

A Special Kind of Stress:

Assessing Feelings of Decisional Distress for Breast Cancer Treatment Decisions

Alannah Shelby Rivers^a and Keith Sanford^a

^aDepartment of Psychology and Neuroscience, Baylor University

Waco, USA

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sector

Corresponding author at One Bear Place 97334, Waco, TX, USA, zip code 76798, (254)

710-2961 (phone), (254) 710-3033 (fax), email: Shelby_Rivers@Baylor.edu

Abstract

Objective

Women with breast cancer need to make difficult treatment decisions and may experience decisional distress (worry, anxiety, and thought intrusion) associated with these decisions. This study investigated ways that decisional distress was both associated with and distinct from other variables regarding decisional process and life functioning, and it investigated the validity of a decisional distress scale.

Methods

A total of 263 women previously or currently diagnosed with breast cancer reported on initial treatment decisions regarding surgery, chemotherapy, or radiation, or decisions involving oral endocrine therapy (either currently or retrospectively). Participants completed online measures of decisional distress, alliance and confusion in patient-practitioner relationships, positive and negative interactions in close relationships, financial and general distress, and decision satisfaction.

Results

Decisional distress demonstrated a unidimensional factor structure invariant across treatment context groups, a wide range of meaningful variation, significant correlations with all hypothesized variables (especially patient confusion), but also key distinctions from other variables.

Conclusion

Decisional distress is a meaningful construct that can be assessed with precision, and important for understanding medical decision-making processes and patient quality of life.

Practice Implications

Assessing decisional distress is crucial for evaluating treatment decision outcomes. One key to reducing decisional distress may involve reducing patient confusion.

Keywords: anxiety, breast neoplasms, clinical decision-making, quality of life

1. Introduction

Breast cancer is an especially common cancer, with over 250,000 women diagnosed with breast cancer each year in the United States [1]. Breast cancer patients often make difficult decisions that involve balancing potentially lifesaving treatment benefits against burdens of debilitating side effects [2–5], including decisions about initial treatments (e.g., surgery, chemotherapy, and radiation) that have a major, often irreversible impact on daily life, and also decisions about later treatments like oral endocrine therapy (OET), which are less aversive and typically prescribed in less deadly cancers for up to 10 years. As a result, breast cancer patients may experience *decisional distress*, a sustained negative affective response to difficult treatment decisions which, like reactions to other traumatic life events, may include components of anxiety, worry, and thought intrusiveness. Theoretically, decisional distress should be important for understanding treatment decision-making, and should be associated with (but also distinct from) key decisional process variables involving treatment context, patient-practitioner relationships [6,7], interpersonal support [8,9], and financial and general distress [10–12]. Given a lack of previous research investigating decisional distress, the first steps are to address psychometric questions regarding this construct, and then to investigate associations and distinctions involving other decisional process variables.

There are several reasons why decisional distress is expected to be a salient and meaningful construct for understanding the experiences of breast cancer patients. First, breast cancer patients frequently report clinically significant levels of distress [6,8,11,13], at least some of which can be attributed to treatment decision-making [6,11,14]. Moreover, for some women, these feelings can continue for years [11,12,15], and the severity and longevity of cancer-related emotional distress mirrors responses to other traumatic events, including the presence of

intrusive thoughts [13,16]. Finally, decisional distress themes (uncertainty, anxiety, and regret) often emerge in qualitative examinations of breast cancer decision-making [17–19].

1.1 Associations with Medical Decision Process Variables

Decisional distress should be an important outcome in research seeking to understand medical decision-making processes. Previous decision-making research has focused on interactions between patients and health-care professionals, and these interactions are especially consequential if they are associated with decisional distress. Previously studied variables include patient involvement in decisions [20], information exchange [21], and patient expectations for health-care appointments [22]. Recent psychometric work has found that these interactions can be reduced to two basic dimensions called alliance (a warm, trusting, and supportive relationship) and confusion (feeling insufficiently informed or experiencing lingering questions after consultations) [23]. Feeling allied with a practitioner reduces psychological distress and improves decision-making satisfaction [6,7,24], whereas feeling confused and underinformed contributes to greater distress, anxiety, and regret [11,12,14,25,26]. Therefore, decisional distress should have clear correlations with both alliance and confusion.

Decisional distress should also be an important outcome in research seeking to understand the general importance of cancer patients' experiences in close relationships. Feeling supported or unsupported can shape experiences with treatment decision-making [18,27,28]; importantly, psychometric work suggests that experiences of positive interactions (support, intimacy, and warmth) and negative interactions (criticism, withdrawal, and miscommunication) represent two distinct, important dimensions [29–32]. Patients experiencing positive interactions may be protected from experiencing severe distress [8], whereas those experiencing negative

interactions experience greater distress [9,33]. Therefore, decisional distress is likely to correlate with both positive and negative interactions in interpersonal relationships.

Decisional distress is important because it is expected to play a role in quality of life and decision satisfaction for breast cancer patients. Negative affectivity surrounding decision-making may contribute to overall distress, and general distress may contribute to negative emotions about treatment decisions [6,11,12]. Distress related to decisions may also exacerbate stress in other areas of living, such as financial stress, and financial hardships may complicate treatment decision-making [10,34]. Finally, distress may produce poorer-quality decisions, and dissatisfaction with decisions should increase distress [6]. Therefore, decisional distress should be associated with general and financial distress and decision satisfaction.

1.2 Distinctions from Medical Decision Process Variables

Although decisional distress and key decisional process variables should be correlated, if decisional distress is a useful construct it also needs to be distinct. Notably, a widely-used instrument called the Decisional Conflict Scale [21] combines several constructs like patient information, confidence in decisions, and interpersonal support. Although this scale assesses something different from decisional distress, it raises a question about whether different components of decision-making experience might be psychometrically indistinguishable and thereby combinable.

