

# Decision-Support Networks of Women Newly Diagnosed With Breast Cancer

Lauren P. Wallner, PhD <sup>1,2</sup>; Yun Li, PhD<sup>3</sup>; M. Chandler McLeod, PhD, MS<sup>3</sup>; Ann S. Hamilton, PhD<sup>4</sup>; Kevin C. Ward, PhD<sup>5</sup>; Christine M. Veenstra, MD, MSHP<sup>6</sup>; Lawrence C. An, MD<sup>1</sup>; Nancy K. Janz, PhD<sup>7</sup>; Steven J. Katz, MD <sup>1,8</sup>; and Sarah T. Hawley, PhD <sup>1,7,8,9</sup>

**BACKGROUND:** Little is known about the size and characteristics of the decision-support networks of women newly diagnosed with breast cancer and whether their involvement improves breast cancer treatment decisions. **METHODS:** A population-based sample of patients newly diagnosed with breast cancer in 2014 and 2015, as reported to the Georgia and Los Angeles Surveillance, Epidemiology, and End Results registries, were surveyed approximately 7 months after diagnosis (N = 2502; response rate, 68%). Network size was estimated by asking women to list up to 3 of the most important decision-support persons (DSPs) who helped them with locoregional therapy decisions. Decision deliberation was measured using 4 items assessing the degree to which patients thought through the decision, with higher scores reflecting more deliberative breast cancer treatment decisions. The size of the network (range, 0-3 or more) was compared across patient-level characteristics, and adjusted mean deliberation scores were estimated across levels of network size using multivariable linear regression. **RESULTS:** Of the 2502 women included in this analysis, 51% reported having 3 or more DSPs, 20% reported 2, 18% reported 1, and 11% reported not having any DSPs. Married/partnered women, those younger than 45 years, and black women all were more likely to report larger network sizes (all  $P < .001$ ). Larger support networks were associated with more deliberative surgical treatment decisions ( $P < .001$ ). **CONCLUSIONS:** Most women engaged multiple DSPs in their treatment decision making, and involving more DSPs was associated with more deliberative treatment decisions. Future initiatives to improve treatment decision making among women with breast cancer should acknowledge and engage informal DSPs. *Cancer* 2017;123:3895-903. © 2017 American Cancer Society.

**KEYWORDS:** breast cancer, breast cancer study, caregivers, decision-support networks, family, informal decision support, treatment decision making.

## INTRODUCTION

Patient-centered care supports engaging patients to make decisions that are both informed and concordant with values and preferences. This can be challenging in breast cancer because of the complexity and number of decisions faced by newly diagnosed patients. To help facilitate decision making, women often seek guidance from multiple source, including family and friends.<sup>1-6</sup> although many studies have examined the roles played by family and friends in caring for patients with cancer,<sup>7-9</sup> there is surprisingly little research on the specific contribution of informal supporters to the decision-making process. Indeed, most women diagnosed with breast cancer have an informal support person in the room with them during the first encounter with a surgeon. Our prior work suggests that partners positively appraised their participation in these treatment decisions,<sup>10</sup> and a recent study indicated that both patients and caregivers believed family involvement was helpful in their cancer treatment decision making.<sup>11</sup> However, who patients involve in these decisions, the

**Corresponding author:** Sarah T. Hawley, PhD, Departments of Internal Medicine and Health Management and Policy and Ann Arbor VA Center for Clinical Management Research, University of Michigan, North Campus Research Complex, 2800 Plymouth Road, Building 16, Room 406E, Ann Arbor, MI 48109-2800; sarahawl@med.umich.edu

<sup>1</sup>Department of Internal Medicine, University of Michigan, Ann Arbor, Michigan; <sup>2</sup>Department of Epidemiology, University of Michigan, Ann Arbor, Michigan; <sup>3</sup>Department of Biostatistics, University of Michigan, Ann Arbor, Michigan; <sup>4</sup>Department of Preventive Medicine, University of Southern California Keck School of Medicine, Los Angeles, California; <sup>5</sup>Department of Epidemiology, Emory University, Atlanta, Georgia; <sup>6</sup>Department of Internal Medicine, Division of Hematology and Oncology, University of Michigan, Ann Arbor, Michigan; <sup>7</sup>Department of Health Behavior and Health Education, University of Michigan, Ann Arbor, Michigan; <sup>8</sup>Department of Health Management and Policy, University of Michigan, Ann Arbor, Michigan; <sup>9</sup>Ann Arbor Veterans Affairs Center for Clinical Management Research, Ann Arbor, Michigan.

