Qualitative accounts of young-people, parents and staff involved with a purpose-designed, pilot short-break service for 18–24 year olds with life-limiting conditions

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Title:

Qualitative accounts of young-people, parents and staff involved with a purpose-designed, pilot short-break service for 18-24 year olds with life-limiting conditions

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Abstract

Purpose: Transition to adult health and social-care services is a time of great uncertainty for young adults with life-limiting conditions; due to improved management, many who would have previously died before they were 18 years old are now surviving into early adulthood. Nevertheless, few services exist to meet their specific needs for specialist short breaks away from home. The purpose of this research was to determine the views and perspectives of young adults parents/carers and staff engaged with a purpose-designed, pilot short-break service for 18-24 year olds with life-limiting conditions. Data were gathered through qualitative individual or focus group interviews involving two young adults, four mothers and fifteen health or social-care staff associated with the service. Data were analysed using Framework Analysis.

Principal results: Emergent themes: (i) The need for a specialist short-break service; (ii) Decision making when using or delivering the service; (iii) Challenges of staffing and financing the service (iv) Meeting young adults' complex needs and preferences (v) Suggestions for how to improve the service

The young adults described how they benefitted from access to specialist, age-appropriate, on-site clinical skills facilities and opportunities to socialise with peers. Mothers said they benefitted from time alone or with other family members in the knowledge that the specialist short break service met the needs and preferences of their child as they made the transition to adult services. However, all participating mothers and staff expressed concern about the future well-being of young adults when they left the service at 24 years old.

Major conclusions: This study provides new information to inform ongoing development of short-break services for the increasing number of young adults with life-limiting conditions who are surviving longer than they would previously have done. This will help to ensure that UK services are responsive to users' needs and preferences.

Key words: Life-limiting condition, Life-shortening condition, young people, young adult; transition, short-breaks

1. Introduction:

Globally, growing numbers of young people with life-limiting, progressive conditions are surviving into adulthood, with a reported increase in the United Kingdom (UK) of 44.8% between the years 2000 and 2010 (1, 2). However, there has been little corresponding health and social-care service provision for these individuals (3). For young adults with life-limiting, progressive conditions and their healthy peers, emerging adulthood is a distinct period demographically, subjectively, and in terms of identity explorations. Yet for those with life-limiting, progressive conditions, around the time they make the transition to adulthood and from child to adult-health and social-care services their conditions often reach a critical point with significant deterioration in their overall wellbeing that requires even more intervention from clinical specialists. The stress and uncertainty associated with this period of transition often also has a negative impact on the wellbeing of the entire family (4-12).

In the United Kingdom (UK) therefore, the Transition Support Programme for young people with life-limiting conditions, was initiated with the aim of raising transition standards (13). In line with this programme, in 2011, a pilot short-break service for young adults aged 18–24 years with life-limiting conditions (hereafter referred to as 'the service') was established in the north east of England in association with, and located beside, an adult hospice. The service is located within an existing short-break service for children and young people (CYP) with life-limiting conditions. The service was developed in response to concerns expressed by and on behalf of young people who became ineligible to access the CYP service once they reached 18 years of age. Informal reports from families and professionals also highlighted that because no suitable service existed for those aged 18 years or over, they either received inappropriate services (for example temporary placement in elderly-care wards) so that their parents/carers could have an urgent respite break, or received no service at all and spent most of their time at home with their parents. These reports reinforced grave concerns expressed in a qualitative study of parents' and teenagers' views on the recently established CYP short-break service that was conducted by the current team. The prior study is reported elsewhere (14) but in brief, interviews with teenagers and parents to determine their views of the CYP service, identified three key themes: (i) accessibility and communication; (ii) needs and boundaries; and (iii) shaping the service. Teenagers using the CYP service enjoyed regular planned residential breaks, access to skilled staff and bespoke facilities to support their clinical, emotional and social needs, opportunities to meet others with life-limiting conditions and fun time away from home. As a consequence parents experienced peace of mind, a regular planned break from care-giving, and opportunities to meet other parents in a similar situation and to spend exclusive time with their other children. The study concluded that if specialist short-break services became part of the national range of services available, children and teenagers with life-limiting conditions and their families could all benefit significantly. However, parents highlighted an urgent need for purpose-designed short-break provision after their child reached 18 years of age (14).

Subsequently, funding was obtained to develop and deliver the service, thereby providing regular, planned short breaks for young adults aged 18 -24 years with life-limiting conditions, after they leave children's services. A Transition Project Lead was appointed to develop policies, work with commissioners and ensure the new service could operate alongside the existing CYP service without compromising the existing care being delivered to either children and young people or young adults.

