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Measuring health-related beliefs of mothers of adolescent and young adult childhood cancer survivors

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Abstract

Childhood cancer has long-term implications for survivors and their family members. While the impact of cancer on the family continues into adulthood, little research exists on family-related issues during this important developmental period. In order to advance our understanding of families of adolescent and young adult (AYA) childhood cancer survivors, a measure of health-related beliefs for parents of AYA cancer survivors was developed. Exploratory factor analysis based on the mothers' data was used to identify four factors among 23 items: Social Competence, Satisfaction with Healthcare, Health Perceptions, and Health Apprehension. The scales are associated with psychological distress, quality of life, and posttraumatic stress symptoms but unrelated to age of the child at diagnosis and cancer treatment intensity. The beliefs identified in this study are consistent with clinical observations of families of young adult survivors and provide indications for the importance of ongoing attention to the families of childhood cancer survivors.

Keywords

beliefs; childhood cancer; survivors; families; parents; adolescents; young adults

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A multidisciplinary team of psychologists, oncology survivorship providers (nurse practitioners, nurses, and a pediatric oncologist), a family medicine physician, and a biostatistician used inductive and deductive methods to develop categories and subcategories of beliefs from our working definition of health competence beliefs and to generate items for the original Health Competence Beliefs Inventory (HCBI). The measure was systematically modified following feedback from a consultative physician expert in survivorship, focus groups, and a feasibility study with 30 participants, resulting in an initial 84-item measure. With the goal of a technically strong but brief scale, iterative oblique exploratory factor analysis was conducted using promax rotation; items with a loading of $> .40$ were retained. The resulting 21-item measure has four factors: Health Perceptions, Satisfaction with Healthcare, Cognitive Competence, and Autonomy.

Advances over the past several decades in treating childhood cancer are among the most striking achievements in pediatrics, with a 5-year survival rate of approximately 80% (Ries, Smith, Guerny et al., 1999). As a result, an increasing number of survivors are now young adults (1 in 640 adults between 20 and 39 years of age is a survivor of childhood cancer, Hewitt, Weiner & Simone, 2003). While cured of their original childhood disease, survivors remain active in the healthcare system because of sequelae of their disease and treatment. Almost 70% have at least one ongoing medical problem that often emerges during the adolescent and young adult (AYA) period. Of these, a quarter has a severe or life threatening condition (e.g., infertility, neuropsychological difficulties, organ failure, second malignancies; Oeffinger et al., 2006). Despite the potential for serious health outcomes, follow-up on recommended medical monitoring is low, with only one-third of survivors following through with recommended care (Nathan et al., 2008; Oeffinger et al., 2009).

Childhood cancer impacts the family both during treatment and survivorship. Although survivors are relatively psychologically resilient, their parents and siblings experience psychological struggles (Alderfer et al., in press; Vrijmoet-Wiersma et al., 2008). Parents play an important role during treatment by making decisions about their child's care, navigating the healthcare system, and by providing emotional support to their children and family (Klassen et al., 2007). Parents also have potentially traumatic experiences related to their child's diagnosis and treatment, and post-traumatic stress symptoms have been shown to persist into survivorship (Alderfer et al., 2005). During young adulthood, parents of childhood cancer survivors remain engaged with survivors around recommended cancer follow-up care. These parents are three times more likely to attend medical appointments than parents of other AYAs, including those with chronic illness (Ressler, Cash, McNeill, Joy, & Rosoff, 2003). There is also evidence that parents may think and worry more about the cancer than the survivor does (Kinahan, Sharp, Arntson, Galvin, Grill, & Didwania, 2008). The benefits or challenges of these observations have not been fully explored. Given the concerns about adherence to follow-up care, exploring how parents may influence adherence could be instructive.

Also relevant to understanding families of AYA survivors are the documented difficulties of survivors in achieving developmental milestones. AYA survivors struggle with achieving normative developmental tasks and identities (Stam, Grootenhuis, & Last, 2005), are less likely than peers to attend college (Boman & Bodegard, 2004) and experience more difficulty with vocational decisions and achievements (Langeveld, Ubbink, Last, Grootenhuis, Voute, & DeHaan, 2003). Socially, AYA cancer survivors have more challenges with romantic/sexual relationships and are less likely to marry when compared with siblings. Not surprisingly, AYA childhood cancer survivors are more likely to live with their parents longer than others (Stam et al., 2005).

