



Protecting an adult identity: A grounded theory of supportive care for young adults recently diagnosed with cancer



Louise Soanes^{a,*}, Faith Gibson^b

^a Teenage and Young Adult Cancer Service, University College Hospital, London, United Kingdom

^b Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID), Great Ormond Street Hospital for Children NHS Foundation Trust and School of Health Sciences, University of Surrey, United Kingdom

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ABSTRACT

Background: For adolescents and young adults living in high-income countries cancer remains the most common disease-related death. Increasing survival rates and projected longevity are positive outcomes, although long-term consequences of cancer and/or its treatment will likely increase the global burden of cancer. In low and middle-income countries the impact and needs of young adults with cancer are largely unknown and require further attention. However, universal studies have revealed that cancer-related needs for this group are multifactorial, complex and largely unmet. In response to these findings, the body of work on supportive care for young adults with cancer is growing. Yet, there is no published research in the context of the United Kingdom, regarding the role young adults play in managing their supportive cancer care needs.

Objective: To explore the experience, purpose and meaning of supportive cancer care to young adults recently diagnosed with cancer.

Design, setting and participants: Using constructivist grounded theory, data were collected in one to one interviews with eleven young adults (seven women and four men aged 19–24 years) being treated for cancer in two English hospitals. Data were analyzed using open and focused coding, constant comparison, theoretical coding and memoing, and this enabled construction of a subjective theory.

Results: Young adults in this study interpreted cancer as an interruption to the events, experiences and tasks forming the biographical work of their adult identity. Data analysis led to the construction of the theory, 'protecting an adult identity: self in relation to a diagnosis of cancer in young adulthood'. This theory arose from three categories: *fragility of self*, *maintaining self in an altered reality* and *mobilizing external resources*. Young adults faced the loss of their early adult identity. Interpreting cancer as a temporary interruption, they sought to re-establish their identity by directly and indirectly managing their supportive care needs.

Conclusions: These findings contribute to the understanding of young adults' desired purpose of supportive cancer care. There are also implications for how health and social care professionals provide supportive care interventions to meet the needs of this population.

What is already known about the topic?

- The impact of chronic illness on identity is widely reported.
- Young adults report unmet supportive care needs.
- Supportive care needs are more often reported in the context of assessment rather than patient experience.

- Side effects thought to be permanent had a greater impact on identity; a changed body no longer represented their identity and how others perceive them is altered.
- Young people will often appoint a family member/friend in the role of an 'emotional anchor' to support them in achieving self-management.

What this paper adds

- The purpose of supportive cancer care, for young adults in this work, is to retain their adult identity.

* Corresponding author.

E-mail addresses: lsoanes@nhs.net (L. Soanes), f.gibson@surrey.ac.uk (F. Gibson).

1. Introduction

1.1. Young adulthood and identity

Defining young adulthood is challenging, unlike adolescence whose arrival is signalled by puberty, it has no biological onset and age limits vary across the world (Geiger and Castellino, 2011). The literature suggests the purpose of this life-stage is the continuation and further exploration of identity formation that began in adolescence (Arnett, 2000; Erikson, 1968; Hill et al., 2016; Scales et al., 2015). Previously young adulthood was thought to be the privilege of those with the time, money and opportunity to test relationships and careers, prolong education, and delay marriage and parenthood (Cote and Levine, 2015; Hendry and Kloep, 2007). However, recent work suggests growing numbers of young adults across the world see changes in societal and cultural norms as opportunities for further identity exploration within the context of their circumstances (Arnett, 2016; Bay-Cheng and Zucker, 2017; Schwartz et al., 2013).

Experimentation and exploration are seen as core components in defining self-identity. McAdams's theory of narrative identity (McAdams, 1985). McAdams (2011) proposes identity begins to be shaped in late-adolescence/young adulthood. Influenced by growing independence and widening social interactions it is selectively modelled into a narrative construction of past events, present circumstances and an imagined future. Studies reveal young adults facing significant events who are able to construct narratives featuring personal agency and redemptive meaning have higher levels of mental health and wellbeing than those who can't (Cote and Levine, 2015; Hammond and Teucher, 2017; McAdams and McLean, 2013).

1.2. Cancer and young adulthood

Applying the increasingly accepted age range of 15–39 years an estimated 1 million young adults are diagnosed with cancer around the world each year (Ferrari and Barr, 2017). Unique biomedical characteristics result in a broad range of cancer diagnoses in this population (Richter et al., 2015). In late adolescence/early adulthood testicular germ cell tumours, bone sarcomas and Hodgkin's lymphoma peak, but cancers common in children, for example, acute lymphoblastic leukaemia can also occur. In adulthood, an increase in the incidence of adult cancers such as breast and colorectal cancer is seen. The aetiology of these cancers is largely unknown; although relationships with human papilloma virus, ultra violet light and certain inherited genetic conditions have been described (Cust, 2011; Tricoli et al., 2017). Due to the low incidence of co-morbidities, young adults are able to receive intensive treatment; subsequently, the severity of their acute and chronic consequences of treatment is reported to be higher than those for children or older adults (Prasad et al., 2015).