However, there are two ways that decisional distress should differ from other decisional process variables. First, compared to other variables, decisional distress should be uniquely associated with *treatment context*. Two specific contexts investigated in previous research include initial treatments like chemotherapy, surgery, and radiation [35], and later, long-term treatments such as OET [15]. Although it should be meaningful to assess decisional distress in

both contexts, distress should be more severe in the context of initial treatment decisions, which may seem especially frightening and irreversible and which may have debilitating side-effects that require further decision-making [36]. On the other hand, OET may seem less frightening, has less severe side effects, allows greater patient choice (including the ability to prematurely discontinue treatment) [37], and is most commonly prescribed for the types of breast cancer that are most effectively treated [1]. Taken together, because decisional distress is an affective response to the decisional context, decisional distress should be lower among women making OET decisions than among women making initial treatment decisions, and it should share a robust association with context that remains significant after controlling for other variables.

Second, it is especially important to demonstrate that decisional distress is not redundant with general distress; although these two constructs should be closely related, decisional distress should represent a more precise estimation of decision-related distress that captures specific experiences related to the treatment context. Specifically, compared to and controlling for general distress, decisional distress should have stronger associations with cancer contextual variables, including treatment context, alliance, confusion, and decision satisfaction. Such a measure would provide greater precision in isolating a specific aspect of distress which may be especially salient, distinct, and uniquely important for research and intervention seeking to clarify the etiology of distress and reduce distress.

1.3 Psychometric Validation

The first step toward investigating the importance of decisional distress is to develop a scale and test its factor structure and discrimination. For content validity, items should capture the most relevant severe distress experiences: in addition to general experiences of worry and anxiety [6,11,14], a growing body of work suggests that experiences related to trauma

(particularly intrusive thoughts) are also a key component of many cancer experiences [13,16]. Because well-validated scales have already been created to assess severe anxiety and intrusive thoughts in medical populations [38,39], these items could be adapted to assess decisional distress with high reliability and precision.

Because scales measuring distress and negative affect are typically unidimensional [40], it should be possible to capture a single underlying dimension of decisional distress, and the unidimensional structure should be invariant across contexts and research settings. Moreover, this measure should discriminate between people across a broad range of distress levels. Some women may experience little to no distress, whereas others may experience extreme distress [6,8,11,13]. Presumably, decisional distress can be meaningfully self-reported and therefore, it should be possible to develop a measure with good discrimination across the full range of distress levels.

1.4 Hypotheses

The goals of the current study were to develop and test a measure of decisional distress across two treatment context groups (one group reporting on OET, and another group reporting on initial treatments involving surgery, chemotherapy, and radiation), and across research settings involving two temporal perspective groups (one group reporting on ongoing treatment and another reporting previous experiences). In a confirmatory factor analysis, the new scale should be unidimensional, and demonstrate measurement invariance across treatment context and temporal perspective groups. In item response theory analyses, individual items and the test should demonstrate good discrimination across a wide range of levels of decisional distress. Decisional distress was expected to correlate with decisional process variables (alliance, confusion, positive and negative interactions, financial distress, general distress, and decision

satisfaction), and the association between decisional distress and treatment context was expected to remain significant controlling for other decisional process variables. Finally, if cancer contextual variables (treatment context, alliance, confusion, and decision satisfaction) are regressed on both decisional distress and general distress, the unique effects for decisional distress should be significantly larger than the unique effects for general distress.

2. Methods

2.1 Participants and Procedure

A sample of 263 female breast cancer survivors ($M_{age} = 60.1$, $SD = 12.7$) was recruited using Qualtrics Panels; 84.8% of participants identified as non-Hispanic White, 8% as Black/African-American, 3% as Hispanic/Latino(a), 1.9% as Asian-American, and 2.3% as other races. Participants were invited to the study through Qualtrics Panels based on responses to a market research profile. After providing informed consent, participants were directed to a screener including the real inclusion criteria obscured in a set of foil diagnoses (e.g., epilepsy). Participants then completed an online questionnaire about their experiences with breast cancer treatment.

The sample was divided into two treatment context groups: OET (169 participants currently or previously prescribed OET who answered questions about OET), and non-OET (94 participants *not* prescribed OET who answered questions about surgery, chemotherapy, and radiation). The sample was also divided into two temporal perspective groups: “present” (146 participants who were currently completing or planning a course of treatment, or recovering from surgery less than one year, and who answered questions about current experiences), and “retrospective” (117 participants who finished or stopped treatment and who answered questions about a previous “target time”). Target times were: a few months following surgery (non-OET);

when it required the most effort to continue OET (completed OET); the month before they stopped OET (discontinued OET); and when they were deciding about OET (declined OET). On average, the target time was 8.38 years prior to the survey ($SD = 6.73$). Group composition is summarized in Table 1. Participants were compensated with gift cards or online credit points with an approximate value of \$2.00.

2.2 Measures

Means, standard deviations, and Cronbach's alphas are in Table 2.

2.2.1 Decisional Distress

Items were adapted from the abbreviated form of the State-Trait Anxiety Inventory [38] and the intrusion subscale of the Impact of Event Scale – Revised [39]. Of the 14 items on these scales, 8 items were selected; items that were potentially redundant or inappropriate to adapt for the treatment decision context were not included in the measure. A preliminary prompt instructed women in the OET group to think about OET treatment decisions, and women in the non-OET group to think about decisions regarding chemotherapy, surgery, and radiation. Decisions involved whether to begin or discontinue treatments (where relevant) as well as timing of treatment, dealing with side effects, and raising concerns with practitioners. Nearly all (98.1%) participants indicated making at least one of these types of decisions; those who did not were asked to describe their general cancer decision-making experiences. Participants then rated the items on a scale ranging from “Strongly disagree” (1) to “Strongly agree” (7). After reverse-scoring, items were summed to create the total score scale (higher scores indicated greater decisional distress). A full list of items is found in Table 3.