The intentions of the new service were to meet the needs of young adults with life-limiting conditions who were no longer eligible to attend purpose designed services for CYP with life-limiting conditions. Furthermore, as young adults, the children's facility was entirely inappropriate for them. Unfortunately though, few young adult appropriate short break services exist in the United Kingdom. Most young adults, therefore, remained at home with their parents and either received short breaks in old people's homes, or in long-stay units alongside adults recovering from an acquired brain injury, or received no access to a short break service outside the home.

The UK Care Quality Commission approved the proposal to extend the existing CYP service by providing young-adult specific facilities such as a separate young-adult lounge, dedicated bedrooms, and outside sport facilities. The pilot project provided funds for these developments as well as the appointment of additional staff to deliver the young adult service, provide a young adults' social group, a young adults' champion and to subsidise the day-to-day costs of running the service.

The design priorities of the young adult service were informed by user engagement from the outset, with young adults with life-limiting conditions being an ongoing part of the design and development team. At the time of this study (2012/13), 12 young adults accessed the service, all were very physically disabled, some were cognitively able and some were not; of those who were cognitively able, some were able to communicate verbally but some were not. The number of short break places available at any time for use by young adults is based on the fact that overall there are only eight beds available and these are shared with the CYP service. Access and length of stay for each young adult is determined by an assessment of need that is conducted by the Department of Health and Social Care and Local Authorities. The staff: young adult ratio is a minimum if 1:1 during the day and 2:1 at night. The living environment includes a specially adapted young adult lounge with a microwave oven, a computer suite and a wide screen television. A monthly Young Adult Group is facilitated by staff and during these meetings the young adults are encouraged to identify and request internal and external activities to enjoy during their short breaks (e.g. attending local football matches and visiting a local bar) which are then arranged and facilitated by the staff.

The aim of the current study was to build on previous research and explore the views and perspectives of young adults, parents/carers and professionals engaged with the service to determine:

- How the service was delivered,
- How the service was experienced, and
- What difference the service makes to the lives of young adults and carers

Study design: A qualitative study to help understand the meaning and context of the service for participants (15, 16)

2-Method

2.1 Sample recruitment:

Young adults were identified using an opportunistic sampling approach, parents and staff were then identified using snowball sampling (15).

Inclusion criteria:

- Young adults who were registered with the service and able to communicate their views using verbal and/or non verbal means
- Parents/carers of young adult service-users
- Health or social-care staff working with the service

A letter of invitation to participate in the study was sent to all families currently engaged with the service, and all staff currently working in the service.

2.2 Data collection

Semi-structured individual or focus-group interviews were conducted with participants, depending on their preferences. Interviews or focus groups were held at a time and place convenient to the participants; some chose to be interviewed in a quiet room in the service (with no service staff present, thereby ensuring anonymity), others chose to be interviewed in their own homes. Discussion was based on topic guides (Appendix 1) designed to stimulate discussion, gain insights and generate ideas in order to pursue topics in greater depth (15). Interviews were conducted by [author 1 and 2] who had previous experience of conducting research interviews and of working with vulnerable young adults with limited communication abilities. All interviews were digitally recorded and later transcribed.

Individual interviews were conducted with two young adults and four mothers; three individual interviews and two focus group interviews were conducted with a total of fifteen health or social care professionals currently associated with the service. Interviews were held at a time and place convenient to participants and digitally-recorded and transcribed.

2.3 Data analysis

Data were analysed using the Framework Technique (17-19). This method sits in a thematic methodology, is systematic, thorough and grounded in the data but also flexible and enables easy retrieval of data to show others, thereby providing a clear audit trail. Framework is a rigorous, matrix based method which allows movement back and forth between levels of abstraction without losing the meaning of ‘raw’ data (15). Key quotations were labelled and identified for later retrieval and reporting (20). In addition, Framework allows both between and within case analysis and involves a process of:

- Familiarisation with the data
- Identification of themes
- Indexing
- Charting
- Mapping and interpretation

2.4 Data quality

Establishing the credibility of qualitative research increases the likelihood that findings will be applied to practice (21). The ultimate test of trustworthiness is whether we believe the findings strongly enough to act on them (22). By using these methods of data collection and analysis we were able to produce a richly detailed report for the funders, incorporating an audit trail of original interview transcripts, field notes, coding frames of key themes in the data and examples of charting according to thematic references. The research process was thereby made transparent thus enhancing its trustworthiness.

