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### **Journal of Advanced Nursing**

DOI:

[10.1111/jan.13811](https://doi.org/10.1111/jan.13811)

Published: 01/12/2018

Publisher's PDF, also known as Version of record

[Cyswllt i'r cyhoeddiad / Link to publication](#)

*Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):*

Noyes, J., Pritchard, S., Pritchard, A., Bennett, V., & Rees, S. (2018). Conflicting realities experienced by children with life-limiting and life-threatening conditions when transitioning to adult health services. *Journal of Advanced Nursing*, 74(12), 2871-2881. <https://doi.org/10.1111/jan.13811>

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**ORIGINAL RESEARCH:  
EMPIRICAL RESEARCH – QUALITATIVE**

# Conflicting realities experienced by children with life-limiting and life-threatening conditions when transitioning to adult health services

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## Funding information

The My Choices study and the secondary analysis was funded by Health and Care Research Wales. The Bridging the Gap study was funded by Together for short Lives

## Abstract

**Aims:** The aim of this study was to report a secondary qualitative analysis exploring the cultural and practical differences that young people and parents experience when transitioning from children's to adult services.

**Background:** Despite two decades of research and quality improvement initiatives, young people with life-limiting and life-threatening conditions still find transition unsatisfactory.

**Design:** Secondary analysis: 77 qualitative interviews with children and young people (20), parents (35), siblings (1), professionals (21).

**Methods:** Qualitative framework analysis completed 2017.

**Findings:** Six conflicting realities were identified: Planning to live and planning to die with different illness trajectories that misaligned with adult service models; being treated as an adult and the oldest “patient” in children's services compared with being treated as a child and the youngest “patient” in adult services; being a “child” in a child's body in children's services compared with being a “child” in an adult's body in adult services for those with learning impairments; being treated by experienced children's professionals within specialist children's services compared with being treated by relatively inexperienced professionals within generalist adult services; being relatively one of many with the condition in children's services to being one of very few with the condition in adult services; meeting the same eligibility criteria in children's services but not adult services.

**Conclusion:** Inequity and skills deficits can be addressed through targeted interventions. Expanding age-specific transition services, use of peer-to-peer social media, and greater joint facilitation of social support groups between health services and not-for-profit organizations may help mitigate age dilution and social isolation in adult services.

## KEYWORDS

adult, child, life-limiting, life-threatening, nursing, palliative care, secondary analysis, transition to adult care qualitative

## 1 | INTRODUCTION

Organization of a young person's transition from children's to adult services is typically a nurse-led process. Young people with life-limiting or life-threatening conditions have highly complex nursing and medical needs and are grouped into four condition categories (Table 1). Irrespective of the young person's diagnosis, transition from children's to adult services for those with life-limiting or life-threatening conditions is commonly described as problematic and challenging (Doug et al., 2011).

### 1.1 | Background

Over 20 systematic reviews on transition problems and practice (including a Cochrane review, Campbell et al., 2016) have been published in the last 15 years (key examples include Doug et al., 2011; Fegran, Hall, Uhrenfeldt, Aagaard, & Ludvigsen, 2014; Joly, 2015; Nehring, Betz, & Lobo, 2015). In the United Kingdom (UK), there is a children's palliative care model and transition care pathway that is drawn on internationally (Together for Short Lives, 2015a,b), published best practice guidance from not-for-profit and professional organizations (e.g., Together for Short Lives, 2009, 2015a,b, 2018; Royal College of Nursing 2013a,b; Queens Nursing Institute 2017); and a National Institute for Health and Care Excellence guideline and standards on organizing transition from children's to adult services (NICE 2016a,b). Nonetheless, feedback from young people and their families continues to suggest that the experience of transition remains highly challenging due to a perceived gulf between children's and adult services. We therefore specifically set out to make explicit the variation in culture, context, and practice (i.e., the gulf) that young people, their parents and health and social care professionals experience in the conflicting realities of children's and adult palliative care services to come up with fresh insights that are amenable to action.

