Published in final edited form as:

Pediatr Blood Cancer. 2014 March ; 61(3): 552–557. doi:10.1002/pbc.24854.

Resilience and psychosocial outcomes in parents of children with cancer

Abby R. Rosenberg, MD, MS^{1,2,3,4}, Joanne Wolfe, MD, MPH^{5,6,7}, Miranda C. Bradford, MS¹, Michele L. Shaffer, PhD¹, Joyce P. Yi-Frazier, PhD^{1,3}, J. Randall Curtis, MD, MPH^{3,8,9}, Karen L. Syrjala, PhD^{2,3}, and K. Scott Baker, MD, MS^{1,2,3}

¹Seattle Children's Hospital, Seattle, WA

²Fred Hutchinson Cancer Research Center, Seattle, WA

³University of Washington, Seattle, WA

⁴Treuman Katz Center for Pediatric Bioethics, Seattle, WA

⁵Boston Children's Hospital, Boston, MA

⁶Dana Farber Cancer Institute, Boston, MA

⁷Harvard Medical School, Boston, MA

⁸Harborview Medical Center, Seattle, WA

⁹UW Palliative Care Center of Excellence, Seattle, WA

Abstract

Background—The psychosocial function of parents of children with cancer can impact the well-being of the entire family. Resilience resources are likely related to psychosocial outcomes and may be amenable to intervention. We hypothesized that parents with lower resources would report worse outcomes.

Methods—In the “Understanding Resilience in Parents of Children with Cancer” study, comprehensive surveys were mailed to consecutive, English-speaking parents of children with cancer who were treated at Seattle Children's Hospital and completed therapy between 01/01/2009 and 12/31/2010. Resilience resources were measured by the Connor-Davidson Resilience Scale; outcome measures included psychological distress, health-related behaviors, social and family function, and perceived communication with the medical team.

Results—96 parents (86% of contactable) completed the survey. Compared to population norms, enrolled parents had lower resilience resources, higher psychological distress, and more commonly reported binge drinking. Conversely, they reported higher social support and family adaptability ($p < 0.001$ – 0.006). Lower resilience resources were associated with higher distress, lower social support, and lower family function ($p < 0.001$ – 0.007). Parents in the lowest quartile of

Correspondence should be addressed to: Abby R Rosenberg, MD, MS, Seattle Children's Hospital, Department of Pediatrics, Division of Hematology/Oncology, 4800 Sand Point Way NE; Mailstop MB.8.501, Seattle, WA 98105, Tel: 206-987-2106, Fax: 206-987-3946, abby.rosenberg@seattlechildrens.org.

Conflicts of Interest: None of the authors has a financial or other conflict of interest to disclose

resilience resources had higher odds of frequent sleep difficulties (OR 5.19, 95% CI 1.74,15.45), lower health satisfaction (OR 5.71, 95% CI 2.05,15.92), and decreased ability to express worries to the medical team (OR 4.00, 95% CI 1.43,11.18).

Conclusions—Parents of children with cancer are at risk for poor psychosocial outcomes and those with low resilience resources may be at greater risk. Interventions directed at promoting resilience resources may provide a novel and complimentary approach towards improving outcomes for families facing pediatric cancer.

Keywords

resilience; psychosocial outcomes; parents; pediatric cancer; whole patient care

INTRODUCTION

There is debate regarding how to define and measure resilience.[1,2] While most agree that the construct describes an individual's ability to maintain emotional and/or physical well-being in the face of stress, whether resilience should be defined by inherent personal characteristics,[3] processes of adaptation that develop over time,[4] or relatively positive psychosocial outcomes[5] is unclear. We have previously described parent perspectives about resilience and proposed a novel conceptual framework for promoting it.[1] Specifically, parents of children with cancer suggest that all three definitions are simultaneously true: resilience is evidenced by an ability to move forward and “live normal” after cancer, and is shaped by both personal “resilience resources”, such as optimism and self-efficacy, as well as by evolving illness experiences such as cumulative stress and personal growth.