2.2.2 Alliance and Confusion

Perceived alliance and experienced confusion were assessed using the Medical Consultation Experience Questionnaire [23]. An example (present tense) alliance item is “Compared to a typical doctor, how much do you feel like part of a team with your oncologist?”. For the 7-item alliance scale, total scores range from 7 to 39, with higher scores indicating greater alliance. An example (present tense) confusion item is “Do you have questions that your oncologist or another medical expert might be able to answer?”. For the 5-item confusion scale, total scores range from 5 to 25, with higher scores indicating more confusion.

2.2.3 Positive and Negative Interactions

Positive and negative interactions were assessed using the 16-item Interpersonal Resilience Inventory [29]. Before responding to the items, participants were instructed to consider relationships with “significant adult people” in their lives, defined as (nonprofessional) relationships with expectations of mutual support. An example of a (present) positive interaction is “In your relationship with a significant adult person in your life, one of you was attentive to the other's needs.” An example of a (present) negative interaction is “In your relationship with a significant adult person in your life, one of you was critical or hostile or blamed the other.” Each scale is 8 items. Participants reported perceived frequency of each interaction over a one-month period using an 8-point scale ranging from “This definitely did not happen” (1) to “This happened a few times a day” (8).

2.2.4 Financial Distress

The 10-item Consumer Financial Protection Bureau Financial Well-Being scale was used to assess financial distress [41]. An example (present) item is “I am just getting by financially.” Responses are made on a 5-point scale ranging from “Describes me completely” (1) to “Describes me not at all” (5). Higher scores represent greater financial distress.

2.2.5 General Distress

Six items representing perceived helplessness [42] were drawn from the 10-item Perceived Stress Scale [43]. An example (present) item is “In the last month, how often have you felt nervous and ‘stressed’?”. Responses are made on a 5-point scale from “Never” (1) to “Very often” (5). Higher scores represent greater distress.

2.2.6 Decision Satisfaction

A single-item (present: “I am satisfied with the treatment decisions I make”) rated on a scale ranging from “Strongly disagree” (1) to “Strongly agree” (7) was used to assess decision satisfaction.

2.2.7 Demographics

Income and education were collected via Likert-style items, and converted into approximate dollar and year equivalents.

2.3 Approach to Analysis

To test factor structure, a one-factor confirmatory factor analysis model was tested using the diagonally weighted least squares estimator. A well-fitting model was defined using a two-index criterion: CFI > .95 and SRMR < .09 [44]. Standardized factor loadings were expected to be “good” (exceed .55) [45]. Then, measurement invariance procedures were conducted by fitting multi-group models (treatment context or temporal perspective groups) beginning with the most stringent model (fixing loadings and thresholds across groups), proceeding to less stringent models, and ending when a well-fitting model was identified [46].

Item response theory analyses were used to evaluate thresholds, item discrimination, and test information using the graded response model [47], and calculated in the R package “ltm” [48]. Threshold values translate between ordinal response options and the latent continuous

variable they represent; each value represents the “threshold” of the latent decisional distress score between one response option and the next highest option. To ensure representation of extreme experiences, at least 5% of average responses were expected to exceed the highest threshold (endorse the most extreme level of distress), and this threshold was expected to correspond with a level of distress at least one standard deviation above the mean [49]. Next, regarding item discrimination, to ensure that items were adequately sensitive across a range of possible responses, all values were expected to have at least “moderate” discrimination (at least 0.65) [50]. Finally, to ensure that the overall measure had good reliability over a wide range of possible responses, total information was expected to exceed 5 for a range spanning at least one standard deviation below to one above the mean. This cutoff value is equivalent to a standard error of .45 ($SE = 1 / \text{information}^{1/2}$) and a reliability of .8 (reliability = $1 - SE^2$), a value typically considered “good.”

Correlations were tested between the new decisional distress scale and decisional process variables (treatment context, alliance, confusion, positive interactions, negative interactions, financial distress, general distress, and decisional distress) with the expectation that all variables would be associated with decisional distress. Then, a partial correlation was calculated between treatment context and decisional distress controlling for all the other decisional process variables. Then each decisional process variable was regressed simultaneously on decisional distress and general distress to examine unique effects. Hypothesized differences between the standardized betas were tested using structural equation models in which decisional distress and general distress were both constrained to have the same association with a decisional process variable. A significant χ^2 test with one degree of freedom indicated a difference between betas.

3. Results

3.1 Factor Structure and Item Response Theory Analyses

The one-factor model fit the data well, $\chi^2(20) = 60.75$ ($p < .001$), CFI $> .99$, SRMR = .05. Factor loadings are in Table 3; all exceeded the “good” criterion. For both invariance tests, the most stringent model (fixing loadings and thresholds) fit well (between treatment context groups, $\chi^2(86) = 109.30$, $p = .05$, CFI $> .99$, SRMR = .06, and between temporal perspective groups, $\chi^2(86) = 167.92$, $p < .001$, CFI $> .99$, SRMR = .06). This suggests that items and response options have equivalent meanings across these groups.

Item response theory analysis results are found in Table 3. Regarding thresholds, across items an average of 10.64% of responses exceeded the highest threshold, which corresponded to an average estimated latent decisional distress value 1.46 standard deviations above the mean. This suggests that a meaningful proportion of participants experienced serious decisional distress. Regarding item discrimination values, all exceeded the “moderate” criterion (and most exceeded the “very high” criterion) [50], suggesting that items were extremely sensitive across a meaningful range of possible responses. The test information curve is depicted in Figure 1. The scale had “good” information for a range exceeding one standard deviation below to one above the mean, suggesting that for most respondents, scores will be highly reliable.