2.5 Ethical issues

Ethical approval was obtained from a local University Ethics Committee. Involving young people and young adults in knowledge creation in the delivery of health-care services is essential if their specific needs and preferences are to be addressed (23, 24). Written and verbal information was presented in a way which was appropriate for the participants' ability and level of understanding. Consent was obtained from all participants who agreed to enrol after receiving both written and verbal explanations. Whenever possible consent was written, however, both young adult participants were unable to write because of their disabilities; therefore, they provided verbal/non-verbal consent and observed an advocate of their choice sign the consent form on their behalf.

Every effort was made to ensure that consent was informed and freely given by encouraging participants to take time to consider and to discuss the project with relatives or primary health care staff. All participants agreed to their interviews being digitally recorded and later transcribed and that the contents would only be shared with the research team. In addition, families were assured by the independent researcher, and without service staff present that declining to enrol or later withdrawing would not jeopardise subsequent care by the service or relationships with health and social-care professionals. All transcripts were stored securely in accordance with local protocols.

Anonymity and confidentiality were maintained at all times. Vulnerable clients have the same rights to confidentiality as any other person (25) and it was explained to all participants, that in order to protect confidentiality and anonymity all hard copy and computerised records would be stored in a locked filing cabinet and/or a password protected computer accessible only to the research team. After transcription, data were fully anonymised and links enabling individuals to be identified were held manually in a secure place, to be accessed only by the researchers when necessary to match up data. This was particularly important because the young adults may not have been in a position to challenge the way in which research findings about them were presented. In this study there was no potential for physical harm, indeed our experience from other studies, including our prior study of the views of families and staff in the short-break service for CYP with life-limiting conditions (14) is that family members and staff often enjoy the opportunity to talk in confidence about their experiences of care. However, any possibility of psychological exploitation was minimised by following the guidelines for conducting research with vulnerable groups and by providing the opportunity to talk in confidence with a Social Worker who was not a member of the research team, if needed. As far as possible the principles of beneficence and non-maleficence were observed and participants' rights were respected at all times (26). Every effort was made to avoid invasiveness and intrusions into family life by arranging interviews at a time and place convenient to the family; and by trying to ensure that any benefits which may result from the study are greater than any potential disadvantages to the participants. To maintain anonymity, pseudonyms are used in reporting participants' quotations

2.6 Participants

A total of 21 participants (comprising 2 current male services users aged 19 and 23 years; 4 mothers of current service users and 15 current service staff) agreed to participate in the study, representing an overall response rate of 29.5%. Non-respondents were not contacted a second time. Only two of those young adults who were able to communicate verbally agreed to participate. A range of service staff were recruited (4 nurses, 5 doctors, 3 support workers, 2 physiotherapists and 1 social worker), thereby facilitating a more inclusive understanding of service staff experiences (Table 1)

[Please insert Table 1 here]

Table 1: Characteristics of participating young adults and parents

Young adults	**Parents**
• Ben aged 19 years who had used the CYP service and had transferred to the new young adult service when he was 18 • Joseph aged 23 years who had used the CYP service until he was 18 years old and became ineligible as the upper age limit was18. He then returned to the new young adult service that was the focus of this current study when he was 21 years old.	• Alison, mother of Ben • Barbara mother of a young adult service-user • Carol mother of a young adult service-user • Denise, mother of a young adult service-user

3 Results

Data presented below are drawn from these interviews and represent the views of all those interviewed.

3.1 Emergent themes

The themes that emerged, with participants' illustrative quotations, are presented below. Within each theme findings are presented from the perspective of young adults and mothers and professionals (identified by their respective discipline, for example: Dr1, Nurse4, Support worker3).

3.1.1 The need for a specialist short-break service:

When talking about the need for the service and his prior experience of previously accessing the CYP Service, Ben recalled that it had involved his parents in:

> .. a lot of fighting to get a place [in the CYP service], it took about 18 months. (Ben)

Both Ben and Joseph emphasised how much they had enjoyed and benefitted from their time at the CYP service and described their anxieties when they were approaching the age of 18. For example, Joseph recalled how worried he was as he approached the time when he would no longer be eligible for the CYP service:

> I thought I was just going to end up in a really bad [elderly] care home, which I kind of did

Ben began to have short breaks in a care home for older people and those recovering from brain injuries. When asked about his experience there he said:

> *Well, if I am being honest, it was like prison… it was just miserable. I didn't look forward to* going in. *It was the fact I was shut in a room. The staff didn't really have time to talk to me or* anything

The mothers who participated in the study said that throughout their child's life they had not been encouraged to plan for their child's transition to adulthood, as until recently children with life-limiting conditions were expected to die in childhood.

