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Consulting with young people: informing guidelines for children's palliative care

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Abstract

Objective: Increasingly the views of young people are sought when improving healthcare; however, it is unclear how they shape policy or practice. This paper presents a consultation with young people commissioned by NICE (National Institute for Health and Care Excellence) to inform clinical guidelines for paediatric palliative care (End of Life Care for Infants, Children and Young People).

Methods: The consultation involved qualitative thematic analysis of data from 14 young people (aged 12-18) with a life-limiting or life-threatening condition, who took part in focus groups or interviews. The topics explored were pre-defined by NICE: information and communication; care planning; place of care; psychological care. Data collection consisted of discussion points and activities using visual cues, and was informed by a pilot consultation group with five young adults (aged 19-24). Findings were shared with participants and feedback helped to interpret the findings.

Results: Four over-arching themes were identified, cutting across the predetermined topic areas: being treated as individuals with individual needs and preferences; quality of care more important than place; emotional well-being; living as a young person. Importantly, care planning was viewed as a tool to support living well and facilitate good care, and the young people were concerned less about where care happens but who provides this.

Conclusion: Young people's priorities differ from those of parents and other involved adults. Incorporating their priorities within policy and practice can help

to ensure their needs and preferences are met and relevant research topics identified.

Background

Palliative care can play an important role for children and young people with life-limiting conditions (LLC), enhancing quality of life for children and their families.[1-3] In England it is estimated that more than 86,000 children and young people have a life-limiting or life-threatening condition (2017/18).[4] These include diseases without a cure which result in early death (e.g. Duchenne muscular dystrophy), and life-threatening conditions for which treatments are available but can fail (e.g. cancer). The prevalence of children with a LLC is increasing,[4] with medical advances resulting in children living longer, often with complex healthcare needs and medical technologies.[5]

In 2016, a clinical guideline for end of life care for infants, children and young people was published by the National Institute for Health and Care Excellence (NICE) to inform and improve clinical practice in England.[6] This followed an independent review of paediatric palliative care in England in 2007,[7] and growing research showing that while some children receive care that enhances their quality of life, others experience poor care co-ordination and communication, and have unmet care needs.[8,9] This includes a small evidence base exploring the views of children and young people, providing unique insights into their care experiences, highlighting, for example, the importance of peer relationships.[9-11]

These insights highlight the value of involving service users in the development of policy and practice, and service user involvement has increased in recent decades and is now embedded in the development of NICE guidelines[12] and in research more generally.[13] However, for children and young people with a serious illness parents often represent them on the committees that make key decisions about them.[6,14] Although parents, as both parents and expert carers of their child, offer an important perspective, the views of parents and young people do not always align.[15]

The NICE Committee developing the end of life care guidelines included parent members, but not young people.[6] To address this the Committee commissioned a consultation with young people focusing on pre-defined aspects of care provision covered by the guidelines. Detailed findings pertaining to each topic were published alongside the guidelines.[16] This paper presents the analytical themes that were identified from the consultation and considers how this evidence informs paediatric palliative care policy and practice.

Methods

The consultation used qualitative research to explore the views and experiences of young people with a LLC about pre-determined topics covered in the NICE guidelines: preferences for place of care; information and communication provision; personalised care planning; and psychological care. The consultation also sought young people's views on how care could be improved.

Sample

We included young people (age 12-18) diagnosed with a LLC, who were aware their condition was potentially life-shortening, were able to communicate verbally and had capacity to consent. Drawing on methodological expertise[17-19] and experiences of conducting research in this area,[9] we aimed to recruit a minimum of 12 young people to explore the diversity of experience.

The consultation took place in three geographical locations in England. Young people were recruited by a national charity for children with life-limiting conditions, who contacted eligible families who already received information from the charity (via email or post). Children's hospices in each locality were also asked to promote the study, e.g. through their newsletters, email communications and in the hospice itself. Due to the short duration of the consultation, a convenience sample was sought in the first instance; however, we purposively sampled towards the end of data collection to include young people of different ages, ethnicity, diagnoses and care experiences. Here, the children's hospices identified eligible young people and invited them by post or email.

