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Providing information about late effects after childhood cancer: Lymphoma survivors' preferences for what, how and when

Hanne C. Lie [a,b,*], Jon H. Loge [a,b], Sophie D. Fosså [b], Hanne M. Hamre [b], Siri L. Hess [b], Anneli V. Mellblom [a], Ellen Ruud [c], Arnstein Finset [a]

[a] Department of Behavioural Sciences in Medicine, University of Oslo, Oslo, Norway
[b] National Advisory Unit on Late Effects after Cancer Treatment, Oslo University Hospital, Radiumhospitalet, Oslo, Norway
[c] Department of Paediatric Medicine, Oslo University Hospital, Rikshospitalet, Oslo, Norway

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ABSTRACT

Objective: Childhood cancer survivors need information about risks of late effects to manage their health. We studied how and when adult, long-term survivors prefer to receive information about late effects.
Methods: Five focus-groups with adult survivors of childhood lymphomas who had completed routine follow-up care and participated in a preceding follow-up study (n = 34, 19 females, mean age = 39). We used thematic analysis to identify themes regarding providing late effects information.
Results: The survivors wanted information about late effects (symptoms, prevention and treatment), lifestyle and social security rights. Information should be tailored, carefully timed, given "face-to-face" and in written format. Many expressed ambivalence regarding receiving information as adolescents, but it was seen as essential "to know" once a late effect occurred. A "re-information" consultation about late effects around age 25 was suggested as beneficial.
Conclusion: Although ambivalent, all survivors wanted information about late effects. They preferred individualized information, disclosed "step-by-step" and in a "re-information consultation" when reaching young adulthood.
Practice Implications: Providing information about late effects should be an on-going process across the cancer care trajectory. (Re-)Informing survivors when older would enhance their understanding of their health risks and could aid better health self-management beyond completion of follow-up care.

1. Introduction

Given the advances in treatment of most childhood cancers, survival is now the norm rather than the exception [1,2]. Survival, however, often comes at a cost in terms of health problems caused by the disease or its treatment, late effects, and early mortality [3,4]. Recently reported cumulative prevalence rates of chronic health problems were 95.5% (any) and 80.5% (disabling/life-threatening) by age 45 years for childhood cancer survivors [5]. It is therefore recommended that survivors attend long-term follow-up care for prevention, early detection and treatment of late effects (e.g. [5,6]).

Similar to practices in other countries [7,8], Norwegian childhood cancer survivors typically attend routine follow-up care at pediatric departments until the age of 18 years. After this, most do not attend formal follow-up care [7,10], although late effects can appear decades after treatment completion [4]. Additionally, the survivors are transitioning into adulthood, which may include relocating and discontinuation of relationships with health care personnel (HCP) who know their medical past. In effect, the adult survivor becomes responsible for further contact with the health care system [10]. It is therefore essential that survivors are adequately informed about their persisting risks to enable them to make informed decisions regarding health care and lifestyle [12]. Adequate information also allow communication of their health risks and care needs to HCP who often lack such knowledge given the rarity of childhood cancer [5,13].

Information provisioning is a fundamental component of patient-centered care, regarded as gold-standard for quality care [14]. Providing adequate information about late effects is increasingly recognized as an important aim of follow-up care (e.g. [15]). However, the majority of adult survivors of childhood cancer appear to be unaware of their risks of late

* Corresponding author at: Department of Behavioural Sciences, Institute of Basic Medical Sciences, University of Oslo, P.B. 1111 Blindern, N-0317 Oslo, Norway. Tel.: +47 22 85 14 66; fax: +47 22 85 13 00.
E-mail address: h.c.lie@medisin.uio.no (H.C. Lie).

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effects [10,16–18]. Additionally, information about late effects is one of the most frequently reported unmet needs amongst survivors of cancer at a young age [19]. These findings emphasize the importance of providing such information during routine care and to ensure that the information has been understood and covered the patient's needs.

Providing information about late effects is challenging. Clinicians have to balance providing sufficient information without provoking unnecessary anxiety [20,21]. Treatment protocols, diagnosis and patient characteristics identify general risk factors for late effects on a group, but not on an individual, level [6]. This prognostic uncertainty may act as a barrier to disclose late effects information to cancer survivors [20]. Pediatric oncologists face additional challenges of communicating with adolescent patients that may not be mature enough or willing to receive health risk information [22].

There is little research to guide clinicians in how and when to best provide late effect information to cancer survivors [20]. The literature on information needs amongst survivors of childhood cancer is also scant, mostly questionnaire-based, and typically report unmet needs for information about survivorship in general and late effects in particular [19,21,23]. Additionally, cancer survivors are often unsatisfied with the information received [24,25]. To our knowledge there are no studies exploring survivors' preferences for receiving such information. A better understanding of their preferences should be useful for the clinician and the health care system at large to more effectively communicate risks of late effects in a patient-centered way.