3.2 Relationships with Decisional Process Variables

Zero-order correlations are reported in Table 4. Decisional distress was associated with all decisional process variables in the expected directions. As hypothesized, the partial correlation between treatment context and decisional distress controlling for all other decisional process variables was significant and moderate in size (partial $r = -.30$, $p < .001$). Standardized betas are reported in Table 4. When decisional process variables were regressed on both types of distress, standardized betas were significantly larger for decisional distress than general distress

when predicting treatment context, alliance, confusion, and decision satisfaction (as hypothesized). As a robustness check, regression equations were also estimated controlling for age, income, and education. This did not meaningfully change betas or significance levels, except that the unique association between decisional distress and positive interactions became significant.

3.3 Abbreviated Scale

As a follow-up analysis, three items (1, 2, and 5) were identified that could be dropped without decreasing reliability by more than $-.01$. This alternate five-item scale produced lower information overall and was not significantly associated with positive interactions, but factor validity and item discrimination continued to meet criteria.

4. Discussion and Conclusion

4.1 Discussion

The current study demonstrated that decisional distress, a negative affective response to the process of making difficult treatment decisions that includes components of anxiety, worry, and thought intrusiveness, can be meaningfully self-reported and assessed with psychometric precision. The new decisional distress scale produced an excellent fit to a unidimensional model and high discrimination across a wide range of distress levels. Decisional distress was associated with decisional process variables (treatment context, patient-practitioner relationships, close interpersonal relationships, general and financial distress, and decision satisfaction), but also demonstrated clear distinctions from these variables; it was associated with treatment context even after controlling for all other variables, and there were clear distinctions between decisional distress and general distress, suggesting that decisional distress is not a redundant construct.

The results highlight two key characteristics of decisional distress: it is both highly variable and strongly associated with general distress. The wide range of meaningful score variability indicated by the item response theory analysis is consistent with other research indicating that, although most newly diagnosed women report some distress associated with treatment decisions [51], for some women, this distress is minimal, whereas for others, this distress is extreme [6]. Although many women experience high distress, it is not an inevitable part of treatment. When decisional distress is extreme, however, it is likely to be consequential, in part because it is strongly associated with general distress. This is important because other research finds that distress and uncertainty can lead to withdrawal from upsetting information about treatment [19], decision regret potentially lasting for years [52], and psychological morbidities following treatment [11].

The current results provide a useful starting point in predicting why some women might experience extreme decisional distress. For example, decisional distress appears more likely in contexts where decisions are especially difficult and consequential. Moreover, decisional distress had particularly large associations with patient confusion, consistent with previous findings suggesting that confusion is associated with greater general distress, dissatisfaction, and regret [11,12,25]. Decisional distress also shared a unique relationship with patient-practitioner alliance. Feeling supported by practitioners may produce more satisfactory outcomes and fewer feelings of anxiety and regret [6,7,24]. Therefore, to build a model specifically predicting decisional distress, it may be especially important to consider treatment context and patient-practitioner relationships.

There are key limitations to the current study. First, responses were collected online and from a primarily white sample. Previous research has found online recruitment produces

high-quality responses from distressed populations of people with cancer [53], but these samples may not be representative of the general population of women with breast cancer. Second, all variables were self-reported. Although decisional distress is a subjective experience, theoretically associated factors, like specific patterns in patient-practitioner communication [54], could be assessed using other methods. Similarly, all data were cross-sectional. Future research should investigate how decisional distress unfolds over time. Finally, only two major treatment contexts were investigated, and other contextual factors involving type and stage of cancer, specific treatments, and recurrence may be relevant for decisional distress. This construct and scale should also be explored in conjunction with other measures of decisional outcomes [20–22].

4.2 Conclusion

The results from this study highlight the potential usefulness of the decisional distress scale and the distinctiveness of the decisional distress construct for understanding the experiences of breast cancer patients. Crucially, confirmatory factor analyses indicated that decisional distress is unidimensional and that it has the same precise meaning in different treatment and temporal perspective contexts. Moreover, the new scale can discriminate across a broad range of decisional distress levels, ranging from women experiencing almost no distress to women experiencing extreme distress. Importantly, although item response theory analyses are infrequently used in health research, scales with poor discrimination may fail to detect clinically relevant effects and it is therefore important to ensure a high level of discrimination [55]. It is also noteworthy that the decisional distress scale demonstrated distinctions; compared to general distress, it was more strongly associated with variables involving cancer treatment, and in contrast to other decisional process variables, it was associated with treatment context. This is important because researchers have developed many measures assessing constructs related to

breast cancer decision-making [20–22], which risks redundancy or overlap between measures, and it is therefore crucial to identify variables that are demonstrably distinct.

4.3 Practice Implications

These findings have clinical implications for decision-making interventions that aim to produce good decision outcomes. First, because decisional distress is a distinct variable associated with patient well-being, it is crucial to assess decisional distress to evaluate patient outcomes. Many interventions fail to evaluate distress, and those evaluating distress often use instruments with poor psychometric properties, or use generalized inventories which conflate different types and sources of distress [56]. The present study provides a means to address this issue. Second, associations with alliance and confusion highlight specific dimensions of patient-practitioner relationships that may be especially important for good decision-making outcomes. This builds on research indicating the general importance of physician-patient relationships [57]; specifically, the present study suggests that it may be valuable to focus on two key dimensions of physician-patient relationships regarding alliance and patient confusion, and the pattern of correlations suggests that of these two dimensions, reducing confusion (providing medical information and helping patients understand and remember this information) may be especially important for reducing decisional distress.