Changes in service provision and entitlements could affect some aspects of care even before the age of 18, for example, some services were no longer available after the age of 16 as Joseph explained:

> *After the age of 16 you're not entitled to a physio [regular physiotherapy services], you're just entitled to someone to manage your physio, someone who will come in and…show someone* else how it [physiotherapy] is done.

This meant that once a child reached the age of 16 years their parents usually had to take on responsibility for administering their physiotherapy.

Mothers, like Alison below, talked at length about the need for a short-break service that would meet their child's increasing needs for the rest of their life, however long they lived.

> Obviously *you are classed as an adult when you're 18, but [son's name] needs from when he was 2,3,4,5,6 years are the same [as they are now] and he's 22 now* (Alison)

Mothers were annoyed that existing service provision [before the service was developed] did not usually address the fact that their child's need for support was likely to increase rather than decrease as they matured, and that additional health problems would be identified as their health condition deteriorated. This was emphasised clearly by Barbara:

> *I feel it's wrong because, yes he's 18 but 18 is just a number …his condition isn't going to get* any better and it is getting worse (Barbara)

Two mothers whose children had left the CYP service at the age of 18 described the difficulties they encountered when trying to find alternative short-break services to meet all their needs. Having searched for a suitable alternative service for three years after her son reached the age of 18, Alison found had none to meet his needs until accessing the service.

Another mother, Denise, had been happy with the personal care provided by the alternative service but dissatisfied because there was only one nurse available to deliver clinical care for all residents at each shift:

> I could not fault them as carers when he was in respite at [name of service] but he never got *out on trips…if a nurse left the place there was no nurse left to care for the others. There would be maybe a couple of board games around the table … but they didn't have a sensory* room and things to stimulate him

Professionals also expressed concern about the dearth of suitable short-break services for young adults after leaving the CYP service at the age of 18:

> We did part company [with young adults when they reached 18] and crossed our fingers and hoped. (Social Worker1)

Palliative care doctors emphasised that the service was more appropriate for young adults with life-limiting conditions than the service provided at an Adult hospice:

> [The service is] not palliative care as I understand it, [its] more about transition (Doctor1)

Staff respondents highlighted that the staff-patient ratio in the service ensured provision of an individualised holistic care package, indeed one doctor explained:

> In hospitals there is not always the resources but in *the [Young Adults] service there's a philosophy … it's about the whole person, the whole family approach … sometimes in these* complex difficult situations [the whole family approach] is required and perhaps we're not always good enough at saying, actually I think we [the service] can do this better than the hospital setting..(Doctor3)

At the service, patient and family-focussed care is arranged around the patient and the whole family; this includes social work support, bereavement counselling, complementary therapy and general care of the family during difficult times.

Professionals reported that they were concerned because they are working with an emerging group of young adults with life limiting conditions that, until recently, would have died in childhood. Therefore, because no suitable short-break services previously existed, professionals have found themselves with the dilemma of supporting parents needing a break and of young adults being offered inappropriate services that they have not enjoyed. This means that parents could not benefit from the breaks due to feeling guilty and worrying about the quality of care provided in non-specialist services. Those who could not access the current service were described by staff as receiving only basic care in other services.

There was a consensus amongst staff that limited provision of short-breaks for young adults was a major national problem. Some hospices offered a compromise, keeping young adults by default because there was nowhere suitable for them to transfer to. This meant, for example that adult patients in their mid thirties were sharing facilities with babies and young children or the elderly or those recovering from brain injuries, where staffing levels did not allow for quality time to be spent with the young adults.

3.1.2 Decision making when using or delivering the service

Discussion around transition was about young adults taking more control of decision- making about their health and living in the community, and parents relinquishing some control of these factors. One of the first decisions that young adults and parents had to make when considering using the service was the fact that it is associated with and located next to an adult hospice. Professionals were aware that the name 'hospice' can often make families and children feel apprehensive because of their pre-conceptions that a hospice is a place where people go to die. However, once they had visited the service they were reassured by the fact that it was specifically designed to accommodate the needs of young adults with life-limiting conditions who may survive for many years, rather than older adults who were in the terminal stages of their illness.

