Peace of Mind and Sense of Purpose as Core Existential Issues Among Parents of Children With Cancer

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Objective: To evaluate issues experienced by parents of children with cancer and factors related to parents’ ability to find peace of mind.

Design: Cross-sectional survey.

Setting: Dana-Farber Cancer Institute and Children’s Hospital, Boston, Massachusetts.

Participants: One hundred ninety-four parents of children with cancer (response rate, 70%) in the first year of cancer treatment.

Main Outcome Measure: The Functional Assessment of Chronic Illness Therapy–Spiritual Well-being sense of meaning subscale.

Results: Principal components analysis of Functional Assessment of Chronic Illness Therapy–Spiritual Well-being sense of meaning subscale responses identified 2 distinct constructs, peace of mind (Cronbach α = .83) and sense of purpose (Cronbach α = .71). Scores ranged from 1 to 5, with 5 representing the strongest sense of peace or purpose. One hundred forty-seven of 181 parents (81%) scored 4 or higher for questions related to sense of purpose (mean [SD] score, 4.4 [0.6]). Only 44 of 185 parents (24%) had scores in the same range for peace of mind (mean [SD] score, 3.2 [0.9]) (P < .001). In a multivariable logistic regression model, parents had higher peace of mind scores when they also reported that they trusted the oncologist’s judgment (odds ratio [OR] = 6.65; 95% confidence interval [CI], 1.47-30.02), that the oncologist had disclosed detailed prognostic information (OR= 2.05; 95% CI, 1.14-3.70), and that the oncologist had provided high-quality information about the cancer (OR= 2.54; 95% CI, 1.11-5.79). Peace of mind was not associated with prognosis (OR= 0.74; 95% CI, 0.41-1.32) or time since diagnosis (OR= 1.00; 95% CI, 0.995-1.003).

Conclusions: Physicians may be able to facilitate formulation of peace of mind by giving parents high-quality medical information, including prognostic information, and facilitating parents’ trust.


Studies in adult patients with cancer suggest that patients often experience illness as an existential crisis; the diagnosis of cancer and the possibility of death call into question personal beliefs about life’s meaning.1-10 Like other traumatic life events, a cancer diagnosis can raise issues such as uncertainty, unfairness, and altered life plans.5,8,10 Ultimately, patients may work to formulate a sense of meaning that incorporates these complex issues.3,11-13

Patients’ struggles to integrate the cancer experience into their core identity and beliefs can have a profound effect on their lives and choices for care. For example, patients with cancer who are able to develop a sense of peace and equanimity in their cancer experience tend to have better quality of life18 and better psychological health2,11,13,15 and are less likely to choose invasive measures at the end of life.2,3 Although the literature suggests that the search for meaning in an illness may lie at the core of many aspects of cancer care, we know little about the extent to which a child’s illness provokes existential distress in the parents or about how parents find meaning in this experience. We therefore aimed to describe the existential issues experienced by parents of children with cancer.

Besides the importance of understanding the existential issues parents experience, we know little about the physician’s role in such experiences. Can physicians support parents in their search for meaning? Previous literature has focused on sociodemographic characteristics and personality traits as influences on meaning formation.6,10,16,17 A choice suggesting that
meaning formation may be intrinsic to one’s self rather than subject to outside influences. However, physicians worry about the extent to which their communication causes distress, particularly when they have to deliver very bad news. Substantial literature suggests that perhaps as a result of these feelings, physicians avoid giving clear and direct prognostic information.18-22 We therefore evaluated the role of physician communication, including prognosis communication, in parents’ experiences of formulating meaning after a child’s cancer diagnosis.

We surveyed parents and physicians of children with cancer to evaluate parents’ knowledge about prognosis and their experiences with prognosis communication.26-28 We present an analysis focused on the existential issues experienced by parents of children with cancer as well as physician characteristics associated with formulation of meaning. For this study, we considered existential distress to be the crisis evoked by the child’s cancer diagnosis. Formulation of meaning, in contrast, is a way of resolving this crisis by integrating the knowledge of a child’s life-threatening illness into one’s core beliefs.

