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The Female Self-Advocacy in Cancer Survivorship Scale: A Validation Study

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Abstract

Aim—To develop and psychometrically test the validity of the Female Self-Advocacy in Cancer Survivorship Scale.

Background—Female cancer survivors need to self-advocate to overcome challenges associated with cancer yet no valid measure of self-advocacy exists.

Design—Instrument development. Mixed-mode cross-sectional survey design.

Participants—We recruited adult females (18+ years) ($N=317$) with a history of invasive cancer from local and national tumor registries and advocacy organizations to complete online or paper questionnaires.

Methods—Between July 2014 and March 2015 to evaluate the construct validity based on evidence of the scale's: (1) internal structure consistent with the underlying model of self-advocacy; (2) sensitivity to differences between groups known to differ in self-advocacy skills; (3) relationships between self-advocacy and key potential predictors (openness and conscientiousness; information engagement; social support) and outcomes (symptom burden and health care utilization); (4) relationships between self-advocacy and related concepts (patient activation; self-advocacy within another patient population); and (5) relationships between self-advocacy and

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All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE*):

1. substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
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criterion measures. Analyses included an exploratory factor analysis, t-tests, and bi-variate correlations using validated, reliable measures for constructs.

Results—Evidence from all five hypotheses supported the construct validity of the Female Self-Advocacy in Cancer Survivorship Scale. The factor analysis confirmed the three underlying dimensions of self-advocacy resulting in a 20-item measure with strong internal consistency that explained almost half of response variance.

Conclusion—The Female Self-Advocacy in Cancer Survivorship Scale is a valid, reliable measure of how well adult female cancer survivors can get their needs met in the face of adversity.

Keywords

nursing; patient advocacy; neoplasm; instrument development; power

INTRODUCTION

Self-advocacy is defined as an individual's ability to get her needs and priorities met in the face of a challenge (Hagan & Donovan, 2013a). Such needs may include uncontrolled symptoms, making decisions about treatment, managing family and professional responsibilities, or any other physical, social, emotional, or situation in which a survivor's health and quality of life are challenged. A cancer survivor (defined as any individual from the time of a cancer diagnosis through the end of life) self-advocates in three separate but complementary skills of making informed, personally-meaningful decisions, communicating preferences and needs to health care providers, and balancing the receipt of support with the giving of care to others (Hagan & Donovan, 2013a). Cancer survivors who self-advocate may excel in one, two, or all three of these domains but can apply any of these skills to ensuring that they are receiving the care they need to receive quality, patient-centered cancer care. Self-advocacy is similar to concepts of self-management and patient engagement in its emphasis on autonomy and self-determination, but distinct in its focus on overcoming challenges within an illness. While self-advocacy is a well-established concept within the HIV/AIDS and disability patient populations (Brashers, Haas, & Neidig, 1999; Test, Fowler, Wood, Brewer, & Eddy, 2005), it has not received the same amount of conceptual clarity within the cancer population (Walsh-Burke & Marcusen, 1999) despite being equally needed and supported by advocacy organizations (Clark & Stovall, 1995; Shapiro et al., 2009). This lack of conceptual clarity prevents providers, patients, and researchers from being able to provide targeted, consistent support to cancer survivors who need to advocate for their needs and priorities. Therefore, we aimed to develop and evaluate the concept of self-advocacy within the context of this nascent but superficial theoretical background.

Background

Existing theories and measurements of self-advocacy from other patient populations inadequately represent the unique needs of individuals with cancer. For example, researchers administered the Patient Self-Advocacy Scale—a measurement tool developed among individuals with HIV/AIDS—to cancer survivors and found that the scale's psychometric properties largely diminished, especially among female participants (Hermensen-Kobulnicky, 2008). Part of the discontinuity between how the two patient populations

responded to the scale may relate to the distinct challenges females face while managing the psychological and physical side-effects of cancer and its treatment.

Gender differences in symptom prevalence and severity (Keogh, 2014), preferences for care delivery (Wessels et al., 2010), and communication with health care providers (Cooper-Patrick et al., 1999; Elderkin-Thompson & Waitzkin, 1999) place female patients with cancer at risk for poor health outcomes, such as increased symptom burden and health care utilization (Bertakis & Azari, 2012). For example, female patients with cancer are known to experience pain, fatigue, and depression at higher levels than male patients with cancer (Miaskowski, 2004). Yet, when communicating and negotiating with health care providers, women tend to prioritize agreement (maintaining the patient-provider relationship) and avoid discordance (questioning or demanding something from the provider), (Sheppard, Adams, Lamdan, & Taylor, 2011) potentially leading to worse outcomes such as poor symptom control and over-utilization of services. Women with cancer are also more likely than men to prefer a passive role in decision-making, which can impact the quality of care they receive (Brashers, Haas, Klinge, & Neidig, 2000; Sharma, Prigerson, Penedo, & Maciejewski, 2015). More broadly, the social cultural context within which female cancer survivors are situated impacts the ways in which they communicate, negotiate, and seek out support from the health care system, her caregivers, and her support system (Surbone & Kagawa-Signer, 2013). Without a valid, reliable measure of self-advocacy specific to the needs of female cancer survivors, clinicians and researchers are unable to assess self-advocacy among cancer survivors, and intervene for patients at risk for poor outcomes associated with low self-advocacy.