Data collection

Focus groups allowed young people to exchange experiences and share ideas about what was important to them. Individual interviews were also offered. Focus groups were structured around a 90-minute topic guide, which included visual cues to stimulate discussion.[20] A pilot focus group with five young adults (age 19-24) was undertaken to test and refine materials.

Three focus groups (with two to seven participants) and two individual interviews, with 14 young people in total, were carried out between October and December 2015. Focus groups were held in public venues or children's hospices. Interviews were conducted in participants' homes. Parent/carers were not present during focus groups or interviews.

The focus groups ranged from 83 to 91 minutes and were facilitated by JA and JT, who are experienced qualitative researchers. Individual interviews, conducted by JT, were 21 and 38 minutes in duration. All groups and one interview were audio recorded and transcribed for analysis. One interview participant chose not to record his interview. Instead, extensive notes were recorded immediately after the interview. Detailed field notes were made during the focus groups by SM.

Data analysis

The Framework thematic analytic approach was used to structure and explore the data.[21] NVivo software (version 11)[22] was used to manage and code the transcripts and field notes. The process of analysis described by Ritchie et al., (2003)[21] was followed and carried out by JT, JA and SM (see Table 1 for details of the analytical process).

Table 1 – Analytical process

Analytical step	*What we did*	*Who was involved*
Step 1: 'conceptual scaffolding'	Identified recurring ideas and concepts (i.e. codes) in the data and developed a coding framework with the predetermined topics as the descriptive categories and codes placed into the best fitting category.	JT, JA, SM

Step 2: 'indexing'	Tested and modified the coding framework by coding a selection of data into the framework using NVivo.	JT with input from JA and SM
Step 3: 'coding'	Coding of data to final framework in NVivo.	JT
Step 4: 'descriptive analysis'	Summarised and synthesised the coded data for each descriptive category (these findings are presented in the main report).	JT, JA, SM
Step 5: 'explanatory analysis'	Explored patterns and relationships within and between the descriptive categories to develop analytical themes that better represented the accounts of participants (these themes are presented in the paper).	JT, JA with input from SM

Quality

Quality of the consultation was assured against several criteria, including dependability (e.g. through employing a standardized approach to data collection and analysis), credibility (e.g. through checking our interpretations with study participants), trustworthiness (e.g. through comprehensive reporting of study methods and potential limitations), and authenticity (e.g. through recruitment of a diverse sample and sense-checking of results with young adults who piloted the topic guide).[23] A detailed account of the consultation methods are provided in the full report.[16]

Ethical considerations

The study was not eligible for NHS ethics review. To ensure high ethical standards the team adhered to the Economic and Social Research (ESRC) Framework for Ethics.[24] Principles of voluntary informed consent, confidentiality and anonymity,

participant burden and rigour underpinned the consultation. All potential participants were provided with written information and given an opportunity to ask questions. Participants provided written, or where appropriate recorded verbal consent. Capacity to consent was assessed by professionals known to young people who expressed an interest in taking part, and for all young people under 16, written consent was also taken from a parent.

Results

Participants included seven males and seven females, from 12 to 18 years. Three young people were from an ethnic minority background. Participants had conditions in the following disease groups: congenital and chromosomal, neuromuscular, cancer, and pulmonary and respiratory. All participants lived at home with their parent/s, and all but one participant accessed children's hospice services. Many of the participants had physical disabilities and two had learning and communication difficulties. All but one participant had lived with their condition for several years.

Four analytical themes were identified from the analysis as particularly significant to the young people.

1. Seeing us as individuals, with individual needs and preferences

This theme centred on the importance of being treated as individuals, rather than being defined by their condition. One young person noted it was important not to make assumptions that they would have similar opinions and needs:

"We're just like a tiny handful of people … [referring to the group], and we have already got so many differences that how are they supposed to presume the young people's opinions." (participant 15, age 17)

This diversity was evident in discussions about involvement and information about their condition. Preferences varied by individual regardless of age and maturity and over time and from decision to decision. *"I think it depends on how important things are, or not"* (participant 5, age 17). Sometimes too much information caused participants to worry about what might happen; for others, not receiving all the information could make them distrust the person providing it.