Given that the majority of children with cancer will grow up, parents continue to be involved in their survivors' health monitoring and impacted by any ongoing medical problems. To gain a greater understanding of these parents' healthcare beliefs, we used the concept of *health competence beliefs*. Health competence beliefs refer to a multidimensional set of perceptions about health and well-being that include current and future health concerns, ability to manage medical issues, ability to relate to others, and attitudes towards health promoting behaviors. These beliefs, measured by the Health Competence Beliefs Inventory (DeRosa et al., in press), are appraisals and interpretations of one's experience.¹

Health competence beliefs may also be relevant for parents. Parents have their own experiences and perspective of their child's illness and treatment (Kazak, McClure et al, 2004.) and how it has impacted their lives. Although some parents permanent changes in their personal outlook and health-related beliefs as a result of their child's illness (e.g. loss in

their positive outlook towards life, personal growth including a positive shift, increased sense of their personal health vulnerability, uncertainty regarding their child's psychological and physical health; Van Dongen-Melman, Van Zuuren, & Verhulst, 1998), these beliefs have not been systematically measured.

This is an initial report about a measure of parent beliefs regarding their health and related competencies. Recognizing that parents' beliefs may be different from survivors' beliefs, the measure was based on a modification of the HCBI. The relationship among beliefs, parent distress, and aspects of the AYA were examined to provide initial evidence for the measure's validity.

Method

Participants and Procedure

This study was part of a larger prospective investigation of long-term outcomes of childhood cancer survivors (Kazak, DeRosa, Schwartz, *et al.*, 2010). For this report, participants were parents who accompanied their 16 to 29 year old child to an oncology follow-up clinic appointment (demographic data of AYA childhood cancer survivor are presented in Table 1). These parents were approached for participation after their child consented to an IRB approved study of psychological outcomes in cancer survivorship from March 2006 through August 2009.

Of 174 survivors eligible for this part of the study, 139 (79%) were accompanied by a parent. Five were excluded due to a non-English speaking parent, resulting in 134 eligible families. At least one parent consented in 134 families (mothers only $N = 101$, fathers only $N = 21$, both parents $N = 24$). Of those consented, 86 (76%) mothers and 23 (70%) fathers completed the questionnaire packet. Due to sample size considerations, only maternal data were used for the primary statistical analyses. In general, the mothers were highly educated and primarily Caucasian (demographic data are presented in Table 1).

The cancer survivors were long-term survivors (without recurrence of cancer for at least five years) of leukemias (45.5%), lymphomas (18.7%) or solid tumors (35.8%). They were currently an average age of 19.90 years ($SD = 2.95$ years) and 52% were male. Their average age at diagnosis was 6.68 years ($SD = 4.80$, range birth - 18 years). For nearly half (46.6%) of the survivors, the highest level of educational achievement was high school. Another third (36.0%) attended some college or graduated from college (11.2%).

Measures

During the visit, parents were administered a questionnaire packet that included a demographic questionnaire, the parent Health Competence Beliefs Inventory (pHCBI), three measures of psychological distress, and a measure of health status and quality of life. Parents completed and returned the questionnaire packet during their clinic visit.

The parent Health Competence Beliefs Inventory (pHCBI) is a measure of parents' perceptions of their own health-related competence. The initial items for this scale were adapted from the item pool generated for the development of a similar scale for AYA health beliefs – the Health Competence Beliefs Inventory (HCBI; DeRosa *et al.*, in press). Seventy items from the original HCBI were retained; 14 items considered more specific to AYAs were removed (e.g., “I would feel uncomfortable if a relationship became sexual”, “I don't think I'll marry or be in a long-term relationship”) and 12 items related to parenting (e.g., “I'm pleased with the way my child has turned out”; “When my child needs a medical appointment, it's difficult to get one”) were added to create the 82-item version that was

completed by the participants. The 4-point Likert scale from the HCBI was used where 1 = Strongly Disagree and 4 = Strongly Agree.

