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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.

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 (Fraser et al., 2012; WHO, 2001). However, there has been little corresponding health and social-care service provision for these individuals (Cameron, Neece, Kraemer, & Blancher, 2009). 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 (ACT, 2009; Arnett, 2007; Coad et al., 2015; Crowley, Wolfe, Lock, & McKee, 2011; Darbyshire, Parsons, & Sanders, 2012; Kirk & Fraser, 2014; Knafl & Gilliss, 2002; Sawyer et al., 2012; Shields et al., 2012).

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 (DH/DCSF, 2008). 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

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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. The prior study is reported elsewhere (Swallow, Forrester, & Macfadyen, 2012) 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 (Swallow et al., 2012).

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 (Maxwell, 2012; Ritchie, Lewis, Nicholls, & Ormston, 2013)

2. Method

2.1. Sample recruitment

Young adults were identified using an opportunistic sampling approach, parents and staff were then identified using snowball sampling (Ritchie et al., 2013).

Inclusion criteria:

- Young adults who were registered with the service and able to communicate their views using verbal and/or nonverbal 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 (Ritchie et al., 2013). 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 (Ritchie &