

# Hospice support and the transition to adult services and adulthood for young people with life-limiting conditions and their families: A qualitative study

*Palliative Medicine*  
2014, Vol. 28(4) 342–352  
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sagepub.co.uk/journalsPermissions.nav  
DOI: 10.1177/0269216313507626  
pmj.sagepub.com  


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## Abstract

**Background:** Transition to adult services and adulthood is now a prospect for young people with life-limiting conditions requiring palliative care. Little is known about their transition experiences or how children's hospices can support a young adult population during/following transition.

**Aims:** (1) To examine how young people with life-limiting conditions and their parents experience transition. (2) To identify families' and hospice staff's perceptions of family support needs during transition. (3) To identify the implications for children's hospices.

**Design:** Qualitative study using in-depth, semi-structured interviews. Analysis used a grounded theory approach.

**Setting/participants:** A total of 39 participants recruited from one children's hospice in the United Kingdom.

**Results:** Transition planning was absent or poorly coordinated; for most families, there were no equivalent adult health/social services. Consequently, it was a time of uncertainty and anxiety for families. Moving to a young adult unit was a positive experience for young people as the building/support model recognised their adult status. However, they had unmet needs for emotional support and accessing information/services to realise their aspirations. Parents had unmet emotional needs and were unclear of support available once their children reached adulthood. Staff identified training needs in relation to working with adults, providing emotional support and acting as an advocate/key worker.

**Conclusions:** Providing an appropriate building is only one aspect of developing support for young adults. A different model of support is needed, one which promotes young people's independence and provides emotional support while continuing to support parents and siblings. Hospices could play a role in transition support and coordination.

## Keywords

Palliative care, adolescent, young adults, hospices, transition to adult services

### Key statements

#### What is known about the topic

- Increasing numbers of young people with life-limiting conditions requiring palliative care are reaching adulthood.
- The difficulties surrounding transition between children's and adult services are well recognised, but there has been a lack of research about the specific experiences and needs of young people with life-limiting conditions.

#### What this paper adds

- This study suggests that children's hospices could play an important role in supporting young people and families in the transition to both adulthood and adult services.
- Young adults with life-limiting conditions and their parents have unmet needs for emotional support.
- Children's hospice staff have training needs in relation to working with adults, providing emotional support and acting as an advocate/key worker.

#### Implications for practice, theory or policy

- Developing hospice services for young adults involves more than just providing a separate building; it involves developing an adult approach to support that recognises the changed status of young people while continuing to offer support for the whole family

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## Introduction

Medical advances are enabling increasing numbers of young people with life-limiting conditions (LLC) requiring palliative care to reach adulthood,<sup>1–5</sup> and there is evidence of children's hospices supporting greater numbers of young people over the age of 16 years.<sup>6</sup> Transition from childhood to adulthood is associated with changes in roles, relationships, expectations, identity and status alongside development of independence and autonomy. Young disabled people experience a number of transitions during adolescence: from children's to adult services, from school to further/higher education or work and from childhood dependence to adult autonomy.<sup>7</sup> Research suggests that in moving from childhood to adulthood, young disabled people face multiple barriers to independence.<sup>8,9</sup> It has also been found to be a time of readjustment and stress for parents.<sup>10</sup>

The difficulties relating to the transition between children's and adult services are well described in the research literature<sup>7–9,11–18</sup> and recognised in government policy<sup>19–22</sup> (summarised in Table 1). Although there is limited evidence on what is effective in ensuring a smooth transition between services and what produces positive outcomes for young people/families, policy recommendations centre on developing coordinated transition processes that involve young people in planning personalised support services.<sup>19,21,23</sup> An evaluation of different transition models found that better outcomes were associated with the presence of a dedicated transition worker and the provision of written transition plans for families.<sup>9</sup>

Service transition in relation to young people with LLC has been less well researched largely because until recently this group did not survive into adulthood.<sup>24</sup> Indeed, there may be no corresponding adult services to which to transfer.<sup>7,25,26</sup> In recent years, service transition for young people with LLC has received increased attention.<sup>27–32</sup> However, in spite of this increased awareness, there remains a lack of research on the particular experiences and support needs of this group of young people and families during and following transition.

