ANALYSIS OF THE DISTRESS THERMOMETER'S PSYCHOMETRIC PROPERTIES AND APPLICABILITY TO SUBGROUPS

By

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Abstract

The current study investigates the psychometric properties of the Distress Thermometer (DT) and its associated problem list, the National Comprehensive Cancer Network's recommended screening tool for distress among cancer survivors. The DT is a self-report tool that includes an overall distress rating (0-10) over the past week and a problem list where a patient can indicate whether or not they have been experiencing difficulties within certain categories over the past week (Fulcher & Gosselin-Acomb, 2007; Roth et al., 1998). This study analyzed DTs completed by 1,205 cancer survivors during their outpatient cancer treatment. Overall, the DT's structure was appropriate for the study population as a whole. In addition, the DT category of Emotional Problems was the only domain that significantly predicted whether someone was at risk for high distress. When the existing DT structure was analyzed in different patient subgroups (i.e., males, females, racial minorities) the structure was not equally applicable to all of the subgroups. Specifically, the existing DT was more applicable for males and whites compared to females and minorities. Further, the factor structures between males versus females and minorities versus whites were too disparate for comparisons. However, the limited sample size of patient subpopulations makes interpretation of these results difficult. Future studies should investigate the DT and problem list within larger samples of these subpopulations in an effort to identify areas where they differ with respect to the applicability of the DT and problem list.

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Analysis of the Distress Thermometer's Psychometric Properties and Applicability to Subgroups

Traditional cancer care has focused on assessing and treating cancer and its physical effects. However, in the past ten years the focus of care has expanded to include assessment and treatment of the psychosocial aspects of cancer (Howel et al., 2010; Jacobsen & Ransom, 2007; Network, 2007). Distress is a term that has been adopted by the National Comprehensive Cancer Network (NCCN) to encompass the psychosocial impact of cancer. The NCCN defines distress as "a multifactorial, unpleasant, emotional experience of a psychological, social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment" (Network, 2007). The term "distress" was adopted by the NCCN instead of other psychological terms as it is less stigmatizing, considered a more "normal" experience, is less embarrassing to endorse, and can be measured through self-report (Network, 2003). Researchers have advocated that psychosocial distress should be seen as an indicator of a patient's overall health and well-being (Bultz & Carlson, 2005). High levels of distress in cancer patients is correlated with lower quality of life, treatment adherence, and satisfaction with care (Bultz & Carlson, 2005). Further, systematic screening for distress may help to provide equal access to psychosocial services versus the more traditional method of provider or patient initiated referrals (Vodermaier, Linden, & Siu, 2009). Due to these findings, some researchers have advocated that distress be added as the "sixth vital sign" to be assessed at regular intervals as part of routine cancer care much like pain was added as the fifth vital sign in 1997 (Bultz & Carlson, 2005).

Distress Screening Questionnaires

There have been a number of different questionnaires and screening tools that have been proposed to assess for psychosocial concerns, such as distress, among cancer patients.

Researchers have advocated that these questionnaires be specific to the illness population. Using questionnaires that are not tailored to cancer patients may be inappropriate because of the experiences this patient population faces. Questionnaires aimed at assessing for more traditional psychiatric disorders may not adequately capture the emotional concerns of cancer survivors.

Patients with cancer may not score high on these general psychiatric questionnaires aimed at assessing disorders such as depression, although they still experience distress and need support (Herschbach et al., 2004). While there have been studies that have investigated the presence of PTSD symptoms in cancer survivors using screening measures (Hegel et al., 2006; Mehnert & Koch, 2007) and diagnostic interviews (Shelby, Golden-Kreutz, & Andersen, 2008), this is only a subset of cancer survivors who are experiencing distress (Hegel et al., 2006) and may be overlooked when measures for more severe symptomatology is used.

Distress screening tools range from "ultra-short" questionnaires (one to two questions) to longer measures. While the longer measures may be more sensitive and have better psychometric properties, the ultra-short screening tools may be more conducive to the time constraints often seen in outpatient oncology clinics (Vodermaier et al., 2009). One study found that approximately 75% of medical providers feel that ultra-short methods (one to three questions) would be acceptable to use in their practice to screen for distress. While there may be advantages to using longer questionnaires, this benefit may be outweighed by the additional time burden such questionnaires place on staff. Further, these differences may be at least partially remedied by adding a supplemental mood or impact thermometer (Vodermaier et al., 2009).

One tool that has been suggested is the Questionnaire on Stress in Cancer Patients

Revised Version (QSC-23 [Herschbach et al., 2004]). This 23 item questionnaire asks patients to indicate if certain problems apply to them, and if so, to what extent it causes distress. In the validation study for this questionnaire, the risk for distress ranged from 40.9% (breast cancer) to 23.5% (upper GI cancer) of patients. When looking at all cancer diagnoses as a whole, there appeared to be no general risk factors for distress; however, there were some risk factors associated with distress in specific cancer diagnoses. When looking at questions on the QSC-23, fear of disease progression was the single most important factor related to distress among all cancer types (Herschbach et al., 2004). While most studies utilize quantitative self-report surveys to assess cancer-related distress, some researchers have advocated for the use of interviews that utilize expert rating scales to assess for distress. Expert rating scales can provide better insight into distress than self-report scales because it can take non-verbal behaviors into account and it can also be administered to patients that may not be able to adequately complete a self-report questionnaire due to mental or physical problems (Herschbach et al., 2004).

Distress Thermometer

One of the most commonly used tools is the Distress Thermometer (DT). The NCCN has advocated for the DT to be used to assess distress in cancer patients. The DT is a self-report tool that includes an overall distress rating (0-10) over the past week and a problem list where a patient can indicate whether or not they have been experiencing difficulties within certain categories over the past week (Fulcher & Gosselin-Acomb, 2007; Roth et al., 1998). While the DT has been well-validated in a variety of cancer populations using other psychosocial distress scales such as the HADS, these studies only investigated the original DT that was comprised of the single-item distress rating without the addition of the problem list (Jacobsen et al., 2005; Ma

et al., 2014; Ransom, Jacobsen, & Booth-Jones, 2006). As the DT was designed mainly for use in cancer patients and contains problem list items most directly associated with oncology treatments (e.g., mouth sores, tingling in hands and feet), there has been no study to date that has looked at the validity of the DT with the associated problem list in other patient populations. However, there have been recommendations to screen for distress in palliative care patients, regardless of medical diagnoses (Kelly, McClement, & Chochinov, 2006).

