

Published in final edited form as:

*Ann Behav Med.* 2011 February ; 41(1): 48–58. doi:10.1007/s12160-010-9228-y.

## Development and Validation of the Health Competence Beliefs Inventory in Young Adults With and Without a History of Childhood Cancer

**Branlyn Werba DeRosa, Ph.D.,**

The Children's Hospital of Philadelphia, South 34th Street, Philadelphia, PA 19104, USA

**Anne E. Kazak, Ph.D., A.B.P.P.,**

The Children's Hospital of Philadelphia, South 34th Street, Philadelphia, PA 19104, USA

The University of Pennsylvania, 3451 Walnut Street, Philadelphia, PA 19104-6243, USA

**Kinjal Doshi, M.A.,**

The University of Pennsylvania, 3451 Walnut Street, Philadelphia, PA 19104-6243, USA

**Lisa A. Schwartz, Ph.D.,**

The Children's Hospital of Philadelphia, South 34th Street, Philadelphia, PA 19104, USA

**Jill Ginsberg, M.D.,**

The Children's Hospital of Philadelphia, South 34th Street, Philadelphia, PA 19104, USA

The University of Pennsylvania, 3451 Walnut Street, Philadelphia, PA 19104-6243, USA

**Jun J. Mao, M.D., M.S.C.E.,**

The University of Pennsylvania, 3451 Walnut Street, Philadelphia, PA 19104-6243, USA

**Joseph Straton, M.D., M.S.C.E.,**

The University of Pennsylvania, 3451 Walnut Street, Philadelphia, PA 19104-6243, USA

**Wendy Hobbie, C.R.N.P.,**

The Children's Hospital of Philadelphia, South 34th Street, Philadelphia, PA 19104, USA

**Mary T. Rourke, Ph.D.,**

The Children's Hospital of Philadelphia, South 34th Street, Philadelphia, PA 19104, USA

**Claire Carlson, B.S.N., R.N., and**

The Children's Hospital of Philadelphia, South 34th Street, Philadelphia, PA 19104, USA

**Richard F. Ittenbach, Ph.D.**

The Children's Hospital of Philadelphia, South 34th Street, Philadelphia, PA 19104, USA

Anne E. Kazak: kazak@email.chop.edu

### Abstract

**Background**—Adolescent and young adult survivors of childhood cancer are a vulnerable population. Health beliefs may be related to necessary follow-up care.

**Purpose**—This study seeks to develop a measure of health beliefs for adolescents and young adults with and without a history of cancer.

**Methods**—Inductive and deductive methods and focus groups were used to develop the Health Competence Beliefs Inventory. Cancer survivors ( $n=138$ ) and comparison participants ( $n=130$ ) completed the Health Competence Beliefs Inventory and other measures. Healthcare providers reported current medical problems.

**Results**—A series of iterative exploratory factor analyses generated a 21-item four-factor solution: (1) Health Perceptions; (2) Satisfaction with Healthcare; (3) Cognitive Competence; and (4) Autonomy. Survivors reported significantly different Health Competence Beliefs Inventory scale scores than comparisons ( $p<.05$ ). The Health Competence Beliefs Inventory was associated with beliefs, affect, quality of life, posttraumatic stress symptoms, and medical problems.

**Conclusions**—The Health Competence Beliefs Inventory is a promising measure of adolescent and young adult perceptions of health and well-being.

## Keywords

Cancer; Survivorship; Young adults; Psychological outcomes; Health; Beliefs

## Introduction

The transition from adolescence to adulthood involves developmentally normal but potentially stressful life changes and choices. These include increasing independence from one's family of origin and decisions about education and career, financial responsibilities and employment, living arrangements, intimate relationships, and commitments to partners and parenthood. An additional change involves assuming greater responsibility for one's health and access to healthcare. Although most adolescents and young adults are healthy and without need for frequent or intensive contacts with healthcare systems [1], those with significant childhood health histories often require ongoing contact with healthcare providers to manage their health.

Adolescents and young adults who survived cancer are especially vulnerable [2]. It is critical that they understand the potential for late effects of cancer and its treatment and engage in healthcare that is matched to their risks and ongoing needs. Late effects may include dysfunction of major organ systems, infertility, neuropsychological problems, and potential second malignancies [3]. Adolescent and young adult survivors may also face psychosocial sequelae of their cancer and treatment, including distress, social and relational difficulties, difficulties in individuation from parents, and cognitive late effects [4-7]. These social, emotional, cognitive, and relational outcomes may also impact optimal engagement in appropriate medical care [8].

It is recommended that all childhood cancer survivors receive, at minimum, annual follow-up appointments that manage current physical, psychological, and cognitive late effects, monitor for future morbidities or second cancer diagnoses, and educate about future risks [9]. Unfortunately, many adolescent and young adult survivors do not engage in follow-up care. In the Childhood Cancer Survivor Study sample, only 35% recognized they could have serious health problems related to their treatment [10], indicating that many may not appreciate the significance of follow-up care. Logistical factors may also stand in the way including lack of health insurance during young adulthood [2, 11] and lack of knowledge of specialists in their new community when moving away from home. Finally, for survivors who have aged out of the pediatric system, there are often limited providers in the adult medical community with the knowledge and expertise to care for adolescent and young adult survivors [12]. Thus, adolescent and young adult survivors are at risk for not appropriately attending to and seeking care for current or future health problems during the transition to adulthood.

Beliefs may be a critical component associated with survivors' attention to their health needs and engagement in appropriate healthcare. Defined as cognitive appraisals or interpretations about the self, the world, and the future, beliefs are known to be important in well-being and health outcomes and are essential components of change in cognitive behavioral theory [13]. The focus on beliefs may provide a non-pathological and clinically useful framework for understanding the health and well-being of young adults in general, and young adult cancer survivors, specifically. Oeffinger [14] proposed that for long-term survivors of childhood cancer, beliefs about susceptibility for and seriousness of late effects interact with beliefs about control and competence to predict participation in follow-up care. Among cancer survivors, specifically, beliefs about the intensity of their cancer treatment and the extent to which survivors' lives were threatened were directly related to their current ratings of psychological distress, whereas objective medical indicators of treatment intensity and life threat did not relate to survivor's distress [7].

