



# Understanding the Engagement of Key Decision Support Persons in Patient Decision Making Around Breast Cancer Treatment

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**BACKGROUND:** Patients with breast cancer involve multiple decision support persons (DSPs) in treatment decision making, yet little is known about DSP engagement in decision making and its association with patient appraisal of the decision process. **METHODS:** Patients newly diagnosed with breast cancer reported to Georgia and Los Angeles Surveillance, Epidemiology, and End Results registries in 2014-2015 were surveyed 7 months after their diagnosis. The individual most involved in each respondent's decision making (the key DSP) was surveyed. DSP engagement was measured across 3 domains: 1) informed about decisions, 2) involved in decisions, and 3) aware of patient preferences. Patient decision appraisal included subjective decision quality (SDQ) and deliberation. This study evaluated bivariate associations with chi-square tests between domains of DSP engagement and independent DSP variables. Analysis of variance and multivariable logistic regression were used to compare domains of DSP engagement with patient decision appraisal. **RESULTS:** In all, 2502 patients (68% response rate) and 1203 eligible DSPs (70% response rate) responded. Most DSPs were husbands/partners or daughters, were white, and were college graduates. Husbands/partners were more likely to be more informed, involved, and aware (all  $P$  values  $<.01$ ). English- and Spanish-speaking Latinos had a higher extent of ( $P = .02$ ) but lower satisfaction with involvement ( $P < .01$ ). A highly informed DSP was associated with higher odds of patient-reported SDQ (odds ratio, 1.46; 95% confidence interval, 1.03-2.08;  $P = .03$ ). A highly aware DSP was associated with higher odds of patient-reported deliberation (odds ratio, 1.83; 95% confidence interval, 1.36-2.47;  $P < .01$ ). **CONCLUSIONS:** In this population-based study, informal DSPs were engaged with and positively contributed to patients' treatment decision making. To improve decision quality, future interventions should incorporate DSPs. *Cancer* 2019;0:1-8. © 2019 American Cancer Society.

**KEYWORDS:** breast cancer, decision making, significant others, social support, treatment.

## INTRODUCTION

Patients with cancer face complex decisions spanning the cancer care continuum. Ensuring high-quality decisions, which are defined as being both informed (based on an accurate understanding of the options) and values-concordant (consistent with the patients' underlying values), is a key element of patient-centered care.<sup>1,2</sup> The importance of others, including family and friends, to achieving patient-centered care has been highlighted.<sup>3</sup> However, relatively little is known about how informal decision support persons (DSPs)—unpaid family members or friends distinct from paid caregivers and the health care team<sup>4</sup>—engage with patients in the treatment decision-making process.

Patients with breast cancer report substantial informal care support even at the time of initial physician visits. We previously found that 77% of patients had someone with them at their surgical appointment.<sup>5</sup> We further found that although 90% reported that at least 1 key DSP was involved in their treatment decisions, there was wide variation in the size and influence of this network.<sup>6</sup> This raises the possibility that some DSPs are less engaged in decision making than others. However, little research has been done on DSP engagement in the medical decision-making process, and even less is known about how such engagement influences the quality of patient decision making and patient outcomes. To date, most research regarding the role of others in breast cancer treatment decision making is limited by patient reports using small samples that lack racial and ethnic diversity. Furthermore, this research focuses on spouses, although nearly 40% of patients newly diagnosed with breast cancer are unpartnered.<sup>5</sup>

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To fill these gaps, we undertook a study using a unique data set consisting of paired data from patients with early-stage breast cancer and their key DSPs. Our aims were to better understand DSP-reported engagement in patients' treatment decision-making process and to investigate associations between DSP engagement and patients' appraisal of their treatment decisions.

## MATERIALS AND METHODS

### *Study Population*

As described previously,<sup>6</sup> the Individualized Cancer Care (iCanCare) study is a large, population-based survey study of women with breast cancer. We accrued 3930 women, aged 20 to 79 years, with newly diagnosed stage 0 to II breast cancer as reported to the Surveillance, Epidemiology, and End Results (SEER) registries of Georgia and Los Angeles County in 2014-2015. Exclusion criteria included stage III or IV disease, tumors larger than 5 cm, and an inability to complete a questionnaire in English or Spanish ( $n = 258$ ).

