



Understanding the experiences of adolescents and young adults with cancer: A meta-synthesis



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ARTICLE INFO

Article history:

Received 28 October 2015

Received in revised form

7 June 2016

Accepted 15 June 2016

Keywords:

Adolescent

Young adult

Cancer

Neoplasms

Meta-synthesis

Qualitative research

Experience

ABSTRACT

Purpose: To conduct a meta-synthesis of qualitative studies exploring experiences of young cancer patients to identify the overarching concepts that inform future service and research directions.

Method: A systematic literature search was conducted, and 51 articles published between January 2004 and March 2014 were collected via CINAHL, Medline and PsycINFO databases. Deductive thematic analysis was conducted to identify major themes, guided by Hermeneutic notions on interpretation.

Results: Cancer impacted a wide range of life domains. These impacts were interconnected and bi-directional. The meanings of these impacts were closely related to their unique developmental needs and a social position as youth. Emotional struggles during these radical changes were evident, but efforts to make sense of their experiences and find meaning pervaded.

Conclusions: Given the interrelated nature of the cancer challenges young cancer patients experience, there needs to be an emphasis on conducting studies which further refine our understanding of these relationships. This can help to structure effective youth cancer services. Generic informational resources and support services should be tailored so that they have relevance to the young person's life context. The treating team has an important role in fostering young patients' ability to make sense of their experiences by providing developmentally-relevant psychosocial support.

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1. Introduction

Adolescents and young adults with cancer (AYA), also referred to as Teenagers and Young adults with Cancer (TYA), are now recognized as constituting a distinct group, with biological differences and various unique psychosocial impacts that warrant specialized health care (Bleyer et al., 2008; Sender, 2011; Zebrack, 2014).

In response, there has been international initiatives taken by a number of government and non-government bodies to improve the care of AYAs. These initiatives emphasized the holistic nature of AYA cancer care, while their first-hand experiences and needs provide the pivotal guidance required for these services (Mathews-Bradshaw et al., 2011; Cancer Australia, 2008; Osborn et al., 2013; Ferrari, 2013; Fern and Whelan, 2013; Johnson, 2013). In

response, key stakeholders have recognized the importance of reflecting on the experiences and needs of this group in their care (Rajani et al., 2011). Drawing on their experiences, qualitative studies were conducted to inform and shape the service delivery (Miedema et al., 2013b; Palmer et al., 2007; Rabin et al., 2011; Taylor et al., 2008; Thompson et al., 2009).

Given the contributions made by the qualitative findings to the care of AYAs, it is important to revisit these findings as a whole in order to identify overarching themes and trends that can inform the care for and service provision to AYA.

1.1. Meta-synthesis

Meta-synthesis is a research method where the qualitative findings relevant to a phenomenon being investigated are reviewed and analyzed in order to produce a new integrative understanding of a given subject (Zimmer, 2006). It is a useful approach when exploring relationships between various dimensions of a particular topic, or identifying overarching mid-range theory which cannot be

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elucidated by reviewing a single study (Finfgeld, 2003; Wong et al., 2013; Zimmer, 2006). It also allows conceptions and mid-range theories to emerge from those people who contributed to the studies (Zimmer, 2006), thereby producing practical evidence to inform service delivery.

The current paper presents a meta-synthesis of qualitative AYA cancer research identified through a systematic search of the literature. By doing so, the current paper offers a comprehensive review of these findings and overarching themes emerging from them. This paper also discusses how these overarching themes can be translated into practice. Finally, it identifies methodological issues and knowledge gaps in current qualitative AYA cancer research.

2. Aims

The aims of the qualitative meta-synthesis were to: firstly, develop a comprehensive synthesis of qualitative AYA cancer research to inform clinical practice; secondly, inform future research directions and project development; and thirdly and finally, identify and describe methodological issues and the knowledge gaps in current qualitative AYA cancer research.