References

- [1] [1] American Cancer Society, Breast Cancer Facts & Figures 2019-2020, American Cancer Society, Inc., Atlanta, GA, 2019.
<https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/breast-cancer-facts-and-figures/breast-cancer-facts-and-figures-2017-2018.pdf> (accessed February 22, 2018).
- [2] T.A. Revenson, J.R. Pranikoff, A contextual approach to treatment decision making among breast cancer survivors, *Health Psychol.* 24 (2005) S93–8.
<https://doi.org/10.1037/0278-6133.24.4.S93>.
- [3] S.J. Katz, P.M. Lantz, N.K. Janz, A. Fagerlin, K. Schwartz, L. Liu, D. Deapen, B. Salem, I. Lakhani, M. Morrow, Patient involvement in surgery treatment decisions for breast cancer, *JCO.* 23 (2005) 5526–33. <https://doi.org/10.1200/JCO.2005.06.217>.
- [4] W. Lam, R. Fielding, M. Chan, L. Chow, E. Ho, Participation and satisfaction with surgical treatment decision-making in breast cancer among Chinese women, *Breast Cancer Res Treat.* 80 (2003) 171–80. <https://doi.org/10.1023/A:1024568732213>.
- [5] L.A. Siminoff, J.H. Fetting, Effects of outcome framing on treatment decisions in the real world: Impact of framing on adjuvant breast cancer decisions, *Med Decis Making.* 9 (1989) 262–71. <https://doi.org/10.1177/0272989X8900900406>.
- [6] L.M. Budden, B.A. Hayes, P.G. Buettner, Women’s decision satisfaction and psychological distress following early breast cancer treatment: a treatment decision support role for nurses, *Int J Nurs Pract.* 20 (2014) 8–16. <https://doi.org/10.1111/ijn.12243>.
- [7] S.T. Hawley, P.M. Lantz, N.K. Janz, B. Salem, M. Morrow, K. Schwartz, L. Liu, S.J. Katz, Factors associated with patient involvement in surgical treatment decision making for breast cancer, *Patient Educ Couns.* 65 (2007) 387–95.
<https://doi.org/10.1016/j.pec.2006.09.010>.
- [8] I. Hasson-Ohayon, G. Goldzweig, M. Braun, D. Galinsky, Women with advanced breast cancer and their spouses: diversity of support and psychological distress, *Psychooncology.* 19 (2010) 1195–204. <https://doi.org/10.1002/pon.1678>.
- [9] S. Manne, D.A. Kashy, S. Siegel, S. Myers Virtue, C. Heckman, D. Ryan, Unsupportive partner behaviors, social-cognitive processing, and psychological outcomes in couples coping with early stage breast cancer, *J Fam Psychol.* 28 (2014) 214–24.
<https://doi.org/10.1037/a0036053>.
- [10] F. Chino, J.M. Peppercorn, C. Rushing, A.H. Kamal, I. Altomare, G. Samsa, S.Y. Zafar, Out-of-pocket costs, financial distress, and underinsurance in cancer care, *JAMA Oncol.* 3 (2017) 1582–84. <https://doi.org/10.1001/jamaoncol.2017.2148>.
- [11] W.W.T. Lam, M. Chan, H.W. Ka, R. Fielding, Treatment decision difficulties and post-operative distress predict persistence of psychological morbidity in Chinese women following breast cancer surgery, *Psychooncology.* 16 (2007) 904–12.
<https://doi.org/10.1002/pon.1147>.
- [12] J.C. Livaudais, R. Franco, K. Fei, N.A. Bickell, Breast cancer treatment decision-making: Are we asking too much of patients?, *J Gen Intern Med.* 28 (2013) 630–6.
<https://doi.org/10.1007/s11606-012-2274-3>.
- [13] L.D. Butler, C. Koopman, C. Classen, D. Spiegel, Traumatic stress, life events, and emotional support in women with metastatic breast cancer: Cancer-related traumatic stress

- symptoms associated with past and current stressors., *Health Psychol.* 18 (1999) 555–60. <https://doi.org/10.1037/0278-6133.18.6.555>.
- [14] J. Sheehan, K.A. Sherman, T. Lam, J. Boyages, Association of information satisfaction, psychological distress and monitoring coping style with post-decision regret following breast reconstruction, *Psychooncology.* 16 (2007) 342–51. <https://doi.org/10.1002/pon.1067>.
- [15] L.L. Beryl, K.A.S. Rendle, M.C. Halley, K.A. Gillespie, S.G. May, J. Glover, P. Yu, R. Chattopadhyay, D.L. Frosch, Mapping the decision-making process for adjuvant endocrine therapy for breast cancer: The role of decisional resolve, *Med Decis Making.* 37 (2017) 79–90. <https://doi.org/10.1177/0272989X16640488>.
- [16] E.-J. Shim, A. Mehnert, A. Koyama, S.-J. Cho, H. Inui, N.-S. Paik, U. Koch, Health-related quality of life in breast cancer: A cross-cultural survey of German, Japanese, and South Korean patients, *Breast Cancer Res Treat.* 99 (2006) 341–50. <https://doi.org/10.1007/s10549-006-9216-x>.
- [17] J.L. Milata, The decision making process in women diagnosed with estrogen receptor-positive breast cancer experiencing side effects related to oral endocrine therapy, (2017). <https://doi.org/10.7912/C2TS4B>.
- [18] J.R. Schubart, M.A. Farnan, R.B. Kass, Breast cancer surgery decision-making and African-American women, *J Cancer Educ.* 30 (2015) 497–502. <https://doi.org/10.1007/s13187-014-0725-8>.
- [19] K. Swainston, C. Campbell, A. van Wersch, P. Durning, Treatment decision making in breast cancer: A longitudinal exploration of women’s experiences, *Br J Health Psychol.* 17 (2012) 155–70. <https://doi.org/10.1111/j.2044-8287.2011.02028.x>.
- [20] D.E. Brashers, S.M. Haas, J.L. Neidig, The patient self-advocacy scale: measuring patient involvement in health care decision-making interactions, *Health Commun.* 11 (1999) 97.
- [21] A.M. O’Connor, Validation of a Decisional Conflict Scale, *Med Decis Making.* 15 (1995) 25–30. <https://doi.org/10.1177/0272989X9501500105>.
- [22] A. Bowling, G. Rowe, N. Lambert, M. Waddington, K.R. Mahtani, C. Kenten, A. Howe, S.A. Francis, The measurement of patients’ expectations for health care: a review and psychometric testing of a measure of patients’ expectations, *Health Technol Assess.* 16 (2012) i–xii. <https://doi.org/10.3310/hta16300>.
- [23] K. Sanford, A.S. Rivers, T.L. Braun, K.P. Schultz, E.P. Buchanan, Medical Consultation Experience Questionnaire: Assessing perceived alliance and experienced confusion during medical consultations, *Psychol Assess.* 30 (2018) 1499–511. <https://doi.org/10.1037/pas0000594>.
- [24] V.B. Sheppard, I.F. Adams, R. Lamdan, K.L. Taylor, The role of patient–provider communication for black women making decisions about breast cancer treatment, *Psychooncology.* 20 (2011) 1309–16. <https://doi.org/10.1002/pon.1852>.
- [25] S.T. Hawley, N.K. Janz, A. Hamilton, J.J. Griggs, A.K. Alderman, M. Mujahid, S.J. Katz, Latina patient perspectives about informed treatment decision making for breast cancer, *Patient Educ Couns.* 73 (2008) 363–70. <https://doi.org/10.1016/j.pec.2008.07.036>.
- [26] Z. Moon, R. Moss-Morris, M.S. Hunter, S. Carlisle, L.D. Hughes, Barriers and facilitators of adjuvant hormone therapy adherence and persistence in women with breast cancer: a systematic review, *Patient Prefer Adherence.* 11 (2017) 305–22. <https://doi.org/10.2147/PPA.S126651>.