DATA COLLECTION

Development of the survey has been previously described.26-28 To assess issues experienced by parents, we used the sense of meaning subscale of the Functional Assessment of Chronic Illness Therapy—Spiritual Well-being scale.14 This scale was developed and validated in adult patients with cancer and includes 9 items designed to measure the extent to which patients feel a sense of meaning in their experience of illness. We made minor modifications in the wording of the items to make them appropriate to parents of children with cancer. Parents were given a series of statements about their experiences (Table 1) 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.

We evaluated the domains of the Functional Assessment of Chronic Illness Therapy—Spiritual Well-being sense of meaning subscale by performing principal components analysis of the Functional Assessment of Chronic Illness Therapy—Spiritual Well-being sense of meaning subscale in our parent population. When we extracted factors with eigenvalues greater than 1, there were 2 major meaning-related domains, which we refer to as peace of mind and sense of purpose. Individual items and the item-total correlations for the 2 subscales are shown in Table 1. Internal consistency was high for both subscales, with a Cronbach’s α of 0.83 for the peace of mind items and 0.71 for items related to parents’ sense of purpose.

We focused on 1 of the identified domains, peace of mind, and sought to ascertain associated physician communication attributes. Among the communication factors we measured was parents’ recall of prognostic disclosure. More extensive disclosure was defined as a parent reporting 2 or more of the following: the physician discussed the prognosis; the physician offered this information rather than the parent having to ask for it; the physician provided numeric information about the prognosis; the physician provided written information about the prognosis; and the parent was satisfied with the amount of information he or she had received about the prognosis (Cronbach’s α = 0.69).28 We also measured parents’ sense of trust in the physician using an item from the Trust in Physician Scale29,30 (“How much do you trust your child’s oncologist’s judgment about your child’s medical care?” with response options of completely, mostly, somewhat, a little, or none at all). We measured parents’ ratings of communication quality (Cronbach’s α = 0.76) using a scale developed and validated for this study, including some previously validated items.31 Finally, parent-rated information quality (Cronbach’s α = 0.87) comprised parent reports on the quality of information they had received about diagnosis, treatment, prognosis, what the diagnosis means for the child’s future, whether there is a cause for the child’s cancer, and how the treatment is working (response categories included excellent, good, satisfactory, fair, and poor).

We also hypothesized that attributes of the child’s illness might affect the extent to which parents are able to find peace of mind. Disease attributes might confound the relationship between peace of mind and physician communication. We therefore measured several disease attributes, including the child’s prognosis. Parents and physicians were each asked, “How likely do you now think it is that your child will be cured of cancer,” with response categories of extremely likely (>90% chance of a cure), very likely (75%-90% chance of a cure), moderately likely (50%-74% chance of a cure), somewhat likely (25%-49% chance of a cure), unlikely (10%-24% chance of a cure), and very unlikely (<10% chance of a cure).32,33 We also measured the type of cancer, treatment received, and time since diagnosis using data collected from physicians.

We previously reported that parents derive hope from physician communication34 and that specific communication behavior including prognostic disclosure is associated with a greater
sense of hope. Because hope has the potential to be a core component of the parents' existential experience, we also assessed the extent to which hope was associated with peace of mind and the extent to which the relationship between hope and prognostic disclosure could explain any associations between disclosure and peace of mind. Communication-related hope was assessed by asking parents how often the "way your child's oncologist communicated with you about your child's cancer made you feel hopeful" (always, often, sometimes, rarely, or never).28

The parent survey also asked about the parent's sex, relationship to the child, age, educational level, marital status, race/ethnicity, and religion. The questionnaire was pilot tested with a series of parents and medical care providers, with iterative revision and retesting in response to pilot testing results.

The institutional review board of the Dana-Farber Cancer Institute approved this study.

STATISTICAL METHODS

Analyses were conducted using the SAS version 9.1 statistical package (SAS Institute, Inc, Cary, North Carolina).

The 3 response categories for individual items of the peace and purpose subscales were converted to scores from 1 to 5, with a score of 5 corresponding to the category of extremely except for the 2 items that required reverse coding. Subscale scores were generated as means of relevant individual item scores.