It has been suggested that adult palliative care services find it challenging to support this group of young people for the reasons summarised in Table 2.<sup>26,27,31</sup> Indeed, a recent report concluded that following transition, families experience a substantial reduction in support at a time when their needs may be greater due to progressive conditions deteriorating and entering an end-of-life stage.<sup>31</sup>

There is evidence that young people are no longer able to access hospice support once they reach adulthood even though there are no suitable alternatives.<sup>33</sup> A recent survey of UK children's hospices found that 14 (33%) had a separate wing/building for young people and that the upper age limit for discharge ranged from 18 to 35 years (mean 22 years).<sup>6</sup> Questions have been raised about the appropriateness of caring for young adults in children's settings,<sup>1,34</sup> and it has been suggested that adult hospices are inappropriate due to their focus on cancer and end-of-life care, whereas young adults supported by children's hospices mainly have neuromuscular, neuro-degenerative and metabolic conditions.<sup>35,36</sup>

In conclusion, there has been a lack of research investigating transition in relation to young people with LLC, how (or whether) children's hospices can support this group and whether this support should change due to the different needs of an adult population. This study aimed to examine this area and contribute to addressing this research gap.

## Methods

A qualitative approach was taken to obtain insights into the experiences of young people, parents and hospice staff. Study aims were as follows:

1. To examine how young people with LLC and their parents experience transition.
2. To identify families' and hospice staff's perceptions of family support needs during transition to adulthood and adult services.
3. To identify the implications for children's hospices.

**Table 1.** Difficulties in the transition between children's and adult services.

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- Lack of effective multi-agency assessment, planning and coordination between children's and adults' services
  - Lack of key/transition workers or services to coordinate transition and promote continuity
  - Use of different transition age points by different services
  - Lack of equivalent adult services
  - Lack of specialist expertise in adult services
  - Loss of the school as the focus of provision
  - Differences in organisation and culture between adult and children's services
  - Problems engaging adult services in transition issues
  - Lack of an individualised and holistic approach
  - Inadequate involvement of young people in transition planning
  - Lack of information for young people and parents about the choices available
  - Little attention paid to the young person's aspirations and their priorities/concerns
  - The loss of long-standing relationships with professionals in children's services
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**Table 2.** Challenges for adult palliative care services in supporting young adults with LLC.

- Group includes young people with a range of diagnoses, disease groups and disease trajectories
- Adult palliative care and physicians may have little experience in 'paediatric' diseases in adult life
- Lack of 'fit' with existing adult palliative care programmes which are usually focussed on older people with advanced progressive illness rather than those with long-term supportive care needs
- Lack of age-appropriate short break facilities or ones that can support young people with very complex health needs
- The population though small in size have expensive and complex multi-agency support needs (including social care, health, education, housing, leisure and employment)

LLC: life-limiting conditions.

All young people aged over 16 years, not at an end-of-life stage, from one children's hospice were invited to participate in the study ( $n = 74$ ). Information packs were posted by the hospice with potential participants contacting the researchers directly (this was repeated to increase response rate). Parents were recruited to the study from the group of participating young people. A hospice staff list was used to recruit a purposive sample of workers with different roles. A total of 35 semi-structured interviews were conducted with young people, parents and hospice workers during February–July 2012. Interviews were conducted by an experienced researcher unknown to participants. Participants chose their preferred location for the interview, and young people had the choice of being interviewed alone or accompanied. Parents identified which parent(s) would participate. Interview topic guides were developed from the literature for each participant group. Issues raised by participants themselves were also explored. Interview audio recordings were transcribed verbatim. Transcripts were analysed using the principles of grounded theory.<sup>37</sup> Both authors were involved in identifying and developing the codes/categories iteratively from the data.

The study was approved by a University Research Ethics Committee. Informed consent was obtained from participants and assurances of anonymity/confidentiality given. Participant distress and safeguarding protocols were established.

