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The 'lost tribe' reconsidered: Teenagers and young adults treated for cancer in adult settings in the UK

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ABSTRACT

Purpose: Although the UK has pioneered the development of specialist adolescent cancer units, the majority of teenagers and young adults (TYAs) continue to be treated at their local hospital or at a cancer centre alongside adults of all ages. This study aimed to elicit young people's views on this experience of having cancer treatment in an adult setting.

Methods: Seventeen participants who had been treated for cancer in an adult hospital between the ages of 15 and 24 were recruited via cancer charities and social media. Telephone interviews were conducted with the participants and the resulting data were analysed using thematic analysis.

Results: Already feeling out of sync as a TYA with cancer, participants felt out of place in the adult setting. Four factors contributed to this negative experience: a lack of affinity with older patients; the challenging issues in the adult setting; the absence of empathy towards TYAs by staff; and the unsuitability of the environment for adolescents.

Conclusion: Staff working with TYAs with cancer in the adult setting should be aware of the potentially detrimental impact of this environment on this cohort of patients, and consider ways of adapting and modifying their approach.

1. Introduction

Approximately 2400 teenagers and young adults (TYAs) aged 15–24 are diagnosed with a malignancy each year in the UK (Cancer Research UK, 2017) and cancer is the leading cause of death from disease amongst this age group (O'Hara et al., 2015). Being diagnosed with cancer as a TYA generally has a worse prognosis when compared to children or older adults (O'Hara et al., 2012; Stark et al., 2015). A cancer diagnosis in the transitional years between childhood and adulthood can also have a life-changing impact (Grinyer, 2009; Zebrack et al., 2014). In terms of service provision, TYAs with cancer were once depicted as a 'lost tribe' (Michelagnoli et al., 2003) in a vacuum between adult and paediatric services. TYA oncology in the UK has since developed enormously: with the goal of improving survival rates and providing an environment supportive to the unique needs of adolescents, 28 specialist Teenage Cancer Trust units have been developed across the UK (Pearce, 2009; Teenage Cancer Trust, 2017). However two-thirds of TYAs with cancer in the UK do not access these units and are treated either at their local hospital or at a regional cancer centre alongside adults of all ages (Birch et al., 2014). This research focused upon this specific cohort of patients, and aimed to develop an in-depth understanding of the experience of TYAs in the UK who received treatment for cancer in an adult setting.

1.1. TYA cancer care in the UK

The first unit dedicated to treating TYAs with cancer opened in 1990 at the Middlesex Hospital in London (Souhami et al., 1996). TYA cancer units developed from the belief that young people undergoing treatment would benefit from the support of their peers and specialist staff, but also that concentrating young people would enable more clinical trials to be conducted and thereby impact upon treatments and survival rates (Whelan, 2003). Centralising care in the paediatric population has resulted in a marked improvement in the survival rates of children with cancer, and it was hoped that this could be replicated in the TYA population (Lewis and Morgan, 2007).

In 1995 the Calman-Hine Report (Department of Health, 1995) recommended that health authorities develop specialist units for TYAs with cancer. In 2005 the guidance *Improving Outcomes in Children and Young People with Cancer* (National Institute for Clinical Excellence,

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2005) established the Principal Treatment Centre (PTC). The guidance recommended that regardless of place of care, all patients diagnosed with cancer between the ages of 16 and 24 should be notified to a PTC, where their care could be overseen by a specialist TYA multi-disciplinary team, enabling access to clinical trials and specialist psychosocial support (Pearce, 2009; Marris et al., 2011). Thirteen NHS trusts in England have PTC status and should be accessible to all young people with cancer, although those aged 19–24 are given the choice of where to have their treatment and may opt to be treated in an adult setting (O'Hara et al., 2013).

Although identified as the ‘gold standard’ of care within the UK (Smith et al., 2016) and supported by government policy (National Cancer Peer Review - National Cancer Action Team, 2013), the evidence base supporting specialist TYA cancer units has been questioned (Smith et al., 2007; Taylor et al., 2011). The impact of these units upon survival rates has not been established, and there is a counter argument that TYAs with cancer will have better survival outcomes if treated by oncologists specializing in tumour type rather than age group (Lewis, 2005; Birch et al., 2013). There is also little research exploring the TYA experience of cancer care or their preferences around place of care (Marris et al., 2011; Taylor et al., 2013). More evidence is therefore required to support the need and policy for specialist TYA cancer units (Ramphal et al., 2011) and this research aimed to add to the evidence base regarding the preferences of young people with cancer around place of care.