Patients were identified via rapid case ascertainment from surgical pathology reports and were mailed surveys approximately 2 months after surgery (median time from diagnosis to survey completion, 7 months). We provided a \$20 cash incentive and used a modified Dillman approach: we included postcard reminders and phone reminders with the option to complete the survey during a phone interview in Spanish or English.<sup>7-9</sup> All materials were sent in Spanish and English to those with Spanish surnames.<sup>5,7</sup> Survey responses were merged with SEER clinical data.

Patients were asked to complete a table describing individuals who played a key role in decisions about locoregional and systemic treatment.<sup>6</sup> They were then instructed to think about the person who was "most helpful" in these decisions (the key DSP) and asked to either 1) provide the name and mailing address of this individual directly to our research team or 2) receive a survey packet to deliver to this individual (including mailing if needed; postage was included). Eligible DSPs were 21 years old or older, were able to read English or Spanish, and resided in the United States. Study enrollment is diagrammed in Figure 1. There were 1713 eligible key DSPs who were surveyed: 783 surveys were sent directly to the DSP, and 930 were given to the DSP via the patient.

The study was approved by the University of Michigan institutional review board and the state and institutional (Emory University and University of Southern California) review boards of the SEER registries.

### *Measures*

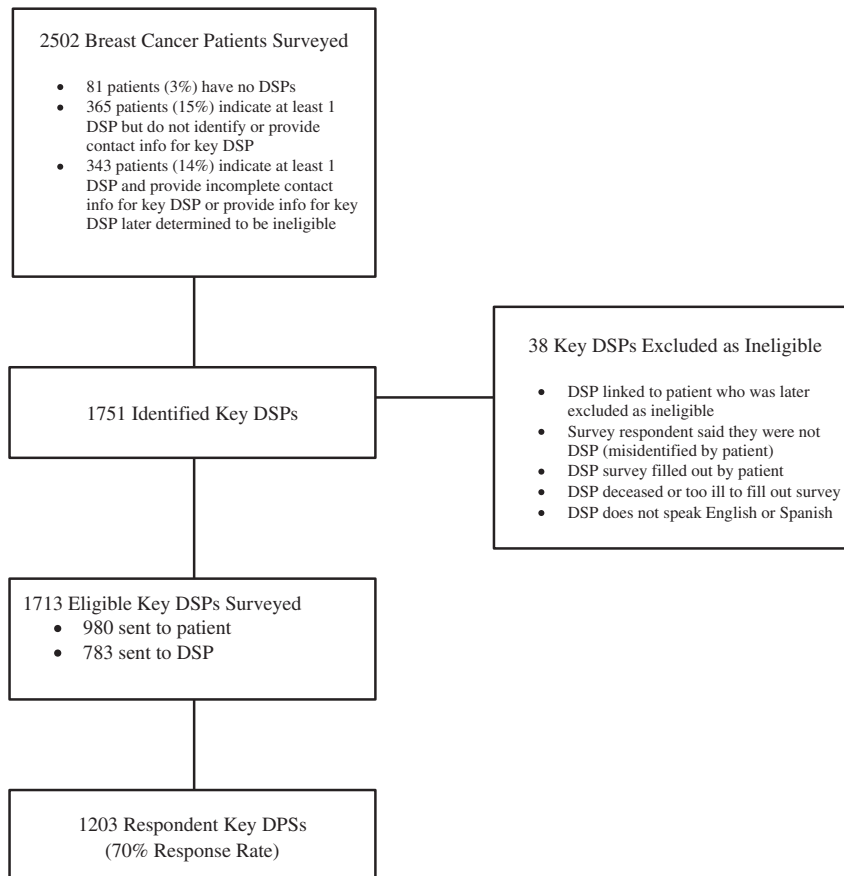
The questionnaire content was developed on the basis of a conceptual framework derived from research on couples dealing with cancer developed by Northouse et al,<sup>10</sup> and it was informed by research on the role of others in decision making.<sup>5,8,11,12</sup> We used standard techniques to assess content validity, including expert reviews and cognitive pretesting and pilot testing of measures in selected patient and DSP populations.

### *DSP engagement*

Guided by our conceptual framework, we asked DSPs about 3 domains of engagement in decision making developed from the concept of patient-centered care: 1) feeling informed about decisions, 2) feeling involved in decisions (extent of and satisfaction with involvement), and 3) feeling aware of patients' underlying values and treatment preferences. The items that compose each domain are based on existing measures or prior studies of patients with breast cancer,<sup>5,12-16</sup> our work surveying significant others,<sup>12</sup> and our cognitive pretesting and piloting in preparation for this study. We used factor analysis, Cronbach's  $\alpha$ , and item response theory to assess each domain of DSP engagement, and we rescaled each domain to a 5-point scale for ease of use.

