

# Qualitative Assessment of Perceived Organizational Support for Employed Breast Cancer Survivors

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**Objective:** A more detailed understanding of unmet organizational support needs and workplace-based best practices for supporting cancer survivors is needed. **Methods:** Ninety-four working breast cancer survivors responded to an open-ended survey question regarding the desired types of organizational support that were and were not received during early survivorship. We performed content-analysis of qualitative data. **Results:** Major themes included instrumental support, emotional support, and time-based support. The need for flexible arrangements and reduced workloads was mostly met. Unmet needs included navigation/coordination, understanding/empathy, and time off for treatment and recovery. **Conclusions:** Organizational support can help cancer survivors manage their health and work roles, diminishing work-health conflict and turnover intent. Study findings can be used to design targeted interventions to fulfill cancer survivors' unmet organizational support needs, which may also apply to workers with other chronic health conditions.

**Keywords:** organizational support, breast cancer, survivorship, employment, social support, unmet needs

In the United States, approximately 3.8 million women are living with a history of breast cancer.<sup>1</sup> Enhancements in early detection, precision diagnoses, and targeted treatment have improved the prognosis of breast cancer such that the overall 5-year relative survival rate for female breast cancer patients is now 91%, although this varies by stage at diagnosis with early-stage cancers having substantially more favorable prognoses than metastatic disease.<sup>2</sup> Although some breast cancer survivors continue to work during treatment,<sup>3</sup> some take time off from work for treatment and recovery while some leave their current employer or the workforce permanently. Johnsson and colleagues<sup>4</sup> reported that 59% of women with breast cancer returned to work 10 months after treatment, but many survivors continue to experience

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## LEARNING OUTCOMES

After completing this educational activity, the learner will be able to:

- Identify three types of organizational support that breast cancer survivors value the most.
- Explain breast cancer survivors' specific unmet organizational support needs that could be considered for future workplace intervention.
- Discuss key sources within employing organizations that can provide needed support to cancer survivors.

difficulties managing their work because of physical or psychosocial issues related to their disease.<sup>5</sup>

Because of the risk of recurrence and potential long-term effects of treatment, breast cancer is often managed as a chronic illness (eg, by making lifestyle changes, monitoring and treating symptoms, and following enhanced screening schedules). Like other chronic illnesses, cancer places new demands on survivors that often continue from diagnosis throughout survivorship. Thus, the term "survivor" applies to anyone diagnosed with cancer from the time of diagnosis through the rest of their life.<sup>6</sup> Much of the cancer-related research has focused on treatment and survival, but additional research is needed on work-related survivorship issues since most survivors will return to work.

In the field of psychosocial oncology, researchers have extensively studied the positive impact of social support on the lives of cancer survivors.<sup>3,7</sup> Broadly, social support refers to the number and quality of helping relationships that any person has.<sup>8</sup> Scholars have most frequently used House's<sup>9</sup> conceptualization of support, which proposed three major types of social support: emotional (empathy, love, trust, and caring), instrumental (direct assistance through practical help, hands-on aid, and services), and informational (information, advice, and suggestions).<sup>10</sup> Furthermore, according to the optimal matching theory of social support, individuals benefit most from the kind of social support that matches their specific need.<sup>11</sup> Surprisingly, only a handful of studies have examined social support provided to cancer survivors within the work domain.<sup>3,12-16</sup>

Employment is essential to many survivors for maintaining their financial stability and health insurance, making social support in the work domain vital, especially for workers with serious ongoing sequelae. Employment also contributes to individual identity, provides social connections, and affords a distraction from health concerns, all of which allow the survivor to regain a sense of normalcy.<sup>17</sup> In general, there are favorable outcomes for both the worker and the organization when workers believe that their employing organization values their contributions and cares about their well-being (ie, when workers perceive they have organizational support).<sup>18</sup>

Social support at work can come from different sources (ie, co-workers, supervisors, the employer organization itself) some of which

have the ability to influence job demands directly.<sup>19</sup> Meta-analytic evidence suggests that the impact of social support is three-fold; it (1) mitigates perceived workplace stressors, (2) reduces experienced strains, and (3) buffers the relationship between workplace stressors and strains.<sup>20</sup> A Finnish study examined cancer survivors' received and needed social support in the organizational context<sup>3</sup> and found workers reported needing more support from three organizational sources (coworkers, supervisors, and occupational health services personnel). Women reported needing both more instrumental and emotional support than men, and coworkers were perceived by both women and men as providing the most support that was needed, followed by supervisors, and lastly occupational health services personnel. Although these<sup>3</sup> findings provide valuable information about the extent to which cancer survivors are receiving social support from sources within the work domain, little is known about the various ways that organizational members are supporting breast cancer survivors.