The three measures of psychological distress included the Brief Symptom Inventory-18 (BSI – 18; Derogatis, 2001), State-Trait Anxiety Inventory (STAI; Spielberger & Gorsuch, 1970), and Posttraumatic Stress Checklist-Civilian Version (PCL-C; Weathers and Ford, 1996). The BSI is an 18 item symptom inventory of psychological distress. The STAI is a widely used 40-item self-report scale of dispositional and situational anxiety. The PCL-C is a 17-item self-report questionnaire assessing DSM-IV symptoms of PTSD.

The Short Form Health Status Questionnaire (SF-12; Ware, Kosinski, & Keller, 1996) was used as a 12-item measure of health status and quality of life.

Medical chart review was used to obtain the age at diagnosis of their child's cancer as well as the information necessary to calculate treatment intensity using the Intensity of Treatment Rating Scale (ITR; Werba, Hobbie, Kazak, Ittenbach, Reilly, & Meadows, 2007).

Statistical Analysis

Due to sample size considerations, only maternal data were used for the primary statistical analyses. Exploratory factor analysis (EFA) was performed with the goal of identifying salient factors and creating a shorter scale. The underlying factor solution was identified using an oblique principal-axis EFA with Promax rotation. Parallel analysis was utilized to estimate the number of viable factors. In consideration of the small sample size, only items with factor loadings greater than 0.45 and that loaded on only one factor were retained. EFA was repeated to ensure that all factors were interpretable with at least 4 salient items and alphas > 0.70. Once an optimal, interpretable underlying factor structure was obtained, the score for each scale of the pHCBIs was computed and internal consistency coefficients were calculated.

Pearson correlations were computed to assess the relationship between each pHCBIs scale and the four standardized measures of health and well-being (i.e. BSI, STAI, PCL-C, and SF-12). The criterion for statistical significance for all models and correlations was held constant at $\alpha = 0.01$ level. We also examined the relationship between pHCBIs scales (mother data) and AYA's age of cancer diagnosis and intensity of cancer treatment, using correlational tests and ANOVA tests respectively.

Results

The EFA process for the pHCBIs yielded a parsimonious 23-item four-factor solution with an overall alpha of .88 (Table 2). Social Competence (Factor 1). Eight items reflect beliefs about how mothers relate to others and view themselves in a social context (e.g., "I believe I make a difference in my community). Health Perceptions (Factor 2). The 6 items on this scale consist of beliefs about the mother's current health and vulnerability to future illness (e.g., "I'm not as healthy as other people my age). Satisfaction with Healthcare (Factor 3). This scale consists of 5 items about satisfaction with, or the effectiveness of, their healthcare provider and system, including beliefs that healthcare providers are able to understand them and offer adequate healthcare (e.g., "I am unable to get good health care). Health Apprehension (Factor 4). This 4-item scale is made up of apprehensive beliefs regarding information about the mother's health as well as their child's health (e.g., "I need to ask questions about my health before I'm convinced that I'll be okay).

Pearson correlations among the four scales were low to moderate, ranging from a low of 0.25 to a high of 0.43 (Median = 0.32). The pHCBIs scales correlated significantly with

measures of psychological distress; more positive beliefs of health-related competence were generally associated with less psychological distress (Table 3). Pearson correlations were low to moderate, ranging from a low of 0.31 to a high of 0.59 (Median = 0.43).

Mothers' report on each of the pHCBI scales was not significantly correlated with the AYA child's age of diagnosis; there was no significant relationship between scores on the pHCBI scales and an objective rating of their child treatment intensity.

Discussion

Given that parents continue to be involved in the follow-up care of their AYA childhood cancer survivors, it is important to identify their health-related beliefs. The goals of this study were to describe the initial development and provide preliminary evidence of validity of a measure that assesses health beliefs of parents of childhood cancer survivors. The parent version of the Health Competence Beliefs Inventory (pHCBI) assesses beliefs in four areas: Social Competence, Satisfaction with Healthcare, Health Perceptions, and Health Apprehension. Each of pHCBI scales provides examples of potentially malleable beliefs of parents that may be relevant to both their own and their AYA child's health-related behaviors.