- [27] G.K.B. Halkett, P. Arbon, S.D. Scutter, M. Borg, The experience of making treatment decisions for women with early stage breast cancer: a diagrammatic representation, *Eur J Cancer*. 14 (2005) 249–55. <https://doi.org/10.1111/j.1365-2354.2005.00565.x>.
- [28] A.L. Stanton, M.A. Estes, N.C. Estes, C.L. Cameron, S. Danoff-Burg, L.M. Irving, Treatment decision making and adjustment to breast cancer: A longitudinal study, *Journal of Consulting and Clinical Psychology*. 66 (1998) 313–22. <https://doi.org/10.1037/0022-006X.66.2.313>.
- [29] A.S. Rivers, K. Sanford, When we say “perceived support,” what do we mean? Contexts and components of support among people with serious medical conditions, *Journal of Social and Personal Relationships*. 37 (2020) 2758–78. <https://doi.org/10.1177/0265407520937350>.
- [30] K. Sanford, L.M. Backer-Fulghum, C. Carson, Couple Resilience Inventory: Two dimensions of naturally occurring relationship behavior during stressful life events, *Psychol Assess*. 28 (2016) 1243–54. <https://doi.org/10.1037/pas0000256>.
- [31] A.S. Rivers, K. Sanford, Negative relationship behavior is more important than positive: Correlates of outcomes during stressful life events, *J Fam Psychol*. 32 (2018) 375–84. <https://doi.org/10.1037/fam0000389>.
- [32] K. Sanford, M.I. Kruse, A. Proctor, V.A. Torres, M.L. Pennington, S.J. Synett, S.B. Gulliver, Couple resilience and life wellbeing in firefighters, *The Journal of Positive Psychology*. (2017) 1–7. <https://doi.org/10.1080/17439760.2017.1291852>.
- [33] S. Manne, M. Glassman, Perceived control, coping efficacy, and avoidance coping as mediators between spousal unsupportive behaviors and psychological distress, *Health Psychol*. 19 (2000) 155–64. <https://doi.org/10.1037/0278-6133.19.2.155>.
- [34] C.R. Meeker, D.M. Geynisman, B.L. Egleston, M.J. Hall, K.Y. Mechanic, M. Bilusic, E.R. Plimack, L.P. Martin, M. von Mehren, B. Lewis, Y.-N. Wong, Relationships among financial distress, emotional distress, and overall distress in insured patients with cancer, *J Oncol Pract*. 12 (2016) e755–64. <https://doi.org/10.1200/JOP.2016.011049>.
- [35] T.F. Hack, L.F. Degner, P. Watson, L. Sinha, Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer, *Psychooncology*. 15 (2006) 9–19. <https://doi.org/10.1002/pon.907>.
- [36] V.C. Hamelinck, E. Bastiaannet, A.H. Pieterse, I. Jannink, C.J.H. van de Velde, G.-J. Liefers, A.M. Stiggelbout, Patients’ preferences for surgical and adjuvant systemic treatment in early breast cancer: A systematic review, *Cancer Treat Rev*. 40 (2014) 1005–18. <https://doi.org/10.1016/j.ctrv.2014.06.007>.
- [37] D.L. Hershman, T. Shao, L.H. Kushi, D. Buono, W.Y. Tsai, L. Fehrenbacher, M. Kwan, S.L. Gomez, A.I. Neugut, Early discontinuation and non-adherence to adjuvant hormonal therapy are associated with increased mortality in women with breast cancer, *Breast Cancer Res Treat*. 126 (2011) 529–37. <https://doi.org/10.1007/s10549-010-1132-4>.
- [38] M.A. Abed, L.A. Hall, D.K. Moser, Spielberger’s State Anxiety Inventory: Development of a shortened version for critically ill patients, *Issues Ment Health Nurs*. 32 (2011) 220–7. <https://doi.org/10.3109/01612840.2010.546493>.
- [39] D.S. Weiss, The Impact of Event Scale: Revised, in: J.P. Wilson, C.S. Tang (Eds.), *Cross-Cultural Assessment of Psychological Trauma and PTSD*, Springer US, Boston, MA, 2007: pp. 219–38. https://doi.org/10.1007/978-0-387-70990-1_10.