One study examining cancer survivors' work experiences<sup>14</sup> found themes related to support and work adjustment. The type of support received by cancer survivors was variable and ranged from instrumental/practical support (eg, work modifications) to emotional support (eg, expressions of sympathy). Most of the reported work modifications pertained to flexibility around or changes to work hours, tasks, and workload. Survivors in the study noted employers' lack of awareness about the support they can and should provide to cancer survivors.<sup>14</sup> Of note, the mean time since diagnosis for this sample of cancer survivors was 59.8 months, or approximately 5 years, and ranged from 11 to 115 months. More research during this period of early survivorship (ie, time from diagnosis through 5-year postdiagnosis) is still needed for a more in-depth understanding of how breast cancer survivors are supported or wish to be supported, particularly if they are to remain active in the workforce.

In the current study, our primary aim was to identify the types of support that breast cancer survivors most value and need from their organizations within early survivorship, as well as the specific types of support that survivors do or do not receive. A secondary aim was to identify which organizational members were sources of support (eg, coworkers, supervisors). Findings are meant to inform the development of interventions that address the unmet needs of breast cancer survivors for organizational support and to improve current workplace practice to help survivors cope with the challenges of maintaining a job while managing cancer treatment and its aftereffects. In the current study, we administered a survey to breast cancer survivors, which contained both closed- and open-ended survey questions, and posed the following three research questions: (1) What types of employment- and health-related support are most valuable to receive from employing organizations during reengagement or remaining in the workforce?, (2) What types of employment- and health-related support are desired but not received from organizations during early survivorship?, and (3) Within the organization, who provides or does not provide support during early survivorship?

## METHOD

The analyses presented in this article are part of a larger participatory action research study conducted in the northeast United States (US) aimed at identifying clinical and organizational support that best facilitates breast cancer survivors' continued employment, health, and quality of life, and using findings to design supportive interventions to be delivered by healthcare providers and employers.

### Participatory Survey Design

A participatory approach was adopted in the survey design phase of this larger participatory action research study, such that subject matter experts (ie, breast cancer survivors, cancer clinicians, and researchers) with experience related to survivors maintaining employment and returning to work following cancer treatment were invited to be members

of a design team (an advisory team tasked with assessing well-being and creating interventions). Together with two academic researchers, the seven-person design team (4 breast cancer survivors, 3 breast cancer clinicians) developed a survey to assess the well-being needs of breast cancer survivors. The survey development process occurred in four 1-hour meetings over 6 weeks and involved conducting focus groups, selecting survey measures, and pilot-testing and refining the survey.

The core of the survey was a generic workforce health assessment (eg, worker health status and behaviors, aspects of the physical and psychosocial work environment), with several measures added to assess the specific population of interest—employed breast cancer survivors (eg, experience with healthcare system, quality of life, organizational support, work information). Measures were mostly quantitative but also included some qualitative items. The final survey was in an online format and took an average of 1 hour to complete. In the current study, we examined responses to a single open-ended question that asked survivors to report on what was the most valued/desired support that they received or would like to have received from members of their organization (ie, employer, supervisor, coworkers) during early cancer survivorship.

### Recruitment

We used a purposive sampling approach, which involves the deliberate sampling of people who possess a specific characteristic or quality.<sup>21</sup> In our study, we recruited employed breast cancer survivors ( $\geq 18$  years) who completed active primary treatment (ie, surgery, chemotherapy, or radiation therapy) within the last 36 months. Participants had to be employed both at the time of their breast cancer diagnosis and eligibility screening (regardless of whether they remained working or took time off during treatment). Exclusion criteria were the inability to speak and read English.

Obtaining this unique sample required the adoption of multiple recruitment strategies. Recruitment flyers were distributed to patients at cancer centers, participants in survivorship programs and support groups, as well as organizers and attendees of breast cancer events. Flyers were also distributed to workers at a public university in the northeastern United States. In addition, our recruitment efforts targeted those who had frequent contact with breast cancer survivors. All study procedures were approved by the university's institutional review board.

Participant recruitment and data collection occurred over a 17-month period (May 2017–October 2018). The recruitment flyer directed interested participants to contact the researchers by phone to determine eligibility. Three doctoral-level graduate students conducted eligibility screening by telephone. Of the 249 individuals who expressed interest, only 153 met all the eligibility requirements and were subsequently invited to complete the survey. In total, 143 breast cancer survivors were eligible to participate and completed the online survey.

### Responses to an Open-Ended Question

Participants who completed the online survey were presented with the open-ended question examined in this study. The question was developed by the design team to collect qualitative information about how organizations can provide employment-related support to breast cancer survivors. This question focused on the alignment of organizational support with the needs and desires of breast cancer survivors in early survivorship, given that social support that matches a cancer survivor's needs improves psychosocial adjustment.<sup>22–24</sup> In addition, the open-ended question was framed to be consistent with the following three major support domains: emotional, instrumental (practical), and informational.<sup>9</sup> The open-ended question examined in this study was: "What information, emotional support, or practical assistance did your employer, supervisor, or coworkers provide you (or could they have provided you) to make it easier to cope with the challenges of having cancer and keeping a job?"

