



'Life then', 'life interrupted', 'life reclaimed': The fluctuation of agency in teenagers and young adults with cancer



Jane Davies*, Daniel Kelly, Ben Hannigan

School of Healthcare Sciences, College of Biomedical and Life Sciences, Cardiff University, Heath Park, Cardiff, Wales, CF14 4XN, UK

ARTICLE INFO

Keywords:

Young people
Cancer
Decision making
Agency
Trajectory
Case study
Personal agency
Proxy agency
Collective agency

Purpose: This paper presents findings from an in-depth study exploring agency in decision making when young people experience cancer.

Methods: Exploratory case studies were utilised to examine all aspects of decision making, beginning with the onset of symptoms followed by diagnosis and treatment. Interviews, observations and documentary analysis were used to generate data. Multiple sources were selected to generate further insights and these included family, partners, friends and healthcare professionals who were close to the young people during their experience.

Results: Three overarching themes were identified during analysis of the data: 'life then', 'life interrupted' and 'life reclaimed'. Key elements of these themes included a number of complex and interrelating factors which were interwoven within the everyday lives of the young people. In the 'life then' phase, 'holding on' to agency prior to diagnosis and the importance of close and intimate relationships was illuminated. In 'life interrupted', agentic power during treatment, in terms of the range of decision making and the complexity of the parental role, were prominent. In 'life reclaimed' the 'different but determined' nature of young people's behaviour and re-aligned agency was transparent as they were near to completing treatment.

Conclusions: This study has culminated in the development of a model of individual cancer trajectories relating to the fluctuation of agency during young people's cancer experiences. These trajectories could be applied in future healthcare practice.

1. Introduction

Teenagers and young adults (TYA) face multiple challenges as they make the transition to adulthood. These challenges for example, may be associated with risk taking (Kelly, 2003; Scholes-Balog et al., 2013) and commonly involve peer group issues (Davis, 2012). Moreover, family difficulties can emerge (Kelly and Emery, 2003). Alongside these experiences TYA are also in the process of gaining increased independence and autonomy. Generally TYA will begin to engage independent decision making, they may of course be guided by others such as peers, parents or other important people in their lives (Bednar and Fisher, 2003). Nevertheless, they begin a process of navigating their paths through decision making including, for example, whether they will continue with formal education or which career they might pursue. They also begin to take control of lifestyle choices which may involve differing levels of risk as well as relationship decisions. It is argued that adolescent development is centrally dependent on being able to make such choices successfully (Downs and Fischhoff, 2009).

TYA with cancer are also in the midst of these same experiences. Their individual circumstances will inevitably differ depending on their stage of development and family background, nevertheless each individual has to negotiate the path towards adulthood. Cancer is uncommon in the 16–24 year age group (Cancer Research UK, 2016). However, for those affected the disease has a significant impact on their lives as they encounter this transition to adulthood.

This paper presents findings from a study with the purpose of exploring how control over treatment and everyday decisions fluctuates in TYA with cancer. The findings result from a three-year research study involving TYA aged between 16 and 24 years who had developed cancer, their families, those closest to them and the healthcare professionals who participated in their care.

2. Background

The freedom with which TYA are able to engage in all types of decision making is governed by a number of individual variables. One

* Corresponding author.

E-mail addresses: daviesjp3@cf.ac.uk (J. Davies), kellydm@cf.ac.uk (D. Kelly), hanniganb@cf.ac.uk (B. Hannigan).

perspective from social theory, agency, provided a theoretical framework to situate the findings from this study. Agency is concerned with the ability to make free and independent choices (Bryant and Jary, 1991; Emirbayer and Mische, 1998; Giddens, 1984). The use of agency was helpful in determining the levels of control that TYA had in all aspects of decision making set against social structures such as the family, healthcare teams and the treatment protocol that could result in restricted freedom. This provided interplay between the theory of agency and the young people's experience. Agency was chosen particularly because of the changing nature of the focus of this theory, which is identified as moving between personal, proxy and collective contexts.

'Personal agency' is identified as individuals acting independently and making free choices (Bungay et al., 2011). 'Proxy agency' is demonstrated when decisions are made on behalf of another person or people (Bjerke, 2011). Finally 'collective agency' is illuminated when actions are chosen which are shared between individuals (Kippax et al., 2013). These different types of agency in decision making provided the backdrop for demonstrating the fluctuation in personal agency for TYA during their cancer experience.

Independence, autonomy and choice, which are also important in decision making, are implicit in representations of agency and have featured much more prominently as valuable features of healthcare settings, particularly during the last decade. Moreover, there is also evidence from the general literature focusing on healthcare issues and TYA (Adams et al., 2014; Hutton, 2005; Schaeuble et al., 2010; Young, 2012). Consequently, there are particular aspects of agency and the ways in which it is relevant that serve to illuminate the TYA cancer experience.

