Published in final edited form as:

Clin J Oncol Nurs. 2018 February 01; 22(1): E23–E30. doi:10.1188/18.CJON.E23-E30.

Exploring the Relationships Between Patient Self-Advocacy and Cancer Symptom Burden

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Abstract

Background—Self-advocacy refers to a patient's ability to get his or her needs met in the face of a challenge. While patient self-advocacy is a critical component of patient-centered care, the association between self-advocacy and symptom burden has received little attention.

Objectives—In this cross-sectional descriptive secondary analysis, we evaluated the degree to which self-advocacy is associated with symptom burden among adult female patients with a history of cancer.

Methods—Participants (N=179) recruited from cancer clinics and advocacy groups completed online or paper questionnaires. We used descriptive statistics and ordinary least squares regression models to analyze the association between the three dimensions of self-advocacy (Female Self-Advocacy in Cancer Survivorship Scale) and two dimensions of symptom burden: symptom severity and interference (MDASI).

Findings—Participants reported moderate levels of symptom burden with fatigue (M=2.98; SD=2.41), disturbed sleep (M=2.59; SD=2.51), memory problems (M=2.24; SD=2.45) being the most common symptoms. Informed Decision Making was positively associated with symptom burden both when considering participant's total symptom burden ($\beta=0.19$, $p=0.04$) and participants' burden across her three most severe symptoms ($\beta=0.18$, $p=0.04$). Effective Communication was negatively associated with participants' total symptom burden ($\beta=-0.25$, $p=0.006$) and the degree to which symptoms interfered with their daily life ($\beta=-0.33$, $p=0.01$).

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Conflicts of Interest:

The authors declare no conflicts of interest.

Background

Healthcare organizations have placed increasing emphasis on promoting patients' abilities to advocate for their health care needs and priorities, and cancer care is no exception (Shapiro et al., 2009). Self-advocacy, generally defined as the ability of someone with cancer to ensure their needs are met in the face of a challenge, is a foundational skill that can help an individual achieve improved health outcomes and quality of life (Walshe-Burke & Marcusen, 1999). Oncology nurses, as patient advocates and experts in symptom management (Oncology Nursing Society, 2016), must understand how the ability of patients to self-advocate relates to their ability to manage their cancer- and treatment-related symptoms. While the concept of self-advocacy originated within the disability and HIV/AIDS populations (Test, Fowler, Wood, Brewer, & Eddy, 2005; Brashers, Haas, Neidig, & Rintamaki, 2002), the language of self-advocacy was broadly accepted by the oncology community though without a unique conceptualization (Hermansen-Kobulnicky, 2008). To provide conceptual clarity to what self-advocacy means for patients with cancer, we conducted a content analysis and discovered that self-advocacy is a behavioral skill that equips individuals with the ability to actively engage in behaviors that support their autonomy and improve their quality of life (source deleted for blinded review). Our research team previously defined the unique ways in which women with cancer advocate for themselves when faced with a challenging situation (source deleted for blinded review). Self-advocacy for female cancer survivors, consists of three primary ways in which they get their needs met in the face of challenge: making informed decisions, balancing personal needs with others' needs, and effectively communicating with members of the healthcare team (source deleted for blinded review).

Adult women with cancer experience high levels of symptom burden both during and after treatment for their cancer (Cheng, Wong, & Koh, 2016; Cheng, Le, Gagliese, & Zimmerman, 2011; Falk et al., 2016). Cancer-related symptoms can persist years after treatment has ended and impact individual's functional ability and quality of life (Huang et al., 2016; Ness et al., 2013). A recent review article of cancer survivors estimated that a third of cancer survivors continue to experience symptoms after their treatment ended with little reduction in severity (Wu & Harden, 2016). Symptom burden is a key area in which women with cancer can self-advocate and a key feature of oncology nursing care. If women are able to apply the skills of self-advocacy to their symptom burden needs, then they may be able to pro-actively manage their symptoms by receiving evidence-based care from their healthcare team and learning how to self-manage their symptoms.