The identification and promotion of personal “resilience resources” may therefore provide an opportunity for improving psychosocial outcomes among parents of children with cancer. The Connor-Davidson Resilience Scale (CD-RISC)[6] is a convenient and well-validated instrument used to measure resilience resources. Higher scores have been associated with lower depression, anxiety, and post-traumatic stress.[3,7–9] Furthermore, studies have suggested that resilience resources measured by the CD-RISC can be taught and promoted, leading to more effective stress management, coping strategies and, in turn, more positive psychosocial outcomes.[10] The relative utility of this scale among parents of children with cancer has not been explored, despite the fact that these parents have high risk of psychological distress,[11,12] worse health-related behaviors,[13] and inferior quality of life.[14]

In this cross-sectional study, we aimed first to compare outcomes among non-bereaved parents of children with cancer and population norms. We then aimed to evaluate the relationships between current parent-reported resilience resources, as measured by the 10-item CD-RISC scale, and psychosocial outcomes such as psychological distress, social function, health-behaviors, and communication with the medical team. Our overall objective was to identify parents at risk for poor outcomes. We hypothesized that lower resilience resources (as indicated by total CD-RISC scores) would be associated with inferior outcomes; and that parents with the lowest resources (empirically defined as the lowest

quartile of CD-RISC scores) would have greater odds of inferior outcomes, and could provide a threshold for future intervention. We anticipate that findings could be used first to inform longitudinal validation studies, and then to guide the development of interventions designed to promote positive and functional outcomes among parents of children with cancer.

METHODS

Participants

The “Understanding Resilience in Parents of Children with Cancer” (URPCC) study was approved by the Seattle Children’s Hospital (SCH) Institutional Review Board. Consecutive pediatric cancer patients who were treated at SCH and completed therapy between 1/1/2009 and 12/31/2010 were identified from the local registry of all successive patients. Patients’ parents or legal guardians were eligible to participate if their registry information included a mailing address without an active request not to be contacted for future research, if they had written command of the English language, and if the patient had completed cancer treatment at least 6 months prior to enrollment. This time-point was selected to ensure that families had some time to adjust to being off-therapy. There was no upper limit to how long patients were off-therapy. Patients’ primary oncology providers sent a written letter of introduction to all potential participants, along with the study survey, an “opt-out” card, and a stamped return envelope. Letters and surveys labeled the study “Understanding Responses of Parents of Children with Cancer” to avoid suggestion from the word “resilience.” Potential participants who did not respond within 2 weeks received an additional letter, followed by a phone-call from the Principal Investigator to determine interest. All surveys but one were returned by mail; a single survey was conducted by phone at the parent’s request. We enrolled one caregiver per family, determined at the family’s discretion, and provided a \$40 incentive for completing the survey.

Study Instruments

The “Resilience in Pediatric Cancer Assessment” (RPCA) is a composite, paper-and-pencil based survey, developed for the present study and comprised of instruments which have been validated among adults and/or parents of children with cancer. Prior to study enrollment, the RPCA was qualitatively tested for content among 18 caregivers of children with cancer, and with experts in the field. The survey is divided into 6 domains: resilience resources, emotional distress, social function, health behaviors, cancer experience, and demographics.

Resilience resources—The RPCA measures resilience resources with the ten-item Connor-Davidson Resilience Scale (CD-RISC-10).[6,8] This scale captures self-perceptions of adaptability, humor, self-efficacy, and hardiness. Prior studies have demonstrated that higher mean scores suggest greater current resilience resources and are associated with improved outcomes, including lower rates of anxiety and depression.[7] The mean score among US adults is 31.8 (SD 5.5).

Emotional distress—The RPCA screens for global psychological distress using the Kessler-6 general psychological distress Scale (K6).[15] This instrument is used by the US National Health Interview Survey and the World Health Organization to assess population level mental health. Scores are reported both as a mean total score ranging from 0–24, and also as proportions of parents with “high psychological distress” (score ≥7).[16] The average K6 score among US adults is 2.5.

Social function—The RPCA captures both general social support and family function. The social support subscale of the Medical Outcomes Study (MOS)[17] addresses functional dimensions of general social support including emotional, informational, and interactive support. US adults report overall support scores of approximately 70.1 (scale 0–100). The Family Adaptability and Cohesion Scale (FACES-II)[18] assesses current and ideal family relationships and attitudes. “Adaptability” reflects the family’s ability to change in response to situational needs, while “cohesion” reflects the emotional bonding that exists between family members. Average scores among US adults are 75.3 for cohesion and 43.1 for adaptability.