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extent to which they are involved, and whether or not their participation influences the quality of these treatment decisions remains largely unknown.

In addition, very little is known about the decision-support networks themselves and how they may vary for different patient groups. For instance, prior research suggests that the involvement and influence of informal decision-support persons (DSPs) may vary by race/ethnicity,<sup>3,10</sup> but much of the research has been limited by small sample sizes with insufficient racial/ethnic diversity and by the inclusion of only spouses/partners.<sup>4-6</sup> Although clinicians have long been recommending that patients bring someone with them to their appointments, clinicians may benefit from a better understanding of the size and characteristics of the networks on which patients rely during their decision making. Such understanding may help clinicians to better incorporate DSPs into treatment discussions and would help guide the development of decision tools that include patients' informal DSPs, with the goal of improving patient-centered care. In particular, establishing whether informal decision-support networks contribute to greater deliberation over treatment options would allow clinicians to provide more evidence-based recommendations that patients use their network of informal supporters when making their breast cancer treatment decisions.

To fill this gap in research on the process of breast cancer treatment decision making, we conducted a study to characterize the size and variation of informal decision-support networks for women newly diagnosed with early stage breast cancer. We further sought to determine whether network size was associated with patient characteristics and patients' appraisal of their decision-making process.

## MATERIALS AND METHODS

### *Study Population*

The Individualized Cancer Care (iCanCare) Study is a large, population-based survey study of women with breast cancer. We identified and accrued 3930 women, ages 20 to 79 years, with newly diagnosed, early stage breast cancer (stages 0-II) as reported to the Surveillance, Epidemiology, and End Results (SEER) registries of Georgia and Los Angeles County in 2014 and 2015. Patients were ineligible if they had stage III or IV disease, had tumors larger than 5 cm, or could not complete a questionnaire in English or Spanish (N = 258). Of the remaining 3672 eligible women who were mailed surveys,

2502 completed the survey (response rate, 68%) and are included in this analysis.

Patients were identified by rapid case ascertainment from surgical pathology reports. Surveys were mailed approximately 2 months after surgery (the median time from diagnosis to survey completion was 7 months). We provided a \$20 cash incentive and, as in prior work,<sup>12-14</sup> used a modified Dillman approach to encourage patient recruitment.<sup>15</sup> This approach allows for a flexible mode of respondent follow-up, which included postcard and telephone reminders with the option to complete the survey during a phone interview in either Spanish or English. All materials were sent in English and Spanish to those with Spanish surnames.<sup>3,13</sup> Survey responses were then merged with clinical data provided by the SEER registries. The study was approved by the University of Michigan Institutional Review Board and the state and institutional review boards of the SEER registries.

### *Measures*

Questionnaire content was developed based on a conceptual framework, which hypothesized variability in the size and influence of decision-support networks across patient-level characteristics.<sup>1-3</sup> We used standard techniques to assess content validity, including expert reviews, cognitive pretesting, and pilot studies, in selected clinic populations. Respondents were queried about the number, influence, and importance of DSPs using adapted measures developed and validated to identify disease management support for patients with chronic diseases<sup>16,17</sup> (see online supporting information: Measures From the Patient Survey).

### *Measuring Decision-Support Networks*

To our knowledge, this is the first study to ask patients to report about specific individuals involved in their cancer treatment decision making. We used a unique methodology in which patients were asked: 1) to indicate up to 3 specific decision-support individuals (using initials only to avoid identification), 2) to indicate each person's relationship to them (eg, partner, daughter, friend), and 3) to rate the importance of, and satisfaction with, each person's involvement in treatment decision making.

### *Size of the Decision-Support Network*

The decision-support network size was determined by assessing the number of individuals indicated by each patient, ranging from 0 to 3 or more. Although it was rare, respondents who did not answer the decision-support questions entirely (n = 256; 10.2%) were

categorized as having a decision-support network size of zero. This categorization was based on prior work and responses to other questions supporting the justification that patients likely did not answer because they did not have a person to name. However, to confirm our findings, we also performed the analyses with these respondents excluded, which yielded very similar results.