## Results

### Research participants

Of the 74 young people approached, 16 young people and 16 parents (12 families) agreed to participate in the study. Nine young people were unable to directly participate due to their profound impairments and therefore parents were the key informants. Ten staff members were approached and seven agreed to participate. Participant characteristics are presented in Tables 3 and 4.

The seven staff members interviewed represented a range of roles within the organisation and lengths of time working at the hospice.

The key themes were transition to adult services, moving to the young adult unit, changing support needs and consequences for hospice staff.

**Table 3.** Participant characteristics: interviews with young people ( $n = 16$ ).

Characteristic	Number	Percentage
<i>Age (years)</i>		
16–17	4	25.0
18–22	8	50.0
23–27	2	12.5
28–31	2	12.5
(Mean age = 20.5 years)		
<i>Gender</i>		
Female	7	44.0
Male	9	56.0
<i>Family structure</i>		
Two parent	6	37.5
Lone parent	7	43.8
Unknown	3	18.8
<i>Condition/diagnosis (by ICD-10 category)</i>		
Duchenne muscular dystrophy	4	25.0
Other nervous system condition	4	25.0
Spinal muscular atrophy	3	18.8
Down's syndrome	2	12.5
Congenital condition	2	12.5
Metabolic condition	1	6.2

ICD-10: International Classification of Diseases–Tenth Edition.

### Transition to adult health and social care services

Families in the midst of transition reported lacking information about the support to be provided once they moved to adult services and a lack of coordinated transition planning and support:

Nobody seems to take ownership of transition, they just pass the buck and nobody does, they don't know what or who to pass him on to, so they just don't do anything. Well, that's what it seemed like, to me, you know, we was left to sort everything out ... you start the transition, supposedly, at fourteen and then, you know, you leave school at nineteen and nothing's in place and it's like as if it's a surprise all of a sudden, ... I rang the transition Social Worker, just less than two years before he left school, because I hadn't heard from her, or anything, and I asked was she aware of D and if so when would she be getting

**Table 4.** Participant characteristics: interviews with parents.

Characteristic	Number	Percentage
<i>Relationship to young person (n = 16)</i>		
Mother	12	75.0
Father	4	25.0
<i>Family structure (n = 12)</i>		
Two parent	8	66.7
Lone parent	4	33.3
<i>Age of children (years) (n = 12)</i>		
16–17	0	0.0
18–22	9	75.0
23–27	2	16.7
28–31	1	8.3
(Mean age = 20.5 years)		
<i>Gender of children (n = 12)</i>		
Female	6	50.0
Male	6	50.0
<i>Condition/diagnosis (by ICD-10 category) (n = 12)</i>		
Cerebral palsy	4	33.3
Pervasive developmental disorder	2	16.7
Congenital condition	2	16.7
Down's syndrome	2	16.7
Metabolic condition	1	8.3
Other nervous system condition	1	8.3

ICD-10: International Classification of Diseases–Tenth Edition.

involved and she said, 'who has given you my number, you shouldn't be ringing me'. (Parent Participant 03)

They seem to have no information. They've got no knowledge ... It's hard, the transition from child to adult, with disability, in this country. Because under 18, you tend to get a lot of support from everywhere. Help with getting you a wheelchair, help getting the house adapted ... you just seem to get a lot of help with the things you need ... whereas when you start getting over 18, it's not quite so clear cut ... it's a lot harder once you're over 18, to get those ... because a lot of funding and things like that, apply for children. There's not a lot of assistance for young adult people and it's hard ... it was hard for me to find the information myself. (Young Adult Participant 14)

Families felt that services failed to take responsibility for transition and reported their sense of abandonment:

I think it seems to, once we've reached 18 it's oh, that's another one we can scrub off, it's not our responsibility anymore, we don't want to know. ... So that's where we are at the minute, in transition nightmare. (Parent Participant 06)

