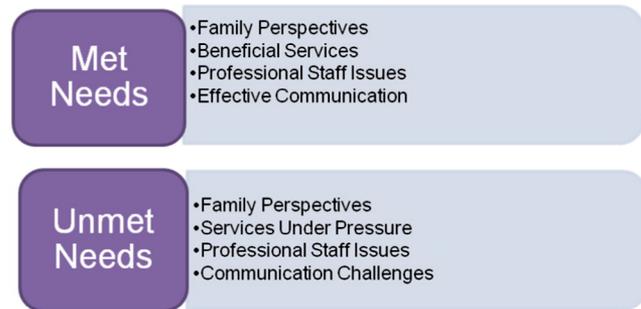
Table 3 Demographic data of study.

	Demographic Data
Adult Participants	Relationship to Child: Mothers: 74% Fathers: 13% Other: 13% (birth and foster grandparents, adoptive parents and carers)
Children and Young People	Age: 0–4: 17% 5–10: 36% 11–15: 15% 16–20: 9% 21–25: 6% (<i>Not Stated: 15%</i>) Gender: Male: 55% Female: 45% Life Threatening/Limiting Condition: Congenital and Chromosomal: 21% Static Encephalopathy: 21% Neuromuscular: 17% Cancer: 13% Prematurity: 4% Other: 4% Pulmonary: 2% (<i>Not Stated: 19%</i>) Education: Special School: 51% Mainstream School: 8%
All Participants	Ethnicity: White British: 67% British Asian: 11% Other: 9% Other Asian Background: 7% White Irish: 2% (<i>Not Stated: 4%</i>)

families that took part had two sons with life limiting/threatening conditions and two families had already had a child with complex needs who had died over two years prior to interview.

Eighteen children and young people were also interviewed, eight in a focus group and 10 in one to one home settings. Table 3 shows that of this sample, 36% of participants were in the 5–10 age banding; 15% were in the 11–15 age banding and 55% of the child/young people were male. The children/young people had a variety of conditions with 21% of conditions falling into the static encephalopathy and congenital and chromosomal group whilst 19% have conditions within the neuromuscular group. Overall, 51% attended special school and 8% attended mainstream schools.

The majority of the participants were White British (67%) which matches the estimated numbers from the Office for National Statistics (2011). British Asians made up 11% of the participants and 7% were from other Asian backgrounds.

**Figure 1** Data themes extracted.

This compares with the Office for National Statistics data which state that 8.5% of the West Midlands population are Asian or British Asian (Office for National Statistics, 2011).

Ethics

Ethical approval for the study was obtained from both the university institutions and National Research Ethics Service (NRES) committee. Separate written study information sheets and consent forms were sent to children under 16 years and young people over 16 years and parents/main adult carers. These were completed before participation to the study.

Data Collection

Semi structured, in-depth interviews were conducted by team members (JC, EB, NA, CO) in the home setting or in a focus group setting, as preferred. In line with the AI approach, interviews included participatory arts-based methods to help participants explore what was good about services (met needs); what could be better about services (unmet needs) and what the ideal future for services would look like.

Data Analysis

All interviews were digitally recorded, transcribed verbatim and checked for accuracy before analysis. Field notes were written after the individual and group interviews. Framework Analysis approach was used which was developed by Ritchie and Spencer (1994) and is frequently often used in large qualitative data sets (Ritchie and Spencer, 1994). For this study this involved:

1. Initially, five interviews (4 adults and 1 child) were subjected to verbatim transcription and two members of Strand 2 read and re-read the narratives in order to become familiar with the data. A coding index was also developed from the initial categories, which were used as a means of sorting and organising the whole data set. Once all data sets were coded, initial categories were refined and sorted into three main sub-categories within the themes of met needs, unmet needs and implications for future needs (Figure 1).

2. Descriptive data were extracted from the remaining transcripts and subjected to descriptive data analysis in NVivo 9, using the qualitative data analysis package.
3. Key quotes were extracted using the broad themes and the overall story of participants' met, unmet and implications for future needs could be told using the framework set.
4. Biases were reduced by ongoing Strand meetings between the research team members and solid verification strategies that were set in place to ensure trustworthiness. These processes were invaluable and enabled critical review associated with the analysis.

