



Childhood leukaemia survivors' experiences of long-term follow-ups in an endocrine clinic – A focus-group study



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ARTICLE INFO

Article history:

Received 10 March 2016
Received in revised form
30 September 2016
Accepted 31 October 2016

Keywords:

Childhood acute lymphoblastic leukaemia
Focus group
Long-term follow-up
Endocrine clinic
Late complications

ABSTRACT

The survival rate after childhood cancer has improved markedly and today more than 80% of patients will survive. Many childhood cancer survivors suffer from late complications due to radiotherapy and chemotherapy. Survivors of Acute Lymphoblastic Leukaemia (ALL), treated with cranial radiotherapy, are at a particularly high risk of having endocrine complications.

Purpose: To illuminate childhood ALL survivors' experiences of a long-term follow-up in an endocrine clinic.

Method: Data collection carried out using semi-structured focus-group interviews. Fifteen ALL survivors were included in the study, divided into 4 groups. Data was analysed with conventional qualitative content analysis.

Results: The survivors' experiences were captured in the theme: “*The need for understanding and support in order to manage daily life*”. An understanding of their situation, as well as support for managing daily life was fundamental. Lack of understanding and support from the community was connected with a fear for the future. The follow-up at the endocrine clinic was shown to be crucial for increasing the survivors' understanding of late complications. The past feeling of being out of control was replaced with an increased self-confidence.

Conclusion: Many leukaemia survivors experienced their daily lives as a struggle and as a complicated issue to cope with. The theme “*understanding and support to manage daily life*” mirrors how the survivors are in need of knowledge and support in order to handle and understand their complex situation after surviving leukaemia. Offering understanding and support with a holistic approach, may be a way in which to strengthen the survivors' health.

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1. Introduction

The survival rate after childhood cancer has improved markedly and today more than 80% of patients with a paediatric malignancy will become 5-year survivors (Howlader et al., 2011). Today one in every 1000 young adults in developed countries is a childhood cancer survivor (Olsen et al., 2009). However, this story of success often has an unpleasant outcome. During the past years, it has become evident that many childhood cancer survivors suffer from late complications due to radiotherapy and chemotherapy. Endocrine complications are among the most commonly diagnosed

chronic conditions in childhood cancer survivors (CCS) (Link et al., 2004; Brignardello et al., 2013). It is established that the largest childhood cancer group, the Acute Lymphoblastic Leukaemia (ALL) survivors, exposed to cranial radiotherapy, not only run a particularly high risk of having endocrine complications, but also of metabolic complications (Link et al., 2004; Follin et al., 2010) and cognitive dysfunction (Link et al., 2006). Today, the use of radiotherapy to treat ALL has been reduced to avoid these late occurring complications. Nevertheless, cranial radiotherapy (CRT) was a crucial part of an effective multimodality therapy to treat as well as prevent the spread of ALL, which means that everyone diagnosed with ALL during the 70s and 80s received CRT. Psychosocial problems including depression, suicide attempts (Lund et al., 2015; Lansky et al., 1986), negative moods, anger and confusion (Zeltzer et al., 1997), may develop as consequences of these complications. Many survivors also experience fatigue as having a negative

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impact on their daily lives (Langeveld et al., 2000). The survivors also report concerns regarding insurance and financial burdens (Zebrack et al., 2007). Studies have shown that CCS need information regarding psychosocial support and social advocacy (Zebrack and Isaacson, 2012). Thus, the challenge is to guide the survivors through the potential late complications and offer care designed to meet their specific needs in order to optimize their quality of life.

Previous studies have found that 75% of the survivors are unaware of potential late complications after illness and treatment during childhood (Kadan-Lotick et al., 2002). Information about potential risks is essential in order to achieve an independent life and to engage in healthy behaviour, such as regular physical activity. Survivors also report a lack of adherence to recommended screening programmes and medical examinations, which places these survivors at a particularly high risk for a chronic condition (Krull et al., 2011). Thus, having a holistic approach, tailored to their specific needs is crucial for their future well-being and quality of life. Survivors who report more late complications have a greater need for follow-up care compared to survivors who were less affected by past treatment and disease, and women rate follow-up care as more important than men (Michel et al., 2009). CCS need a long-term relationship with qualified health-care professionals and it has been suggested that CCS should be offered life-long follow-up care. However, this is not always a realistic scenario (Johnson et al., 2004). The success of the model of follow-up care depends on the survivors' attendance, which is associated with the survivors' preferences and understanding. (Friedman et al., 2006; Absolom et al., 2006).