### **Patient Satisfaction With and Importance of DSPs**

For each individual listed, respondents reported on how important the opinion of each DSP was in treatment decision making and how satisfied they were with the level of involvement (each on a 5-point scale, from “not at all” to “very”). Overall mean scores (across all DSPs reported by each patient) were then estimated for both importance and satisfaction and were categorized into high (scores of 4 or greater) versus low/moderate (scores less than 4). We chose this cutoff based on prior research<sup>3,10</sup> and our desire to assess the highest levels of patient-reported involvement and satisfaction.

### **Patient-Reported Network Involvement**

Respondents also were asked how often their DSP(s) attended their appointments, took notes during appointments, talked to them about their treatment options, and shared information with them from other sources about their treatment options (on 5-point scales, from “not at all” to “often”), as we have done in prior studies.<sup>3</sup> Overall mean scores were then estimated for each item and categorized into often/always (scores of 4 greater) versus never/rarely (score less than 4).

### **Patient Appraisal of Decision Making**

We used a measure of “treatment decision deliberation” using a 5-item scale derived from measures of public deliberation adapted for cancer treatment-related decisions.<sup>18-20</sup> These items assessed the extent to which a patient weighed the pros and cons, talked to other family members and friends, talked to other patients with breast cancer, and thought through and spent time thinking about the decision (on 5-point Likert-type scales, from “not at all” to “very much”). An overall deliberation score was created using the mean of the responses to the 5 items (range, 1-5) (Cronbach  $\alpha = .85$ ), with higher scores representing more deliberation.

### **Patient Characteristics**

Survey items assessed demographics, including age, educational attainment (high school graduate or less, some college, or college degree or more), insurance status

(private, Medicaid/Medicare/Veterans Administration, or none/missing), and the number of comorbid health conditions (0, 1 or more). The level of acculturation among Latinas was assessed using the Short Acculturation Scale for Hispanics, as done in our prior studies.<sup>21</sup> We also asked patients to report their treatment, as done in prior work,<sup>12</sup> including primary surgical treatment modality (lumpectomy, unilateral mastectomy, bilateral mastectomy), receipt of chemotherapy (yes/no), and receipt of endocrine therapy (yes/no). Breast cancer stage (0, I, II) was obtained from the SEER record.

### **Statistical Analyses**

All statistical analyses incorporated weights to account for differential probabilities of sample selection across patient subgroups and nonresponse. Weighting assures that sample distributions resemble those of the target population and reduces the potential bias because of nonresponse.<sup>22</sup> The overall distributions of network characteristics (size, relationship), DSP involvement, and patient-reported satisfaction with and influence of the DSP were estimated. The distributions of network size across levels of patient demographic and clinical characteristics were compared using Rao-Scott chi-square tests. Because of the anticipated inherent association between network size and marital status, we then estimated the associations between patient factors (age, race/acculturation) and network size, stratified by marital status, and compared them using Rao-Scott chi-square tests. Multivariable linear regression was used to estimate the adjusted mean deliberation scores for each level of network size, adjusting for age, race/acculturation, insurance, partner status, comorbidity, surgical treatment, and stage. All analyses were performed using SAS version 9.4 (SAS Institute, Cary, NC) with 2-sided tests, and  $P$  values  $< .05$  were considered statistically significant.

## **RESULTS**

### **Network Size**

Table 1 displays the characteristics of the sample of 2502 women both overall and by level of informal decision-support network size. More than one-half of the women (51%) listed 3 DSPs during their treatment decision making, 20% listed 2 DSPs, 19% listed 1 DSP, and 10% had a network size of zero. Network size decreased with increasing age ( $P < .001$ ). Variation in network size also existed across race/acculturation ( $P < .001$ ). Both African American and Latina women reported larger network sizes compared with white women, because 58.3% of African American women and 52.3% and 56.4% of high-

**TABLE 1.** Distribution (weighted %) of Patient Demographic and Clinical Characteristics by Decision Supporter Network Size