Many participants' responses to the open-ended question were multifaceted because of the complexity of the question and

**TABLE 1.** Coding Manual of Most Valued or Desired Types of Support From Employer

Major Theme	Subtheme	Received or Not	Codebook Description of Type of Support
Instrumental support	Job modifications/flexible arrangements	Received or not received	Instrumental support related to job modifications and allowing/supporting survivors to adopt flexible work arrangements. Job modifications included reduced workload and hours (per day or week). Flexible arrangements included flextime (discretion over start/end times, break times) and flexplace (working from home, meeting virtually).
	Navigation/coordination	Received or not received	Instrumental support related to navigating the paperwork, policies, and procedures associated with leave, insurance, and return to work, as well as assistance with coordination between the various stakeholders involved in these processes.
	Shared workload/replacement coverage	Received or not received	Instrumental support related to members of the organization sharing or increasing their workload/responsibilities to lessen survivors' workload/responsibilities. In some instances, job-sharing arrangements were made or temporary replacement workers covered survivors' workload/ responsibilities.
	Support for personal life	Received or not received	Instrumental support related to members of the organization providing support for survivors' life outside of work including providing meals for them and their families, accompanying/transporting them to medical appointments, and assisting them financially (eg, raising money for medical bills).
	Work-related check-ins	Received or not received	Instrumental support related to members of the organization regularly checking in, to communicate regarding work issues.
Emotional support	Understanding/empathy	Received or not received	Emotional support related to members of the organization being understanding and empathic to the needs and feelings of survivors.
	General emotional support	Received or not received	Emotional support in general, without a specific motivation or associated outcome.
	Uplifting spirits	Received or not received	Emotional support related to members of the organization sending cards or gifts, or supporting cancer organizations in the survivor's name (eg, fundraising walks and events, creating and purchasing merchandise).
	Emotional check-ins	Received or not received	Emotional support related to members of the organization regularly checking in to communicate care for the survivor in a compassionate way.
	Learning/Respecting Survivor's Wishes	Received or not received	Emotional support related to learning and respecting the wishes of the survivor regarding whether and how others acknowledge the survivor's illness (ie, whether they desire that others give them privacy, share their concern, or treated the survivor as if "everything was normal.")
Time-based support	Paid sick/disability leave	Received or not received	Time-based support related to allowing and supporting survivors to take paid time off, including sick days (accumulated or donated) and disability leave.
	Unpaid job-protected leave	Received or not received	Time-based support related to allowing and supporting survivors to take unpaid job-protected time off by taking leave granted for medical reasons.
	General leave	Received or not received	Time-based support related to allowing and supporting survivors to take time off, with no specific leave type mentioned.
	Paid vacation time	Received or not received	Time-based support related to allowing and supporting survivors to take paid time off, in the form of vacation time.
Nonspecific support	General support	Received or not received	Support in general provided by members of the organization, without a specific motivation or associated outcome.
No support	No support offered	Received or not received	No support was offered to survivors.
	Job type as a barrier to support	Received or not received	Survivors attributed lack of support from members of their organization to their job type, which made the provision of support difficult.
	Nondisclosure of cancer as a barrier to support	Received or not received	Survivors attributed lack of support from members of their organization to the fact that they did not disclose cancer to anyone at work.

the large word limit (2000 characters). Several strategies were used to ensure that all relevant information was captured in our coding process. First, three members of the research team (A.D., R.D., S.N.) subdivided responses into "meaningful units," which are the smallest and simplest units of comprehensible meaning.<sup>25</sup> When necessary, responses were subdivided into more than one meaningful unit and each meaningful unit was assigned a code.<sup>26</sup> For example, the response, "My supervisor was very empathetic and supportive. She allowed me to work from home several days a week, and to have flexible hours when I needed treatment or had to go to doctors' appointments" was segmented into two meaningful units. "My supervisor was very empathetic and supportive" (coded emotional support) and "She allowed me to work from home several days a week, and to have flexible hours when I needed treatment or had to go to doctors' appointments" (coded instrumental support).

**Analysis of Responses**

We examined open-ended responses using content analysis, which allows researchers to systematically examine and interpret the

frequency of textual responses. Utilizing the constant comparative method, we identified recurrent themes until reaching saturation.<sup>27</sup> There is no threshold (eg, a certain percentage of coded responses) for determining that a theme exists; rather, themes emerge from the data and are recurrent experiences (and their variant manifestations) that can be understood together as a meaningful whole, unified by commonalities in their nature or basis of experience.<sup>28</sup> To code responses with themes, we used the qualitative software program ATLAS TI,<sup>29</sup> which facilitates consistent coding, because of the ease of assigning codes to text and the ability to set strict defining parameters to the codes.<sup>30</sup> Intercoder discrepancies were resolved via discussion, consensus, and refinement of coding definitions.

