The Patient - Patient-Centered Outcomes Research
https://doi.org/10.1007/s40271-025-00744-8

ORIGINAL RESEARCH ARTICLE

What Constitutes High-Quality Paediatric Palliative Care? A Qualitative Exploration of the Perspectives of Children, Young People, and Parents

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Accepted: 11 May 2025

Abstract

Background Globally, over 21 million children need palliative care each year. Although guidelines exist to support paediatric palliative care delivery, they are not informed by the experiences of children themselves.

Objective We aimed to determine what constitutes good quality palliative care from the perspectives of children with life-limiting or life-threatening conditions and their parents.

Methods We analysed semi-structured qualitative interviews using reflexive thematic analysis informed by the European Association for Palliative Care charter of palliative care for children and young people, and Bronfenbrenner's bioecological model. Participants included 26 children aged 5–17 years, and 40 parents of children aged 0–17 years, with a range of cancer and non-cancer diagnoses in nine UK paediatric palliative care services (hospitals and hospices).

Results Quality paediatric palliative care can be both enacted or interrupted across the five domains of the bioecological model. Honest timely communication with the child and family (microsystem), and collaborative relationships between care teams and others in the child's life (mesosystem), are vital. Care experiences are negatively affected by inequities in care provision (exosystems), and society's reluctance to discuss mortality in childhood (macrosystem). Children need to enjoy what matters to them, and maintain social connections, and plan for the future, even if facing a shortened life (chronosystem).

Conclusions Children and parents are experts in their condition and should be actively involved in care discussions, through communication tailored to the child's pace and preferences, and support advocating for and coordinating care services. Fostering strong and collaborative relationships builds trust and helps children and families to feel safe, included and supported.

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Key Points for Decision Makers

Quality care for children and parents is characterised by timely and sensitive communication that includes the child in discussions where possible, and offers them opportunities to ask questions and be involved in decision making.

Children with life-limiting conditions need support to maintain familial and social relationships, build new social connections and to continue to pursue activities they enjoy.

Health and social care professionals need to recognise the central role of families in providing care, and support and advocate for them as they navigate care services.

1 Introduction

There are >21 million babies, children and young people (hereafter "children") aged ≤18 years worldwide who need palliative care each year [1–3]. The World Health Organization (WHO) states that paediatric palliative care "is the active total care of the child's body, mind and spirit", it involves giving support to the family, continues from diagnosis regardless of treatment, and requires multidisciplinary evaluation and care [4]. In high-income countries (as defined by the World Bank [5]), improvements in diagnosis and treatment mean that children are surviving for longer with complex conditions and clinical uncertainty, many of whom have the potential to benefit from palliative care [6, 7]. In England, the number of children with a life-limiting or life-threatening condition (hereafter "life-limiting conditions") rose approximately 160% between 2001 and 2018 to 86,625 [8]. In the WHO European Region alone, it is estimated that 170,000 children per year die in need of palliative care [7].

Despite the growth of children's palliative care services globally [2, 9], many countries have no provision [9]. Guidelines exist to support development and delivery, mainly in higher income countries, i.e. IMPaCCT (International Meeting for Palliative Care in Children, Trento 2016) for use in Europe [10]; GO-PPaCS (Global Overview, PPC Standards 2022) updated the IMPaCCT standards to globalise standards and recognise the context of care delivery [11]; and the National Institute for Health and Care Excellence (NICE 2016) planning and management guideline for the care of children with life-limiting conditions in England [12].

Valuable insights have been gained from research with parents about what constitutes good-quality paediatric palliative care [13]. Parents described the importance of collaborative relationships with trusted clinicians, and care that is flexible, responsive, and recognises both the needs of and the care contribution of the family [14]. However, the United Nations Convention on the Rights of the Child states that children (under the age of 18 years) who can form their own views must have the right to express those views in matters that affect them, and have them considered appropriately [15]. Indeed, children's care priorities differ from their parents—they want to focus on normalcy and value kindness from clinicians—while parents are immersed in the constant fight to access services and resources, and value clinicians who will fight for them [16]. To our knowledge however, there are no recent studies that have explored how *children* themselves conceptualise high-quality paediatric palliative care. This study aimed to address this evidence gap through the following research question: what constitutes good-quality care from the perspectives of children with life-limiting conditions and their parents?

2 Methods

2.1 Study Design

This study sits within a sequential mixed-methods programme to develop and validate a novel outcome measure for children living with life-limiting conditions and their families (Children's Palliative care Outcome Scale [C-POS]: UK) [17–30]. This qualitative study is underpinned by social constructivism [31], which recognises that understanding and knowledge are constructed through interaction with others. This supplementary secondary analysis [32] of data collected for the programme described above falls within the aims and objectives of the original study, but provides a more in-depth analysis of one emergent feature of the data only partially reported in the primary study [20], namely quality care from the perspectives of children with life-limiting conditions and their parents. The study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Studies (COREQ) [33].

2.2 Setting

We recruited participants from nine specialist palliative care services (six National Health Service [NHS] hospitals, and three hospices predominantly charity funded and run as third sector organisations, receiving 10–20% of their funding from the NHS) across two UK nations.

2.3 Inclusion Criteria

We included children (aged 5–17 years) with a life-limiting condition, with support from their parents if required; and/or parents and carers of children (aged 0–17 years) with a life-limiting condition.

2.4 Exclusion Criteria

We excluded children unable to participate in a qualitative interview, and children, parents and carers who speak a language not supported by NHS translation services, currently enrolled in another research study or unable to consent/assent.

2.5 Sampling

Purposive sampling was utilised to achieve a heterogeneous sample, led by age and condition. Recruitment stopped once sufficient data had been collected to meet the study aim. The concepts of pragmatic saturation [34] and information power [35] were used to inform this assessment, which place the focus on the relevance and richness of the data gathered, in relation to the specific aims and objectives of the original study. Given the heterogeneity of the population, a relatively large sample was needed, including parents to capture the views of children with cognitive impairment or who are non-verbal. Iterative data collection and analysis, and completion of reflexive diaries were used to inform discussions within the team regarding acquisition of sufficient data and stopping recruitment.

2.6 Recruitment

Potential participants were identified at multidisciplinary team meetings, ward rounds and outpatient appointments. The study was introduced verbally by the clinical team either during appointments or admissions or over the phone. If individuals expressed an interest, they were provided with an information sheet and given time to consider participation. Those who confirmed interest were referred to the research team to arrange an interview.

2.7 Data Collection

Interview topic guides (see Electronic Supplementary Material) were developed by the study steering group, and informed by the WHO definition of paediatric palliative care [36], and evidence of paediatric palliative care symptoms and concerns [13]. Semi-structured interviews were conducted by three researchers: DB (experienced qualitative researcher), LC (paediatric palliative care nurse, new to qualitative research) and AR (new to qualitative research), with study support provided by KB, CES, RH and MBL (experienced qualitative methodologists). Most interviews were face to face in the participant's preferred location. A subset were conducted remotely (telephone or video call) because of coronavirus disease 2019 social distancing restrictions. Interviews commenced with basic demographic questions, and questions about the child's interests and hobbies to build rapport. Interviews focussed on the impact of the child's condition on their life, and what matters to them. The research team used play and drawing techniques and offered regular breaks. Interviews were audio-recorded, transcribed verbatim and pseudonymised. A reflexive diary captured emergent themes and reflections on the interviews. It was not possible to return transcripts or summarised findings to participants for checking.

2.8 Ethical Considerations

Study design and conduct were informed by a child and young person's advisory group [37]. Many children want to participate in research, and find it rewarding [38]. As potentially vulnerable people, the following steps were taken to minimise risks of participation. Guided by the parent/caregiver, potential child participants had the study explained to them at an appropriate time, using language and study materials aligned to their communicative abilities. They were given at least 24 hours to consider participation. To minimise potential distress, researchers gave information about the interview content in advance of the consent process. Researchers were trained to identify signs of distress, and gave opportunities to pause, rearrange or terminate the interview as needed. All interviews concluded with a 10-min debrief to assess the impact upon participants. Any distress was responded to, and participants were referred to the clinical team or community support sources as required.

2.9 Analysis

Four phases of analysis were conducted, supported by NVivo software (version 12).

2.9.1 Phase 1

A deductive thematic analysis [39] was conducted using a coding frame guided by the domains of the European Association for Palliative Care (EAPC) Charter on Palliative Care for Children and Young People [40]. The Charter was developed through consensus by the EAPC Children and Young People's Reference Group, comprising clinicians, researchers, clinical academics and advocacy organisations for children with palliative care needs [40], and draws on existing guidance on the delivery of paediatric palliative care [10–12, 40]. Data were coded to ten themes within the charter: dignity and respect; communicating diagnosis and prognosis; supporting communication; keeping children, young people and their families at the centre of decision making; location of care; symptom management; psycho-social and spiritual needs; everyday life; end of life; and public awareness.