Patient-Level Factors	Overall, N = 2502	Decision Supporter Network Size, Weighted %				<i>P</i> <sup>a</sup>
		0, N = 256	1, N = 460	2, N = 501	3, N = 1285	
Age, y						
<45	8.2	3.3	14.9	20.9	60.9	.001
45-54	20.4	10.7	16.9	21.9	50.6	
55-64	31.3	8.5	20.3	18.2	53	
>65	40.1	12.5	19.8	20.9	46.9	
Race/acculturation						
White	54.2	9.5	21.4	21	48	< .001
Black	18	9.4	15.3	17	58.3	
Latina, high acculturation	7.9	12.8	14.9	19.9	52.4	
Latina, low acculturation	7.7	10.2	15	18.4	56.4	
Asian	9.8	9.2	19.1	24.5	47.2	
Other/unknown/missing	2.5	25	15.5	17.8	41.6	
Education						
≤High school graduate	29.9	10.7	18	18.6	52.8	.26
Some college	29.8	8.6	18.2	20.3	52.8	
≥College graduate	40.3	9.3	20.8	21.9	48	
Insurance						
None or missing	20.2	15.7	14.1	16.8	53.4	< .0001
Medicaid, Medicare, or VA	35.2	9.7	18.6	21	50.7	
Private or other	44.6	8	21.5	21.2	49.4	
Partner/marital status						
Not partnered/married	38.9	15.5	15.9	19.3	49.3	< .0001
Partnered/married	61	6.2	21.1	21.2	51.6	
No. of comorbidities						
0	67.8	10.4	19.8	20.6	49.2	.24
≥1	32.2	9.6	17.1	19.6	56.7	
SEER stage						
0	24.9	11.7	20.4	18.6	49.3	.26
I	50.1	9.3	19.7	20.2	50.8	
II	24	10.8	15.5	21.4	52.4	
Surgical treatment						
Lumpectomy	64.6	10.5	20.4	19.9	49.1	.11
Unilateral mastectomy	17.4	9.3	14.9	19.9	55.9	
Bilateral mastectomy	18	8.1	17.5	21.1	53.3	

Abbreviations: DSPs, decision-support person; SEER, Surveillance, Epidemiology, and End Results; VA, Veterans Administration.

<sup>a</sup>*P* values were calculated from Rao-Scott chi-square tests for association.

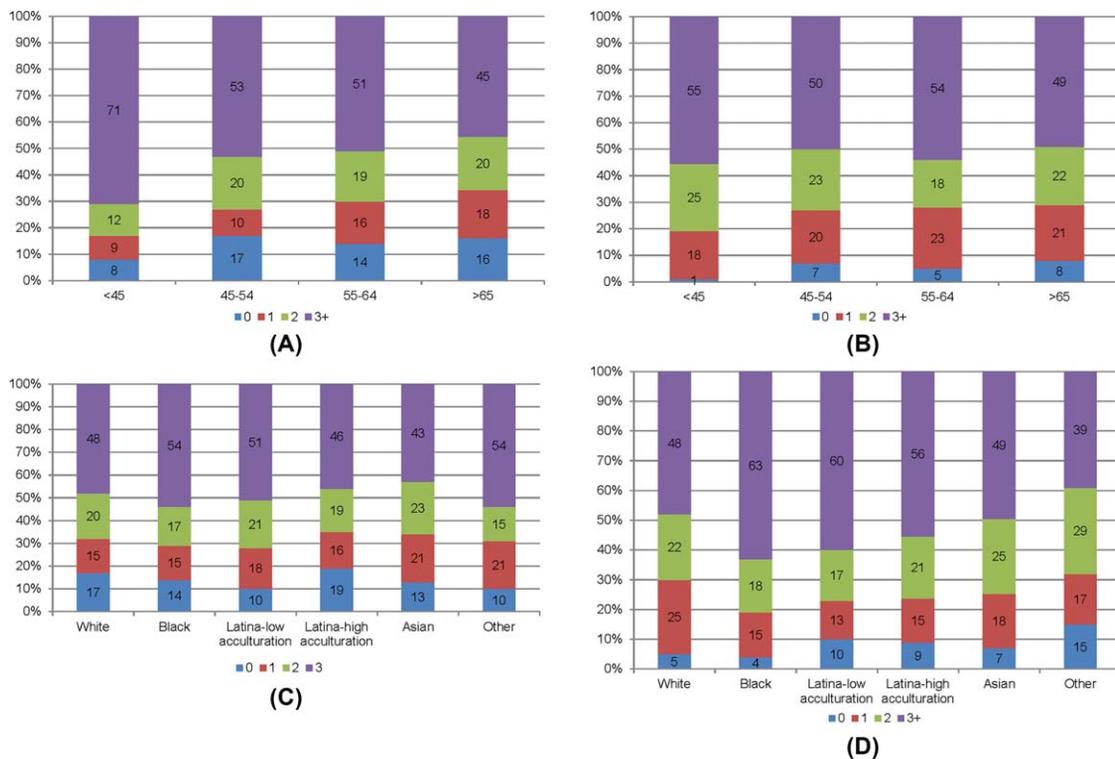
acculturated and low-acculturated Latina women reported a network size of 3 or more, compared with 48% of white women ( $P < .001$ ). Marital status, as expected, was positively associated with network size: Among women who were partnered/married, 51.6% reported a network size of 3 or greater compared with 49.3% of women who were not married or partnered ( $P < .001$ ) (Table 1).

