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ORIGINAL ARTICLE



Perceptions of support among Swedish parents of children after end of successful cancer treatment: a prospective, longitudinal study

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ABSTRACT

Introduction: Most children survive childhood cancer, however parenting a child diagnosed with cancer is a major challenge. The main aim of the current study was to describe Swedish parents' need, opportunity and benefit of support from healthcare professionals and significant others after end of a child's successful cancer treatment.

Material and methods: Data was collected from approximately one week after end of successful treatment/six months after transplantation (T4, n = 212) up to five years thereafter (T7, n = 137). Parents answered questions via telephone about need, opportunity and benefit of talking to psychologists, social workers, partners and friends.

Results: The proportion reporting need of support from healthcare professionals varied between 73% (mothers' need of support from social workers, T4) and 7% (fathers' need of support from psychologists/social workers, T7). Need of support from significant others varied between 99% (mothers' and fathers' need of support from partners, T4) and 27% (fathers' need of support from friends, T7). The proportion reporting need of support decreased over time (p < .001), no decrease occurred from three months after end of treatment/nine months after transplantation (T5) to one year after end of treatment/18 months after transplantation (T6). More mothers than fathers reported need of support from friends at T5 (p < .001) and T7 (p < .05) and from psychologists at T7 (p < .05). Opportunities for support from healthcare professionals varied, most reported opportunity for support from significant others. Almost all reported benefit from received support.

Conclusion: A declining number reports a need of support over time, however subgroups report an unmet need and almost every parent perceive support from healthcare professionals as beneficial. More parents should get access to psychosocial support services after end of a child's cancer treatment/transplantation.

ARTICLE HISTORY

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Introduction

The diagnosis of childhood cancer is one of the most intense and disruptive challenges a parent can experience. The challenge includes receiving the diagnosis, seeing the child suffer from treatments and side effects and dealing with the risk of losing the child. Successful treatment completion is often a celebrated milestone for the entire family, yet many challenges remain thereafter [1]. The time after end of treatment is a vulnerable period for parents [2], characterized by significant distress, including fear of recurrence, fatigue and loneliness [1]. The period between active treatment and long-term survivorship deserves increased research and attention. Five years after end of treatment a subgroup (27%) reports a clinically relevant level of general psychological distress [3] and 19% of mothers and 8% of fathers report symptoms of posttraumatic stress (PTSS) [2]. Families with a history of childhood cancer are at high risk for financial burden potentially having a negative impact on family members' emotional health [4]. Negative consequences of parenting a child diagnosed with cancer are pronounced among mothers who report a higher level of PTSS and tend to be more disadvantaged in their professional life than fathers [2,5].

Recently published guidelines for how children diagnosed with cancer and their family members should be cared for, recommend standardized psychosocial and financial risk assessments and referrals across the disease trajectory into long-term survivorship [4,6]. A substantial group of Swedish parents of children on cancer treatment reports a need to talk to psychologists, but few get the opportunity to do so [7]. In Sweden, parents of children diagnosed with cancer are not offered psychological support on a regular basis after the end of the child's treatment and findings [2] indicate an unmet need of psychological support. Staff availability, models of assessment and delivery of services, as well as size and location of pediatric cancer centers may hinder provision of support [6]. Swedish parents of children who have completed treatment for cancer and who experience a need for support from healthcare professionals are most often directed to primary care. Healthcare professionals in primary care do not necessarily have the experience and knowledge to provide these parents with adequate support. Services from a psychologist or a social worker are rarely accessed by parents after completion of cancer treatment [8]. In Sweden, psychologists most often provide psychological and emotional support whereas social workers most often provide social and practical (e.g., financial) services. However, services vary between healthcare centers and there is no clear-cut definition regarding which kind of support psychologists and social workers provide in Sweden.