Before coding responses, we developed a coding manual that included a primary and secondary coding scheme. Two research team members (A.D., R.D.) reviewed all responses and created two coding schemes. The development of the coding manual was an iterative process that occurred over several meetings. The primary coding scheme was created to code meaningful units pertaining to types of organizational support, whether received or not (Table 1). The secondary

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**TABLE 2.** Coding Manual of Sources of Support in the Organization

Major Theme	Received or Not	Codebook Description of Source of Support
Coworker support	Received or not received	Survivors identified coworkers as a source of support (eg, providing understanding/empathy, or support for personal life).
Supervisor support	Received or not received	Survivors identified supervisors as a source of support (eg, providing general emotional support, allowing job modifications/flexible arrangements, supporting use of paid sick/disability leave).
Employer support	Received or not received	Survivors identified their employer as a source of support (eg, providing paid sick or vacation leave, allowing replacement coverage and subsequently absorbing the associated costs).
Human Resources support	Received or not received	Survivors identified Human Resources as a source of support (eg, assisting with unpaid job-protected leave, and coordinating insurance benefits).
Multiple sources of support	Received or not received	Survivors identified multiple sources of support (ie, supervisors, coworkers, employer).
Other (union or client/customer)	Received or not received	Survivors identified their union as a source of support (eg, filing grievances with the union) as well as their clients/customers (ie, providing support for personal life, including meals).
None identified	Received or not received	This code was assigned when no specific organizational member was referenced.

coding scheme was created to code meaningful units pertaining to the source of organizational support (Table 2).

**Coding Type of Support**

The primary coding scheme was created using both the inductive and deductive development of codes/themes (ie, a hybrid approach).<sup>31</sup> First, we adopted a deductive theory-driven approach to identify themes because House’s<sup>9</sup> conceptual framework of three types of support—emotional, instrumental, and informational—was integrated into the wording of the open-ended question. However, after familiarization with the data (see the study by Nowell et al<sup>32</sup>), we noted that no meaningful units referenced informational support, resulting in two major themes from House’s framework: instrumental support and emotional support. We then used an inductive data-driven approach<sup>33</sup> to code responses that fell outside of House’s<sup>9</sup> framework. This approach resulted in the identification of the following three additional major themes: time-off support, nonspecific support, and no support offered. We used an inductive approach (derived from data) to identify subthemes. Lastly, coders assigned one of two codes (“received” or “not received”) to all meaningful units, to distinguish whether support was received or not.

The coding manual was used to code responses. A two-coder approach was adopted, which increases the reliability of the coding as the final set of codes is derived from the input of two coders rather than a single coder.<sup>33</sup> Two coders (R.D., S.N.) were trained on the coding procedures. After recommendations on how to improve intercoder reliability, both coders independently coded all responses.<sup>26</sup> The decision to code the entire set was based on our small sample size. It was necessary to consider all responses to capture the variation in breast cancer survivors’ experiences.<sup>26</sup> Initial intercoder agreement was good (90%). Three members of the research team (A.D., R.D., S.N.) examined all coding inconsistencies and resolved discrepancies through consensus (ie, complete agreement of three people).

**Coding Sources of Support**

Many of the responses referenced support from a specific organizational member (Table 2). An inductive approach was adopted to create the secondary coding scheme, which added a level of detail so that coders assigned a “received” or “not received” code to all meaningful units. Coders (R.D., S.N.) independently coded all responses using this secondary coding scheme and the intercoder agreement was 87%. Inconsistencies were resolved by the principal investigator (A.D.).

**RESULTS**

One hundred forty-three breast cancer survivors completed the online survey and 94 participants (65%) responded to the open-ended question central to this study and were included in the content analysis. Responses ranged in length from four characters to 950. The mean

length was 142 (approximately three short sentences). The 94 responses were subdivided when necessary, resulting in 145 meaningful units which were all coded.

**Sample Characteristics**

Table 3 describes the characteristics of respondents and nonrespondents. All participants were residents of one New England state. Participants ranged in age from 24 to 72 years (M = 51.1, SD = 9.8). A majority of the sample identified as female (98%) and White, European, or European American (98%). Most were married or lived with a partner (70%), had annual family incomes of \$100,000 or more (58%), and had a college or graduate degree (79%). Most participants reported currently being employed full-time (85%) while the rest of the sample worked part-time. The majority (59%) reported that they stopped working due to their cancer treatment, while the rest remained working throughout.