Around 49,000 children aged 0–18 years in the UK are living with a life-limiting or life-threatening condition and around 13,000 are in the 18–25 age group (Fraser et al., 2012). Similar to other countries, in the UK, planning for transition services can commence at around age 14 years and continues up until transfer between the ages of 16–18 years. This age group are typically referred to as young people rather than children, although they are managed within children's services. Children's services are generally commissioned for age 0–18 years and adult services beyond 18 years. Specific “transition” clinics have been commissioned in some areas to help bridge the gap between children's and adult services. Some transition services have also been commissioned in the hospice sector for young people age 16–25 years. Aspects of palliative care may be provided by National Health Service (NHS) generalist services (for everyone) or specialist services (condition-specific or specially commissioned) or not-for-profit organizations such as hospices and parent support organizations.

The current study looked at practice in the UK, but findings are likely to have international implications as global studies in high-

#### Why is this research needed?

- Over two decades of research and quality improvement initiatives have attempted to understand and improve the transition experience of young people with life-limiting and life-threatening conditions and their parents from children's to adult services.
- We do not fully understand what the differences in culture and practice between children's and adult palliative care services are that create difficulties for young people.
- We do not fully understand how the differences in culture and practice between children's and adult palliative care services affect their transition experience and assimilation into adult services.

#### What are the key findings?

- Six areas were identified that created conflicting realities experienced by young people and their parents in children's services compared to adult services.
- Four conflicting realities were structural, including: planning to live at the same time as planning to die that did not align with adult models of palliative care and services offered; experiences of being the oldest and one of many with the condition in children's services and then being the youngest and one of few with the condition in adult services; differing experiences of children growing up as adults with learning impairments and entering adult services; and differing eligibility criteria for receiving the same children's or adult funding streams.
- Two conflicting realities were staff or training related, including: differing experiences of communication and person-centred care between children's and adult services and differences in and expertise with managing conditions originating in childhood in adult services.

#### How should the findings be used to influence policy/practice/research/education?

- Inequity and skills deficits can be addressed through targeted interventions.
- Use of peer-to-peer social media and greater joint facilitation of social support groups between health services and not-for-profit organizations may help mitigate age dilution and social isolation in adult services.
- Expanding age-specific transition services may help mitigate the gap in culture, context, and practice between children's and adult palliative care services.

income countries highlight similar problems and many countries base their children's palliative care services on the UK model of palliative care developed by Together for Short Lives (2009).

**TABLE 1** Categories of life-threatening and life-limiting conditions. (Developed by Together for Short Lives (no date & 2015a,b)

Category 1: Life-threatening conditions for which curative treatment may be feasible but can fail. Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment, there is no longer a need for palliative care services.	<i>Examples: Cancer, irreversible organfailures of heart, liver,kidney.</i>
Category 2: Conditions where premature death is inevitable. There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.	<i>Examples: Cystic fibrosis, Duchennemuscular dystrophy.</i>
Category 3: Progressive conditions without curative treatment options. Treatment is exclusively palliative and may commonly extend over many years.	<i>Examples: Batten disease,mucopolysaccharidoses.</i>
Category 4: Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.	<i>Examples: Severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex healthcare needs and a high risk of an unpredictable life-threatening event or episode.</i>

## 2 | THE STUDY

### 2.1 | Aim

To explore the variations in culture, context, and practice that young people, their parents and health and social care professionals experience in the different realities of children's and adult palliative care services. A secondary aim was to develop the first composite transition palliative care model.

### 2.2 | Design

We undertook a combination of an amplified secondary analysis that combined data from two or more primary studies for comparison and enlarging the sample, and a supplementary secondary analysis which enabled a more in-depth collaborative investigation of an emergent issue and aspect of the data, which was not addressed in the primary study (Heaton, 2000).

We conducted two back-to-back funded studies on similar topics with participants who had a life-limiting or life-threatening condition as categorized in Tables 1 and 2 and Supporting Information Table S1. Table S1 provides a summary of the source studies and interview topic guides. Both studies produced a large amount of rich qualitative data on the experiential context of children's and adult services and transition that was not central to developing the study outputs and was not analysed in depth. We subsequently obtained additional funding to undertake this secondary analysis of the combined interview data from these two studies, which was completed in 2017.

### 2.3 | Participants and data for secondary analysis

The combined sample contained interviews with 77 respondents (Table 2). Additional demographic information can be found in Supporting Information Tables S2A and S2B.

### 2.4 | Ethical issues

Ethics approval was not required by the NHS ethics committee as the analysis was conducted by the same team as the original studies.

