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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.

3. Results

The analysis resulted in identification of three superordinate themes:

1. Strategies to achieve normal life.
2. Expectations of follow-up.
3. Preferences for different models of care.

3.1. Strategies to achieve normal life

Achievement of normal life is important to all survivors, but we identified two basic approaches. These included blunting information about late-effects and playing down the importance of follow-up; or careful monitoring of health, including placing considerable value on clinic attendance.

Thus, some wanted to forget all about it, discontinue follow-up and move on: '*At some point I think a line has to be drawn under it- the child is cured*'; '*if there were any late-effects, we would know by now, therefore it carries less and less weight*'. Without exception, families praised the medical care received on diagnosis, but this was contrasted with the more clinical and procedural nature of follow-up appointments: '*mechanical process – boxes to be ticked*'. Some parents implied that follow-up was minimal and inconsequential: '*you only get weighed and measured don't you, that's all*'.

Parents knew late-effects could occur many years after the end of treatment and that little is known about the exact risks: '*you could have a lull in the middle and then 10 or 15 years down the line … you would pick that up before it gets going*'. Attendance was therefore important for early identification and treatment of any late-effects: '*they already picked something up twice that the drugs have caused, not actually from the illness itself but the treatment she was given*'. Despite the differences in views, all survivors and parents reported being reassured by attendance, felt more secure, and that they were doing something positive for their health.

3.2. Expectations of follow-up

Families wanted facts and information, including written test results for reassurance, to aid memory and enable them to discuss the illness with others. They were often frustrated by inadequate communication about test results. This was especially important given the time between appointments. Some families received letters with results of tests, others thought this was sent to their GP and others assumed 'no news was good news'.

Some survivors reported not being able to remember if information was given: '*they tell you once, I forget the next year so I think I just need reminding*'. In the absence of appropriate information, some survivors turned to general, often less personally relevant sources: '*you look at information on the Internet and think god I wish I'd never seen it*'. Despite the criticisms, survivors acknowledged that their needs changed over time: "*its years on when you think I don't know what treatment I had*'. Thus, there was a need for careful timing of explanations about different risks, and some warning of potential problems ahead: '*it would have been nice to know at the beginning about the fertility status when you finish treatment*'.

Although families wanted to know about risks to future health, equally important was advice about self-care and how survivors could optimise their own health. Too often information about risk status was given with inadequate information about susceptibility or what could be done. Information was often described as incomplete: '*it's alright but they only give you bits, so they'll say that and then nothing*' and '*they tell you the worse scenario, with no suggested plan*'. Thus, information sometimes lacked sensitivity to an individual's position: '*I am likely to have an early menopause and so they say to have children earlier rather than later. But I don't have a boyfriend so what can I do?*'.

They also wanted advice for everyday living,including how to talk to friends and employers about their illness, as many were hesitant to explain why they needed to go to clinic: '*I don't feel any different to anybody else*'. They discussed the need to access other services to provide advice about job applications or health insurance as well as counsellors and social workers: '*people don't understand the problems with getting insurance for holidays*'; 'we *need the opportunity to access other services through the follow-up*'.

In addition to factual information, survivors and parents wanted more information and advice regarding the psychosocial consequences: '*It's all clinical, clinical, clinical… it's all the emotional things that go with it you don't* [deal with]. Families urged that follow-up services need to address residual emotional issues: '*I suppose the purpose of follow-up should be broader round… it should address some of the trauma and emotional disability*'. They also focused on the need to include the whole family: '*you tend to think of things that concern you but it's a family issue*'. Families wanted counselling and advice: '*parenting and family life just takes the most incredible knocks*', and help to stay positive and resolve any 'survivor guilt' they experienced in relation to those families who had been less fortunate. Parents also suggested that getting together with other families with a child survivor of cancer would be helpful.

3.3. Preferences for models of care

Models of follow-up were discussed in relation to purpose (individual, doctor and future patient benefit);

alternative models of care (hospital, GP or nurse-led) as well as specific concerns of parents.

In terms of purpose, attendance at follow-up was primarily for individual benefit: 'its peace of mind that you are getting looked after and you know everything's ok'. There was also understanding that follow-up was of benefit to doctors: 'they want to see if their work comes through basically – if they've done well 'the individuals concerned probably don't benefit usually, but medical science benefits''; and to help others: 'I suppose they want to see how we do for future people'.