Health Behaviors—Respondent health and health-related behaviors are assessed with questions from the RAND 36-item Health Survey (SF-36)[19] and the Center for Disease Control (CDC) Behavioral Risk Factor Surveillance System (BRFSS).[20] Specifically, participants are asked to rate their general health with a 5-point Likert scale (“poor,” “fair,” “good,” “very good,” and “excellent”), and their overall health-satisfaction with a 4-point Likert scale (“very satisfied,” “satisfied,” “dissatisfied,” and “very dissatisfied”). In addition, they are asked about several behaviors during the last month: frequency of sleep difficulties (5-point Likert scale of “never,” “rarely,” “sometimes,” “frequently,” and “always”), impact of sleep difficulties on important areas of life (“not at all,” “a little bit,” “moderately,” “quite a bit,” and “extremely”), any current cigarette smoking, any drinking at least 4 alcoholic beverages on a single occasion, and any “driving after having perhaps too much to drink” (dichotomous yes/no responses). The CDC provides state level population norms based on routine BRFSS data to enable comparisons with minimal regional inconsistencies; for this analysis, Washington state population norms were collected from the CDC/BRFSS web-site. [20]

Cancer experience—Caregivers’ perceptions of the medical experience, including communication and financial hardship, are measured with the Survey about Caring for Children with Cancer (SCCC).[21] This instrument was previously refined based on expert opinion and focus groups, and has been used recently in similar studies conducted in pediatric oncology settings.[11] Caregivers refer to their average experience when communicating with their child’s main care team, for example: “During discussions with your child’s medical team, were you able to express your [hopes/worries]?” Response options are “a great deal,” “a lot,” “somewhat,” “a little,” and “not at all.”

Demographics—Respondents are asked to provide basic demographic and clinical information including sex, race/ethnicity, education, income, religion, self-reported

“religiousness,” and frequency of religious service attendance. The survey also collects information about the child’s cancer, including diagnosis, dates and duration of therapy.

Analyses

Statistical analyses were conducted with the Stata 12 (StataCorp LP, College Station, TX) and SAS version 9.2 (SAS Institute Inc., Cary, NC) software packages. Descriptive statistics were used to characterize groups, based on published instrument standards. Means and standard deviations (SD) were used for continuous scales when data were approximately normally distributed, and medians and interquartile ranges (IQR) otherwise. For scales with pre-defined cut-off points for dichotomous outcomes, frequencies and proportions were used. Similarly, we dichotomized health behaviors and communication variables at clinical cut-points (e.g., “excellent”/“very good” versus “good”/“fair”/“poor” health, or “frequent” versus “sometimes” sleep difficulties). Normal adult population comparison values were identified from validation studies describing each individual instrument (CD-RISC,[8] K6, [22] social support subscale of MOS,[17] FACES-II[18]), or from public population-based prevalence statistics (BRFSS[20]). Differences between the parent sample and population norms were assessed with one-sample binomial, *t*-, or Wilcoxon signed-rank tests.

To examine the relationships between resilience resources measured by the CD-RISC and psychosocial outcomes, we fit two sets of logistic regression models using resilience resources as the independent variable. First, we assessed changes in psychosocial outcomes given single point decreases in total CD-RISC score (hypothesis 1). Second, because we hypothesized *a priori* that parents with the lowest resilience resources would be at the greatest risk, we used a person-centered approach[23] and assessed changes in psychosocial outcomes given categorical “low resilience” (empirically defined by the lowest quartile of CD-RISC score) versus all others (hypothesis 2). Exploratory analyses evaluated the roles of additional socio-demographic variables and time since completion of therapy, but only sex was selected for use as an adjustment variable, since the sample was predominantly female and no other variables were found to have statistically or clinically important associations.

RESULTS

We identified 154 potentially eligible families and mailed surveys to all. Of these, 112 had valid mailing or phone contacts, and 96 enrolled (86% of those reachable and 67% of those eligible; Figure 1). Most respondents were married, white mothers who had received at least some college level education (Table I). Their children with cancer were a median of 4 years old at the time of diagnosis (IQR 2–10); 45% had a hematologic malignancy, 17% had a brain tumor, and 39% had a non-central nervous system (CNS) solid tumor.

Compared to US and Washington state population norms, parents of children with cancer had mixed outcomes (Table II). They had lower resilience resources, higher global psychological distress, and lower levels of family cohesion ($p<0.001$ – 0.006). Conversely, they also had higher social support and family adaptability ($p<0.001$ for both). Parents of children with cancer were less likely to smoke cigarettes (19% versus 11%, $p=0.046$), but more likely to binge drink (defined as drinking 4 or more drinks on 1 or more days of the past month, 18% versus 39%, $p<0.001$).