There is a current lack of information about survivors' experiences of follow-up methods, and their knowledge of late complications (Earle et al., 2005; Gibson et al., 2005). In addition, the lack of existing resources for follow-up in adult life is also a realistic scenario for some survivors.

Health-care providers need more knowledge about how these survivors experience follow-up care, and how such care may influence the survivors' life situations as adults, in order to be able to optimize and adapt the follow-up according to the survivors' needs. Therefore, this study aims to illuminate childhood ALL survivors' experiences of long-term follow-ups, 33–38 years after ALL diagnosis, in an endocrine clinic.

2. Method

2.1. ALL survivors and context

The Late Effects Clinic of the Department of Oncology at Skåne University Hospital in Sweden refers childhood cancer survivors treated with cranial radiotherapy and total body irradiation to the Endocrinology Clinic. At the Endocrinology Clinic, the survivors are tested for endocrine disorders and the most frequent conditions are pituitary insufficiency, hypogonadism and hypothyroidism. The ALL survivors are provided with an endocrine nurse, specialised in late complications after childhood cancer, who plays a key role in the care of the survivors. When diagnosed with an endocrine disorder the annual follow-up of late complications consists of visits to an endocrinologist and the nurse. In Lund in Sweden we have a late effect clinic, but with very limited resources. Those patients who are referred to the endocrinology clinic receive all of their late effects care, including the endocrine follow up, coordinated with the late effects clinic to ensure that no important monitoring is overlooked. As the survivors with endocrine complications often suffer from psychosocial problems the endocrine clinic aims to provide a broad care with a nurse as a coordinator.

2.2. Ethical consideration

The study was conducted in accordance with the Helsinki Declaration and was approved by the Regional Ethics Board, Lund, Sweden (Reg. no. 2014/392).

2.3. Recruitment and participants

Adult ALL survivors who had participated in the follow-up at the Endocrinology Clinic at Skåne University Hospital for a minimum of 5 years, and who were living in the south of Sweden were considered to be eligible for the study. Thirty survivors were identified and were sent an information letter about the study including an informed consent form to be signed and returned if they were willing to participate. Two weeks later the authors phoned the patients to give further information about the study and to ask them if they were willing to participate in the interviews. A total of 15 survivors participated in the present study. Nine survivors declined participation due to a lack of time, four survivors due to a fear of talking in front of others, and two failed to come to the interviews. The survivors median age at interview was 38 years and they were interviewed in median 35 years after ALL diagnosis. All survivors were treated with cranial radiotherapy and chemotherapy, according to the common protocols of the Nordic countries (Gustafsson et al., 1981), at the Children's Hospital Lund in Sweden. Demographic characteristics and received treatment are shown in Table 1.

2.4. Data collection

During data collection, we conducted four focus-group interviews with between three and four respondents in each group (see Table 2). The interviews lasted from 90 to 120 min and were conducted in a separate room at the hospital library. The authors took into account variations in sex and age among the ALL survivors when planning the interviews. However, the survivors also had the opportunity to request a specific interview occasion to which they preferred to attend.

A semi-structured interview guide was used in order to facilitate focus on the aim of the study. The moderator concentrated on helping the respondents focus on the topic. The observer assisted by asking probing questions and taking notes and by having follow-up discussions that needed clarification during the interviews. The observer concluded the interview by giving a short summary thereof (Krueger and Casey, 2009). The interview started with an open question: "How would you describe your experience of the follow-up clinic at the Endocrinology Clinic in Lund?" Areas that the authors aimed to highlight were: "What do you believe is the purpose of the follow-up?", "How is your experience of the follow-up clinic and its impact on your situation?"

2.5. Data analysis

The interviews were recorded as a data file and transcribed verbatim. Data were analysed by means of a conventional qualitative content analysis (Hsieh and Shannon, 2005). The two authors who conducted the interviews analysed them all together with a co-examiner who had not been involved during the focus-group interviews. The analysis was carried out in several steps. The first step included reading the text as a whole to gain a general understanding of it. In the second step, the text was read again, word for word, with a focus on identifying codes that captured key concept and thoughts. As the analysis proceeded, labels for codes emerged that were reflective of more than one key thought, and together the codes resulted in the initial coding scheme. Codes were then sorted

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