Distress in parents of children with advanced cancer enrolled in the PediQUEST Study

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ABSTRACT

Purpose: Psychological distress (PD) in a parent may have an effect on their children and other members of their family. We sought to describe the prevalence and predictors of PD among parents of children with advanced cancer.

Patients and Methods: Parents of children with progressive, recurrent, or refractory cancer who were treated at one of 3 large children's hospitals and enrolled in the Pediatric Quality of Life and Evaluation of Symptoms Technology (PediQUEST) study completed the Survey of Caring for Children with Cancer (SCCC). Parent PD was measured by the Kessler-6 general psychological distress scale. K6 scores of ≥ 7 suggest high distress and those ≥ 13 indicate serious psychological distress (SPD, U.S. SPD prevalence is 3%). Linear and logistic regression models were used to evaluate associations between PD and child/ parent factors.

Results: 86 of 104 enrolled parents completed SCCC (83% participation); 81 had complete K6 data. Over 50% of parents reported high distress and 16% met criteria for SPD. Parent and child demographic factors were not associated with parent PD in this study; however, parent perceptions of prognosis, goals of therapy, perceived child symptoms/suffering, as well as financial hardship were. In multivariate analyses, parent PD scores were higher among those whose care goals were incongruent with their prognostic understanding, whose child was suffering highly, and who perceived great economic hardship due to their child's illness.

Conclusions:

Parenting a child with progressive cancer can profoundly affect mental health. Interventions aimed at aligning care goals with prognostic understanding, easing child suffering and financial hardship may improve parental emotional wellbeing.

INTRODUCTION

Caring for a child with cancer can be profoundly distressing to parents.[1,2] Not only do parents witness their child's protracted physical and emotional suffering,[3,4] they also must contend with the ultimate threat to their child's life,[5] as well as dramatic changes in their family structure and function, potential needs for relocation, changes in employment and financial challenges.[1-4,6] Prior studies have shown that this distress may affect the entire family; parental psychological symptoms have been correlated with poor adjustment, low quality of life, and poor mental health in both pediatric cancer patients[7-13] and their siblings.[14,15]

Psychological distress (PD) is an indicator of overall mental health.[16] Parents of children with cancer have higher than average levels of PD which may persist for up to 5 years after their child completes cancer-therapy.[6] Parental PD has been described in various cancer-settings, including among children on- and off-therapy,[1,3,12,13] and children undergoing hematopoietic stem cell transplantation (HST).[13,17,18] It has been associated with "medical factors" such as the child's type of cancer,[19] duration of illness,[1,12,18,20] or completion of treatment;[3,6] "child factors" such as the presence of child physical or emotional distress;[19,21] as well as "parent factors" such as sociodemographic characteristics, economic hardship and degree of social support.[8,9,17] Parents who lose a child to cancer are at greater risk for poor psychological outcomes.[22-36]

Despite this large body of literature, few studies have focused specifically on the effects of parenting a child with progressive, relapsed or refractory cancer, and available results are contradictory. In one study, parents of children with recurrent, but curable, disease were evaluated and found to be more likely to report depression, anxiety, feelings of helplessness and loneliness than parents of children in remission.[37] Investigators noted that the lack of positive parental expectations was strongly related to negative emotions. Conversely, another study assessed the health status of parents with terminally ill children and found parents' physical and emotional health to be similar to that of the general population. These discrepancies may be due to the use of different instruments in different settings; the generic instruments used in the latter study may have lacked the sensitivity to detect parent distress in the setting of serious child illness. [38] In order to provide optimal support to families who are experiencing this difficult circumstance, a better understanding of parent psychological wellbeing is needed.

In this study, we aim to describe the prevalence of psychological distress among parents of children with advanced cancer who were enrolled in a pilot randomized controlled trial, the PediQUEST (Pediatric Quality of Life and Evaluation of Symptoms Technology) Study. In addition, we explore whether parental distress is associated with known "medical," "child", and "parent" factors. Ultimately, this research has the potential to better enable clinicians to identify parents and their families who are most at risk for psychological distress.

METHODS

As part of the PediQUEST Study, we surveyed all parents or legal guardians of enrolled children. The PediQUEST pilot RCT assessed the effects of measuring child-reported symptoms and quality of life, and providing feedback to providers and families, using the PediQUEST computerized system. Participating children were at least 2 years of age, had at least a 2-week history of progressive, recurrent or non-responsive cancer, and received cancer care at the Dana-Farber Cancer Institute/Children's Hospital Boston (DFCI/CHB), Children's Hospital of Philadelphia (CHOP), or Seattle Children's Hospital (SCH). Parents or legal guardians were eligible if they had written command of English, and were able to understand and complete self-administered surveys. Parents of enrolled children were mailed or handed the survey at the time of enrollment, along with a self-addressed, stamped return envelope. Two bi-weekly reminders were in place (by phone or face-to-face if patient came to clinic) for parents who did not respond. 104 children were enrolled from December 2004 to June 2009.