Table 1 shows the specific items composing each domain of engagement. We measured the domain of feeling informed by asking DSPs whether they had received enough information about various aspects of therapy (yes/no). Responses were tabulated as a count of the number of items for which DSPs responded that they had received enough information, and they were scored from 0 to 5 (Cronbach's  $\alpha = .82$ ), with higher scores indicating a higher degree of being informed.

We measured the domain of feeling involved by asking DSPs to report on the extent of and satisfaction with their involvement in the decision-making process. Extent of involvement was measured by 6 items asking DSPs how often they had attended appointments, taken notes, talked or shared information about treatment options, helped to manage side effects, and taken the patient to appointments (on a 5-point Likert scale ranging from not at all to almost always). Responses to these items were averaged to create a composite scale (Cronbach's  $\alpha = .80$ ), with higher scores indicating greater involvement. Satisfaction with involvement was measured by 4 items asking DSPs' level of satisfaction with their involvement in patients' decisions (on a 5-point Likert scale ranging from not at all to very much). Responses to these items were averaged to



**Figure 1.** Flow of DSPs, starting with the initial patient sample, into the study. DSP indicates decision support person.

create a composite scale (Cronbach's  $\alpha = .83$ ), with higher scores indicating higher levels of satisfaction.

The domain of feeling aware was measured by 4 items asking DSPs how much the patient had discussed treatment preferences with them (on a 4-point Likert scale ranging from not at all to a lot). Responses to these items were averaged to create a composite scale (Cronbach's  $\alpha = .76$ ), with higher scores indicating higher levels of awareness. All 4 scales were rescaled to range from 0 to 5 for ease of comparison.

#### Other DSP variables

DSPs were asked to specify their relationship with the patient and were then categorized into DSP types: husband/partner, daughter, other family member, or friend/other nonfamily member. DSPs also reported their age, race and ethnicity (including the primary language spoken among Latino DSPs), and educational attainment (high school graduate or less, some college, or college degree or more). We also assessed DSPs' objective knowledge

about different treatment options with a validated 5-item knowledge scale for locoregional treatment<sup>17</sup> adapted from a prior 12-item knowledge scale.<sup>18</sup>

#### Independent patient variables

Because of expected colinearity between DSP and patient sociodemographic factors, only relevant patient clinical factors were included in these analyses. Patients reported their comorbid health conditions ( $0/\geq 1$ ) and their cancer treatment in agreement with prior work,<sup>19</sup> including the receipt of chemotherapy (yes/no), the receipt of radiation therapy (yes/no), and the primary surgical treatment (lumpectomy/mastectomy). The breast cancer stage (0, I, or II) was obtained from SEER.

#### Measures of patient appraisal of decision making

We assessed 2 related but distinct domains of patients' appraisal of their own decision making: 1) subjective decision quality (SDQ) and 2) deliberation (or the extent of "thinking through" the treatment options). As previously

**TABLE 1.** Domains of Decision Support Person-Reported Engagement in Treatment Decisions

Domain	Definition	Items
Informed	Knowledge of risks and benefits of treatment options	When her treatment decisions were being made, did you get enough information about (yes/no) <ul style="list-style-type: none"> <li>• Risks/benefits of surgical treatment options?</li> <li>• Coping with your loved one's/friend's cancer and treatment?</li> <li>• Helping your loved one/friend to manage side effects?</li> <li>• Long-term effects of treatment?</li> <li>• Risk of breast cancer recurrence?</li> </ul>
Involved	Extent of involvement in decision making	During the treatment decision-making process, how often did you (on a 5-point scale ranging from never to very often) <ul style="list-style-type: none"> <li>• Attend physician appointments where decisions about her treatment were discussed?</li> <li>• Take notes for her during a doctor's appointment?</li> <li>• Talk to her about treatment options?</li> <li>• Share information with her from other sources about treatment options (eg, from the Internet)?</li> <li>• Help her to manage side effects?</li> <li>• Help to take her to follow-up appointments?</li> </ul>
	Satisfaction with involvement in decision making	Would you say you (on a 5-point scale ranging from not at all to very much) <ul style="list-style-type: none"> <li>• Would like to have had more information when making treatment decisions?</li> <li>• Would like to have participated more in making treatment decisions?</li> <li>• Are satisfied with the amount of involvement you had when your loved one/friend was making treatment decisions?</li> <li>• Are satisfied that you were adequately informed about the issues important to the decision about treatment?</li> </ul>
Aware	Awareness of patients' preferences and values	How much did your loved one/friend talk to you about how she felt about the pros and cons of (on a 4-point scale ranging from not at all to a lot) <ul style="list-style-type: none"> <li>• Different surgical options?</li> <li>• Having radiation?</li> <li>• Keeping or losing her breast(s)?</li> <li>• Having chemotherapy?</li> </ul>