In line with these views, parents and young people wanted to keep attending follow-up because they saw this to be the single most important path to future health while also ensuring that their experiences contributed directly to improvements in care for future patients. Consequently, GP-led clinics were not seen to be appropriate, since the specialist knowledge was not available, nor were GPs in a position to modify future protocols. In contrast, clinics led by specialist nurses were perceived as more acceptable, in offering both specialist expertise and opportunities for appropriate feedback.

Any changes to delivery of care were of special concern to parents. They discussed the legal implications of trying to gain access to information once their child was over 16 years. There were also problems where parents disagreed strongly with clinic policy: '*He doesn't need to know all this about future risk; he has as much chance as I have as you have; as anybody has of, maybe I don't know slightly enhanced risk*'. Others emphasised that there were still difficult decisions to be made even after treatment ends. Through these examples, parents emphasised their wish to remain involved in care, and this was supported by all survivors present.

4. Discussion

Clinic attendance poses some challenge to achievement of a normal life, not least by requiring survivors to acknowledge the possibility of late-effects. We identified a range of views to describe how families dealt with this dilemma. Some families believed there was less to be gained from attendance over time. These families were also of the view that the possibility of late-effects was small. Their views contrasted with those who held a more vigilant approach to monitoring health and saw clinic attendance as an integral part of that process.

Families were generally positive about follow-up and gained reassurance from attendance. However, given that some families had reservations about the benefits of follow-up, it is important that the service addresses survivors' interests and meets their expectations. There were calls for more written information about the illness and possible consequences for future health. They also wanted more psychosocial support and practical advice about insurance and job applications. These findings emphasise the potential value of written information, such as the revised 'After-Cure' booklet [15], now widely available.

Given the increasing numbers of survivors of childhood cancer, there has been considerable discussion about alternative models of care. Suggestions for a stratified system of follow-up have been proposed [16,17]. Based on information about initial treatment [16] care could be offered at different levels, and for some survivors, might include GP or nurse led care as well as postal or telephone methods. Our data provide some insight into the potential acceptability of different models of care for survivors themselves. There was little enthusiasm for GP led follow-up, but nurse-led care would be more acceptable, providing a doctor was available where necessary. In establishing alternative models of follow-up care, consideration must be given to individual information needs and preferences.

In common with other focus group research [18,19], there are several limitations to the study. These include issues of recruitment, bias reduction, methods of analysis and that interactions between participants may influence discussions.

4.1. Recruitment

Our sample size is small, but typical for studies of this kind. The low response rate may reflect lack of interest in the topic, or concern about the focus group method and anxiety about talking about sensitive issues in front of others. In our previous work, no difficulties recruiting survivors were noted [12]. However, this involved completion of a questionnaire during a clinic visit, and thus impacted much less on everyday life than making a special trip, usually of an evening, to take part in a focus group.

4.2. Bias reduction

Although we received positive comments from those who took part in the study, our sample was self-selected and the results may not reflect the views of survivors more generally, including those who choose not to attend follow-up care. In addition, parents and survivors may have been reluctant to discuss certain issues in front of each other, again resulting in bias. Researcher bias was reduced by including themes for discussion rather than structured questions.

4.3. Methods of analysis

Our purpose in conducting focus groups rather than individual interviews was to ensure a broad spectrum of views rather than determine how attitudes are influenced by others' perspectives. For this reason, IPA

was considered appropriate for analysis. Although individual views are inevitably influenced by the interactions and context of the discussion [20], it is relatively uncommon that focus group studies include analysis of group interactions [21]. However, it is important to be aware of the influence of group interactions on the data. Several steps can be taken to account for this [22].

4.4. Interactions between participants

Most differences in views were a consequence of specific diagnoses and treatments or chronological age, rather than disagreements. These differences were potentially a source of difficulty to the extent that survivors became aware that, for example, they had late-effects that were not shared by everyone else, or that they were on more frequent follow-up. However, we did not experience any conflict resulting from differences of opinion in the groups, perhaps because there was considerable respect and sympathy between individuals. In situations where an individual was distressed, group members were highly supportive, and acknowledged how helpful it was to meet others with similar conditions. Feedback has been provided to survivors by letter and orally to the relevant ethical committee.

Despite the differences in organisation of care between the UK and US, our findings concur broadly with those described by Zebrack *et al.* [11]. We have identified a range of views amongst survivors. These include those who wish to move on, lead a normal life, and not worry about future health risks. In contrast, there are others who persistently monitor their health, want more risk information, seem more anxious and are keen to maintain links with the hospital. These divergent views emphasise the need to take account of individual expectations about follow-up care and are crucial to the success of any major restructuring of health care delivery for these patients.

Conflict of interest statement

None declared.

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