Study Instrument

Parents were administered an adapted version of the Survey about Caring for Children with Cancer (SCCC).[39] This comprehensive paper and pencil, self-administered survey evaluates parents' perceptions about the child's illness (current treatment, and perceived prognosis, treatment goals, and suffering from treatment or the illness), care received (type of care, delivery of "good" or "bad"

news, communication, team work), and emotional and financial impact of illness. In addition, the SCCC collects parent-reported socio-demographic information. Child's age, gender, diagnosis, and dates of disease progression were abstracted from the medical records.

Main Dependent Variable

Parent psychological distress was the main dependent variable and was measured by Kessler-6 (K6) general psychological distress scale.[40] This 6-item scale was developed for the US National Health Interview Survey and is used by the World Health Organization's World Mental Health Initiative. It has been widely validated showing high discriminative properties.[40,41] The instrument asks: "During the past 30 days, how often did you feel (a) nervous? (b) hopeless? (c) restless or fidgety? (d) so depressed that nothing could cheer you up? (e) that everything was an effort? (f) worthless?" Possible responses are "none of the time," "a little of the time," "some of the time," "most of the time," and "all of the time." Reponses are scored on a 5-point Likert scale and summed to generate a total symptom score between 0-24; scores of 7 or more are indicative of high distress and scores of 13 or greater suggest serious psychological distress (SPD).[42] In the United States, mean K6 scores are approximately 2.5 for well-adults.[43] Serious, debilitating psychological distress is rare, with an estimated prevalence of 2-3%,[44] with higher prevalence among adults with chronic or life-threatening illness.[45] Parental distress is reported as mean K6 scores and as proportion of parents with SPD.

Independent Variables

Child and Medical Factors

Child-related variables included the child's gender, age, cancer type, current or on-going receipt of cancer-directed therapy, time from first disease progression to survey date, and child suffering during past month due to symptoms and treatment. Child age was stratified into 3 groups: pre-school (ages 2-6 years), school-age (7-12 years), and adolescent (13+ years). Child suffering and whether the child was receiving cancer-directed therapy were reported by parents on the SCCC. All other variables were abstracted from the medical chart.

Parent Factors

All parent factors were obtained from the SCCC. Socio-demographic variables included parents' gender, age, race/ethnicity, marital status, level of education, annual income and social support. Parent age and social support scores were dichotomized at the 25th percentile. Annual family income was dichotomized to below and above the poverty level of $25,000 for a family of 4 or more in the year 2007.[46] Social support was assessed using an adapted, 9-item, validated version of the social support subscale of the Medical Outcomes Study (MOS-SS).[47] MOS-SS raw scale scores (i.e., simple algebraic sums) were transformed into a 0-100 scale; the higher the score, the better the perception of social support. Parents were also asked to share: (i) their understanding of their child's current prognosis, (ii) what goals were they pursuing by providing the current

medical therapy to their child, (iii) degree of child suffering, and (iv) degree of family economic hardship due to their child's cancer. Responses were elicited using 4 and 5 points Likert type scales.

Goals of therapy (to cure, keep hoping, do everything, extend life without a hope of cure, and lessen suffering), were categorized as "congruent" or "incongruent" depending on parent's understanding of prognosis [Figure 1]. Specifically, when parents believed cure was likely *and* endorsed cure, or when parents believed cure was unlikely *and* were focused on "extending life" or "lessening suffering," goals were considered congruent. On the other hand, when parents recognized that cure was unlikely but aimed to cure, the goal was considered incongruent. In addition, when treatment goals were to "keep hoping" or "do everything", because of their poor alignment with prognostic information, they were always categorized as incongruent.

Statistical Methods

Analyses were performed using STATA statistical software (Statacorp LP, College Station, Texas). A complete case analysis was performed; missing data were not imputed. Frequencies and means were used to characterize parent, medical and child variables. To evaluate the association of parental psychological distress and child and parent factors, we built linear and logistic regression models. Multivariate analyses were adjusted for parent's gender and increasing child age group based on prior associations described in the

literature.[16,45] Where variables were clustered by clinical similarity, we selected those with the most clinical significance *a priori*. For example, several questions address parent perceptions of child-symptoms and suffering; we used "overall suffering" in our model as it captured elements of both physical and psychological suffering.