Support from significant others can have a positive impact on parents of children diagnosed with cancer [9], mothers of survivors perceive social support as one of the rare positive aspects of parenting a child diagnosed with cancer. Social support has a positive impact on mothers' psychosocial adjustment and coping [10] and fathers' dissatisfaction with support during and after a child's cancer treatment increases the risk for emotional distress [11]. Parents of children diagnosed with cancer report a decreasing level of support from the time of treatment into survivorship [12] and marital strains, loneliness and social isolation have been described by parents years after end of treatment [1,13].

To summarize, psychosocial support for families with a history of childhood cancer has positive effects for parents [9,10] and is recommended by international guidelines [4,6]. Such support not only help parents, but also their family members. Parental stress predicts interpersonal relations, school/work functioning and self-care/self-fulfillment in survivors of childhood cancer [14] and psychosocial interventions addressing parents' distress may promote children's health-related quality of life [15].

Previous research in the area is mainly cross-sectional and longitudinal research is needed to reveal parents' needs of support at different times after end of a child's cancer treatment. The main aim of this study was to contribute to this knowledge by describing parents' need, opportunity and benefit of support from healthcare professionals and significant others from shortly after, up to five years after end of a child's successful cancer treatment. An additional aim was to explore the relation between parental and child characteristics and parents' need, opportunity and benefit of support.

The research questions were:

- How many parents report a need, an opportunity if a need and benefit if an opportunity, to talk with psychologists, social workers, partners and friends, respectively?
- 2. Is there change over time with regard to the proportion of parents who report a need to talk with psychologists, social workers, partners and friends, respectively?
- 3. Is there a difference with regard to the proportion of mothers and fathers who report a need, an opportunity if a need and benefit if an opportunity, to talk with psychologists, social workers, partners and friends, respectively?
- 4. Is there a difference between parental and child characteristics with regard to the proportion of parents who report a need, an opportunity if a need and benefit if an

opportunity, to talk with psychologists, social workers, partners and friends, respectively?

Material and methods

The results are based on data collected at four assessments (T4-T7) within the project: 'Occurrence and development of post-traumatic stress disorder among Swedish parents of children with cancer', investigating psychological and economic consequences of parenting a child diagnosed with cancer. Data was collected: one week after end of successful treatment six months after transplantation (T4), three months after end of successful treatment/nine months after transplantation (T5), one year after end of successful treatment/18 months after transplantation (T6) and five years after end of successful treatment/transplantation (T7). The expression 'end of successful treatment' refers to the time when the child has completed treatment at the time considered successful by the responsible pediatric oncologist. After discussions with pediatric oncologists, six months after transplantation was decided to be comparable to one week after end of successful treatment (due to compromised immune system and thereby susceptibility to infections during the first three to six months after transplantation, together with the gradually decreasing amount of follow-up visits after transplantation). End of successful treatment and transplantation are hereafter referred to as end of treatment.

Sample

Parents (including step-parents) of children diagnosed with cancer at four of the six Swedish pediatric oncology centers were consecutively recruited shortly after the child's diagnosis during 18 months from 2002 to 2004. Data for T7 was collected from July 2008 to August 2013. At T1, 259 parents of 139 children participated. Data on parents' need of support during treatment (T1–T3) have been reported [7], corresponding data collected after end of treatment (T4–T7) are reported herein.

The inclusion criteria were: Swedish-speaking and/or English-speaking parents (including step-parents) of children 0–18 years, diagnosed ≤14 days previously with a primary cancer diagnosis and scheduled for chemotherapy and/or radiotherapy (not applicable for CNS tumors). Additionally, parents should have contact with the child, be physically and emotionally capable to participate and have access to a telephone. For more information about the sample at T1 and study enrollment, see previous reports [2,7].

At T4, we contacted 215 eligible parents of 117 children, of which 45 were diagnosed with leukemia, 23 with lymphoma, 12 with a CNS tumor and 37 with other cancer diagnoses. Consequently, the sample had an overrepresentation of parents of children diagnosed with blood cancers and an underrepresentation of children diagnosed with CNS tumors in comparison with national childhood cancer incidence rates in Sweden [16]. In addition, at T1, parents of children with a CNS tumor were less likely to participate (γ^2 (2,

Table 1. Number of participants at T4-T7 respectively.

	T4	T5	T6	T7
Eligible parents (children)	215 (117)	213 (116)	196 (108)	175 (97)
Excluded				
Child death		2 (1)	15 (8)	9 (5)
Relapse				10 (5)
Parent death			2 (2)	
No contact with child				2 (2)
Declined				
Too emotional	1 (1)			
Not able to prioritize under circumstances		1 (1)		
Not interested or reachable			3 (2)	17 (13)
Not able			1 (1)	1 (1)
No time				2 (1)
No reason given				16 (13)
Prefers a written questionnaire				2 (1)
Administrative failure	2 (1)	2 (1)		
Participating	212 (116)	210 (115)	192 (107)	137 (80)
Mothers	109	109	98	70
Fathers	103	101	94	67

n = 388) = 14.60, p = .001) than parents of children with other diagnoses [2].

Fifteen children of participating parents had a transplant during the study period. At T4, 11 children had received a transplant. At T5, two more children had received a transplant and at T6, additionally two children had received a transplant. At T7 no additional child had received a transplant. See Table 1 for the number of participants at T4, T5, T6 and T7 respectively.

Instruments

Parents were asked via telephone by a PhD student or research assistant about their need, opportunity and benefit from talking with: psychologists, social workers, partners and friends. For each source of support the first question identified the need to talk about the child's disease: How great need have you had to talk about your child's disease with psychologists/social workers/partners/friends during the past month? The second question identified the opportunity to talk about the child's disease: How often have you had an opportunity to talk about your child's disease with psychologists/social workers/partners/friends during the past month? The third question identified benefit from talking about the child's disease: How much have you benefited from talking about your child's disease with psychologists/social workers/ partners/friends during the past month? Questions were answered on a 5-point-response scale ranging from none/ never (1) to very great/very often (5).

Procedure

Ethical approval was obtained by local ethical committees (Dnr: 02-006) and the Regional Ethical Review Board in Uppsala (Dnr: 2008/109). Potential participants were approached by a coordinating nurse who provided written and oral information about the study and asked for permission for the research group to contact the parent over the telephone to ask for oral informed consent. A research assistant or a PhD student administered data collection via telephone. The interviewers had no contact with the parents besides performing the interviews. Permission to contact the parent at the subsequent interview (T5-T7) was acquired at the end of each interview (T4-T6). A nurse at the respective pediatric oncology center collected the child's medical data from the medical charts in order to update the research group before each interview. See previous reports for more information about study procedure [2,7].

Data analyses

The 5-point-response scales were comprised to dichotomous variables: 1 = no/2 - 5 = yes [7]. If a need was reported, a score for opportunity was calculated and if an opportunity was reported, a score for benefit was calculated. Some parents reported having had an opportunity for support, however expressed that they had not taken the opportunity. Answers regarding benefit from these persons were not included in the analysis for benefit.

At the respective assessment, only data from parents of survivors was included in the analysis. Support needs from partners were only asked for from those who were in a relationship. Descriptive statistics were used to report the proportion reporting a need, an opportunity and a benefit of support (from psychologists, social workers, partners and friends) at T4-T7 (research question 1). The Cochran's Q test for more than two related categories was used to investigate potential differences over time (T4-T7) with regard to the proportion reporting a need of support (research question 2). Post-hoc analyses were conducted using non-parametric McNemar tests with Bonferroni adjustments. Parents who became bereaved during the study were excluded from the longitudinal analyses. The 137 participants at T7 had participated at all assessments T4-T7 and were included in the longitudinal analyses. These parents did not differ from those who did not participate at each assessment (including those who became bereaved) (n = 78) regarding their age, gender, civil status, education; child's age, gender or diagnosis (CNS tumor vs. other diagnoses), or support needs at T4.

Chi-square tests were used to examine potential differences with regard to the proportion of mothers and fathers

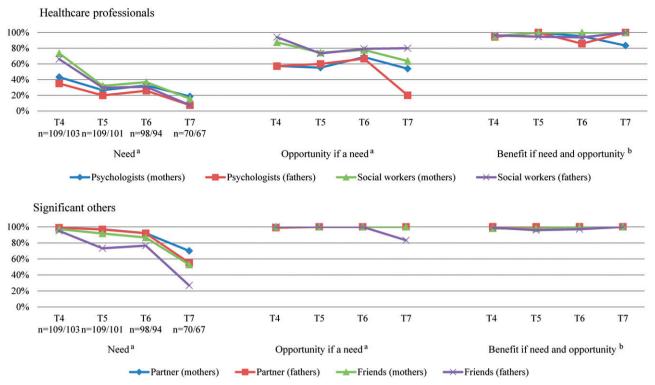


Figure 1. The proportion of mothers and fathers reporting a need, an opportunity and a benefit of support from healthcare professionals and significant others at T4–T7, respectively. The proportions are calculated on the basis of participants at the respective assessment. ^aMissing values: fathers' need of support from psychologists n = 1/T6, fathers' opportunity for support from psychologists n = 1/T6, fathers' opportunity for support from social workers n = 1/T4. ^bThose who reported having but not taking an opportunity are not included for benefits: psychologists n = 8/T4, n = 2/T5, n = 3/T6, n = 1/T7; social workers n = 12/T4, n = 4/T5, n = 10/T6, n = 1/T7; partner n = 1/T5, n = 3/T7; friends n = 1/T5, n = 1/T6, n = 6/T4. Those who reported not having a partner were not included regarding support from partner; mothers n = 9/T4, n = 1/T5, n = 9/T6, n = 10/T7; fathers n = 6/T4, n = 7/T5, n = 9/T6, n = 9/T4.

who report a need, an opportunity and benefit of support at the respective assessment (research question 3) and between parental (work, education, civil status, native country) and child (gender, diagnosis) characteristics with regard to the proportion reporting a need, an opportunity and benefit of support at the respective assessment (research question 4).

The significance level was set at p < .05 and all significant results are presented below. Data was analyzed using SPSS Statistics Version 22.0 (SPSS Inc., Chicago, IL, USA). Data from mothers and fathers was analyzed separately to handle dependency in the data caused by parents of the same child participating.

Results

Need, opportunity and benefit of support

See Figure 1 for a presentation of the proportion of parents who reported a need, an opportunity and benefit of support from psychologists, social workers, partners and friends at T4–T7.

At T4, 43% of mothers and 35% of fathers reported a need of support from psychologists. At T7, the corresponding percentages were 19 and 7%, respectively. At T4, 73% of mothers and 66% of fathers reported a need of support from social workers. At T7, the corresponding percentages were 16 and 7%, respectively. Over 90% reported a need of support from partners at T4–T6. At T7, 70% of mothers and 55% of fathers reported a need of support from partners. At T4, 97% of mothers and 95% fathers reported a need of support from

friends. At T7, the corresponding percentages were 53 and 27%, respectively.

At T4, 57% of mothers and fathers reported an opportunity for support from psychologists. At T7, the corresponding percentages were 54 and 20%, respectively. At T4, 88% of mothers and 94% of fathers reported an opportunity for support from social workers. At T7, the corresponding percentages were 64 and 80%, respectively. At all assessments, all mothers reported an opportunity of support from partners and friends. At T4–T7, all fathers reported an opportunity of support from partners. At T4–T6, all fathers reported an opportunity of support from friends, the corresponding percentage at T7 was 83%.

Almost all parents who reported an opportunity to talk to psychologists, social workers, partners and/or friends at T4–T7 reported having benefited from doing so.

Differences over time

See Table 2 for the proportion of parents who participated at all assessments who reported a need to talk to psychologists, social workers, partners and friends at the respective assessment.

A decreasing proportion of mothers reported a need of support from psychologists Q (3, n=70) = 19.5, p<.001, social workers Q (3, n=70) = 61.2, p<.001, partners Q (3, n=70) = 44.5, p<.001 and friends Q (3, n=70) = 62.0, p<.001. McNemar tests with Bonferroni adjusted p values showed a decrease between T4 and T5 for psychologists

Table 2. The proportion of mothers and fathers who reported a need to talk to psychologists, social workers, partners and friends at T4-T7 respectively.

		Psychologists			Social workers			Partners				Friends				
	T4	T5	T6	T7	T4	T5	T6	T7	T4	T5	T6	T7	T4	T5	T6	T7
Mothersa	44%	24%	37%	19%	73%	31%	37%	16%	81%	80%	76%	56%	97%	93%	90%	53%
Fathers ^b	37%	22%	28%	7%	69%	36%	36%	7%	82%	81%	78%	48%	96%	76%	84%	27%

 $a_{n} = 70.$

(p < .001) and social workers (p < .001) and a decrease between T6 and T7 for psychologists (p < .01), social workers (p < .001), partners (p < .001) and friends (p < .001).

A decreasing proportion of fathers reported a need of support from psychologists Q (3, n = 67) = 22.7, p < .001, social workers Q (3, n = 67) = 67.0, p < .001, partners Q (3, n = 67) = 44.5, p < .001 and friends Q (3, n = 67) = 96.2, p < .001 over time. McNemar tests with Bonferroni adjusted p values showed a decrease between T4 and T5 for social workers (p < .001) and friends (p < .001) and a decrease between T6 and T7 for psychologists (p < .01), social workers (p < .001), partners (p < .001) and friends (p < .001).

Differences between mothers and fathers

More mothers than fathers reported a need of support from friends at T5, χ^2 (1, n = 210) = 12.6, p < .001 and T7, χ^2 (1, n = 137) = 9.6, p < .01 and psychologist at T7 χ^2 (1, n = 137) = 3.7, p < .05. More mothers than fathers reported having had an opportunity of support from friends at T7 χ^2 (1, n = 55) = 6.5, p < .05.

Differences related to parental and child characteristics

More mothers with a university degree than lower education reported a need of support from social workers at T5 χ^2 (1, n = 109 = 7.45, p < .01 and partners at T6 χ^2 (1, n = 89) = 5.406, p < .05. More non-working parents than working parents reported a need of support from social workers at T5 (mothers χ^2 (1, n = 109) = 6.106, p < .05) and psychologists at T5 (fathers χ^2 (1, n = 101) = 5.115, p < .05). More foreign-born than native-born mothers reported a need of support from psychologists at t T6 χ^2 (1, n = 98) = 5.154, p < .05 and fewer foreign-born than native-born fathers reported an opportunity for support from social workers at T4 χ^2 (1, n = 67) = 14.691, p < .001. More fathers of children treated for a CNS tumor than fathers of children with other diagnoses reported a need of support from psychologists at T5 χ^2 (1, n = 101) = 5.115, p < .05 and T6 χ^2 (1, n = 93) = 4.606, p < .05 and from friends at T5 χ^2 n = 101) = 4.504, p < .05.

Discussion

This longitudinal study describes parents' reports of need, opportunity and benefit of support from healthcare professionals and significant others up to five years after end of a child's successful cancer treatment. Shortly after the end of treatment, a substantial number reported a need of support from healthcare professionals, subgroups reported such a need five years after end of treatment. A substantial number reported a need of support from significant others throughout the study. The proportion who reported having had an opportunity of support from healthcare professionals varied, whereas opportunities for support from significant others were available for the vast majority over the study period. Almost all parents reported having benefited from received support. Over time, the proportion reporting a need of support from healthcare professionals and significant others decreased. More mothers than fathers reported a need for support from friends and from psychologists. Higher level of education as well as not working was related to need of support after end of treatment. In addition, more foreign-born than native-born parents reported a need of support and were less likely to receive such support.

The fact that a subgroup reported a need of support from healthcare professionals five years after end of treatment agrees with previous findings demonstrating that a significant number of parents of children diagnosed with cancer report a clinically relevant level of distress years after end of treatment [2,3]. We have reported that 37% of parents report a need to talk to a psychologist and 63% report a need to talk to a social worker, four months after a child's cancer diagnosis [7]. The current study illustrates that shortly after end of treatment, the corresponding proportions are comparable as need for support from psychologists was reported by 43% of mothers and 35% of fathers and need for support from social workers by 73% of mothers and 66% of fathers. Previous reports have proposed that the time following a child's cancer treatment completion is a vulnerable period for parents [1,3], which is supported by the findings of this study.

Our results show that the proportion of parents reporting support needs decreases from shortly after up to five years after end of treatment. It has been proposed that parental distress abates over time [1]. However, in a previous report from this project we showed that PTSS in parents of children diagnosed with cancer is stable from three months after end of treatment up to five years after end of treatment [2]. Findings from this study suggests that the proportion of parents reporting a need of support from healthcare professionals at treatment completion is comparable to the proportion reporting such a need during treatment [7]. However, the longitudinal design reveals a decrease in the proportion of parents reporting a need of support, most evident between one year after end of treatment/18 months after transplantation and five years after end of treatment. It should be acknowledged that a substantial proportion of parents report a need of support beyond treatment

 $^{^{}b}n = 67.$

completion and that psychosocial services should be provided to parents at least throughout the first year following end of a child's cancer treatment.

More mothers reported a long-term need of support from friends and psychologists. This corresponds with results showing that mothers have an elevated risk of psychological long-term negative consequences of childhood cancer [2,5]. At all assessments, all mothers who reported a need to talk to partners and/or friends reported having had such an opportunity. The same holds true for fathers at the first assessments; however, five years after end of treatment not all fathers who reported a need to talk to partners reported having had such an opportunity. These results agree with findings showing that mothers of children diagnosed with cancer receive more social support from their family and extended networks than fathers [17]. The gender difference appears to need particular attention after end of treatment as no gender differences were found in our previous report of parental support needs during the child's treatment [7].

Importantly, almost all parents reported having benefited from received support. Previous studies have shown that psychosocial support and evidence-based interventions [8] and support from the partner and parents in the same situation help parents to cope with a child's cancer disease [18]. However, our findings illustrate that adequate support is not accessible to all parents in Sweden. Wakefield et al. have suggested that families with a history of childhood cancer may 'suffer in silence' after end of treatment [8], which is in line with our findings.

During treatment, parents of children with CNS tumors with higher education report more caregiver distress than those with lower education [19] and unemployed fathers report a higher level of distress than working fathers [20]. Our findings show that level of education and employment situation is related to parents' need of support after end of treatment. The results also show that more foreign-born than native-born parents report a need of support, however are less likely to receive such support. These latter results support findings illustrating that foreign-born parents of children diagnosed with cancer experience obstacles such as language barriers to support-seeking related to their foreign background [21]. Our study was not primarily designed to identify 'risk groups' for elevated support needs. However, until such groups are identified we suggest systematic identification of needs of support from healthcare professionals among all parents of children treated for cancer, in line with the standards of psychosocial care for parents of children with cancer [22].

Parents of children treated for CNS tumors were underrepresented in our sample, yet we found that more fathers of children treated for CNS tumors than other diagnoses reported a need of support from psychologists at T5 and T6 and from friends at T5. Children treated for CNS tumors are characterized by an elevated risk for late effects, which may be one reason accounting for this finding. The result highlights the importance of special attention to needs of support among parents of children treated for a CNS tumor.

According to recent guidelines for the psychosocial care of families of children diagnosed with cancer, 'access to

appropriate interventions for parents and caregivers should be facilitated to optimize parent, child and family well-being' [22]. This study shows that there is room for improvement with regard to parents' access to support from psychologists and social workers after end of a child's cancer treatment. The standards of psychosocial care recommend that pediatric cancer centers should have at least one staff member with education or training in supportive care (social work, psychology or counseling) [6]. A further recommendation is to ensure access to appropriate multimedia resources for parents and children throughout the disease trajectory [6]. Web-based methods enhance communication between healthcare professionals and pediatric oncology patients and their families [23]. We have shown that online psychological support decreases PTSS and depression among parents of children on cancer treatment [24]. Others have reported promising results for feasibility and acceptability of online psychological support for parents of children previously treated for cancer [25]. In response to previous research [2] and findings from this study we have developed an online psychological self-help program for parents of children previously treated for cancer in co-operation with people with lived experience of parenting a child treated for cancer.

We believe that the prospective, longitudinal design and the inclusion of mothers as well as fathers are methodological strengths of the study that contribute to the novelty of the results as well as to their clinical relevance. However, some potential methodological limitations should be considered. The assessment of need, opportunity and benefit of support was done by single questions and the 5-point-response scales were transformed to dichotomous variables. The transformation provides a measure of the presence of a need vs. no need and allows comparability with our corresponding findings for the treatment period [7]. However, such a categorization reduces variance and thus the power to detect potential differences over time and between groups. Some parents reported having had an opportunity but had not taken it. We do not know the reason for not having taken the opportunity and whether this circumstance had an influence on the findings regarding benefit. We would also like to mention that the data reported in this study was collected over many years which may have an influence on the validity of the findings. However, to the best of our knowledge, not much has changed in Sweden regarding access to support for parents of children diagnosed with cancer during these years. Taking potential limitations in consideration we believe that the findings fill an important gap in the literature regarding met and unmet needs of support experienced by parents of children diagnosed with cancer after end of successful treatment. Importantly, bereaved parents were excluded from this report and their needs of support remain to be elucidated.

Conclusion and implications

The proportion of parents reporting a need of support from healthcare professionals and significant others declined over



time. Still five years after end of treatment, a substantial group reported a need of support from significant others and a subgroup reported a need of support from healthcare professionals. Importantly, almost every parent perceived received support from healthcare professionals as beneficial. The findings illustrate that access to psychosocial services needs to increase for parents of children successfully treated for cancer. Future studies evaluating accessible, evidencebased psychological support for parents targeting the vulnerable period after end of a child's cancer treatment are encouraged.

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References

- Wakefield CE, McLoone JK, Butow P, et al. Parental adjustment to the completion of their child's cancer treatment. Pediatr Blood Cancer. 2011;56:524-531.
- Ljungman L, Hovén E, Ljungman G, et al. Does time heal all wounds? A longitudinal study of the development of posttraumatic stress symptoms in parents of survivors of childhood cancer and bereaved parents. Psycho-oncology. 2015;24:1792-1798.
- Wijnberg-Williams BJ, Kamps WA, Klip EC, et al. Psychological adjustment of parents of pediatric cancer patients revisited: five years later. Psycho-oncology. 2006;15:1-8.
- Pelletier W. Bona K. Assessment of financial burden as a standard [4] of care in pediatric oncology. Pediatr Blood Cancer. 2015;62:S619.
- Lindahl Norberg A, Montgomery SM, Bottai M, et al. Short-term and long-term effects of childhood cancer on income from employment and employment status: a national cohort study in Sweden. Cancer. 2017;123:1238-1248.