### 2.5 | Data analysis

The same framework approach to qualitative data analysis was used to analyse data (Ritchie & Spencer, 2002). Transcripts were coded against an a priori framework to look for differences in experience, culture, and context between children's and adult services from different key stakeholder perspectives. Coded data were then transformed into six analytical themes through a process of discussion and reflection. The process is shown in more detail in Supporting Information Figure S1. Following the analysis, through a process of further discussion and reflection and stakeholder engagement, and drawing on findings from both studies and the secondary analysis, we developed a composite model of children's and adult palliative care to support the transition of young people into adult services.

### 2.6 | Validity and rigour

The same criterion for establishing rigour and reflexivity in a primary qualitative study was applied to this secondary analysis (Attia & Edge, 2017). Core team members contributed to collecting data for both studies and were therefore able to draw on their experience of conducting the studies. The team used reflexive approaches (such as key stakeholder engagement meetings) to challenge data interpretation and support development of findings. Beliefs and assumptions were made transparent and their potential impact on findings discussed. For example, the research assistant also had a service user perspective and had completed transfer from children's to adult services within the last 5 years. Her unique experiential perspective that informed data analysis combined with wider stakeholder engagement gave new insights and enabled a new composite transition model of palliative care to be developed. Findings and the model were presented to an audience of around 100 palliative care specialists, service users, and parents/carers for feedback.

## 3 | FINDINGS

We identified six areas where conflicting realities existed that help explain the confusion, anger, and alienation that young people and their parents experienced.

**TABLE 2** Brief summary of source studies

	My Choices	Bridging the Gap	Combined
Aim and purpose	To develop advance care planning tools for children and young people with life-limiting and life-threatening conditions and their parents to enable them to have more control when planning ahead. To create a population level needs assessment and economic model, and a health-promoting model of children's palliative care	To explore the palliative care needs of young people with life-limiting and life-threatening conditions during transition from children's to adult services. To develop care planning tools to support transition from children's to adult services	Explored experiences of child and/or adult services and the transition between services.
Sample	39	38	77
Parents	11 mothers 3 fathers	17 mothers 4 fathers	28 mothers 7 fathers
Siblings	1		1
Young people with life-limiting or life-threatening condition	11 (preschool to young adult)*parents commonly gave proxy or joint accounts with preschool children or those with more profound learning impairments. Three older children were interviewed independently.	9 (age 14–25 years)	20
Health and Social Care Professionals	13	8	21
Data collection and analysis	Face-to-face interviews. Interviews lasted around an hour and were recorded digitally, transcribed verbatim, and uploaded into Atlas Ti. Qualitative framework analysis completed in 2016.	Face-to-face and small group interviews. Interviews lasted around an hour and were recorded digitally, transcribed verbatim, and uploaded into Atlas Ti. Qualitative framework analysis completed in 2014.	Qualitative framework analysis of 77 transcripts completed in 2017.
Recruited from	Two children's hospices, four adult hospices, Hospice at Home and NHS hospital and community services that provide complex and palliative care. Participants only took part in one study		
Ethical issues	Both studies were approved by a NHS ethics committee. Written, informed consent was obtained from adult participants, who were assured of anonymity and that they could disengage at any time. Parents consented for children under 16 years. Where appropriate, children gave their additional assent.		Additional ethics approval not required
Research team make-up	Overlapping membership. Included nurses, psychologists, parents, and social scientists who were supported by a wider advisory group representing young people, parents, and the multidisciplinary palliative care teams in children's and adult services.		
References	Noyes, Hastings, et al., 2013; Noyes, Tudor Edwards, et al., 2013; Bennett, 2017.	Noyes et al., 2014a,b	

### 3.1 | Planning to live at the same time as planning to die and the uncertainty of these conflicting realities

Within the children's palliative care model, most young people and their families actively planned to live (some relatively long lives), whilst at the same time being mindful of their mortality and likelihood of planning for a shortened and uncertain life. It was also evident that young people and their parents lived in the face of considerable uncertainty concerning condition trajectory and death. Many young people survived episodes of life-threatening deterioration to enjoy periods of relative stability and "good health," whilst remaining astute to the terminal trajectory of their condition. The recurring episodes of acute critical illness accompanied by unpredictability illustrated the conflicting realities with which these young people and their families live with on a daily basis. Many parents

said that their children had outlived their original prognoses and overcome several near death episodes:

I mean, six, seven times, probably more, we've actually thought "this is it", she's not going to get through this and she's been so ill, well, she's been on that many antibiotics, her face has been that swollen she couldn't even open her eyes, and you know, we've thought, she's just not going to make this, and she does.