Of the four scales, Social Competence and Health Apprehension assess particularly novel and clinically relevant beliefs. Social competence may reflect the overall positive adjustment and competence associated with childhood cancer survival. From the point of diagnosis onward parents are encouraged to become advocates for their children and many do so effectively. Social competence may reflect the continued confidence that these parents (particularly mothers) have in navigating the healthcare system and interacting with healthcare providers around health related risks, even as their children grow up and continue to experience the consequences of treatment (Nathan et al., 2007). It is not surprising that these mothers continue to attend medical appointments with their AYA offspring, often with the child's encouragement (Kinahan et al., 2008). Health Apprehension reflects the understandable uncertainty and anxiety associated with having a child who survived cancer. Novel to this investigation are data that indicate that these mothers also worry about their own health, suggesting that their experiences may have contributed to some generalizability about health concerns in the family. Important future questions include understanding how parental beliefs about both social competence and health apprehension facilitate or complicate the AYA survivors' ability to accomplish developmental tasks of adulthood and to assume greater responsibility for their own healthcare.

Parents who accompany their young adult survivor children to medical visits have been reported to have persistent psychological vulnerabilities (Hardy et al., 2008). Consistent with this finding, across all four scales of the pHCBI there were significant associations with health-related quality of life, anxiety, depression and post-traumatic stress in our sample. These beliefs show relationships with well known outcome measures in the related literature and suggest that health competence beliefs, including satisfaction with healthcare and how parents perceive their child's ongoing health issues, may help identify parents with higher levels of distress and subsequently become targets for interventions to reduce distress. The scales of the pHCBI were not associated with the child's treatment regimen, indicating that more objective aspects of treatment do not have a significant impact on their long-term beliefs. Although it might be expected that age at diagnosis (reflecting the length of time as a parent and the developmental phase during which the child was ill) would be related to parent health competence beliefs, this was not the case in this sample, consistent with other research on parental beliefs during treatment (Kazak et al., 2004).

There are limitations of this preliminary study related to the small sample size and the relative homogeneity of the sample. Mothers who participated were engaged with the healthcare system and were following recommendations for their children to attend annual visits to the survivorship clinic. They were also primarily Caucasian and over half were college graduates. Therefore, these mothers may not reflect the broader population of families of AYA cancer survivors. Future studies are needed to validate the measure in a population of parents of clinical and non-clinical groups of AYA childhood cancer survivors that is more representative of the US population. In addition, this report only includes data from mothers and not fathers. Research has shown that fathers and mothers of childhood cancer survivors endorse different beliefs (Leventhal-Belfer, Bakker, Russo, 1993). Thus, the pHCBi should be administered to fathers to understand how it performs and determine if beliefs differ among mothers and fathers.

In summary, this study provides preliminary evidence that the pHCBi is a reliable, valid, and feasible self-report method for assessing the beliefs of parents (particularly mothers) of AYA childhood cancer survivors. Maternal beliefs about healthcare were related to mothers' well-being. Yet, little is known about how and to what extent parental involvement is adaptive or inhibiting for their offspring's development and autonomy (Banner, Mackie, & Hill, 1996), and how it may impact their child's healthcare. Such beliefs are likely to be amenable to interventions that help eliminate barriers to optimal health care utilization and health promotion. Therefore, future research may examine how these beliefs may relate to the cancer survivor's development and adjustment and how they may be utilized to foster adaptive engagement in healthcare that also facilitates the developmental challenges of the AYA period for these survivors.