Once all data sets were coded and initial categories refined we sorted our findings into four main sub-categories within the themes of **met needs and unmet needs** (Figure 1). We synthesised findings to then discuss implications for future needs.

Findings

Theme 1: Met Needs

Family Perspectives

Children, young people and their families were living as normal lives as possible in abnormal circumstances. Family coping strategies included siblings, parents and carers such as grandparents and adult siblings, educating themselves and knowing all they need to know to help them to deal with what was happening. Some parents and carers recognised the limitations of what they were able to do and this was important in helping them to discuss their needs and to develop adequate coping strategies. In some cases children, young people and their families drew strength from cultural and religious beliefs. For example, three participants who had a consanguineous marriage discussed this in a positive way because of their strongly held cultural beliefs. There were also occasions when parents acknowledged the importance of talking to their child about the condition and involving the child or young person in decisions that affected them as illustrated; *"I never hide anything from...[named child]. I always find a way of telling him. I might make a story out of it or something — I never hide anything — he can't talk but he can hear everything."* (Participant 37, Mother)

Beneficial Services

Having trust and confidence in services and delivering high quality holistic care for the child/young person and the whole family was very important. In delivery of services, what was really beneficial was information that was relayed in a positive, clear way which is highly valued by parents/carers. All of the parents felt that every child and young person had the right to expect care to be provided at home and that hospital admission should be prevented or reduced to the minimum. Children's hospice services were also perceived as very beneficial to the family members who had used them. Through the opportunity to access children's hospices facilities, parents and carers were given time and

space to separate themselves from their normal caring duties. They felt that the staff were knowledgeable and compassionate to their specific individualised needs but also provided the specialist skills for life-limited children, young people and their families.

Support within schools for children/young people with life-threatening and life-limiting conditions was very varied but overall was reported to be important in meeting needs. Support for transition between phases of education is varied, but generally it was felt that families were included in decisions. Services that are provided through schools (e.g. physiotherapy) which were accessible under one space/area were very useful for families. These needed to be tailored to families in their required environment and the locality to home was important.

Professional Staff Issues

All the children, young people and families felt that both the personal and professional attributes possessed by staff were important. This impacted on their views of the service and the two were often reliant on the other. Being the single port of call, in many cases, they were ideally placed to listen to and care for children/young people with life-threatening and life-limiting conditions and their families at home, whilst allowing parents to share both their joys and concerns on a daily basis. Parents and family carers also felt that they were experts in their child's care and there was evidence cited of some individual professionals being dismissive of parental skills.

Effective Communication

Children, young people and families reported that other essential professional skills included excellent communication and listening. A single port of call, in many cases, was called for as this was felt that one person could ideally be placed to listen to them and support their needs. A number of families also spoke about having a lead discharge nurse in the hospital or hospices and/or a team available that had enabled them to be discharged 'earlier'. Front line health professionals such as qualified community-based nurses often acted as advocates to the parents, for example offering to be present when other professionals such as doctors were informing them of changes in the care packages. Accessibility of support was highlighted as important as was being able to make contact and to receive support out of normal working hours. *"...to know that I can just phone up and have somebody to talk too who knows all about us and [...], today, anytime, twenty four hours a day is wonderful...now that she knows everyone and she's built up a good relationship with the team in [a hospital]...I just can't fault it..."* (Participant 53, Mother)

Theme 2: Unmet Needs

Family Perspectives

In many of the interviews parents and carers, especially mothers (who were frequently the main carers), expressed

their frustrations about being 'exhausted' especially if 'breaks' in care were not provided. The complex psychological support needs of family members were thought to often be left unmet, because of the focus on treating the affected child/young person. Fathers often concentrated on technology needs and equipment during the interviews whilst mothers discussed wider care issues. Many families referred to the pervasion of caring for a child at home and although no participant said that they would want this to be different, some commented that their family home was more like a hospital or clinical setting than a real home. This was not only because of the amount of equipment, but the actual presence of carers, especially health services, coming in and out of the family home all the time. Family privacy was therefore compromised.

Being able to take part in social activities was difficult to arrange and therefore families would benefit from services which enabled them to take time out in leisure pursuits. Some participants referred to changes in family and social dynamics and circumstances due to situation of having a child with a complex life-threatening/life limiting condition. This frequently added to the strain of couple relationships; *"Our home ...it's just a public building I said that to my husband — we both feel like that"* (Participant 9, Mother).