A recent meta-analysis found that approximately 39% of cancer patients are considered to be at high risk for distress (Mitchell, 2007). When looking at individual studies, rates have varied from 22.8% (VanHoose et al., 2014) to 61.6% (Graves et al., 2007). However, it is important to note that the cutoff score for being at risk for clinically significant distress has been lowered from five (Network, 2003) to four (Holland, 2015) based on research indicating that a cutoff score of four yields better sensitivity and specificity for detecting distress (Jacobsen et al., 2005; Roth et al., 1998). Thus, it is important to understand that distress rates between research studies may not actually be comparable. Recent studies have also investigated the predictive ability of the endorsement of problem list items on overall distress (Jacobsen et al., 2005; Ransom et al., 2006; Shim, Shin, Jeon, & Hahm, 2008; VanHoose et al., 2014). Findings from these studies vary with significant relationships between high distress cut-off scores and 19 to 32 (often out of 34) problem list items (Jacobsen & Ransom, 2007; Ransom et al., 2006; Shim et al., 2008; Tuinman, Gazendam-Donofrio, & Hoekstra-Weebers, 2008). In addition, other studies have found between four to six problem list items to be significant predictors of high distress cut-off scores via logistic regression analyses (Graves et al., 2007; Johnson, Gold, & Wyche, 2010; VanHoose et al., 2014).

The DT and problem list is recommended by the NCCN to screen for distress in cancer patients; however, there has been some research to suggest that the standard DT may not be adequate in detecting the emotional needs of this patient population. One study looked at the addition of Emotion Thermometers (ETs) to the existing DT tool. Specifically, separate visual analog scale thermometers for depression, anxiety, and anger were paired with an adapted version of the DT and given to patients. It was found that of the cancer survivors scoring below four on the DT (i.e., not identified as being at high risk for distress), 51% indicated some emotional problems on the additional ET scales (Mitchell, Baker-Glenn, Granger, & Symonds, 2010). The addition of depression, anger, and need for help thermometers was about 10% more accurate at detecting distress than the DT alone when using the Hospital Anxiety and Depression Scale (HADS) as a reference (Mitchell, Baker-Glenn, Park, Granger, & Symonds, 2010). These findings suggest that some emotional concerns experienced by cancer patients may not be appropriately captured with the original DT (Mitchell, Baker-Glenn, Granger, et al., 2010). Further investigation of the DT's psychometric properties may be the first step in identifying which, if any, areas of emotional concern are not appropriately identified and should be added.

While assessment for distress in cancer patients is recommended and now actively encouraged as part of routine vital signs assessments, some researchers have questioned the cost-effectiveness and impact on mood outcomes of such regular assessment. For example, one study conducted a randomized control trial to look at the effect of completing a DT with a nurse on mood (measured via the Profile of Mood States questionnaire) at 12 month follow-up. The findings of this study found that there was no significant effect of distress screening on mood states at 12-month follow up. Further, the cost of administering the DT was \$28 per patient and was not offset by lower medical costs (Hollingworth et al., 2013). However, other research has

indicated that while some symptoms of distress may remit over time without intervention, regular screening gives health care providers the opportunity to inquire about these symptoms at a later time (Graves et al., 2007).

It is important to note however, that the Hollingworth study (2013) looked at distress screening as an intervention in and of itself, which is not usually the intent of such screenings. The NCCN states that assessment and recognition of distress is only one component of distress management. It is important that once distress is identified, it is properly documented and quickly treated (Network, 2003). While distress screening can be helpful to start a dialogue about distress between patients and providers (Dabrowski et al., 2007) it is important to remember that administration of screening measures, such as the DT, is meant to be one step in a process and not an intervention; thus, screening should be followed by recommendations and treatment for those that are identified as at risk for distress (Jacobsen & Ransom, 2007; Snowden et al., 2011).

Interventions for Cancer-Related Distress

Interventions have been created to help reduce distress levels among cancer patients. One such intervention has been developed that utilizes an orientation program to help newly diagnosed patients. This orientation consists of a virtual tour of the cancer center, a talk by a nurse about potential treatment side effects, and an opportunity to meet with the patient's care team (Chan, Webster, & Bennett, 2009). Currently, no outcome data exist for this orientation program, but it seems that incorporating screening as part of orientations may help in early identification and treatment of distress. Another study found that the effect of psychosocial interventions was moderated by a patient's pre-intervention distress level. Specifically, the intervention had more of an effect on anxiety and depression outcomes for those that endorsed higher levels of distress prior to the intervention (Schneider et al., 2010). It is difficult, however,

to compare psychosocial interventions such as these, as many vary in delivery method and profession of the person delivering the intervention (Galway et al., 2012). Implementation of regular distress screening can help to identify those patients that might benefit most from psychosocial interventions.

Adherence of Professionals to Screening Recommendations

There is research to suggest that medical professionals are not consistently assessing for distress in cancer patients. One study found that while 96% of medical professionals have an interest in detecting mood disorders in patients, only about 2/3 attempted to detect mood disorders in patients on a regular basis while the remaining providers either only assessed occasionally or waited until the patient spontaneously brought up any psychosocial issues; however, about 3% of providers reported that they avoided screening for emotional distress because they were uncomfortable. In addition, of the professionals that assessed for mood difficulties, only 10% of specialists used a formal questionnaire. The majority of providers used their clinical skills or used more informal questioning (Mitchell, 2007). This reliance on clinical skills may be problematic as a clinician's estimation of distress may not be the same as results from validated self-report measures such as the DT (Dabrowski et al., 2007). In addition, one study found that only 40% of physicians surveyed felt that they had enough time available to give to distressed patients (Mitchell, 2007). This suggests that even if distress is screened for, providers may not be able to spend time to discuss issues with patients who are distressed.

A study aimed at investigating the compliance to distress screening recommendations among NCCN institutions found that 7 out of the 15 institutions did not conduct routine screenings as of 2007 when the study was conducted, however all of these institutions reported that they were currently developing screening processes. Of the eight that reported routine

screenings, only three conducted screenings with every patient. The remaining five only screened certain patients, but information was not provided as to which patients were screened or how this determination was made. Among the institutions that indicated regular distress screenings, three reported that relied only on interviews with no self-report questionnaires. Of the five institutions that used self-report measures, only three using the DT (the NCCN recommended screening tool) (Jacobsen & Ransom, 2007). These studies suggest that there may be a need for better guidelines regarding distress screening. These guidelines may be helped by better understanding the psychometric properties of the NCCN recommended screening measure (the DT).