2.9.2 Phase 2

A second phase of inductive coding was conducted to identify any themes not captured within the charter.

2.9.3 Phase 3

Subsequently, a process of theoretical engagement was undertaken to aid the interpretation of the findings. Bronfenbrenner's bioecological model [41] and Navarro and Tudge's neo-ecological theory [42] were used to inform this phase. These theories were selected as they were designed to understand the interactions that shape children's experiences and development and have great applicability for this work. They take a child-centred approach focusing on four elements: 'Proximal processes', 'Personal characteristics', 'Context' and 'Time'. 'Proximal processes' refers to the frequent interactions between a child and those in their immediate environment (e.g. with family, school, care team). 'Personal characteristics' relates to relevant characteristics of the individual (e.g. children living with a life limiting condition), and how their characteristics evolve as a result of the proximal processes. 'Context' refers to the proximal environment and how it may influence the child (e.g. home setting, hospital/hospice) and more distal influences (e.g. healthcare system, culture, society). Last, 'Time' relates to the duration of those proximal processes (e.g. relationships with healthcare providers over time), but also the current time or era. These elements are considered across the various systems (from proximal to distal) that may influence the child. These are referred to as the microsystem, mesosystem, exosystem, macrosystem and chronosystem. The neo-ecological theory [42] extends the bioecological model [41] to reflect the virtual networks that children exist within today alongside physical networks. Incorporating these theories at the stage of interpretation enabled the research team to map the complex interactions that influence the quality of care a child and their family may receive, and consider how the different domains of the EAPC Charter may be operationalised at the various system levels. While the bioecological model has previously been used to explain complexity in adult palliative care [43], these theories have not been applied to paediatric palliative care.

2.9.4 Phase 4

During the final phase of analysis, the three preceding phases were integrated to inform a set of recommendations for quality paediatric palliative care. The benefits of integrating these different phases were two-fold: (i) the recommendations within the EAPC Charter are necessarily broad and aspirational. By applying these domains as codes to our data, we were able to see how to enact these recommendations in practice increasing the transferability of the findings; and (ii) overlaying these findings by EAPC charter domain onto the neo-ecological theory ensured that the subsequent recommendations were underpinned by theory, presented at the system level to increase applicability and accessibility, but ultimately grounded in the best available guidance on quality paediatric palliative care delivery. Analysis was led by DB and KB, with regular meetings with the wider research team.

3 Results

3.1 Participants

Sixty-six semi-structured one-off interviews were conducted between April 2019 and September 2020 (Table 1). Participants included: 26 children (17 female, 9 male), aged 5–17 with a range of conditions (gastrointestinal, cancer, neurological, congenital, metabolic and respiratory), and 40 parents (30 mothers, 10 fathers) of children aged 0–17 years, with a range of conditions (neurological, metabolic, congenital, cancer, gastrointestinal, infectious, genitourinary and perinatal). Two sets of parents were interviewed together, in the remainder of interviews only one parent and the researcher were present. Three children were interviewed alone by the researcher, the remainder were accompanied by a parent ($n = 18$), a sibling ($n = 1$), a parent and a sibling ($n = 1$), or a paid caregiver ($n = 3$). There were 53/66 interviews conducted face to face, and the remainer via video or telephone call. Mean interview duration was 37 minutes (range 12–81 minutes) for children and 63 minutes (range 33–161 minutes) for parents. No children became distressed during interviews, but some parent participants became upset during interviews. All were offered an opportunity to take a break or stop the interview, but all wanted to carry on. Parents shared that they expected interviews to provoke some distress, owing to the nature of the research study. However, they all found the level of distress experienced acceptable.

3.2 Findings

The findings are presented according to the five systems of the neo-ecological theory including a brief description of each system at the start of each section: (a) microsystems; (b) mesosystems; (c) exosystems; (d) macrosystems; and (e) chronosystems (Fig. 1). See Table 2 for a presentation of all themes and subthemes, and Tables 3, 4, 5, 6, 7 for example quotes by the system within the model that they represent, and the cross-cutting domain(s) within the EAPC charter.

3.2.1 Microsystems: Strengthening Relationships and Interactions Between Children and Health and Social Care Providers

Microsystems are the most proximal contexts within which the child interacts "on a fairly regular basis" [41], including for example their family setting, friendship group or education setting. Our focus is on the health and social care microsystem in which children with life-limiting conditions exist as a patient, and their interactions with health and social care professionals (hereafter "professionals"). Children valued being actively involved in their care decisions, which was achieved in various ways.

3.2.1.1 Telling Children About Their Condition Children described wanting professionals to involve them in discussions about their condition, treatment and symptoms. Being communicated with, rather than about, was fundamental. This supported children to feel involved and informed (Table 3, quote 1 [T3Q1]), and ensured the care was child centred. Instances of not being informed about matters concerning them in a sensitive or timely way were a source of distress for children (T3Q2).

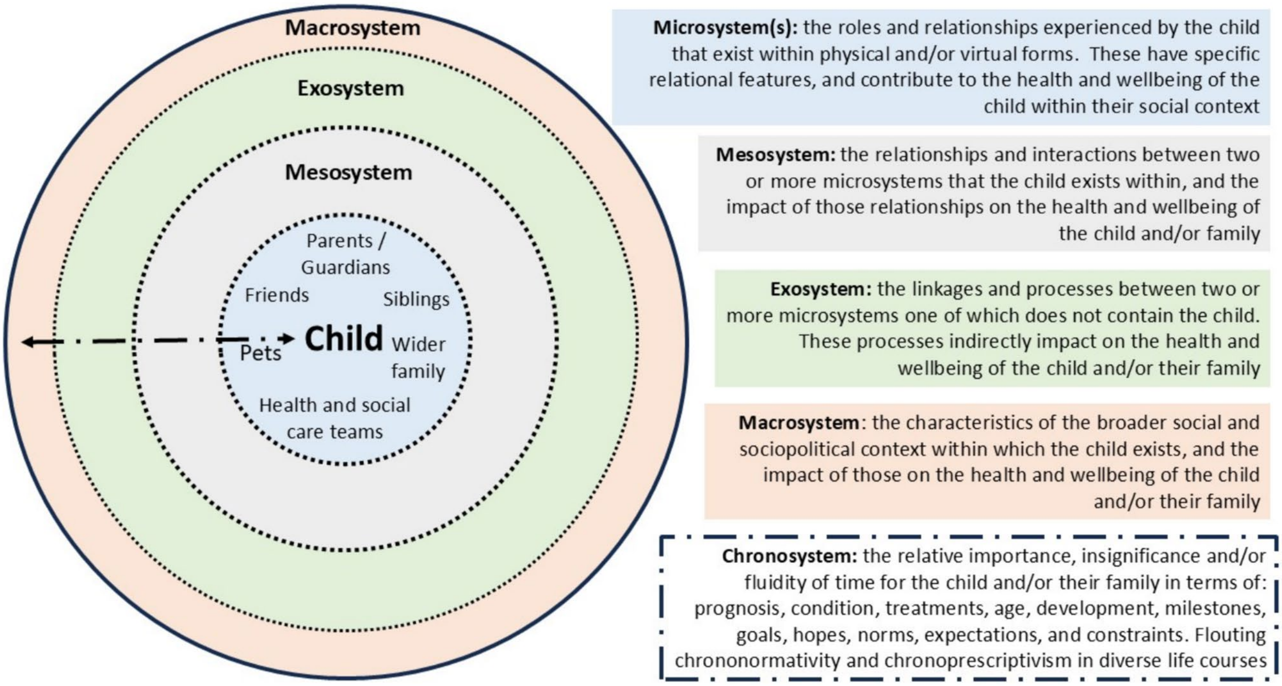
3.2.1.2 Asking Children Questions About Their Condition and Care Children valued professionals taking the time to ask them questions about their symptoms and how they are doing, as this helped them feel they had influence over the decisions made about their care (T2Q3). While some children were ready to answer questions independently, others spoke about the importance of their parents being part of conversations too (T3Q4). As their understanding of their condition developed, some children valued their maturity being recognised through increased involvement in treatment decisions (e.g. asking to assent/consent) [T3Q5].

3.2.1.3 Enabling Children to Ask Questions About Their Condition and Care Children also valued professionals that would answer their questions, so they can understand what is happening and make informed care decisions. Developmentally, older children appreciated the space to ask questions and discuss more substantial aspects of treatment (e.g. administration of chemotherapy) [T3Q6].