reported,<sup>20,21</sup> SDQ was measured with a 5-item scale assessing the degree to which patients felt informed, involved, satisfied, and not regretful with respect to the locoregional treatment decision-making process. Deliberation was measured with a 4-item scale developed from a public deliberation scale<sup>6</sup> assessing the degree to which patients thought through their treatment-related decisions. In agreement with prior studies, both measures were dichotomized with high and low cut points; an overall SDQ score higher than 4 indicated greater SDQ,<sup>7,22</sup> and an overall deliberation score higher than 4 indicated a more deliberative decision.<sup>23</sup>

### Statistical Analyses

Analyses were performed in 2 steps. First, we investigated decision outcomes among all patients for associations between whether or not a patient had a DSP and her SDQ and deliberation. Then, among those patients with paired data from key DSPs, we investigated the components of DSP engagement and associations between DSP engagement and patient decision outcomes. Using chi-square tests, we evaluated bivariate associations between each domain of DSP engagement (informed, involved, and aware) and independent DSP variables. We used analysis of variance and multivariable logistic regression to compare the

domains of DSP engagement with the patient-reported decision outcomes of SDQ and deliberation.

To reduce potential bias due to nonresponse, weights were created with a logistic regression of DSP nonresponse on demographic characteristics of the patients, and they were used in the multivariable analysis.<sup>24</sup> All statistical tests were 2-sided; *P* values <.05 were considered significant. Analyses were conducted with SAS 9.4 (SAS, Cary, North Carolina).

## RESULTS

### Study Cohort

Of the 3672 eligible patients surveyed, 2502 completed the survey (68% response rate); 1203 DSPs returned surveys (70% response rate) for a final analytic cohort for this article of 1203 patients and their corresponding key DSPs. Response rates were significantly lower for DSPs of patients who were nonwhite, had lower incomes, were unpartnered, and were in Georgia.

### Decision Outcomes for Patients With and Without DSPs

Of the 2502 patients who responded to the survey, 81 (3%) said that they had no DSP. Compared with

patients who had at least 1 DSP (whether or not they provided their contact information), patients with no DSPs had lower mean deliberation scores (mean difference, 0.54; 95% confidence interval, 0.29-0.79;  $P < .01$ ). There was no significant association between whether or not patients had a DSP and SDQ (data not shown).

### DSP Characteristics

Just under half of the DSPs (43%) were husbands/partners; 23% were daughters, 23% were other family members, and 10% were friends or other nonfamily members. Most DSPs were 65 years old or younger, white, and college graduates; 21% were Latino, 17% were black, and 20% had a high school education or less. Among the patients, 56% had stage I disease. Just more than 30% received chemotherapy, 50% received radiation, 62% underwent lumpectomy, and 38% underwent mastectomy (including unilateral and bilateral mastectomy; Table 2). Further details regarding variations in DSP types and characteristics by patient characteristics have been reported previously.<sup>6</sup>

### Engagement Measures and Engagement by DSP Characteristics

In bivariate analyses, husbands/partners were significantly more likely to report higher scores on all domains of engagement (informed, involved [extent and satisfaction], and aware) than other types of DSPs (all  $P$  values  $< .01$ ). Other findings include a higher mean extent of involvement among English- and Spanish-speaking Latinos ( $P = .02$ ) in comparison with other racial/ethnic groups but lower satisfaction with their involvement ( $P < .01$ ). The mean score and interquartile range for each domain as well as further details of variations in DSP engagement by DSP characteristics are shown in Table 3.

### DSP Engagement and Patient Decision Appraisal

After adjustments for DSP and patient covariates, having a highly informed DSP was associated with higher odds of greater patient-reported SDQ (odds ratio, 1.46; 95% confidence interval, 1.03-2.08;  $P = .03$ ). Having a highly aware DSP was associated with higher odds of a more deliberative decision (odds ratio, 1.83; 95% confidence interval, 1.36-2.47;  $P < .01$ ; Table 4).