The earliest studies of the DT and problem list focused on validating this screening tool in various populations and settings (Graves et al., 2007; Hegel et al., 2008; Jacobsen et al., 2005; Ransom et al., 2006; Roth et al., 1998). Further, there are a small number of studies to determine which specific problem areas assessed are most salient for those at risk for distress (Johnson et al., 2010). Of the limited number of studies that have investigated the relationship between individual items and overall distress, relationships have been found between distress and all problem list items except mouth sores (Jacobsen et al., 2005; Ransom et al., 2006; Shim et al., 2008).

Better Understanding the Distress Thermometer

To date, no research has been conducted to investigate the psychometric properties of the problem list items using an advanced statistical technique, such as structural equation modeling. Further, while the original NCCN guidelines advocated for the DT problem list to be modified by the institutions that use the screening measure, no recommendations are provided as to which items to remove. A study that investigates the psychometric properties of the problem list would help to identify those items that are of great significance and should not be removed in the case

of modification. By identifying the problem list items that are most important, a short-form version of the DT could be created for use when administration of the full measure is not feasible. In addition, the identification of problem list items that are most related to overall distress can help to guide conversations medical professionals have with patients. Finally, better understanding of screening tools such as the DT may aid in increasing adherence to screening recommendations among health care professionals.

Gender Differences in Cancer-Related Distress

While there have been a number of studies that have investigated gender differences in distress and coping among couples dealing with cancer (Goldzweig et al., 2009; Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008), there is a scarcity of research looking at the differences in distress between male and female cancer patients. The research that does address this issue has yielded mixed results. A number of studies have demonstrated higher rates of distress among female cancer patients and caregivers (Dolbeault et al., 2008; Jacobsen et al., 2005; Keir, Calhoun-Eagan, Swartz, Saleh, & Friedman, 2008; Ransom et al., 2006; Strong et al., 2007), but others have seen no effect of gender on distress (Graves et al., 2007; Özalp, Cankurtaran, Soygür, Özdemir Geyik, & Jacobsen, 2007; Shim et al., 2008). In fact, a previous study conducted by this author and collaborators also found no relationship between gender and distress ratings of global health (VanHoose et al., 2014). Some researchers believe that distress may be overestimated in women and may be due to a tendency on the part of women to report physical and emotional symptoms and pursue care more than men (Keller & Henrich, 1999). However, these studies have focused on the relationship between overall distress levels and gender without investigating possible relationships between gender and specific problems addressed by the DT problem list.

Previous studies that documented types of symptoms that were specific to gender, were not based on, or correlated with, overall distress rating levels on the DT. It is helpful, though, to note that in those studies women tend to report higher rates of nausea, depression, shortness of breath, early satiety, anxiety, swelling, physical limitations, and loneliness as well as a higher sense of well-being (Bradley, Davis, & Chow, 2005; Keller & Henrich, 1999; Schmidt et al., 2005; Walsh, Donnelly, & Rybicki, 2000). Males were found to report higher rates of dysphagia, hoarseness, significant weight loss, sleep problems, and sexual problems (Schmidt et al., 2005; Walsh et al., 2000). Given these differences, it is important to investigate the quality of the DT problem list structure and predictive ability to overall distress between men and women.

Racial and Ethnic Differences in Cancer-Related Distress

There has also been research regarding the differences in cancer stage, side effects, and comorbid conditions between racial majority and minority groups in the United States (Jemal et al., 2008; Tammemagi, Nerenz, Neslund-Dudas, Feldkamp, & Nathanson, 2005; Ward et al., 2004). Further, some researchers have suggested that studies with Caucasian cancer patients may not generalize to other races. For example, African Americans have unique social and cultural components that may constitute risk and protective factors profiles that are different than Caucasian counterparts (Lincoln, Chatters, & Taylor, 2003). There has also been research investigating psychosocial problems and coping styles among ethnic minorities in the United States. One study investigated the predictors of depression among older African American cancer patients and found that younger age, lack of or having to terminate employment due to illness, lack of insurance, living alone, having symptoms associated with the cancer disease or treatment was related to depression in this patient population (Agarwal, Hamilton, Moore, & Crandell, 2010). When comparing differences of emotional responses and coping between ethnic

minorities and Caucasians, one study found that self-reported distress and depression were higher and health-related quality of life was lower among ethnic minorities compared to white cancer patients (Luckett et al., 2011). A different study found that a number of distressing physical symptoms were higher in African American versus Caucasian, but not other minority breast cancer survivors (Russell, Von Ah, Giesler, Storniolo, & Haase, 2008). Finally, a literature review also found that many studies have found that African American cancer patients had lower quality of life ratings compared to Caucasian cancer patients (Powe et al., 2007).

Given these differences, it is important to investigate the problem list structure between white and non-white cancer patients. The knowledge gained from assessing the possible differences in the applicability of the DT and problem list between genders and races can help aid medical professionals in identifying problem list items that may uniquely impact a person's overall level of distress.

Hypotheses

Hypothesis 1: Examine the psychometric properties of the DT problem list using the measurement component (similar to a confirmatory factor analysis) of a structural regression (SR) model. The existing DT model will appropriately fit the data (i.e., the factor structure will be appropriate for the given data).

Hypothesis 2: Examine the predictive ability of the problem list categories to overall distress ratings using SR modeling.

<u>Hypothesis 2a:</u> The emotional category will significantly predict DT ratings.<u>Hypothesis 3:</u> Examine the differences in the applicability of the DT problem list structure among groups.

Hypothesis 3a. Investigate the fit of the predictive model between males and females. The problem list structure will more adequately fit the male patients compared to female patients.

Hypothesis 3b. Investigate the fit of the predictive model between whites and non-whites. The problem list structure will more adequately fit the white patients compared to non-white patients.