No demographic characteristics were associated with resilience resources in this sample, including caregiver sex, age, income, education, religion, religiousness, or child sex, age, cancer type, or time since end of therapy/death. Single point decreases in resilience resources were associated with greater psychological distress ($\beta=0.32$, $R^2=0.26$, $p<0.001$), and lower social support ($\beta=-1.16$, $R^2=0.09$, $p=0.007$), family cohesion ($\beta=-0.71$, $R^2=0.20$, $p<0.001$) and adaptability ($\beta=-0.53$, $R^2=0.22$, $p<0.001$). In addition, for every point-decrease in resilience resources, the odds of various negative psychosocial outcomes increased (Table III). For example, a single point decrease in resilience resources was associated with 9% higher odds of drinking and driving (OR 1.09, 95% CI 1.01, 1.26).

Parents with “low resilience resources” (defined by lowest quartile CD-RISC score) had higher odds of negative outcomes including high psychological distress (OR 3.71, 95% CI 1.17, 11.72), frequent sleep difficulties (OR 5.19, 95% CI 1.74, 15.45), and lower health satisfaction (OR 5.71, 95% CI 2.05, 15.92). In addition, these parents reported less ability to express their hopes and worries with their medical team (OR 3.08, 95% CI 1.12, 8.49; and OR 4.00, 95% CI 1.43, 11.18, respectively; Table 3).

DISCUSSION

Pediatric cancer affects the entire family.[24] Parent psychosocial outcomes can affect the well-being of patients, their siblings, and the larger community.[25–27] Promoting positive psychosocial outcomes has therefore become a clinical and research priority;[28] however, formal evidence-based descriptions of how to do so have not been well developed. Our findings confirm that parents of children with cancer have comparatively high rates of poor outcomes such as psychological distress, and that those with limited resilience resources may be at even greater risk.

To our knowledge, this is the first description of parent-reported resilience resources among parents of children with cancer. Parents in this study reported fewer resilience resources than population norms, although there is no reason to suspect they had lower resources at the time of their child’s diagnosis. Likewise, parents in this sample reported mixed psychosocial outcomes, including more emotional distress, but enhanced social function and family adaptability. Thus our findings suggest that elements of the child’s cancer experience impact not only parent resilience resources, but also, their ultimate level of function, both positively and negatively.

These findings support our previously proposed resilience framework[1] and suggest that resilience resources are independently associated with psychosocial outcomes. What is unclear from this study, however, is when and how in the cancer experience these resilience resources develop, change, or wane. Current standards of cancer care include screening for psychological distress,[29] and interventions designed to minimize distress may improve parent adjustment.[30] Our findings suggest that concurrent and/or longitudinal assessment of resilience resources may provide a complimentary opportunity to improve parent, and subsequently patient outcomes.

The construct of resilience is controversial and likely overlaps with multiple other elements of psychosocial function.[1,5] The intention of this study was not to answer the question of how to define resilience, but rather to examine the utility of an existing and validated measure of resilience resources in a previously under-studied, but at-risk population. In addition, the CD-RISC has potential as a screening tool since CD-RISC scores can be modified with intervention, and such modifications have been associated with improved psychosocial outcomes.[7,8] Interventions that target resilience resources such as stress-management[31] or that promote meaning-making[32] or benefit-finding[33] have been associated with improved adjustment to life after cancer. Targeted skills-training in goal-setting,[34,35] problem-solving,[36] and positive reframing[37] have also shown promise in other patient populations. In order to identify parents at risk for poor outcomes, we empirically defined low resilience resources using the lowest quartile of CD-RISC scores and demonstrated these parents have higher odds of poor outcomes. Future larger studies should validate instrument cut-points and explore the protective role of high resilience resources that may direct clinical care and/or intervention.

There are several limitations of this study, including its cross-sectional nature. Such a design does not allow identification of directional associations. For example, we cannot determine which comes first: resilience resources, psychological distress, or health-related behaviors. This lack of directionality, in turn, limits the ability to design appropriate interventions. In addition, we had no control group of parents of similar demographics. While we tried to narrow our comparisons where applicable (for example, we compared parent reported behaviors to those of well adults in Washington State rather than nationwide), our comparisons to generic population norms should be interpreted cautiously. Nevertheless, we endeavored to describe novel relationships and generate hypotheses for future studies. Our current on-going investigations include a longitudinal assessment of the RPCA among adolescents with cancer and their parents; this project will allow for greater exploration and understanding of the here-described constructs. Second, eligibility for this study included having a valid filed mailing address and willingness to be contacted for future research. Our sample is therefore biased to include those parents willing to be reached and perhaps invested in on-going research, a sample that may be more “resilient” at baseline than is typical. Likewise, even within our sample, not all parents responded to questions about health behaviors such as drinking and driving; our findings may be biased by those who were willing to respond to these questions. Additionally, we only requested one respondent per family and most were mothers. Our findings are therefore more generalizable to mothers, even though we adjusted for parent sex in multivariate analyses. Furthermore, our sample lacked ethnic and demographic diversity. We were unable to assess multi-cultural aspects of distress and resilience. Indeed, another element of psychosocial outcomes must include cultural perspectives.