To assess the factors that may facilitate adolescent and young adult well-being and disease management during the transition to adulthood, a new measure—the Health Competence Beliefs Inventory (HCBI) was developed. We define *health competence beliefs* as a multidimensional set of perceptions about health and well-being. These include current and future health concerns, attitudes about health care, perceived ability to manage medical issues, and perceived ability to relate to others. We propose that these beliefs are important indicators of how young adults understand their health and how beliefs shape health-related decisions. Although the eight-item Perceived Health Competence Scale [15] assesses self-efficacy related to healthcare, the multidimensional aspects of health relevant to this population, such as healthcare knowledge, distress, and subsequent follow-up care, are not addressed by existing measures but have been identified as important for instrument development [16]. Understanding how these beliefs relate to changes in these outcomes could provide directions for how to encourage multiple resilient outcomes, including active participation in follow-up medical care. Given that beliefs are potentially malleable, they may be amenable to intervention.

The Health Competence Belief Inventory is also expected to meet a specific need for adolescent and young adult measures of general health-related well-being. There are currently few developmentally sensitive instruments designed for individuals from late adolescence to young adulthood, in general, and for childhood cancer survivors in particular [2]. The goals of the current study were to: (1) develop a measure of health competence beliefs for adolescents and young adults, (2) compare adolescent and young adult survivors and comparison participants on these beliefs, and (3) provide preliminary evidence of validity by demonstrating the association of scores on this measure with other measures of beliefs, health, and well-being.

## Method

### Phase I: Item Development

Phase I was the initial item development of the Health Competence Beliefs Inventory, which included focus groups and a small feasibility study. A multidisciplinary team of psychologists, oncology survivorship providers (nurse practitioners, nurses, a pediatric oncologist), a family medicine physician, and a biostatistician met together or in subgroups weekly over 9 months to design the instrument. Inductive and deductive methods were used to develop categories and subcategories of beliefs from our working definition of health competence beliefs. The group developed an item pool using an inductive approach, specifically by brainstorming items that represented selected categories of beliefs from the working definition: a multidimensional set of perceptions about health and well-being about current health status, vulnerability to illness, ability to promote healthy outcomes, address

healthcare needs, navigate the medical system, and interpersonal relationships. A deductive process was used to identify aspects of each category represented by individual items. This process resulted in second- and third-order categories that were subsequently reviewed to determine overlap and balance—at this point, two of the original categories were combined (address healthcare needs and navigate the medical system). Next, multiple items were selected to represent the five main categories and 26 subcategories (a total of 143 items). The team reviewed each item and retained no more than three items within a subcategory. This process resulted in a 76-item pool. A 4-point Likert scale was selected as the optimal response set (strongly disagree, somewhat disagree, somewhat agree, strongly agree). A consultative expert in survivorship reviewed item content and coverage. Items were evaluated for readability and estimated to be written at the fourth grade level using MS Words' Flesch–Kincaid readability index.

Focus groups with young adult survivors of childhood cancer ( $n=5$ ) and those without a history of serious illness ( $n=3$ ) were conducted to elicit feedback on our conceptualization of health competence beliefs and item wording, appropriateness, and inclusiveness. Feasibility was also evaluated by administering the measure to survivor ( $n=15$ ) and comparison participants ( $n=15$ ) using recruitment strategies similar to the larger prospective study described below and published previously [17]. Based on feedback from focus groups, minor changes were made to the Health Competence Beliefs Inventory including rewording 11 items, adding three items to assess interpersonal relationships, and adding four items with similar content to identify inconsistencies in response patterns (e.g., ensure participants were responding similarly at different points during measure completion). Preliminary results of the feasibility study supported its use with survivor and comparison samples. Additional minor wording changes were completed to improve readability and comprehension, and one new item was added, resulting in the 84-item measure tested in Phase II. A detailed account of the steps in the development of the Health Competence Beliefs Inventory is available [18].

## Phase II: Data Collection, Factor Analyses, and Modeling

**Participants**—Adolescents and young adults participated ( $n=268$ ), ranging in age from 16 to 30 years ( $M=20.74$ ,  $SD=3.35$ ). For survivors ( $n=138$ ), eligibility criteria included a diagnosis of cancer before age 21, at least 5 years from cancer diagnosis, English-speaking, and able to read independently at the fifth grade level. Comparison group participants ( $n=130$ ) met the following eligibility criteria: no history of life threatening or chronic illness or injury, English-speaking, and able to read independently at the fifth grade level. Comparison participants were excluded if they endorsed a psychiatric condition requiring hospitalization (e.g., schizophrenia, eating disorder) or were currently pregnant, due to the potential for increased health concerns during pregnancy. Among cancer survivors, specific diagnoses were leukemias (42%), lymphomas (21%), and solid tumors (37%). Reasons for attending a primary care visit for the comparison participants were routine visit (45%), minor acute illness (31%), or follow-up visit (24%).

**Procedures**—Participants were recruited at university-affiliated medical practices from March 2006 through August 2009 as part of a larger prospective investigation of long-term outcomes of childhood cancer survivors [17]. The study was approved by the relevant institutional review boards. Survivors ( $n=138$ ) were recruited during visits to a cancer survivorship clinic in the Division of Oncology at a major Northeastern pediatric medical center. The comparison group ( $n=130$ ) was recruited from: (a) an urban family practice office ( $n=94$ ), (b) a suburban adolescent medicine practice ( $n=20$ ), and (c) a university student health center ( $n=16$ ). Comparison group recruitment was targeted to the age, gender, and race/ethnicity of our anticipated survivor population. A targeted recruitment strategy

with the goal of balancing the groups with respect to age, race, and gender was used. The projected number of participants (by group) for gender (male, female), race (Caucasian, non-Caucasian), and age (16 to 18, 21 to 25, 26 to 30) was based on characteristics of the expected survivor group. The actual distribution of enrolled participants in both groups was reviewed monthly and targeted recruitment (of comparison group participants) was used as needed to achieve balance between the groups.

Eligible patients were approached in the waiting room by a research assistant who described the purpose of the study (to understand adolescent and young adult physical and emotional adjustment as they approached adulthood, for cancer survivors and others) and completed the informed consent procedure. Study participation included three data collection points for survivors and two for comparisons. Time 2 data, collected by mail approximately 2 months after study enrollment, are reported in this paper. Time 2 data were used because all participants completed the forms by mail and the data were less likely to be influenced by situational aspects of the healthcare visit. Participants received \$20 for completing the initial measures and \$30 for completing Time 2 measures.

Of the 479 participants approached, 388 consented (81%). Of those consented, 349 (90%) completed Time 1 study measures and were eligible for Time 2. Of those 349 participants, 271 (78%) completed Time 2 measures. Thus, of the 388 consented, 271 (70%) went on to complete Time 2 measures. Three additional participants were excluded in the analyses based on insufficiently completed measures, bringing the final sample to 268. The only demographic difference obtained between participants who completed Time 1 and Time 2 was that slightly fewer males completed Time 2; still, there were no gender differences between samples at Time 2. Figure 1 describes the study design and participant flow.