## DISCUSSION

In this study, we assessed a novel construct—the engagement of key DSPs in the decision-making process of patients with breast cancer—in 3 domains:

**TABLE 2.** Characteristics of DSPs (n = 1203 DSPs) and Patients (n = 1203)

Characteristic	No. (%)
<b>DSPs</b>	
DSP type	
Husband/partner	512 (43)
Daughter	277 (23)
Other family	268 (23)
Friend/other nonfamily	122 (10)
Age	
≤50 y	469 (40)
51-65 y	412 (35)
>65 y	302 (26)
Race	
White	629 (53)
Black	198 (17)
Asian	89 (8)
Latino, English-speaking	160 (13)
Latino, Spanish-speaking	99 (8)
Other	12 (1)
Education	
High school or less	241 (20)
Some college	383 (32)
College graduate	563 (47)
<b>Patients</b>	
Comorbid conditions	
0	800 (67)
≥1	403 (33)
Stage	
0	187 (16)
I	653 (56)
II	327 (28)
Chemotherapy	
Yes	371 (31)
No	811 (69)
Radiation	
Yes	591 (50)
No	587 (50)
Surgery	
Lumpectomy	747 (62)
Mastectomy	456 (38)

Abbreviation: DSP, decision support person.

Percentages may not add up to 100% because of rounding; n values may not add up to 1203 because of missing values.

informed, involved, and aware. We found that DSPs felt highly engaged in the decision-making process and that this varied with the sociodemographic characteristics of the DSPs.

Ours is the first study to suggest that among patients with a key DSP, engaging that person can have a positive influence on important decision appraisal outcomes, including SDQ and deliberation. Our findings suggest that having an informed DSP may be one way to achieve better SDQ. This may be because being informed is a key component of SDQ, and the informed DSP contributes to that component.<sup>20</sup> Although feeling informed is not the same as possessing objective knowledge, our measure of DSPs' objective knowledge was not associated with SDQ. Importantly, the 2 measures were not correlated in our data, and this suggests that a DSP



**TABLE 3.** Bivariate Analyses of the 3 Domains of DSP Engagement by DSP Characteristic

Characteristic	Involved							
	Informed (Mean Score, 3.75; IQR, 3-5)		Extent (Mean Score, 3.63; IQR, 3-4.59)		Satisfaction (Mean Score, 4.1; IQR, 3.67-4.83)		Aware (Mean Score, 3.82; IQR, 2.92-5)	
	Mean Score	P	Mean Score	P	Mean Score	P	Mean Score	P
DSP type		<.01		<.01		>.01		<.01
Husband/partner	4.07		4.15		4.10		3.41	
Daughter	3.55		3.95		3.81		3.18	
Other family	3.55		3.71		3.81		3.23	
Friend/other nonfamily	3.27		3.18		3.84		3.22	
Age		<.01		.76		.07		.16
≤50 y	3.52		3.92		3.84		3.23	
51-65 y	3.86		3.91		3.99		3.34	
>65 y	3.98		3.89		4.02		3.32	
Race and ethnicity		.81		.02		<.01		<.01
White	3.82		3.91		4.19		3.37	
Black	3.71		3.75		3.77		3.10	
Asian	3.53		3.78		3.37		3.08	
Latino, English-speaking	3.55		3.97		3.82		3.35	
Latino, Spanish-speaking	3.98		4.17		3.34		3.27	
Education		.01		.61		<.01		.65
High school or less	4.10		3.92		3.67		3.25	
Some college	3.79		3.89		3.96		3.30	
College graduate	3.63		3.93		4.03		3.31	

Abbreviations: DSP, decision support person; IQR, interquartile range.

**TABLE 4.** Multivariable Regression Models of Patient Decision Appraisal

DSP Characteristic	Subjective Decision Quality <sup>a</sup>		Deliberation <sup>b</sup>	
	Odds Ratio (95% CI)	P	Odds Ratio (95% CI)	P
Informed	1.46 (1.03-2.08)	.03	0.76 (0.56-1.02)	.06
Involved	0.89 (0.63-1.38)	.54	0.92 (0.68-1.23)	.57
Aware	0.86 (0.60-1.23)	.40	1.83 (1.36-2.47)	<.01
Objective knowledge	0.91 (0.66-1.27)	.59	1.25 (0.94-1.65)	.12

Abbreviations: CI, confidence interval; DSP, decision support person.

<sup>a</sup>DSP race was also significantly associated with subjective decision quality.