Services Under Pressure

There were many instances cited when services had not met needs, broken down and when professionals' interpersonal skills were felt to be inadequate. Equipment needs at home such as feeding equipment, disposables such as syringes or dressings, nappies and ventilation equipment were a repeated source of concern and contention for the family carers, especially mothers. This was felt to be largely because many parents reported that services were not joined up for this group of children and felt that more responsive systems and resources needed to be in place for the growing numbers and needs.

Professional Staff Issues

In all the regional areas studied, participants reported they had to retell their 'stories' many times to professionals because collaboration within and between service providers was often fragmented. Many of the children and young people frequently experienced an acute medical crisis and had to be admitted to hospital as an emergency. Here, there appeared to be few systems in place which enabled a child or young person's case history to be retrieved immediately on their admission to hospital. Parents and legal guardians were frustrated by the length of time taken giving information about their child when it is obvious to them that their child is in a critical condition and they need medication.

Communication Issues

A large number of families said that they would like more opportunities which enabled them to communicate with other families across the world who were in similar

circumstances. This included electronic communication such as social networking through the Internet. Some parents would welcome an opportunity to attend voluntary support groups where they could meet other parents and carers with a child or young person diagnosed with a life-threatening and life-limiting condition. There would appear to be a lack of centralised information about voluntary services/support groups which is easily accessible to families.

In spite of the fact that many parents and carers had become experts in the practical care they delivered to their child (including complex medical procedures), there were a number of occasions reported where they felt that hospital nurses and consultants either addressed them in patronising ways or conversely spoke in medical jargon. This could be because professionals are unaware of the expertise that families have developed and the complexity of the care they provide for their child. Further, there were several occasions reported of consultants only talking to the mother when both parents and the child/young person were present. Children and young people with long term, life-threatening and life-limiting conditions also endorsed a need to voice their views and the importance that professionals place on children and young people's contributions to their holistic care. This is illustrated; *"Whenever we get asked it's always my mum gets askedthey won't ask us."* (Participant 11.2 Child, Boy and 11.3 Child, Boy).

Discussion

Whilst set in one large area of the UK this study had international implications. What is new about our study is that we interviewed children, young people and family members about their perceptions of met and unmet needs in terms of palliative care services. Their accounts do have resonance with other settings and research internationally in this field but offer a unique perspective from views of children, young people and family carers. There are many implications for delivery of future services for children, young people and families from this study, which are discussed below.

There were numerous examples when children, young people and parents in our study demonstrated resilience and determination which challenge the assumption that families will always struggle with the knowledge that their child's life is at risk (Radriguez & King, 2009). Against all the odds, families often maintained a sense of optimism and this sense of hope appeared to help their determination to continue living their life as fully as possible. Parents and carers frequently said that other parents with a child with a life-threatened/life-limiting condition were worse off than they are. There was a sense and need of empathetic awareness where parents were able to meet with other parents in similar situations so that they are able to engage in altruistic support.

Improvements in technology and medicine mean that children and young people with life-threatening or life-limiting conditions are surviving longer and many very complex, dependent children and young people are living at home as preferred. A concern from our findings was that in this dependency, a young person's autonomy is overlooked because the focus may be on adults making decisions on their behalf. Many of the young people who participated in our study were very knowledgeable about their prognosis and future care needs. The outcomes of the interviews indicated that planning transition from paediatric to adult services has become a vital component in holistic care and demands that service provision is expanded and improved.

Trust and confidence in delivering holistic care are some of the hallmarks of good service delivery and findings highlighted the importance of effective joined up working and collaboration between service providers. Despite financial constraints, many families reported examples of good medical and nursing care. Inequity of service provision in children's and young peoples' palliative care was highlighted which has been reported as an international challenge ([Worldwide Palliative Care Alliance, 2014](#)). Interestingly, some families felt that if they voiced any concerns, the care they receive may be compromised, and in a few cases, that their child's survival may be jeopardised as some individual professionals were reportedly being dismissive of parental skills and knowledge of their child's condition. There was no hard evidence for this but a feeling, although clearly important for service providers. An important finding was the importance of matching care to the needs of families including psychological support throughout the trajectory of illness ([Gamondi, Larkin, & Payne, 2013](#)).