RESULTS

Of the 104 enrolled families, 86 parents (83%) completed the survey. Child's age, type of cancer and survival in the respondent and non-respondent groups were similar. This analysis reports on the 81 parents (78% of the total sample) with complete K6 data.

The mean parental distress (K6) score was 7.9 (SD 4.4) and 50% of parents had a score of 8 or higher (inter-quartile range, IQR, 5-11). Thirteen parents (16%) met criteria for serious psychological distress. Fifty-five parents (69%) reported that they felt more distress than usual, 14 (18%) said they felt the same distress as usual, and 10 (13%) reported less distress than usual. Parent distress was strongly linked to their child's health. Seventy parents (89%) reported that their child's health contributed "a lot or a great deal" to their distress and these parents tended to have higher K6 scores than parents who reported their child's health contributed less to their distress [Figure 2]. Parent distress was not associated with recent receipt of "bad news".

Table I presents the main characteristics of the sample with corresponding mean parental K6 scores and likelihoods of parent SPD. At the time of enrollment, most children were receiving cancer-directed therapy and 85% had been diagnosed with progressive disease for at least 2 months (median duration of progressive disease was 195 days, inter-quartile range 86-353 days). There was a trend toward higher distress scores among parents of younger children; mean scores in parents of pre-school children were on average 2 points higher than those of parents of older children ($p=0.081$). Other child characteristics were not associated with increased risk of parent SPD. Parent-respondents were predominantly White women who were older than 38 years of age and married. There were trends towards higher mean K6 scores among women ($p=0.100$) and parents younger than 38 years ($p=0.072$). Non-White parents also were at higher risk for SPD (OR 6.2, 95% CI 1.1-35.5). Parents reported high levels of social support (standardized median score 83%). Fourteen percent of the respondents who provided annual income data were below the poverty level. No other parental demographic factors were associated with mean K6 scores (all other p-values >0.100) or risk of SPD .

Parents' perceptions about their child's likelihood of cure and goals of therapy are presented in Figure 3. Fifty-four percent of parents believed that cure for their child's cancer was currently "unlikely" or "very unlikely". This group was more likely to report incongruent goals compared to those who believed cure was "likely" (69% vs. 12% respectively, $p<0.001$); they also reported higher K6 mean

scores. Parents with incongruent goals, regardless of their understanding of prognosis, not only had higher mean K6 scores, but also greater risk for SPD (see Table II).

Perceptions of child suffering and corresponding K6 scores are also presented in Table II. Parents who believed their child benefited from current therapy tended to have lower distress and those who felt their child was suffering from therapy had greater distress. While somatic symptom-related suffering was not related to parental distress, child emotional or psychiatric suffering was. Parents who believed their child was suffering highly from psychological distress or was afraid had higher distress scores and a higher risk of SPD. Additionally, parents who believed that their child was suffering “a lot” overall tended to have higher average distress scores and a higher likelihood of SPD.

Twenty-four families (30%) perceived “great” economic hardship due to their child’s cancer. Annual income was not associated with parental distress levels, but those who perceived economic hardship had increased mean K6-scores as well as increased risk of SPD.

In multivariate analyses adjusted for parent gender and child-age, incongruent goals, overall suffering, and perceived economic hardship were independently related to parental distress (Table III).

DISCUSSION

This study indicates that psychological distress is highly prevalent among parents of children with advanced cancer. Over half of parents suffer from high levels of psychological distress and approximately 1 in 7 experience serious psychological distress. In comparison, for example, parents of children with progressive cancer are four times more likely to develop SPD than parents of well children,[48] and over two times more likely to develop SPD than adults with cancer or other serious medical conditions.[45,49] These findings imply that parenting a child with progressive cancer can profoundly affect mental health.

Our results are consistent with models of resilience which suggest that psychosocial outcomes may be mediated by experiences and processes of adaptation during the cancer experience. Here, perceptions of illness including prognosis, child physical symptoms, psychological suffering, and family financial hardship all impacted parent mental health. Indeed, parental distress is a critical component contributing to parental resilience.[50]

Our findings suggest that holding treatment goals which are aligned with understanding of prognosis is associated with lower levels of parental distress, even if parents understand the child's disease to be incurable. This finding is akin to theories of cognitive dissonance which evaluate the psychological effects of conflicting beliefs (i.e., understanding of prognosis), and behaviors (i.e., goals of therapy).[51] Studies have shown that the dissonant state may be resolved by

changing beliefs to match behaviors; however it may have lasting, psychologically detrimental effects if the inconsistencies endure.[52] Because the potential death of a child challenges a parents' basic assumptions, the level of cognitive dissonance, and consequent psychological distress may be greater in this population.[53]