Table 1 Participant characteristics

	n or mean (range)
Children (n = 26)	
Age (years)	12 (5–17)
Sex	
Female	17
Male	9
Diagnosis	
Cancer	6
Congenital	3
Gastrointestinal	10
Metabolic	1
Neurological	5
Respiratory	1
Interview duration (minutes)	37 (12–81)
Parent/carers (n = 40)	
Age (years)	40 (21–65)
Gender	
Female	30
Male	10
Relationship to child	
Mother	30
Father	10
Diagnosis of child	
Cancer	6
Congenital	7
Gastrointestinal	4
Genitourinary	1
Infectious disease	2
Metabolic	9
Neurological	10
Perinatal	1
Age of child with life-limiting condition (years)	12 (0–17)
Interview duration (minutes)	63 (33–161)

3.2.1.4 Exploring and Incorporating Activities That Are Important to the Child Alongside discussions about their health, children of all ages described the importance of professionals getting to know them and their interests, and support them to do things they enjoy. Children valued a space with home comforts or activities that enabled them to stay in touch with things or people that mattered to them (T3Q7), and opportunities to be distracted within the care setting (e.g. hydrotherapy pool, computer games). Incorporating these activities, and talking about what matters to them, restored a sense of normality and was vital for child-centred quality care (T3Q8). These conversations also provided vital insights into the impact of the condition for the



Microsystem(s): the roles and relationships experienced by the child that exist within physical and/or virtual forms. These have specific relational features, and contribute to the health and wellbeing of the child within their social context

Mesosystem: the relationships and interactions between two or more microsystems that the child exists within, and the impact of those relationships on the health and wellbeing of the child and/or family

Exosystem: the linkages and processes between two or more microsystems one of which does not contain the child. These processes indirectly impact on the health and wellbeing of the child and/or their family

Macrosystem: the characteristics of the broader social and sociopolitical context within which the child exists, and the impact of those on the health and wellbeing of the child and/or their family

Chronosystem: the relative importance, insignificance and/or fluidity of time for the child and/or their family in terms of: prognosis, condition, treatments, age, development, milestones, goals, hopes, norms, expectations, and constraints. Flouting chrononormativity and chronoprescriptivism in diverse life courses

Fig. 1 Applying the bioecological model (Brofenbrenner and Morris 2006) and neo-ecological theory (Navarro and Tudge, 2022) to the concept of quality in paediatric palliative care

child and their goals and aspirations such as getting back to activities they used to enjoy but were not currently able to participate in.

3.2.2 Mesosystems: Interactions Around the Child That Impact Their Palliative Care

Mesosystems can be understood as the interaction between the child's different microsystems. Ensuring that those within a child's life work together requires oversight and careful management. One of the most crucial mesosystems is the relationship between the child's family and their health and social care teams.

3.2.2.1 Strengthening Relationships and Interactions Between Children and Family, and Health and Social Care Providers

Timely Communication About Diagnosis and Prognosis

> Conversations about diagnosis and prognosis were often difficult, but provided vital updates and clarity (T4Q9). Parents preferred when information was made available ahead of discussions with professionals, so they could process it in advance, enabling them to be informed and involved. However, sometimes the timing of discussions created tension. Parents described noticeable delays and a lack of clarity in diagnosis discussions, leaving them to seek answers and unverified information online (T4Q10). They also described being overwhelmed with discussions about diagnosis and conversations about preparing for their child's death at the same time, even when death was not imminent, leaving them without space to process difficult information. Other parents reported feeling misinformed, or given false hope, leading to mistrust of professionals. While children rarely talked directly about the point of diagnosis, one child described waiting for a protracted period for a conversation to occur, despite being aware her parents had already been informed (T4Q11).

Recognising and Respecting the Central Role of Families in Providing Care

Good-quality care was facilitated when those people surrounding the child worked together, and when the contribution of the family was recognised (T4Q12). Parents are experts in their own child, and feel frustrated when professionals fail to recognise this (T4Q13). Children also put their faith in this parent-professional relationship, relying on parents to relay information to them, answer their questions and provide their care (T4Q14, T4Q15). In the absence of child-friendly information, some parents took it upon themselves

Table 2 Themes and subthemes identified

Main themes	Subthemes	
Microsystems: strengthening relationships and interactions between children and health and social care providers	Telling children about their condition	
	Asking children questions about their condition and care	
	Enabling children to ask questions about their condition and care	
	Exploring and incorporating activities that are important to the child	
Mesosystems: interactions around the child that impact their palliative care	Strengthening relationships and interactions between children and family, and health and social care providers	Timely communication about diagnosis and prognosis
		Recognising and respecting the central role of families in providing care
		Recording, updating, using and communicating care plans
		Supporting families to navigate different care services
		Incorporating independence into care
	Encouraging social connections	Supporting existing connections
		Facilitating new connections through care
		Facilitating new connections through charities
		Maintaining connections to school
Exosystems: influencing children's care from a distance	Making health and social care systems equitable	Improving availability of resources
		Increasing access to vital assistive technology
		Increasing equity in provision of support for the family
	Making education systems inclusive and fit for purpose	
Macrosystems: societal and cultural impacts on children's palliative care	Addressing taboos and challenging the dominant discourse	
	Challenging and changing the infrastructure and environment	
	Respecting children's agency	
Chronosystems: the (in)significance of time in a potentially shortened life	Moving at the child's pace	
	Supporting hopes that shift with prognosis	

to ensure information from professionals was communicated to their child in an appropriate way (T4Q16).

Recording, Updating, Using and Communicating Care Plans

Children, and their parents, wanted to know that the different teams who cared for them knew about their condition and preferences, ideally without having to repeat information. This reassured them, made them feel safe and understood, and improved care experiences (T4Q17). Developing these trusting relationships was vital in supporting families to make child-centred care decisions (T4Q18).

Supporting Families to Navigate Different Care Services

Shared care, involving different care setting and teams, is common for life-limiting conditions. Over time, families develop strong connections and knowledge of the specific care teams, and who to contact for certain concerns (T4Q19). However, clarity in the division of responsibilities, and shared insight across teams is required, so that children and families feel supported, know which team to contact for each concern and can access the care they need in a timely manner (T4Q20).

Incorporating Independence Into Care

Often as children developed, so too did their desire for independence and privacy. This was evident across conditions, and throughout multiple domains, from basic physical needs such as toileting, to the psychological impact of the powerlessness and confinement imposed by their condition (T4Q21). It was not always possible for children's preferences for independence to be met, owing to complex care needs. However, careful engagement with their wishes for autonomy, with support from professionals and families, was important for children to feel respected and heard. Some parents recognised a need to adjust their level of involvement as children matured, to give their child enhanced dignity, but guidance was needed to support such a transition (T4Q22).

3.2.2.2 Encouraging Social Connections Social connections with peers are important in child-centred care. While parents recognised the meaning of these connections, they

Table 3 Example quotes by neo-ecological theory system level and cross-cutting EAPC Charter domains (microsystem)

Quote	EAPC charter domain(s)	Quote
1	Communicating diagnosis/prognosis; supporting communication	*"She sees everything that's going on. Generally when a doctor comes in and we start discussing things ab- about her, she's just there like, stop talking [laughs]. […] I think she doesn't like being talked about, without being talked to […] Yeah, so I think erm probably having er communication where the child is involved, or on a child level"* (Parent of 4-year-old living with cancer)
2	Communicating diagnosis/prognosis; supporting communication	*"sometimes I think about when I, when we get the blood results, like the different indicators. Like I wonder what they actually mean, so like when I hear things like A or T and AST or something […] I wonder what they actually mean and erm, obviously I also wonder what, what is going on in my body. Like what is actually going on with my liver, things like that."* (Child aged 17, living with gastrointestinal condition)
3	Communicating diagnosis/prognosis; supporting communication	*"I think it's important that nurses can or doctors stop and talk to you and know how do you feel or if you need something or whatever because it can be helpful for them to know what is really going on and if the medicine is working or whatever. And even for me to feel better because I, they show to me that they actually care"* (Child aged 15, living with metabolic condition)
4	Supporting communication; everyday life	*"I: does anybody ever ask you about things that matter to you?* *P: Not really medical people, no. Mum might, you know, my Nan might but not nurses […] Just ask me what would make it easier or something, I don't know, ask me. Just be nice, you know be- Talk, talk to my mum and I will pitch in."* (Child aged 14, living with congenital condition)
5	Keeping children and their families at the centre of decision making	*"I'm a bit older now um I've I understand things a lot more and you know they have to ask my consent and you know my opinion on things and because I understand it I'm more I'm able to make quite a few decisions for myself as well you know with being able to discuss it with my parents as well as the doctors and stuff."* (Child aged 14, living with cancer)
6	Communicating diagnosis and prognosis; supporting communication; keeping children and their families at the centre of decision making	*"when I got told they couldn't remove one of the metastasises inside my lungs he said, 'You can have chemotherapy, just to see if it prolongs it and things like that, the growth and things.' So I had that. And then, it was just horrible. Really didn't like it. […] I said 'What's the point if I am having that for a week, but feeling better for a week. I am only getting a week out of it.'… So when [HSCP] was talking to me about switching to oral chemo I had quite a lot of anxiety about it. And thinking about whether I do, or I don't. And how long that's going to change things and stuff. So luckily I spoke to [my consultant] and things like that so and he kinda put my mind at rest about what's the best option"* (Child aged 15, living with cancer)
7	Everyday life; psycho-social and spiritual needs	*"Because some guys came in [to the hospital] with erm…[healthcare professionals] all around the ward, checking, looking at people and umm, talking to them and they even umm…was doing something and I erm was like umm … she was … so [healthcare professional] took me to try and find some nail varnish when they…they done it and we found some in a drawer in a big, big erm, a big case of nail varnish and I picked umm … yellow, two reds for my nails, so they would match my Spain top"* (Child aged 5, living with gastrointestinal condition)

Table 3 (continued)

Quote	EAPC charter domain(s)	Quote
8	Everyday life; psycho-social and spiritual needs	*"that's why I'm often a bit like weird around them, because they don't know who I am, they only know me from my diagnosis. So they don't really know like anything that would be good for me. So like say if it was a 7 year old boy who was really into his like superheroes or something, then they can have something to talk to about and make him happy and calm but in the same way with me, if they knew what I thought was important, and what I liked, and who I was as a person, then I think that would help a lot more."* (Child aged 17, living with cancer)

EAPC European Association for Palliative Care

often needed to work hard with professionals to enable children to maintain and develop friendships.