The importance of good communication within and between services was highlighted as a significant factor in how well families cope with a life-threatened or life-limited child ([Coad et al., 2014](#)). Our findings highlighted that good communication meant to families 'honest' conversation with professionals to prepare families for care needs and in the event of premature death. Also, many of the family interviews returned to the time when the child/young person was diagnosed. Having to repeat their story many times can impact on the trust families place in a service or on the relationship with the professionals concerned. Evidence from children and young people who participated in our study challenged the assumption by some professionals that children and young people are unable to express their opinions which concurs with other work including [Down and Simons \(2006\)](#). If communication is not limited to verbal dialogue, even pre-verbal young children and those who use augmented and assisted communication systems can express what they need and how they feel. Therefore, it is important to assess the service needs of children and their families both individually and as a unit but support is needed to face questions and painful decisions. Our findings strongly support that professionals need skills, confidence and

information to find out what each family wants and organisational structures, which are sufficiently flexible to enable them to provide it.

According to research by [Simons \(2002\)](#) parents and carers frequently glean information in a piecemeal way. Our findings concur with the Simons' findings, revealing that the parents interviewed often gleaned information from other parents or, haphazardly through voluntary organisations. Parents and legal guardians also made a heartrending plea for easily accessible information, using information technology systems that were responsive and preferably obtainable from a single port of call.

Having a sick child inevitably leads to extra costs and it is far more difficult for parents with a life-threatened or life-limited child to manage on the same income as families where people enjoy good health. Many families with a sick child have fewer opportunities to earn, and despite the range of benefits and other help available, they may struggle to find their way through the maze and claim their full financial entitlements. Although the support system in the UK recognises the potential implications of financial hardship for families, there was evidence from our work that financial support currently available did not always match the additional costs incurred. Therefore, some families were caring for many years, and the cumulative effect of exhaustion was felt to impact on parents' health and wellbeing. We need to therefore better understand those needs and the associated 'costs'.

Recommendations

We recommend that families need to be supported as a whole, both for their emotional and physical needs. This includes bereavement support for all family members from the time of the child's diagnosis to the end of life and beyond. Improved provision of professional, emotional support for children, young people with life threatened and life limiting conditions and families is strongly recommended, most especially at diagnosis. Families need to be fully informed of their rights to receive financial support with systems in place to assist with relevant paperwork, so not adding to the parent/carer workload.

Information about available services needs to be communicated more explicitly and in a variety of formats in order to ensure that families can make fully informed choices. For example families need more opportunities in the community which will support care throughout the trajectory of the child's or young person's illness. This includes the development of support forums/groups, using up to date, responsive information technology systems that encourage the voice of the child, young person and families to be heard which informs service delivery. Services need to be increasingly user-led as well as user-centred.

We recommend improved partnership and collaboration across services to take into account the holistic needs of families from diagnosis onwards. This requires specialised training for carers to meet the complex needs of children; training for doctors in communicating sensitive information and professional development for healthcare staff to meet the emotional and physical needs of parents and children. In addition, information technology systems to support communication across services and databases which can ‘talk’ across agencies and settings, thus facilitating the sharing of information and developments such as telemedicine.

Conclusion

Using Appreciative Inquiry and framework analysis, this study in the UK reported on in-depth interviews of met and unmet palliative care needs from the perspective of 51 families. This included children, young people with long term, life threatening and life limiting conditions and their parents, grandparents and siblings. It has international implications for care for the growing needs of this group. The expected outcome is to influence and inform health, education and social care services and policymakers which is at a critical stage internationally in its evolution of this field. The challenge highlighted from our findings is that if international palliative children’s services are to move forward there needs to be joined up and seamless practice across health, social care and education services. Moreover, this research has also shown how important children, young people and family voices are. Consequently, any service planning and delivery must be in partnership with the children and young people with long term, life threatening and life limiting conditions and their families. Only with respect for their diversity and listening to their voices can provision of services continue to grow in order to meet the unique needs of everyone concerned (Together for Short Lives, 2013).