Mother of two young women with life-limiting conditions.

The emotional and psychological effects on children and young people and their families of planning to live whilst experiencing continuous uncertainty and loss, originating from

diagnosis and continuing through to end-of-life care were prominent in child and parent accounts. Some parents, who were often the primary caregivers, found it difficult to think beyond planning for living to consider the fact that their child would eventually die:

There's differences within families as well.. some families will talk openly about end-of-life, and dying and what they want and they'll talk openly about it almost from when you're going in. Other families perhaps are more in shock and denial and angry and perhaps not really talking and you're treading on egg shells really.  
 Nursing service team leader

Many children with life-threatening and life-limiting conditions received care from children's palliative services to support their daily lives (and those of their families), and additional care (when needed) to manage symptoms, acute episodes of illness, and to mitigate the psychological impact throughout childhood. Ongoing daily care and support (including active treatment) and palliative care lasted several decades and into adulthood. Planning to live and achieve goals (sometimes in the medium to long term) whilst maintaining sight of the future mortality of a young person (i.e., planning to die) presents a challenging situation when it comes to a young person's transition beyond the care of children's services where the focus is more on supporting end-of-life care in adult services.

In contrast to the lifelong approach in children's services, adult palliative care generally focussed on people with terminal illnesses for which treatment was no longer possible. In comparison to children who accessed palliative care from diagnosis onwards, most adults do not access palliative care until much later in their illness trajectory. Although the aim of adult palliative care is to promote living remaining life to the full through good symptom management and holistic support, this is in the full knowledge that death will happen within a fairly short-term trajectory.

It was, however, evident that the absence of a consistent and coherent definition and focus of palliative care across children's and adult service providers and the common misconception of palliative care as synonymous only with end-of-life care (specifically in adult services) can further reinforce the differences experienced by young people and their parents during transition:

... it's like with the adult services, palliative, everybody thinks.... terminal, and that means that the palliative person (i.e young person in transition) feels really down, because they are not terminal they're palliative, but because the people there have got this terminal attitude, it's sort of.... Gets in the way of everything.

Because they can't see beyond.

Father of girl 18 years old with an undiagnosed condition.

From the perspective of the young person and their family, the philosophy and service provision associated with children's palliative care was a much better "fit" when they were planning to live at the same time as planning to die.

### 3.2 | Being treated as an adult and the oldest "patient" in children's services compared with being treated as a child and the youngest "patient" in adult services

Young people usually reached the end of their eligibility to be accommodated within children's health services by their 18th birthday, by which time they were generally being treated as adults and were the oldest "patients" in children's services. When they moved to adult services, they automatically became by far the youngest "patients," and frequently felt as if they were treated like children again. Young people commonly described an age gap of several decades between them and other patients typically managed within adult services.

Concerns were also raised about a perception that, in some cases, mental capacity to make decisions was not consistently afforded to young people with complex physical healthcare needs who did not have cognitive impairment. It was commonly reported that involvement within decision-making and self-advocacy was not an embedded, core principle underpinning their care within adult healthcare services. Time and again, healthcare professionals were described as failing to recognize the young person as a "whole person" with basic developmental, physical, mental, and social needs that were distinct from those of an older adult. A young man and his mother recalled a typical experience of an adult service:

Mother	One doctor even came out and got me and took me in a separate room, to discuss [name of young man].
Young male	I think I drove off that day [in his own car]...
Mother	"You did, and I didn't know where you'd gone. And the doctor said "where's my patient gone?" and I said "I don't think he liked you talking to me behind his back" and he didn't seem to have a clue that he'd done anything..."
	Young man 25 years of age with life-limiting condition, and mother.

Insufficient opportunity and lack of encouragement to self-advocate negate a young person's opportunity to voice their preferences, thoughts, and concerns, pertaining to their own transitional palliative care. Inevitably, the lack of an individualized service resulted in a generalized care plan that fell short of fulfilling the unique needs of the individual:

They should just think for two-seconds before they approach – they pick up a file, they go right, I've got to weigh this child, I've got to do this, that and the other, and you think, can't you just think for two-



seconds, this is (name of child), she can't jump out of the wheelchair and get to the scales and I think that personal, individual process throughout the services, lacks sometimes.