STUDY

Aim

The purpose of the current study is to evaluate the construct validity of the Female Self-Advocacy in Cancer Survivorship (FSACS) Scale in order to test the accuracy by which it can be used to make inferences about women's abilities to self-advocate.

Methodology

We completed a multi-phase instrument development process to create a measure of self-advocacy specific to female cancer survivors. Prior to the current study, we conducted a literature review (Hagan & Donovan, 2013a) and focus group study (Hagan & Donovan, 2013b) that defined the concept of self-advocacy and lived experiences of cancer survivors overcoming challenges related to their health and care. Using the initial dimensions of self-advocacy uncovered in these two studies, we developed a preliminary scale to define the behaviors of self-advocacy among female cancer survivors. Next, we conducted a content validity study with a panel of content experts to further refine the scale (Hagan, Cohen, Stone, & Donovan, 2016). Finally, we evaluated the scale's initial reliability as a necessary precursor to construct validity (Hagan et al., 2016). Combined, these studies resulted in a novel measurement model and a measure of self-advocacy for female cancer survivors that demonstrated face validity and consistency of participant responses. Our final phase of instrument development was to test the validity of the measure.

According to the American Educational Research Association (1999), establishing the construct validity of a measure is a process of developing and testing hypotheses about how the interpretation of a measure's scores should perform if it truly captures the intended construct. In the absence of a standard measure of self-advocacy specific to female cancer survivors, we used the literature and our previous research to build hypotheses about how the FSACS Scale should perform compared to valid, reliable measures currently in the literature. By constructing proposed relationships between the interpreted scores of a new measure and scores of validated measures, a researcher can build an argument that the new measure's scores accurately reflect the presence of a latent concept. We applied our previously developed measurement model illustrating how self-advocacy among women with cancer relates to potential predictors and outcomes, as well as related concepts (Figure 1) to validate the FSACS Scale.

Participants

We used a cross-sectional mixed-mode survey study design. The inclusion criteria were: (1) female, (2) invasive cancer diagnosis 18 years old, and (3) ability to read and write in English. We recruited using a mixture of random and convenience sampling from the Pennsylvania Tumor Registry, a patient registry at the University of Pittsburgh, and seven national and local advocacy organizations. We aimed to recruit a representative sample of female cancer survivors including multiple cancer types and times since diagnosis. Pennsylvania Tumor Registry is a statewide data system that collects information on all new cancer diagnoses in the state including roughly 76,000 new cases per year. We randomly selected members of the registry from a list of women diagnosed with any type of invasive cancer for 15 selected years between 1985 and 2013. We recruited a convenience sample by asking leaders of the patient registry and advocacy organizations to notify their members about the study through email, newsletters, and/or in-person meetings. Interested women contacted the principal investigator who screened potential participants and mailed online or paper-based questionnaires to all eligible participants based on their preference. Tinsley and Tinsley (1987) and Comrey's (2013) recommendations for factor analyses justify a sample of at least 300 participants.

Measures

The FSACS Scale measures the ability of female cancer survivors to get their needs, priorities, and desires met in the face of a challenge. Based on a previous content analysis and qualitative exploration of self-advocacy, we developed an initial scale that was then tested among 40 women for initial reliability and face validity. A team of psychometric and content experts met to refine the scale and delete poor-performing items based on face validity results (e.g., feedback regarding items' relevancy, clarity, and importance) and psychometric performance (e.g., internal consistency, test-retest reliability) (Hagan et al., 2016). From those findings, we derived a 57-item, 6-point Likert-type self-advocacy scale consisting of three dimensions. (1) "Application of Information" captures a woman's ability to find trustworthy information and apply it to herself. (2) "Connected Strength" refers to a woman's ability to balance her needs with the needs of others and gain strength through her relationships. (3) "Leading my Health Care" exemplifies how a woman can build productive,

respectful relationships with her health care team. Higher scores on the FSACS Scale indicate higher self-advocacy skills.