<sup>b</sup>DSP race and education as well as patient comorbid conditions and surgery type were also significantly associated with deliberation. Models were also adjusted for DSP age, patient stage, receipt of chemotherapy, receipt of radiation, and Surveillance, Epidemiology, and End Results site without significant associations with patient decision appraisal.

who feels more informed is better able to provide decision support that feels helpful to the patient.

In prior work, we found that women who involved greater numbers of DSPs in their treatment decisions reported more deliberative decisions.<sup>6</sup> We believe that this analysis expands this work by showing that having a more aware key DSP is also associated with more deliberation. We acknowledge that a more deliberative decision is not necessarily a “good” one; patients and DSPs may spend a lot of time thinking through a decision and ultimately choose a treatment against the recommendation of their health care provider.<sup>25</sup> Yet, studies suggest that the process of decision making is an important outcome in itself,<sup>26</sup> and feeling rushed

may cause dissatisfaction with this process.<sup>20</sup> Further work to assess the clinical outcomes of these decisions is needed.

Our results linking DSP engagement to patient-reported decision appraisal have important clinical implications. The need for interventions to support patient decision making as a means of improving decision quality and patient-centered care has been identified.<sup>1</sup> Our findings and limited other work suggest that to have the greatest impact, interventions designed to support patient decision making should incorporate informal decision supporters. We believe that there may be an opportunity for decision aids to include modules for patients to view together with their DSPs and to facilitate interaction over

geographic distance for DSPs who do not live with or near the patient. Such interventions would promote DSP engagement beyond just husbands/partners and potentially translate into positive impacts on patients' decision appraisal.

Our findings also highlight the potential for interventions aimed at DSPs themselves to support engagement with patients in treatment decision making. Such interventions could include educational modules to better meet the informational needs of DSPs and suggest meaningful ways to become involved in patients' decision making. Exercises to improve DSPs' awareness of patients' values and preferences could also be included. Our finding that Latino DSPs reported a higher extent of but lower satisfaction with involvement is consistent with our prior work identifying a mismatch between actual and desired involvement in partners of Latina patients with breast cancer.<sup>12</sup> Together, these results suggest a need to help to better align patient and DSP expectations and preferences for involvement in a potentially vulnerable population in which language and health literacy may represent barriers to achieving optimal decision processes. Given their high reported extent of involvement, Latino DSPs may be an ideal population to include in further research because an intervention would not need to "bring them to the table" but could instead focus on maintaining their engagement in a meaningful way. The distinct domains of DSP engagement assessed in this study together represent a taxonomy of engagement to be further explored in future research.

Although our study was a large, population-based survey of a diverse sample of patients and DSPs with high response rates and used novel methodology to identify and survey DSPs, there are potential limitations. Recall bias is possible; to mitigate this, we anchored questions around specific memorable activities. It is possible that DSPs who did not respond may have had lower engagement. Our innovative measures of DSP engagement were based on existing frameworks and subjected to extensive pilot testing, but we created them *de novo*, and they should be validated in other populations of DSPs and cancer patients. The findings for race/ethnicity should be viewed with caution because they may reflect cultural differences in how DSPs respond to the questions rather than underlying differences in engagement. Finally, our study included only women who had received breast cancer treatment in Georgia and Los Angeles and their DSPs and, therefore, may not be geographically generalizable.

In conclusion, informal decision supporters are engaged in the treatment decision-making processes of patients with breast cancer. Such engagement is associated with positive appraisal of this process among patients, yet there are subgroups of DSPs with low engagement. Our work has important clinical implications not just for patients but also for families, who are also affected by the cancer and treatment experience. Armed with the knowledge about the key role played by DSPs, clinicians and researchers can develop decision support tools to be used by patients along with their DSPs as well as DSP-facing interventions to improve engagement. Ultimately, such tools may improve the quality of patients' decision making, their satisfaction with their decisions, and their clinical outcomes.

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## CONFLICT OF INTEREST DISCLOSURES

The authors made no disclosures.

## AUTHOR CONTRIBUTIONS

**Christine M. Veenstra:** Conceptualization, methodology, investigation, writing—original draft, writing—review and editing, and visualization. **Lauren P. Wallner:** Writing—original draft, writing—review and editing, and visualization. **Paul H. Abrahamse:** Methodology, software, formal analysis, investigation, writing—original draft, writing—review and editing, and visualization. **Nancy K. Janz:** Conceptualization, methodology, investigation, and writing—review and editing. **Steven J. Katz:** Conceptualization, methodology, investigation, and writing—review and editing. **Sarah T. Hawley:** Conceptualization, methodology, investigation, writing—original draft, writing—review and editing, and visualization.

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