The average job tenure was 11.8 years (SD = 9.2). The most reported occupational groups were Office and Administrator Support (14%) and Business and Financial Operations (13%), likely because a sizable portion of our sample (36% of participants) were workers from a public university in the northeastern United States. More than half of the participants worked for organizations with more than 500 employees (60%) and slightly more than one third had supervisory responsibility (40%). Most of the sample (54%) had been diagnosed with later-stage breast cancer (stages 2 or 3). The majority were also in the very early survivorship period; at the time of survey completion, the average time since diagnosis was 17.4 months, or approximately 1.5 years, ranging from 0.5 to 48 months.

Only 65% of the sample responded to the open-ended question central to this study. Therefore, respondents and nonrespondents were compared on each of the demographic variables (Table 3).  $\chi^2$  analyses revealed that there were few significant differences between respondents and nonrespondents. However, respondents did differ in race, such that those who identified as Asian or Asian American, as well as those who identified as Black, African American, or African, responded at a lower rate to the open-ended question ( $P < 0.05$ ). Those who identified as White European or European American responded more frequently to the open-ended question ( $P < 0.001$ ). In addition, respondents whose treatment included surgery plus radiation, chemotherapy, or reconstruction surgery responded more frequently to the open-ended question ( $P < 0.01$ ), while those who only had surgery responded less frequently ( $P < 0.001$ ).

**Five Major Themes**

The content analysis revealed five major themes, as well as several subthemes, related to the type of support breast cancer survivors need from organizational members to manage their work and health. The five major themes included instrumental support (eg, subthemes included

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**TABLE 3.** Characteristics of Respondents and Nonrespondents to Open-Ended Question About Organizational Support

	Respondents (n = 94), n (%)	Nonrespondents (n = 49), n (%)	P
Sex			0.304
Female	92 (98%)	49 (100%)	
Male	2 (2%)	0 (0%)	
Race (check all that apply)			
White, European, European American	91 (98%)	36 (75%)	<0.001***
Black, African American, or African	2 (2%)	8 (17%)	0.002**
Asian or Asian American	0 (0%)	3 (6%)	0.015*
Ethnicity			0.391
Hispanic or Latino	3 (3%)	3 (6%)	
Not Hispanic or Latino	91 (97%)	45 (94%)	
Age by group			0.900
20–40	14 (15%)	7 (14%)	
41–60	64 (68%)	35 (72%)	
>61	16 (17%)	7 (14%)	
Marital status			0.139
Married or partnered	66 (70%)	40 (82%)	
Divorced/separated, widowed, or single	28 (30%)	9 (18%)	
Annual family income			
<\$75,000	26 (28%)	10 (20%)	0.606
\$75,000–99,999	13 (14%)	7 (14%)	
≥\$100,000	54 (58%)	32 (65%)	
Education			0.736
Graduate degree	47 (50%)	22 (46%)	
College degree (2 or 4 yr)	27 (29%)	16 (33%)	
Some college	15 (16%)	9 (19%)	
High school graduate or GED	5 (5%)	1 (2%)	
Stage diagnosed			0.110
Early-stage cancer (stages 0 or 1)	43 (46%)	29 (60%)	
Later-stage cancer (stages 2 or 3)	50 (54%)	19 (40%)	
Treatment (check all that apply)			
Surgery only	12 (29%)	29 (71%)	<0.001***
Surgery plus radiation	81 (80%)	20 (20%)	<0.001***
Chemotherapy	68 (80%)	17 (20%)	<0.001***
Endocrine therapy	50 (68%)	24 (32%)	0.587
Reconstruction surgery	33 (53%)	29 (47%)	0.007**
Employment status			0.423
Full-time	80 (85%)	43 (88%)	
Part-time	13 (14%)	5 (10%)	
Other	1 (1%)	1 (2%)	
Employer size			0.840
1–50 employees	21 (22%)	9 (18%)	
51–100 employees	17 (18%)	10 (21%)	
>500 employees	56 (60%)	30 (61%)	
Supervisory responsibility			0.907
No supervisory responsibility	56 (60%)	30 (61%)	
Some supervisory responsibility	37 (40%)	19 (39%)	
Occupations (largest groups)			0.872
Office and administrator support	13 (14%)	10 (20%)	
Business and financial operations	12 (13%)	6 (12%)	
Healthcare practitioners and technical	10 (11%)	4 (8%)	
Healthcare support	8 (8%)	3 (6%)	
management	8 (8%)	5 (10%)	
Education, training, and library	8 (8%)	4 (8%)	
Life, physical, and social science	7 (7%)	3 (6%)	
Other	28 (31%)	14 (30%)	
Job tenure by group			0.448
0–5 yr	23 (25%)	11 (23%)	
6–15 yr	42 (46%)	18 (38%)	
16–25 yr	16 (17%)	14 (29%)	
>26 yr	11 (12%)	5 (10%)	

Percentages were calculated by excluding missing cases.