Supporting Existing Connections

For developmentally older children who had access to and the capacity to use technology, connecting with friends through virtual microsystems (e.g. Instagram, Snapchat, WhatsApp) offered an opportunity to stay connected (T4Q23). However, some children spoke about losing connections, and not being able to maintain friendships throughout their treatment. Providing support for friends and siblings to visit children in hospital or hospice helped keep them connected, and strengthened their relationships (T4Q24). During periods when children were not in hospital or hospice, supporting friends and extended family to understand and deliver the day-to-day care needs for the child enabled some children to stay connected and retain a sense of normality and freedom (T4Q25).

Facilitating New Connections Through Care

Children valued when professionals supported them to make new social connections within the care environment. One child spoke about open wards and how careful placement of children can be a gateway to new social connections at a time when their usual social networks recede (T4Q26). Others reflected on the value of social spaces on wards, which enabled new connections, brought them happiness and enriched their care (T4Q27).

Facilitating New Connections Through Charities

Children spoke of the value of opportunities to build social connections with other children living with similar conditions, such as through charity-run trips and events (e.g. theme parks, camp-outs, musicals, fundraisers). These enabled them to build new and lasting connections to children like them, make memories, feel less alone and (re)established normalcy (T4Q28). However, these opportunities were only available where charities were known and accessible to families and professionals. Knowledge, time and often money are needed to support these activities, but the rewards for children are tangible; offering them an opportunity to reframe and strengthen their self-perceptions.

Maintaining Connections to School

Children's links with their school and peer group were important for their psychosocial well-being. However, experiences varied according to their condition, current symptoms and the support available to them within the schooling system. They appreciated the efforts made by their care teams and their school to maintain these connections. Some children and parents spoke about important links between schools and care teams, which provided the reassurance needed for children to attend school (T4Q29). Other children spoke of the trust they had in their nurses and teachers to keep them connected when they could not attend, which relieved pressure so they were able to focus on their health (T4Q30).

3.2.3 Exosystems: Influencing Children's Care From a Distance

Interactions between people in a child's immediate microsystems is vital to their care; however, the care is also contingent on broader institutions. Although children do not interact with these institutions directly, the decisions institutions take have an impact upon the resources and services available to them. For example, integrated care boards, responsible for local area health budgets across England, decide how much of their allocated funds to spend on NHS trusts and non-NHS providers, such as charitable organisations. This impacts the facilities and support on offer to children with life-limiting conditions and their families.

3.2.3.1 Making Health and Social Care Systems Equitable *Improving Availability of Resources*

Parents often wanted to be the ones to provide their child's care, and home usually offered the most familiar and comfortable environment for this within everyday family

Table 4 Example quotes by neo-ecological theory system level and cross-cutting European Association for Palliative Care Charter domains (mesosystem)

9	Communicating diagnosis and prognosis; supporting communication	*"I think communication is, is an important thing, that you feel that you've been communicated with and that you know we, we wanted very much to do, which is- would be different for different people, but we wanted to be treated very much, to be told straight, but to be told in a sensitive way, but be told directly enough to be actually told where we stood, so we knew what was happening and what to expect"* (Parent of child under 1 year old living with genitourinary condition)
10	Communicating diagnosis and prognosis; supporting communication	*"no one really talked to us about what was going to happen or why it was happening and I was quite frustrated […] I can understand that some of it is a difficult conversation but I think it's, I think this should be the most important thing they do. They sit down with the parents and tell them face to face, and even if it's a hard conversation, that this is it, we don't know why it's happening, it could be this or that but at least the parents know, or they're given options. Because what I felt, they were kind of avoiding us. […] So we Googled it obviously and read lots of articles and Facebook groups, they were Facebook groups where I would chat to parents. […] But I think we should have been given maybe a paper saying this is it, this is polymicrogyria, a short explanation. You know, it's not a thing because to this date I don't really know exactly what he has."* (Parent of 1 year old, living with congenital condition)
11	Communicating diagnosis and prognosis; supporting communication	*"They didn't send me home [after the MRI scan], I still stayed in the hospital and then all the evening when I was about to go to bed, I heard my mum crying and my nurse was talking to her and I guessed she must have told her something. I don't know what is was, I actually went out and said, "Mum why are you crying?" and she said, "Oh no its fine, don't worry about it, just go to bed". So I went to bed. Two days later a group of doctors came in, actually no, one of them came in and told me, "[Patient name] would you please come with us? We have something to tell you." So he took me to a quiet room where there was nobody there and then that's when they told me the news that I'd been diagnosed with cancer."* (Child aged 13, living with cancer)
12	Dignity and respect; supporting communication	*"everyone we work with now, [palliative care doctor], [consultant], [doctor], they all know and respect my input. You know so we do work together now"*—(Parent of 10-year-old, living with neurological condition)
13	Dignity and respect; supporting communication	*"By not acknowledging my knowledge, having been a specialist in [child] or relegating me to the hysterical mother stereotype is awful… and it happens to so many mothers I know. […] people don't really listen, they delegate me to some weird corner or some weird stereotype and then not take note of my knowledge. Especially when it's so rare. And I know him best. And what's the bet that the consultant has never heard of what he's got. It's just frustrating as well, so I wish they would be less condescending and less patronising and take the time to listen to us."* (Parent of 2-year-old, living with metabolic condition)
14	Communicating diagnosis/prognosis; supporting communication	*"I: So, do you have any questions either about sort of your illness or like how you're looked after?* *P: No, because I know how I'm- I know most of the things, so yeah* *I: Mmhmm and who was it that told you most of the stuff that you know?* *P: The doctors and mummy and daddy"* (Child aged 12, living with respiratory condition)

Table 4 (continued)

15	Symptom management	*“we’ve learnt lots as we’ve gone along, with each thing that happens. So I can do oropharyngeal suctioning, I can do his oxygen, he’s on loads and loads of medications. I do chest physio, everything really that [child name] needs day to day we do here. And as any new symptom appears, if it needs something doing, we’re always trained to be able to do it.”* (Parent of 14-year-old, living with metabolic condition)
16	Communicating diagnosis/prognosis; supporting communication	*“we've got a fair selection of child friendly books, that explain the treatment that she's having done and she seems to really respond to those. […] she’s a little bit aware that we're trying to make her better, that she has poorly blood erm and that all the medicine that we're giving her is to make her better. But I I think erm if we were to do all this without actually saying anything to her, I think she'd probably find that even more distressing. Yeah, yeah, yeah, we we explain to her in a dige- we try and take everything that they've given us and flip it as best we can to child friendly”* (Parent of 4-year-old living with cancer)
17	Communicating diagnosis and prognosis; supporting communication; keeping children and their families at the centre of decision making	*“so that reassurance that they you know they know what’s happened in the past and they know they you know they know about me and what my history is and what I’m going through and that this isn’t just like my first time having chemo and you know what happened with all the different operations I’ve had so they know what’s going with me and that what they need to look out for and they know what to expect”* (Child aged 14, living with cancer)
18	Supporting communication; location of care; keeping children and their families at the centre of decision making	*“what my problem was, we didn’t have mine and (partner’s) wishes put in place and I was absolutely terrified that she’d go to hospital and either, one die in hospital which we don’t want or two they do things to her that we didn’t want to happen. So I never took her to hospital, just kept her out and then when they…once they did the DNR and…and all of our wishes…erm that’s when I…I felt more comfortable to be able to take her in.”* (Parent of 8-year-old, living with neurological condition)
19	Supporting communication	*“a consultant we’d been with pretty much since the beginning right through, he was always on the other end of the phone and email or whatever so whatever cropped up I knew I could speak with his secretary or email him or things and he would always get back to me. And it’s pretty much the same now. We’ve got new-ish consultant to us but I’ve known him for many years because he’s worked at the hospital for many years. And again the community nurses, the symptom management team, yeah, anything.”* (Parent of 14-year-old, living with metabolic condition)
20	Supporting communication	*P*: “*it’s due to the shared care, and I often don’t know, I get a bit muddled up about which hospital is dealing with which problem, what they’re doing. I think there’s a bit of a communication issue between both of the hospitals. So I think I get a bit confused because I’m like, “which hospital is dealing with which problem? Who should I contact if something goes wrong with this problem?”[…] I mean I know that (Hospital 2) often has, it deals mostly with my sickness and (hospital 1) often deals with my seizures, but other than that, there are loads of other problems like mobility and like, just generally health and stuff and I just don’t think, I’m really confused who is doing what. I’m like okay.* *I: Okay, no, and if you do have a general question, who would you normally go to?* *P: My dad* *I: Okay yeah, and then he’ll find the right team?* *P: (Dad will) just email a bunch of people and see which ones say ‘Oh yeh okay, we’ll deal with that’*” (Child aged 17, living with cancer)

