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The experience of acute leukaemia in adult patients: A qualitative thematic synthesis

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ABSTRACT

Purpose: The aim of this review was to systematically identify and synthesise all qualitative evidence on how adult patients diagnosed with acute leukaemia experience living with their illness.
Methods: A systematic search strategy was developed comprising of two search strings: i) acute leukaemia and ii) qualitative methodology. The search strategy was run in seven electronic databases (Medline, CINAHL, PsychINFO, EMBASE, BNI & Archive, SSCI and ASSIA). Nine qualitative studies in adult patients with acute leukaemia, published in peer reviewed journals between 01/1990 and 01/2013 were included in the final sample.
Results: The qualitative thematic synthesis resulted in the development of a conceptual model describing a person's path to build a renewed self. Following the initial blow of diagnosis with the range of initial reactions, patients with acute leukaemia are living in a contracting world; they have to deal with the life in hospital, the several losses and the impact of their illness on their emotions and interpersonal relationships. Several factors take up a buffering role at that stage: coping, support, information and hope. Finally, patients accommodate acute leukaemia in their lives through re-evaluating personal values and assigning new meaning to their experience.
Conclusions: Results from this thematic synthesis are indicative of the impact of acute leukaemia on patients' lives and the processes they use to make sense and accommodate the illness in their life. Increasing our understanding of these processes is warranted to improve patient care.

Introduction

Latest worldwide incidence rates for all types of leukaemia are estimated at 350,434 new cases, while there are approximately 257,000 leukaemia-related deaths (Ferlay et al., 2010). Acute leukaemia refers to a group of haematological malignancies characterised by an increase in the number of myeloid cells or lymphocytes in the bone marrow and an arrest in their maturation, resulting in haemopoietic insufficiency with or without leukocytosis (Cornell and Palmer, 2012; Ferrara and Schiffer, 2013; Meenaghan et al., 2012). There are two main types of acute leukaemia: acute lymphoblastic leukaemia (ALL) and acute myeloid leukaemia (AML); these are further classified according to cellular maturity (Cornell and Palmer, 2012; Meenaghan et al., 2012). AML is the most common form of acute leukaemia in adults and its incidence increases with age (Cornell and Palmer, 2012). ALL is the most common form of leukaemia in childhood, with a secondary increase after the age of 40 years (Cornell and Palmer, 2012; Shaw et al., 2004). The advancements in treatment, molecular profiling and supportive care of leukaemia have increased overall 1-year survival to 64.5% and 5-year survival to 44% of all diagnosed cases (Ferrara and Schiffer, 2013; UK).

As patients with acute leukaemia require prolonged and intensive chemotherapy treatment in the hospital, the impact of their illness on their lives can be profound. Living with leukaemia can challenge their physical, emotional and psychological well-being and functioning (Oliva et al., 2011; Redaelli et al., 2004; Schumacher et al., 1998). Moreover, quality of life has been shown to be mostly affected during the period of active chemotherapy treatment and within the first months after bone marrow transplantation (Hjermstad et al., 1999; Persson et al., 2001; Schumacher et al., 1998, 2002; Tschuschke et al., 2001). At this period, receiving social support has been shown to increase survival (Pinquart et al., 2007).

Understanding patients' experiences of acute leukaemia and the meanings they ascribe to them can help to support patients' coping

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processes (Steeves, 1992; Xuereb and Dunlop, 2003). Synthesising the available evidence deriving from primary qualitative studies has the potential to provide a more in-depth and coherent understanding of patients' experiences (Dixon-Woods and Fitzpatrick, 2001; Flemming, 2010; Sandelowski and Barroso, 2007; Tong et al., 2012) as well as to inform care provision.

The aim of this review was to systematically identify and synthesise qualitative evidence on how adult patients diagnosed with acute leukaemia experience living with their illness. Reporting of this thematic synthesis follows the guidelines for Enhancing Transparency in Reporting the synthesis of Qualitative research (ENTREQ) statement (Tong et al., 2012).

Methods

Research question

The research question of this qualitative thematic synthesis was the following: how do adult patients with acute leukaemia experience their illness?