Based on our previous research, Figure 1 illustrates the potential associations between predictors, moderators/covariates, and outcomes of self-advocacy that were uncovered by our team's content analysis (source deleted for blinded review). This model proposes that high levels of the three dimensions of self-advocacy on the Female Self-Advocacy in Cancer Survivorship (FSACS) Scale lead to improvements in symptom burden and healthcare utilization, though this relationship is moderated by patients' demographics (i.e., age, education, income, insurance status) and health history (e.g., type of cancer, years since diagnosis, treatment status). To date, this model has not been tested, in particular the ways in which the three self-advocacy dimensions relate to symptom burden.

The purpose of this exploratory study was to evaluate whether the different subscales scores of self-advocacy were associated with symptom burden scores among adult female cancer survivors. We hypothesized that higher scores on the three self-advocacy subscales would be associated with lower symptom burden.

Methods

Sample

This is a secondary analysis of data from the Self-Advocacy Study, a cross-sectional psychometric survey study of the FSACS Scale (source deleted for blinded review). Eligibility criteria for the parent study ($N=318$) included: female survivors of an invasive (e.g., not in situ or cervical intraepithelial neoplasia) cancer after the age of 18; and the ability to read and write in English. We did not limit the time since the woman's cancer diagnosis in order to capture the breadth of survivors' experiences. We recruited women from July 2014 to March 2015 using a mixture of (a) random sampling from the Pennsylvania tumor registry including women diagnosed with cancer from 1985–2013 and (b) convenience sampling from a patient registry and seven local and national advocacy organizations. We recruited from various sources in an attempt to recruit a diverse sample of women based on their type of cancer, geographic area, racial and ethnic and background, and socioeconomic status. Informed consent was obtained from all participants prior to survey administration. Each participant completed a web- or paper-based questionnaire packet (based on participant preference) including a battery of patient-reported outcomes. For this analysis, we only wanted to capture the symptom burden of participants experiencing any symptoms and therefore excluded participants ($n=139$) who reported having no symptoms (e.g., scoring 0 on all thirteen symptom items) resulting in a final sample of $N=179$. Participants received a \$10 gift certificate after completing all surveys. The University of Pittsburgh Institutional Review Board approved this study.

Measures

Self-Advocacy (Predictor)—The FSACS Scale is an assessment of how female cancer survivors advocate for their needs and priorities in the face of a challenge (source deleted for blinded review). Table 1 lists the general item topics within each sub-scale. This multidimensional scale is comprised of three distinct, complementary domains of patient self-advocacy: (a) making informed decisions about her healthcare based on information that is relevant and trustworthy (Informed Decision Making), (b) gaining strength by both giving and receiving support to her family and friends (Connected Strength), and (c) communicating effectively with her healthcare team (Effective Communication). The conceptual model of self-advocacy proposes that if a woman with cancer develops skills in any of these dimensions, she will be more likely to ensure that her needs are met (source deleted for blinded review) (e.g., the need of managing her cancer- and treatment-related symptoms).

The FSACS Scale is a 20-item Likert-type self-report survey in which higher scores indicate that patients have greater abilities to self-advocate. The scale's psychometric properties are strong with subscales' Cronbach's α ranging from 0.79 to 0.85 and strong evidence for

validity (source deleted for blinded review). Given that the three subscales assess complementary yet distinct constructs, we used individual subscale total scores in all analyses.

Symptom Burden (Outcome)—The MD Anderson Symptom Inventory (MDASI) consists of two subscales measuring the severity of 13 common cancer- and treatment-related symptoms (symptom severity) and the extent to which those symptoms interfere with different activities in an individual's life (symptom interference) (publicly available at <http://bit.ly/2neomqm>). The severity subscale asks participants to rate the severity of each symptom within the past 24 hours on an 11-point scale where 0 = “not present” and 10 = “as bad as you can imagine.” The interference subscale asks participants to report how their symptoms interfered with six different life activities over the past 24 hours on an 11-point subscale where 0 = “did not interfere” and 10 = “interfered completely.” The MDASI is a widely-used with excellent psychometric properties (Aktas, Walsh, & Kirkova, 2015) within heterogeneous cancer populations with strong reliability (Cronbach's α 's = 0.91–0.94) and validity properties (Cleeland et al., 2000).

