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Persistently Low Peace of Mind in Parents of Cancer Patients: A 5-Year Follow-Up Study

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Abstract

Background: Pediatric cancer affects the well-being of the entire family. Previously, our group found that 76% of parents experience low peace of mind after diagnosis. Herein, we present a 5-year follow-up study of these same parents, aiming to determine whether low peace of mind persisted, and what baseline variables associate with persistently low peace of mind.

Procedure: Cross-sectional survey of parents of children with cancer between April 2004 and September 2005 within 1 year of diagnosis, and a follow-up questionnaire administered at least 5 years later.

Results: 66% of parents whose children were living and who were able to be contacted completed follow-up questionnaires (91/138). Of these parents, 77% (70/91) were parents of disease-free survivors and 23% (21/91) had recurrent disease. The majority of parents (66%, 53/88) had low peace of mind 5 years after diagnosis, regardless of relapse status or prognosis. Additionally, 28% of parents of disease-free survivors reported being very/extremely worried about relapse (18/66), late toxicities (19/66), and late effects (19/66). Each worry was associated with low peace of mind (OR between 9.66 and 20.09 for each worry). In bivariable logistic regression, low peace of mind at 5 years was negatively associated with trusting the physician completely at baseline, with and without adjustment for relapse status (OR 0.32, 95% CI 0.12 to 0.87, $p=0.032$, adjusted for relapse).

Conclusion: Most long-term studies and interventions have focused on parental bereavement. Our findings show that most parents are changed by pediatric cancer, even when children survive and the future is bright.

Keywords

Peace of mind; psychosocial oncology; pediatric oncology; survivorship; parents; parent care

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Introduction

The diagnosis of pediatric cancer is traumatic and negatively affects the well-being of the entire family. For example, 56% of parents in one study reported significant psychological distress during treatment.¹ In another study, mothers of children undergoing cancer treatment reported decreased social functioning, general health, vitality, and mental health.² Data regarding long-term parental psychosocial outcomes, however, are not as clear. One study found that few parents demonstrated poor social functioning five years post-treatment, but worse social functioning was associated with high-risk treatment.³ Parents of cancer survivors in another study reported persistent but decreasing post-traumatic stress symptoms five years after treatment.⁴ For some parents, long-term psychosocial consequences persist long into survivorship.⁵ However, a Swedish study of bereaved parents found that 74% of parents had worked through most or all of their grief by 4 to 9 years after their child's death.⁶ All of these studies were limited by being cross-sectional and thus unable to prospectively identify potential predictors of parental psychological and existential outcomes.

Existential distress is a crisis evoked by life-altering or life-threatening news, such as the diagnosis of cancer in one's child. This existential distress can possibly be resolved or lessened through the formulation of meaning.⁷ In a previous study from 2009, we identified two domains of existential distress: peace of mind and sense of purpose.⁸ Peace of mind relates to a sense of harmony within oneself, feeling peaceful, feeling able to reach deep down for comfort, and the confidence that things will be okay no matter what happens with the illness of one's child. Sense of purpose relates more so to having a reason for living, feeling a sense of meaning and purpose, and feeling productive. Our group found that only 24% of parents experienced high peace of mind during their child's cancer treatment, whereas 81% endorsed high sense of purpose. High peace of mind was associated with high-quality communication and information from physicians, but not the child's prognosis. Herein, we report a 5-year follow-up survey of these same parents that aimed to determine whether low peace of mind persisted, and whether baseline variables predicted long-term peace of mind.

Methods

We surveyed parents of children treated for cancer who had previously participated in a survey study about medical communication at Dana-Farber/Boston Children's Hospital at least 5 years prior. In the original study, parents and oncologists of 194 children with cancer responded to surveys between 30 days and 1 year after diagnosis.^{9–11} We asked the parent with primary responsibility for decision making to participate. If both parents equally shared decision-making roles, they chose which parent participated.

In this follow-up study, we administered the same survey items to parents at least 5 years after the initial cancer diagnosis. Potential participants received a mailed letter inviting them to participate, with a postcard to return if they declined participation. Parents who agreed to participate took part in telephone or in-person interviews by trained interviewers who read aloud the study questionnaire question by question along with response options. Outside of

routine follow-up care, these parents did not receive any specific educational interventions between the administration of first and second surveys.

We excluded parents whose children had died (n=26), those unable to be reached (n=24), and those whose physician declined permission to contact (n=6), leaving 138 eligible parents (Supplemental Figure S1). Bereaved parents were excluded from this analysis given its focus on long-term outcomes and worry about the future. Parents of children in remission and children with relapsed disease were included in this analysis to ensure we fully captured the spectrum of psychosocial outcomes and parental needs. To evaluate for relapse, we asked primary oncology providers of each patient whether the patient had experienced relapse prior to approach. We confirmed this with chart review.

Separate analogous questionnaires were administered to parents of children with relapsed and non-relapsed disease. The majority of questions were identical, but only the questionnaire for parents of disease-free survivors included items about the child's current state of health and life after cancer treatment, because we felt that current health was likely influenced by relapse, and questions about life after cancer treatment may not be applicable to all parents of children with relapse. Questionnaires in this study utilized items or modified items from the previously developed questionnaire,^{9–11} along with new questions based on literature review and general principles of survey design (which were subjected to pilot testing with parents for clarity and face validity before use). Physicians were surveyed at baseline, during the initial study of children in the first year of cancer treatment, to estimate prognosis. This study was approved by the institutional review board at Dana-Farber Cancer Institute.

Data Collection

In the 5-year follow-up survey, peace of mind was assessed using the peace of mind subscale of FACIT-Sp scale.⁸ Parents were presented with statements about their experiences (I feel peaceful; I am able to reach down deep into myself for comfort; I have trouble feeling peace of mind; I feel a sense of harmony within myself; I know that whatever happens with my child's illness, things will be okay) and asked to report the extent to which these statements applied to them by choosing a response of extremely, very, somewhat, a little, or not at all.⁸ To evaluate parental worry, parents were asked the following questions: "How worried are you now that your child's cancer could come back at some point in the future;" "How worried are you now that your child could experience new side effects of treatment at some point in the future;" "How worried are you now that your child's cancer or its treatment will affect your child's well-being at some point in the future." Responses included "extremely", "very", "somewhat", "a little", and "not at all."

Additionally, the following variables were evaluated in the baseline questionnaire in the first year after diagnosis. Trust in the oncologist was assessed with a question from the Trust in Physician scale ("How much do you trust your child's oncologist's judgment about your child's medical care?")^{12,13} Communication quality was assessed at diagnosis using a previously described scale,^{14,15} including questions about oncologist sensitivity ("How often does your child's oncologist convey information in a sensitive manner?"); time for questions ("How often does your oncologist take enough time to answer your questions?"); clarity

(“When you ask questions, how often do you get answers that are understandable?”); and listening (“How often has the way your child’s oncologist communicated with you about your child’s cancer made you feel listened to?”). Response categories included always, usually, sometimes, and never. Information quality was assessed with a previously developed scale^{8,10} that asked parents to rate information given about diagnosis, treatment, prognosis, functional outcome, cause of cancer, response to treatment, and overall information.

Data Analysis

We evaluated 5-year parental peace of mind for parents of relapsed versus disease-free children using Chi-square test. For peace of mind, scores were dichotomized at a score of 4 or greater, a cutoff chosen to correspond approximately to the categories “extremely” or “very” that we felt generally indicated a strong sense of peace of mind, which is consistent with prior publications.⁸ This cutoff also allowed us to compare findings with our initial report of findings in the year after diagnosis.⁸

We performed McNemar’s test to determine if the proportion of parents with low peace of mind changed over time. We next used logistic regression to assess the association of low peace of mind at 5 years with each baseline variable, including gender, race/ethnicity, parent education level, favorable prognosis, high-quality oncologist communication style, high quality information, and trust in oncologist, and adjusting for relapse status. Finally, we analyzed the association between worries and peace of mind at 5-years using Chi-square test and bivariable logistic regression, with each “worry” question dichotomized at very/extremely worried. All reported p-values are two-sided at the 0.05 significance level, and statistical analyses were conducted using SAS statistical package v9.4.

Results

Of 138 eligible families, 91 agreed to participate (response rate 66% of those eligible, 54% of those alive). 86 parents completed both baseline and follow-up scales on peace of mind, representing 62% of those eligible. Seventy participants were parents of disease-free survivors and 21 were parents of children with recurrent/refractory disease. No additional information was collected on disease status, including whether children with relapse were receiving active therapy or their extent to response to prior therapy. Physician-rated prognosis at baseline was good (>75% chance of cure) for 65% of children with cancer. The majority of parent respondents were female, Caucasian, and well educated. (Table 1)

Long-term Peace of Mind

At least 5 years after diagnosis, the majority of parents demonstrated low peace of mind (53/88, 60%), and this outcome did not differ based on relapse status ($p=.86$, Chi-square test). (Table 2) A lower proportion of parents reported low peace of mind at 5 years (52/86, 60%) compared to baseline (65/86, 76%) ($p=0.03$, McNemar’s test). (Table 3) To further evaluate low parental peace of mind, we performed bivariable analyses comparing low peace of mind at 5 years to baseline variables. Low peace of mind at 5 years was negatively associated with trusting the physician completely at baseline, with and without adjustment for relapse status (OR 0.32, 95% CI 0.12 to 0.87, $p=0.032$, adjusted for relapse). (Table 4)

We did not find an association between low peace of mind at 5 years with any other variables, including parent gender, race/ethnicity, education level, prognosis, quality of information, or quality of physician communication style (all $p > .05$).

Long-term Parental Worry

At the 5-year time point, an equal proportion of parents reported being very/extremely worried about relapse (19/69, 28%), new side effects in the future (19/68, 28%), and effects of cancer or treatment on their child's future well-being (19/68, 28%). (Table 5) Low peace of mind at 5-years was associated with the presence of each worry in parents of disease-free survivors ($p < .001$ for each worry, Chi-square test). (Table 6) We also performed logistic regression to assess the strength of association between individual worries and low peace of mind: worry about relapse (OR 20.09, 95% CI 2.47 to 163.28, $p = .005$); worry about new side effects of treatment in the future (OR 9.66, 95% CI 2.00 to 46.58, $p = .005$); worry about effect of cancer or treatment on future well-being (OR 9.66, 95% CI 2.00 to 46.58, $p = .005$).

Discussion

Sixty percent of parents in this follow-up study reported low peace of mind 5 years after the child's cancer diagnosis. Although the proportion of parents reporting low peace of mind decreased slightly over time, this existential burden persisted for the majority of parents. Additionally, many parents reported persistent worries, with 28% of parents of disease-free survivors being very or extremely worried about relapse, late toxicities, and late effects. These worries were highly associated with low peace of mind, suggesting that persistent worry is a contributor or driver of this low peace of mind.

Parents might be expected to worry about late toxicities and late effects, given that up to 80% of survivors of pediatric cancer will experience at least 1 chronic late effect and 25% will experience a severe or life-threatening chronic health condition.^{16,17} However, clinicians should still aim to mitigate the potential negative effects of these worries. Such worries might be addressed by enhancing longitudinal communication about late effects and toxicities, reinforcing signs and symptoms that parents should monitor, providing a clear explanation of the laboratory and imaging monitoring strategy, and explaining contingency planning should late effects or toxicities arise. In prior work, we found that nearly every parent whose child was undergoing cancer therapy found late effects information to be very or extremely important near time of diagnosis, 4 months after diagnosis, and 12 months after diagnosis.¹⁸ By effectively providing late effects information and supporting an active role for parents in monitoring and managing these side effects and late toxicities, clinicians might help parents to better manage their uncertainties and worries, thereby improving peace of mind. Additionally, the act of opening up conversation about these issues and acknowledging difficult emotions and fears may be therapeutic in itself. By listening and acknowledging these worries, the clinician can reinforce to the parents that many people feel the same way they do and that they are not alone.

Fear of relapse was also prominent for many parents in this study. Although worry about relapse was associated with low peace of mind, actual relapse status was not. This suggests that worrying about relapse is distressing to most parents, yet parents may adapt

psychologically to the reality of relapse when it actually happens. Although surprising, this finding fits with psychological and neurobiological models that identify uncertainty and anticipation as key contributors to anxiety.^{19,20} Chronic worry itself is considered a state of anticipatory anxiety.²⁰ Clinicians should be aware of how burdensome continuing uncertainty can be for parents of children with cancer.

This worry about relapse persisted despite the fact that most relapses would have occurred by 5 years post-treatment. It is possible that parents were not aware of this fact and would have benefitted from more complete disclosure of information. However, worry may persist for some parents *despite* understanding that relapse is unlikely. Pediatric cancers are rare diseases, so it may be difficult for parents to feel reassured by hearing that “relapse is extremely unlikely at this point.”

The only variable at baseline associated with high peace of mind was “completely trusting the physician.” Fostering a healing relationship is a core function of communication in oncology, and one aspect of a strong therapeutic alliance is trust between the parent and physician.^{21,22} In pediatrics, this healing relationship is supported when clinicians communicate with sensitivity,^{23,24} honesty,²⁵ and empathy.^{26,27} This relationship can also be supported by the provision of high-quality information^{23,28} even if it is upsetting.¹¹ For some parents, this trusting relationship is also bolstered when clinicians offer a professional opinion during decision-making.^{22,28,29} Although some patients may have changed providers during survivorship, patients at our institution often continue care with their primary oncology team over time. While this healing relationship can serve as a foundational support as parents and their children navigate active treatment, our results suggest that such a healing relationship can also have long-standing effects into survivorship.

Notably, several individual parents had changes in their peace of mind over time, with some transitioning from low to high peace of mind and other transitioning from high to low. For parents whose peace of mind worsened, it is possible that new toxicities developed over time leading to increased worries. Alternatively, these parents may have developed new worries as clinical follow-up became less frequent. For parents whose peace of mind improved over time, perhaps time away from acute treatment without severe toxicities was reassuring. Additionally, life events or experiences unrelated to the child’s cancer might have influenced peace of mind. These changes over time highlight the importance of considering the individual characteristics and needs of each family.

Combined, our results raise several questions worthy of further study. Are these worries modifiable or inherent to parenting? Can effective communication during and after treatment better mitigate the existential angst of parents? If so, which members of the medical team should provide this communication and support to parents during survivorship? Parents can also find mutual support among family members or peer support groups. Should clinicians further promote these groups to parents as they transition to survivorship? Future studies should seek to understand how to minimize existential angst and better support parents as they and their children transition to survivorship.

This study, however, should be interpreted in light of limitations. First, 91 of 138 eligible parents participated in this follow up study. Twenty-four parents were excluded because they were unable to be reached, and 6 had physicians who declined permission to contact them. These exclusions raise the possibility of selection bias. Furthermore, this cohort was predominantly white, female, and well-educated, and this study was performed at a single center, all of which might affect generalizability of the results. The small sample size and predominance of hematologic malignancies might also affect generalizability. Lastly, our small sample size had limited power to identify predictors of low peace of mind.

In this study, we found that the majority of parents experience persistently low peace of mind 5 years after their child's diagnosis of cancer, regardless of relapse status or prognosis. Persistent worries seem to be a major contributor to this low peace of mind, and completely trusting the physician at baseline was associated with higher peace of mind. While most long-term studies and interventions have focused on the bereavement process, clinicians should recognize that all parents and families are changed by the diagnosis and treatment of cancer, even when children survive and the future is bright. Future studies should seek to understand longitudinal psychosocial and existential distress of parents in order to develop strategies to provide effective and lasting support.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations:

CI Confidence Interval

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Table 1.

Parent and Patient Characteristics

	Disease Relapsed		Disease-Free Survivor	
	n=21	%	n=70	%
Parent age				
<30	1	5	0	0
30 to 39	6	28	14	20
40+	14	67	56	80
Parent gender				
Female	16	76	58	84
Male	5	24	11	16
Parent race/ethnicity				
White	18	86	63	90
Black	1	5	1	1
Hispanic	2	9	4	6
Other	0	0	2	3
Parent education				
High school graduate or less	5	24	7	10
College graduate or technical school	10	48	43	61
Graduate/professional school	6	28	20	29
Parent marital status				
Married/living as married	18	86	54	77
Other	3	14	16	23
Child age at diagnosis				
0 to 2	9	43	16	23
3 to 6	6	29	26	37
7 to 12	2	9	14	20
13 to 18	4	19	14	20
Child gender				
Female	12	57	36	51
Male	9	43	34	49
Diagnosis				
Hematologic malignancy	9	43	49	70
Solid tumor	5	24	11	16
Brain tumor	7	33	150	14
Physician-rated prognosis				
>75% chance of cure	13	62	53	76
50% – 74%	3	14	10	14
<50%	5	24	7	10
Parent-rated prognosis				