Finally, we conducted multiple exploratory and hypothesis-generating comparisons and this approach may increase the risk of type 1 errors. Even with our large number of sub-scales, this analysis provided a limited view into the multitude of measurable psychosocial covariates and outcomes. There are many more (e.g., trait-optimism, sense of coherence, spirituality, coping, degree of involvement of psychosocial clinicians, benefit-finding, and post-traumatic growth) that likely relate to this complex picture. While we queried self-

reported “religiousness,” for example, we did not assess spirituality, which has been related to meaning making and coping.[38] Still, we met our objective to identify associations that could inform the design of larger studies and/or interventions.

CONCLUSIONS

Supporting the psychosocial wellbeing of parents of pediatric cancer patients is a critical component of whole patient care.[28] This cross-sectional study provides preliminary evidence that resilience resources are related to parent psychosocial health and functional outcomes. Future studies should evaluate the trajectory of resilience resources over time and should assess the corresponding relationships between changing resilience resources and outcomes. Interventions that target and improve resilience resources have the potential to improve parent, and by extension patient, wellbeing.

Acknowledgments

ARR is a St. Baldrick’s Foundation Fellow and is supported by a Conquer Cancer Foundation of ASCO Jane C. Wright, MD Young Investigator Award, supported by the ASCO and Conquer Cancer Foundation Board of Directors. Any opinions, findings and conclusions expressed in this material are those of the author(s) and do not necessarily reflect those of the American Society of Clinical Oncology, the Conquer Cancer Foundation, or the ASCO and the Conquer Cancer Foundation Board of Directors. This research was supported by the Ruth L. Kirschstein National Research Service Award T32CA009351. We would like to thank Barbara Stansfeld for her assistance in the coordination of this study. We are grateful to the parents and caregivers who participated and offered their thoughtful consideration to this work.

REFERENCES

1. Rosenberg AR, Baker KS, Syrjala KL, et al. Promoting Resilience among Parents and Caregivers of Children with Cancer. *J Palliat Med*. 2013
2. Bonanno GA, Mancini AD. The human capacity to thrive in the face of potential trauma. *Pediatrics*. 2008; 121(2):369–375. [PubMed: 18245429]
3. Connor KM. Assessment of resilience in the aftermath of trauma. *J Clin Psychiatry*. 2006; 67(Suppl 2):46–49. [PubMed: 16602815]
4. Rolland JS, Walsh F. Facilitating family resilience with childhood illness and disability. *Curr Opin Pediatr*. 2006; 18(5):527–538. [PubMed: 16969168]
5. Bonanno GA, Westphal M, Mancini AD. Resilience to loss and potential trauma. *Annu Rev Clin Psychol*. 2011; 7:511–535. [PubMed: 21091190]
6. Connor KM, Davidson JR. Development of a new resilience scale: the Connor-Davidson Resilience Scale (CD-RISC). *Depress Anxiety*. 2003; 18(2):76–82. [PubMed: 12964174]
7. Campbell-Sills L, Cohan SL, Stein MB. Relationship of resilience to personality, coping, and psychiatric symptoms in young adults. *Behav Res Ther*. 2006; 44(4):585–599. [PubMed: 15998508]
8. Campbell-Sills L, Stein MB. Psychometric analysis and refinement of the Connor-davidson Resilience Scale (CD-RISC): Validation of a 10-item measure of resilience. *J Trauma Stress*. 2007; 20(6):1019–1028. [PubMed: 18157881]
9. Davidson, JR.; Stein, DJ.; Rothbaum, BO.; Pedersen, R.; Tien, XW.; Musgnung, J. Resilience as a predictor of remission in post-traumatic stress disorder. New Orleans, LA: US Psychiatric and Mental Health Congress; 2006.
10. Steinhardt M, Dolbier C. Evaluation of a resilience intervention to enhance coping strategies and protective factors and decrease symptomatology. *J Am Coll Health*. 2008; 56(4):445–453. [PubMed: 18316290]
11. Rosenberg AR, Dussel V, Kang T, et al. Psychological Distress in Parents of Children With Advanced Cancer. *JAMA Pediatr*. 2013;1–7. [PubMed: 23460048]