Basically the best thing that can happen [for adult services] is that, the worst case scenario for us, is that A, basically, dies and then they don't have a problem, you know. ... If we ignore this, just brush it under the carpet, kids like this, they don't last very

long, they don't live very long, their life expectancy is short, so probably by the time they come towards an adult, then they may not be around for us to have to worry about, so why worry about providing a service. (Parent Participant 08)

There's no support whatsoever. In adult care they don't seem to bother, there's no care because they don't care. And I say you don't care if my kid lives or dies, but I do. (Parent Participant 11)

Consequently, transition was described as a time of uncertainty and anxiety for families:

It was one of the worst years, I mean, in my life, I found it really stressful and frustrating and that was due to the lack of transition into, supposedly, adult services and the frustrations ... I knew it wouldn't be easy, but a lot of it, I think, was just made really difficult, unnecessarily harder than it needed to be, because any change is hard, isn't it? But when you just feel so isolated and so, I just get frustrated, ... it's nearly beaten me, last year I just felt, like, you know, throwing the towel in, it just, really, really broke me and I just can't believe how frustrating it was and unnecessarily difficult. (Parent Participant 11)

I think transition is a stressful time but it's been much worse than it probably needed to be. ... nobody knows what's meant to be happening, ... one of the things that really stresses me out, well it's the main thing that stresses me out actually is the bureaucracy around it all ... when you get in a battle with bureaucracy that's when you start getting stressed. (Parent Participant 26)

Following transition, families reported a loss or reduction in services, particularly for those with complex, specialised needs:

It's been a nightmare really, we've gone from 28 nights a year respite on the Home from Home scheme it's called, and four hours a week through children's services on the Voucher scheme. Well now E's turned 18 that has all stopped. ... nothing's been done, so all services have stopped, we've no adult budget for her, we've no care plan, we've no support package, there's just nothing ... at the minute we're just in the black hole of nowhere ... everybody seems to be discharging her; we've been discharged from the physios, discharged from the OT, discharged from the dietician. (Parent Participant 06)

Since she was 18 everything's stopped ... nothing changes they say, but everything changes ... children with poorly conditions died quite young so they never sort of got to the transition stage, and now with the drugs and the interventions these kids keep growing and growing and lasting longer and longer and there isn't anything. There's no services for them. ... If they want to keep them alive they should be providing some sort of care. (Parent Participant 17)

Transition is poor, it's extremely poor. You get such a lot of support with children's services, but as soon as you move to

adult services it's just terrible. It's non-existent. ... we had a paediatrician one day and then we had nobody the next. It's poor post-school as well. What do adults like Y do when they leave school at 19? A lot of them, nothing ... it just seems you get to 18 and it just all stops, as if you don't need it anymore, but you do. To reach your full potential and to have the opportunities that other people have, you do. You do need it. You need it as much, not less, or not at all. (Parent Participant 02)

Some participants felt hospices could play a role during transition in relation to planning and coordinating the transfer to health/social care services.

Although the hospice was seen as a place of stability and continuity in the midst of transition to adult services, it was evident from participants' accounts that transition occurred within the hospice setting as young people moved to a different building with a different approach to support.

### *Transition within the hospice: moving to the young person's unit*

As adulthood approached, young people moved to a self-contained building which symbolised their new status. Young people described how the different environment and approach to support promoted their autonomy and independence as they now had autonomy over planning hospice visits and increased control over their personal and nursing care:

You can eat whenever you want. It's not a set time. At the hospice you have to eat when they tell you [that] you have to eat. So like, if you have a late night and you don't get up, at 10 o'clock you can't have your breakfast ... You'd only have lunch ... You can go out whenever you want as well ... At the hospice we had to be back by nine so ... you can go out whenever. (Young adult participant 21)

It's really good, they give you a lot of respect and privacy. It's more about what you want than just getting it done. Which it can be with a lot [of carers] and it doesn't matter if it hurts, it will only be a minute, just let us do it fast. (Young adult participant 23)