Validity and reliability

We chose valid, reliable measures to capture the hypothesized predictors, outcomes, and related concepts in the literature. Table 1 describes each construct along with its associated measure, Cronbach alphas, and scoring options. Predictors of self-advocacy included being open to new experiences and conscientiousness (International Personality Inventory Pool) (Goldberg, 1999), comfort and engagement in health information (Health Information Orientation Scale) (DuBenske, Beckjord, Hawkins, & Gustafson, 2009), and perceived availability of social support (Interpersonal Support Evaluation List) (Cohen, Mermelstein, Kamarck, & Hoberman, 1985). Outcomes of self-advocacy included symptom burden which encompasses both the severity of specific symptoms and symptom interference with life activities (MD Anderson Symptom Inventory) (Cleeland et al., 2000) and participants' self-reported health care utilization within the past three months (investigator-developed). Related concepts to self-advocacy included the Patient Activation Measures (Hibbard, Stockard, Mahoney, & Tusler, 2004) and the Patient Self-Advocacy Scale (PSAS) created among individuals with HIV/AIDS (Brashers et al., 1999). Higher scores for each respective measure indicate more pronounced attitudes and traits, self-advocacy skills, higher symptom burden, etc.

Data collection

Between July 2014 and March 2015, participants completed a set of eight valid, reliable questionnaires, the new FSACS Scale, and one investigator-developed health history questionnaire. Dillman's (2002) Tailored Design Method of administering paper and online surveys guided the design and delivery of both mailed and online questionnaires. This evidence-based process for designing and delivering surveys aims to reduce survey error and improve data quality by leveraging principles of social exchange and leverage-saliency theories that emphasize building trust, increasing perceived rewards, and limiting perceived costs of survey participation. We included refusal forms in the initial mailing to members of the Pennsylvania Tumor Registry to understand reasons for non-participation. We mailed participants paper questionnaires with a pre-addressed, pre-stamped return envelope. We emailed online questionnaires through Qualtrics, a secure web-based data management system. If participants did not return questionnaires, we sent them three reminder postcards or emails. We wrote instructions at the beginning of the paper and online questionnaires advising participants to read and sign the informed consent form prior to completing any study questionnaires. Participants completed all survey questionnaires in about 30 to 45 minutes. Participants received a \$10 gift certificate after returning the questionnaire.

Ethical considerations

We proactively addressed potential risks associated with this study including breach of confidentiality and privacy by using robust data security available through the HIPAA approved Qualtrics data management system and data management procedures among our research team members including the use of de-identified data and researcher trainings. The study was approved by our university's Institutional Review Board.

Data analysis

We developed five *a priori* hypotheses to evaluate the FSACS Scale's performance and build evidence for construct validity based on the scale's factor structure; known differences between survivors [e.g., sub-groups of survivors with various educational backgrounds and times since diagnosis who we anticipated would have dissimilar self-advocacy skills based on our previous work (Hagan & Donovan, 2013a; Hagan & Donovan, 2013b; Hagan et al., 2016); and the relationship with self-advocacy and its theoretical predictors, outcomes, related concepts. Figure 1 illustrates our self-advocacy measurement model and how the hypotheses (marked in red and described below) relate self-advocacy to its predictors, outcomes, and related concepts. For ease of readability, we provide more details for each of the five hypotheses immediately prior to reporting the results. We determined the level of evidence for construct validity based on whether or not we rejected these hypotheses. Data analyses were conducted using SPSS Version 22.

RESULTS

A total of $N=317$ adult female cancer survivors completed study questionnaires. Among the sample, participants had an average age of 58.4 (median = 59; observed range=21–95). Most participants were White ($n=281$, 89.5%), married ($n=194$, 61.8%), earned at least a bachelor's degree ($n=167$, 53.3%), and had a median household income of at least \$50,000 ($n=164$, 54.4%). Table 2 describes participant socio-demographic and health information.

A response rate was not able to be calculated for recruitment sites that privately advertised the study to their membership. Paper mailings sent to members of the Pennsylvania Tumor Registry had a response rate of 17.3%. All potential participants were given the option to refuse participation and provide general, non-identifiable demographic information that we anticipated would be related to self-advocacy including age, time since diagnosis, race, and education. Each items had 3 to 5 categorical response options (e.g., age was categorized into 18–29, 30–49, 50–69, or 70 years old; time since diagnosis was categorized into 0–1, 1–5, or >5 years; education was categorized into high school or GED, Associate's/2-year degree, Bachelor's/4-year degree, and graduate or professional degree; and race was categorized into the census categories). Women who refused to participate were significantly older (χ^2 (4, $N=411$)=94.4, $p < .001$), further from their time of diagnosis (χ^2 (2, $N=405$) = 8.5, $p = .015$), more likely to come from a racial minority (any non-White potential participant) (χ^2 (6, $N=407$) = 15.0, $p = .020$), and less educated (χ^2 (4, $N=402$) = 79.3, $p < .001$) than women who did participate in the study.