Synthesis methodology

The method selected for analysing the qualitative material was the thematic synthesis approach by Thomas and Harden (2008). Thematic synthesis is an approach that combines elements from meta-ethnography and grounded theory and allows methodologically heterogeneous studies to be synthesised (Barnett-Page and Thomas, 2009; Thomas and Harden, 2008). It is philosophically underpinned by critical realism according to which the "knowledge of reality is mediated by our perceptions and beliefs" (Barnett-Page and Thomas, 2009). The end synthetic product has the added value of informing policy makers and health care practice.

Search strategy

In order to ascertain that the relevant literature on the chosen topic would be accessed, a sensitive systematic search strategy was developed and run in seven electronic databases: Medline, CINAHL, EMBASE, PsychINFO, BNI & archive, SSCI and ASSIA. The strategy consisted of two strings combining free text terms, thesaurus terms and broad-based terms (Flemming and Briggs, 2007): one for qualitative methods, based on the Rochester qualitative filter adapted by Jones (Jones, 2004) and one for acute leukaemia, created initially for Medline and then adapted for the rest of the databases. The search strategy can be found in the Appendix provided.

Study eligibility criteria

Papers were included in the study if the following criteria applied:

- Studies using qualitative methods to elicit patients' in-depth experiences of acute leukaemia.
- Study samples of adult patients (>18 years of age) diagnosed with acute leukaemia.
- Published in peer reviewed journals.
- Time period: 01/1990–01/2013 (updated from 10/2010–01/2013).
- English language.

Due to time constraints grey literature, conference abstracts and thesis dissertations were excluded from this review.

Screening process

The electronic search was initially conducted in November 2010; however in order to keep the synthesis up-to-date with research being conducted, the search was repeated in 01/02/2013 to identify new studies published until January 2013. Aggregated results from both searches are reported in Fig. 1. The search yielded 15,125 papers. Following the screening process, the final sample consisted of seven original articles reporting six studies conducted exclusively with patients with acute leukaemia (Bertero and Ek, 1993; Farsi et al., 2012; Friis et al, 2003; Koehler et al., 2011; Koenigsmann et al., 2006; Meenaghan and Dowling, 2010). The authors decided to also include two additional studies, which also included patients with chronic leukaemia but where at least 75% of the sample were patients with acute leukaemia (Bertero, 1998; Persson and Hallberg, 1995). The reference lists from the ten included studies were then hand-searched. Further searches were conducted across all seven databases using the authors' names from the ten relevant papers as keywords. Additionally, archive, hand searches were performed in three selected journals (*Leukaemia research, Psycho-oncology, Qualitative Health Research*). Finally, authors from the included studies were contacted by email and asked if they were aware of any other relevant studies or if any relevant papers were in press. None of these additional search strategies yielded new articles.

Appraisal process

As there is no consensus on a list of criteria by which to appraise qualitative evidence, three different methods were employed, to enhance rigour: a guide proposed for reading qualitative articles (Sandelowski and Barroso, 2007), a validated scoring system (Hawker et al., 2002) and a typology for classifying findings (Sandelowski and Barroso, 2007) (Table 1). Appraisal of all selected papers was carried out by CP; a subsample ($n = 3$) of articles was independently appraised by BMJ and MTH. Independent scores were cross-checked for consistency, and any differences were resolved within the team. All papers were considered to be of reasonable methodological quality and included in the final synthesis (Table 1).

Data management

The thematic synthesis was guided by the steps described by Thomas and Harden (2008). The first stage of analysis included free sentence-by-sentence coding of all passages under the heading "findings" or "results". At the end of this process all members of the team ensured that all text corresponded at least to one code and were consistently interpreted. In the second stage one reviewer (CP) looked for similarities and differences between the free codes from the previous stage. In that way the free codes were organised in hierarchical order under a range of descriptive themes. These were subsequently discussed and agreed upon within the team. For these two stages of the synthesis the computer software NVivo©8 was used to facilitate the process. In the final synthesis stage the development of four analytical themes occurred, by further conceptually organising the descriptive themes, in an effort to answer the research question.

Results

Description of the final sample

A summary of the characteristics of the articles reviewed is provided in Table 2. The final sample for this thematic synthesis