As they're doing it [providing care] they'll ask you if they're doing it right and stuff. Like they're always, they always go the extra way to make sure that you feel comfortable of how they're doing it ... they just ask you how, how you want them to do it basically. (Young adult participant 05)

Young adult participants reported that the 'child-free' nature of the unit facilitated the creation of this adult environment, while its 'parent-free' policy promoted their independence. They described how they were now involved in care planning which could lead to increased self-esteem and a sense of being respected:

They always go do you want to do your care plan or does your mum or do you both? ... it's good how they do that though like

you get the choice ... I think it makes you feel, don't know, it makes you feel good about yourself I suppose. Because they're just treating you how they treat everyone ... with respect. (Young adult participant 05)

The promotion of autonomy and transfer of decision-making to young people was recognised by parents:

I mean they do talk to him and treat him like a young adult now. Just generally the way they talk to him, practical things like when we're doing the support plan, when in the past X would disappear and watch television or something while I did the support plan, whilst now they expect, and I expect him to stay there. And I still end up answering a lot of the questions but he's there and involved and having an input where and when he can. (Parent Participant 26)

They treat her, not like a child, but more of an adult, giving her choices and that. (Parent Participant 15)

While young people valued the 'parent-free' nature of the young people's unit, many parents expressed concerns over this approach – mainly due to anxiety over their child staying alone.

Many parents felt that their access to support had reduced following transition. Parent hospice visits were more infrequent leading to fewer opportunities for receiving support from staff and other parents. There was considerable uncertainty among parents about the hospice support available to them after transition. They were unclear about whether they could still access family short-breaks and other forms of parental support including at the end-of-life stage and bereavement:

I just wonder what would be the situation where he was sick and it came to the point where they said, right sadly this is going to happen, obviously I would want to be there. That's what you do in the hospice, if you know that time has come you stay with them, so I'm not quite sure, I have wondered about that quite a lot actually what the setup is for that ... would we perhaps be able to stay in the hospice? ... I'm not sure it's a bit of a grey area ... it would be nice to know before the time happened what the plans were for staying, I'm sure they must have some plans in place, but I would like to know what they would be really. (Parent Participant 10)

Hospice staff participants recognised that parental and sibling support reduced after transition due to a refocusing of support on the young adult rather than the family as a whole:

Parents share a lot here. They share a lot of their life, what's going on for them, ... and when you are looking after a child here and you're supporting that family, for me, I'm looking after mum as well. If mum's staying, whoever stays, you're looking after them as well. So that's the biggest difference there [at the unit], that really the focus is on the young person.

And I think that's why the young people like it because they don't have to share it ... I think it's probably more of a problem for parents ... I suppose with looking at it from young person and staff's perspective it probably works quite well. From a parent's perspective, ... when you're used to here [hospice] and staying and getting your emotional support – because a lot of them do – I think it probably feels quite isolating. (Staff Participant 01)

### *The changing support needs of young people*

Participants described how young peoples' needs changed as they moved into adulthood.

**Emotional support.** Young adults expressed their need to discuss a range of issues including conflicts with parents or boy/girlfriends, their life-limiting condition and feelings of loss following the death of friends. It appeared to be difficult for young people to openly discuss their feelings with family members due to the desire to protect them. Staff participants described how young adults grieved for the 'loss of their own lives' and were concerned about the impact of their death on their families:

Many of the young people we realised were already grieving for the loss of what their peers had got. Loss of their own lives; they were concerned about what would happen to their parents when they die. (Staff Participant 04)

You start hearing about their isolation. You hear about, you know, actually their friends have gone to college now or university and they've left home and their friends have dropped away, and that sense of isolation ... I think, you know, there's a big protection racket goes on between young people and the parents. So parents don't want to discuss something because ... they don't want to upset their teenager, young adult. But equally, or I think more prevalent, the opposite is true, that the young people are not as open sometimes with their parents because they know that will upset them. You know, they know about their conditions, they know their futures. They know what's possible and probably what's not likely ... [one young person said] 'I want you to be there [staff member] because I can't be as honest in front of my mum because ... I don't want to upset her and I want to tell, I want to say what I want to say'. (Staff participant 05)

Participants saw the hospice as playing an important role in providing emotional support for young adults. Young adults reported how they felt able to discuss their feelings with most staff members, although some sought this support from staff with whom they had well-established relationships. Some participants felt that accessing 'specialist' emotional support from counsellors/psychologists might be helpful.