3. Design

3.1. Search methods

Three electronic databases were searched - CINAHL, Medline, and PsycINFO - and limited to peer-reviewed articles published in the English language between January 2004 and March 2014. The literature search was conducted by the first author. The search protocols were repeated several times to ensure that all studies meeting the criteria were included for the meta-synthesis. In each database, searches for terms defining the population, the disease, and the methodology were retrieved and combined. As an example, the search algorithm used for Medline is presented as follows: (a) the population-limiting terms included [teen\$, adolescen\$, youth\$, young\$, young adult\$ or emerging adult\$] in title; (b) the disease limiting terms included [cancer] and [malignanc\$] in title; and (c) the methodology was limited by using the filter 'Qualitative' under clinical queries with 'maximizes sensitivity'. As a secondary measure to capture qualitative studies, the keywords of [qualitative] and [experience\$] were searched in title and abstract. Manual search involved snowballing strategies including reference lists reviewing, author tracing, and reviewing related articles until no additional articles were identified.

To limit the age group, using the keywords deemed more appropriate than limiting it by MeSH terms of 'adolescent' and 'young adult' for two reasons. First, the scope of MeSH term 'young adult' is limited to the population aged between 19 and 24 when many AYA cancer studies now extend participants' age to their late 20 s. Second, using those MeSH terms did not limit to studies specifically targeting AYAs, but also partially included AYAs, consequently lacking sensitivity.

3.2. Inclusion and exclusion criteria

Inclusion criteria were original research papers illustrating any domains of qualitative descriptions of AYA cancer patients' own accounts of their experiences with cancer. The inclusion criteria for the participants' age parameter was set at 10–40 years of age. This was because the consensus as to what age range is appropriate for AYA cancer research has not been met, and many studies had been conducted on this basis (Barr et al., 2011). This means that setting a narrow age range as an inclusion criterion can under-represent the

existing qualitative findings on the experiences of AYAs. The lower age limit can range from 13 to 15 while the upper age limit can range from 24 to 39, depending on the geopolitical contexts of the study. To accommodate study findings in varying geopolitical contexts, this meta-synthesis incorporated studies if they included participants aged between 10 and 40, and discussed its findings in relation to other existing AYA or TYA literature.

Exclusion criteria were articles in which: (a) the majority or all participants were childhood cancer survivors, (b) experiences were described by families or friends, (c) research methods were not articulated (e.g. editorials), and (d) children under the age of 10 were included.

3.3. Search outcome

Following the search of databases, the resulting 1387 articles were screened by title, and abstracts were reviewed when further information was required. The primary reasons for the studies not meeting the inclusion criteria were: (a) lack of specificity to the targeted age group, (b) data not being a first-hand experience of AYA (e.g. family members' experiences, or family describing AYA's experience), and (c) qualitative investigation undertaken to evaluate an intervention, therefore not capturing a naturally occurring experience of AYAs.

Several studies used the term 'younger' as an intention to make a distinction from the older population, in which case they did not situate the findings in the context of AYA cancer research. These studies were excluded. If parts of an article contained narratives of family members, we included the article but extracted only the narratives and findings regarding young people with cancer.

The screening algorithm is presented in Fig. 1, and a summary of the included studies is outlined in Table 1.

3.4. Quality appraisal

Quality appraisal was guided by the Critical Appraisal Skills Programme (CASP) tool (Critical Appraisal Skills Programme, 2014). This tool has been utilized widely in quality assessments of qualitative studies in many contexts (Angus et al., 2015). It provides ten appraisal domains with prompt questions to determine the logical and coherent flow of the research process, ethical compliance, as well as the theoretical and practical contributions to the field. The quality was rated as strong, moderate, or weak, terms which are included in the summary table (Table 1).

3.5. Data abstraction and synthesis

There were two levels of interpretation. The first level focused on identifying categorical themes through deductive thematic analysis. The second level focused on identifying implicit links and commonalities across studies to identify overarching concepts.

For the first level of analysis, the first author read the included studies to become familiar with the body of literature. The first author then returned to the data to produce exhaustive code lists. Once no more new codes were noted, the first author returned to the data and noted coherent stories within these codes and grouped them into a larger unit of themes. The first author repeatedly went back and forth between the study findings and preliminary themes for refinements. No data extraction was carried out, in an effort to examine the data within the context of a particular study. For the second level of analysis, the first author went back to the data and focused on identifying implicit links and commonalities across included studies. This led to conceptualization of overarching concepts.

Once these two levels of analysis were completed by the first

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