## Measures

**Demographic/Medical Information**—A demographic form assessed age, gender, ethnicity/race, education, income, and household composition. The comparison group participants recorded the reason for their clinic visit (routine appointment, follow-up care, or minor acute problem).

## Belief Measures

**General Self-Efficacy Scale**—The General Self-Efficacy Scale [19] is a ten-item self-report scale of general self-efficacy and is included in order to provide a validation instrument that assesses general beliefs, ones that may vary by situation and that are not health-specific. Participants rate their confidence in handling stressful situations on a 4-point Likert scale. In samples from 23 nations, coefficient alphas ranged from 0.76 to 0.90, with the majority in the high 0.80s [20]. Criterion-related validity has been documented with optimism, and work satisfaction, as well as inverse relationships with depression, anxiety, stress, and health complaints. Responses on the total score demonstrated good reliability in this sample ( $\alpha=0.88$ ).

**Perceived Health Competence Scale**—An eight-item instrument, the Perceived Health Competence Scale [15], assesses perceived self-efficacy towards positive health outcomes. The Perceived Health Competence Scale provides validation with a one-dimensional measure of health competence. Responses on the Perceived Health Competence Scale total score demonstrate concurrent validity with health locus of control beliefs [15] and high internal consistency across samples and in the current sample ( $\alpha=0.87$ ).

## Health and Well-Being Measures

**The Health Knowledge Inventory—Provider Version (HKI-P):** The Health Knowledge Inventory—Provider Version was developed in the larger prospective study to assess provider (physician, nurse practitioner) report of patient current health problems and to assess the relationship between provider report of problems and the psychological measures, including the HCBI [21]. Providers endorse whether the patient has each of 35 categories of health problems (e.g., heart/blood, immunological, sleep). Summary scores are the sums of endorsements for major medical problems (organic/major problems; 22 problems) and other types of non-life-threatening or somatic problems including fatigue, headaches, and aches/pains (constitutional/other problems; 13 problems). Providers also indicate if the patient attended the visit alone or with a parent.

**Brief Mood Rating Scale:** This measure consists of adjectives for positive (happy, joyful, fun, pleased) and negative affect (depressed/blue, unhappy, angry/hostile, frustrated, worried/anxious; [22]). Significant correlations between the positive and negative affect scales and other measures of distress have been found across studies (e.g., [23]). Positive affect and negative affect scores were used in this study. Both subscales have demonstrated excellent internal consistency in prior studies and in this sample ( $\alpha=0.92$  for positive affect and 0.86 for negative affect).

**Posttraumatic Stress Checklist—Civilian Version:** This 17-item self-report questionnaire assessed DSM-IV symptoms of posttraumatic stress disorder (PTSD; [24]). The Posttraumatic Stress Checklist—Civilian Version identified PTSD in survivors of breast cancer [25] and adult bone marrow transplant survivors [26]. The Posttraumatic Stress Checklist—Civilian Version Total Score, used in this study, demonstrated excellent internal consistency in the current sample ( $\alpha=0.91$ ).

**Short-Form Health Status Questionnaire:** This brief 12-item measure assesses perceptions of health status and the impact of health on quality of life [27]. It yields two summary scores of physical and psychosocial health and responses, with evidence of good reliability and validity across populations [28].

## Statistical Analysis

Our first goal was to develop the Health Competence Beliefs Inventory by reducing the number of items from the initial pool and to identify interpretable, clinically meaningful factors. We began this iterative item reduction process by using oblique exploratory factor analysis with promax rotation using all experimental form items and all 268 respondents for whom complete data were available. Specifically, parallel analysis [29] and minimum average partial test [30], in addition to other well-established criteria for factor determination (e.g., eigenvalues  $>1$ , scree plots), were used to estimate the number of factors to retain. An iterative approach to factor analysis was deemed most appropriate given the newness of the construct, the lack of available empirical information from which to draw, and our need to develop a tentative yet meaningful measure of health competence beliefs [31-33]. Hence, items with factor loadings in excess of 0.40, and for which there was no co-loading across factors, were retained for subsequent analysis. Principal factor analysis was computed from the correlation matrix, with squared multiple correlations as estimates of communality along the principal diagonal until the following three conditions were achieved: a minimum of three salient items per factor, moderately high (0.75) measures of internal consistency for each factor for unit-weighted items, and an underlying factor structure that remained both interpretable and stable across solutions. An oblique solution was most appropriate given the likelihood of moderately correlated factors. Exploratory factor structures were also generated for each of the two subgroups, using the same common



factor technique as was used for the entire sample of young adults, to see if comparable factor loadings emerged across both subgroups. Data were analyzed using SAS v9.1 (SAS Institute, Cary, NC).

Our second goal was to determine if adolescent and young adult survivors would respond differently from controls on selected Health Competence Beliefs Inventory scales. Regression-based ANCOVA models were used with each of the four Health Competence Beliefs Inventory scale scores obtained from the factor analytic process, individually, as the outcomes. The testable covariate in each model was group status (i.e., adolescent and young adult survivors (1), adolescent and young adult healthy controls (0)). All models were adjusted for age due to the small but significant age difference between groups. Prior to specifying and testing the group-based models, the groups were compared on relevant demographics using either a two-sample *t* test, a  $\chi^2$  test of independence, or Wilcoxon rank sum test, as appropriate. The criterion for statistical significance for these models were held constant at the unadjusted  $\alpha=0.05$  level.

Our third goal was to provide evidence that Health Competence Beliefs Inventory scale scores are related to other measures of beliefs, health, and well-being. Pearson correlations were computed to estimate the strength and directionality of the relationships between Health Competence Beliefs Inventory total and scale scores with three published measures of beliefs and five measures of well-being, and for survivors only, one additional measure of provider reported health status. The criterion for statistical significance for all correlations were held constant at the unadjusted  $\alpha=0.01$  level. Data for both the second and third goals were analyzed using SPSS v16 (SPSS Inc, 2009).

## Results

### Preliminary Demographic Analyses

The groups were comparable on the majority of demographic variables (Table 1). A small but statistically significant age difference was found between groups such that survivors were slightly younger (20.25 years) than comparison participants (21.25 years). In addition, the comparison group achieved significantly higher educational level (Table 1). There was a strong association between age and education level ( $r=0.86$ ); after adjusting for the effect of age, the groups no longer differed significantly in education.

