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Follow-up care for childhood cancer survivors: A focus group analysis

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Abstract

Follow-up of survivors of childhood cancer is recommended to improve detection of late-effects, and provide individuals with information and advice. This study aimed to follow-up survivors of childhood cancer and report on their attitudes to current follow-up methods. Twenty-six survivors (13–25 years) of childhood cancer and their parent(s) attended focus groups ($n = 7$) to discuss views about follow-up care. Transcripts were analysed using interpretative phenomenological analysis (IPA). Three themes were identified: strategies to achieve a normal life (through playing down possibility of late-effects or careful monitoring of health); expectations about follow-up (facts and information, advice about self-care, everyday living, and psychosocial consequences) and preferences for different models of care. Given that some families had reservations about the benefits of follow-up, it is important that services address survivors' interests and meet their expectations. Changes to service delivery must take account of individual needs and expectations. Possible limitations of focus group methods (recruitment, bias reduction, methods of analysis and influence of other participants' views) are discussed.

Keywords: Childhood cancer; Survivors; Focus groups; Interpretative phenomenological analysis; Models of care

1. Introduction

Current figures suggest survival rates in childhood cancer approaching 80%, depending on the specific form of the disease. Survival rates for some cancers (*e.g.* retinoblastoma) currently approach 95%, although remain lower for some brain tumours and other rare cancers [1]. Innovations in medical and nursing care, and establishment of national and international randomised clinical trials, have contributed to improved survival rates [2]. However, treatment of childhood cancer, involving combinations of chemotherapy, radiotherapy and surgery, can be associated with significant morbidity in later life [3]. In practice, almost all systems of the body may be adversely affected by some aspect of cancer treatment [3]. The challenge is to sustain and improve current survival rates whilst optimising quality of life.

As many as two-thirds of survivors are unaware that treatments for a previous malignancy can lead to serious health problems in the future [4]. Information about potential risks is thought valuable in order to promote autonomy and independence in decision-making [5], but care needs to be taken to avoid unnecessary anxiety. The hope is that survivors who are aware of their individual risks will be more likely to

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attend follow-up care and screening [6], self-monitor health and engage in healthy behaviours [7]. For the clinician, follow-up also offers the chance to document late-effects and modify future protocols to reduce risks for future patients.

Given the risks of late-effects, there have been calls for increased and improved screening, education and treatment for children who are at risk of late-effects [8]. Provision of follow-up services is fragmented and variable [9], and many survivors do not receive appropriate care [4,10]. Barriers to attendance have been categorised as survivor related (lack of knowledge; financial costs); psychological (anxiety about being diagnosed with cancer again); health provider related (lack of trained personnel with wide ranging specific skills needed); and health system related (lack of insurance or availability of programmes). These findings highlight the need to understand follow-up from survivors' perspectives [11]. At the same time, differences in organisation of care in the US limit piecemeal application to the UK.

Survivors hold different views from their parents about the reasons for, and importance of, follow-up. Further, those who understand more about the reasons for follow-up are more positive about attendance [12]. On the assumption that organisation of follow-up services must take account of survivors' views, we conducted a series of focus groups involving survivors and parents. Our aims were to describe advantages and disadvantages as perceived by survivors, and identify differences in views between parents and survivors.

2. Patients and methods

2.1. Sample

Inclusion criteria were survivors of childhood cancer who were off treatment for at least 5 years; currently well and in remission; English speaking; and with no learning disabilities. The sample included 26 (10 males) survivors of childhood cancer (age range = 13–25 years, mean = 22 years) and one or both of their parents ($n = 33$). Diagnoses included central nervous system (CNS) tumours, Germ cell tumours, acute lymphoblastic leukaemia (ALL), acute myeloid leukaemia (AML), Wilm's tumour, and lymphoma. The mean age on diagnosis was 4.6 years (age range = 1–12) and mean length of treatment was 71 weeks (range = 19–230). Time since the end of treatment was 12 years (range 7–16). One individual had previously relapsed but was currently in remission. Six survivors attended follow-up every 2 years, 18 annually and 2 were currently attending every few months.

2.2. Procedure

Approval to conduct the study was obtained from the local Ethics Committee. Three hundred and twenty eligible survivors were identified from medical records, and were informed about the study by letter. Those interested were invited to telephone research staff for more information. This procedure resulted in a relatively low response rate (8%). There were no demographic or clinical differences between participants and non-participants. Those who responded but chose not to participate cited anxiety about talking with others and concerns about recollecting the experience as explanations.

The groups ($n = 7$) consisted of between 4 and 6 participants and were run by a facilitator and co-facilitator (CE and EE) in a room in the university. Primarily for family convenience, to reduce anxiety and to simplify travel arrangements, focus groups included both parents and survivors together. Recommended procedures for conducting focus groups were followed [13]. Survivors and their parents were first given the opportunity to ask questions about the study. Focus groups were tape recorded with written permission from all participants. Themes for discussion included: understanding of reasons for follow-up; what they liked and did not like about follow-up; views about current and future health; and knowledge of late-effects, feedback and communication.

2.3. Treatment of data

Tapes were transcribed and analysed using interpretative phenomenological analysis (IPA) 14. This is a method developed to understand the subjective experience of an individual and the cognitions and emotions that underlie their views about particular subjects, with the emphasis on personal attitudes and perceptions. IPA is a data driven analysis that results in identification of themes rather than frequency counts (content analysis). The small samples typically used in focus group work limits the value of including frequencies of individual statements and themes.

In practice, analysis involved the following steps:

(i) Each transcript is read several times, noting all examples of meaning, comments and views; (ii) these examples are then grouped into themes based on their inter-relationships; (iii) themes are further grouped to create 'super-ordinate themes' for the purpose of clarity in explaining the data; (iv) transcripts are independently coded by a second researcher and discrepancies resolved by discussion; (v) a reflexive diary was used to ensure awareness of previous statements, conversations threads, disagreements and opinions and tried to limit researcher bias by focusing the discussion round general themes rather than using structured questions.