Parent perception of child suffering was also related to their experience of psychological distress. Child psychological, but not somatic, symptoms were associated with parental distress. Parents may have greater emotional struggles when they feel that their child is unhappy or afraid. Similarly, they may feel less knowledgeable or more helpless in the face of their child's emotional symptoms than they would with other, cancer-related somatic complaints. Others have described a relationship between child emotional distress and parent distress,[30] but have been challenged to determine causality.[54] Indeed, it may be that parents who are currently experiencing psychological distress are more likely to report child psychological symptoms. The nature of our study design precludes inference regarding the direction of the relationship between parent mental health and child suffering.

Unlike prior studies, we did not find a relationship between parent sociodemographic factors, including income, and parent distress. However, perceived financial hardship was an important factor related to parent distress. We have previously described financial hardship among parents of children with

cancer and have shown that poor families have greater hardship.[55] The present findings suggest that families who perceive economic stressors are more likely to be psychologically distressed, regardless of their baseline financial resources.

The study has several limitations. First, while our data were collected during the child's illness and are not retrospective, they also are not longitudinal. We cannot infer trends in parental distress over time, nor can we estimate potential causality in the described associations. Second since we do not report concurrent child-reported distress, we cannot validate parent-reported child experience. Third, while our population represents a comparatively large sample-size in relation to other studies conducted among parents, the absolute number of subjects was not large, and so even moderate relationships could not be assessed reliably. For example, despite notable trends, we could not confirm with confidence that child or parent age or parent gender was associated with parent PD. Finally, though are study is multi-institutional, the characteristics of our sample are somewhat narrowly distributed to White women with annual incomes above the poverty level, and mainly represent families cared for at large tertiary level cancer centers. It may be difficult to generalize our findings to families of varying backgrounds cared for in other settings.

CONCLUSIONS

This is the first study to describe the experience of distress in parents of children with advanced cancer. Distress levels in this population are high and are

associated with parent experiences during their child's cancer care. Importantly, our findings suggest ways in which providers may ease parental psychological distress by eliciting their views on prognosis and treatment goals, perceived child suffering and economic hardship. Future research should focus on family interventions aimed at easing distress among parents of children with advanced cancer.

AUTHOR'S DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflict of interests.

AUTHOR'S CONTRIBUTIONS

Conception and design: AR, VD, JW

Collection and assembly of data: VD

Data analyses and interpretation: AR, VD, NW, JW

Manuscript writing: All authors

Final approval of manuscript: All Authors

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Table I. Parental Kessler-6 (K6) Scores and Risk of Serious Psychological Distress (K6 score of 13 or larger) in relation to Child and Parent Characteristics. Univariate analysis.