Pearson correlation coefficients were used to assess relationships between subscale scores, and the paired t test was used to compare their mean values.

The subscale score for peace of mind was dichotomized at a score of 4 or higher, a cutoff chosen to correspond approximately to the categories (extremely or very) that we felt generally indicated a strong sense of peace of mind. Physician communication variables were also dichotomized to simplify presentation and interpretation of results. For communication and information quality, individual question responses were summed and the sums were dichotomized at the sample median for analysis.

Bivariable and multivariable relationships were described using logistic regression with generalized estimating equations to account for clustering of patients within physicians. To select independent variables for the model of peace of mind, we first selected variables for which bivariable associations were significant at the P < .10 level. Variables considered were parent-rated communication quality and information quality, prognostic disclosure, and trust in the physician. Models also included the physician-rated likelihood of a cure, the degree of discrepancy between parent and physician ratings of the likelihood of a cure, parent's sex, race/ethnicity, and educational level, time since diagnosis, and diagnostic category (hematologic malignant neoplasm, brain tumor, or other solid tumor) regardless of the significance of their coefficients. Starting with the least significant variable in the multivariable model, variables were removed sequentially until all remaining independent variables were significant at the P < .05 level. We performed sensitivity analyses using the parent-rated likelihood of a cure, using peace of mind as a linear outcome variable, and including communication-related hope as a covariable.

RESULTS

Most of the participating parents were the mothers of children studied (Table 2); about 21% were fathers. Nonrespondents did not differ significantly from respondents with respect to the child's sex (P = .70), age at diagnosis (P = .95), or diagnosis (P = .07). Nonrespondents were more likely than respondents to have children with solid tumors and less likely to have children with hematologic malignant neoplasms, but this difference was not statistically significant (P = .07).

Physicians estimated a range of prognoses for the children studied and said that more than half of them had a likelihood of a cure greater than 75%.

Parents' scores for peace of mind and sense of purpose were moderately correlated (r = 0.45). However, parents' scores for peace of mind were lower on average (mean [SD] score, 3.2 [0.9]) than their scores for sense of purpose (mean [SD] score, 4.4 [0.6]) (P < .001). Overall, 147 of 181 parents (81%) had scores of 4 or higher for sense of purpose. In contrast, only 44 of 185 parents (24%) had scores in this range for peace of mind.

Because relatively few parents had high scores on the peace of mind scale, we focused bivariable and multivariable analyses on this attribute with the outcome of a score of 4 or higher for parental peace of mind. Sociodemographic attributes, including parent's race, education, and sex, were not associated with peace of mind (Table 3). In addition, the child's likelihood of a cure was not associated with parents' peace of mind (odds ratio [OR] = 0.86; 95% confidence interval [CI], 0.67-1.10). However, several communication attributes, including information quality (OR = 4.41; 95% CI, 2.05-9.49), trust (OR = 7.20; 95% CI, 2.57-20.11), and prognostic disclosure (OR = 2.47; 95% CI, 1.44-4.25), were associated with parental peace of mind in bivariable analyses.

These bivariable associations persisted in the multivariable model (Table 4). A multivariable logistic regression model showed that parent report of more ex-
...communication-related hope were considered, although the effect was slightly attenuated.

Having a child with cancer is obviously an intensely painful experience, but the degree of suffering experienced, as indicated by more than three-quarters of parents who did not meet our criteria for peace of mind, is profound. In our study, this distress was as common among parents whose children had been diagnosed 1 year ago or longer as among those whose children had been diagnosed in the last month, and it was as common among parents whose children had good prognoses as among parents whose children had cancer that was unlikely to be cured.

Indeed, the finding raises the question of whether peace of mind is even possible for most parents of children with cancer. However, some parents in our study were able to find peace of mind, and our findings suggest that the physician can have a significant role in this experience.

Perhaps most strikingly, parents were more likely to find peace of mind when the physicians had discussed the child's prognosis. Previous studies have suggested that physicians are often reluctant to provide clear and direct prognostic information because of concerns about causing distress to patients and their families. Some physicians even describe the process of delivering difficult news as a deeply painful process for themselves and akin to doing violence to the patient or family. Although the practice of nondisclosure may have its basis in a deep empathy with the family, the lack of understanding a poor prognosis can have significant clinical consequences, including pursuit of aggressive end-of-life care when the benefits of such care are limited.