Female, 18 years of age with Chronic Leukaemia

Furthermore, this impersonalized adult service approach was seen to create a rift in interpersonal relationships between not only the young person and the healthcare professional in adult services but also between healthcare professions and family members:

If I go to the appointment with him, I'm considered an interfering busy body mother, who can't let [name]do things for himself.

If I'm advocating on your behalf they seem to think that I'm not advocating on your behalf, I'm advocating on my behalf.

Mother of male, 25 years of age.

From the perspective of the young person and their family, neither the children's or adult palliative care models promoted communication and decision-making in a way that completely met the needs of young people. Many young people wanted a half-way house, whereby they could make the decisions, but they commonly (but not always) wanted their parents to be involved and to help them.

### 3.3 | Being a "child" in a child's body in children's services compared with being a "child" in an adult's body in adult services for those with sensory and learning impairments

For young people with complex health and palliative needs and sensory and learning impairments, parents described the conflicting realities of their child being a "child" in a child's body within children's services and then remaining a "child" but growing into an adult's body during the process of transferring to adult services. Parents saw their adult child developmentally remaining in a child-like state, but having to cope with legislation that classified them as adults, and professionals who were not equipped to communicate with their adult children with learning impairments in healthcare settings. An adequate understanding of a young person's physical and psychological development was considered essential when treating and promoting their child's general well-being. This was particularly true not only within adult palliative services but also for clinicians who habitually treat both child and adult patients, for example, in Accident and Emergency departments or General Practitioner surgeries:

I mean, I know they're not children, but they're like children.

Mother of male, 15 years of age with complex needs and sensory/learning impairment.

Parents were disappointed that all staff who came into contact with their adult children with learning impairments were not skilled in developmentally and age appropriate communication. Although there were exceptions, they generally said that children's services seemed better equipped and more experienced at communicating with adult children with learning impairments and life-limiting or life-threatening conditions.

### 3.4 | Being treated by experienced children's healthcare professionals within specialist children's services compared with being treated by relatively inexperienced adult healthcare professionals within more generalist adult services

The conflicting realities of being treated by experienced and frequently specialist healthcare professionals within children's services and then commonly being treated by generalized healthcare professionals within more generic adult services was a clear concern for parents and young people. Of those young people who had been through transition, most had experienced a single handover clinic between the children's and adult services and there was a clear perception that you received a worse adult service:

In paediatrics everything just seems to be there and you have a lot of support, and people contacting you, particularly, you know, specialist nurses. Then when you go into adult it's very much you go to clinic and then that's finished, you don't get that [the same services and follow-up]...

Parent of young person over 18 years who attended hospice.

The withdrawal of experienced healthcare professionals or a service that was previously provided by children's services resulted in a lack of trust and confidence that young people in particular could manage by themselves once transferred to adult services:

One of my biggest worries is because mum knows all the medical side of it, you know, I don't know it all like, and I'm worried that something wrong is going to really happen.

Female, 18 years of age with Chronic Leukaemia

In addition, there were genuine concerns about the lack of an equivalent adult service and a general deficiency in understanding the person as a whole:

I think unfortunately it will be a case as, as I understand it often is, a question of shoe horning the

individual into what exists [in adult services], rather than it being person centred and saying; 'well actually this would be the ideal provision for the individual, and let's provide for it and work around that.'

Father of male, 18 years of age, with very complex needs.

Young people and their families often established strong relationships with children's healthcare professionals based on trust and confidence that had been built up over many years. This was particularly true with regard to children's palliative care community nursing services:

She's been with the [Specialist Community] Nurses quite a while, she's built relationships up with the carers and the nurses and you just don't know if they are going to be pulled out tomorrow. And that can happen and (name of child) and I would have nobody. And she'll lose people like that that she's built up relationships with. Mother of female, 18 years of age with life-limiting condition

There was also a clear lack of appropriate hospital environments that were well suited to the age and stage of development of these young people. Often, vulnerable young people with highly complex health needs were placed on generic adult wards as there no alternatives, which left them scared and isolated:

Being in an adult hospital ward, is like being in a dementia ward, and that is really difficult for an 18/19 year old who's terrified, with all due respect. There's a total lack of appropriate care.

Mother of girl 18 years old with an undiagnosed condition.