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Table 1

Demographic characteristics

	Mothers ¹ (n = 86)	
Age in years M (SD)	50.62 (5.16)	
Ethnicity/Race	n	Frequency (%)
African-American	1	1.2%
Asian	2	2.3%
Caucasian	80	93.0%
Hispanic	1	1.2%
Native American	0	0%
More than one race	1	1.2%
Education		
< High school graduate	0	0%
High school graduate	22	25.6%
Some college	17	19.8%
Graduated college	19	22.1%
Graduate study	26	23.3%
Employment		
Not employed	12	14.3%
Part time	17	20.2%
Full time	55	65.5%
Marital Status		
Single	6	7.0%
Married (first)	55	64.0%
Married (second or more)	11	12.8%
Separated/Divorced	7	8.2%
Widowed	1	1.2%
Other	4	4.7%

¹Two mothers did not complete the demographic form.

Table 2

Factor Loadings for Parent Health Competence Beliefs Inventory (pHCBI)

Item (Belief)	Social Competence **	Health Perceptions **	Satisfaction Healthcare **	Health Apprehension **
I can trust that my good friends will be there for me when I need them	0.81	-0.02	-0.06	0.08
I've been successful at keeping my friends	0.75	0.10	0.02	-0.18
It's easy for me to make friends	0.67	0.01	0.05	-0.16
I'm a good parent	0.62	-0.06	0.09	0.06
I believe I make a difference in my community	0.60	-0.05	0.15	0.08
My doctor listens to my concerns	0.59	0.04	0.12	-0.06
When I have a question for my doctor, I ask it	0.58	-0.07	-0.09	0.26
I'm pleased with the way my child has turned out	0.56	0.04	-0.10	0.06
I'm not as healthy as most people my age *	0.05	0.81	0.02	-0.11
I have more aches and pains than other people my age *	-0.06	0.82	0.06	0.06
My physical health does not limit the activities that I do	-0.05	0.75	0.02	0.02
My future health is uncertain *	-0.06	0.61	0.09	0.14
I can't exercise as much as most people *	0.01	0.55	0.10	0.02
It's hard for me to change unhealthy habits *	0.24	0.50	-0.27	-0.02
When my child needs a doctor's appointment, it is difficult... *	0.02	0.08	0.82	-0.07
When I need a doctor's appointment, it is difficult for me to get one *	-0.02	-0.12	0.83	0.01
I am unable to get good healthcare *	0.15	0.04	0.48	0.01
My insurance prevents me from getting good healthcare *	0.05	-0.02	0.45	0.19
It's a hassle to get to the doctor's office, even... *	-0.03	0.18	0.48	-0.01
I need to ask a lot of questions about my child's health before... *	-0.08	0.11	0.02	0.77
Waiting for test results is really hard for me *	0.03	0.02	0.09	0.66
I need to ask questions about my health before I'm convinced... *	0.03	-0.16	0.06	0.69
I am a worrier *	0.06	0.15	-0.15	0.59
Eigenvalue	5.97	2.21	1.58	1.27

Item (Belief)	Social Competence**	Health Perceptions**	Satisfaction Healthcare**	Health Apprehension**
Percent Variance	40.39	36.55	33.07	24.42
Alpha	0.86	0.83	0.77	0.78

Note

* Reverse-scored items.

** Higher scores indicate more positive beliefs

Table 3

Pearson Correlation Coefficients between Scales of the Parent Health Competence Beliefs Inventory (pHCBI) and Validation Measures

	SF12 Physical	SF12 Mental	STAI State	STAI Trait	BSI GSI	PCLC
Social Competence	.15	.47*	-.43*	-.38*	-.49*	-.40*
Health Perceptions	.47*	.36*	-.38*	-.14	-.59*	-.51*
Satisfaction with Healthcare	.30*	.15	-.49*	-.25	-.50*	-.47*
Health Apprehension	.26	.02	-.39*	-.21	-.31*	-.36*

Note

No adjustments were made for multiple comparisons.

BSI (GSI) = Brief Symptom Inventory – Global Severity Index; PCL-C = Posttraumatic Stress Disorder Checklist-Civilian Version; SF-12 Physical = 12-Item Short Form Health Survey Physical Health Scale; SF-12 Mental = 12-Item Short Form Health Survey Mental Health Scale, STAI-State = State Trait Anxiety Inventory, State Subscale; STAI-Trait = State Trait Anxiety Inventory, Trait Subscale

* Items have a $p < 0.01$.