Taking into account the heterogeneity of symptoms women experienced, we evaluated the symptom severity subscale in two different ways. First, we computed participants' mean scores across all 13 symptoms included on the MDASI. Second, we selected the top three symptoms that participants reported as being most severe and calculated the mean symptom severity scores for just the top three most severe symptoms. For the symptom interference subscale, we calculated participants' mean interference scores across the six interference items.

Socio-demographic and Health History Information—We measured participants' socio-demographic characteristics using the revised Center for Research in Chronic Disease socio-demographic form (Sereika & Engberg, 2006). We captured health characteristics using an investigator-developed health questionnaire including cancer stage at diagnosis and years since diagnosis.

Statistical Analysis

After ensuring that all data met test assumptions, we conducted our analyses. To address our primary aim, we performed a stepwise multiple regression analysis to test the association between the self-advocacy subscales and the two symptom burden subscales. We conducted separate models for the symptom severity (both for mean severity across all symptoms and mean severity for participants' top three symptoms) and symptom interference outcomes. Regression models were adjusted for age, highest educational level, years since diagnosis, and cancer stage at diagnosis because these variables were shown to correlate with self-advocacy in our previous research (source deleted for blinded review) as well as symptom burden (Cataldo et al., 2013; Mao et al., 2007). We performed all analyses using SPSS® (Version 23) statistical software.

Results

Descriptive statistics for the sample are reported in Table 2. Participants ($N = 179$) had a mean age of 59 years ($SD = 13.5$; Observed range: 21 to 88 years). Most participants were married (65.2%), self-identified as White (88.8%), and had private healthcare insurance (48.6%). While more than half (60.9%) of all participants had a breast or ovarian cancer diagnosis, women reported over 20 different cancer diagnoses. Many participants (42.9%) were more than five years out from their initial cancer diagnosis. These estimates are similar to the larger population of female cancer survivors in western Pennsylvania and the U.S. (Siegal, Miller, & Jemal, 2015). Participants reported a variety of educational and income levels.

Descriptive statistics for self-advocacy and symptom burden are reported in Table 3. The self-advocacy scale's three dimensions demonstrated sufficient variability in scores. These subscales had low to moderate inter-correlations with Pearson correlations ranging from 0.29 to 0.49. Across all symptoms, the five most severe symptoms reported by women in order of decreasing severity included fatigue ($M = 2.98$; $SD = 2.41$), disturbed sleep ($M = 2.59$; $SD = 2.51$), memory problems ($M = 2.24$; $SD = 2.45$), drowsiness ($M = 2.04$; $SD = 2.35$), and depression ($M = 1.78$; $SD = 2.33$). Women reported that their symptoms interfered most with their work ($M = 1.66$; $SD = 2.41$), walking ($M = 1.48$; $SD = 2.38$), and enjoyment with life ($M = 1.41$; $SD = 2.34$). For their self-selected top three most severe symptoms, participants reported mild symptom severity ($M = 3.96$; $SD = 2.12$) and symptom interference ($M = 2.49$; $SD = 2.06$).

Symptom Burden and Self-Advocacy

The three subscales of self-advocacy demonstrated low correlations with the two subscales of symptom burden (Table 4). Informed Decision Making and Connected Strength did not demonstrate any significant associations. Effective Communication was negatively associated with symptom severity across all symptoms ($r = -0.18$, $p < 0.02$) (but not for the top three symptoms) and symptom interference ($r = -0.33$, $p < 0.001$). Table 5 reports the stepwise multiple regression results describing the association between symptom burden and self-advocacy which are reported below.