1.3. The impact of cancer on young adults

A diagnosis of cancer, its treatment and the long-term consequences are known to be disruptive to the social and personal maturation processes involved in young adult identity formation (Kim et al., 2016; Patterson et al., 2012, 2015). Although resilience (Bellizzi et al., 2012) and post-traumatic growth are described (Penn et al., 2017), evidence suggests young adults are at risk of distress, depression and anxiety (Lang et al., 2015; Warner et al., 2016) and their psychosocial needs are often described as underestimated or unmet (Lauer, 2015; Zebrack et al., 2014). Key predictors of unmet need include lack of social support (Tremolada et al., 2016), poor access to age-appropriate care (Cheung and Zebrack, 2017) Sawyer et al., 2017 and being in the first year from diagnosis (Bibby et al., 2016; Zebrack et al., 2014).

The impact of chronic illness on identity is widely reported (Bury, 1982; Charmaz, 1983, 1994, 2016). For Bury (1982), personal biography is disrupted by the loss of physical confidence and a subsequent

decline in social interaction. Later, Bury (1991) describes how an active response to chronic illness, through treatment and biographical adjustment, can reconnect the identity before illness to the present and perceived future self. Alternatively, Charmaz (1983, 1994, 2016) considers the experience of chronic illness to be more insular the loss of physical confidence and an assumed life resulting in uncertainty and loss of present and future self-identity. Adjustment work focuses on adapting to a new identity rather than re-connection (Charmaz, 1983, 1994). In her work with young adults, Grinyer (2007) reports long-term effects on biographical work due to cancer including; disruption to body image; relationships; education; and work. Findings mirrored in contemporary work (Iannarino et al., 2017; Matheson et al., 2016). The pattern of recurrent biographical disruptions caused by chronic illness occurring concurrently with normal age specific-stage transitions can have a double impact on young adults' biographical work (Saunders, 2017): these findings may also be applicable to young adults for whom cancer treatment and/or its consequences can last for years.

In the United Kingdom (UK), approximately 700 young adults aged 19–24 years are diagnosed with cancer per annum, with an overall survival rate of 84% (Cancer Research UK, 2016). To meet their needs, and those of teenagers aged 16–18 years, an age-appropriate bio-psychosocial network of support involving the National Health Service (NHS) and third sector providers is available (National Institute for Health and Clinical Excellence (NICE), 2005). This network aims to mediate many of the challenges young adults with cancer face, however; access to these services remains variable. As a result, the diagnostic and treatment pathway for this group is an emerging picture (Gibson et al., 2017; Furness et al., 2017). There is limited qualitative work describing young adults' experiences of care soon after diagnosis and little is known how they define their needs or seek support. To inform service development and address these limitations a qualitative research study was undertaken to explore the supportive care experiences of young adults living with cancer soon after diagnosis.

2. Methodology

Grounded theory is defined as the inductive, abstraction and conceptualization of data through a systematic, constant comparative method of simultaneous data collection and analysis to establish a theory (Charmaz, 2012, 2014; Glaser and Strauss, 1967). From its origins, it has been used to construct theory on issues of importance to people's lives (Glaser and Strauss, 1967). In choosing which variation to use the philosophical and practical approach of both classical and constructivist grounded theory were considered.

Seeing the researcher as independent from participants and as an observer without preconceptions (usually taken to mean without reference to literature) classical grounded theory is often defined as positivist (Hallberg, 2006). Later the researcher's perspective is acknowledged, indeed Glaser (1978) suggests the researcher interview themselves and this is included as data, so a shift to post-positivism occurs (Hallberg, 2010). In contrast, the researcher is central to constructivist grounded theory; their participation is seen across data collection, analysis and theory construction (Charmaz, 2014), creating a relativist and pragmatic methodology (Higginbottom and Lauridsen, 2014).

In both approaches, data collection and analysis are systematic, recursive and hierarchical limiting theory generation until categories and the relationships between them are developed (Charmaz, 2012, 2014; Glaser and Strauss, 1967). However, there are philosophical and contextual differences; one example is the use of published work. In classical grounded theory the use of literature is accepted. Initially, this should be broad, to prevent preconceptions and forcing of data (Glaser, 1992). Later, professional literature is used to compare, test and challenge emerging theories (Glaser and Strauss, 1967). In contrast, constructivist grounded theory allows professional literature to be reviewed before research begins and throughout data analysis and theory

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