Group differences were assessed using  $\chi^2$  analysis.

\* $P < 0.05$ ; \*\* $P < 0.01$ ; \*\*\* $P < 0.001$

job modifications/flexible arrangements, navigation/coordination, shared workload/replacement coverage, support for personal life, and work-related check-ins), emotional support (eg, understanding/

empathy, general emotional support, uplifting spirits, emotional check-ins, and learning/respecting survivor’s wishes), time-off support (eg, paid sick/disability leave, unpaid job-protected leave, general

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leave, and paid vacation time), nonspecific support (eg, general support), and no support (eg, no support offered, job type as a barrier to support, and cancer nondisclosure as a barrier to support). In addition, we categorized each theme and subtheme based on whether the needed support was received or not.

**Valued and Received**

**Instrumental Support**

Overall, instrumental support was the most valued and received type of support (see Table 4) and pertained mostly to helping survivors maintain their existing work role. Instrumental support was the most valued type of support with 39% of the meaningful units assigned to this category, and 86% of respondents indicating that they received this type of support. The following three subthemes related to instrumental support were especially valued: job modifications/flexible work arrangements (*n* = 26), navigation/coordination (*n* = 11), and shared workload/replacement coverage (*n* = 10). Each subtheme will be discussed in detail hereinafter.

**Job Modifications/Flexible Work Arrangements**

The most frequently cited (*n* = 26) type of instrumental support was job modification (reduced hours or workload) and the utilization of and support for flexible work arrangements (flextime or flexplace). Most survivors who cited this as an important type of support (96%) indicated that they received it. The single survivor who reported not receiving this type of support reported a desire for a modified workspace, specifically one that was a quiet and clean place to work during the time when she was going through chemotherapy, to reduce exposure to people and germs.

*“She allowed me to work from home several days a week, and to have flexible hours when I needed treatment or had to go to doctors’ appointments (which were numerous).”* – Participant 12

*“Now, I’m allowed to work from home 1–2 days/week to avoid flu season issues as well as get some rest.”* – Participant 75

*“I returned to work part-time for several weeks.”* – Participant 105

*“Being able to cut my hours during radiation was fantastic.”* – Participant 123

**Navigation and Coordination**

A second important subtheme (*n* = 11) was navigation and coordination, which pertains to accessing benefits or resources such as Family and Medical Leave Act (FMLA) leave, short-term disability, and health insurance, as well as completing associated paperwork and coordinating the various entities involved (ie, human resources [HR] staff, insurance companies, supervisors). Only 45% who cited this as an important type of support reported receiving it; the other 55% reported trouble navigating paperwork and employer benefits. Survivors also reported poor coordination from HR.

*“Our personnel department was fantastic! They made an appointment to meet to explain FMLA, took care of the notification to my supervisor. Even helped me switch insurance within our plan from co-pay to HSA, even though the deadlines had passed. Only recommendation would be for personnel to better explain to department supervisors what FMLA is.”* – Participant 68

*“I did all of the paperwork myself and handled all of the disability. I felt like I had to handle it on my own.”* – Participant 8

*“More information, support could have been offered through the human resource department. I felt as though I was drowning in paperwork.”* – Participant 47

**Shared Workload/Replacement Coverage**

Lastly, within the instrumental support domain, breast cancer survivors commonly reported others helping them with or sharing their workload and responsibilities (*n* = 10). Most of those (90%) who cited this as an important type of support reported receiving it, with members of the organization increasing their own workload and responsibilities to lessen survivors’ work demands. Some participants reported managers and coworkers informally and voluntarily covering their workload, whereas others reported more formal means of lessening their workload, such as job-sharing or their organization hiring a temporary replacement.

*“Some coworkers took on additional duties.”* – Participant 25

*“My supervisor planned for a temporary replacement to do my job while I was out on disability.”* – Participant 75

*“I did not know how I was going to feel from day to day. It would have been good if they told me not to worry about work at all and they*