### Goal 1: Health Competence Beliefs Inventory Development—Item Reduction and Identification of Interpretable Factors

The process of identifying factors and reducing items, based on item and subscale properties and clinical judgment, consisted of a series of exploratory factor analyses [33]. The first step in reducing the number of Health Competence Beliefs Inventory items was removal of items with item-total correlations less than 0.20. We also examined the four-item pairs with similar content, which were originally added to alert us to any inconsistency in responses; no substantive inconsistencies were found, and one item from each pair was subsequently omitted. Parallel analysis and minimum average partial tests revealed that the number of possible factors fell within the range of 5 to 8, and exploratory factor analysis was performed using each of these estimates to finally determine a 5-factor solution as the appropriate starting point for item reduction. After each exploratory factor analysis, we reviewed factors and their constituent items for both groups. Our goal at each step was to reduce items in a way that insured variance was distributed primarily among items of interest and maximized on items that were most relevant. We also inspected the items to ensure responses demonstrated high reliability and validity and were therefore items with moderate to high communalities. In addition, we only retained factors that had an internal

consistency 0.75 with a meaning that could be interpreted in the context of the measure, which resulted in the removal of the last factor. The iterative exploratory factor analysis process yielded a parsimonious 21-item measure with a four-factor solution and an overall alpha of 0.85.

Table 2 provides the factor loadings, percent variance explained by each factor, along with other descriptive statistics. The multidisciplinary group that developed the items named the factors. Factor analyses conducted for the two subgroups similarly to that of the entire cohort revealed remarkably comparable patterns of factor loadings across the two groups (see Table 2). Although not a primary aim of the current study, the subgroup analyses were conducted to purely complement the factor structure of the broader cohort for interpretability purposes.

**Health Perceptions (Factor 1)**—The six items on this scale consist of beliefs about the participant's current health and the likelihood of future illness, reflecting anxieties about health and vulnerability (e.g., "I have a reason to worry about my health" and "I'm not as healthy as other people my age"). Higher scores indicate that participants believe their health is comparable to others their age and do not feel vulnerable to imminent health problems.

**Satisfaction with Healthcare (Factor 2)**—This five-item scale describes beliefs about satisfaction with, or the effectiveness of, their healthcare provider and health system, including beliefs that healthcare providers understand and know how to take care of them. Higher scores indicate greater satisfaction with their healthcare.

**Cognitive Competence (Factor 3)**—This factor includes five items of beliefs about one's ability to concentrate, remember, and learn information relative to their peers. Higher scores indicate greater perceived cognitive competence.

**Autonomy (Factor 4)**—The Autonomy scale, with five items, contains beliefs related to independence from parents, both in navigating the health system (e.g., getting medical appointments, going to appointments) and more generally (e.g., relying on family). Higher scores indicate greater autonomy. Once an optimal underlying factor structure was obtained, summary statistics were computed by item and scale (factor).

## **Goal 2: Compare Adolescent and Young Adult Survivors and Comparison Participants on Health Competence Beliefs Inventory Scales**

Controlling for age, survivors scored significantly lower (less positive) on the Health Perceptions, Cognitive Competence, and Autonomy scales, indicating beliefs that they were more vulnerable to health problems, less capable cognitively, and less autonomous than the comparison group (Table 3). In contrast, survivors reported significantly higher scores on the Satisfaction with Healthcare scale (Factor 2), indicating more competent beliefs on this dimension than the comparison group (Table 3).

## **Goal 3: Provide Preliminary Evidence of Validity by Demonstrating the Association of Health Competence Beliefs Inventory Scores with Other Measures of Beliefs, Health, and Well-Being**

Each Health Competence Beliefs Inventory scale was significantly related to the General Self-Efficacy Scale and Perceived Health Competence Scale, such that higher scale scores were associated with greater self-efficacy and perceived health competence; correlations for each scale ranged from 0.17 to 0.50 (Table 4).



Of the four scales, Health Perceptions and Cognitive Competence were most strongly negatively associated with measures of negative affect ( $r=-0.32$  and  $r=-0.37$ , respectively) and posttraumatic stress ( $r=-0.40$  and  $r=-0.42$ , respectively). The Satisfaction with Healthcare scale was more weakly associated with positive and negative affect, posttraumatic stress, and mental health quality of life. Autonomy was significantly related to posttraumatic stress ( $r=-0.16$ ). For survivors only, provider data were obtained to examine the relationship between each Health Competence Beliefs Inventory scale with physician-reported health problems. Notably, the Health Perceptions scale (Factor 1) evidenced the strongest relationship with both Health Knowledge Inventory major medical problems ( $r=-0.30$ ) and somatic/other problems ( $r=-0.41$ ; Table 4).

## Discussion

Beliefs about health and well-being during emerging adulthood offer a means by which ongoing self-care and healthcare access may be understood, particularly for populations at risk for ongoing health difficulties. To this end, we developed the Health Competence Beliefs Inventory, a 21-item multidimensional measure that assesses young adults' beliefs about health perceptions, satisfaction with healthcare, cognitive competence, and autonomy. The Health Competence Beliefs Inventory demonstrated a meaningful and strong factor structure and demonstrated associations with measures of beliefs, well-being, and health. The four empirically and clinically derived scales assess separate, yet related, clinically relevant beliefs. The Health Competence Beliefs Inventory taps beliefs about developmental, social, and health issues that are meaningful for this developmental stage and differentiated between childhood cancer survivors and never seriously ill peers. Each of the scales provides examples of potentially malleable beliefs that could be addressed in efforts to promote optimal participation in healthcare.

The first factor, Health Perceptions captures beliefs about current health status and the likelihood of future illness. Consistent with their actual increased risk for health problems [3], cancer survivors perceived themselves to be more vulnerable to health problems than the comparison group. In this sample, lower scores (more perceived risk) were related to their healthcare provider's report of medical problems. Thus, the beliefs endorsed appear to be grounded in the reality of the medical vulnerability of this group who participate in follow-up survivorship care. At the same time, those endorsing more competent (resilient) beliefs on this factor may provide illustrations of the more positive, growth promoting aspects of coping with illness; higher scores on this scale were associated with less psychological distress.

Satisfaction with Healthcare is a particularly important dimension for cancer survivors because of the necessity that they be engaged with consistent follow-up care. In general, perceived acceptability and satisfaction with medical care are strong predictors of medical outcomes [34]. Higher scores obtained by the survivor group are understandable given that these are survivors who visit a survivorship clinic annually and are cared for by specialists; indeed, patient satisfaction has been shown to be strongly associated with continuity of care [35]. Given that ongoing monitoring is necessary for cancer survivors, yet the majority of survivors do not participate in follow-up care [36], satisfaction beliefs may be an important indicator of both follow-up care and follow-through with survivorship care recommendations.