Table 1 reports descriptive statistics for all measures. We tested the assumptions for a maximum likelihood factor analysis, sub-group analyses, and planned comparisons prior to data analyses. We used estimation maximization to address missing data (8.0%) in the FSACS Scale responses. We managed skewness and kurtosis concerns on the FSACS Scale related to ceiling effects by collapsing the first two response options into the third response option (e.g., 1 and 2 into 3) resulting in four rather than six response options.

We used data from our factor analysis of the FSACS's original 57 items to select a final, parsimonious set of items. We deleted 37 items based on their individual communalities,

inter-item correlations, item-to-total correlations, factor loadings, previous input from content validity experts, and conceptual meaningfulness. We explored alternative extraction methods including forced two- and four-factor solutions, orthogonal rotation, or retention of individual poor-performing items, and these results did not result in significantly different item-total correlations, extracted factors, or explanation of variance in item responses. The Kaiser-Meyer-Olkin measure of sampling adequacy was 0.89, indicating sufficient common item variance to proceed with a factor analysis. Bartlett's test of sphericity was significant ($\chi^2(190)=2.53, p<0.001$), indicating that the correlation matrix was not an identity matrix.

Hypothesis 1: Internal Structure

We performed an Exploratory Factor Analysis using maximum likelihood method, oblique rotation because factors were assumed to be correlated, and scree plots to test if the internal structure of the FSACS Scale reflected its theoretical underpinnings. The factor analysis of the 57-item FSACS Scale resulted in a final set of 20 items with a three-factor structure broadly consistent with theoretical dimensions of self-advocacy. We renamed the final three factors to be consistent with the content and themes of the retained items within each dimension: "Application of Information" became "Being an Informed Decision Maker" (six items); "Leading My Health Care" became "Communicating with My Health Care Providers" (seven items); and "Connected Strength" remained the same (seven items).

These three factors explained 45.9% of the variance in participant responses. Factor 1 had the largest extracted sums of squared loadings (29.1%) and eigenvalue (5.8) though Factor 2 (11.2%, 2.3) and Factor 3 (5.6%, 1.1) contributed significantly as well. Table 3 shows the factor loadings for all three dimensions. We considered a factor loading of 0.4 indicative that an item was loading onto a specific factor, though our decisions were based on the totality of the item's performance. Three items on the "Communicating with My Health Care Providers" subscale closely cross-loaded onto Factor 1, and one of these items also had low factor loadings. We considered multiple strategies to account for these overlapping score variances by evaluating the scale's performance with these items deleted, moved onto Factor 1, or retained on Factor 3. We also considered the performance of these three items during our previous face validity testing, cognitive interviews, and pilot reliability study. We decided to retain these three items onto Factor 3 because they were heavily endorsed as a part of communication during our previous content validity study (Hagan et al., 2016), performed strongly during previous reliability testing, and since deleting these items did not impact the overall subscale or scale performance whereas deleting or moving these items reduced the subscales reliability and explanation of item variance.

The three factors had weak to moderately-high inter-correlations. "Being an Informed Decision Maker" correlated moderately with "Connected Strength" ($r=0.32, p<0.01$) and "Communicating with My Health Care Providers" ($r=0.56, p<0.01$). "Connected Strength" also correlated moderately with "Communicating with My Health Care Providers" ($r=0.31, p<0.01$). Based on these associations, we decided to report on FSACS subscale scores to provide a more granular understanding of how each aspect of self-advocacy relates to other constructs though a total score is appropriate for general use of the scale.

Hypothesis 2: Sensitivity to Known Groups

We tested the measure's sensitivity to detect differences between women anticipated to have varying levels of self-advocacy. We hypothesized that FSACS subscale scores would be significantly higher among (1) women with 5 years since diagnosis compared to women within one year of cancer diagnosis and (2) women with more than a bachelor's degree compared to women with a high school degree or less. We purposefully selected women on the extremes of both of these groups to detect differences between these groups. We used two-sided student t-tests to test these comparisons with a level of significance set at $\alpha = 0.05$ (used across all hypotheses). Table 4 compares FSACS subscale scores of these groups of participants. As hypothesized, women with higher levels of education scored significantly higher on all three FSACS subscales compared to women with lower levels of education. However, long-term survivors only had significantly higher scores than women within a year of cancer diagnosis on the "Being an Informed Decision Maker" subscale.