- Steele AC, Mullins LL, Mullins AJ, et al. Psychosocial interventions and therapeutic support as a standard of care in pediatric oncology. Pediatr Blood Cancer. 2015;62:S585-S618.
- Pöder U, von Essen L. Perceptions of support among Swedish parents of children on cancer treatment: a prospective, longitudinal study. Eur J Cancer Care. 2009;18:350-357.
- Wakefield CE, McLoone JK, Butow P, et al. Support after the completion of cancer treatment: perspectives of Australian adolescents and their families. Eur J Cancer Care (Engl). 2013;22:530-539.
- [9] Abu-Raiya H, Hamama L, Fokra F. Contribution of religious coping and social support to the subjective well-being of Israeli muslim parents of children with cancer: a preliminary study. Health Soc Work. 2015:40:e83-e91.
- [10] Willard VW, Hostetter SA, Hutchinson KC, et al. Benefit finding in maternal caregivers of pediatric cancer survivors: a mixed methods approach. J Pediatr Oncol Nurs. 2016;33:353-360.
- [11] Wijnberg-Williams BJ, Kamps WA, Klip EC, et al. Psychological distress and the impact of social support on fathers and mothers of pediatric cancer patients: long-term prospective results. J Pediatr Psychol. 2006;31:785-792.
- Norberg AL, Boman KK. Parents' perceptions of support when a child has cancer: a longitudinal perspective. Cancer Nurs. 2007;30:
- Ljungman L, Cernvall M, Grönqvist H, et al. Long-term positive [13] and negative psychological late effects for parents of childhood cancer survivors: a systematic review. PLoS One. 2014:9:e103340.
- Hile S, Erickson SJ, Agee B, et al. Parental stress predicts functional outcome in pediatric cancer survivors. Psycho-oncology. 2014;23:1157-1164.
- [15] Pierce L, Hocking MC, Schwartz LA, et al. Caregiver distress and patient health-related quality of life: psychosocial screening during pediatric cancer treatment. Psycho-Oncology. 2017 [cited 2016 Jun 201.
- Gustafsson G, Kogner P, Heyman M. Childhood cancer incidence and survival in Sweden 1984-2010. Report from the Swedish Childhood Cancer Registry. Stockholm: Karolinska Institute; 2013.
- Clarke NE, McCarthy MC, Downie P, et al. Gender differences in [17] the psychosocial experience of parents of children with cancer: a review of the literature. Psycho-oncology. 2009;18:907-915.
- Gibbins J, Steinhardt K, Beinart H. A systematic review of qualitative studies exploring the experience of parents whose child is diagnosed and treated for cancer. J Pediatr Oncol Nurs. 2012; 29:253-271.
- Choi EK, Yoon SJ, Kim JH, et al. Depression and distress in caregivers of children with brain tumors undergoing treatment: psychosocial factors as moderators. Psycho-oncology. 2016;25: 544-550.
- [20] Sloper P. Predictors of distress in parents of children with cancer: a prospective study. J Pediatr Psychol. 2000;25:79-91.
- [21] Pergert P, Ekblad S, Björk O, et al. Resourcing: an approach used by foreign-born parents struggling on in childhood cancer care. Eur J Oncol Nurs. 2016;23:1-7.
- Kearney JA, Salley CG, Muriel AC. Standards of psychosocial care for parents of children with cancer. Pediatr Blood Cancer. 2015; 62:S632-S683.
- [23] Akard TF, Wray S, Gilmer MJ. Facebook advertisements recruit parents of children with cancer for an online survey of web-based research preferences. Cancer Nursing. 2015;38:155-161.
- [24] Cernvall M, Carlbring P, Ljungman L, et al. Internet-based guided self-help for parents of children on cancer treatment: a randomized controlled trial. Psycho-oncology. 2015;24: 1152-1158.
- Wakefield CE, Sansom-Daly UM, McGill BC, et al. Acceptability and [25] feasibility of an e-mental health intervention for parents of childhood cancer survivors: "cascade". Support Care Cancer. 2016;24: 2685-2694.