12. Rosenberg AR, Baker KS, Syrjala K, et al. Systematic review of psychosocial morbidities among bereaved parents of children with cancer. *Pediatr Blood Cancer*. 2012; 58(4):503–512. [PubMed: 22038675]
13. Pollock EA, Litzelman K, Wisk LE, et al. Correlates of physiological and psychological stress among parents of childhood cancer and brain tumor survivors. *Acad Pediatr*. 2013; 13(2):105–112. [PubMed: 23384776]
14. Eyigor S, Karapolat H, Yesil H, et al. The quality of life and psychological status of mothers of hospitalized pediatric oncology patients. *Pediatr Hematol Oncol*. 2011; 28(5):428–438. [PubMed: 21707473]
15. Kessler RC, Andrews G, Colpe LJ, et al. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychol Med*. 2002; 32(6):959–976. [PubMed: 12214795]
16. Kessler RC, Barker PR, Colpe LJ, et al. Screening for serious mental illness in the general population. *Arch Gen Psychiatry*. 2003; 60(2):184–189. [PubMed: 12578436]
17. Sherbourne CD, Stewart AL. The MOS social support survey. *Soc Sci Med*. 1991; 32(6):705–714. [PubMed: 2035047]
18. Olson, DH.; Portner, J.; Bell, RQ. *FACES II: family adaptability and cohesion evaluation scales*. University of Minnesota; 1982.
19. Ware JE Jr, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care*. 1992; 30(6):473–483. [PubMed: 1593914]
20. Prevention) CCfDca. [Accessed 01/01/2013] Behavioral Risk Factor Surveillance System. 01/01/2013 <www.cdc.gov/brfss/>
21. Wolfe J, Klar N, Grier HE, et al. Understanding of prognosis among parents of children who died of cancer: impact on treatment goals and integration of palliative care. *JAMA*. 2000; 284(19):2469–2475. [PubMed: 11074776]
22. Kessler RC, Green JG, Gruber MJ, et al. Screening for serious mental illness in the general population with the K6 screening scale: results from the WHO World Mental Health (WMH) survey initiative. *Int J Methods Psychiatr Res*. 2010; 19(Suppl 1):4–22. [PubMed: 20527002]
23. Masten AS. Ordinary magic. Resilience processes in development. *Am Psychol*. 2001; 56(3):227–238. [PubMed: 11315249]
24. Patterson JM, Holm KE, Gurney JG. The impact of childhood cancer on the family: a qualitative analysis of strains, resources, and coping behaviors. *Psychooncology*. 2004; 13(6):390–407. [PubMed: 15188446]
25. Phipps S, Long A, Hudson M, et al. Symptoms of post-traumatic stress in children with cancer and their parents: effects of informant and time from diagnosis. *Pediatr Blood Cancer*. 2005; 45(7):952–959. [PubMed: 15806541]
26. Barakat LP, Kazak AE, Meadows AT, et al. Families surviving childhood cancer: a comparison of posttraumatic stress symptoms with families of healthy children. *J Pediatr Psychol*. 1997; 22(6):843–859. [PubMed: 9494321]
27. Packman W, Weber S, Wallace J, et al. Psychological effects of hematopoietic SCT on pediatric patients, siblings and parents: a review. *Bone Marrow Transplant*. 2010; 45(7):1134–1146. [PubMed: 20383219]
28. Medicine Io. Cancer care for the whole patient: meeting psychosocial needs. 2007 05/20/2011 <<http://www.iom.edu/Reports/2007>>.
29. Carlson LE, Waller A, Mitchell AJ. Screening for distress and unmet needs in patients with cancer: review and recommendations. *J Clin Oncol*. 2012; 30(11):1160–1177. [PubMed: 22412146]
30. Pai AL, Drotar D, Zebracki K, et al. A meta-analysis of the effects of psychological interventions in pediatric oncology on outcomes of psychological distress and adjustment. *J Pediatr Psychol*. 2006; 31(9):978–988. [PubMed: 16514049]
31. Carver CS. Enhancing adaptation during treatment and the role of individual differences. *Cancer*. 2005; 104(11 Suppl):2602–2607. [PubMed: 16247785]
32. Phipps S. Adaptive style in children with cancer: implications for a positive psychology approach. *J Pediatr Psychol*. 2007; 32(9):1055–1066. [PubMed: 17698880]