Hypothesis 3: Relationships to Key Potential Predictors and Outcomes

Concordant with our measurement model's hypotheses, FSACS subscale scores should be positively correlated to our predictors and negatively correlated to our outcomes. Bi-variate correlations were computed between FSACS Scale scores and other scale scores. Table 5 illustrates the correlations between FSACS subscale scores and those of predictors and outcomes of self-advocacy. FSACS subscale scores were positively correlated with all predictors. The only predictor that did not perform as expected was information engagement which was positively correlated with "Connected Strength" but negatively correlated with "Communicating with My Health Care Providers."

FSACS subscale scores showed mixed evidence for the hypothesized relationships with symptom burden and health care utilization. The "Being an Informed Decision Maker" subscale was negatively correlated with symptom interference only. The "Connected Strength" subscale was not related to either symptom burden subscale. The "Communicating with My Health Care Providers" subscale was negatively correlated with both symptom severity and symptom interference. For participants' self-reported health care utilization, the "Being an Informed Decision Maker" subscale was negatively correlated with having had a home health visit and was positively correlated with being hospitalized and emergency department visits in the past three months. The "Connected Strength" subscale was negatively correlated only with home health visits. The "Communicating with My Health Care Providers" subscale was positively correlated with both being hospitalized and emergency department visits.

Hypothesis 4: Concurrence with Related Concepts

Higher scores on the FSACS Scale should be positively associated with scores on the Patient Activation Measure (PAM). Subscale correlations between the FSACS Scale and the Patient Self-Advocacy Scale (PSAS) were expected to vary by subscale. Bi-variate correlations were computed between the FSACS Scale scores and those of the PAM and PSAS to evaluate concurrent validity. Table 5 reports correlations between the FSACS subscale scores and related concepts. In line with our hypothesis, patient activation scores were positively correlated with each of the FSACS subscale scores. The FSACS subscales demonstrated

similarities and differences with the subscales of the PSAS. This confirmed that the two self-advocacy scales measure distinct concepts.

Hypothesis 5: Criterion Measures

We tested criterion validity by comparing FSACS Scale scores and PSAS total scores on outcome measures. We expected that FSACS Scale scores should be more highly correlated with the outcome measures of symptom severity and interference and health care utilization than the PSAS total score. We calculated bi-variate correlations between the PSAS scores and outcome variables and compared with the strength of association between the FSACS Scale and outcomes. The FSACS subscales were more highly correlated with the outcomes of symptom burden and health care utilization than the PSAS total score (Table 5). The PSAS scores were only related (positively) to hospitalizations in the past three months.

DISCUSSION

Results of our five *a priori* hypotheses largely provided evidence for using the FSACS Scale as a measure of self-advocacy while also pointing to areas for future investigation. The internal structure of the FSACS Scale was consistent with the theoretical underpinnings of self-advocacy among female cancer survivors and provided a parsimonious set of 20 items tapping into three distinct dimensions of self-advocacy specific to a female oncology population. In this model, women's self-advocacy is defined as a woman (1) preparing and making informed health care decisions consistent with her priorities; (2) finding strength through mutually supporting and being supported by other cancer survivors, friends, and family; and (3) openly and confidently communicating her concerns, problems, and confusions with her health care providers and working with them to find solutions. While the first two subscales performed strongly during factor analysis testing, the communication subscale requires further investigation to refine the items and verify the meaning and extent of how effective communication with health care providers relates to a woman's self-advocacy ability.

The FSACS Scale adeptly detected differences between women with high and low levels of education. The minimal difference between women at different times since diagnosis may reflect the long-term survivors' distance from the health-related problems or the paucity of recently diagnosed women in the sample. If women further from diagnosis and treatment experience fewer challenges related to being a cancer survivor, then their need for self-advocacy may naturally decrease over time. The lack of difference may also reflect the current lack of training in self-advocacy skills for cancer survivors. Given that both informed decision making and communication are amenable to intervention (Au et al., 2012; Meropol et al., 2013); self-advocacy may also be a modifiable variable if directly targeted by an intervention.

The FSACS subscale scores largely performed as expected with the potential predictors of self-advocacy. While the association between health information orientation and "Connected Strength" was expected, the inverse relationship with communication with health care providers was unexpected. This may reflect a tendency for cancer survivors who have strong communication with their providers to view providers as their most trusted source of health

information and therefore reduce their need to actively seek outside sources of health information (Chawla & Aurora, 2013; Mazor *et al.*, 2013).

Several hypothesized outcomes were associated with “Being an Informed Decision Maker” and “Communicating with My Health Care Providers.” The higher a woman’s score on these self-advocacy subscales, the less likely her symptoms were to interfere with her life. A woman who discusses her symptoms with her health care provider may be more likely to receive effective recommendations on how to treat them. Surprisingly, higher self-advocacy scores on these same two dimensions were positively correlated with hospitalizations and emergency department visits. This unexpected finding could be because a woman (1) is engaged in making health decisions and communicates openly so refers herself or receives a referral from her health care providers to go to a hospital or emergency department or (2) has several medical problems that cause her to have hospital admissions and emergency department visits which then necessitate decision-making and communication with her health care providers. Unfortunately, there is no way to determine whether a woman’s health care utilization was appropriate or not. Therefore, it remains unclear whether self-advocacy is associated with a woman’s ability to seek and obtain medical attention when such attention is prudent.

Limitations

Limitations to this study are consistent with those of most survey studies. We were unable to verify self-reported disease and treatment information, and our response rate from the tumor registry was low though we successfully recruited individuals from advocacy organizations. Since we were unable to compare our measure to a gold standard, we conducted tests of associations to evaluate the bivariate relationships of constructs within our measurement model; based on these findings we will conduct more powerful model testing in the future that includes longitudinal assessment of predictors and outcomes of self-advocacy. In accordance with principles of instrument development, the sample in this study was purposefully broad in order to capture the full breadth of self-advocacy and be generalizable to all adult female cancer survivors. Future research explicitly will explore variations in self-advocacy among women who are likely to face greater challenges during their cancer experience including women with advanced cancers, recurrences, lower levels of education, financial problems, and from countries that do not share Western assumptions of autonomy, female gender, and self-determination. Additionally, future research should focus on refining the communication subscale to clearly capture how cancer survivors get their needs met through communicating with their health care providers. We will continue to test and validate the FSACS Scale and measurement model with especially as we apply it to male cancer survivors and diverse cultures with different gender norms and health care systems (Bryzski, Kozka, Squires & Brzostek, 2016; McGorry, 2000).

CONCLUSION

The FSACS Scale is a psychometrically-sound measure of self-advocacy among female cancer survivors. In an environment in which patient-reported outcomes and patient-centered care require precise measurement, the FSACS Scale captures a critical construct like patient

self-advocacy. As the first psychometric analysis of a measure of self-advocacy tailored to female cancer survivors, additional testing of the FSACS Scale will continue to refine the model and find targets for intervention. We will also use this measure to assess if a new intervention improves survivors' self-advocacy abilities and leads to improved symptom burden and health care utilization. This measure will assist clinicians and researchers in being able to support women ill-equipped to address their problems, needs, and wants throughout their cancer experience.

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Summary Statement

1. Why is this research or review needed?

- Currently, no scale for patient self-advocacy exists for cancer survivors (i.e., anyone with a history of a cancer diagnosis).
- Based on our previous qualitative research findings, a review of the literature, and a content validity study of our preliminary scale, we created a theoretically-based scale of self-advocacy for female cancer survivors in addition to a measurement model relating self-advocacy to its predictors, moderators, and outcomes.
- Women with cancer self-advocate in specific ways both due to gender differences in communication, negotiation, and specific unmet needs they have related to their care.

2. What are the key findings?

- Our evaluation of five *a priori* hypotheses about how the Female Self-Advocacy in Cancer Survivorship Scale should function if it captures the construct of patient self-advocacy showed that the scale demonstrated sufficient construct validity and reliability evidence to be considered psychometrically strong.
- The scale's three dimensions of Being an Informed Decision Maker, Connected Strength, and Communicating with My Health Care Team are unique and complementary sub-scales within self-advocacy.

3. How should the findings be used to influence policy/practice/research/education?

- This scale can be used to assess a woman's ability to stand up for herself in the face of a challenge.
- Our measurement model of self-advocacy in which self-advocacy is positively related to improved symptom burden and appropriate use of health care services indicates that women who struggle to self-advocate may require additional assistance in managing their symptoms and navigating the health care system.
- While we will conduct additional analyses and testing to continue to refine the scale, the construct of self-advocacy among female cancer survivors is robust enough to begin developing theoretically-consistent programs to address the needs of women who struggle to self-advocate.

FEMALE SELF-ADVOCACY SCALE

Figure 1.
Measurement model of the Female Self-Advocacy in Cancer Survivorship Scale with hypotheses for construct validity testing

Table 1
Background and Descriptive Statistics of Self-Advocacy, Predictor, and Outcome Variables and Related Concepts ($N=317$)

Construct (possible score range)	Measure	Cronbach's α	Mean	SD	n	%
<i>Self-Advocacy Subscales*</i>						
Being an Informed Decision Maker (6–36)	FSACS Scale	0.82	34.57	4.67		
Connected Strength (7–42)	FSACS Scale	0.85	33.13	5.95		
Communicating with My Health Care Providers (7–42)	FSACS Scale	0.79	29.84	4.41		
<i>Predictor Variables**</i>						
Openness and conscientiousness (20–100)	International Personality Inventory Pool	0.81–0.82	76.51	9.63		
Information engagement (0–32)	Health Information Orientation Scale	0.65	23.57	4.19		
Perceived availability of social support (12–48)	Interpersonal Support Evaluation List	0.31–0.81	43.44	5.64		
<i>Outcome Variables</i>						
Symptom severity (0–130)	MD Anderson Symptom Inventory	0.85	11.92	16.86		
Symptom interference (0–60)	Investigator-developed	0.91	5.02	9.99		
Health care utilization in past 3 months	Hospital admissions	n/a			39	12.5%
	Emergency Department visits	n/a			36	11.5%
	Primary care provider visits	n/a			188	59.9%
	Home care visits	n/a			13	4.2%
<i>Related Concepts</i>						
Patient activation (13–52)	Patient Activation Measure	0.91	43.61	6.23		
Patient self-advocacy (12–60)	Patient Self-Advocacy Scale	0.60–0.82	43.33	5.00		

FSACS: Female Self-Advocacy in Cancer Survivorship

* Subscales are reported because the lack of scale unidimensionality prohibits the use of a total scale score.

** Items from the demographic and disease characteristics questionnaires were also included within our measurement model as predictors of self-advocacy. Because these questionnaires contain categorical items, we did not report total scale statistics here. See Table 2 for detailed information regarding descriptive statistics for these scales' items.

Table 2

Sample Demographics

	n	%
Age (Mean, Standard deviation)	58.4	13.4
Cancer Type		
<i>Breast</i>	149	46.9
<i>Ovarian</i>	69	21.7
<i>Thyroid</i>	21	6.7
<i>Lymphoma</i>	18	5.7
<i>Endometrial</i>	18	5.7
<i>Other</i>	42	13.2
Stage at Diagnosis		
<i>Pre-cancer or DCIS</i>	19	6.0
<i>Stage I</i>	87	27.5
<i>Stage II</i>	66	20.9
<i>Stage III</i>	56	17.7
<i>Stage IV</i>	29	9.2
<i>Unknown</i>	19	6.0
<i>Not sure</i>	40	12.7
Time Since Cancer Diagnosis		
<i>< 1 year</i>	63	20.1
<i>1–5 years</i>	109	34.7
<i>> 5 years</i>	142	45.2
Highest Degree Earned		
<i>Less than high school</i>	2	0.6
<i>High school</i>	71	22.7
<i>Associates</i>	72	23.0
<i>Bachelor's</i>	83	26.5
<i>More than Bachelor's</i>	84	26.8
Household Annual Income		
<i>< \$20,000</i>	34	11.3
<i>\$20–49,999</i>	65	21.6
<i>\$50–79,999</i>	70	23.2
<i>\$80–150,000</i>	74	24.6
<i>> \$150,000</i>	20	6.6
<i>Unknown/decline</i>	35	11.6
Marital Status		
<i>Currently married</i>	194	61.8
<i>Separate/Divorced</i>	42	13.4
<i>Never married</i>	31	9.9
<i>Living with partner/significant other</i>	22	7.0
<i>Widowed</i>	22	7.0

	n	%
<i>Other</i>	3	1.0
Race		
<i>White</i>	281	89.5
<i>African American/Black</i>	25	8.0
<i>American Indian/Alaska Native</i>	2	0.6
<i>Asian</i>	3	1.0
<i>Other</i>	3	1.0
Ethnicity		
<i>Hispanic or Latino</i>	7	2.2
Types of Health Insurance		
<i>Private</i>	243	76.4
<i>Medicare</i>	122	38.4
<i>Medicaid</i>	25	7.9
<i>Disability</i>	14	4.4
<i>Other</i>	30	9.5

Table 3

Hypothesis 1: Communalities, Factor Loadings, and Reliability Statistics of FSACS Scale Items and Factors with Oblique Rotation

	Communality	Factor 1	Factor 2	Factor 3
<i>Being an Informed Decision Maker</i> ($\alpha = 0.82$; $r = 0.98^{**}$) (Variance explained = 29.1%)				
I gather information before making decisions about my cancer care.	0.57	0.82	-0.04	-0.13
I weigh my options carefully before making important decisions about my cancer care.	0.65	0.79	0.04	0.00
I prepare myself to make decisions about my cancer care	0.58	0.77	-0.06	0.02
I use my skills to solve the problems I face as a cancer survivor.	0.42	0.64	0.15	-0.13
When it comes to making decisions about my cancer care, I know what my priorities are.	0.45	0.63	-0.07	0.12
I am comfortable asking for a second opinion.	0.25	0.44	0.03	0.09
I know where to get an answer if my provider can't give me one.	0.16	0.39	0.05	-0.03
<i>Connected Strength</i> ($\alpha = 0.85$; $r = 0.89^{**}$) (Variance explained = 11.2%)				
I try to raise awareness about cancer.	0.56	-0.05	0.76	0.02
Helping other cancer survivors also helps me.	0.60	0.14	0.72	-0.02
Telling other people my story makes me feel good.	0.51	-0.15	0.72	0.10
I seek out support from other cancer survivors.	0.45	0.17	0.65	-0.20
I am comfortable sharing my cancer experience with others.	0.49	-0.17	0.64	0.26
When I hear that someone has cancer, I try to reach out to them.	0.40	0.02	0.63	-0.03
It helps me to know that other cancer survivors have gone through what I am going through.	0.34	0.10	0.57	-0.10
<i>Communicating with My Health Care Providers</i> ($\alpha = 0.79$; $r = 0.98^{**}$) (Variance explained = 5.6%)				
I don't talk about a health concern with my provider unless I think there is a solution. ^R	0.57	-0.07	-0.03	0.80
I rarely tell my provider about problems I am having related to cancer. ^R	0.55	-0.04	0.05	0.74
I have a hard time voicing my preferences to my provider. ^R	0.35	0.18	-0.05	0.50
I question my provider if I don't agree with his or her recommendations.	0.30	0.41	-0.10	0.25
I ask my provider to explain his or her recommendations.	0.52	0.40	0.09	0.39
I ask questions when I don't understand what my provider is telling me.	0.48	0.42	0.00	0.38

FSACS: Female Self-Advocacy in Cancer Survivorship

Primary factor loadings for each item are indicated in **bold** text.

Reliability statistics are in parentheses following each dimension's name. The scale's total internal consistency was $\alpha = 0.87$ and its total Pearson Product Moment Correlation was $r = 0.93^{**}$.

* indicates correlation is significant at a level below $p = 0.01$

** indicates correlation is significant at a level below $p = 0.001$

^R = Reverse-scored item

Table 4

Hypothesis 2: FSACS Scale Sensitivity to Differences between Individuals with Varying Times since Diagnosis and Educational Levels

	Being an Informed Decision Maker		Connected Strength		Communicating with My Health Care Providers	
	M (SD)	t (p-value)	M (SD)	t (p-value)	M (SD)	t (p-value)
<i>Time since Diagnosis</i>						
Within 1 year (<i>n</i> = 63)	33.21 (5.85)	-2.15 (0.03) *	32.76 (5.98)	-1.01 (0.31)	29.27 (5.33)	-1.06 (0.29)
Greater than 5 years (<i>n</i> = 142)	34.75 (4.20)		33.65 (5.76)		29.99 (4.06)	
<i>Highest Level of Education</i>						
High school or less (<i>n</i> = 72)	33.32 (4.19)	-4.27 (<.001) **	32.89 (5.89)	-0.89 (0.38)	28.37 (4.62)	-4.28 (<.001) **
More than a bachelor's degree (<i>n</i> = 83)	36.01 (3.73)		33.76 (6.41)		31.23 (3.73)	

FSACS: Female Self-Advocacy in Cancer Survivorship

* *p* 0.05 two-tailed significance** *p* 0.01 two-tailed significance

Table 5

Hypotheses 3, 4, and 5: FSACS Subscale and PSAS Correlations with Predictor and Outcome Variables and Related Concepts

	Being an Informed Decision Maker	Connected Strength	Communicating with My Health Care Providers	Patient Self-Advocacy Scale
<i>Predictor Variables</i>				
Openness and conscientiousness	0.46 **	0.24 **	0.44 **	
Information engagement	0.06	0.13 *	-0.13 *	
Social support	0.24 **	0.19 **	0.23 **	
<i>Outcome Variables</i>				
Symptom severity	-0.08	0.03	-0.14 *	-0.10
Symptom interference	-0.17 **	-0.05	-0.27 **	-0.03
Hospital admissions	0.20 **	0.03	0.13 *	0.16 **
Emergency Department visits	0.15 **	-0.06	0.12 *	-0.01
Primary care visits	0.01	0.03	-0.12	0.08
Home health visits	-0.15 **	-0.15 **	-0.09	0.04
<i>Related Concepts</i>				
Patient self-advocacy	0.50 **	0.24 **	0.34 **	
Patient activation	0.54 **	0.26 **	0.49 **	

FSACS: Female Self-Advocacy in Cancer Survivorship

PSAS: Patient Self-advocacy Scale

* p 0.05 two-tailed significance

** p 0.01 two-tailed significance