References

- Association for Children with Life-threatening or Terminal Conditions and their Families (ACT), & Royal College of Paediatrics and Child Health (RCPCH) (2003). *A guide to the development of children’s palliative care services* (2nd ed.). Bristol: ACT and RCPCH.
- Avis, M., & Reardon, R. (2008). Understanding the views of parents of children with special needs about the nursing care their child receives when in hospital: A qualitative study. *Journal of Child Health Care*, *12*, 7–17.
- Brown, E. (2007). *Supporting the child and the family in paediatric palliative care*. London: Jessica Kingsley.
- Brown, E. (2012). The education of the life-limited child. In A. Goldman, R. Hain, & S. Liben (Eds.), *The Oxford textbook of palliative care for children*. Oxford: Oxford University Press.
- Carter, B., Coad, J., Bray, L., Goodenough, T., Moore, A., Anderson, C., et al. (2012). Home-based care for special healthcare needs: Community children’s nursing services. *Nursing Research*, *61*, 260–268.
- Coad, J., Patel, R., & Murray, S. (2014). Disclosing terminal diagnosis to children and their families: Palliative professionals’ communication barriers. *Death Studies*, *38*, 302–307. <http://dx.doi.org/10.1080/07481187.2012.753555>.
- Cooperrider, D., & Whitney, D. (1999). Appreciative Inquiry: a positive revolution in change. In P. Holman, & T. Devane (Eds.), *The Change Handbook: Group Methods for Shaping the Future* (pp. 245–261). Berrett-Koehler Publishers: San Francisco.
- Cooperrider, D., & Whitney, D. (2005). “What is Appreciative Inquiry?” A positive revolution in change: Appreciative Inquiry, 01 May 2005. <http://appreciativeinquiry.cwru.edu/intro/whatisai.cfm>
- Craig, F. (2006). Adolescents and young adults. In A. Goldman, R. Hain, & S. Liben (Eds.), *Oxford textbook of palliative care for children* (pp. 108–118). London: Oxford University Press.
- Dangel, T. (2002). The status of paediatric palliative care in Europe. *Journal of Pain Symptom Management*, *24*, 160–165.
- Danvers, L., Freshwater, D., Cheater, F., & Wilson, A. (2003). Providing a seamless service for children with life-limiting illness — Experiences and recommendations of professional staff at The Diana Princess of Wales Children’s Community Service. *Journal of Clinical Nursing*, *12*, 351–359.
- Department of Health (2008). *Better care: Better lives — Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions*. London: Department of Health.
- Down, G., & Simons, J. (2006). Communication. In A. Goldman, R. Hain, & S. Liben (Eds.), *Oxford Textbook of Palliative Care for Children* (pp. 28–41). London: Oxford University Press.
- Downing, J., Marston, J., & Boucher, S. (2010). Children’s palliative care in South Africa. *Australian Journal Cancer Nursing*, *11*, 3–10.
- Fraser, L., Miller, M., Hain, R., Norman, P., Alridge, J., McKinney, P., et al. (2012). Rising national prevalence of life-limiting conditions in children in England. *Pediatrics*, *129*, 923–929.
- Friebert, S., & Huff, S. (2009). *National Hospice and Palliative Care Organization pediatric standards: A key step in advancing care for America’s Children*. Alexandria: NHPCO, 9–13.
- Gamondi, C., Larkin, P., & Payne, S. (2013). Care competencies in palliative care: An EAPC White Paper on palliative care education. *European Journal of Palliative Care*, *20*, 86–91.
- Goldman, A., Hain, R., & Liben, S. (2012). *Oxford textbook of palliative care for children* (2nd ed.) (978-0-19-959510-5 | 24 May 2012. Oxford).
- Hospice Palliative Care Association of South Africa (2008). *A toolkit for children’s palliative care programme in Africa*. Cape Town: Hospice Palliative Care Association of South Africa, 5–8.
- Huijter, H., Sagherian, K., & Tamin, H. (2013). Quality of life and symptom prevalence in children with cancer in Lebanon: The perspective of parents. *Annals of Palliative Medicine*, *2*, 59–70.
- Hunt, A., Brown, E., Coad, J., Staniszewska, S., Hacking, S., Chesworth, B., et al. (2013). Why does it happen like this? Consulting with users and providers prior to an evaluation of services for children with life-limiting conditions and their families. *Journal of Child Health Care* (<http://chc.sagepub.com/content/early/2014/01/02/1367493513510630>).
- Jassal, S., & Sims, J. (2006). Working as a team. In A. Goldman, R. Hain, & S. Liben (Eds.), *Oxford, Oxford textbook of palliative care for children* (pp. 518). Oxford University Press.
- Knapp, C., & Contro, N. (2009). Family support services in pediatric palliative care. *American Journal of Hospital Palliative Care*, *26*, 476–482.
- Knapp, C., Woodworth, L., Wright, M., Downing, J., Drake, R., Fowler-Kerry, S., et al. (2011). Paediatric palliative care provision around the world: A systematic review. *Paediatric Blood Cancer*, *57*, 361–368.
- Lenton, S., Stallard, P., Lewis, M., & Mastroyannopoulou, K. (2001). The effects of childhood non malignant life threatening illness on parent health and family functioning. *Journal of Child Psychology and Psychiatry*, *7*, 823–829.
- Lobchuk, M. (2007). The memorial symptom assessment scale: Modified for use in understanding family caregivers’ perceptions of cancer