**TABLE 4.** Most Valued or Desired Types of Support From the Employer: Received Versus Not Received

Major Theme/Type of Support	Subtheme/Specific Support	Total, <i>n</i> (%)	Support Received, %	Support Not Received, %
Instrumental support		56 (39%)	86%	14%
	Job modifications/flexible arrangements	26 (18%)	96%	4%
	Navigation/coordination	11 (8%)	45%	55%
	Shared workload/replacement coverage	10 (7%)	90%	10%
	Support for personal life (meals, transport, finances)	6 (4%)	100%	0%
	Work-related check-ins	3 (2%)	100%	0%
Emotional support		29 (20%)	90%	10%
	Understanding/empathy	8 (6%)	75%	25%
	General emotional support	7 (5%)	100%	0%
	Uplifting spirits (cards, gifts, support for cancer orgs.)	6 (4%)	100%	0%
	Emotional check-ins	5 (3%)	100%	0%
	Learning/respecting survivor’s wishes	3 (2%)	67%	33%
Time-based support		23 (16%)	74%	26%
	Paid sick/disability leave	9 (6%)	67%	33%
	Unpaid job-protected leave	6 (4%)	67%	33%
	General leave	5 (4%)	100%	0%
	Paid vacation time	3 (2%)	67%	33%
Nonspecific support		12 (8%)	100%	0%
No support	General support	12 (8%)	100%	0%
	No support offered	25 (17%)	4%	96%
	Job type as a barrier to support	17 (12%)	0%	100%
	Nondisclosure of cancer as a barrier to support	5 (3%)	20%	80%
		3 (2%)	0%	100%

*N* = 145 meaningful units.

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would cover for me. But that did not happen, they expected me to do the same job through the treatments and surgery.” – Participant 53

Additional forms of valued support within the instrumental support domain included members of the organization offering support for survivors' personal lives including providing meals for them and their families, accompanying/transporting survivors to medical appointments, and financial assistance in the form of fundraisers for medical expenses ( $n = 6$ ), as well as work-related check-ins ( $n = 3$ ).

“Also, when I was out after the surgeries, they set up a rotation and fed me and my family every night for two weeks.” – Participant 123  
 “Colleagues provided support, attended appointments with me.” – Participant 36

“Many of my colleagues put money together and provided me with a check to help with medical bills if needed.” – Participant 120  
 “Weekly chats with my direct supervisor.” – Participant 72

### Emotional Support

Emotional support was valued and mostly received by breast cancer survivors. Twenty percent of the meaningful units were categorized as emotional support; of these responses, 90% indicated receipt of this type of support. Within the emotional support theme, there were two important subthemes, understanding and empathy ( $n = 8$ ) and general emotional support ( $n = 7$ ).

### Understanding and Empathy

The most frequently cited subtheme was related to members of the organization being understanding and empathic to the needs and feelings of survivors ( $n = 8$ ); most of those who cited this as an important type of support (75%) reported receiving it.

“My supervisor was very supportive, was able to talk to her freely, she was very understanding.” – Participant 6

“My old supervisor was very supportive...he had a medical heart condition... so we spoke a lot about the importance of life... very understanding.” – Participant 103

However, two survivors reported not receiving this type of support, indicating that others at work were not understanding or empathic.

“...but my supervisor would often complain about the impact my being out would have on her. In other words, I was given the time to take off because the law allowed for it, but there were often backhanded comments when work piled up.” – Participant 91

### General Emotional Support

A second important subtheme was nonspecific emotional support (eg, open and caring communication), which refers to emotional support without a specific motivation or outcome. All ( $n = 7$ ) who referred to this type of support, reported receiving it (100%).

“Emotional support with an open door.” – Participant 148

“They were verbally supportive.” – Participant 29

Additional subthemes included members of the organization uplifting survivors' spirits by giving gifts and cards, and supporting breast cancer organizations on the survivors' behalf ( $n = 6$ ), checking in with an attitude of compassion ( $n = 5$ ), and learning/respecting the wishes of survivors regarding whether and how others acknowledge that they have cancer (ie, whether they desire that others give them privacy and do not bring it up, show concern by talking about it, or treat the survivor as if they did not have cancer and everything was status quo “normal” ( $n = 3$ )).

“My coworkers were phenomenal, created a support team, special t-shirts and sponsored a walking team in my name at the Annual (Breast Cancer) Walk.” – Participant 31

“I received flowers and many cards and emails offering support.” – Participant 120

“During chemo, supervisor and coworkers would check in with me regularly and were very caring.” – Participant 109

“On all levels, supervisors, coworker and people I supervise kept my information quiet and respected my request to which made it so much easier upon my return.” – Participant 71

“In general, people just pretended that I was not going through treatment and that everything was the same as always.” – Participant 43

## Valued but Not Received

### Time-off Support

A unique theme emerged that could not be categorized as instrumental, emotional, or informational support. Many meaningful units were best understood as a type of time-based support related to allowing and supporting survivors to take job-protected time off to disengage from their work role to receive medical treatment and follow-up, and for physical, mental, and emotional recovery. Overall, time off support was valued but the least-received type of support. Sixteen percent of meaningful units were categorized as time-off support, and of these responses, 74% indicated receipt of this type of support. We identified two important subthemes: paid sick/disability leave ( $n = 9$ ) and unpaid job-protected leave (ie, FMLA) ( $n = 6$ ), which we will discuss in detail hereinafter.

### Paid Sick/Disability Leave

The most frequently reported subtheme was paid sick/disability leave ( $n = 9$ ). Of those who referenced this type of support, 67% reported receiving it. Some survivors reported the need for sick time and paid time off to be available to part-time employees.