Table 4 (continued)

21	Dignity and respect; everyday life; psycho-social and spiritual needs	*"I can't really stay home alone. I can't really have much- well I want more independence. I want to do more things. But, I don't really have that many responsibilities because I am too tired to do them and I'm- like I feel to poorly to do them. So I kind of just sit around. Kind of not doing a lot most of the day. And I don't really do as much as normal people would. Like going to town, have friends"* (Child aged 14, living with congenital condition)
22	Dignity and respect; everyday life	*"she'll never be independent just because…I mean the seizures for one, so she needs 24-hour care because of the seizures. Her behaviour, the autism. So, she will, yeah so, I suppose that's another thing with the school, even the special needs school you'd think they get it and they keep saying, you know promoting independence. I keep saying to them without being, sounding negative, she is not gonna be independent. […] so I can't see any future when she's not at home. So, I think she's, she's gonna be here. So, whether it's here with me or here with a carer, so we'll see. But yeah, I do think that with the transition we could do with a lot, lot more guidance."* (Parent of 15-year-old with neurological condition)
23	Everyday life; psycho-social and spiritual needs	*"I've probably been texting a lot more [during chemotherapy] but when I'm at I was at hospital anyway I probably if I was speaking to anyone I'd be texting them anyway so probably it's probably just about the same but just a little bit more of it"* (Child aged 14, living with cancer)
24	Everyday life; psycho-social and spiritual needs	*"So, the people who come and visit or people who erm, decide to make food for me and come and visit, kind of shows that they care and erm, like some of my friends now who are, erm checking up on me and you know calling me to see if I'm okay, kind of just shows you amongst the friends, all the friends that I have, who are the ones that actually care and want me to actually get better."* (Child aged 17, living with cancer)
25	Everyday life; psycho-social and spiritual needs	"*She's got a cousin who when she's out in town at the moment she looks after her. They sit together in coffee shops. And she knows about trachy sort of things*" (Parent of 15-year-old living with neurological condition)
26	Everyday life; psycho-social and spiritual needs; dignity and respect	*"in (hospital 1), I have always been with kids younger than me, yeah, but in (hospital 2), I spent a lot of time in the teenage cancer unit, but even then there was like, 23 year old girls, but even then, the thing is about that is that I could talk to them and more like, we are more similar on that level than I would be to, let's say, so that's like 5 years, so talking to a 11 year old, which I often wasn't able to talk to an 11 year old. I was often sat there with a 7 year old boy opposite me. It's a bit like uncomfortable because you're a lot older and obviously, he's 7 years old and I don't know like- and he often like, I often hear Peppa Pig in the night if they're a bit younger so (laughing)"* (Child aged 17, living with cancer)
27	Everyday life; psycho-social and spiritual needs	*P: "I had a friend and I didn't know her, her name but she kept coming into my [hospital] room and she kept playing with my stuff in my suitcase […] another patient.* *I: And how did that make you feel?* *P: Actually, a bit happy. […] We went into the playroom with, with each other. We kept playing like stuff and I had to do a really- and it was like a baby one, so I had to do all these easy stuff with her and I even made a person with the blocks on the wall. […] And a doctor came in to do her obs in the…they…you don't always need to do it in their room because erm…they have like a machine coming out"* (Child aged 5, living with gastrointestinal condition)

Table 4 (continued)

28	Everyday life; psycho-social and spiritual needs	*"So, like we went away [on trip run by charity] and had a whole night out in the forest. We literally, we had two trees, a bit of string, tarpaulin and that's all we slept on. It was-I thought a badger was gonna come and eat me (laughter) […] Yeah so we did that and then we like slept and did high ropes, climbing and everything and then (nurse) the nurse here, yeah, she came. We were the only two from (Hospital) so we were like Team (Hospital) and we were together"* (Child aged 13, living with gastrointestinal condition)
29	Everyday life; psycho-social and spiritual needs	*"even if I'm in school, like inside the school and I feel that I have a problem I don't need to go to my nurse in school, I just need to contact [the clinical nurse specialist]"* (Child aged 15, living with metabolic condition)
30	Everyday life; psycho-social and spiritual needs	*"I think was it the erm [nurse] did she she either let them know so we have erm my (charity) nurse they usually go in if I ever start anything new and they or you know I start a new treatment or anything like that they go in an let the school know what's going on so that they're all aware and if anything does happen you know that they know what's happening"* (Child aged 13, living with gastrointestinal condition)

life. Many children also preferred to be in their own homes (T5Q31). However, some care teams were unable to support the interventions that children required (e.g. long-term ventilation, total parenteral nutrition, intravenous medication), with specialists often located in urban centres requiring long-distance travel and associated logistical planning for families. Enabling parents to provide care at home is complex and sometimes requires more resource than local organisations can provide. Medical interventions (e.g. medications, syringe drivers) were vital for symptom management in the home; however, nursing staff were not always available out of hours to support administration. Availability of other equipment, such as wheelchairs, was variable with some families having to buy equipment themselves to avoid lengthy delays in provision via NHS or social services (T5Q32). Non-pharmacological services (e.g. hydrotherapy, acupuncture, art therapy, physiotherapy, psychology, counselling) were also utilised to manage symptoms. Children and their parents spoke about the importance of their psychosocial needs being supported by specialists (T5Q33, T5Q34). However, availability varied geographically, and over time was often only available during working hours (Monday to Friday, 9am-5pm) with some services being cut despite the benefits they afforded.

Increasing Access to Vital Assistive Technology

Assistive technology acts as a gateway to opportunities that would otherwise be unavailable to the child. Wheelchairs are a vital example of this, with many children discussing the important role they played in their life (T5Q35). They provided mobility, which in turn enabled freedom and independence (T5Q36). They also offered some children access to leisure activities. Yet this relied on parents having the opportunity to be made aware of those activities, and the resources to actively engage in them (T5Q37, T5Q38).

Increasing Equity in Provision of Support for the Family

Respite care offers families time to take a break from caring, to ensure they can continue to care well for the child (T5Q39). However, for some children, respite was hard to arrange and maintain, which added stress for parents (T5Q40). For others, the logistical challenges and stress of taking respite eroded potential benefits. Parents spoke about siblings who were involved in caring, and in turn offered parents periods of respite (T5Q41). Given the vital role of parents in children's palliative care, one important aspect of quality care for children is the psychological support provided to parents and families, to ensure that they can provide the best possible care to the child. However, the availability of resources again impacts on accessibility (T5Q42).

Making Education Systems Inclusive and Fit for Purpose

Some children were fortunate to be able to access a school that could provide required support for their healthcare needs (T5Q43). However, the collaborative resources needed to secure and maintain the education of a child with a life-limiting condition were sometimes overwhelming for parents. The support offered regarding education varied geographically and was complex to navigate. Parents were not always convinced that the healthcare offered to their child at school would be sufficient. This sometimes led to homeschooling, which brought other challenges regarding funding and the availability of support for educational resources and staff (T5Q44). Notably, some local systems had invested in technology, which enabled children to engage in education even when they could not be physically present. One 10-year-old

Table 5 Example quotes by neo-ecological theory system level and cross-cutting European Association for Palliative Care Charter domains (exosystem)

