Original Article

Parents' Perceptions of Their Child's Symptom Burden During and After Cancer Treatment

Lena Hedén, PhD, Ulrika Pöder, PhD, Louise von Essen, PhD, and
Gustaf Ljungman, MD, PhD

Department of Women's and Children's Health, Pediatric Oncology (L.H., G.L.); Department of Public Health and Caring Sciences, Psychosocial Oncology and Supportive Care (U.P., L.v.E.); and Department of Public Health and Caring Sciences, Caring Sciences (U.P.), Uppsala University, Uppsala, Sweden

---

Abstract

Context. Previously reported studies of children with cancer mostly provide cross-sectional knowledge of the prevalence of symptoms but do not show when during the disease trajectory and after the end of successful treatment certain symptoms are most prevalent and/or distressing.

Objectives. The aim was to describe parents' perceptions of their child's symptom burden longitudinally during and after cancer treatment and to investigate whether parents' perceptions vary with child characteristics and parent gender.

Methods. One hundred sixty parents (49% fathers) of 89 children answered a modified version of the Memorial Symptom Assessment Scale (MSAS) 10–18 at six different time points from one week after the child's diagnosis (T1) to 12–18 months after the end of successful treatment (T6).

Results. Feeling drowsy, pain, and lack of energy are initially the most prevalent symptoms. During treatment, the most prevalent symptom is less hair than usual. Pain, feeling sad, and nausea are initially the most distressing symptoms. Pain is both prevalent and distressing throughout the treatment. The child's symptom burden decreases over time. There is no difference regarding the reported symptom burden between the parents of a daughter or a son, or parents of a child older or younger than seven years of age. Mothers' and fathers' assessments of the symptom number, total MSAS and the subscales, are associated, but mothers' assessments are often higher than fathers' assessments.

Conclusion. The prevalence and distress of symptoms and symptom burden decrease over time. However, even though the cancer is cured, feeling sad is reported as being prevalent and psychological distress is an issue. A dialogue between staff and the family about distressing symptoms and when they can be expected may increase acceptance and adaptation in children and parents during the disease trajectory. J Pain Symptom Manage 2013;46:366–375. © *2013 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Address correspondence to: Lena Hedén, PhD, Department of Women's and Children's Health, Unit for Pediatric Hematology and Oncology, Children's University Hospital, SE-751 85 Uppsala, Sweden. E-mail: lena.heden@kbh.uu.se

Accepted for publication: September 13, 2012.

0885-3924/$ - see front matter
http://dx.doi.org/10.1016/j.jpainsymman.2012.09.012

Key Words
Cancer, children, distress, parent, perception, symptom

Introduction

In Sweden, approximately 300 children are diagnosed with cancer annually.[1] Treatment lasts from about four months up to two and a half years or more, provided that no relapse or complicating condition occurs. Chemotherapy, surgery, and radiation are the most common treatment methods.[2] Side effects are not unusual during the treatment period. Physiological symptoms, such as cough, drowsiness, lack of appetite, lack of energy, nausea, and pain, as well as psychological symptoms, such as feeling irritable, feeling nervous, feeling sad, and worrying, are cited as the most prevalent symptoms according to children with cancer aged 10–18 years.[3] Furthermore, feeling irritable, feeling sad, lack of appetite, nausea, and pain are the most distressing symptoms according to these children.[3] In a cross-sectional study of 158 children being treated for cancer, parents reported that missing activities with friends, feeling worried about treatments, procedures and side effects, and pain are the most common, severe, and bothersome symptoms for the children.[4] Another study demonstrated that fatigue, nausea, and pain are the most distressing symptoms for children 0–19 years of age on and off cancer treatment, according to children, parents, and nurses.[5] Our research group has previously shown that, according to parents, pain is the most distressing and prevalent symptom for children receiving treatment for cancer.[6] Other findings show that children report pain as the most feared symptom during cancer treatment.[7] Symptoms such as fatigue, sleep disturbances, and pain rarely occur in isolation and may together have a negative impact on the distress experienced.[8] Findings reported above provide cross-sectional knowledge of the prevalence of symptoms but do not show when during the disease trajectory certain symptoms are most prevalent and/or distressing.

To the best of our knowledge, this is the first study to longitudinally investigate the prevalence of and distress caused by cancer-related symptoms at certain times after diagnosis and at the end of successful treatment.

The following research questions were posed according to parents' perceptions:

1) Which are the most prevalent and distressing symptoms for children at certain times after diagnosis and after the end of successful treatment?

2) Is there a difference over time with regard to symptom burden?

3) Is there a difference over time with regard to symptom burden related to the child's characteristics?

4) Do mothers' and fathers' perceptions of their children's symptoms differ and/or are they associated?

Methods

This study had a longitudinal design and is part of the ongoing project "Occurrence and Development of Post-traumatic Stress Disorder Among Swedish Parents of Children With Cancer." Data were collected via telephone interviews at six assessments (T1–T6); the first three (T1–T3) in relation to the child's diagnosis and the next three (T4–T6) in relation to the end of successful treatment: T1 = one week after diagnosis; T2 = two months after diagnosis; T3 = four months after diagnosis; T4 = one week after the end of successful treatment (ST) or six months after bone marrow or stem-cell transplantation (SCT); T5 = three months after ST or nine months after SCT; and T6 = one year after ST or 18 months after SCT.

In a previous article from our group, the Memorial Symptom Assessment Scale (MSAS) scores were reported from T1 to T3, focusing on which symptoms, according to parents, cause the most problems for children receiving cancer treatment, and exploring the