The other big transition problem, and the age gap, is if a child is admitted from sixteen upwards they very often go to the adult ward. It's a huge, huge problem. Whereas ... it's difficult enough on a paediatric ward for somebody to meet a child with complex needs, on an adult ward it is five times as hard because they're so busy and the staffing levels are so different. But that is a huge thing within transition ...

I've had two instances of families actually hearing the doctors fighting over whether this child should be on their ward.

Children's nurse

Young people expected (but did not always experience) that their adult healthcare professionals would be expert in their condition. This issue was acknowledged by adult professionals who

generally felt more skilled at managing conditions such as cystic fibrosis and muscular dystrophy for which they had more years of experience:

Even just [adult health care professionals] knowing about the condition and ... just generally knowing ...

Male, aged over 18 with life limiting condition.

The differences between the services offered and lack of seamless like for like specialities between children and adult services were a recurrent issue raised by young people and their parents. Within the context of transition to adult services, young people wanted reassurance and continuity of the vital specialist care received from children's services to meet their physical healthcare needs beyond childhood. It was clear that young people's needs required skilled administration of highly complex "technical care" by experienced healthcare professional but that the level of experience and competence in delivering such care varied across children's and adult services.

Modifications to standardized treatment regimes were common in children's services but unfamiliar within adult services. This was particularly true regarding medication such as "off-label" use of drugs (not licenced for children), and equipment such as paediatric ventilators and child-specific modes of operation. A nurse within children's community nursing team clarified the issues:

The medication is a lot more different... When you have the standardised doses for adult services, the children that we're on with such complex needs, they have incredible regimes that aren't anywhere in guidelines or anything.

.. becoming familiar with the equipment that's being used on a regular basis is really important.

Nurse within a children's community nursing team.

Dragging out the ultimate withdrawal of experienced children's healthcare professionals was a tactic used by parents to ensure what they perceived to be better continuity and personalized care for as long as possible. There was a clear explanation as to why parents sometimes tried to "drag out" their child's transition to adult services. Parents and young people were concerned by their experiences of the conflicting realities of being cared for by condition-specific children's services and subsequently being shoehorned into existing general adult services where knowledge of childhood conditions was commonly less.

### 3.5 | Being relatively one of many with the condition in children's services to being one of very few with the condition in adult services

If young people survive to a point where they transition to adult services, they commonly move from a children's service where they



were one of many with the same or similar condition to being one of very few (or the only one) with the condition within adult services. Mortality steadily increases with age (decreasing numbers), and children's services tend to provide specialist services covering a wide geographical area (concentrated numbers). However, post transfer the young person can commonly be cared for by a local general adult service (geographically dispersed caseload), that manages large numbers of patients from age 18 years until death with almost exclusively conditions originating in adulthood and a wide age span. Being one of many with the condition within children's services allowed healthcare professionals and other families to use previous experiences to compare and relate different circumstances. For the young person and their family, it provided reassurance that they were not alone:

Because I've got a boy and a girl about the same age, about ten ish and they were diagnosed about the same time, and they like talking to each other about [the condition and life in general], but they don't like talking to the parents about specific issues, but they like talking to each other. Children's outreach nurse

Although there were some exceptions, from the perspective of the young person, it was clear that they preferred to be one of many, and therefore, children's services more closely met their need for proximity with others with similar conditions.

### 3.6 | Meeting eligibility criteria for continuing care in children's services compared with not meeting the same eligibility criteria for continuing care in adult services

If a person's healthcare needs were highly complex and could not be met by existing general and specialist NHS services, then a bespoke package of care was commonly organized and paid for by what is called "NHS continuing care" provision. There is a "continuing care" policy for children (NHS 2016) and a separate older "continuing care" policy for adults (NHS 2012). Each policy has eligibility criteria to determine a threshold that needs to be reached in order for a person to be considered for "continuing care" funding.

Young people and their parents highlighted the conflicting realities between the assessment and allocation of continuing care funding when they moved from children's to adult services. They experienced differences in eligibility criteria when they moved between children and adult services. Unpredictability of illnesses and the inconsistent nature of conditions often resulted in young people not meeting the adult continuing healthcare criteria because they were stable for some of the time. This meant that specialized continuing care provision that they had been received within children's services (sometimes for years) was reduced or completely discontinued following transfer to adult services. Young people were described as "falling through a gap" and left to fend for themselves:

When the criteria goes over to adult's some of the children are not meeting the continuing healthcare status because they're stable, even though they may have a neuromuscular degenerative disease, because they're relatively stable at the time that they transferred they're not meeting the status. So the specialised care that they're having from paediatrics is significantly reduced, if not completely withdrawn.