"If the doctor isn't giving you all the information, the doctor's not being honest. I think that they should give you all the information." (participant 3, age 14)

2. Emotional well-being

Young people described a range of negative feelings they experienced related to having a serious health condition, including sadness, frustration, anger, depression, worry, loneliness, disappointment, feelings of loss and fear. Problems associated with growing up with their condition, care they received or limited information about tests and treatments affected their wellbeing.

"I got loads of really bad infections in my ear … I was angry, disappointed at the doctors because they'd said your ear's fine for years … I had depression over it and cried a lot because I couldn't hear or anything and the pain was really awful." (participant 2, age 14)

Young people explained that thinking about their condition and how it impacted on their life could make them feel sad and stressed.

"Even if I compare myself to when I was younger like, say, my arms like I could lift them right into the air, whereas now I can't. So it's like, well, what am I taking for granted now that I won't be able to use in the future." (participant 5, age 17)

They also worried about their family.

"*I think with feelings and emotions it's a lot more easier to try and protect them [parents] from that because you don't want them to feel guilty or anything."* *(*participant *5, age 17)*

Participants reported a range of distraction and avoidance techniques to avoid negative thoughts and overthinking. These included reading, art, music, playing computer games, relaxation, and social media. One participant kept a journal to "*let out my feelings*" (participant 14, age 12). Some participants felt that talking things through with the right person was important. However, some said it was hard to find the right person, "*no-one understands anything"* (participant 2, age 14). Some said therapy was useful and recommended it for others, "*get a psychologist to go and see the child, so they can express their feelings and they can help"* (participant 14, age 12). Others expressed a reluctance to seek professional help. One young person explained, *"there's a stigma attached around it [therapy] but there shouldn't be"* (participant 10, age 17).

3. Quality of care more important than place

The analysis revealed the importance of quality of care to the participants, rather than just considering place. They referred to particular factors they associated with good quality care, irrespective of place, which helped them to feel safe and looked after. These included: having known and accessible specialists with knowledge of their condition; being treated as an individual; carers taking the time to meet their personalised care needs; and continuity of relationships.

"It's been good that I've known the nurses because it feels more friendly rather than just clinical people just looking at you." (participant 5, age 17)

Having home comforts when away from home, and their own technologies and access to the internet were important to young people, who used their devices to stay in touch with friends and to distract them when they felt lonely or sad.

When away from home, ensuring care plans included personalised information about them as individuals as well as their care needs was important to some participants, although there were concerns about the type of information that was shared as they did not want everybody knowing all personal things about them. They identified the need for improvements in the sharing and updating of care plans. As one young person explained, this could also ease the pressure on young people to ask for help and reduce their need to explain their condition and care regimen repeatedly.

"Because I've got my disability it feels like I can't really do things myself and I'm scared to ask people I don't know to do it for me, and sometimes my mum's not there." (participant 2, age 14)

4. Living as a young person

The young people emphasised the importance to them of living well with the condition, rather than the focus being on their deteriorating health and preparing them for dying. Many participants were clear that their condition and the healthcare they received was only one aspect of their lives.

"I don't need information referring to my disability all the time" (participant 3, age 14)

For young people with a disability, having the right equipment at the right time was more central to their wellbeing than their future health care plans:

"I wouldn't be the person that I am today without the right wheelchair because I wouldn't be as sociable, I wouldn't get out as much." (participant 3, age 14)

Interestingly, young people chose not to talk about care plans in relation to end of life care or advance care planning, despite the use of sensitive prompts from group facilitators. Instead, they highlighted how care planning could enable them to live their lives better, allowing them to avoid the need to repeat details about their condition and care needs to others, and to manage their life around upcoming treatments.

"I'd like to have one [a care plan] when I was having my chemo because I'd know when I was going to go in and how long I'd stay in." (participant 14, age 12)

Discussion

In this qualitative consultation with young people with a life-limiting condition, the analytical themes were: to be seen as individuals, with individual needs and preferences; emotional well-being; quality of care more important than place; and living as a young person. These themes cut across the pre-determined topics we explored, and raise questions about whether the priorities of young people are aligned with those of the adults who advocate for and support them. Examples of this difference can be seen in relation to care planning and place of care.