Symptom Severity—For the model considering all 13 symptoms, the self-advocacy subscales and covariates significantly explained 11% of the variance in symptom severity scores ($R^2 = 0.11$, $F(6, 167) = 3.44$, $p = 0.003$). In this model, the Informed Decision Making ($\beta = 0.19$, $p = 0.04$) and Effective Communication ($\beta = -0.25$, $p = 0.006$) subscales demonstrated significant associations with symptom severity. The higher a woman's ability to gather and apply health information to her illness, the more severe her symptoms were. Women who had a higher ability to communicate with their providers reported less severe her symptoms. The model considering only the top three symptoms explained 8% of the variance in symptom severity scores ($R^2 = 0.08$, $F(6, 167) = 3.44$, $p = 0.003$). In this model, the Informed Decision Making subscale demonstrated a significant association with symptom severity ($\beta = 0.18$, $p = 0.04$). Lower levels of education were associated with higher symptom severity in both models.

Symptom Interference—For the MDASI symptom interference subscale, the regression model explained 20% of the variance in how symptoms interfered with women's lives ($R^2 = 0.20$, $F(6, 168) = 3.77$, $p = 0.002$). Effective Communication was the only self-advocacy subscale significantly associated with symptom interference ($\beta = -0.33$, $p = 0.005$).

Specifically, the more a woman was able to communicate her needs and priorities to her provider, the less the symptoms she was experiencing interfered with her life. None of the moderators (age, years since diagnosis, cancer stage at diagnosis, and highest educational level) were independently associated with symptom interference.

Discussion

Women in our sample reported moderate rates of both symptom severity and interference. The most prevalent symptoms included fatigue, disturbed sleep, memory problems, and depression which are consistent with other studies describing the most common symptoms reported by cancer survivors (Huang et al., 2016). Our regression analyses demonstrated that specific subscales of self-advocacy significantly related to each symptom burden subscale. In particular, a woman's ability to make informed decisions about her health was associated with higher symptom severity, and her ability to communicate effectively with her healthcare team was associated with lower symptom severity and interference. The Connected Strength subscale did not independently associate with either symptom burden subscale.

The positive association between informed decision making and symptom severity contradicted our hypothesis and suggests that women who are comfortable gathering and applying health information to their cancer experience may also be acutely aware of their cancer-and treatment-related symptoms. Alternatively, these findings may also reflect that women who experience a high number of symptoms may be more likely to gather and apply health information. However, higher levels of education were associated with lower symptom severity. Therefore, while a woman's level of education may broadly indicate her socioeconomic status and access to healthcare resources, her ability to engage in informed decision making may specifically relate to how she addresses concerns regarding her body (e.g., symptoms, side effects, reactions to cancer and treatment).

The negative association between effective communication and symptom severity only existed when considering all 13 symptoms and not for a woman's three most severe symptoms. Moreover, effective communication strongly negatively associated with symptom interference. These findings suggest that a woman who can openly and thoughtfully discuss her concerns with her providers may receive relevant, useful information that may help her address her symptoms. The results highlight the need for cancer survivors to engage in high-quality communication regarding symptom management with their healthcare team (Donovan, Hartenbach, & Method, 2005; Street, Makoul, Arora, & Epstein, 2009), especially since the most severe symptoms were also symptoms that are notoriously difficult to treat (e.g., fatigue, drowsiness, and memory problems).

While being a self-advocate may raise patients' awareness of symptoms, it may equip patients with skills like communication that enable them to address those concerns. Dong and colleagues (2016) found similar connections between self-advocacy and the experience

of multiple symptoms among patients with cancer. In this qualitative study, patients described how cancer- and treatment-related symptoms impinged on their abilities to remain autonomous and independent, therefore requiring patients to self-advocate. This finding helps clarify the positive relationship we found between symptom severity and informed decision making. This suggests that the relationship between self-advocacy and symptoms we present in Figure 1 may be bidirectional, implying that self-advocacy skills develop in response to high symptom burden, which

Clinical oncology nurses can use these findings while providing care for patients with cancer. Nurses can assess (1) if their patients are able to actively engage in decision-making about their healthcare and (2) their level of comfort discussing their concerns with their healthcare providers. If patients struggle in these respects, then the nurse should pay special attention to their symptom management needs. Even if patients engage in decision-making and are educated, this does not mean they are able to manage their symptoms effectively. Oncology nurses can support their patients in learning how to engage in open communication, thus providing them with skills they can use in addressing their symptoms. While it was surprising that our results showed decision-making related to higher symptom burden, nurses can help their patients apply their decision-making skills to directly addressing their symptom management needs and ensure they are effective at improving their symptoms.