31	Location of care; everyday life; psycho-social and spiritual needs	*"I: out of everything that we've spoken about, what do you think matters most to you?* *P: To go home […] Because I'm bored here"* (Child aged 10, living with gastrointestinal condition)
32	Symptom management	*"I feel like our NHS services especially are so overwhelmed that often I am fighting fights that I shouldn't have to. An example would be, we now buy our own syringes because he is tube fed. We buy them. Our nurses can only they give us a handful for a month. So I might get 10 syringes per month from nurses and I had to ask them. But he- I don't know, 15-20 meds a day. Like we use 24 syringes for his meals that doesn't include flushes and water. Like there is no way that 10 syringes a month will get us through. It wouldn't last a month if we had to use that much, so we buy our own syringes now. Which is, as I say we are a single income family now, but the peace of mind for that. But there are other things that we can't afford […] Like we bought our SATs monitor because the community wouldn't give us one. And that SATs monitor has kept us out of hospital a lot… And I know that's not the nurse fault, it's not the community's fault. They are working to a budget and they are severely underfunded."* (Parent of 2-year-old, living with metabolic condition)
33	Psycho-social and spiritual needs; everyday life	*"I love playing with [the hospice therapy dog] […]* I play up in the garden, I play fetch with her […] And then I take her for a walk as well.*"* (Child aged 17, living with congenital condition)
34	Symptom management	*"[The number of seizures are] lowering down right now because I'm having some acupuncture which is helping… it usually happens after I have retched or vomited or I've had like bowel movements."* (Child aged 17, living with cancer)
35	Psycho-social and spiritual needs; everyday life	*"I: when you feel poorly, is there anything that you can't do?* *P: Hmm, I can't go in my wheelchair"* (Child aged 8, living with congenital condition)
36	Psycho-social and spiritual needs; everyday life; dignity and respect	*"[child] is hoping to get a power wheelchair, which means she, we are hoping it will give her a little bit more independence from me as well. So she doesn't always ask me, you know "can you take me here" or "push me over here". She could just nip off herself"* (Parent of 14-year-old, living with congenital condition)
37	Psycho-social and spiritual needs; everyday life	*"Oh, there's one thing that I can't do right now, but I usually love to do, which is power chair football."* (Child aged 10, living with neurological condition)
38	Psycho-social and spiritual needs; everyday life;	*"(child) had a carer that worked in the P.E. department and she introduced it to (child) when she joined the school in year 7. […] So they got a team at school so they could travel and go to boccia [wheelchair bowling] competitions."* (Parent of 15-year-old, living with neurological condition)
39	Location of care; psycho-social and spiritual needs	*"We've been to [hospice name] about 2 weeks ago for the weekend and that was really nice. They offered that to us as well, just to have some respite because he's on the syringe driver now and it's not that you can't move, I mean I can take him out but it's not necessarily the most fun because then I'm worried about his breathing."* (Parent of 1-year-old, living with congenital condition)
40	Location of care; psycho-social and spiritual needs; symptom management	*"I get very worried about care being taken away. So, they will constantly review the night care and that is at times, threatened to be taken away. So, it's, well as all parents say, it's the fighting, we're continuously fighting to keep what we have, to get what we need and erm, yeah, I think it's very much a full time job for me. And I've, I had to give up my job, and I've never worked as hard as I am now."* (Parent of 4-year-old, living with metabolic condition)

Table 5 (continued)

41	Location of care; psycho-social and spiritual needs; symptom management	*"I could go out for a few hours and know that (sibling 1) is fully capable of looking after (child). She can do her machine, she can do her medication. She can do everything that's needed and even (sibling 2) I mean he's 10 next week, he can suction her. You know because if I'm in the kitchen, he's in here, I hear when he puts the machine on, he suctions her"* (Parent of 15-year-old, living with neurological condition)
42	Psycho-social and spiritual needs	*"I think there are lots of anxieties, like I could definitely benefit from more therapy especially when, this life is crazy. But I have had to give up my job and we're a single income family and I could never afford therapy. We have therapy through hospice but it's like once a month, which is not enough for us to even touch the surface of anything. It's just a safe place for me and my partner, to like to teach us how to talk to each other. But it's not especially, I don't feel like its effective. Yeah, I don't know how other special needs parents do it. Like we, I am really struggling emotionally. But mostly you just pack it down and move on because you have got no choice but to not feel the feels and just get on with it."* (Parent of 2-year-old, living with metabolic condition)
43	Location of care; psycho-social and spiritual needs; symptom management; everyday life	*"Parent: And who carries [your oxygen at school]?* *Child: The classroom assistant. Or the teacher.* *Parent: Or the teacher yeah. They're all very good, they are really good. He goes to a special needs school, and they're all very very fond of him"* (Child aged 17, living with congenital condition)
44	Psycho-social and spiritual needs; symptom management; everyday life	*"education's a whole other issue…erm we've had a lot of problems with this. We've been fighting to get him a tutor for over a year. […] we've had a hell of an issue trying to get him education and it's only been sorted out in the last few months really…umm so he has someone come in here, but that was because I didn't wanna let him to school because of his condition […] because of our concerns, mine and my husband's with that, you know one because of the vent - trusting someone to look after it […] being at school, you know if he's not looked after properly risk of infections, erm there's lots of various reasons why, you know (child) not being comfortable, not being able to sit in a chair all day, needing to lie down and, and like I say, just trusting people to look after him properly and I can't do it. So that's why I chose the home schooling, but it caused a- opened up a big can of worms"* (Parent of 6-year-old, living with neurological condition)

child described a school robot, which meant they could be virtually present to attend class and to talk to their friends who were in physical attendance.

3.2.4 Macrosystems: Societal and Cultural Impacts on Children's Palliative Care

Macrosystems reflect the broader societal context within which the child exists. Societal recognition of the reality of life-limiting conditions and death occurring in childhood was only touched upon indirectly by participants. However, the wide-reaching impacts of these belief systems could be seen across several areas.

3.2.4.1 Addressing Taboos and Challenging the Dominant Discourse Children talked about the importance of people around them still seeing them for who they are, not defined by their condition. They described some friends distancing themselves from them when they became unwell, or isolating themselves from their friends, suggesting a lack of comfort with or understanding of life-limiting conditions (T6Q45). However, other children demonstrated their willingness to be open about their condition, which helped them to maintain connections to friends (T6Q46). Parents also alluded to the unspoken nature of serious childhood illness. As an example, they talked about the complete absence of content related to the potential for child death in antenatal settings (T6Q47).

3.2.4.2 Challenging and Changing the Infrastructure and Environment Participants described the challenge of environments not being fit for purpose for those living with a physical disability. They described ways in which the built environment disables wheelchair users, making

Table 6 Example quotes by neo-ecological theory system level and cross-cutting European Association for Palliative Care Charter domains (macrosystem)

45	Location of care; psycho-social and spiritual needs; symptom management; everyday life; public awareness	*"I was quite separate, so like during my treatment I didn't want anybody to come and see me because I was, my thought was, I don't want them to see me as the sick (child name) and the one that isn't able to do stuff. I want them to remember me as the girl that they used to hang out with and stuff. So that's, I was pretty firm on them not really coming to the hospital. I don't really know. I'm obviously messaging some of them on Instagram, and we sometimes we will Snapchat and stuff but I don't think I've properly had a conversation with them since, my treatment"* (Child aged 17, living with cancer)
46	Psycho-social and spiritual needs; everyday life; public awareness	*"when we're getting changed for like P.E. and like football and stuff and I think it was like a few weeks ago, I was getting changed for football in the toilets and umm, my friend, weren't like in like a mean way, it was just like he wanted to learn like where I got the scars from and then also my (other friend) said like 'he don't really like talking about it' and then I said 'I don't really mind' and I can't remember if I told him or not."* (Child aged 10, living with gastrointestinal condition)
47	Communicating diagnosis/prognosis; supporting communication; end of life; public awareness	*"they did a two week check after that and we got a bad prognosis then where they err, explained that it was unlikely that she would be surviving, err probably not birth at all, but definitely not err, longer than a day or two […] So rather than the plan that we had been doing like NCT courses and things like that, shelved those things and, and things towards preparing for her coming home and was preparing basically for the funeral and things like that"* (Parent of baby under 1 year old living with genitourinary condition)
48	Psycho-social and spiritual needs; everyday life; public awareness; dignity and respect	*"(sibling) had been to the same school as well and we wanted (child) to go to the same school because all her friends were going to the same school as well. So we went to have a look around and I made them aware about 2 years before she was gonna go there that she's got a powered wheelchair. And (staff name) said 'that's fine we'll see what we can do when it comes to it'. But then they said 'oh it's an old building we won't be able to do anything'. And then when we went with (child's) OTs and physios they said they could make changes to the timetable so that (child) could have access to all the lessons and be able to participate. Until one of the ladies who does the actual timetables, and she said, 'oh there's a school ready for (child) in (place name) so she can go there'. And, but we said, why would we want to take her there […] we'd have to get transport to sort of pick her up and drop her off there."* (Parent of 15-year-old, living with neurological condition)
49	Supporting communication; keeping children and their families at the centre of decision making	*"I: what do you want the Drs and Nurse to ask you about?* *P: Just how I am feeling and how I am feeling that day, how I have been doing on the medicine. How I have been getting on an everything, so they can increase the medicine."* (Child aged 12, living with cancer)

vital aspects of a child's life and care, such as school and friends, inaccessible (T6Q48).

3.2.4.3 Respecting Children's Agency The quality of the care that a child can access is undoubtedly affected by society's view of children. At the heart of child-centred care lies the belief that many children with life-limiting conditions know what is best for them and should be agents in their own care where possible. However, paternalistic assumptions about age and abilities mean that children do not always feel part of their care (T6Q49).