For example, Ben and Joseph (who had accessed the children's short break service until they reached the age of 18 years) were pleased to have been asked to contribute to planning the young adult service; they had met with the architect when the new lounge area was being discussed, and were part of the consultation group for new policies and procedures. When talking about the use of the lounge Joseph said:

> I agreed wit*h it [proposed plans for the lounge]…. it's worked very well.*

Both talked enthusiastically about the twilight staff shifts [additional staff employed from 1800-0200 hrs] that were introduced when the young adult service commenced and Ben said:

> *… that's* made it better the fact that I can go out on a night and not have to be in for [staff] handover time at 9.00pm.

Indeed, young adults were happy that they were involved in decision making on a daily basis, as Ben described:

> I have had quite a lot of input and some support workers can also drive my [adapted] *van…so I can decide on the day where I'm going (Ben).*

All mothers were pleased that the young adults could choose when to have a short-break away from their parents/carers, for example, Carol reported:

> He gets the break away from home which is nice, getting away from every day life at home. Wonderful to be amongst his *friends and mix with them…He's 22, doesn't want his mum and* dad around him all the time.

Mothers said that they and their partners also needed to 'recharge their batteries' so that they could continue to be effective carers, and that this is very easy for them to achieve when their sons are at the service; mothers totally trust staff at the service who offer both clinical and social support.

Mothers enjoyed the opportunity to relinquish the caring role whilst their child was in the service; this compared very favourably with their prior experience of taking their child to other settings such as respite homes or acute hospital wards. For example, they described medication errors occurring and a lack of understanding about their son's clinical condition by staff in other settings. These experiences meant that instead of a relaxed break, mothers felt worried and guilty about leaving the young adults. It appears from mothers’’ accounts that no other care setting or hospital can offer the high level of staff/young adult ratio that is available at the service. The lower staff/young adult ratio in other care settings does not instil confidence in the parents, as one mother, Denise reported:

> *We were offered an old people’s home [because that’s the only service avai*lable] because he *is 18, no disrespect to the elderly but my son‘s not an old person, he needs to be around kids his own age, to be able to go out and not just sit in a chair and stare out of a window. That’s not what I want for [son’s name] and if he had* gone there he would have seeped into *depression, so that’s not good for an 18 year old. I wouldn’t even leave him for five minutes elsewhere. I don’t let anybody else do his medication, but when I bring him here [the service] I* never worry).

Staff generally felt that, when developing the service, they had been naïve about how the service would operate as they had not fully considered the importance of a shift in decision making from parents to young adults, and the need for policies, procedures and practices that would be different. They reflected for instance on how easy it was to forget about appropriate bedtime choices or about clothing, and emphasised the importance of:

> *…trying to keep the focus on the young adult [as opposed to on the parent/carer] in*cluding those with no speech at all and no method of communication, [whereas] we are still maybe speaking on behalf of them and hoping that this is what they want to do (Physiotherapist1)

Staff sometimes struggled with sharing information about the young adult with their parents because of the fact that some parents believe that as their children are now adults they should be making their own decisions, but some parents did not share this view. An example of this dilemma was reported by a professional who had encountered a situation where a young adult’s health rapidly deteriorated while his parents were abroad on holiday and he did not want them to be notified about this:

> It was a really, really difficult situation because I think you try to look at it yourself as a mother, *and I would’ve been very upset as a mother, abroad, knowing my son was getting a 999 ambulance to come and pick him up, if I hadn’t been told, regardless of how old he was….*(Nurse3)

The doctors participating in this study reported that they had no experience of working with the rare conditions that some young adults in the service are diagnosed with, as until recently young adults with these conditions did not survive to adulthood.

> I think the disability is not the challenge, I think with *this group of people it’s the* [rare] conditions *that we’re not familiar with* (Doctor4).

3.1.3 Challenges of staffing and financing the service:

In the service, staff are able to spend a lot of time with young adults, this differed from the young adults' experiences when they have been hospital in-patients:

> They [staff at the service] have got a lot more time than staff in hospital (Ben)

Mothers' greatest concern when their young adults have their short break is to know that their medical needs are being effectively met, as Barbara explained:

> *There's a nurse there who would use their initiative if he needed to go to hospital… there's a physio… there are people that make him laugh.*

It was recognised that a key strength of the team at the service is its multi disciplinary makeup.

When asked to describe what attributes nursing and non-nursing staff need in order to work effectively with young adults, Ben answered:

> They need to be cool

When this was explored a bit further with mothers this meant that they had to relate to young adults in a way that was not patronising, recognising that they are working with adults whose needs may be different to non-disabled adults. For example, Alison explained:

> *It's a blend of being able to nu*rture young adults, but also about being an adult with them

Mothers discussed the cost of individual care packages and understand the pressures that health and social care services are under. There is a lot of pressure for parents to agree to short-breaks that cost much less than those provided by the service. Mothers agreed that it was hard to keep fighting the system but if advising others in the same situation they would say:

> *…hang on for what you want, and don't give up till you get it.*

Funding issues are a bit of a mystery to doctors who find it difficult to understand that commissioners will only pay one third of the cost of care in the service, whilst paying the full cost in other settings.