Staff participants recognised the importance of their emotional support role due to their existing relationships

with young people and described how this was not a discrete activity but an integral to their role:

I think we all do emotional support on a day-to-day basis because I always find that they'll chat to you when they're doing something. Rather than saying can I have a chat with you and we'll go and find a room, you know what I mean. If they're sat on a computer and you're sat in here, they'll just start reeling stuff off to you. (Staff Participant 03)

**Promoting independence and autonomy.** Young people felt that they needed help in obtaining information about the services/support available to them:

If you had someone who was an advocate who knew the system ... they'd know how to get information ... I didn't know who to talk to or where to get the information. (Young adult participant 14)

Staff participants noted that many young adults would benefit from independent advocacy to help them access appropriate services, express their views/aspirations and support their independence:

They need people to speak up for them. ... Some of these young people would love to live independently. ... their money is swallowed up into the family household. ... Some of them have said to me, 'I could never live on my own because my money keeps our family going'. (Staff participant 04)

### *Changing support needs of parents and siblings*

While there was a perception that hospice support for parents and siblings had reduced after transition, parents described continuing and changing support needs as their children moved into adulthood.

**Emotional support.** Parents described how they continued to need emotional support; for some, this had become more important. Some parents needed support in adjusting to their child's 'life-limiting' status now that the physical impact of their diagnosis was becoming apparent in adulthood:

They've said that he was worse than he was, he's started to get worse. ... I'm struggling with that at the moment and that feeling of moving from a, yes somebody who had a terminally ill label but you could ignore that most of the time, to looking after somebody who is much more obviously sick ... I'm finding that quite a hard adjustment to make. (Parent Participant 26)

Indeed, staff participants noted how promoting young people's independence, particularly in relation to achieving independent living, could create additional needs for parental emotional support.

Parents valued ad hoc opportunities to discuss their feelings with hospice staff. In their accounts, they highlighted the importance of developing and maintaining trusting relationships with hospice staff and how such relationships

were regarded as fundamental to emotional support, particularly at the end-of-life stage. However, parents felt that a more formalised approach to emotional support was needed now that direct hospice contact was reduced, particularly in relation to preparing for the end-of-life stage. Some parents felt that it would be helpful to be able to access 'specialist' counselling although they emphasised this needed to be provided by counsellors with experience of working with parents of children with LLC:

I don't stay with him now whereas I always did, ... which meant I got a break as well. And I used to really, really look forward to that, I got a lot out of that, both just having a break but also having a chance to chat to people in a more relaxed time ... parents and staff, they're all very good and when you're staying in there you know, you do have time to sit and have a cup of tea and a chat with them at different times and things. So I got a lot out of that ... I'd feel rested and looked after and you know it would really give me a boost. (Parent Participant 16)

Parents were unsure where or how to obtain emotional support now that their child was an adult.

**Peer support.** Peer support was seen as an important source of support by parents because it enabled them to share experiences and feelings with parents in the same situation as themselves and reduced their sense of social isolation. However, many parents no longer had contact with other parents once their child moved to the young person's unit and thus lost the informal support once received:

I like sitting down with everybody around the table with the other parents to get to know them. No matter how old your child is, you meet families like yourself and pass on information, I think that's really important. (Parent Participant 16)

You don't get to talk to anyone, no socialising [at the unit] ... I really like the hustle and bustle of the hospice, there is always lots of talking, laughing and socialising there. (Parent Participant 19)

**Sibling support.** Parents reported that siblings had benefited from the emotional support, pre-bereavement counselling and peer support provided via sibling support groups. However, most siblings no longer attended these groups as they were regarded as more appropriate for younger siblings. Nevertheless, as one mother noted, older siblings continue to need support:

I do think there is a place for, like, for instance, say this last month when Y has been really poorly, that, you know, just to have somebody there or a system for older siblings, that they can access ... I don't mean a group, but just that they may have a contact person ... if they need to make a phone call or are kind of bogged down or just need a chat, that they have somebody to have contact with. (Parent Participant 08)

### *Consequences for hospice staff*

Staff working at the young people's unit came from a range of disciplinary backgrounds (nursing, social work and allied health). Supporting young adults had implications for their role development and training needs as many had been educated to work with children and families.