Methods and Materials

This study utilized a secondary data analysis to investigate the psychometric properties of the National Comprehensive Cancer Network's (NCCN) recommended distress screening tool (The Distress Thermometer [DT]) and to investigate the relationship between the DT problem list items and overall distress ratings. The original study was approved for research with human subjects through the University of Kansas Medical Center Human Subjects Committee. The data analysis was completed on DTs completed by patients seen at the University of Kansas Cancer Center (KUCC) between February 2005 to February 2009. In addition, patient demographics were collected from KUCC's electronic health record through the Healthcare Enterprise Repository for Ontological Narration (HERON) system.

Instrument

The DT is a paper and pencil brief self-report screening tool recommended by the NCCN to assess distress among cancer patients. In addition, the DT can also be used to generate referrals to providers such as psychologists, social workers, dieticians, and physical therapists based on the patient's endorsement of problem list items (Lynch, Goodhart, Saunders, & O'Connor, 2010). The original DT consisted of single item that assessed overall distress rating using an 11-point scale. A list of problems commonly encountered by cancer patients was later

added to assess specific concerns. These list items are grouped by domains to help refer the patient to appropriate supportive services (Fulcher & Gosselin-Acomb, 2007).

KUCC implemented the DT in 2005 and modified the original version of the DT (Roth et al., 1998) for use in oncology clinics. This tool has an 11-point scale that is depicted as a thermometer and ranges from 0 (no distress) to 10 (extreme distress) on one side of the page. On the opposite side of the page there is a list of problems for the patient to identify specific problem areas they have experienced over the past week. Each item is directly related to one of five domains: practical, relationship, emotional, spiritual, or physical (Fulcher & Gosselin-Acomb, 2007). A total of 34 items comprise the original DT problem list: five practical, two relationship, five emotional, two spiritual, and 20 physical items. KUCC modified the problem list to include problems with the cancer center's facilities (e.g., parking and waiting) and problems dealing with others; further, the item assessing problems with fatigue was removed. These modifications were made based on feedback of patient advisors that believed the addition and removal of these items would be important to assessing problems commonly seen at KUCC. An additional area is also provided for patients to add any other problems they are experiencing that are not included in the problem list; however, this open-ended area was not included in the KUCC-modified version. See Figure 1 for the original DT and Figure 2 for the KUCC-modified DT. The single-item DT (the overall distress rating) has been shown to be comparable to other longer measures of psychological distress (Jacobsen et al., 2005; Ransom et al., 2006). Further, many studies utilize a validated cut-off score of four to distinguish those patients that are or are not at-risk for high distress (Jacobsen et al., 2005; Ma et al., 2014; Roth et al., 1998). For this study, only those questions that are included in both the original and KUCC-modified DTs will be included in the analysis (i.e., the analysis will not include the facility, dealing with others, or fatigue items).

Inclusion Criteria

This study will include all first time distress screens completed during 2005-2009 by adults, at least 18 years of age that received services at KUCC. Although several participants had completed more than one assessment, only the first and second assessments completed will be included in this analysis. During this timeframe, DTs were provided to patients by outpatient oncology clinic nurses or social workers and were completed prior to being seen by the medical provider. While the administration of this screening measure was not always given at the first visit, the first administration of this measure was always completed within the first six months of receiving services at KUCC. All primary and secondary malignant neoplasm diagnoses were included will be included in the secondary data analysis.

Data Analysis

Descriptive statistics will be calculated for patient demographics and cancer diagnoses. In summary, a structural regression (SR) model will be conducted to investigate the psychometric properties of the problem list categories (Hypothesis 1) as well as examine the relationship between the problem list items and overall distress ratings (Hypotheses 2 and 3; See Figure 3).

Hypothesis 1. A strength of the SR model is that is incorporates a measurement component into the analysis, similar to a confirmatory factor analysis (CFA). This CFA-type measurement component is appropriate for analyzing measures in which the number of individual observed variables (i.e., problem list items) and their relationship with latent variables (i.e., domains) are explicitly specified based on past research or theory (Kline, 2011). Given that the DT problem list is already arranged by problem factor, this measurement is suitable for assessing the properties of the existing arrangement of the problem list. This measurement component of the SR model enables the identification of appropriateness of the DT's problem

list domains. In addition, factor loadings are also calculated to assess the relationship between the factors and indicators. For this particular dataset, all problem list items are dichotomous (i.e., yes or no) and require an adjustment in the calculation by using a Robust Weighted Least Squares extraction that estimates a tetrachoric correlation matrix instead of the traditional Maximum Likelihood extraction used in CFA models with continuous variables that produces a Pearson correlation matrix ("How can I do CFA with binary variables?," 2015; Muthén, 1978).

As SR analyzes both the measurement and structural components of the model simultaneously, it is difficult to assess whether poor fit is an indication of either or both of these components. In the event that the SR model poorly fits the data, a two-step model will be used to identify the source of poor fit. In this modeling procedure, the SR model is respecified as a CFA model and analyzed to determine whether or not it fits the data. In some situations, removing factors with poor relationships to indicators can improve the fit of the model (Kline, 2011). Once the measurement component of the model has been appropriately identified, the initial SR model can be compared to the modified model. This modification of the measurement model has great clinical utility, as it can identify factors (i.e., problem list items) that could be removed and can aid in the development of a short-form version of the DT.

Hypothesis 2. The use of a SR model also enables the investigation of causal effects between latent (unobserved) variables (Kline, 2011). This analysis is appropriate for the given dataset as it will test the predictability of the problem list indicators (i.e., domains) to distress ratings. Specifically, the model will predict the relationship between the respecified model (refer to data analysis plan for Hypothesis 1) of problem list item domains and overall distress ratings.

Hypothesis 3. Analyses will be conducted to assess the problem list structure's applicability among subgroups using multiple group CFA modeling.

Hypothesis 3a. Two measurement models will be conducted using the respecified model (if necessary – see data analysis plan for Hypothesis 1) of problem list items in males and females separately. By conducting separate analyses, it is possible to compare the fit indices of the model thus better understand the applicability of the model/screening tool between the sexes.

Hypothesis 3b. Two measurement models will be conducted using the respecified model (if necessary – see data analysis plan for Hypothesis 1) in white and non-whites separately. By conducting these analyses, it is possible to compare the fit indices of the model between whites and non-whites.