For physicians whose good intentions lead them to consider withholding prognostic information, the knowledge that prognostic disclosure and parental peace of mind can coexist may offer some reassurance in this difficult situation. Avoiding a discussion about difficult information may not reduce the likelihood of parents worrying about poor outcomes. Instead, it may eliminate one opportunity for discussing these issues and obtaining accurate information about what is ahead for their child.

Parents were more likely to experience peace of mind when they felt they had received high-quality medical information about several aspects of the child's cancer, treatment, and prognosis and when they trusted the oncology care provider. What is particularly striking is that peace of mind was not associated with parental or clinical characteristics, including time since diagnosis and the child's prognosis. Taken together, these findings suggest that physicians can play an important role in helping parents come to terms with the child's illness.

We found that relationships between peace of mind and physician communication attributes, including prognostic disclosure, were similar to those we have previously reported with communication-related hope. Thus, it is possible that hope and peace of mind are overlapping constructs. There was a modest relationship between the 2 variables, implying that hope and peace of...
mind are related. However, controlling for parents’ hope did not fully explain the relationship between disclosure and peace of mind, suggesting that the 2 constructs have some unique properties. Both constructs deserve further exploration in future studies.

Our study has some limitations. Perhaps most importantly, the association between physician communication and parental peace of mind is not necessarily evidence of causation. It is possible that physicians are more likely to disclose prognostic information to parents with a peaceful demeanor. Similarly, parents who have greater peace of mind could be more likely to absorb and recall aspects of conversations with physicians, including prognostic information. Either possibility could explain the association we have seen. However, even if disclosure does not result in peace of mind, we also did not find that prognostic disclosure diminishes peace of mind. In light of previous findings that most parents want prognostic information about their children with cancer,24 we find no reason to recommend routinely withholding prognostic information.

Our parent population included limited numbers of parents whose children were in the poorest prognostic group and limited numbers of parents who experienced peace of mind. We were therefore not able to explore in depth experiences with peace and prognostic disclosure among parents of children with the poorest prognoses, and it is possible that prognostic disclosure was associated with peace of mind simply because so many children had good prognoses. However, our finding that even parents of children in the best prognostic category had deep existential distress suggests that the prognosis itself offers little reassurance to parents. Rather, more complex issues may contribute to distress and its alleviation; the honest and trusting physician relationship that forms the context for prognostic disclosure may be more important than the probability of cure in itself. Future work should attend to these complex issues and in particular should assess the experiences of parents whose children have the poorest prognoses.

We used a questionnaire to assess a complex, highly personal construct. The 2 existential issues we identified were embedded in the Functional Assessment of Chronic Illness Therapy—Spiritual Well-being scale. If we defined parents to determine their personal sense of meaning, we might have identified different domains. In addition, we sought to answer a somewhat narrowly defined question about the physician’s role in parents’ formulation of meaning. In doing so, we did not assess the full array of potentially related issues, such as personal faith and spirituality, community, and support. Many of these issues might best be assessed through in-depth interviews and qualitative research methods rather than a questionnaire. Future research may help us to understand some of these complex issues in greater depth. The study population also had limited racial, ethnic, and socioeconomic diversity, reflecting the patient population at our center. This study was cross-sectional, and although parents’ scores for peace of mind did not vary with time from diagnosis, we could not fully assess how parents’ peace of mind and sense of life purpose changed over the child’s disease course.

Although relatively few parents in our study were able to find peace of mind, our findings suggest that physicians may be able to help parents transcend their suffering. Parents find meaning in their own ways. However, the literature on the distress physicians feel about providing prognostic information underscores how much physicians want to help in this circumstance. Our finding that a physician can help parents simply by giving honest information is reassuring. Not only can physicians support decision making with honest information, a practice that is an ethical obligation, but also in doing so they may be able to help alleviate the deep personal and existential suffering that parents experience as they care for their children with cancer.

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REFERENCES