	Total N=81 (100%)[a]	K6 score Mean[b] (SD)	p-value[c]	Total SPD N=13 (% of subgroup)[a]	Likelihood of SPD[d] OR (95% CI)
CHILD CHARACTERISTICS					
Child's gender					
Female	43 (53)	7.2 (4.2)	0.136	5 (12)	0.5 (0.2, 1.7)
Male	38 (47)	8.7 (4.5)		8(21)	1.0 (--)
Child's age					
2-6 years	23 (28)	9.1 (3.5)	0.081[e]	5 (22)	1.6 (0.8, 3.2)
7-12 years	19 (23)	7.6 (5.4)		4 (21)	1.5 (0.4, 5.6)
13 years or older	39 (48)	7.3 (4.3)		4 (10)	1.0 (--)
Child's diagnosis					
Hematological malignancy	27 (33)	7.8 (4.2)	0.917[e]	4 (15)	0.6 (0.2, 2.4)
Solid Tumor (non-CNS)	45 (56)	7.9 (4.6)		6 (13)	0.6 (0.2, 1.3)
Brain Tumor	9 (11)	8.1 (4.5)		3 (33)	1.0 (--)
Currently receiving cancer-directed therapy (n=80)					
Yes	73 (91)	8.0 (4.3)	0.748	12 (16)	1.2 (0.1, 10.9)
No	7 (9)	7.3 (6.0)		1 (14)	1.0 (--)
Duration of progressive disease					
< 2 months	12 (15)	8.3 (3.9)	0.661	2 (17)	1.1 (0.2, 5.5)
≥ 2 months	69 (85)	7.8 (4.5)		11 (16)	1.0 (--)
PARENT CHARACTERISTICS					
Gender					
Female	70 (86)	8.2 (4.2)	0.100	12 (17)	2.1 (0.2, 17.9)
Male	11 (14)	5.6 (5.1)		1 (9)	1.0 (--)
Parental age (n=80)				(n=12)	
< 38 years	17 (21)	9.6 (4.9)	0.072	5 (29)	3.3 (0.9, 12.4)
≥ 38 years	63 (79)	7.3 (4.0)		7 (11)	1.0 (--)
Race/Ethnicity (n=78)					
Other Race/Hispanic	6 (10)	11.0 (8.2)	0.286	3 (50)	6.2 (1.1, 35.5)
Caucasian/Non-Hispanic	72 (90)	7.6 (4.0)		10 (14)	1.0 (--)
Marital Status					
Never Married, Divorced or separated	70 (86)	8.1 (4.2)	0.317	1 (9)	2.0 (0.2, 18.0)
Married or living with partner	11 (14)	6.5 (5.3)		12 (17)	1.0 (--)
Standardized Social Support Score (n=78)				(n=12)	
< 69%	19 (24)	8.6 (4.8)	0.385	4 (21)	1.7 (0.4, 6.5)
≥ 69%	59 (76)	7.5 (4.2)		8 (14)	1.0 (--)
Education					
High School, GED, or less	25 (31)	7.6 (4.7)	0.679	4 (16)	1.0 (0.3, 3.7)
College and higher education	56 (69)	8.0 (4.3)		9 (16)	1.0 (--)
Annual income (n=73)				(n=11)	
Below poverty level (< $25,000)	10 (14)	9.1 (6.5)	0.430	3 (33)	3.0 (0.6, 13.9)
Above poverty level (≥ $25,000)	63 (86)	7.5 (3.9)		8 (13)	1.0 (--)

[a] Denominator indicated in rows for specific variables with missing data
[b] Kessler-6 scores (range 0-24); higher scores suggest greater distress
[c] Based on univariate linear regression models; categorical variables with 2 degrees of freedom used for child's age and child's diagnosis

[d] Unadjusted OR

Table II. Parent Perceptions of Child's Illness associated with Serious Psychological Distress (SPD) (Kessler 6 score of 13 or larger). Univariate analysis.

	Total N=81 (100%)[a]	K6 score Mean (SD)	p-value	Total SPD N=13 (% of subgroup)[a]	Likelihood of SPD[b] OR (95%CI)