Results

Patient Population

1,205 patients met inclusion criteria for this study. The majority of participants were English speaking (n= 1071; 88.88%) Caucasian (n= 1065; 88.38) married (n=798, 66.22%) women (n= 833, 66.13%). See Table 1 for a list of the racial composition of the study sample. The mean age of the group was 58.42 years (SD = 12.87) and ages ranged from 18-93. The most represented cancer diagnosis in this patient sample was breast cancer (25% of patients), followed by gynecological (14.17%), genitourinary (11.91%), and gastrointestinal (10.73%). See Table 2 for a list of all the cancer diagnoses represented in this study.

Hypothesis 1

A SR model was created using the existing DT factor structure (i.e., the problem list items were kept within their respective categories). Specifically, the model included the existing problem list domains as latent variables with their associated items as observed variables. The Practical Issues domain included the following problem list items: housing, insurance, work/school, transportation, child care, financial issues, and facility (i.e., parking, waiting). The

Relationship Issues domain included the following problem list items: dealing with partner, dealing with children, other. The Emotional Issues domain included the following problem list items: worry, fears, sadness, depression, and nervousness. The Spiritual Issues domain included the following problem list items: relating to God and loss of faith. The Physical Issues domain included the following problem list items: pain, nausea, sleep, getting around, bathing/dressing, breathing, mouth sores, eating, indigestion, constipation, diarrhea, changes in urination, fevers, skin dry/itchy, nose dry/congested, tingling in hands/feet, feeling swollen, sexual, and appearance. As there was no theoretical basis for identifying a specific marker variable, the standard (default) method was employed and the first indicator of each factor was used as the reference indicator to set the metric for the model. Further, there was no theoretical reasoning behind standardization so the traditional method for standardization was used (i.e., the marker variables were set to 1.0). The model was over-identified and thus was found appropriate to be run; however, the Spiritual Issues domain (latent variable) only consisted of two observed variables (problem list items) and thus this latent variable was just-identified and had to be removed from the model to allow for constraints for testing the measurement aspect of the model. Thus, the final model included the Practical Issues, Relationship Issues, Emotional Issues, and Physical Issues domains with their associated problem list items.

Model estimation was ran using MPlus 7.4. As all observed variables in the model were dichotomous, tetrachoric correlations/asymptotic covariances were used for estimation. Further, the presence of dichotomous variables justified the use of the weighted least squares with mean and variance (WLSMV) adjustment estimator. The overall goodness of fit test was significant $(\chi 2 = 1340.706, df = 6, p = 0.000)$, which traditionally indicates that the model was not a good fit for the data (Tennant & Pallant, 2012). However, research has suggested that for larger datasets,

the $\chi 2$ test of model fit may be artificially inflated to be significant and may not be appropriate as a test of model fit (Kline, 2011). The fit indices indicated a good model fit (MacCallum, Browne, & Sugawara, 1996; RMSEA = 0.019, 90% C.I. 0.016, 0.022; CFI = 0.985; TLI = 0.984) for the initial model (i.e., all problem list domains aside from Spiritual Issues). Further, all problem list items had appropriate and significant parameter estimates (See Table 3 for all unstandardized and standardized parameter estimates), suggesting that the problem list items appropriately fit the model.

Hypothesis 2

The second component of the SR model tested the predictability of problem list domains (latent factors) on overall distress ratings. Given the previous research indicating the clinical utility of dichotomizing the overall distress rating into "at risk" and "not at risk" (Jacobsen et al., 2005; Ma et al., 2014; Roth et al., 1998), this categorization was used as the outcome variable. Specifically, the SR model investigated the ability of latent variables (Practical Issues, Relationship Issues, Emotional Issues, and Physical Issues) to predict being at risk or not at risk for distress. The results of the SR model showed that only Emotional Issues significantly predicted risk status in this study (Standardized residual = 0.920, p < .001). See Table 4 for results of the SR model.

Hypothesis 3

Per recommendations (Brown, 2015), individual CFAs were conducted for the separate groups to identify any model issues as a first step in running multiple group CFAs. When CFAs were conducted separately for males and females, the resulting models were too disparate to conduct a multiple group CFA between males and females. The male-only CFA model (containing all latent variables aside from Spiritual Issues and their related problem list items)

had to be modified to exclude child care as this variable was an empty cell in the bivariate correlation table with housing, insurance, and work/school problem list items. In models that contain binary variables, CFA models with empty cells cannot be run and the conflicting variable must be removed and the modified model can be re-run. A modified CFA model containing only males was run and the overall goodness of fit test for the model was significant (χ 2 = 459.166, df = 6, p < 0.001). The fit indices indicated an adequate model fit (MacCallum, Browne, & Sugawara, 1996; RMSEA = 0.020, 90% C.I. 0.009, 0.027; CFI = 0.978; TLI = 0.976) for the modified model (i.e., all problem list domains aside from Spiritual Issues and the observed variable housing). Further, all problem list items had appropriate and significant parameter estimates (See Table 5) for all unstandardized and standardized parameter estimates), suggesting that the remaining problem list items appropriately fit the model.

The female-only CFA model (containing all latent variables aside from Spiritual Issues and their related problem list items) had to be modified to exclude child care, changes in urination, and mouth sores as the inclusion of these variables created empty cells in bivariate correlation tables. A modified CFA model containing only females was ran and the overall goodness of fit test for the model was significant ($\chi 2 = 975.756$, df = 6, p < .001). The fit indices indicated an adequate model fit (MacCallum, Browne, & Sugawara, 1996; RMSEA = 0.021, 90% C.I. 0.017, 0.025; CFI = 0.986; TLI = 0.985) for the modified model (i.e., all problem list domains aside from Spiritual Issues and the observed variables of child care, changes in urination, and mouth sores). Further, all remaining problem list items had appropriate and significant parameter estimates (See Table 6 for all unstandardized and standardized parameter estimates), suggesting that the remaining problem list items appropriately fit the model.

As a multiple group CFA was unable to be conducted, an additional analysis was run to investigate whether there was a difference in the rates of those patients at high risk for distress between genders. The findings show that there was no significant difference in the percentage of males at risk for distress (22%) versus females (23.2%) (χ^2 = .185, p = .710).