3.1.4 Meeting young adults' complex needs and preferences

Stays at the service are special; as Joseph explained this is because:

> *I can get around; it's a bigger place, more to do. The gardens are really nice.* Just chatting *with the staff…I like a good chat. Different from hospital stays because there is more time and in hospital it's all rushed, they've got to do things qu*ickly because they need to get to the next *person…It's like home [the service], a home away from home*

One mother said that as a result of her son being able to access short breaks, they [her and her son's father] had been able to enjoy doing other activities for their own benefit. Another mother had returned to work and taken holidays with her husband. Those with more than one child appreciated the time they have been able to give to their other, healthy child. Furthermore, Denise reflected that others might think that the service would be a sad place, but actually it is always a happy place:

> *I wish I could put my finger on what makes it special… from the minute* you walk in the *door…there's laughter going on*

Mothers were asked what the young adults would say if they were asked what they thought about the service and three proxy responses included:

It's fantastic, absolutely fantastic (Alison)*…*and… *it's home from home. Wonderful to be among* friends (Barbara) and…. *I'm doing what is within my capability…the atmosphere is happy. It's fun* (Carol)

Staff reported that the most important thing that makes the service special is the high staff/young adult ratio which ensures that staff have sufficient time to meet the young adults'' physical care needs and to provide for their social needs also: *It's a big thing, that one to one* (Nurse).

During development of the service, young adults had been the main focus and they had a strong voice which was listened to. The living space was developed through close consultation with them and the young adults are very proud of what has been achieved. The garden was later developed as more money was donated and again this was done in consultation with the young adults. Young adults can access physiotherapy, complementary therapy and have symptom control whilst having their short breaks. These are things that are not regularly available to them at home once they are adults:

> I think the social activities that have been tailor-made for them have far outweighed our expectations (Denise- mother)

Doctors suggested that the ability to deal with medical, social, emotional and psychological issues under one roof is very special and unusual:

.

> I would say that it [what the service provides] is successful, that it has done what it said on the *tin…it provides ongoing support for young adults who do not have anything else that can address their needs, either physical or emotional. It provides a lot of fun…as well as looking* at what needs tweaking in their lives to keep them on top (Dr3)

All staff agreed that these young adults are quite isolated at home; some staff would like to develop a day service which would allow young adults to attend the service more regularly with others living with similar challenges

Professionals said that parents are very happy with the service but, as illustrated in the following quotation by a participating doctor, some professionals worry about what will happen when each young adult is no longer eligible to access the service:

> As some are living longer due to better management, [short break service] places should be offered up to age 30 (Dr5)

3.1.5: **Suggestions for how to improve the service**

Staff and mothers provided suggestions for how the service could be improved further, there were no suggestions for improvements from young adults. In particular many staff members and mothers said they would like the referral pathway to be amended to include young adults who do not need nursing care and those aged up to 30 years, and that the number of places available should be increased, because:

> There are limited places, limited availability for the number of children that fulfil the entrance criteria, and we feel that as [young adults with life-limiting conditions] are living longer due to better management, places should be offered up to age 30

Table 2 summarises other common suggestions arising from parent and staff interviews:

Table 2: Suggestions for improving the service

Have more young adults staying for short breaks at the same time to enhance peer support
Build a separate unit for young adults
Build a hydrotherapy pool
Closer working with the CYP service and the adult hospice
Investigate what would make access to an Occupational Therapist and Wheelchair Services easier
If the capacity to offer overnight stays to more young adults cannot be realised, that an outreach service be developed
Provide ongoing emotional assessment and support and guidance on accessing information and services to realise their personal aspirations..
Provide emotional support for mothers, their partners and other children
Provide specific training for staff in relation to working with adults with life limiting conditions, providing emotional support and acting as an advocate/key worker

4 Discussion

Fraser et al (1, 27) reported a 44.8% increase in the prevalence of young people with life limiting conditions between the years 2000 and 2010. This highlights the importance of a national debate about the transition from child to adult services in order for transition to be a meaningful experience for all those involved. Based on our data, engaging young adults in decision making is clearly a positive finding from this study. An informed decision is one that is made well and is based upon a person's evaluations of accurate information about the advantages and disadvantages of all the options and their consequences, in accordance with the person's beliefs and personal trade-offs between these evaluations(28). The action of involving young adults in planning the service demonstrated respect for their ability to articulate their personal needs and preferences despite their disabilities, and increases the likelihood that services will be tailored to the recipients' wishes rather than developed to meet the stated preferences of professionals or parents only (24).