Prognosis and Goals of Therapy					
"What is your understanding now of how likely it is that your child will be cured?" (n=70)					
"Unlikely"/"Very Unlikely"	37 (53)	9.0 (4.8)	0.042	9 (24)	2.3 (0.7, 8.8)
"Likely"/"Very Likely"	33 (47)	6.8 (3.9)		4 (12)	1.0 (--)
Overall goal of medical care "congruent" (n=70)					
No	29 (41)	10.2 (4.7)	0.001	9 (31)	4.2 (1.1, 15.4)
Yes	41 (59)	6.4 (3.7)		4 (10)	1.0 (--)
Perceived Child Symptoms and Suffering					
Benefit from current cancer-directed treatment (n=68)				(n=11)	
"Not at all"/"A little"	5 (7)	10.0 (1.9)	0.012	0	0
"Somewhat"/"A lot"/"A great deal"	63 (93)	7.5 (4.4)		11 (100)	1.0 (--)[c]
Suffering from current cancer-directed treatment (n=76)					
"A lot"/"A great deal"	16 (21)	11.0 (3.6)	<0.001	5 (31)	3.0 (0.8, 10.9)
"Not at all"/"A little"/"Somewhat"	60 (79)	7.1 (4.3)		8 (13)	1.0 (--)
Frequency of feeling afraid?" (n=75)					
"Some"/"Most"/"All" of the time	29 (39)	9.4 (4.6)	0.036	7 (24)	2.1 (0.6, 7.2)
"None"/"A little" of the time	46 (61)	7.1 (4.1)		6 (13)	1.0 (--)
Frequency of feeling calm or peaceful?" (n=78)				(n=11)	
"None"/"A little" of the time	10 (13)	10.7 (5.0)	0.032	3 (33)	3.2 (0.7, 15.2)
"Some"/"Most"/"All" of the time	68 (87)	7.2 (3.9)		8 (12)	1.0 (--)
Suffering from anxiety (n=69)					
"A lot"/"A great deal"	12 (17)	11.8 (5.9)	0.013	6 (50)	7.1 (1.8, 28.7)
"Not at all"/"A little"/"Somewhat"	57 (83)	7.4 (3.8)		7 (12)	1.0 (--)
Suffering from sadness (n=69)					
"A lot"/"A great deal"	7 (10)	12.4 (6.3)	0.042	4 (57)	7.9 (1.5, 41.6)
"Not at all"/"A little"/"Somewhat"	62 (90)	7.6 (3.9)		9 (15)	1.0 (--)
Suffering from pain (n=75)					
"A lot" to "great" suffering	29 (39)	9.0 (5.1)	0.192	7 (24)	2.1 (0.6, 7.2)
"None" to "some" suffering	46 (61)	7.6 (3.8)		6 (13)	1.0 (--)
Suffering from nausea or vomiting?" (n=74)					
"A lot" to "great" suffering	17 (23)	9.9 (4.7)	0.053	6 (35)	2.5 (1.1, 1.4)
"None" to "some" suffering	57 (77)	7.5 (4.2)		7 (12)	1.0 (--)
Suffering from sleep disturbances?" (n=67)					
"A lot" to "great" suffering	17 (25)	7.5 (4.5)	0.408	2 (12)	0.5 (0.1, 2.4)
"None" to "some" suffering	50 (75)	8.5 (4.5)		11 (22)	1.0 (--)
Overall suffering (n=80)					
"A lot"/"A great deal"	12 (15)	10.6 (5.2)	0.045	5 (42)	5.4 (1.4, 21.9)
"Not at all"/"A little"/"Somewhat"	68 (85)	7.4 (4.1)		8 (12)	1.0 (--)
Financial Hardship					
Perceived financial hardship due to child's illness (n=79)					
"Great"	24 (30)	10.1 (5.3)	0.009	8 (33)	5.0 (1.4-17.6)
"No"/"Little"/"Moderate"	55 (70)	6.9 (3.7)		5 (9)	1.0