- patients' symptom experiences. *Journal Pain Symptom Management*, 1, 644–654.
- Marston, J., & Chambers, L. (2013). International aspects. In A. Goldman, R. Hain, & S. Liben (Eds.), *Oxford textbook of palliative care for children*. Oxford: Oxford University Press.
- McNamara-Goodger, K., & Feudtner, C. (2012). History and epidemiology. In A. Goldman, G. Hain, & S. Liben (Eds.), *Oxford textbook of palliative care for children* (2nd ed.). Oxford: Oxford University Press.
- Midson, R., & Carter, B. (2010). Addressing end of life care issues in a tertiary treatment centre: Lessons learned from surveying parents' experiences. *Journal of Child Health Care*, 14, 52–66.
- Morris, C., Gibbons, E., & Fitzpatrick, R. (2009). *Child and parent reported outcome measures: A scoping report focusing on feasibility for routine use in the NHS*. Oxford: Patient Reported Outcome Measurement Group (http://phi.uhce.ox.uk/pdf/PROMs_withchildren).
- Noyes, J. (2006). Resources use and service costs for ventilator-dependent children and young people in the UK. *Health and Social Care in the Community*, 14, 508–522.
- Office for National Statistics (2011). *Census 2011*. London: Office for National Statistics.
- Radriguez, A., & King, N. (2009). The lived experience of parenting a child with a life-limiting condition: A focus on the mental health realm. *Palliative Support Care*, 7, 7–12.
- Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research, Bryman and Burgess. *Analysing Qualitative Data* (pp. 173–194). London: Routledge.
- Simons, J. (2002). Practical issues in the care of the dying child. In A. Goldman (Ed.), *Care of the dying child* (2nd ed.). Oxford: Oxford University Press.
- Sloper, T., & Beresford, B. (2006). Families and disabled children: Social and economic needs are high but remain largely unmet. *British Medical Journal*, 333, 928–929.
- Social Policy Research Unit (SPRU) (2010). *Together for Short Lives, Help the Hospices and The National Council for Palliative Care*. Health and social care (children and young adults): Supporting health transitions for young people with life-limiting conditions: Researching positive practice (the STEPP project) (www.togetherforshortlives.org.uk, accessed 12th May 2014).
- Together for Short Lives (2013). The big study. www.togetherforshortlives.org.uk
- Trajkovski, S., Schmied, V., Vickers, M., & Jackson, D. (2013). Implementing the 4D cycle of appreciative inquiry in health care: A methodological review. *Journal of Advanced Nursing*, 69, 1224–1234, <http://dx.doi.org/10.1111/jan.12086>. Epub 2013 Jan 14.
- UNESCO (1989). *United Nations convention on the rights of the child*. Geneva: UNESCO.
- Worldwide Palliative Care Alliance (2014). In S. Connor, & C. Sepulveda (Eds.), *Worldwide Palliative Care Alliance, Global atlas of palliative care at the end of life*. London: Worldwide Palliative Care Alliance.
- Wright, M., Lynch, T., & Clark, D. (2008). *A review of donor organizations that support palliative care development in five world regions*. Lancaster: International Observatory on End of Life Care and Lancaster University.
- Wright, M., Wood, J., Lynch, T., & Clark, D. (2008). Mapping levels of palliative care development: A global view. *Journal Pain Symptom Management*, 35, 469–485.