Limitations to this analysis include the cross-sectional nature of the study including the self-reported symptom burden measure. Symptom burden was assessed in the “past 24 hours,” and we do not know if the symptoms participants reported were directly related to their cancer or another illness. Since we are interested in the association between self-advocacy and symptom burden, the etiology of the symptoms may not matter as much as the woman’s ability to actively manage those symptoms. We did not assess participants’ co-morbidities. Finally, our sample included women who were both recently diagnosed with cancer as well as those who are long-term survivors and included patients diagnosed with any type of invasive cancer. Our sample did not include patients with diverse cultural, social, and religious backgrounds that likely impact women’s experiences of self-advocacy (e.g., poverty, under- or uninsured populations, cultural norms that place less emphasis individualism). While such heterogeneity may reduce the specificity of our results, it does provide an inclusive review of symptom burden which has yet to be investigated among women with cancer.

In conclusion, this study demonstrates that two of the three dimensions of self-advocacy (Informed Decision Making and Effective Communication) are associated with symptom severity and interference among adult female cancer survivors. Prospective studies are needed to reveal the temporal relationship between self-advocacy and symptom burden at different stages of the cancer experience.

Acknowledgments

Funding:

Teresa Hagan was supported by a Doctoral Degree Scholarship in Cancer Nursing, DSCN-14-077-01-SCN from the American Cancer Society. This study was also supported by the National Institute of Nursing Research/National Institute of Health F31NR014066 (Hagan).

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Figure 1. Model of patient self-advocacy among female cancer survivors

Table 1**Female Self-Advocacy in Cancer Survivorship Scale Summary**

Sub-Scale	Item Topics
Informed Decision Making	<ul style="list-style-type: none"> • Using skills to solve cancer-related problems • Gather information about healthcare • Weighing options before making decision • Prepare to make a decision • Knowing my priorities • Comfortable asking for second opinion • Knowing where to get an answer for a question
Connected Strength	<ul style="list-style-type: none"> • Ask questions if I don't understand something • Question providers if I don't agree with their recommendations • Don't discuss problem unless there is a solution • Don't share problems with provider • Difficult to share my opinion with provider • Ask providers to explain their recommendations
Effective Communication	<ul style="list-style-type: none"> • Seek support from other cancer survivors • Helping others with cancer helps me • Reaching out to others with cancer • Helps knowing others have gone through what I am going through • Telling my story makes me feel good • Raise awareness about cancer • Comfortable sharing my story

Table 2

Sample Characteristics

Characteristic	Total N = 179	
	n	%
<i>Socio-demographic Characteristics</i>		
Age		
20–39 years	17	9.5
40–59 years	78	43.6
60–79 years	70	39.1
80+ years	14	7.8
Relationship status		
Married or living with partner	116	65.2
Not married or living with partner	62	34.8
Highest educational level		
High school diploma or less	47	26.7
Vocational or 2-year degree	50	28.4
Bachelor's degree	44	25.0
Some graduate school or more	35	19.9
Race		
White	159	88.8
Black	14	7.8
Other	6	3.4
Healthcare insurance		
Private only	87	48.6
Private and Medicare	27	15.1
Social Security Income, Veteran's Administration, or Disability	43	24.0
Medicare or Medicaid	22	15.7
Household annual income		
<\$20,000	17	9.5
\$20,000–49,000	35	19.6
\$50,000–79,000	46	25.7
\$80,000–149,000	37	20.7
\$150,000	8	4.5
<i>Health History Characteristics</i>		
Type of cancer ^a		
Breast	74	41.3
Ovarian	35	19.6
Other	70	39.1
Time since cancer diagnosis		
< 1 year	40	22.6
1 – 5 years	61	34.5

Characteristic	Total <i>N</i> = 179	
	<i>n</i>	%
5 years	76	42.9

^aOther types of cancer include thyroid, endometrial, lymphoma, colorectal, cervical, melanoma, uterine, bladder, kidney, liver, vaginal, brain, leukemia, stomach, pancreatic, spleen, and 13 other cancer types.