- [40] A. Khan, C.-W. Chien, N.W. Burton, A new look at the construct validity of the K6 using Rasch analysis, *International Journal of Methods in Psychiatric Research*. 23 (2014) 1–8. <https://doi.org/10.1002/mpr.1431>.
- [41] Consumer Financial Protection Bureau, CFPB Financial Well-Being Scale, Consumer Financial Protection Bureau, Washington, D.C., 2017.
- [42] J.M. Taylor, Psychometric analysis of the Ten-Item Perceived Stress Scale., *Psychol Assess*. 27 (2015) 90–101. <https://doi.org/10.1037/a0038100>.
- [43] S. Cohen, T. Kamarck, R. Mermelstein, A global measure of perceived stress, *JJ Health Soc Behav*. 24 (1983) 385–396. <https://doi.org/10.2307/2136404>.
- [44] L. Hu, P.M. Bentler, Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives, *Structural Equation Modeling: A Multidisciplinary Journal*. 6 (1999) 1–55. <https://doi.org/10.1080/10705519909540118>.
- [45] A.L. Comrey, H.B. Lee, A first course in factor analysis, 2nd ed., Psychology Press, Hillsdale, N.J, 1992.
- [46] N.K. Bowen, R.D. Masa, Conducting measurement invariance tests with ordinal data: A guide for social work researchers, *Journal of the Society for Social Work and Research*. 6 (2015) 229–249. <https://doi.org/10.1086/681607>.
- [47] F. Samejima, Estimation of latent ability using a response pattern of graded scores., Byrd Press, Richmond, 1969.
- [48] D. Rizopoulos, ltm: An R package for latent variable modeling and item response theory analyses, *J Stat Softw*. 17 (2006) 1–25. <https://doi.org/10.18637/jss.v017.i05>.
- [49] K. Sanford, A.S. Rivers, Treatment Adherence Perception Questionnaire: Assessing patient perceptions regarding their adherence to medical treatment plans., *Psychol Assess*. (2019). <https://doi.org/10.1037/pas0000782>.
- [50] F.B. Baker, The basics of item response theory, 2nd ed., ERIC Clearinghouse on Assessment and Evaluation, College Park, MD, 2001. <https://eric.ed.gov/?id=ED458219> (accessed July 1, 2018).
- [51] M.T. Hegel, C.P. Moore, E.D. Collins, S. Kearing, K.L. Gillock, R.L. Riggs, K.F. Clay, T.A. Ahles, Distress, psychiatric syndromes, and impairment of function in women with newly diagnosed breast cancer, *Cancer*. 107 (2006) 2924–2931. <https://doi.org/10.1002/cncr.22335>.
- [52] K.A. Martinez, Y. Li, K. Resnicow, J.J. Graff, A.S. Hamilton, S.T. Hawley, Decision regret following treatment for localized breast cancer: Is regret stable over time?, *Med Decis Making* 35 (2015) 446–457. <https://doi.org/10.1177/0272989X14564432>.
- [53] J.J. Arch, A.L. Carr, Using Mechanical Turk for research on cancer survivors, *Psycho-Oncol*. 26 (2016) 1593–1603. <https://doi.org/10.1002/pon.4173>.
- [54] C. Richard, E. Glaser, M. Lussier, Communication and patient participation influencing patient recall of treatment discussions, *Health Expect*. 20 (2017) 760–770. <https://doi.org/10.1111/hex.12515>.
- [55] R.D. Hays, L.S. Morales, S.P. Reise, Item response theory and health outcomes measurement in the 21st century, *Med Care*. 38 (2000) II28–II42.
- [56] H.L. Bekker, F. Legare, D. Stacey, A. O’Connor, L. Lemyre, Is anxiety a suitable measure of decision aid effectiveness: a systematic review?, *Patient Educ. Couns*. 50 (2003) 255–262. [https://doi.org/10.1016/S0738-3991\(03\)00045-4](https://doi.org/10.1016/S0738-3991(03)00045-4).

[57] J.N. Fuertes, A. Toporovsky, M. Reyes, J.B. Osborne, The physician-patient working alliance: Theory, research, and future possibilities, *Patient Educ. Couns.* 100 (2017) 610–615. <https://doi.org/10.1016/j.pec.2016.10.018>.

Table 1

Treatment context and temporal perspective group characteristics

Treatment characteristics	<i>n</i>
OET group	169
Present group	92
Completing a course of OET	92
Retrospective group	77
Completed OET	39
Stopped OET before completing course	19
Declined OET	19
Non-OET group	94
Present group	25
Recovering from surgery less than one year	7
Completing a course of chemotherapy	4
Completing a course of radiation	2
Planning to receive treatment	12
Retrospective group	69
Completed treatments (surgery was more than 1 year ago)	69
Surgery	69
Chemotherapy	39
Radiation	42

OET = Oral Endocrine Therapy

Table 2

Means, standard deviations, and alpha coefficients

Scale	M (SD)	α
Decisional distress	29.70 (12.27)	.92
Alliance	26.55 (8.84)	.93
Confusion	12.72 (5.03)	.88
Positive interactions	32.89 (12.18)	.88
Negative interactions	18.55 (13.16)	.84
Financial distress	28.08 (10.44)	.93
General distress	16.59 (6.27)	.94
Decision satisfaction	5.96 (1.25)	—