**Working with adults.** Hospice staff rotated between the main hospice and the young people's unit, and for most participants, this was not problematic as they enjoyed working with young adults. However, it appeared that some staff preferred caring for younger children. The reasons for this were the nature of the physical/personal care needed by young adults and difficulties experienced in interacting with young people. Consequently, staff participants were not convinced that staff should work in both settings:

Some staff are very passionate about the young person's unit and love it, and other staff don't. We have to be honest. Some will prefer the hospice ... I'd like people who were only passionate for the young people [to be at the unit] ... I want people who want to be there and want to work there. You are going to get the best out of them, and young people are going to relate to them easier, if they want to be there. (Staff Participant 02)

Most young people and parents regarded the rotation system positively. Parents felt that it meant that their children were cared for by familiar staff, which was particularly important for those young people who did not communicate verbally. Young people described valuing the opportunity to meet new staff:

Most of the staff don't really change so they always like know you. ... it's not like it's changed and you've never seen them before and you have to explain who you are and everything, it's not like that. (Young adult participant 05)

It's a good thing ... You don't always have the same staff every time so ... You get to know different, like new staff. (Young adult participant 21)

A lot of the staff are still there from when B was 13. A lot of them know her really well. They've been there a long time, and it's just like dropping her off at her auntie's or her grandma's or a family member now. ... although the first time she had been to the unit she settled really well, we phoned a couple of hours after we had left her and said how was she? And she said, 'Oh, she's absolutely fine, because she knows us' ... because some of the staff from the hospice were at the unit ... so she knew people. (Parent Participant 02)

**Development of roles and skills to work with young adults.** Staff participants identified a range of skills/personal qualities they felt were important in working with young adults with palliative care needs. These included good listening skills,

confidence to discuss sensitive topics, empathy, advocacy and enthusiasm to work with young people. Young people emphasised more personal qualities/values such as a sense of humour, motivation and respect. All participant groups felt it was important for staff to adopt an individualised approach to working with young people and to encourage their autonomy and independence rather than ‘mother’ them:

Some young people just don’t get on with some staff because of you know, they’re mothering them basically and so they will openly say please don’t put me with her or him and it’s not them being horrible they’re just saying I’d rather have [someone] who I know is going to just let me do what I want to do and have a bit of a laugh with rather than a mother hen. (Staff Participant 03)

As the majority of staff participants had a background in children’s health/social care, they recognised they needed to develop particular skills to support young adults such as emotional support, advocacy skills and approaching issues of disability and sexuality. The latter was highlighted as important because it was seen as a key area of difficulty for staff reluctant to work with young adults:

When they’re talking about dying and you have difficult conversations with them and expected times and places. I just think it’s not tackled by some staff, it’s let’s put our head in the sand and just give them a great time, which is obviously what we’re about. But there’s huge amounts going on in those heads, they’ve all seen their friends die or brothers and sisters die and I think we’ve just got to be there alongside them. But I think it’s got to be staff that really want to do it. (Staff Participant 06)

I think they [some staff] do struggle with sexuality, when the lads are talking about the sexuality and stuff, yeah, I think they do get embarrassed a little bit; don’t know how to deal with this. And I think you’ve got to have staff that are prepared to tackle those sort of things with the youngsters, working with them. (Staff Participant 05)

## Discussion

This research contributes to knowledge by examining the experiences and support needs of young adults with LLC and their parents and how children’s hospice staff experience supporting this group of families and the implications for their role/training needs. The limitations to the study are that participants were recruited from one children’s hospice that may have developed a particular approach to supporting young adults with LLC. Although findings about sibling support are reported, these are parent perceptions of their needs.