A limited number of studies have explored the issues of control in decision making in this age group. Some of these studies are not confined to the TYA age group, and instead draw on a much wider age range, including younger children (Coyne et al., 2013; Dunsmore and Quine, 1995). The paucity of background evidence presented particular challenges, therefore, in terms of the age group selected for the study. A study undertaken by Hokkanen et al. (2004) identified six categories of decision making. These included:

'Joint decision making, inadequate chances for decision making, independent decision making, illusion of decision making, reluctant to make decisions, and excluded from decision making' (pg. 325).

The number of categories identified in Hokkanen's study mirrors the ideas presented in the introduction to this paper and supports differing levels of control in decision making.

In another study findings specifically documented a loss of control in decision making during cancer treatment and detailed some of the frustration that this caused for TYA (Wicks and Mitchell, 2010). This study related almost exclusively to treatment decisions. However, the results also suggest 'benefit finding'; reflecting positive experiences from cancer which enabled TYA to make decisions about their future lives. This was a useful account of the presence of independent decision making prior to a cancer diagnosis, compared to a lack of control whilst having treatment. Despite this, positive effects were illuminated which reflected a renewed independence as a result of cancer. Additionally, there is evidence of decision making prior to achieving a cancer diagnosis (Gibson et al., 2013). Overall, however, this research base remains limited. An exploration of shared decision making from the perspectives of children, adolescents, parents and healthcare professionals (Coyne et al., 2014) provide some useful findings in relation to older children who expressed frustration at limitations on decision making as they saw them; leading to a loss of control.

Treatment decision making may be specific to a particular procedure and this issue has been examined in the literature. This includes clinical trials and decision making, parental decision making, survivorship and decision making and fertility and decision making (Barakat et al., 2014; Barnett et al., 2014; Fern et al., 2013; Kilicarslan-Toruner and Akgun-Citak, 2013; Scherer et al., 2013; Stein et al., 2014;

Wakefield et al., 2011). Time frames in relation to the cancer trajectory include; during and following the completion of treatment and, in a more limited way, the decision making experience prior to diagnosis (Gibson et al., 2013). However, gaps remain in the literature in terms of non-treatment or everyday decision making in this age group across the cancer experience. The aims of the study therefore were to elucidate:

- > The experiences of choice and control in decision making for a group of teenagers and young adults during their cancer journey.
- > The experiences of parents or carers, health or social care professionals, partners and friends relating to TYA choice and control in decision making during the cancer experience.
- > The nature of interactions involving decision making taking place in oncology outpatient settings where the TYA were receiving care.
- > The evidence within written medical notes from each of the TYA, which records, and thus contributes to, insights into choice and control in the decision making process.

3. Design

A longitudinal multiple exploratory case study design was used in this research. This enabled, as is common in this design, the selection of a small number of individual contemporary cases to be studied in depth using a range of data collection methods. Traditionally in individual case studies sample sizes do not normally reach double figures and commonly between five and seven cases are selected for study (Yin, 2009). An important facet of case study research is the opportunity to study the lives of participants in some depth, with the aim of eliciting rich accounts of individual experience. Case study research, because of the small samples required also allows for information to be collected over a period of time, from a range of sources and using a number of different data collection methods. Carrying out the study over a relatively lengthy period, also meant that interviews undertaken at different time points provided the potential to explore further the degree of agency TYA had encountered at different times during their treatment. The geographical area adopted for this study provided only a small number of potential participants who were in the selected age group. Thus the use of case study was a pragmatic attempt to ensure that participants could indeed be recruited. Full ethical approval was sought and granted from the University and the NHS sites being utilised for the study.

3.1. Participants

The sample were TYA between the ages of 16 and 24 who were selected based on the common application of these age parameters in UK service provision. This helped to provide a benchmark, especially given the recent debate relating to the age range of TYA with some commentators suggesting in terms of young adulthood, this can be as wide as 15–39 years (Geiger and Castellino, 2011). Participants were not interviewed during the first three months following diagnosis as this would have been taking place at a time when they would be managing a great deal of information and change. Other inclusion criteria further limited recruitment in this small population. This included, only TYA who were undergoing curative treatment at the time of recruitment. Those receiving palliative care were excluded as were those who did not have the capacity to consent to participation. This approach also provided the opportunity to begin by involving the young person and acknowledge them as central to the study. Following the exploration of their initial individual experience, perspectives were gathered from others who were known or related to the TYA in some way. This could include either partners or friends who had cared for them during their cancer trajectory (Gillham, 2000; Stake, 1995; Yin, 2009).

Characteristics relating to each of the five case studies can be seen in Table 1. Maximum variation was used as much as possible in recruitment of the sample to allow for potential differences in the variability of

Download English Version:

<https://daneshyari.com/en/article/8569425>

Download Persian Version:

<https://daneshyari.com/article/8569425>

[Daneshyari.com](https://daneshyari.com)