The theory of emerging adulthood (11) is a useful way of conceptualising the lives of people in the period between late teens and mid-to-late twenties in industrialised societies and is arguably a new term for a new phenomenon. This is indeed the case for young adults with life limiting conditions who are fortunately often: "living longer than you thought I would" as reported by a participant with a life-limiting condition in an earlier report by this team (29). This is reinforced by mothers and staff in this current study whose suggestions for improving the service included an amendment to the inclusion criteria so that young adults aged up to 30 years can access the service.

Participants in the current study reported that transition planning had been absent or poorly coordinated; for most there were no equivalent adult health/social care services to transfer to. Consequently, transition from child to adult services was a time of uncertainty and anxiety for families. Moving to the service was a positive experience for the young adults as the building and the support model used recognised their adult status. However, they had unmet needs for emotional support and for accessing information and services to realise their aspirations. Mothers also had unmet emotional needs and were unclear of support available once their children reached adulthood. In addition, staff identified professional training needs in relation to working with adults with life limiting conditions, providing emotional support and acting as an advocate/key worker (10) (23, 30-32)

As outlined in the introduction, few short-break services for young adults with life-limiting conditions exist in the UK and few studies have explored the subjective experiences of young adults, mothers and staff on the services that do exist. This qualitative study adds to the current literature by reporting the views and experiences of young adults using a pilot short-break service, their mothers and the staff involved in their care. The use of qualitative interviews and focus groups to gather information and framework analysis allowed the comparison of different respondent groups and the charting of emergent themes.

It was a challenge to involve young adults in the development of the service (29), particularly as 'adult focussed' staff had been used to communicating with parents and carers rather than the young adults themselves for decision making. However, our findings illustrate that the young adults were especially pleased to be consulted and for their ideas and wishes to be acted upon. This is consistent with the new concept of Emerging Adulthood which is the period that focuses on ages 18–25 years. This concept supports the idea that emerging adulthood is a distinct period demographically, subjectively, and in terms of identity explorations. However, emerging adulthood exists only in cultures that allow young people a prolonged period of independent role exploration during the late teens and twenties (11) and this is a key goal of the young adult pilot service.

Mothers' greatest concern was that their child should receive short-breaks in an environment that meets their medical and emotional needs, that they enjoy a good time and that the whole family would benefit from the family-centred care provided (7)

All professionals felt families benefit from the service. However, in the current difficult financial climate there was concern about whether the service would extend beyond the pilot phase. Our findings will inform the wider Transition agenda as did an earlier report (29) which described in detail the setting up of the short break service for children with life limiting conditions. During the pilot phase of the Young Adult service, there has been wide recognition that young people with life-limiting conditions are reaching young adulthood in greater numbers. This trend is set to continue; the Care Quality Commission is currently conducting targeted Transition inspections looking at the transfer of child to adult health services and has highlighted the need to make plans for this group sooner than currently occurs (33).

There are several gaps in the existing service provision for young adults with life limiting conditions which the current study has highlighted and discussed from the perspective of young adults, mothers and staff. This pilot service cannot currently accommodate anyone over the age of 25 as it would not be appropriate to increase the age range under the current arrangements. Furthermore, providing an appropriate building is only one aspect of developing support for young adults. A different model of support is therefore needed, one which promotes young adults' independence and provides emotional support for them, while continuing to support parents and siblings. Potential solutions would be for service commissioners to prioritise this growing cohort of young adults who would previously have died before reaching adulthood, and for more hospices to play a role in transition support and coordination.

Limitations

It was not possible to elicit the views of non-verbal young adults. As in other studies (34, 35) this is a weakness but in-depth interviews with those who can participate, in the way this study has done, can only increase the knowledge needed to develop services for this group. Further research involving creative research designs that are supported by assistive technologies would help address this challenge. We were unable to recruit fathers or male carers due to none being available at the time of the study. However, our previous work has demonstrated the importance of involving fathers in research about their use of health services for and with their children (36-38), so future research is needed that includes the views of fathers as well as mothers. Several staff who were interested in participating in this study said they were unavailable due to other commitments, in future, telephone or digital interviews may be a preferred approach for those people (39).