Figure 1 displays the size of decision-support networks across age and race, stratified by partner status. Very little heterogeneity was observed in the association between age and network size across partner status. Among both partnered and nonpartnered women, a greater proportion of younger women reported a larger network size compared with older women, although these associations did not reach statistical significance (not partnered,  $P = .06$ ; partnered,  $P = .10$ ) (Fig. 1A,B).

The association between race/acculturation and network size varied noticeably across partner status. Among women who were partnered, race/acculturation was significantly associated with network size ( $P < .001$ ), because 63% of black women, 56% of high-acculturated Latina women, 60% of low-acculturated Latina women, and 48% of white women reported a network size of 3 or more (Fig. 1D); however, this association was mitigated among women who were not partnered ( $P = .80$ ) (Fig. 1C).

### Characteristics of Networks

Table 2 displays the distributions of the size, relationship, and involvement of decision-support networks both overall and stratified by married/partnered status. Of the DSPs that respondents identified, overall, most (31.2%)



**Figure 1.** The distribution of network size according to partner status is illustrated by age among (A) nonpartnered women ( $P=.06$ ) and (B) partnered women ( $P=.09$ ) and by race/acculturation among (C) nonpartnered women ( $P=.80$ ) and (D) partnered women ( $P<.001$ ).

were children, followed by partners/spouses (21.2%), friends/other (18.8%), siblings (11.3%), other family members (7.4%), and parents (6.1%). Partnered/married women most often reported their partner as their main DSP (37.9%), whereas nonpartnered/unmarried women most often reported children as their main DSP (38.4%). In addition, women who were not partnered or married more often reported siblings (15.5%) or friends (22.3%) as their DSPs compared with partnered/married women ( $P<.001$ ).

#### Satisfaction With and Involvement of Networks

Overall, women reported that their DSPs participated in key activities related to their decision making. The majority of women reported that their DSPs often/always talked to them about their treatment options (74.2%) and frequently attended their appointments (73.3%), and these activities were more common among partnered women compared with nonpartnered women ( $P<.001$  for both). However, women overall were less likely to report that their DSPs had taken notes (50.5%) or shared treatment information with them from other sources (56.8%).

The majority of women were highly satisfied with their DSP being involved in their treatment decisions (76.5%) and greater than two-thirds (68.6%) believed that their DSP was very important in their treatment decision making. However, both satisfaction and importance were significantly different across partner status; partnered women were more likely to be highly satisfied and perceive that their DSP was of high importance compared with nonpartnered women ( $P<.001$  for both). In addition, younger women, black women, Latina women, and those with less education were more likely to perceive that their DSP was highly important (results not shown) (Table 2).

#### Association With Decision Deliberation

There was a significant association between network size and treatment deliberation scores after adjustment for age, race, insurance, partner status, comorbidity, SEER stage, and surgical treatment. Mean treatment deliberation scores were lowest among women who had a network size of zero (mean deliberation score, 3.04) and were highest among those with a network size of 3 or more (mean deliberation score, 3.59;  $P<.001$ ) (Fig. 2).

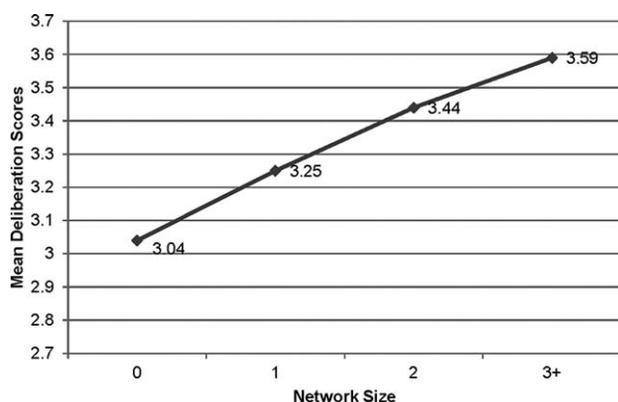
**TABLE 2.** Network Characteristics and Decision Supporter Involvement in Treatment Decision Making (N = 2502) Stratified by Partner Status