Nurse within a children's community nursing team.

The differences in eligibility criteria and the resultant loss of services and support created an insurmountable chasm between children's and adult services, which young people and their parents could do nothing about, but which had a huge and negative impact on their lives following transition to adult services.

### 3.7 | A new composite model of palliative care to support transition

Underpinning the differences in the conflicting realities experienced by young people during and post transition is the wide variation in the respective children's and adult palliative care philosophies and models. To help address this gap, we developed a composite model that could better represent the core elements of care and support required by young people with life-limiting and life-threatening conditions during transition (Table 3).

## 4 | DISCUSSION

Our analysis enabled new interpretations of the experiences of young people, parents, and health- and social-care professionals by articulating the conflicting realities present in children's and adult services that were absent from existing literature. Findings help explain why service improvement initiatives have commonly had little impact on the young person's transition experience.

Elements of the phenomena that we found are reported in the literature, but not conceptualized as a conflicting reality. The need to plan to live whilst planning to die exposed a stark contrast in the philosophies, purpose, and recipients of children's and adult palliative care. The children's palliative care model takes a holistic whole family approach from diagnosis onwards (Together for Short Lives 2009). Planning to live and planning to die are conceptualized as "parallel planning" in the Together for Short Lives children's standards framework (Together for Short Lives, 2015a,b). The adult model of palliative care was not sufficiently flexible to accommodate parallel planning for young people who have long periods of good health with ongoing palliative care needs interspersed with acute episodes of life-threatening illness.

Relatively higher levels of uncertainty exist in children's prognoses and illness trajectories compared with adults, which makes any type of planning challenging (Hain, Devins, Hastings, & Noyes, 2013; Murray, Kendall, Boyd, & Sheikh, 2005). There is better

**TABLE 3** Core elements of a composite child/adult palliative care model

1	Continuity of health promotion, active treatment, and holistic palliative care from diagnosis onwards through transition and into adulthood.
2	Continuity of pain and symptom management to ensure that pain and discomfort and other adverse symptoms are kept under control.
3	Continuity of skilled communication and joint decision-making inclusive of young people/young adults and their families and carers. Timely and developmentally appropriate and dynamic assessment of mental capacity of young people and young adults in complex decision-making.
4	Continuity of family-centred care and person-centred support inclusive of the entire family, including siblings of the young person/young adult.
5	Continuity of key working as a core component of family and person-centred palliative care for a young person/young adult; helping to negotiate the multiple services that a young person/young adult and their family may need access to.
6	Continuity of condition-specific care planning/care pathways that refer to the purposive and supportive planning with a young person/young adult for the delivery of their care needs both now and into the future and through transition to adulthood and beyond.
7	Continuity of advance care, transition and post transition planning to ensure that young people/young adults and their families receive equitable access to the holistic support and care they need in a timely manner.
8	Continuity of multiagency care to ensure that the young person/young adult is placed at the centre of what can be a complex care system including GP, local hospital, community nursing team, hospice, social services, school and higher education, employment, and housing services.
9	Continuity of psychological support for both the young person/young adult and for the family.
10	Continuity of short breaks/respite care for the benefit of the young person/young adult and the family.
11	Continuity of end of life care planning including provision for the young person/young adult to die in their own home, if this is their choice.
12	Continuity of bereavement support for the family during the young person/young adult's illness and following their death.

epidemiological data and more certainty about adult illness trajectories and timelines to death (Murray et al., 2005). As advances in medical technology, drug therapies and improved nursing care further evolve, young people with life-limiting and life-threatening conditions are increasingly defying medical expectations and surviving longer and therefore require palliative care for longer (sometimes decades) (Hain et al., 2013). Hence, greater numbers of young people are surviving to transfer to adult services and encounter the conflicting realities described here for the first time.