5 Conclusions

The service was viewed very positively by all study participants, yet all expressed concern over what will happen when these young adults are no longer eligible to use the service. The service cannot currently accommodate anyone over the age of 24 as it would not be appropriate to increase the age range under the current arrangements. Furthermore, providing an appropriate building is only one aspect of developing support for young adults. A different model of support is needed, one which: educates staff on the most appropriate approaches to support young adults with life limiting conditions; promotes young people’s independence and provides emotional support; while continuing to support parents and siblings. Hospices could also play a role in transition support and coordination.

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Appendix 1

Topic guides used to guide interview discussion

Introduction and Background

All information shared during this research will be anonymised when reported unless information is shared that is of a nature that it must be shared to ensure the safety of the individual or others. At the beginning of interviews participants will be reminded that all conversations are confidential unless information that would compromise someone's safety is shared. All interviews will be digitally recorded and transcribed. Information will be encrypted for storage purposes to ensure confidentiality. All recorded information will be destroyed when the research is complete

Young Adult Interviews

Introduction and Background

1. Knowledge and understanding of the service

- How did you first find out about the service?
- What did you know about the service before your first visit?
- How was information given and by whom?
- Having experienced the service, how would you describe the service to your friends?
- Any anxieties /concerns about using the service

2. Views and experiences in relation to the skill mix of staff

- General e.g. what makes a good worker?
- Qualities e.g. what should they be like?
- Skills, e.g. what should they be good at?
- Knowledge e.g. what should they know about?
- Experience e.g what kind of things should they have done before?
- Any particular concerns/anxieties about

3. Impact 'short breaks' have had on access to leisure activities

- How would you describe the leisure opportunities at St Oswald's?
- Any difference in your opportunities to access leisure activities since joining the service.

4. Views on what makes the service 'specialist'.

- Eg facilities, philosophy, staff skill mix

5. Views on involvement in decision making

- When did the you first hear about the service
- How would you describe your feelings when the service was first mentioned?
- What do you think are important factors in involving you and your family in decision making?

6. **Suggestions on how we can improve the service**
7. **What difference does if any it make to you being able to access the service**

Parent Interviews

Introduction and Background

1. **Knowledge and understanding of the service**

- How did you first find out about the service?
- What did your young adult know about the service before their first visit?
- How was information given and by whom?
- Having experienced the service, how would your young adult describe the service to his/her friend?
- Any anxieties /concerns about using the service

2. **Views and experiences in relation to the skill mix of staff**

- General e.g. what makes a good worker?
- Qualities e.g. what should they be like?
- Skills, e.g. what should they be good at?
- Knowledge e.g. what should they know about?
- Experience e.g. what kind of things should they have done before?
- Any particular concerns/anxieties about

3. Impact 'short breaks' have had on access to leisure activities

- How would your young adult describe the leisure opportunities at St Oswald's?
- Any difference in your young adult's opportunities to access leisure activities since joining the service.

4. Views on what makes the service 'specialist'.

- E.g. facilities, philosophy, staff skill mix

5. Views on involvement in decision making

- When did the young adult first hear about the service
- How would you describe your feelings when the service was first mentioned?

6 Suggestions on how we can improve the service.

7. What difference, if any, does it make to you being able to access the Service

Staff interviews

1. Knowledge and understanding of the service

- Before the service opened, what picture did you have 'in your head' about what the service would provide.
- What is your current understanding and knowledge about what the service provides.
- Does that match expectation
- How was information given and by whom?
- Having experienced the service, how would you describe it to, a friend, a parent?
- Any anxieties /concerns about using the service for young adults

2. Views and experiences in relation to the skill mix of staff

- General e.g. what makes a good worker?

- Qualities e.g. what should they be like?
- Skills, e.g. what should they be good at?
- Knowledge e.g. what should they know about?
- Experience e.g. what kind of things should they have done before?
- Any particular concerns/anxieties about the staffing, levels or skill mix.

3. Impact ‘short breaks’ have had on access to leisure activities

- Any difference in young adult’s opportunities to access leisure activities since joining the service.
- Views on barriers and catalysts to accessing appropriate leisure activities.

4. **Views on what makes the service ‘specialist’.**

- Give examples
- Does the service provide anything different from other residential services?
- Views on how the word ‘specialist’ is perceived by young adults/families /professionals.

5. Views on the young adults involvement in decision making

- Views on how and when the young adult was involved in the decision about using the service.
- Has there been enough involvement.
- How would the person describe young adult’s feelings when the service was first discussed?

6. Suggestions on how we can improve the service.

7. **What difference if any does it make to young adults being able to access the service**