The Cognitive Competence scale taps relevant self-perceptions that one can think clearly, pay attention, avoid fatigue, and learn, as well as peers. Cognitive functioning is particularly relevant to cancer survivors; up to 40% of childhood cancer survivors reported dysfunction in one or more neurocognitive domains in the Childhood Cancer Survivors Study [5]. The

scale score does not provide information about whether these beliefs reflect accurate or inaccurate perceptions about their cognitive functioning. Regardless, our findings that survivors perceive themselves to be less cognitively competent than their peers suggest that these beliefs could negatively impact their educational motivation and healthcare navigation. This information, along with more objective data about cognitive functioning, could provide clinicians with potentially useful information in considering ways to support survivors as they make educational decisions and transition to adult-based healthcare.

Finally, the Autonomy scale assessed the extent to which young adults believe they are independent, or becoming independent, from their family of origin. Survivors reported that they have less autonomy from their family of origin than the comparison group. This finding is consistent with the high rate of parental attendance at young adult child's survivorship clinic visits [37]. It is important to understand how family relationships may be a resource or restraint for long-term survivors [38] and how parental involvement in healthcare could differentially impact care over time. Unfortunately, very little is currently known about how autonomy beliefs impact healthcare access as childhood survivors become young adults. If survivors do not progressively manage their health needs, or if they feel less efficacious about doing so, these beliefs could contribute to suboptimal healthcare utilization as they age out of the pediatric system.

Given that cancer survivors, as a group, score within the normative range on measures of psychological adjustment [5], beliefs provide a unique and important way of understanding factors that may be associated with important developmental and health outcomes. The pattern of correlations shows that the Health Competence Beliefs Inventory is associated with measures of posttraumatic stress, positive and negative affect, and health-related quality of life. They also demonstrate that beliefs measured by the Health Competence Beliefs Inventory are conceptually distinct; the measure was associated with general measures of self-efficacy and health competence in the expected directions, but at a greater level of specificity to health outcomes (e.g., health maintenance, healthcare participation) relevant to cancer survivors and adolescents and young adults.

The Health Competence Beliefs Inventory has strengths supporting its clinical and research utility. It was developed to be reliable and valid for adolescents and young adults in general—it is developmentally relevant yet not cancer-specific. Given Health Competence Beliefs Inventory items are worded as beliefs rather than symptom descriptions, the Health Competence Beliefs Inventory may be less susceptible to identified difficulties (e.g., social desirability) noted in studies of cancer survivorship [39]. Beliefs may be creative alternatives to symptom checklists to understand resiliency and risk in this population. Because beliefs are modifiable, competence-based interventions can be developed to promote resilient beliefs and potentially reframe those associated with negative outcomes. Although beliefs offer promising alternatives to symptoms, they may not correspond with actual skills. Further probing of whether beliefs reflect "reality" in terms of functioning will be important for purposes of intervention (e.g., should intervention address beliefs or the underlying skill set?). Future research should also examine how health competence beliefs and functional outcomes change as survivors make the transition to adulthood and adult care, and if there are critical periods at which intervention would be most helpful at promoting resiliency during that transition.

As with any instrument in early stages of development, there are limitations to this work. The sample was drawn from a clinical (medical) setting; both survivor and comparison participants already had some level of engagement with the healthcare system and were assessed at the time of a medical appointment. Adolescents and young adults seeking healthcare may be more worried or preoccupied about their health than the general

population, which could mask some differences between controls and survivors. On balance, however, this control group provides a rather unique, clinically relevant comparison and contrast for survivors in clinical care. Understanding the relevance of the Health Competence Beliefs Inventory factors for non-clinical groups of cancer survivors and their peers will be important next steps. Other evidence of reliability and validity should also be established. These include factor invariance in more ethnically diverse samples, discriminant validity, and metrics of sensitivity to change.

In summary, the Health Competence Beliefs Inventory shows promise as a reliable, valid, and feasible self-report measure for assessing how adolescents and emerging adults perceive important aspects of their health and well-being. As more pediatric patients transition to adulthood and adult care, this measure may facilitate understanding of their unique health beliefs during this vulnerable period. Such beliefs are likely to be amenable to interventions that help eliminate barriers to optimal healthcare utilization and health promotion.

## Acknowledgments

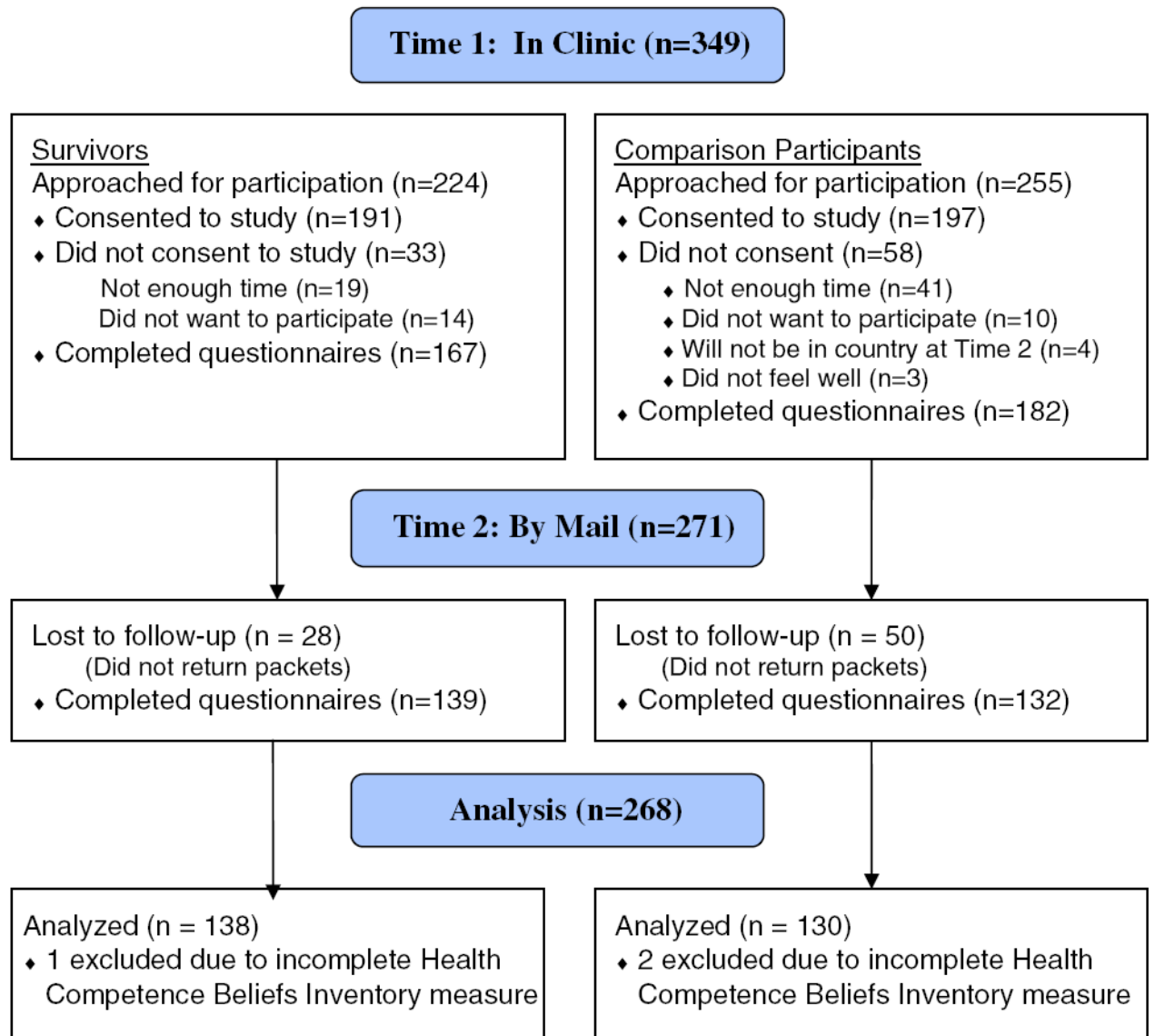
This research was supported by the National Cancer Institute (CA106928). The authors thank the study participants. We also thank Sue Ogle, CRNP, Stephanie K. Bui, MD, Janice K. Hillman, MD, FACP, Evelyn Wiener, MD, Michele Demski, BSN, RN, and Maureen Reilly, BSN, RN for assisting with recruitment and access to patients; and Andrew Gaffney, Emily Knudsen-Strong, Muhammad Monsour, Ifigenia Mougianis, Sonali Sanyal, Mary Caitlin St. Clair, James Wolf, and Mindy Yang for serving as research assistants and Kevin Oeffinger, MD for his review of the proposed items. The authors also thank the members of Writers Seminar of The CHOP/PENN Mentored Psychosocial Research Curriculum, supported by a K05 award to Dr. Kazak (CA128805). Requests for a copy of the Health Competence Beliefs Inventory may be sent to Dr. Kazak (kazak@email.chop.edu).