2. Methods

A qualitative methodology was employed to enable participants to share their unique perspective of being a TYA having cancer treatment in an adult setting. In order to ensure rigour in a qualitative study, a self-conscious, transparent and systematic approach was adopted at all stages of the research process (Mays and Pope, 2000; Lincoln et al., 2011). The study was approved by Lancaster University's Research Ethics Committee (FHMREC 13016).

2.1. *Eligibility*

The inclusion criteria for participation were: a diagnosis of cancer between the ages of 15–24; some cancer treatment in an adult setting; aged 18 or over at the time of interview; a minimum of 6 months post active treatment; and possessing the emotional suitability to participate in an in-depth interview. The exclusion criteria were: still receiving active treatment; receiving palliative care; or non-English speaking.

2.2. *Recruitment*

An approach was taken to recruitment that was intended to be appealing to young people and circumvent some of the barriers to recruitment in this ‘hard to reach’ group (Gibson, 2008). Social media has been shown to increase participation in research with the TYA age group (Gorman et al., 2014). Fifteen organisations with a connection to TYA oncology were therefore approached and all agreed to promote the study on their Facebook and Twitter accounts, as well as on their websites, in newsletters and by word of mouth. This approach was supplemented with snowball sampling.

2.3. *Participants*

Seventeen people self-selected to take part in the research. The demographics of these participants are detailed in Table 1. Researchers often assume that anonymity is preferable, however participants do not necessarily want to be anonymous (Grinyer, 2002). All but one of the participants requested that their first name be used in any publications, in order to have ownership of their words in print. With one exception, real names have been used with participants' permission. Participants also gave permission for verbatim quotes to be used. Other identifying features, such as family name or treating hospital, have been removed.

An additional six people agreed to participate, but did not meet the inclusion criteria or later decided not to participate. Participants were spread across the 15 to 24 age range at diagnosis, and a range of malignancies was represented. Twelve participants were female and five were male. Three participants had also experienced some treatment on a Teenage Cancer Trust unit. The participants were dispersed across the UK and were aged between 21 and 40 at the time of interview.

2.4. *Data collection*

This study employed semi-structured interviews, enabling the experience of treatment in the adult setting to be broadly defined, but allowing the participant sufficient freedom to express their views and offer new insights (Silverman, 2013). Participants were offered a choice of interview options, but all opted for a telephone interview. A topic guide was developed as a basic structure for the interviews, based upon clinical experience, the findings of a literature review and a pilot interview. All of the interviews were conducted by the same interviewer (SM) and commenced with an informal, conversational phase. Participants were then asked about their cancer diagnosis and treatment, before being asked about their experience in the adult setting. The subsequent direction of the interview was not prescriptive, rather the participant was engaged in a flexible dialogue that enabled key issues to be identified and developed (Grbich, 1999). With the participants' consent, all of the interviews were audio-recorded and transcribed verbatim.

2.5. *Data analysis*

The data obtained from the seventeen interviews were analysed using thematic analysis. The aims of understanding, describing and analysing the TYA experience of cancer treatment in an adult setting corresponded with the aims of thematic analysis (Howitt, 2010). Employing thematic analysis enabled patterns to be identified and described across the seventeen interviews, which became the basis of the subsequent data analysis (Fereday and Muir-Cochrane, 2006). The six step approach developed by Braun and Clarke (2006) was followed as a broad and flexible template. Rather than using a framework or pre-existing coding frame, a data-driven approach was employed, to enable the researcher to identify and develop themes inductively from the data (Pope et al., 2000).

3. Results

The overriding finding from the interviews was that participants felt completely out of place in the adult setting. There were few confounding voices within the data as the experience of the participants was almost entirely negative. The factors contributing to this negative experience have been synthesized into four themes. The four themes are presented below, using direct quotes from the interviews to illustrate each theme.

Lack of affinity with older patients.

Despite having cancer and treatment in common, participants did not feel a sense of shared experience with other older patients:

> ‘even though we were all cancer patients or we were all kind of in the same boat, it felt very different and their needs were completely different to mine and that was the main problem - I didn't need to call the nurse to help me go to the toilet, I could do it myself - obviously they were very immobile - I was mobile’.
>
> (Jessica)

Participants also voiced a belief that older people perceived their illness differently: