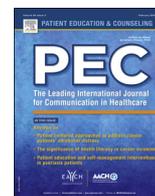




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Do negative emotions expressed during follow-up consultations with adolescent survivors of childhood cancer reflect late effects?

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ABSTRACT

Objective: To explore whether negative emotions expressed by adolescent cancer survivors during follow-up consultations were associated with potential late effects (persisting disease or treatment-related health problems).

Methods: We video-recorded 66 follow-up consultations between 10 pediatricians and 66 adolescent survivors of leukemia, lymphoma or stem-cell transplantations. In transcripts of the recordings, we identified utterances coded as both 1) expressions of negative emotions (VR-CoDES), and 2) late effect-related discussions. Principles of thematic content analysis were used to investigate associations between the two.

Results: Of the 66 video-recorded consultations, 22 consultations contained 56 (49%) utterances coded as both emotional concerns and discussions of potential late effects. Negative emotions were most commonly associated with late effects such as fatigue ("I'm struggling with not having energy"), psychosocial distress ("When I touch this (scar) I become nauseous"), pain ("I'm wondering how long I am going to have this pain?"), and treatment-related effects on physical appearance ("Am I growing?").

Conclusions: Negative emotions expressed by adolescent cancer survivors during follow-up consultations were frequently associated with potential late effects. These late effects were not the medically most serious ones, but reflected issues affecting the adolescents' daily life.

Practice implication: Eliciting and exploring patients' emotional concerns serve as means to obtain clinically relevant information regarding potential late effect and to provide emotional support.

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1. Introduction

The growing population of childhood cancer survivors face many challenges after treatment completion, including risk for disease- and treatment-related health problems (late effects), such as cardiorespiratory disorders, endocrine dysfunction, secondary cancers, neurocognitive impairments and fatigue [1–5]. Late effects can appear during or immediately after cancer therapy or up to decades after end of treatment, potentially interfering with physical, psychological and social functioning and well-being [6]. Up to 80% of childhood cancer survivors develop a serious or life-

threatening late effect by the age of 45 [4]. A subgroup of survivors also struggles with ongoing psychosocial problems following the cancer experience, with increased levels of anxiety and depression compared to healthy peers [6–9].

Childhood cancer survivors typically attend follow-up care 5–10 years after treatment completion. Aims of follow-up care are to detect recurrence, and at later stages detect and manage late effects, as well as educating patients about their health risks and future health care needs [4,10,11]. Clinicians may be reluctant to burden their patients with information about risks of late effects to avoid causing concerns about late effects that may never arise [12], while survivors have expressed ambivalent feelings towards receiving such information [13]. Yet, information about late effects is one of the most commonly reported unmet information needs among childhood cancer survivors [13].

We have previously investigated to what extent information about late effects is provided [14] and the expression of emotional

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concerns [15] during follow-up consultations with adolescent survivors of childhood cancers and pediatricians. We found that a vast majority of the consultations contained discussions about late effects and half of the consultations contained expressions of emotional concerns, with cancer-related concerns being one of the most common themes.

To what extent discussions of potential late effects were associated with expressed emotional concerns were, however, not explored. Knowledge of potential relationships between late effects related issues and patients' expressions of emotional concerns would be helpful for clinicians to both adapt information provided about late effects and to serve as an indication of which late effect are of particular concern for young survivors.

In this article, we perform a secondary analysis to examine 1) to what extent the expressions of emotional concerns are associated with (potential) late effects, and 2) which late effects are most often associated with expressions of emotional concerns during follow-up consultations.

2. Methods

2.1. Sample and procedures

The sample consists of video-recordings of 66 routine follow-up consultations between 66 adolescent childhood cancer survivors and 10 pediatricians at the pediatric oncology department at Oslo University Hospital in Norway 2010–2012. One or both parents were present in 87% of the consultations. The follow-up consultations were typically scheduled for 30 min. Patients treated for leukemia, lymphomas or who had received a stem-cell transplant preceded by high dose chemotherapy treatment were consecutively recruited. Invitations were included with the consultation appointment letter from the hospital. A small video-recorder was placed in the corner of the consultation room and the video-recordings were transcribed verbatim. Of 88 patients invited, 70 consented to participate, and 66 had resulting video-recordings that could be analyzed (further details are provided in [15]).