## References

1. Park MJ, Mulye TP, Adams SH, Brindis C, Irwin CE Jr. The health status of young adults in the U.S. *J Adolesc Health*. 2006; 39:305–317. [PubMed: 16919791]
2. National Cancer Institute, LIVESTRONG Young Adult Alliance. Closing the gap: Research and care imperative for adolescents and young adults with cancer, report of the adolescent and young adult oncology progress review group. 2006 NIH Publication No 06-6067.
3. Oeffinger KC, Mertens MD, Sklar CA, et al. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med*. 2006; 355:1572–1582. [PubMed: 17035650]
4. Stam H, Hartman EE, Deurloo JA, Groothoff J, Grootenhuys MA. Young adult patients with a history of pediatric disease: Impact on course of life and transition into adulthood. *J Adolesc Health*. 2006; 39:4–13. [PubMed: 16781955]
5. Zeltzer LK, Recklitis CJ, Buchbinder D, et al. Psychological status in childhood cancer survivors: A report for the childhood cancer survivor study. *J Clin Oncol*. 2009; 27:2396–2404. [PubMed: 19255309]
6. Schwartz L, Drotar D. Defining the nature and impact of goals in children and adolescents with a chronic health condition: A review of research and a theoretical framework. *J Clin Psychol Med Settings*. 2006; 13:393–405.
7. Rourke MT, Hobbie WL, Schwartz LA, Kazak AE. Posttraumatic stress disorder (PTSD) in young adult survivors of childhood cancer. *Pediatr Blood Cancer*. 2007; 49:177–182. [PubMed: 16862538]
8. Lee YL, Santacroce SJ, Sadler L. Predictors of healthy behaviour in long-term survivors of childhood cancer. *J Clin Nurs*. 2007; 16:285–295. [PubMed: 17931322]
9. American Academy of Pediatrics and the Children's Oncology Group. Long-term follow-up care for pediatric cancer survivors. *Pediatrics*. 2009; 123:906–915. [PubMed: 19255020]
10. Kadan-Lottick NS, Robison LL, Gurney JG, et al. Childhood cancer survivors' knowledge about their past diagnosis and treatment: Childhood cancer survivor study. *J Am Med Assoc*. 2002; 287:1832–1839.
11. Reiss JG, Gibson RW, Walker LR. Health care transition: Youth, family, and provider. *Pediatrics*. 2005; 115:112–120. [PubMed: 15629990]