3.2.5 Chronosystems: The (In)Significance of Time in a Potentially Shortened Life

The chronosystem centres the role of time in a child's health and development. In the case of the quality of care for children with life-limiting conditions, it captures significant

Table 7 Example quotes by neo-ecological theory system level and cross cutting European Association for Palliative Care Charter domains (chronosystem)

50	Location of care; psycho-social and spiritual needs; everyday life	*“I: do you think it would help if the Drs and nurses asked you things about going home?* *P: No. I think any talk about home when I can’t actually go home, ‘cause otherwise I just want to go home even more.”* (Child aged 12, living with cancer)
51	Communicating diagnosis/prognosis; supporting communication keeping children and their families at the centre of decision making	*“there’s not many questions, it’s just like me doubting myself what the future is about. But I don’t really have any questions because they always involve me and in all the conversations”* (Child aged 13, living with gastrointestinal condition)
52	Location of care; supporting communication	*“I’m not sure if it’s long term yet, so maybe like I should ask that. […] Yeah because they were talking about, because like when, when we’ll be 16 they were talking about, transferring us to like the [pause] like the adult or like the- there’s like a transfer between, before you go into like the adult’s section”* (Child aged 15, living with gastrointestinal condition)
53	Psycho-social and spiritual needs; everyday life	*“when I first noticed it and I started chemo and I was having my very first operation and things like that I was in primary school and so I was just going to like SATs and things like that but even even then I was able to either do them at home or you know go in just for a certain amount of time so I it wasn’t too bad then, but then I suppose because I’m at high school I think things feel a little bit more serious and sometimes I I might you know worry about missing things but erm there act- the hospital are really good because they say that I can go after school and so you know they work the times around me which is really helpful”* (Child, aged 14, living with cancer)
54	Psycho-social and spiritual needs; everyday life	P: *“I’m gonna be a Police* *I: You’re gonna be the Police, are you? Why do you want to be in the Police?* *P: Umm…because I want to … erm like … umm have a big job arresting people* *I: Oh, you have to be quite brave to do that as well don’t you? Yeah* *P: Ow, I’m gonna have a Police motorbike”* (Child aged 5, living with gastrointestinal condition)
55	Psycho-social and spiritual needs; everyday life	*“when I go to a new school I wanna be grown up […] And to be allowed to go horse riding sometimes and when I grow up, I wanna be a gold racing car driver”* (Child aged 15, living with neurological condition)
56	Psycho-social and spiritual needs; everyday life	*"I think there's, sometimes there's a tendency to, for me to worry about erm, err where I am. So, how, how do I say this? So, like, obviously I wanna be, I, where I want to be, if I'm not there yet. I guess sometimes I worry about that, so maybe in terms of, maybe like my academics or erm, me, you know my piano playing. You know like maybe if I see someone playing piano and he's the same age as me, I think, oh you know if I could be like that but then again like I, I remember that, you know this is my journey and in, if I may not, I may not be as good as them or may not be as smart as other people in my school, but in the end this is the journey that has been placed on me and I have to walk that journey to the best of my ability and if, if I'm not doing the best that I can do, then it’s up to me to make that change and to not put too much pressure on myself, but to just enjoy, enjoy the journey that I'm going through.”* (Child aged 17, living with gastrointestinal condition)

Table 7 (continued)

57 Psycho-social and spiritual needs; everyday life	*"I think making memories with my family mostly, that's probably the most important thing. That's probably it.* *I: Yeah. And does anyone ever ask you about that so do your care team ask?* *P: Yeah [nurse] helps, [consultant] not mostly, he's more medical terms and things. But [nurse] she helps a lot with organising things, and she branches off to other people, like play workers and things who can help with that. And so they organise a lot of events that I want to do before certain things happen and what I want to do. So they help a lot with that too. […] They just kind of said 'oh what's on your list of what you want to do and things.' And then they would jot it down and then say we will see what we can do about that."* (Child aged 15, living with cancer)
58 Keeping children and their families at the centre of decision making; symptom management; psycho-social and spiritual needs; end of life	*"it is the worst thing in the world knowing that (child's) gonna die and knowing that I can't do anything about it, like literally I cannot…we… we'd do anything. […] So I…and I'm just like he's gonna die. Why … why put him through … through hours of … of stand … in a standing frame, when it just causes him so much pain. […] It's not gonna achieve anything. It's like his spine, he's got kyphoscoliosis. You know he could have had spine surgery. He could have been put you know in a brace, but then … or having his hips done. He's got no hip sockets or hip … or erm … you know his ball of his hips they … they disintegrated, and he literally has none. You know he could have hip replacement if we push for it, but then he'd be convalescent for like six months and then what … and then what? Is it gonna make him walk, is it gonna help? Yeah, it might be a little less painful for him, but the pain he's gonna have to go through for six months to recover, it could kill him […] So, good quality of life to me is him smiling and being happy and laughing and not crying in pain"* (Parent of 14-year-old, living with metabolic condition)

events regarding health that happen directly for the child, but also related shifts in the meaning and understanding of life goals.

3.2.5.1 Moving at the Child's Pace For some children, being supported to manage their condition day to day was what they found most helpful (T7Q50), rather than discussing things that may not be possible. In the face of an uncertain future, some children raised questions about what their lives would look like both in terms of practicalities, but also existential questions about the meaning and trajectory of their lives (T7Q51). For others, there was a need to consider both long-term prognosis and day-to-day practicalities. A readiness to discuss these varying and changing matters, at the right time for the child, supported children through their care (T7Q52).

3.2.5.2 Supporting Hopes That Shift with Prognosis Children often recognised their changing needs over time, and the chrono-normative expectations based on other children of the same chronological age. They appreciated care teams who did what they could to enable their lives to progress in the way they expected and hoped (T7Q53). Developmentally younger children spoke about their hopes, which enabled them to imagine and plan for a different every-day. Imagining was part of children's processing, and younger children used role play to pretend to do things that other children were able to do, such as eating. They also spoke about what they wanted to be when they grew up, even in the context of a potentially shortened life (T7Q54, T7Q55). Enabling these discussions and activities supports the child to have hopes and wishes for the future, and flouts societal chrono-prescriptivism (what we *should/should not* engage with in relation to now or the future) for children with a life-limiting condition, by demonstrating the value of engaging with an imagined future.

Some developmentally older children were able to take a broader view on their lives and understood the ways they could bring meaning into it (T7Q56). However, others needed more help to plan activities, reflect and find meaning day to day, in order to bring richness to their lives (T7Q57). Parents had questions and fears about what end of life would entail for their child, and were particularly focused on an absence of pain. They described making tough decisions for their child, given the limited time they had, including for example refusing interventions that might afford a functional benefit but cause pain (T7Q58). These decisions also pushed back against societal chrono-prescriptivism, of what we *should* be encouraging children to do at particular stages. Last, many parents had made decisions for care at end of

Table 8 Recommendations for quality paediatric palliative care informed by children and their families

Care delivery	
Strengthen relationships and interactions between children and health and social care providers	Tell children about their condition Ask children questions about their condition and care Enable children to ask questions about their condition and care Explore and incorporate activities that are important to the child Move at the child's pace Support hopes that shift with prognosis
Strengthen relationships and interactions between children and family, and health and social care providers	Enable timely communication about diagnosis and prognosis Recognise and respect the central role of families in providing care Record, update, use and communicate care plans Support families to navigate different care services Incorporate independence into care where possible
Encourage social connections	Support existing social and familial connections Facilitate new connections through care Facilitate new connections through charities Maintain connections to school
Service innovation and policy	
Make health and social care systems equitable	Improve geographical availability of resources Increase access to vital assistive technology Increase equity in provision of support for the family
Make education systems inclusive and fit for purpose	Support children to access education in the place most appropriate for them and their family Increase access to resources and technology to enable children to remain engaged with and connected to their education setting Increase equity in provision of education support for children and families
Society and culture	
Challenge the dominant discourse	Address taboos around death, dying and illness in childhood Challenge and change the infrastructure and environment to enable all children to participate in line with their needs and preferences Respect children's agency by involving them in their care where possible

life and were clear on what they wanted their child's final moments to look like, sometimes involving siblings in these decisions. Others did not want to think about the possibility of death until absolutely necessary.

4 Discussion

4.1 Main Findings

This novel work conceptualises quality care for children facing life-limiting conditions from the perspective of the children themselves and their parents. Communication between children, parents and clinicians that is timely, sensitive and tailored to the needs and preferences of the child is at the heart of quality paediatric palliative care. Children welcome being involved in discussions and decisions about their care, and parents value being recognised as experts in their child: together these build trust and facilitate discussions about future care.