[a] Denominator indicated in rows for specific variables with missing data
[b] Unadjusted OR
[c] No parents met criteria for SPD; 95% CI not calculated

Table III. Parent Perceptions of Child's Illness associated with Increasing Psychological Distress. Multivariate analysis

	Increased Parental Distress Scores [a]		
	Average increased K6 Score (β)	95% CI	p-value
"Incongruent" goals of medical care	3.9	1.1-5.9	0.005
Overall child suffering "a lot" or "a great deal"	3.6	1.8-5.9	<0.001
"Great" financial hardship due to child's illness	3.2	1.0-5.3	0.004

[a] Multivariate linear regression model adjusted for parent gender and child age

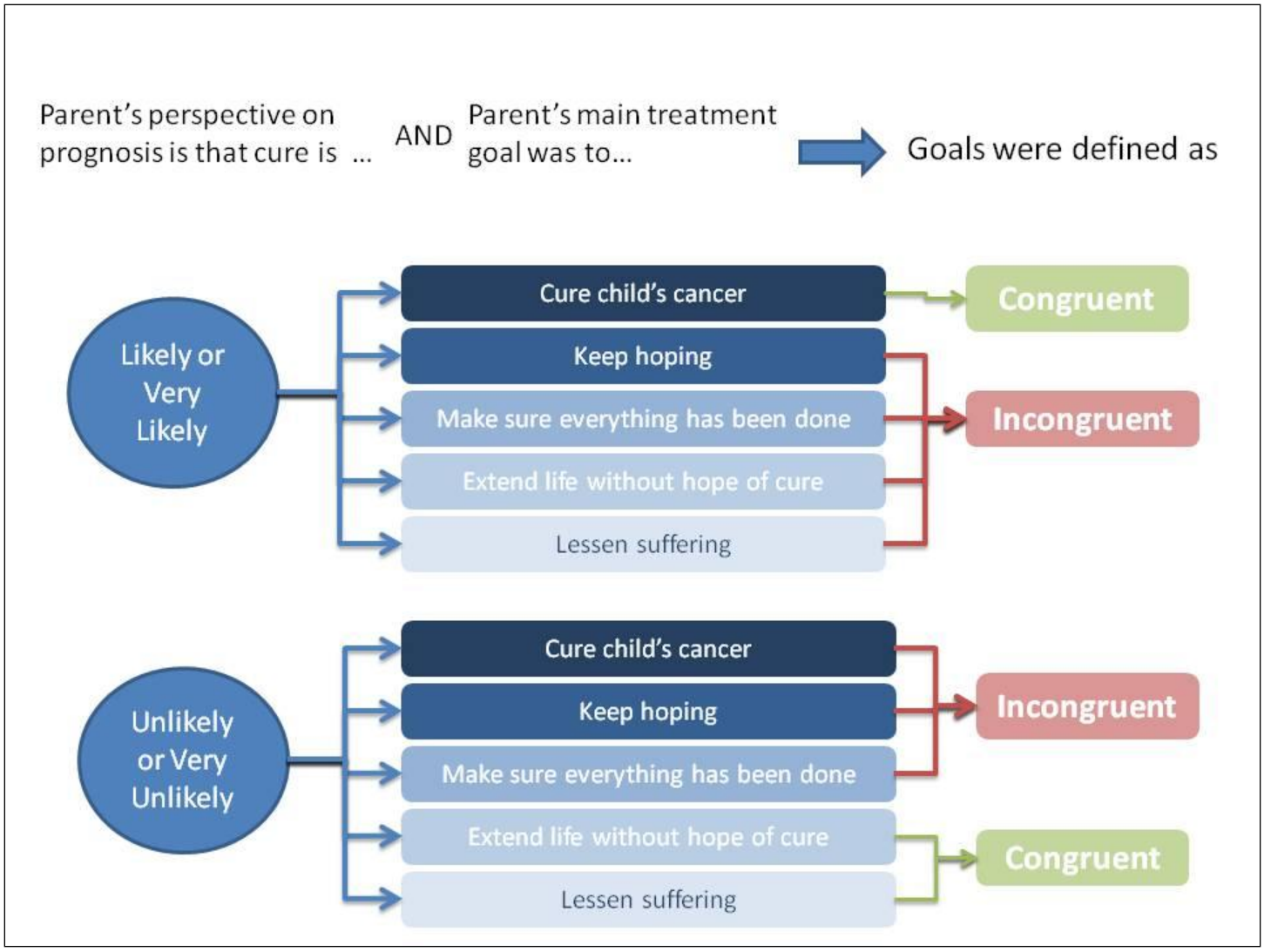

Figure 1. Parents Prognosis Views and Treatment Goals. Description of how parents' treatment goals were classified as congruent or incongruent in relation to their understanding of child's prognosis.

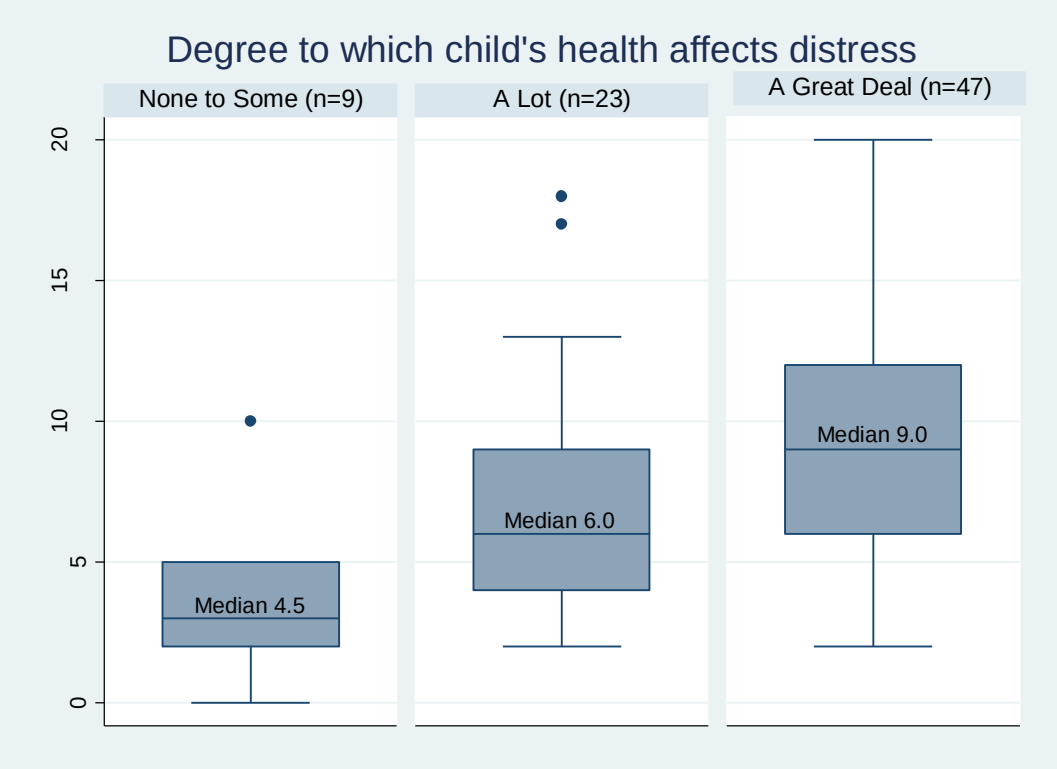

Figure 2. Parent Kessler-6 scores stratified by “the degree to which child’s health affects distress.” Distribution of parental distress scores as defined by the Kessler-6 scale. Distributions stratified by parent responses to the question: “During the last 30 days, to what extent has your child’s health contributed to these feelings?” with options “a great deal,” “a lot,” “somewhat,” “a little,” or “not at all” (p=0.0003 based on Kruskal-Wallis test).