12. Ginsberg JP, Hobbie WL, Carlson CA, Meadows AT. Delivering Long-Term Follow-Up Care to Pediatric Cancer Survivors: Transitional Care Issues. *Pediatr Blood Cancer*. 2006; 46:169–173. [PubMed: 16320315]
13. Haller DA, Sanci LA, Sawyer SM, Patton G. Do young people's illness beliefs affect health care? A systematic view. *J Adolesc Health*. 2008; 42:436–449. [PubMed: 18407038]
14. Oeffinger KC. Longitudinal risk-based health care for adult survivors of childhood cancer. *Curr Probl Cancer*. 2003; 27(3):143–167. [PubMed: 12748583]
15. Smith MS, Wallston KA, Smith CA. The development and validation of the perceived health competence scale. *Health Educ Res*. 1995; 10:51–64. [PubMed: 10150421]
16. Zebrack B. Developing a new instrument to assess the impact of cancer in young adult survivors of childhood cancer. *J Cancer Surviv*. 2009; 3:174–180. [PubMed: 19434501]
17. Kazak AE, DeRosa BW, Schwartz LA, et al. Psychological outcomes and health beliefs in adolescent and young adult (AYA) survivors of childhood cancer and controls. *J Clin Oncol*. 2010; 28:2002–2007. [PubMed: 20231679]
18. Author. The Health Competence Beliefs Inventory: A technical report of scale development. Author Institution; 2009.
19. Schwarzer, R.; Jerusalem, M. Generalized Self-Efficacy scale. In: Weinman, J.; Wright, S.; Johnston, M., editors. *Measures in health psychology: A user's portfolio Causal and control beliefs*. 1995. p. 35-37.
20. Scholz U, Dona B, Sud S, Schwarzer R. Is general self-efficacy a universal construct? Psychometric findings from 25 countries. *Eur J Psychol Assess*. 2002; 18:242–251.
21. Schwartz L, Mao J, DeRosa B, et al. Self-reported health problems of young adults in clinical settings: Survivors of childhood cancer and healthy controls. *J Am Board Fam Med*. 2010; 23:306–314. [PubMed: 20453176]
22. Diener E, Emmons RA. The independence of positive and negative affect. *J Pers Soc Psychol*. 1985; 47:1105–1117. [PubMed: 6520704]
23. Gill KM, Carson JW, Porter LS, et al. Daily stress and mood and their association with pain, health-care use, and school activity in adolescents with sickle cell disease. *J Pediatr Psychol*. 2003; 28:363–373. [PubMed: 12808013]
24. Weathers, FW.; Ford, J. Psychometric review of the PTSD Checklist. In: Stamm, BH., editor. *Measurement of stress, trauma, and adaptation*. 1996. p. 250-251.
25. Andrykowski MA, Cordova MJ, Studts JL, Miller TW. Posttraumatic stress disorder after treatment for breast cancer: Prevalence of diagnosis and use of the PTSD Checklist-Civilian Version (PCL-C) as a screening instrument. *J Consult Clin Psychol*. 1998; 66:586–90. [PubMed: 9642900]
26. Smith MY, Redd WH, DuHamel KN, Vieckberg SMJ, Ricketts R. Validation of the post-traumatic stress disorder checklist-civilian in survivors of bone marrow transplantation. *J Trauma Stress*. 1999; 12:485–499. [PubMed: 10467557]
27. Ware JE Jr, Kosinski M, Keller SD. A 12-item short-form health survey: Construction of scales and preliminary tests of reliability and validity. *Med Care*. 1996; 34:220–33. [PubMed: 8628042]
28. Jenkinson C, Chandola T, Coulter A, Bruster A. An assessment of the construct validity of the SF-12 summary scores across ethnic groups. *J Public Health Med*. 2001; 23:187–194. [PubMed: 11585190]
29. Hayton JC, Allen DG, Scarpello V. Factor Retention Decisions in Explorator Factor Analysis: A Tutorial on Parallel Analysis. *Organizational Research Methods*. 2004; 7:191–205.
30. Zwick WR, Velicer WF. Comparison of five rules for determining the number of components to retain. *Psychol Bull*. 1986; 99:4327–4442.
31. DeVellis, R. *Scale development: Theory and applications*. 2. Thousand Oaks, CA: Sage Publications, Inc.; 2003.
32. Kline, P. *The new psychometrics: Science, psychology and measurement*. London: Routledge; 1998.
33. Worthington RL, Whittaker TA. Scale development research: A content analysis and recommendations for best practices. *Couns Psychol*. 2006; 34(6):806–838.

34. Alazri MH, Neal RD. The association between satisfaction with services provided in primary care and outcomes in Type 2 diabetes mellitus. *Diabet Med.* 2003; 20:486–90. [PubMed: 12786685]
35. Fan VS, Burman M, McDonell MB, Fihn SD. Continuity of care and other determinants of patient satisfaction with primary care. *J Gen Intern Med.* 2005; 20:226. [PubMed: 15836525]
36. Oeffinger KC, Mertens AC, Hudson MM, et al. Health care of young adult survivors of childhood cancer: A report from the childhood cancer survivor study. *Ann Fam Med.* 2004; 2:61–70. [PubMed: 15053285]
37. Ressler IB, Cash J, McNeill D, Joy S, Rosoff PM. Continued parental attendance at a clinic for adult survivors of childhood cancer. *J Pediatr Hematol Oncol.* 2003; 25:868–873. [PubMed: 14608196]
38. Banner LM, Mackie EJ, Hill JW. Family relationships in survivors of childhood cancer: Resource or restraint? *Patient Educ Couns.* 1996; 28:191–199. [PubMed: 8852094]
39. O’Leary TE, Diller L, Reklitis CJ. The effects of response bias on self-reported quality of life among childhood cancer survivors. *Qual Life Res.* 2007; 16:1211–1220. [PubMed: 17624814]



**Fig. 1.**  
 Study design and participant flow from Time 1 through data analysis



Table 1

## Demographic characteristics by group

	Survivors (n=138)			Comparison (n=130)			p
	M	SD		M	SD		
Age (years)	20.25	3.22		21.25	3.43		0.02
	Frequency	%		Frequency	%		
Female Gender	77	56		78	60		0.49
Ethnicity/Race							0.19
African-American	6	4		14	11		
Asian	5	4		3	2		
Caucasian	122	88		104	80		
Hispanic	3	2		5	4		
More than one race	2	1		4	3		
Education *							0.03
<HS graduate	36	26		23	18		
HS graduate	17	12		25	19		
Some college	55	40		34	26		
Graduated college	30	22		48	37		
Annual Family Income (\$)							0.09
<\$5,000	17	13		34	29		
\$5,000–\$14,999	40	32		34	29		
\$15,000–\$24,999	50	39		26	22		
>\$25,000	20	16		25	21		

\* Wilcoxon rank sum test was used due to the ordinal nature of the variable

Table 2

Factor loadings (promax rotated) for items of the Health Competence Beliefs Inventory<sup>1</sup> (HCBI;  $n=268$ )