Hypothesis 4

Individual CFAs were again conducted for the separate groups to identify any model issues as a first step in running multiple group CFAs. When CFAs were conducted separately for whites and racial minorities, the resulting models were too disparate to conduct a multiple group CFA between the two categories of races. The CFA model for those identified as white (containing all latent variables aside from Spiritual Issues and their related problem list items) was run and the overall goodness of fit test for the model was significant (χ 2 = 1182.626, df = 527, p = 0.000). The fit indices indicated an adequate model fit (MacCallum, Browne, & Sugawara, 1996; (RMSEA = 0.019, 90% C.I. 0.016, 0.022; CFI = 0.984; TLI = 0.982) for the modified model (i.e., all problem list domains aside from Spiritual Issues). Further, all problem list items had appropriate and significant parameter estimates (See Table 7 for all unstandardized and standardized parameter estimates), suggesting that the problem list items appropriately fit the model.

The CFA model composed of ethnic minorities (containing all latent variables aside from the Spiritual Issues items and their related problem list items) had to be modified to exclude child care, facility, worry, appearance, bathing/dressing, breathing, diarrhea, eating, feeling swollen, fevers, getting around, indigestion, mouth sores, nausea, pain, sexual issues, tingling in hands/feet as the inclusion of these variables created empty cells in bivariate correlation tables. A modified CFA model containing only ethnic minorities was run and the overall goodness of fit

test for the model was significant ($\chi 2 = 309.171$, df = 6, p = 0.000). The fit indices indicated an adequate model fit (MacCallum, Browne, & Sugawara, 1996; RMSEA = 0.000, 90% C.I. 0.000, 0.041; CFI = 1.000; TLI = 1.001) for the modified model (i.e., all problem list domains that remained). See Table 8 for all unstandardized and standardized parameter estimates.

As a multiple group CFA was unable to be conducted, an additional analysis was run to investigate whether there was a difference in the rates of those patients at high risk for distress between the two racial groups. This analysis found that there was no significant difference in the percentage of whites at risk for distress (21.7%) versus non-whites (23%) (χ^2 = .111, p = .830).

Discussion

This study investigated the psychometric properties of the DT and its associated problem list as well as the ability of problem list items to predict overall distress score within a cancer survivor population receiving care in outpatient clinics. In addition, the applicability of the problem list structure was examined in different patient subgroups. A structural regression (SR) model was created to examine both the psychometric properties and prediction ability of the problem list structure. The SR model included all problem list domains and problem list items except for the Religious Issues domain and items. The measurement component of the SR model indicated that the problem list item structure appropriately fit the data. Specifically, the findings indicated that the proposed structure (i.e., individual problem list items being categorized into their respective domains) was appropriate in this patient sample.

When investigating the ability of the problem list domains to predict distress level, it was found that only Emotional Issues predicted being at risk or not at risk for distress. This is consistent with previous research showing that problems list items in the emotional domain were among those most related to distress. Specifically, two studies conducted chi-square analyses and

found that of the problem list domains, the emotional domain was the only domain that had all items with higher ratings among those at risk for distress compared to those not at risk (Jacobsen et al., 2005; Shim et al., 2008). In addition, another study conducted a logistic regression and found that the problem list item with the highest odds ratio was worry, and item located in the emotional domain (VanHoose et al., 2014).

The relationship between Emotional Issues and overall distress point to the need for healthcare professionals to screen for a patient's emotional concerns in addition to physical symptoms. In addition, emotional concerns may need to be assessed in more detail as this study suggest they are more predictive of overall distress, and thus possibly poorer satisfaction with care or health outcomes (Bultz & Carlson, 2005). It is important, however, to consider that distress is on its face value, an emotional term and that the predictive relationship between emotional issues and overall distress score may be a product of the fact that the DT is measuring the same thing in these two areas.

In an effort to investigate the psychometric properties of the problem list structure among different patient populations, individual four CFAs were conducted with males, females, whites, and non-whites with an eye toward conducting multiple group CFAs among males/females and white/non-whites. However, when the individual CFAs were conducted, the models were too disparate to conduct multiple group CFAs. It is important however, to recognize that the small sample size for subpopulations makes interpretation of these results difficult. It is important that future studies aim to investigate

These results suggest that the problem list structure may not be applicable to different patient subgroups. Further, the modified CFA models for males-only (33 versus 31 out of the 36 original problem list items for males and females, respectively) and whites-only (34 versus 17 of

the original problem list items for whites and non-whites, respectively) contained more of the original problem list items. This indicates that the original problem list structure may be more appropriate for males and whites compared to females and non-whites. Specifically, given that racial minorities have been shown to have poorer access to care and are diagnosed at later stages, they may endorse more items related to access to care or symptoms/side effects related to later cancer stages (Jemal et al., 2008) and these items may be more strongly related to overall distress scores. In addition, past research has suggested that females may be more likely to report emotional concerns (Keller & Henrich, 1999), thus the DT's emotional items may be more predictive of overall distress among females compared to males.

These findings are somewhat consistent with previous research showing that there have been differences in the endorsement of problem list items between males and females (Bradley et al., 2005; Keller & Henrich, 1999; Schmidt et al., 2005; Walsh et al., 2000). While there has been no previous research investigating the differences in problem list items between races, the findings of this study are consistent with previous studies suggesting that research among Caucasian cancer survivors may not generalize to other races (Lincoln et al., 2003) due to the differences in factors related to cancer diagnosis between patients among racial minorities and majorities (Jemal et al., 2008; Tammemagi et al., 2005; Ward et al., 2004).

Limitations

While this study aims to begin the discussion of thee DT's applicability to subgroups, the limited sample size makes broad generalizations difficult. Further, this study collapsed different racial minority categories into one category to increase numbers for statistical purposes. By doing this, it is not possible to investigate the differences between these groups. Further, it is difficult to know how the method of administration of the DT (e.g., administered by nurse versus

mental health provider) may have impacted the participants' responses. The dataset used in this study did not contain that information as was not possible to add as a covariate.

Conclusion

While distress is considered a "normal" reaction to cancer, high levels of distress are sometimes related to worse quality of life, poor treatment adherence, and dissatisfaction with care (Bultz & Carlson, 2005). Thus, it is important to understand how to best assess for distress in patient populations as well as which concerns are predictive of distress. Overall, this study showed that while the problem list structure is applicable to the patient population as a whole, it may not hold up when investigated within subpopulations. Further, the emotional domain was the only domain that significantly predicted risk status in this study. Future studies should investigate the DT and problem list in more detail with larger subpopulation groups in an effort to identify areas where they differ with respect to the applicability of the DT and problem list. As there is limited research on how the problem list items were selected and categorized, it may be important to conduct qualitative research to better understand which concerns cancer survivors are concerned with as well as which problems they believe impact overall distress.