The findings about transition to adult services are consistent with previous research (Table 1). Children’s hospices could play a role in supporting young people and families in the transition to both adulthood and adult services. This could take an advocacy approach (Table 5) which has been associated with enhancing young people’s involvement in

**Table 5.** Elements of an advocacy approach.

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- Helping young people to express views and make decisions
  - Accessing information
  - Navigating the service system
  - Accessing education/training/employment
  - Help with housing/independent living
  - Advising/liaison in relation to financial matters and equipment
- 

decision-making and improving self-esteem and independence.<sup>38–40</sup>

Advocacy has been recommended in relation to young people with cancer<sup>41</sup> and is of increasing importance in the United Kingdom with the move to self-directed support.<sup>42,43</sup> As it is important that advocacy is based on trusting relationships,<sup>44</sup> hospice staff could be ideally placed for this role, although independent advocacy may prevent conflicts of interests.<sup>39</sup> Key working is another potential approach, encompassing providing information/advice, service coordination and emotional support as well as advocacy.<sup>45</sup> Key working during transition and in relation to palliative care has been recommended,<sup>9,27,46–48</sup> although few participating families reported having a dedicated key/transition worker. Moreover, it appeared key worker/advocate support was also needed after transition.

Young adults and parents appear to have unmet emotional support needs. There was a perception of a reduction in parental emotional support due to reduced interactions with hospice staff and fewer opportunities for peer support. Although this particular group of parents have not been studied before, parents of children with LLC and family caregivers can lack psychosocial support.<sup>49–54</sup> The psychosocial needs of young adults with LLC have been under-researched apart from in relation to cancer.<sup>55</sup> The study suggests that young adults and parents need the opportunity to discuss their feelings with a trusted, appropriately skilled professional. This may involve accessing counselling services; however, important emotional support appears to be provided in informal encounters with hospice staff with whom parents/young people have established relationships. This study supports other research that has recommended that who provides emotional support within the hospice setting and what this constitutes need to be communicated to families.<sup>56</sup> In addition, appropriate forms of emotional support need to be developed for young adults with profound impairments and for older siblings.

Young adults valued a personalised approach to hospice support tailored to their individual needs/preferences. This enabled them to exercise control over during hospice visits, thus acknowledging their adult status. Other studies have noted the importance of autonomy and participation in decision-making.<sup>57–60</sup> However, evidence suggests that participation is poor, particularly if young people have complex needs, and that their involvement needs promoting.<sup>12,61,62</sup>

**Table 6.** Recommendations for research.

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An investigation of the impact of hospice transition key workers on service transition experiences
An examination of how to support young people and parents as roles change during transition
An exploration of the experiences and support needs of siblings of young adults with LLC
An evaluation of key worker and advocacy roles in supporting young adults with LLC following transition to adult services
A comparison of transition experiences between young adults with LLC who use hospice services and those who do not
An exploration of how to develop emotional support for young people with profound impairments
An evaluation of different approaches to providing emotional support to young adults with LLC and their parents

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LLC: life-limiting conditions.

Staff training needs were identified in relation to working with young adults, emotional support provision and developing an advocacy/key working role. Others have found that palliative care professionals have unmet training needs in relation to providing psychosocial support<sup>56,63</sup> and discussing sexual issues.<sup>55</sup> This could be addressed by a combination of formalised training and role modelling, and could involve young people themselves as 'trainers'. Table 6 presents recommendations for research.

This study suggests that developing hospice services for young adults involves more than providing a separate building; it involves developing an adult approach to support that recognises the changed status of the young person while continuing to offer support for the whole family.

### Acknowledgements

The researchers would like to thank the young people, parents and hospice staff who took part in the study for sharing their views and experiences with us.

### Declaration of conflicting interests

The authors declare that there is no conflict of interest.

### Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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