	Entire Sample ( $n=268$ )				Survivors ( $n=138$ )				Healthy Controls ( $n=130$ )			
	HP	SH	CC	AT	HP	SH	CC	AT	HP	SH	CC	AT
I have a reason to worry about my health	<b>0.78</b>	-0.06	0.04	0.09	<b>0.77</b>	-0.07	0.04	0.11	<b>0.73</b>	0.00	0.10	0.03
I'm not as healthy as other people my age	<b>0.75</b>	0.06	-0.05	0.05	<b>0.80</b>	0.05	-0.04	0.06	<b>0.62</b>	-0.07	-0.02	0.16
I'll probably have a serious health ...	<b>0.72</b>	0.09	0.04	-0.06	<b>0.75</b>	0.10	-0.04	-0.02	<b>0.62</b>	0.12	0.11	-0.10
My future health very uncertain	<b>0.74</b>	0.08	-0.01	-0.04	<b>0.73</b>	0.10	-0.05	-0.02	<b>0.64</b>	-0.02	0.22	-0.10
I could still die from a medical condition...	<b>0.63</b>	-0.04	0.02	-0.01	<b>0.61</b>	-0.07	0.09	-0.08	<b>0.54</b>	0.10	-0.11	0.04
I have bad luck with my health	<b>0.63</b>	0.02	0.06	0.04	<b>0.57</b>	0.10	0.03	0.00	<b>0.56</b>	0.04	0.20	-0.01
*My doctor understands my concerns	0.04	<b>0.75</b>	0.01	-0.01	0.04	<b>0.70</b>	0.09	0.03	0.00	<b>0.83</b>	-0.06	-0.08
*I can reach my doctor or nurse...need to	-0.13	<b>0.69</b>	0.02	0.04	-0.09	<b>0.75</b>	0.00	0.00	-0.14	<b>0.63</b>	0.00	0.13
*My healthcare providers know how ...	0.10	<b>0.68</b>	-0.02	0.01	0.08	<b>0.54</b>	0.11	-0.04	0.12	<b>0.70</b>	-0.10	0.08
*My doctors understand my...history	0.05	<b>0.67</b>	0.03	-0.23	0.13	<b>0.54</b>	0.11	-0.18	0.10	<b>0.69</b>	-0.02	-0.21
*If I needed to, I could get copies ...	0.09	<b>0.60</b>	-0.03	0.13	0.11	<b>0.67</b>	-0.13	0.15	0.20	<b>0.37</b>	0.09	0.17
*I learn new things as easily as other...	-0.10	-0.01	<b>0.69</b>	0.11	-0.15	-0.01	<b>0.76</b>	0.12	0.17	0.08	<b>0.42</b>	0.14
It's hard for me to pay attention	0.12	0.02	<b>0.62</b>	-0.04	0.11	0.07	<b>0.66</b>	-0.10	0.09	0.04	<b>0.61</b>	-0.03
I get tired very easily	0.10	0.04	<b>0.56</b>	-0.03	0.08	0.17	<b>0.62</b>	0.02	0.10	-0.16	<b>0.49</b>	-0.05
My memory is not as good as others	0.09	-0.03	<b>0.61</b>	-0.10	0.14	0.03	<b>0.64</b>	-0.13	-0.02	-0.05	<b>0.56</b>	-0.04
Most people my age are smarter than me	-0.04	-0.01	<b>0.60</b>	0.13	-0.04	-0.06	<b>0.61</b>	0.15	0.20	0.00	<b>0.44</b>	0.20
*I feel comfortable...doctor by myself	-0.02	0.16	0.02	<b>0.77</b>	-0.03	0.15	0.07	<b>0.73</b>	-0.11	0.25	0.14	<b>0.66</b>
*I can schedule a medical appointment...	-0.16	0.28	-0.01	<b>0.67</b>	-0.24	0.39	-0.03	<b>0.54</b>	-0.10	0.15	0.18	<b>0.64</b>
I prefer having my parents...appointment	0.10	-0.19	-0.03	<b>0.66</b>	0.04	-0.02	-0.11	<b>0.64</b>	-0.12	-0.16	0.22	<b>0.59</b>
I...my free time with parents or siblings	0.06	-0.19	0.07	<b>0.45</b>	-0.01	-0.29	0.24	<b>0.46</b>	0.26	-0.03	-0.34	<b>0.53</b>
I rely on my parents ...people my age	0.33	-0.11	-0.01	<b>0.46</b>	0.39	-0.17	0.04	<b>0.58</b>	0.39	-0.16	-0.17	<b>0.51</b>
Percent variance	33.20	25.34	20.50	20.96	33.18	24.58	19.08	23.16	31.52	26.53	20.52	21.43
Cronbach's alpha	0.87	0.81	0.75	0.76	0.87	0.79	0.81	0.72	0.82	0.79	0.71	0.70
Test-Retest reliability ( $r$ )	0.78	0.63	0.79	0.81	0.81	0.67	0.81	0.79	0.58	0.58	0.73	0.73

HP = Health Perceptions, SH = Satisfaction with Healthcare; AT = Autonomy; CC = Cognitive Competence  
 Salient factor loadings for each factor are in bold

\* Items marked with are not reverse scored. Some items are abbreviated due to space considerations in the table

**Table 3**Health Competence Beliefs Inventory Scale Scores by group ( $n=268$ )

	Survivors ( $n=138$ )		Comparison ( $n=130$ )		<i>F</i>	<i>p</i>	Effect size ( $R^2$ )
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
Health Perceptions	17.50	4.26	20.67	3.15	51.54	0.00	0.17
Satisfaction with Healthcare	17.11	2.43	15.13	2.73	38.406	0.00	0.13
Cognitive Competence	15.16	3.29	15.94	2.62	4.18	0.04	0.02
Autonomy	14.38	3.04	16.94	2.70	45.67	0.00	0.27

Table 4

Inter-correlations among the HCBI, measures of beliefs, well-being, and health ( $n=268$ )

	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)	(13)
HCBI													
(1) Health Perceptions	1.00	0.08	0.43 *	0.32 *	0.21 *	0.48 *	-0.40 *	0.23 *	-0.32 *	0.30 *	0.20 *	-0.30 *	-0.41 *
(2) Satisfaction with Healthcare		1.00	0.21 *	-0.03	0.19 *	0.35 *	-0.23 *	0.22 *	-0.22 *	0.07	0.22 *	-0.04	-0.03
(3) Cognitive Competence			1.00	0.28 *	0.50 *	0.41 *	-0.42 *	0.36 *	-0.37 *	0.18 *	0.30 *	-0.22	-0.31 *
(4) Autonomy				1.00	0.28 *	0.17 *	-0.16 *	0.01	-0.12	-0.10	0.02	-0.06	-0.10
Beliefs													
(5) GSES					1.00	0.43 *	-0.28 *	0.39 *	-0.37 *	0.19 *	0.30 *	-0.08	-0.12
(6) PHCS						1.00	-0.41 *	0.37 *	-0.45 *	0.31 *	0.35 *	-0.05	-0.17
Well-Being													
(7) PCL-C							1.00	-0.50 *	0.62 *	-0.17 *	-0.42 *	0.11	0.18
(8) BMRS Pos Affect								1.00	-0.67 *	0.14	0.54 *	-0.03	-0.13
(9) BMRS Neg Affect									1.00	-0.16 *	-0.47 *	-0.01	0.08
(10) SF-12 Physical										1.00	-0.23 *	-0.06	-0.14
(11) SF-12 Mental											1.00	-0.15	-0.13
Health													
(12) HKI-Provider Major Med												1.00	0.47 *
(13) HKI-Provider Other Med													1.00

HCBI/Health Competence Belief Inventory, GSES General Self-Efficacy Scale, PHCS Perceived Health Competence Scale, PCL-C Posttraumatic Stress Disorder Checklist—Civilian Version, BMRS Pos Affect Brief Mood Rating Scale Positive Affect Subscale, BMRS Neg Affect Brief Mood Rating Scale Negative Affect Subscale, SF-12 Physical 12-Item Short-Form Health Survey Physical Health Scale, SF-12 Mental 12-Item Short-Form Health Survey Mental Health Scale, HKI-Provider Major Med Health Knowledge Inventory Provider Report of Major Health Problems (survivor only), HKI-Provider Other Med Health Knowledge Inventory Provider Report of Somatic/Constitutional Problems (survivor only)

\*  
p<0.01