N: Number of patients in the total sample

n: Number of patients who have a specific characteristic

%: Percent of patients who have a specific characteristic out of the total sample

Table 3

Outcome Descriptive Statistics

Variable (Range of possible scores)	Mean	Standard Deviation
<i>Self-Advocacy (Predictor)</i>		
Informed Decision Making (7 – 42)	34.04	4.75
Connected Strength (7 – 42)	32.98	5.94
Effective Communication (6 – 36)	29.66	4.42
<i>Symptom Burden (Outcome)</i>		
Symptom Severity: mean across all symptoms (0–10)	1.59	1.38
Symptom Severity: mean for patients' 3 most severe symptoms (0–10) severe symptoms (0–10)	3.96	2.12
Symptom Interference: mean across all items (0–10)	1.37	1.97

Table 4

Bivariate Pearson Correlations between Self-Advocacy and Symptom Burden

Self-Advocacy Subscales	Symptom Burden Subscales					
	Symptom Severity (all symptoms)		Symptom Severity (top 3 symptoms)		Symptom Interference	
	<i>Pearson r</i>	<i>p-value</i>	<i>Pearson r</i>	<i>p-value</i>	<i>Pearson r</i>	<i>p-value</i>
Informed Decision Making	0.021	0.784	0.070	0.354	-0.129	0.208
Connected Strength	0.078	0.307	0.062	0.407	-0.087	0.396
Effective Communication	-0.180	0.017*	-0.077	0.303	-0.330	<0.001**

Pearson *r*: Indicates the linear relationship between two variables. The closer this value is to 1.0, the stronger the relationship.

Tests of significance:

* *p* 0.05 (5% chance that finding is due to chance)

** *p* 0.01 (1% chance that finding is due to chance)

Table 5

Standardized Beta Coefficients from Linear Regression Describing Relationship Between Symptom Burden and Self-Advocacy

	Standardized Beta Coefficient β	Standard Error	Test of significance <i>p</i> -value	95% Confidence Interval
<i>Symptom Severity (all symptoms)</i>				
Informed Decision Making	0.186	0.334	0.035 *	0.049 – 1.367
Connected Strength	0.072	0.246	0.374	–0.266 – 0.704
Effective Communication	–0.245	0.357	0.006 **	–1.707 – –0.297
Age	–0.139	0.115	0.105	–0.416 – 0.040
Education	–0.263	0.694	0.001 **	–3.764 – –1.024
Years since diagnosis	–0.064	0.175	0.296	–0.481 – 0.209
<i>Symptom Severity (top 3 symptoms)</i>				
Informed Decision Making	0.178	0.118	0.041 *	0.010 – 0.426
Connected Strength	0.031	0.089	0.384	–0.142 – 0.210
Effective Communication	–0.131	0.127	0.137	–0.440 – 0.061
Age	–0.132	0.041	0.123	–0.145 – 0.018
Education	–0.271	0.251	0.001 **	–1.382 – –0.392
Years since diagnosis	–0.085	0.062	0.296	–0.188 – 0.058
<i>Symptom Interference</i>				
Informed Decision Making	0.107	0.276	0.351	–0.290 – 0.808
Connected Strength	–0.069	0.235	0.545	–0.610 – 0.324
Effective Communication	–0.327	0.293	0.005 **	–1.427 – –0.262
Age	–0.198	0.102	0.081	–0.383 – 0.023
Education	–0.147	0.614	0.134	–2.149 – 0.292
Years since diagnosis	–0.152	0.147	0.162	–0.499 – 0.085

β = Standardized beta coefficient: Indicates the strength of the relationship between symptom burden and self-advocacy in addition to other variables in the regression equation (e.g., age, education, years since diagnosis). Larger numbers indicate stronger relationships.

Standard Error: Indicates the accuracy of the standardized beta coefficient β . Larger standard errors indicate less accuracy.

Tests of significance:

* p 0.05 (5% chance that finding is due to chance)

** p 0.01 (1% chance that finding is due to chance)

95% Confidence Interval: The range of standardized beta coefficients β for which we are 95% certain that the true β exists.