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Table 1.

Self-reported Race

beij-reported Race	
White	88.4% (n = 1065)
Black	6.7% (n = 81)
American Indian	0.8% (n = 10)
Asian	0.7% (n = 8)
Other	3.3% (n = 40)
Declined to answer	.1% (n = 1)

Table 2

Cancer diagnoses represented

Cuncer diagnoses represented		
Type of cancer	Frequency	Percent
Breast	517	18.08
Gynecological	299	10.45
(e.g., ovarian, uterine)		
Genitourinary	249	8.71
(e.g., prostate, bladder)		
Gastrointestinal	228	7.97
(e.g., colon, stomach)		
Lymphatic/Hematopoietic	191	6.68
Lung	191	6.68
Skin	164	5.73
Bone	141	4.93
Head and Neck	109	3.81
(e.g., lung, mouth)		
Neuroendocrine	15	0.52
Other/Unknown	756	26.43
Total	2860	

Note. Total > 1,205 as some participants had more than one cancer diagnosis.

Table 3 *Measurement Model Results*

Measurement Mo				
	Practical	Family	Emotional	Physical
	Problems	Problems	Problems	Problems
<u>Item</u>	<u>Unstandardized/</u>	<u>Unstandardized/</u>	<u>Unstandardized/</u>	<u>Unstandardized/</u>
	<u>Standardized</u>	<u>Standardized</u>	<u>Standardized</u>	<u>Standardized</u>
Child care	1.000/0.738			
Housing	1.093/0.767			
Insurance	1.036/0.750			
Financial issues	1.908/0.902			
Transportation	0.939/0.717			
Work/school	1.010/0.741			
Facility	0.629/0.567			
Dealing with		1.000/0.798		
partner				
Dealing with		0.947/0.782		
children				
Dealing with		0.754/0.707		
others				
Depression			1.000/0.910	
Fears			1.212/0.936	
Nervousness			0.842/0.879	
Sadness			0.987/0.908	
Worry			1.818/0.970	
Appearance				1.000/0.821
Bathing/dressing				0.849/0.773
Breathing				0.590/0.646
Changes in				0.547/0.618
urination				
Constipation				0.706/0.712
Diarrhea				0.605/0.656
Eating				0.823/0.763
Feeling swollen				0.802/0.755
Fevers				0.664/0.690
Getting around				0.641/0.677
Indigestion				0.787/0.749
Mouth sores				0.451/0.543
Nausea				0.888/0.787
Nose dry				0.647/0.681
Pain				1.281/0.878
Sexual				0.674/0.695
Skin dry/itchy				0.624/0.668
Sleep				0.958/0.809
Tingling in				0.833/0.767
hands/feet				

Table 4
Structural Regression Model Results

	0 11	
	Overall	
	Distress	
<u>Item</u>	<u>Unstandardized</u>	Standardized
Practical	0.551	0.407
Problems		
Family	-0.241	-0.193
Problems		
Emotional	0.767*	0.697*
Problems		
Physical	-0.088	-0.072
Problems		
* <i>p</i> < .001		

Table 5

CFA Results – Males Only

-				
	Practical	Family	Emotional	Physical
	Problems	Problems	Problems	Problems
Item	Unstandardized/	Unstandardized/	Unstandardized/	Unstandardized/
<u>Item</u>	Standardized Standardized	Standardized Standardized	Standardized/	Standardized Standardized
Housing	1.000/0.790	Standardized	Standardized	Standardized
Insurance	0.896/0.756			
Financial issues	1.297/0.858			
Transportation	0.796/0.716			
Work/school	1.038/0.801			
Facility	0.606/0.615			
Dealing with	0.000/0.013	1.000/0.927		
partner		1.000/0.72/		
Dealing with		0.782/0.888		
children		0.70270.000		
Dealing with		0.272/0.559		
others		0.2727000		
Depression			1.000/0.927	
Fears			1.144/0.943	
Nervousness			0.764/0.884	
Sadness			0.993/0.926	
Worry			1.258/0.952	
Appearance				1.000/0.831
Bathing/dressing				1.016/0.835
Breathing				0.680/0.712
Changes in				0.764/0.752
urination				
Constipation				0.681/0.713
Diarrhea				0.573/0.650
Eating				0.905/0.804
Feeling swollen				0.625/0.682
Fevers				0.850/0.785
Getting around				0.714/0.729
Indigestion				0.949/0.817
Mouth sores				0.462/0.568
Nausea				0.812/0.771
Nose dry				0.674/0.709
Pain				1.325/0.892
Sexual				0.591/0.661
Skin dry/itchy				0.590/0.661
Sleep				0.778/0.758
Tingling in				0.835/0.780
hands/feet				

Table 6

	Practical	Family	Emotional	Physical
-	Problems	Problems	Problems	Problems
<u>Item</u>	<u>Unstandardized/</u>	<u>Unstandardized/</u>	<u>Unstandardized/</u>	Unstandardized
	<u>Standardized</u>	<u>Standardized</u>	<u>Standardized</u>	<u>Standardized</u>
Housing	1.000/0.767			
Insurance	0.935/0.745			
Financial issues	1.926/0.917			
Transportation	0.843/0.710			
Work/school	0.819/0.699			
Facility	0.549/0.549			
Dealing with		1.000/0.761		
partner				
Dealing with		0.931/0.738		
children				
Dealing with		0.941/0.741		
others				
Depression			1.000/0.904	
Fears			1.223/0.933	
Nervousness			0.871/0.879	
Sadness			0.990/0.902	
Worry			2.244/0.978	
Appearance				1.000/0.832
Bathing/dressing				0.787/0.763
Breathing				0.527/0.620
Constipation				0.681/0.714
Diarrhea				0.599/0.668
Eating				0.748/0.746
Feeling swollen				0.853/0.788
Fevers				0.592/0.664
Getting around				0.573/0.652
Indigestion				0.703/0.726
Nausea				0.866/0.792
Nose dry				0.610/0.675
Pain				1.216/0.877
Sexual				0.796/0.767
Skin dry/itchy				0.619/0.681
Sleep				0.994/0.830
Tingling in				0.793/0.765
hands/feet				