	Disease Relapsed		Disease-Free Survivor	
	n=21	%	n=70	%
>75% chance of cure	16	80	60	86
50% – 74%	4	20	6	8
<50%	0	0	4	6

Missing Data: parent gender (1), parent-rated prognosis (1)

Table 2.

Peace of mind and Relapse Status 5 years after Diagnosis of Cancer

	Disease Relapsed		Disease-Free Survivor	
	N (21)	%	N (70)	%
Peace of Mind				
High peace of mind (4+)	8	38	27	40
Low peace of mind (Less than 4)	13	62	40	60

p=.86 by Chi-square test. Missing data: Disease-Free Survivor (3)

Table 3.

Parental Changes in Peace of Mind over Time

	5 Year Survey		Total
Baseline Survey	Low peace of mind (<4)	High peace of mind (4+)	
Low peace of mind (<4)	41 (48%)	24 (28%)	65 (76%)
High peace of mind (4+)	11 (13%)	10 (11%)	21 (24%)
Total	52 (60%)	34 (40%)	86

p=.028, by McNemar's Test. Missing data: baseline survey (3), 5-year survey (2).

Table 4.

Variables at Baseline Associated with Low Peace of Mind at 5 years

	OR (95% CI), unadjusted	P Value	OR (95% CI), adjusted for relapse	P Value
Parent gender male	1.61 (0.51, 5.12)	0.42	1.6 (0.5, 5.1)	0.43
Nonwhite race/ethnicity	1.36 (0.32, 5.85)	0.68	1.35 (0.31, 5.82)	0.69
Parent education college graduate or higher	0.46 (0.12, 1.83)	0.27	0.46 (0.11, 1.86)	0.27
Child is extremely or very likely to be cured (physician report)	0.75 (0.28, 2.02)	0.57	0.76 (0.28, 2.06)	0.58
High quality physician communication style *	1.14 (0.49, 2.7)	0.76	1.15 (0.49, 2.7)	0.76
High quality information *	0.53 (0.22, 1.28)	0.16	0.53 (0.22, 1.29)	0.16
Trust in Physician completely	0.33 (0.12, 0.88)	0.03	0.32 (0.12, 0.87)	0.03

n=91. Missing data: gender (1), physician communication style (1), quality of information (4), peace of mind (3)

*
Less than or equal to median was considered low quality.

Table 5.

Long-term Worry in Parents of Disease-free Survivors 5 years after Diagnosis

	N (70)	Percent
Worry about relapse		
Extremely	7	10
Very	12	18
Somewhat	23	33
A little	22	32
Not at all	5	7
Worry about new side effects of treatment in the future		
Extremely	10	15
Very	9	13
Somewhat	24	35
A little	16	24
Not at all	9	13
Worry about effect of cancer or treatment on future well-being		
Extremely	12	18
Very	7	10
Somewhat	24	35
A little	17	25
Not at all	8	12

n=70. Missing data: worry about relapse (1), worry about new side effects (2), worry about effect of cancer or treatment (2).

Table 6.

Long-term Worries associated with Low Peace of Mind 5 Years after Diagnosis

	Low peace of mind (<4)	High peace of mind (4+)	Total	P Value
Worry about relapse				0.0003
Very/Extremely	17	1	18	
Not Very/Extremely	22	26	48	
Total	39	27	66	
Worry about new side effects of treatment in the future				0.0014
Very/Extremely	17	2	19	
Not Very/Extremely	22	25	47	
Total	39	27	66	
Worry about effect of cancer or treatment on future well-being				0.0014
Very/Extremely	17	2	19	
Not Very/Extremely	22	25	47	
Total	39	27	66	

n=66. Missing data: worry about relapse (3), worry about new side effects (3), worry about effect of cancer or treatment (3).