



Health-related quality of life in teenagers with a parent with cancer



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ABSTRACT

Purpose: Health-related quality of life (HRQoL) in teenagers exposed to parental cancer has shown divergent results as an outcome measure. In this study we wanted to: 1) compare the HRQoL of teenagers exposed to parental cancer (CASES) with normative European HRQoL data (NORMs) measured close to parental diagnosis and treatment; 2) study changes in the HRQoL of CASES from baseline to follow-up; 3) explore sex differences in the HRQoL of CASES; and 4) explore eventual confounders of HRQoL of CASES at baseline.

Methods: Forty-five families with one parent diagnosed with primary invasive cancer were included, these families had 69 teenagers. At the follow-up, 26 families with 29 teenagers complied. Both parents and teenagers filled in electronic questionnaires over the Internet. HRQoL in teenagers was self-rated by the KIDSCREEN-27 at baseline and follow-up, and the responses were compared to a European normative sample (NORMs).

Results: 1) The teenagers scored significantly lower on the *Physical well-being* dimension compared to the NORMs at baseline, while no significant differences were observed concerning the four other HRQoL dimensions. 2) Some significant improvements were observed on HRQoL dimensions from baseline to follow-up. 3) CASES girls showed a trend towards lower HRQoL scores compared to boys. 4) Parental cancer-related characteristics and family function were not related to teenagers' HRQoL, but so were teenagers' self-esteem.

Conclusions: At group level, living with a parent who receives curative treatment for a recently diagnosed cancer affects teenagers' HRQoL to certain extent. Self-esteem is a confounder to teenagers' HRQoL in our sample.

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1. Introduction

Many studies have reported an increased risk of psychosocial problems like anxiety/depression, confusion, sadness, anger, feelings of uncertainty, and loneliness in children and teenagers living with a parent affected by cancer. Particularly girls seem to be more affected by a higher level of anxiety and depression compared to boys (Krauel et al., 2012; Krattenmacher et al., 2012; Visser et al., 2004). Other studies have considered parental cancer as a

negative life event triggering resilience in most offsprings with only a minority of them reacting with permanent psychosocial problems (Jeppesen et al., 2013; Schmitt et al., 2008; Vannatta et al., 2010).

Another important outcome measure commonly used in clinical cancer research is health-related quality of life (HRQoL), which has been defined as: the physical, psychological, and social domains of health, seen as distinct areas that are influenced by a person's experiences, beliefs, expectations, and perception (Testa and Simonson, 1996). Cancer in a parent is a potentially traumatic event, and thereby could be a risk factor for psycho-social problems in the children since they must adapt to various negative consequences of the parental disease (Krattenmacher et al., 2012). In contrast to younger children, teenagers understand more about the parental disease and its practical, emotional and existential

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consequences for the family. In addition to the external stressor of parental cancer, such teenagers also must cope with challenges of their own phase-specific developmental issues. Because of the complexity in adaptation, HRQoL is a better and broader outcome measure and could represent a supplementary outcome to the psychosocial problems that have been mostly studied in offspring of parents with cancer.

Generic HRQoL instruments are used to collect information on healthy as well as ill children, at the population level or in clinical practice, and allow for the comparison of children (11–17 years) of single mothers with breast cancer and cohabiting mothers. They observed no significant differences in HRQoL dimension scores between the groups of children rated by the KIDSCREEN-27 (Ravens-Sieberer et al., 2014c).

In a multi-hospital study Krattenmacher et al. (2013) collected 115 mother and 29 fathers with cancer among which 67% was diagnosed less than a year previously. Their 125 adolescent offspring completed the KIDSCREEN-10, and 97% reported good HRQoL, with no significant sex difference. High HRQoL was significantly associated with the coping mechanisms of active problem solving and social support seeking.

A population-based study by Bultmann et al. (2014) studied HRQoL measured by KIDSCREEN-10 Index proxy in children (6–18 years) of cancer survivors (<6 years post diagnosis) compared to NORMs. Children in general, particularly those aged 12–18 years, boys, and those who were distressed during parental cancer treatment had significantly higher HRQoL than NORMs. Having a mother with cancer, living with a single parent, and worse parental physical and mental health were significantly associated with reduced HRQoL in children. Cancer characteristics showed no significant associations with HRQoL.