The variation in experiences can partly be explained by the differing epidemiology of childhood and adult conditions that require palliative care. Three hundred and seventy-six different life-limiting and life-threatening diagnoses and conditions originate in childhood,

for which adult services and healthcare professionals commonly have little or no experience (Hain et al., 2013). There are some exceptions (such as cystic fibrosis and muscular dystrophy) where life expectancy has been extended by decades and there is now much more experience of managing the condition in adult services. A much narrower set of conditions leading to palliative care needs are diagnosed in adulthood (such as cancer, neurodegenerative disease (including dementia), stroke, and heart disease). Although the incidence is not equally distributed, and the types vary, the common condition across both childhood and adulthood is cancer.

Health promotion is now considered a critically important component in children's and adult palliative care, but for different reasons. Health promotion in children's palliative care is particularly important as life-expectancy can be extended by health promoting interventions, such as active treatment and psychological support alongside palliative care such as symptom management and pain control (Bennett, 2017). Health promotion in adult palliative care is more focussed on supporting people with terminal illnesses to achieve a "good death" for the patient with a positive caring and bereavement experience for family members.

Although there were exceptions, parents generally felt that children's services seemed better equipped and more experienced at meeting their child's holistic needs—especially for those with learning impairments. This may be due to not having sufficient time since transfer to adult services for professionals to build up a relationship and understand an individual's needs such as communication, or more generally an indication that adults with learning disabilities consistently have worse outcomes because professionals do not know how to communicate and assess their complex health problems (NHS England 2018). The issue of staff competence and experience in adult services to care for this small and highly complex and diverse group of young people is common and not confined to the UK (Goodman, 2011; Heaton, Noyes, Sloper, & Shah, 2005; Howell & Hamblin, 2011; Sonneveld, Strating, van Staa, & Nieboer, 2013). Rees (2016) also identified that unless parents can "let go" of all the negative experiences of their child's journey and fighting for access to children's services and support, then they are ill-equipped and sometimes unable to move forward any plans for transition to adult services.

The new transition model and the principles it contains can be used in conjunction with a transition theory (such as Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000). The *transition conditions* and *patterns of response* domains of Meleis' transition theory, for example, may help nurses proactively identify the contextual nature of the problems experienced by young people. In addition, nurses could proactively assess transition readiness and transition experience by using one of the available tools for young people and parents (Zhang, Ho, & Kennedy, 2014).

#### 4.1 | Strengths and limitations

Although this was a secondary analysis, it was conducted with the same rigour as the original data analysis and within a contemporary timeframe. The combined sample size is large, but findings may not be transferrable to other health systems.

## 5 | CONCLUSION

Young people with life-threatening and life-limiting conditions originating in childhood transfer the legacy of their infancy and childhood experiences with them throughout their lives and into adult services. Childhood experiences of care and services clearly shape expectations in adulthood and of adult services. The conflicting realities of children's and adult services help explain why young people and their parents experience a seemingly unassailable gulf between the two services. Some of the conflicting realities such as inconsistencies between children's and adult eligibility criteria for continuing care funding and the need for additional training to ensure that all professionals are competent to communicate with and care for these young people can be addressed with targeted interventions. Other conflicting realities experienced by young people and their parents (such as the impact of age differences between children's and adult services on patient experience, or the dilution of numbers of young people with life-limiting or life-threatening conditions originating in childhood in adult services) are more challenging to overcome and hence the apparent lack of progress in improving the young person and their family's experience of transition. Nonetheless, if these physical issues are not resolvable within services, then young people deserve more psychological support so that they are better equipped and prepared for the differences in adult services. The new transition palliative care model will help nurses take account of transition needs and in turn may inspire nurses to be more creative by devising other ways of providing the kind of care and support that young people and parents are used to when transferring from children's services. This could be achieved by commissioning specific 16–25 year transition services, greater engagement with relevant not-for-profit support groups, and using digital technologies to create communities of support for young people with rare conditions in adult services.

## ACKNOWLEDGEMENTS

We thank the young people, parents, and professionals for participating in the study and the study advisors, and Lucie Hobson for undertaking some of the interviews.

## CONFLICT OF INTEREST

No conflict of interest was declared by the authors in relation to the study itself. Note that Jane Noyes is a JAN editor but, in line with usual practice, this paper was subjected to double blind peer review and was edited by another editor.

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**How to cite this article:** Noyes J, Pritchard S, Pritchard A, Bennett V, Rees S. Conflicting realities experienced by children with life-limiting and life-threatening conditions when transitioning to adult health services. *J Adv Nurs*. 2018;00:1–11. <https://doi.org/10.1111/jan.13811>

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