Care planning and in particular advance care planning is recommended for children with a life-limiting condition,[6,14] and the latter is increasingly used as a measure of quality care.[2,3,25] However, this was not identified as a priority by the young people themselves, who emphasised the role of care planning in helping them to live well in addition to facilitating good care. In relation to place of care, which is also commonly used as a measure of good palliative care,[25] the young people emphasised quality over place, with continuity and expertise in the people providing care identified as key indicators of quality. Incorporating these priorities into care planning tools, which are sometimes developed without young people's involvement,[14,26] may help to improve their acceptability and uptake in practice, and provide clinicians with important cues about what matters to young people.[27]

Both examples illustrate the finding that the young people wanted their individuality recognised. They varied considerably in their preferences for how much information they wanted, from whom and when, and this variability is evident in other adolescent patient groups.[28] Medical experts and parents were important sources of information, but other young people had 'the lived

experience' of their condition, which could be important for making decisions about their care. The young people also noted that preferences can change over time and vary depending on specific circumstances. They recognised this can make it difficult for health professionals to know how to involve them in decision-making, and one suggestion was that, for each decision, they could be asked how involved they would like to be. This may help to prevent a mismatch between preferences and experiences, which a systematic review found can have negative emotional consequences for adolescents with long-term conditions.[28]

The consultation revealed unmet psychological care needs. Living well and dealing in an emotionally healthy way with the challenges of a potentially life-shortening condition alongside the other developmental challenges of adolescence can be a considerable struggle.[8,29] The young people who had specialist psychological input found it invaluable and recommended it to others; however, there were barriers to obtaining such help and sometimes reluctance to talking about emotions with others and seeking help for these. Ensuring psychological care is prioritised alongside medical care may help to open up conversations with young people about their emotions. Integrating specialist psychological input into care pathways at an early stage may also help to reduce perceived stigma. Care pathways for paediatric oncology offer an exemplar of good practice in this area.[30]

The importance of this theme reflects wider concerns about mental health issues in young people and the poor provision of appropriate and specialist care.[31] Young people with long-term conditions and complex healthcare needs have been identified as a particularly vulnerable groups, and a recent systematic review

found comparatively high prevalence of depression and anxiety in children with a life-limiting condition, with older age being associated with higher risk.[32] This is pertinent as more young people with life-limiting conditions are living longer into adulthood,[4] and research is needed to understand what psychological interventions are most likely to benefit this growing population.[6]

Conclusion

This consultation provides useful insights into the priorities of young people with life-limiting conditions. These are not always the same as those of their parents or adults working in the area. Whilst aware of the potentially life-limiting nature of their conditions and the physical and emotional challenges they faced, the emphasis of the young people was upon wanting to live the life they had as fully and richly as possible. They did not focus upon end of life care, place of death and preparing for death, but they did articulate what good quality care looks like. Incorporating these priorities within policy and practice may help to ensure that conversations between healthcare professionals and young people start with what's important to young people, and that care planning focuses as much on how to minimise the disruption that episodes of care can cause in young people's lives and addressing psychological needs, as it does on planning for end of life.

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Contributors

JT, LC and JA contributed to the design of the study. JT, JA and SM carried out data collection and analysis. JT and JA drafted the manuscript with contributions from SM and LC. The final manuscript was approved by all authors.

Competing interests

None declared

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What is already known on this topic?

Parents are often asked to represent the needs of children and young people with life-limiting conditions in the development of policy and clinical guidelines.

An increasing evidence-base highlights the important unique insights and experiences about care provision that children and young people can offer themselves.

What this study adds

Presenting young people's voices in current policy can highlight differences in the priorities of young people and the adults who care and advocate for them.

Young people with life-limiting conditions prioritised quality of care over place, and care plans were most valued when they supported 'living well'.

There are unmet psychological needs among young people with life-limiting conditions and perceived barriers to accessing help for these.

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