On this background, we wanted to study HRQoL with the KIDSCREEN-27 in teenagers of parents who recently had been diagnosed and treated for cancer. We chose a longitudinal design, and the following study aims were defined: 1) to compare the HRQoL of teenagers exposed to parental cancer (CASES) with normative European HRQoL data (NORMs) measured close to parental diagnosis and treatment (baseline); 2) to study changes in the HRQoL of CASES from baseline to follow-up six to eight months later, when the parents had lived longer with cancer. 3) to explore sex differences in the HRQoL of CASES; and 4) to explore eventual confounders of HRQoL of CASES at baseline. Such confounders could be both parental and teenager characteristics as well as general family function.

Previous research have demonstrated risk for psychosocial problems in children and teenagers with cancer in a parent we therefore hypothesized that HRQoL mean scores of CASES would be significantly lower on all dimensions compared to the European normative scores, and with significantly lower mean scores on all dimensions in CASES girls compared to boys. We also hypothesized that the follow-up HRQoL mean scores of CASES would be significantly higher compared with at baseline due to better adaptation over time to the stressor of parental cancer. Finally based on previous research we hypothesized that depression in parents, low self-esteem in CASES and poor family function would be negatively and significantly associated with the HRQoL of CASES.

2. Material and methods

2.1. Recruitment of families and procedures

Families eligible for the present study included a father or a mother diagnosed with invasive cancer between 1 and 12 months before the contact, treated with curative intent and living with teenagers aged 13–19 years. We had to exclude patients eligible for

other ongoing studies at the Department and patients in palliative phase.

Oncologists and oncological nurses at the Department of Oncology, Oslo University Hospital, screened female patients with breast cancer, gynecological cancer, and lymphomas, and male patients with lymphomas or colorectal cancer for the eligibility criteria during the 12 month sampling period (2011/2012). Both single parent and two-parent families were eligible. All teenagers in the families had to be aware of the cancer diagnosis of their parent.

The screening procedure identified 51 eligible families (Fig. 1). The first author (EJ) then contacted the cancer patients by phone, gave more information about the study, and invited all family members to participate. Six mothers with breast cancer declined to participate resulting in a sample of 45 families with 69 teenagers.

Patients gave written informed consent in a meeting with the first author, and the parental interview was decided. After obtaining informed consent from all family members, all parents and teenagers received the electronic questionnaires on their individual mail addresses. Additionally, the all parents and eventual spouses participated in a semi-structured interview concerning family function performed with the first author at baseline.

After e-mailing the questionnaire to the teenagers, the first author also contacted them by phone in order to assess additional needs for information, to preclude unreasonable fears, and to emphasize the protection of their anonymity.

All participants confirmed their willingness to take part in the follow-up assessment six to eight months after baseline (Fig. 1). However, when contacted for that procedure only 26 of the 45 families (57%) with 29 of 69 teenagers (44%) agreed to participate.

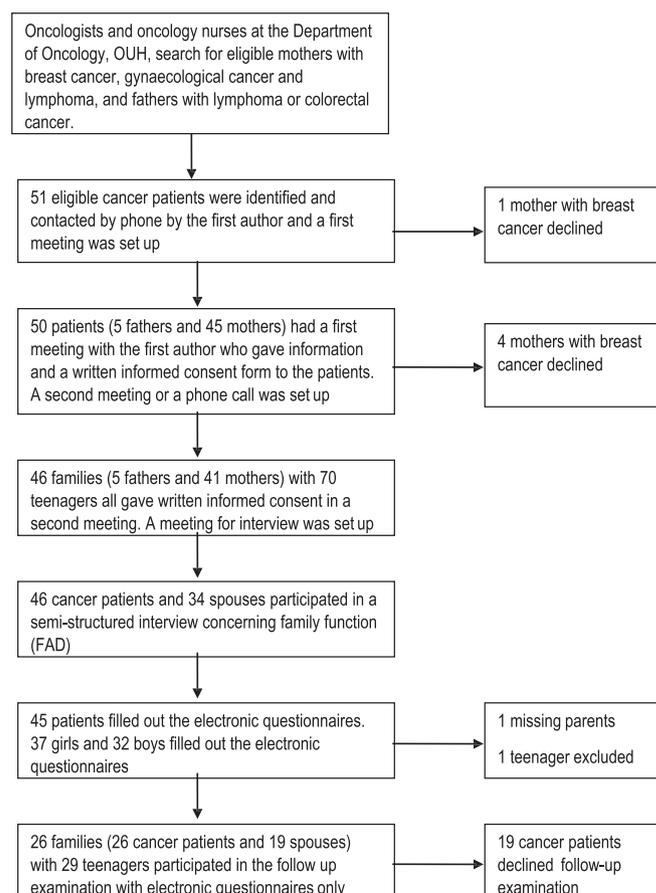


Fig. 1. Flowchart.

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