The role of collaboration and advocacy within and across services was also recognised as central to quality care for children and families. Parents need support to navigate the complex network of care providers, particularly in the context of inequities in available services and resources. Children need close and collaborative relationships between their various networks (e.g. healthcare, and school) in order to receive holistic care, and to be able to engage with education, socialise and enjoy the things that matter to them. At times the infrastructures and institutions that deliver care, support, education and other vital services were not fit for purpose. They disable the child and interrupt their ability to access the care and support they need, and engage in the things that matter to them. At a broader societal and cultural level, the pervasive dominant discourse that obfuscates death, dying and illness in childhood contributes to the marginalisation, isolation, and negative outcomes experienced by children and their families.

Integrating the EAPC Charter domains alongside the bioecological model [41] and neo-ecological theory [42] ensured that the novel findings and subsequent recommendations from this study are underpinned by theory, but ultimately grounded in the best available guidance on quality paediatric palliative care delivery [10–12]. Specific recommendations for quality care have been identified at the level of care delivery, service innovation and policy, and broader society and culture (Table 8).

4.2 What This Study Adds

Guidelines to support quality paediatric palliative care have been developed following systematic and transparent processes, but they rely heavily on professional stakeholder insights and consensus [11, 12], owing to a lack of robust evidence from children and families. Only one study has explored family views of the quality of paediatric palliative care delivery, focussing on the experiences of parents who described the need for improvements across all areas covered in the NICE quality standards in England [14]. To understand paediatric palliative care quality fully, we must also consider the experiences of children receiving that care.

The results presented in this study extend existing insights about quality paediatric palliative care that can inform decision making and care provision with and for children with life-limiting conditions. Children of varying age, health conditions and developmental stages must be considered individually in terms of how they are involved in their care. Where children can be involved, previous research demonstrates that they want to be part of discussions about the care they receive, and this can be facilitated through clear communication [44]. However, a recent systematic review demonstrates that the involvement of children in shared decision making with parents and professionals about their care was more likely when the decision being made had lower stakes [45]. This is problematic for children with life-limiting conditions, where many decisions and discussions may have serious implications. The present study demonstrates that children with a range of life-limiting conditions want to be asked about their care by professionals, both directly and in collaboration with parents. Children also want to be provided with clear opportunities to ask questions, so that they are kept informed about their lives. Where possible, giving children the choice to be involved in discussions about their care, if they are able to, is crucial. This may be challenging to navigate where parents would prefer to withhold information from their child [46, 47]. However, evidence from our data suggest that children want to be involved, and may well have more insight than parents and professionals realise.

Maintaining social connections is recognised as vital for children with life-limiting conditions [48]. This study extends our understanding of this with specific examples that were valued by children. Supporting socialisation with friends and family, facilitating activities that the child enjoys or even just talking about the things that matter to them were valued. Engaging in these activities, and meeting other children like them, helped to deliver some normality to their lives. Maintaining access to education was also vital for children; however, this was often fraught with battles for resources, concerns about safety or inequities in access to support [49, 50]. For parents, this was one of the many coordination tasks that dominated their lives because of the complex care needs of their child [14].

Many children are experts in their own condition, and show the ability to combine medical jargon alongside their own lexicon [24]. However, treatment and care plans are often complex and evolving. It is vital to recognise the understanding the child has capacity for, ask what the preferences of the child are and support them at their pace. Revisiting understandings can help to ensure children's care remains congruent with the things that are important to them at that time. Ultimately, the involvement of children with capacity in their own care hinges on the trust we have in those children to know what is best for them. The United Nations Convention on the Rights of the Child states that children (under the age of 18 years) who are capable of forming their own views must be afforded the right to express those views in all matters that affect them, and have them considered appropriately [15]. In July of 2024, Scotland became the first UK nation to incorporate these rights into law [51]. It remains to be seen how these rights are enacted globally for children and young people with life-limiting conditions and their families.

4.3 Strengths and Limitations

This study has several strengths and adds important evidence to the literature on quality paediatric palliative care. First, this novel work provides vital data on how children themselves conceptualise quality care. This represents a significant advance in our understanding. Of note, children expressed their views across all systems of the bioecological model. However, the exosystem was most often discussed by parents for whom the practicalities related to accessing, sourcing, and navigating services and support are a central part of their role as carer and advocate for their child. This was less of an immediate concern for children, or not within their purview. Second, the available guidelines often include aspirational recommendations (such as 'treat children with dignity and respect'), which can be hard to implement. Our work takes forward these recommendations by providing practical steps to achieving quality care for children and their families. Third, the participant sample was varied, including data from children aged 5–17 years, with a range of life-limiting conditions. Parents were also included, which ensured that family members who are understood as central in delivering quality care were able to share what was important to them, and what they believed important to their children. This is particularly pertinent for children unable to participate themselves, such as those who are non-verbal, or living with cognitive impairments. This study also had some limitations. Ethnicity of participants was not collected, which prevents consideration of potential similarities and differences across ethnic groups. Socioeconomic status was also not collected, which prevents consideration of deprivation of palliative care experience and quality. These demographic characteristics are particularly important in order to examine inequities in access and delivery of care given the known higher prevalence of life-limiting conditions amongst certain ethnic groups and in areas of deprivation [8]. Future work should focus on understanding experiences of quality care for children from minoritised ethnic groups and their families, and fathers, who remain underrepresented in the paediatric palliative care literature. Alongside the work to develop, validate and implement the C-POS PROM (within which this analysis was conducted) [30], further work is also needed to support clinicians to tailor their communication to the needs and preferences of each child. Last, guidance on paediatric palliative care delivery also requires refinement to move from aspirational to practical and measurable processes and outcomes, informed by the needs and preferences of children with life-limiting illnesses and their families.

5 Conclusions

Children's care experiences and priorities, and therefore their understanding of good care, may differ from those of their parents. By centring the child in the complex and layered systems that surround them, we have advanced the evidence of quality care for children. Quality paediatric palliative care requires children and family to be treated as experts in their condition, through open and honest communication shaped by the child's needs and wishes, and directed towards them as participants in their care. Fostering strong and collaborative relationships with all those who are important to the child and their life builds trust and helps children and families to feel safe, included and supported. Because of inequities in the support and services available, and the challenges of understanding and navigating care services, children and families need help with advocacy for and coordination of services to support their well-being. Last, by challenging the dominant discourse and talking openly about death, dying and illness in childhood, we can begin to eradicate the taboos and reduce the marginalisation that children and their families experience.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s40271-025-00744-8.

Acknowledgements The Children's Palliative care Outcome Scale (C-POS) Study Steering Group members, AK Anderson, Jo Bayly, Lydia Bates (PPI), Debbie Box, Rachel Burman, Lizzie Chambers, Alan Craft, Finella Craig, Aislinn Delaney, Jonathan Downie, Sara Fovargue, Jane Green (PPI), Jay Halbert, Julie Hall-Carmichael, Irene Higginson, Michelle Hills, Mevhibe Hocaoglu, Vanessa Holme, Gill Hughes, Joanna Laddie, Angela Logun (PPI), Eve Malam, Steve Marshall, Linda Maynard, Andrina McCormack, Catriona McKeating, Lis Meates, Eve Namisango, Veronica Neefjes, Cheryl Norman, Susan Picton, Christina Ramsenthaler, Ellen Smith, Michelle Ward, Frances Waite, and Mark Whiting and the Young Person's Advisory Group at Great Ormond Street Hospital provided supported throughout this study.

Declarations

Funding The authors disclosed receipt of the following financial support for the research, authorship and/or publication of this article: the Children's Palliative care Outcome Scale was funded by a European Research Council's Consolidator Award (Grant ID: 772635) with the overall aim to develop and validate a person-centred outcome measure for children, young people, and their families affected by life-limiting and life-threatening conditions. Principal Investigator: Richard Harding. This article reflects only the authors' views and the European Research Council is not liable for any use that may be made of the information contained therein. Fliss E.M. Murtagh is a National Institute for Health and Care Research (NIHR) Senior Investigator. The views expressed in this article are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care. Hannah M. Scott, King's College London, is supported by the NIHR Applied Research Collaboration South London (NIHR ARC South London) at King's College Hospital NHS Foundation Trust. The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

Conflict of interest Debbie Braybrook, Lucy Coombes, Hannah M. Scott, Daney Harðardóttir, Anna Roach, Jemimah Bariuan, Clare Ellis-Smith, Julia Downing, Fliss E.M. Murtagh, Myra Bluebond-Langner, Lorna K. Fraser, Richard Harding and Katherine Bristowe have no conflicts of interest that are directly relevant to the content of this article.

Ethics approval Ethics approval was granted by the Bloomsbury Research Ethics Committee (HRA:19/LO/0033).

Consent to participate Not applicable.

Consent for publication Not applicable.

Availability of data and material It is not possible for the data from this study to be made available.

Code availability Not applicable.

Author contributions All authors: conception and design of the work. LC, DB and AR: data collection. KB and DB: data analysis. All authors: interpretation of data. KB and DB: draft manuscript preparation. All authors: critical review and revision of the manuscript.

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