We conducted focus-group interviews with adult survivors of childhood malignant lymphomas to extend the current knowledge of how to best disclose information about late effects. The survivors had all been informed about late effects during a preceding follow-up study [10,26,27]. Our aims were to explore their experiences with, and preferences for, receiving information about late effects. In particular, what information they wanted and how and when such information should be provided.

2. Methods

2.1. Sample and recruitment

Participants were recruited from a sample (n = 127) of adult long-term survivors of childhood malignant lymphomas who had previously participated in a comprehensive long-term follow-up study of late effects in 2007–2009 (the "follow-up study") [10,26,27]. Recruitment procedure for the follow-up study were in brief: survivors were identified through the Norwegian Cancer Registry, diagnosed and treated for Hodgkin's (HL) and non-Hodgkin's lymphoma (NHL) between 1970 and 2000 at a national University hospital, alive as of 2007, survival of >5 years, age at diagnosis ≤18 years, and 18 years of age or older at the time of participation. Of 223 survivors invited, 130 (58%) accepted and 127 participated in the follow-up study (see [27] for further details).

For the focus-group study, we chose to recruit survivors who had participated in the follow-up study for two main reasons. First, we knew that 66% reported no knowledge about late effects before attending the follow-up study [10]. Second, we knew that they all had received information about late effects during the follow-up study. They should therefore be able to judge the relevance and perceived usefulness of such information.

For the focus-group interviews, survivors living within 400 km of the study location (n = 73) were invited to participate by mail during 2010. Of these, five did not receive the invitation (one had died, four had unknown address); 32 did not respond; and two did not show up for the focus-groups. No attempts were made to contact non-responders. The remaining 34 (50%) survivors participated in one of five focus-groups

2.2. Procedures and study design

Focus-groups were chosen as the study design as it is well suited to provide a deeper understanding of the rationales, processes and contexts that shape patients' perceived needs for information about late effects [28]. Five groups, consisting of 4-8 survivors, an experienced facilitator (AF) and a co-facilitator (HCL), were held in a suitable room at the University of Oslo. The focus group interviews were audio-recorded. Each focus-group lasted between 2.5 and 3 h and contained three parts: (1) group discussion; (2) a clinician from the follow-up study (JHL, SDF or ER) came and informed about study results and answered questions; and (3) the clinician left and the group discussion continued. The "clinician information" session was included as an incentive to participate by offering an opportunity to ask questions and hear results from the follow-up study.

The focus-groups followed recommended procedures, including the use of a semi-structured interview guide [29], based on study aims, literature searches and discussions with clinicians (ER and JHL) to ensure clinical relevance (available upon request). On close examination of the transcripts of the focus groups, there appeared to be no new topics emerging in the last two focus groups, but rather elaborations of already discussed topics. Thus, the data was considered sufficiently saturated to allow exploration of the survivors' experiences with, and needs for, information about late effects. Based on the literature, we expected participants to want information about late effects and that receiving such information would be perceived as useful by most.

2.3. Ethical considerations

Participants provided written consent. Participants' travel costs were reimbursed. A clinical psychologist (AF) was always present to provide support if required. The audio-recordings were transcribed verbatim excluding person-identifying information. The study was approved by the Regional Committee for Medical Research Ethics of South-Eastern Norway.

2.4. Data analysis

Due to a technical problem with the audio-recordings of one group, only the last section was included in the analysis. The transcripts were checked and corrected, then analyzed following procedures for thematic analysis [29,30]. This is a data driven analysis, rather than a content-analysis (e.g. frequency counts), as the nature of focus-groups limits the value of quantifying individual statements and themes [31]. HyperRESEARCH 3.5.1™ (ResearchWare.Inc) was used to manage and code the data. First, broad, preliminary categories were independently extracted by two of the authors (ER and HCL). These categories were based on the interview guide and repeated, thorough readings of the material where recurrent themes, patterns or words were noted and grouped based on similarity. Second, two of the transcripts were independently coded line-by-line using the preliminary categories by AVM and HCL. Any disagreements, adjustments of major categories and the addition of sub-categories were resolved through discussions. Finally, all transcripts were re-coded with the final codes by HCL. To enhance credibility of the findings, coders used a reflexive diary to track changes in codes, discussions and reasons for recoding as an attempt to limit researcher bias. A summary of our results was sent to all participants for a members' check, after which no changes were necessary [32].