2.2. Previous analyses of expressions of emotional concerns and discussions of (potential) late effects

Expressions of emotional concerns by the patients or the parents were identified using the Verona Coding Definitions of Emotional Sequences (VR-CoDES) [16,17]. The VR-CoDES is a consensus-based coding system that distinguishes between emotional concerns expressed as “cues”, a vague, implicit expression of emotion, and a “concern”, an unambiguous, explicit expression of a negative emotion [17]. Expressions of cues and concerns can be elicited spontaneously by the patient/parent or in response to a question or utterance by the physician. Half of the patients expressed at least one emotional concern, and 10% expressed many (>7).

Communication about potential late effects was identified using a list of topics and symptoms reflecting late effects compiled by a pediatric oncologist. Patient, parent and pediatricians' utterances containing these topics or symptoms were coded accordingly, regardless of who initiated the topic. The pediatrician's utterance would be coded as communication about potential late effect regardless of what the patient replies (for more details see [14]). Communication about late effects was identified in 85% of the consultations [14].

2.3. Analysis for associations between expressions of emotional concerns and discussions of potential late effects

We adapted principles of thematic content analysis [18] to investigate associations between emotional concerns and

potential late effects-related discussions. First, we identified consultations containing expressions of emotional concerns. Second, in these, we examined each utterance coded as emotional concern or as potential late effects and extracted those coded as both. Third, the utterances were coded for the theme of the emotional concern expressed. Themes were then grouped according to overarching themes of potential late effects.

3. Results

Patients' characteristics are shown in Table 1. In brief, about two-thirds of the sample was female, with an average age of 15 years, on average six years from diagnosis, with leukemia being the most common diagnosis (Table 1).

Of the 66 video-recorded consultations, 33 contained expressions of in total 114 emotional concerns. Of these, 22 consultations contained 56 (49%) utterances coded as both emotional concerns and discussions of potential late effects (41 expressed by the patients and 15 by a parent), and thus formed the basis for further analyses (Fig. 1).

Seventeen of these patients were female and four patients (all female) were alone with their pediatrician. Twelve patients expressed 1 cue/concern, 6 expressed 2–4 cue/concerns and 4 expressed 7 cues/concerns.

3.1. Associations between emotional concerns and late effects

The themes of the late effects-related emotional concerns expressed are presented in Table 2. Fatigue was the potential late effect discussed the most frequently during the consultations and was the most common theme of late-effects related emotional concerns (e.g. “I'm struggling with not having any energy”, female 18 years). The second most frequently expressed late effects-related emotional concern was psychological distress, encompassing sub-themes such as depressive symptoms and anxiety (e.g. *I think that I soon . . . You have to hit the bottom before it can get better*, female 19 years old). Other common late effects-related emotional concerns were pain (e.g. “I'm wondering, how long am I going to have this pain?”, female 17 years old), treatment-related change of physical appearance (“Do I grow, is my height normal?”, male 13 years old) and school-related issues (“I don't understand anything in school (cries)”, female 15 years old).

Discussions of the potentially more serious or even life-threatening late effects such as cardiac disease, endocrinopathy

Table 1

Characteristics of the total sample of adolescent cancer survivors.

Patients characteristics	Patients included (n=66) Mean (SD, range)
Current age	15.3 (2.3, 12–20)
Age at diagnosis in years	6.7 (4.0, 0–16)
Years since treatment	6.3 (3.4, 0–16)
Gender	Number (%)
Female	45 (68)
Diagnoses	
Leukemia	47 (71)
Lymphoma	14 (21)
SCT ^a for benign disorder	5(8)
Late effect risk ^b level 2	44 (67)
Late effect risk level 3	22 (33)

Note: Level 2: low to moderate doses of alkylating agent, anthracycline, bleomycin, or epipodophyllotoxin and no radiation. Level 3: high doses, radiation and/or stem cell transplant.

^a Stemcell transplantation.

^b Patients' risk of late effects was calculated according to Oeffinger et al. criteria [19].

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