33. Ishibashi A, Ueda R, Kawano Y, et al. How to improve resilience in adolescents with cancer in Japan. *J Pediatr Oncol Nurs*. 2010; 27(2):73–93. [PubMed: 20176917]
34. McCarty CA, Violette HD, McCauley E. Feasibility of the positive thoughts and actions prevention program for middle schoolers at risk for depression. *Depress Res Treat*. 2011; 2011:241386. [PubMed: 21152188]
35. Gillham JE, Reivich KJ, Freres DR, et al. School-based prevention of depressive symptoms: A randomized controlled study of the effectiveness and specificity of the Penn Resiliency Program. *J Consult Clin Psychol*. 2007; 75(1):9–19. [PubMed: 17295559]
36. Sahler OJ, Dolgin MJ, Phipps S, et al. Specificity of Problem-Solving Skills Training in Mothers of Children Newly Diagnosed With Cancer: Results of a Multisite Randomized Clinical Trial. *J Clin Oncol*. 2013
37. Southwick SM, Charney DS. The science of resilience: implications for the prevention and treatment of depression. *Science*. 2012; 338(6103):79–82. [PubMed: 23042887]
38. Sherman AC, Plante TG, Simonton S, et al. Prospective study of religious coping among patients undergoing autologous stem cell transplantation. *J Behav Med*. 2009; 32(1):118–128. [PubMed: 18855130]

FIGURE 1.

Flow of approach and enrollment in the Understanding Resilience in Parents of Children with Cancer (URPCC) study. NBR: Non-Bereaved; BR: Bereaved

TABLE I

Characteristics of enrolled parents and their children with cancer (N=96)

<u>Relationship to child (n=95)</u>	<u>N</u>	<u>(%)</u>
Mother	75	(79)
Father	17	(18)
Other	3*	(3)
<hr/>		
<u>Age in years</u>	<u>Mean</u>	<u>SD</u>
	42	7
<hr/>		
<u>Education (n=91)</u>	<u>N</u>	<u>(%)**</u>
High school or less	25	(28)
Some college	48	(53)
Master's/professional degree	18	(20)
<hr/>		
<u>Current family annual income (n=88)</u>	<u>N</u>	<u>(%)</u>
< \$12,000	26	(30)
\$12,000–\$49,999	32	(36)
\$50,000	30	(34)
<hr/>		
<u>Marital status (n=94)</u>	<u>N</u>	<u>(%)</u>
Married/partnered	82	(87)
Not married or partnered	12	(13)
<hr/>		
<u>Number of children, including deceased patient</u>	<u>N</u>	<u>(%)**</u>
Patient only	12	(13)
2	38	(40)
3 or more	46	(48)
<hr/>		
<u>Race</u>	<u>N</u>	<u>(%)</u>
White	72	(75)
Native American/Alaska Native	4	(4)
Black	2	(2)
Asian	4	(4)
Other/Unknown/Prefer not to answer	14	(15)
<hr/>		
CHILDREN		
<hr/>		
<u>Sex</u>	<u>N</u>	<u>(%)</u>
Male	48	(50)
Female	48	(50)
<hr/>		
<u>Age at Diagnosis in years</u>	<u>Median</u>	<u>IQR</u>
	4	2–10
<hr/>		
<u>Cancer type</u>	<u>N</u>	<u>(%)**</u>
Hematologic malignancies	43	(45)

Brain tumor	16	(17)
Non-CNS solid tumor	37	(39)
<hr/>		
<u>Time since end-of-therapy in months</u>	<u>Mean</u>	<u>SD</u>
	34	14
<hr/>		
<u>Time since diagnosis in months</u>	<u>Mean</u>	<u>SD</u>
	45	14

*
2 grandmothers, 1 adoptive mother

**
Percents may not add up to 100% due to rounding

TABLE II

Psychosocial function among parents of children with cancer compared to published USA population norms

	ENROLLED PARENTS (N=96)	USA ADULTS	p-value*
Resilience Resources (n=94)	<u>mean CD-RISC score $\pm$ SD</u> 30 $\pm$ 6	31.8	<0.001
Psychological Distress (n=94)	<u>median K6 score (IQR)</u> 3 (1–6)	2.5	0.006
Serious Psychological Distress (n=94)	<u>N (%) with K6 $\geq$ 13</u> 7 (7%)	3	0.017
Overall social support	<u>median social support score (IQR)</u> 86 (64–97)	70.1	<0.001
Family cohesion (n=93)	<u>mean FACES-II score $\pm$ SD</u> 65 $\pm$ 10	75.3	<0.001
Family adaptability(n=93)	<u>mean FACES-II score $\pm$ SD</u> 48 $\pm$ 7	43.1	<0.001
Smoker (n=95)	<u>N (%) based on BRFSS</u> 10 (11%)	19%**	0.013
$\geq$4 drinks on 1 or more days of month (n=91)	<u>N (%) based on BRFSS</u> 25 (39%)	18%**	<0.001