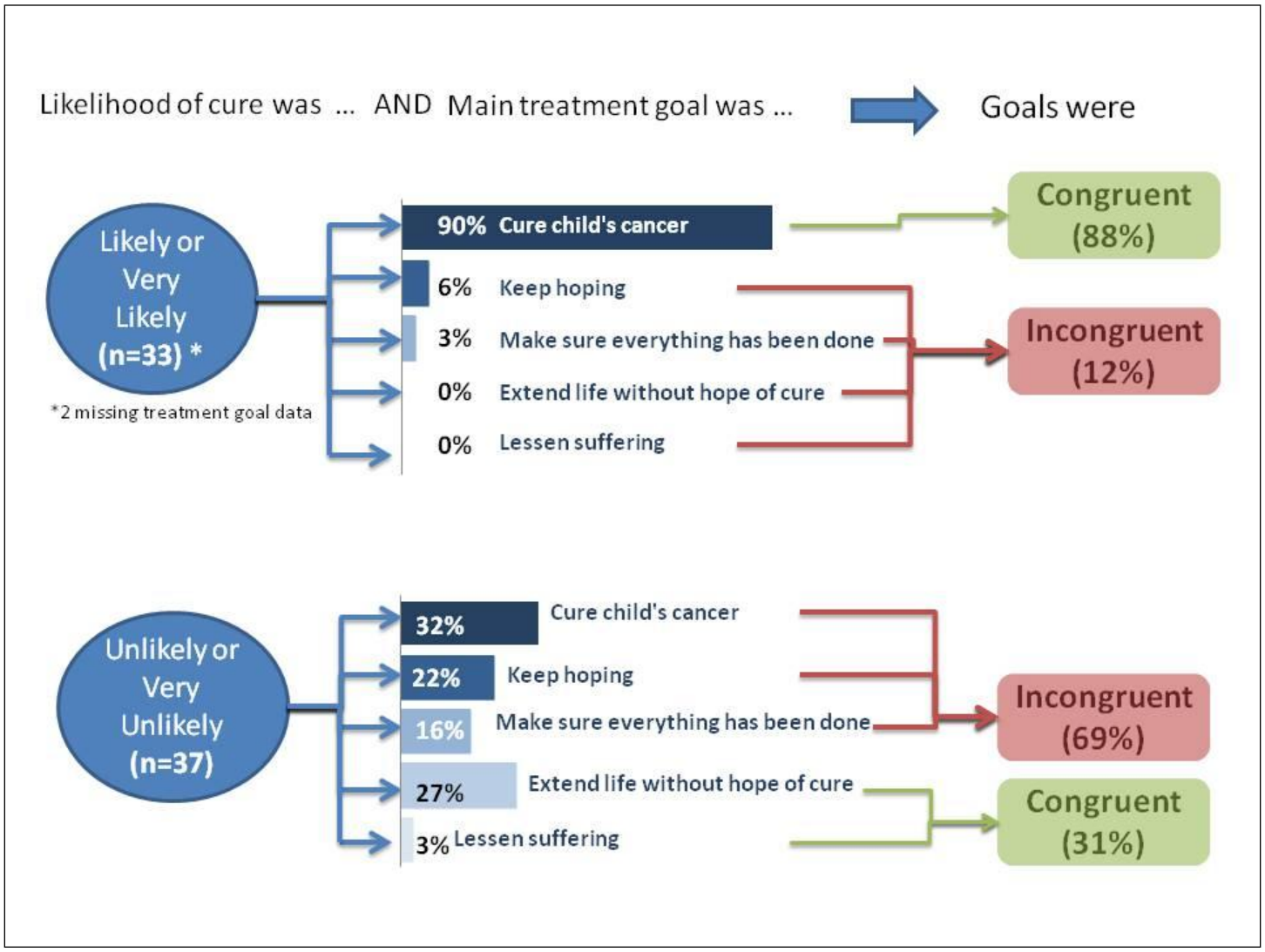

Figure 3. Congruence Between Parent Prognosis Views and Treatment Goals. Distribution of parents' treatment goals according to their understanding of prognosis of their child.