Network Characteristic	Weighted %			P
	Overall, N = 2502 <sup>a</sup>	Not Partnered, N = 961	Partnered, N = 1496	
Network size, n = 2457				< .001
0	9.8	15.5	6.2	
1	19	15.9	21.1	
2	20.5	19.3	21.2	
≥3	50.7	49.3	51.6	
DSP relationship to patient <sup>b</sup>				< .001
Partner/spouse	21.2	2.3	37.9	
Children	31.2	38.4	27	
Siblings	11.3	15.5	8	
Parent	6.1	6.4	5.5	
Other family members	7.4	11	4.6	
Friends/other	18.8	22.3	13.5	
Multiple	4	4.1	3.6	
DSP involvement				< .001
Attended appointments, n = 2394				
Never/rarely/often	26.7	37.7	19.8	
Very often/always	73.3	62.3	80.2	
Took notes during appointments, n = 2377				.076
Never/rarely/often	49.5	51.9	47.9	
Very often/always	50.5	48.1	52.1	
Talked with them about treatment options, n = 2364				< .001
Never/rarely/often	25.8	32.9	21.3	
Very often/always	74.2	67.1	78.7	
Shared information about treatment from other sources, n = 2380				.49
Never/rarely/often	43.2	44.1	42.6	
Very often/always	56.8	55.9	57.4	
Patient-reported DSP measures				< .001
Patient-reported satisfaction with DSP, n = 2457				
Low/moderate (<4)	23.5	30.4	19	
High (≥4)	76.5	69.6	81	
Patient-reported DSP importance, n = 2457				< .001
Low/moderate (<4)	31.4	38.7	26.8	
High (≥4)	68.6	61.3	73.2	

Abbreviations: DSP, decision support person.

<sup>a</sup>The number is unweighted and does not add up to 2502 because of missing data.

<sup>b</sup>Relationships were categorized for all reported DSPs for each patient.



**Figure 2.** Adjusted mean treatment deliberation scores are illustrated by network size ( $P < .001$ ). Analyses were adjusted for age; race; insurance status; education; partner status; comorbidity; Surveillance, Epidemiology, and End Results stage; and surgical treatment.

## DISCUSSION

In this study, for which we used a unique methodology to understand how family and friends contribute to the treatment decisions made by patients with breast cancer, most reported having a large, informal decision-support network and also believed that their supporters were both important and influential. Women with larger networks also reported more deliberative surgical treatment decisions, which is a promising outcome, particularly at a time when there is concern that patients may be rushing into making breast cancer treatment decisions.<sup>23-25</sup> Our results suggest that engaging DSPs in the treatment decision process may be an important mechanism for slowing these decisions down, potentially allowing patients to more deeply consider them.

Our findings confirm prior work demonstrating that most women do not make their breast cancer treatment decisions on their own and, instead, heavily involve other support people in these emotional and difficult decisions.<sup>1-6,11,26</sup> Our study extends this work by revealing that the decision-support network for patients with newly diagnosed breast cancer is larger than previously understood. In fact, we observed that the majority of patients with breast cancer reported having large networks, which we defined in this study as having 3 or more informal DSPs, and we further discovered that these supporters often included family members and friends beyond just partners or spouses. In our large sample of nonmarried/nonpartnered women—which have not previously been well represented in studies of informal support—we observed that children and friends were commonly considered key DSPs. Yet, we also demonstrated that, even among married/partnered women, children and friends played an important DSP role. These results underscore the need to recognize the significant impact of informal DSPs—partners, children, friends—in the treatment decision-making process and choices of patients with breast cancer.

We did observe some variation in network size among different patient subgroups, as expected, with younger and minority women indicating that they had larger decision-support networks. Prior research suggests that racial/ethnic minorities are more likely to rely on family for emotional/spiritual support and caregiving functions,<sup>1,27</sup> but the current study is 1 of the first to demonstrate that this is also the case specifically for decision support. In addition, although African American women tended to be partnered/married at lower rates in our sample, they still had large networks that supported their decision making. Likewise, Latina women with low acculturation also reported larger network sizes, underscoring that, for minorities who have potential language barriers that make communication with their physicians more challenging,<sup>13,14</sup> the inclusion of DSPs offers another opportunity to educate patients about their treatment options. Efforts by clinicians to engage with the DSPs of minority women and to recognize that women often have DSPs beyond their spouses or partners may be beneficial in ensuring that information is communicated in a culturally sensitive and understandable manner.