Table 3

Confirmatory factor analysis loadings and item discrimination

Item	Loading	Thresholds (% exceeding threshold)						Discrimination
		1	2	3	4	5	6	
1. When thinking about my treatment decisions, I feel content. (reverse coded) ^a	.65	-1.21 (74.5)	0.21 (39.9)	0.88 (24.3)	1.48 (14.0)	2.16 (7.2)	2.52 (4.9)	1.40
2. Any reminder seems to stir up feelings about my treatment decisions. ^b	.72	-1.91 (90.1)	-0.91 (73.0)	-0.66 (66.5)	0.26 (39.9)	0.81 (24.7)	1.63 (9.5)	1.88
3. Thinking about my treatment decisions has caused me to have trouble sleeping. ^{bc}	.89	-0.96 (77.9)	-0.30 (57.4)	-0.02 (47.1)	0.25 (36.8)	0.64 (23.1)	1.05 (13.3)	3.65
4. When thinking about my treatment decisions, I feel nervous. ^{ac}	.91	-1.21 (84.4)	-0.62 (69.2)	-0.50 (65.0)	-0.20 (54.0)	0.41 (30.0)	0.90 (15.9)	4.20
5. When thinking about my treatment decisions, I feel relaxed. (reverse coded) ^a	.76	-1.80 (89.4)	-0.90 (71.9)	-0.32 (54.4)	0.26 (36.1)	0.94 (19.4)	1.69 (8.0)	2.07
6. I think about my treatment decisions at times when I don't want to. ^{bc}	.82	-1.38 (85.2)	-0.70 (70.4)	-0.48 (63.6)	0.01 (46.1)	0.45 (31.3)	1.24 (12.2)	2.61
7. When thinking about my treatment decisions, I feel upset. ^{ac}	.87	-1.00 (77.9)	-0.28 (55.5)	0.04 (43.7)	0.38 (31.5)	0.81 (18.6)	1.32 (9.1)	3.35
8. I have waves of strong feelings about my treatment decisions. ^{ac}	.79	-1.45 (86.3)	-0.74 (70.7)	-0.46 (62.3)	0.10 (43.7)	0.60 (27.7)	1.29 (12.2)	2.46

Note. Response options: “Strongly disagree” (1), “Disagree” (2), “Somewhat disagree” (3), “Neither agree nor disagree” (4), “Somewhat agree” (5), “Agree” (6), “Strongly agree” (7). Thresholds were computed after reverse-coding where relevant.

^aItems adapted from the State Anxiety Inventory.

^bItems adapted from the Impact of Events Scale-Revised.

^cItems selected for the five-item version of the decisional distress scale.

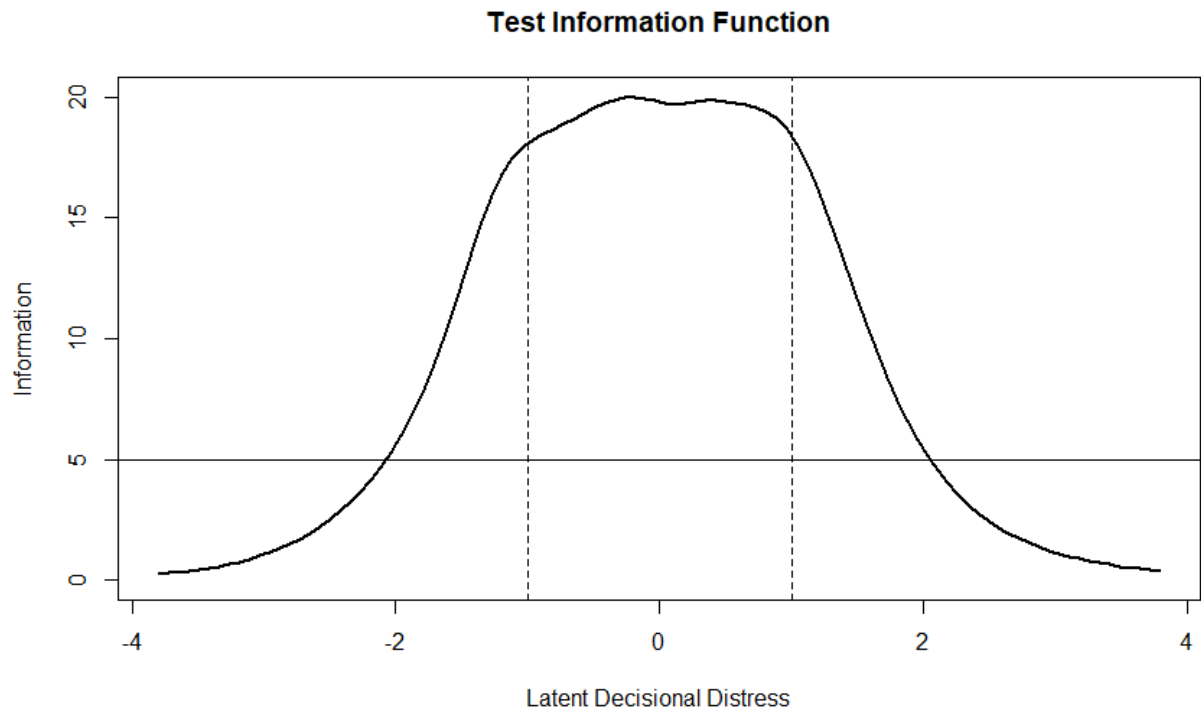


Fig. 1. Test information function for the eight-item decisional distress scale. Vertical dashed lines indicate the area between one standard deviation below and one standard deviation above the mean. The solid horizontal line indicates an information value of five, equivalent to “good” reliability.

Table 4

Correlations and partial correlations

Variable	Zero-order correlations	Standardized betas		
	Decisional distress	Decisional distress	General distress	χ^2
<i>Cancer context</i>				
Treatment context	-.22***	-.34***	.20**	6.47*
Alliance	-.30***	-.33***	.05	18.21***
Confusion	.60***	.54***	.09	15.68***
Decision satisfaction	-.51***	-.50***	.01	65.48***
<i>General context</i>				
Positive interactions	-.14*	-.12	-.03	0.40
Negative interactions	.32***	.01	.55***	22.86***
Financial distress	.26***	.02	.33***	8.64**
General distress	.61***			

Note. Treatment context was coded such that a value of 1 indicated oral endocrine therapy, and a value of 0 indicated surgery, radiation, or chemotherapy. Bolded coefficients represent hypothesized effects. Standardized betas are from regression equations where decisional process variables were regressed on decisional distress and general distress simultaneously. Chi-square values indicate differences between standardized betas.