CD-RISC: Connor-Davidson 10-item Resilience Scale; K6: Kessler-6 Psychological Distress Scale; social support score: Medical Outcomes Survey social support subscale; FACES-II: Family Adaptability and Cohesion Scale; BRFSS: Behavioral Risk Factor Surveillance System. Empty boxes due to lack of national comparisons.

* one-sample binomial test for binary variables, t-test for continuous variables with normal distributions, and Wilcoxon signed-rank otherwise;

** Comparisons to WA State population norms.

TABLE III

Adjusted Odds Ratios* of psychosocial outcomes given single point decrease in CD-RISC score or low resilience resources* (N=96)

	SINGLE POINT DECREASE IN TOTAL CD-RISC SCORE [†]			LOWEST RESILIENCE RESOURCES QUARTILE COMPARED TO ALL OTHERS [‡]		
	OR	95% CI	p-value	OR	95% CI	p-value
EMOTIONAL DISTRESS (n=93)						
Low psychological distress (K6 score < 7)	1	(ref)		1	(ref)	
High psychological distress (K6 score ≥ 7)	1.16	(1.04, 1.29)	0.007	3.71	(1.17, 11.72)	0.026
HEALTH BEHAVIORS						
In the past month, how often do you have difficulty falling asleep? (n=95)						
“Never / rarely (less than once/week) / sometimes (1–2 times/week)”	1	(ref)		1	(ref)	
“Frequently (2–4 times/week) / always (5–7 times/week)”	1.16	(1.05, 1.29)	0.004	5.19	(1.74, 15.45)	0.003
Have your sleep difficulties affected important areas of your life? (n=85)						
“Moderately / a little bit / not at all”	1	(ref)		1	(ref)	
“Quite a bit / extremely”	1.13	(1.01, 1.26)	0.029	3.38	(1.16, 9.85)	0.026
In the past 30 days, how many times have you driven when you’ve had perhaps too much to drink? (n=93)						
None	1	(ref)		1	(ref)	
1 or more	1.09	(1.01, 1.17)	0.033	7.85	(0.77, 80.03)	0.082
In general, would you say your health is (n=93)						
“Excellent / very good”	1	(ref)		1	(ref)	
“Good / fair / poor”	1.18	(1.08, 1.29)	<0.001	6.86	(2.52, 18.65)	<0.001
In general, how satisfied are you with your health? (n=95)						
“Very satisfied”	1	(ref)		1	(ref)	
“Satisfied / dissatisfied / very dissatisfied”	1.13	(1.00, 1.28)	0.056	5.71	(2.05, 15.92)	0.001
COMMUNICATION WITH MEDICAL TEAM						
During discussions with your child’s medical team, were you able to express your hopes? (n=95)						
“A great deal”	1	(ref)		1	(ref)	
“A lot / Somewhat / A little / Not at all”	1.16	(1.04, 1.28)	0.006	3.08	(1.12, 8.49)	0.030
During discussions with your child’s medical team, were you able to express your worries? (n=95)						
“A great deal”	1	(ref)		1	(ref)	

	LOWEST RESILIENCE RESOURCES QUARTILE COMPARED TO ALL OTHERS [‡]		
	SINGLE POINT DECREASE IN TOTAL CD-RISC SCORE [†]		
"A lot / Somewhat / A little / Not at all"	1.18	(1.07, 1.31)	0.001
		4.00	(1.43, 11.18)
			0.008

CD-RISC: Connor-Davidson 10-item Resilience Scale; K6: Kessler-6 Psychological Distress Scale;

* Multiple logistic regression models adjusted for parent sex.

[†] CD-RISC score as independent variable; for every point increase in CD-RISC score, the odds of the corresponding outcome score changes by OR (e.g., for every point increase in CD-RISC score, the odds of having high psychological distress are 0.86 times lower).

[‡] Low resilience resources (defined as lowest 25 percentile of CD-RISC) as independent variable; for parents with low resilience resources, the odds of the corresponding outcome score changes by OR (e.g., for parents with low resilience resources, the odds of having high psychological distress are 3.71 times higher than those of parents with normal or high resilience resources).