Our results also suggest that informal DSPs are actively engaged with patients throughout their treatment decision making and that there may be a real benefit to having a decision-support network during this process. In addition to the strong association between the number of

supporters and more treatment deliberation, the majority of women in this sample also reported that they were highly satisfied with their DSP's level of involvement and believed the DSP played an important role in their treatment decision making. Prior work from Shin and colleagues also suggests that patients and caregivers value family involvement in cancer treatment decision making.<sup>11,26</sup> Our findings that the majority of women also reported having DSPs who often attended their appointments, took notes, discussed their treatment options, and shared information with them from other sources suggests that support networks are also highly involved throughout the decision process. This involvement may be particularly helpful around the time of diagnosis, when patients are struggling to absorb information while simultaneously coping with their cancer diagnosis. It also suggests that there may be a benefit to addressing decision supporters within structured tools, or decision aids, designed to improve treatment decision making. Although there are many decision aids available for patients with breast cancer, none of them currently address the role of informal supporters in helping women navigate these treatment decisions, and none directly engage supporters. Therefore, future decision aids and other interventions focused on improving breast cancer decision making should address the role of the DSP more directly.

Taken together, the results from this study suggest that the involvement of informal supporters in breast cancer treatment decisions provides an opportunity for clinicians to better incorporate them into these treatment decisions. Clinicians should be aware that women who include more informal supporters in their treatment decisions may take longer to fully weigh treatment options and require additional time to make value-concordant and preference-concordant decisions. Therefore, clinicians might discuss with patients the availability of informal DSPs and encourage their involvement early in the treatment consultation process. Clinicians should also anticipate delivering treatment information to at least 1 person beyond the patient and should also realize that, among married/partnered women, the spouse/partner is not necessarily the family member that the patient considers to be her informal decision-support person. Equally important, however, is recognizing that women who do not have an informal support person—as reported by 10% of patients in our sample, including a small proportion of women who were married/partnered—may be vulnerable to lower quality treatment decisions and thus may require additional decisional support.

Although the current study was a large, population-based survey in a diverse sample with a high survey response rate, there are some potential limitations that merit consideration. This was a cross-sectional survey; therefore, inferences regarding causality are limited. We relied on patient report of their DSPs, including their influence and importance, which may be subject to recall bias. However, we captured this information on average only 2 months after surgery, thus minimizing the potential for this bias. We only asked women to identify up to 3 DSPs, thus our estimates about the size of the decision-support networks are most likely conservative. Finally, this sample only included women who received treatment for breast cancer in Georgia and Los Angeles; therefore, the generalizability of our findings may be limited.

## CONCLUSIONS

Although prior research on breast cancer treatment decision making has tended to focus on the patient, our study is 1 of the largest to date that highlights the need to consider patients in the context of their informal decision-support networks. Patients turn to others, including spouses, children, and friends, to help support them in these difficult and complicated decisions, and these others are actively involved in helping patients make their decisions. The effectiveness of future initiatives to improve treatment decision making among patients with breast cancer, including decision-support tools, may be limited if they do not acknowledge and engage informal decision supporters.

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## CONFLICT OF INTEREST DISCLOSURES

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## AUTHOR CONTRIBUTIONS

**Lauren P. Wallner:** Conceptualization, methodology, investigation, writing—original draft, writing—review and editing, and visualization. **Yun Li:** Methodology, software, formal analysis, investigation, writing—original draft, writing—review and editing, and visualization. **M. Chandler McLeod:** Methodology, software, formal analysis, investigation, writing—original draft, writing—review and editing, and visualization. **Ann S. Hamilton:** Investigation, resources, writing—review and editing, and project administration. **Kevin C. Ward:** Investigation, resources, writing—review and editing, and project administration. **Christine M. Veenstra:** Writing—original draft, writing—review and editing, and visualization. **Lawrence C. An:** Conceptualization, investigation, and writing—review and editing. **Nancy K. Janz:** Conceptualization, methodology, investigation, and writing—review and editing. **Steven J. Katz:** Conceptualization, methodology, investigation, resources, writing—original draft, writing—review and editing, visualization, supervision, project administration, and funding acquisition. **Sarah T. Hawley:** Conceptualization, methodology, investigation, writing—original draft, writing—review and editing, and visualization.

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