Table 7

CFA Results – Whites Only

CFA Results – W				
	Practical	Family	Emotional	Physical
	Problems	Problems	Problems	Problems
<u>Item</u>	Unstandardized/	<u>Unstandardized/</u>	<u>Unstandardized/</u>	<u>Unstandardized/</u>
	Standardized	<u>Standardized</u>	Standardized	Standardized
Child care	1.000/ 0.738			
Housing	0.957/ 0.723			
Insurance	1.008/ 0.741			
Financial issues	2.142/0.920			
Transportation	0.975/0.730			
Work/school	1.052/ 0.755			
Facility	0.610/0.555			
Dealing with		1.000/ 0.758		
partner				
Dealing with		1.003/0.759		
children				
Dealing with		0.755/ 0.660		
others				
Depression			1.000/ 0.909	
Fears			1.135/ 0.927	
Nervousness			0.815/0.871	
Sadness			0.980/0.906	
Worry			1.868/0.971	
Appearance				1.000/ 0.826
Bathing/dressing				0.878/0.789
Breathing				0.623/ 0.674
Changes in				0.505/ 0.595
urination				
Constipation				0.702/0.717
Diarrhea				0.643/ 0.686
Eating				0.843/0.777
Feeling swollen				0.818/ 0.768
Fevers				0.721/0.726
Getting around				0.622/ 0.673
Indigestion				0.770/ 0.748
Mouth sores				0.448/ 0.549
Nausea				0.905/0.798
Nose dry				0.624/ 0.675
Pain				1.202/ 0.870
Sexual				0.677/ 0.704
Skin dry/itchy				0.581/ 0.648
Sleep				0.959/ 0.815
Tingling in				0.752/ 0.741
hands/feet				

Table 8

CFA Results – Minorities Only

	Practical	Family	Emotional	Physical
	Problems	Problems	Problems	Problems
<u>Item</u>	<u>Unstandardized/</u>	<u>Unstandardized/</u>	Unstandardized/	<u>Unstandardized/</u>
	Standardized	Standardized	Standardized	Standardized
Housing	1.000/0.982			
Insurance	0.288/0.834			
Financial issues	0.230/0.770			
Transportation	0.156/0.633			
Work/school	0.165/0.654			
Dealing with		1.000/0.967		
partner				
Dealing with		0.579/0.910		
children				
Dealing with		0.875/0.957		
others				
Depression			1.000/0.907	
Fears			1.700/0.965	
Nervousness			1.265/0.939	
Sadness			1.282/0.940	
Appearance				1.000/0.832
Changes in				0.737/0.741
urination				
Constipation				0.632/0.688
Nose dry				0.550/0.636
Skin dry/itchy				1.015/0.836
Sleep				0.727/0.737
Sleep				0.727/0.737

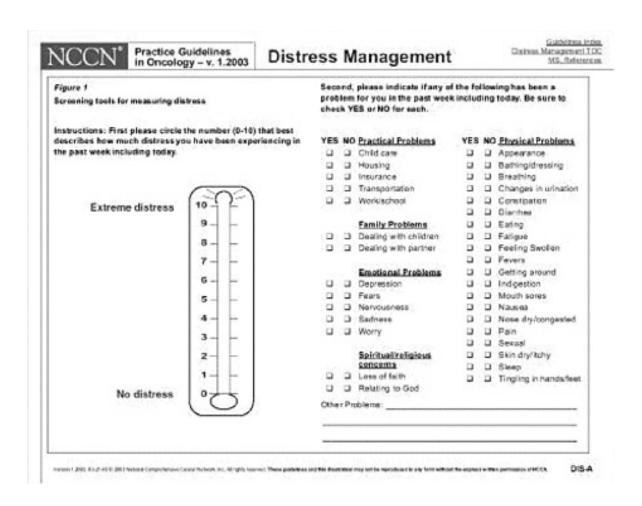


Figure 1. Version 1 of the Distress Thermometer.



Distress Management

Distress is a term used to describe unpleasant feelings or emotions that may interfere with the ability to cope with serious illness, its physical symptoms, and its treatment. Distress is a normal response when you or a family member receives a diagnosis of a serious illness.

SCREENING TOOLS FOR MEASURING DISTRESS

scribes how much distress you have been periencing in the past week, including today.			the past week, including to O or YES for each.
	NO	YES	2 2022 10
			Practical Issues
Extreme ()		Ц	Housing
Distress 40			Insurance
	닏	Н	Work/School
	H	Ц	Transportation -
	님 .	H	Child Care
	H	H	Financial Issues
	П		Facility: i.e. parking, waiting Relationship Issues
0. Salit 5 4 5 5 6 7 7 8			Dealing with Partner
6-88-			Dealing with Children
	Ш	\sqcup	Other
5-88	_		Emotional Issues
	Ц	Н	Worry
	님	님	Fears
	H	H	Sadness
	H	H	Depression
		П	Nervousness
			Spiritual Issues Relating to God
1144	H	H	Loss of Faith
			Physical Issues
No Distress			Pain
	H	H	Nausea
	H	H	Sleep
THE PERSON NAMED IN COLUMN TWO IS NOT THE PERSON NAMED IN COLUMN TWO IS NAM	H	H	Getting around
	H	Ħ	Bathing/Dressing
☐ I would like to see a Social Worker	Ħ	. Н	Breathing
	Ħ	Ħ	Mouth Sores
	Ħ	Ħ	Eating
	Ħ	П	Indigestion
Physician Signature	Ħ	Ħ	Constipation
V	Ħ	Ħ	Diarrhea
	П	Ħ	Changes in urination
RN Signature	Ħ	\Box	Fevers
-			Skin dry/itchy
			Nose dry/congested
			Tingling in hands/feet
Social Work Signature			Feeling swollen
			Sexual

Figure 2. KUCC-modified Distress Thermometer.

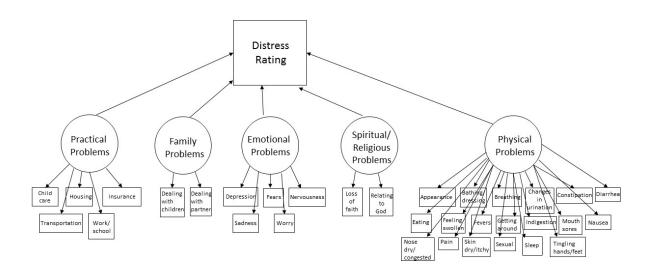


Figure 3. Structural regression model.