“I was able to use accumulated sick time and I used 90 sick days. I also participate in a sick day bank that was available if I did not have enough.” – Participant 44

“Would have been nice to have paid time for the surgeries.” – Participant 57

“The company was not flexible in giving me more sick days for tests and treatment. I had to take time-off without pay.” – Participant 78

“Provide a benefit for sick time/paid time-off to part-time employees. I went back to work too soon because I had to for money.” – Participant 41

### Unpaid Job-Protected Leave

The second most frequently reported subtheme ( $n = 6$ ) was unpaid job-protected leave per the national FMLA. In the United States, FMLA provides certain employees with up to 12 weeks of unpaid, job-protected leave per year. It also protects health benefits during the leave. Of those who referenced this type of support, 67% reported receiving it. Some survivors experienced backlash for using FMLA, and others reported a need for FMLA for part-time employees.

“I applied for FMLA to protect my job status. Immediate supervisors and coworkers were very supportive about me taking the time-off, as needed, for treatment and recovery.” – Participant 110

“...I felt my supervisor was cold and somewhat resistant to filling out my continued FMLA but did when I pushed for it to get done ASAP otherwise disability would stop.” – Participant 109

“I did not qualify for FMLA since I was part-time.” – Participant 17

Additional time-off support subthemes included general leave ( $n = 5$ ) and vacation time ( $n = 3$ ).

“And they really encouraged for me to take the time I needed to recover physically, mentally, and emotionally. I am truly blessed!” – Participant 16

“And having been there ten years, I had a healthy bank of vacation time to use for doctor appointments and surgery recovery.” – Participant 61

### Nonspecific Support

Some responses did not reference a type of support and thus were categorized as nonspecific support.

### General Support

Eight percent of the meaningful units were categorized as non-specific general support, as many survivors reported general support without a specific motivation or outcome ( $n = 12$ ).

*“My supervisors, colleagues and others were very supportive.”* – Participant 127

*“They were supportive in every way possible.”* – Participant 4

### No Support

Many of the responses did not reference a type of support but instead indicated that the survivor did not receive any support (17%). These responses were further divided into the following three subthemes: no support offered ( $n = 17$ ), job type as a barrier to support ( $n = 5$ ), and cancer nondisclosure as a barrier to support ( $n = 3$ ).

### No Support Offered

Seventeen meaningful units indicated that no support was offered to survivors by members of their organization.

*“I didn’t. No one came to my house. The emails and texts stopped almost immediately after surgery. When I returned to work, I was expected to work 60 hours a week with short turnarounds.”* – Participant 63

*“They didn’t provide me with any. I had to file a grievance with the union.”* – Participant 96

### Job Type as a Barrier to Support

Five meaningful units indicated that the type of job or position that the survivor had was related to the lack of support provided by organizational members. One survivor referenced the job as a barrier to support but still reported receiving support, whereas the others reported not receiving support because of their job type.

*“There was no real way to accommodate my cancer treatment with the business of being an ER or OR nurse.”* – Participant 8

*“I am a trial judge and was/am on the bench so I can’t work from home.”* – Participant 33

### Cancer Nondisclosure as a Barrier to Support

A small number of breast cancer survivors ( $n = 3$ ) reported that they did not disclose cancer to members of the organization and thus did not receive support.

*“I didn’t get any support for supervisors or coworkers because they didn’t know I had breast cancer or that I was going through treatment.”* – Participant 93

*“If I had a better, more trusting relationship with my boss, I would have liked to tell him of the breast cancer diagnosis. It would have been helpful and less awkward.”* – Participant 30

### Sources of Support

In addition to the type of support, we were also interested in sources of support to provide insight into our third research question regarding who in the organizational setting did or did not provide employment-related support to survivors. A substantial portion of responses ( $n = 46$ ) referenced a particularly supportive organizational member (Table 5), but because we did not ask specifically about sources of support, this list is not exhaustive (ie, there may be other members of the organization not on the list who also offered support). We only created codes for the specific organizational members cited in the responses to our question. Many referenced the role of multiple sources of support ( $n = 21$ ), and of those, 95% reported receiving support from multiple sources.

*“My boss, coworkers, and friends were absolutely amazing during everything I went through, before, during and after my diagnosis. I could not have asked for a better group of people.”* – Participant 7

**TABLE 5.** Sources of Support in the Organization: Received Versus Not Received

Major Theme/Source of Support	Total, <i>n</i> (%)	Support Received, %	Support Not Received, %
Multiple sources	21 (15%)	95%	5%
Supervisor	16 (11%)	81%	19%
Coworker	15 (10%)	100%	0%
Employer	8 (6%)	75%	25%
Human Resources	5 (3%)	30%	60%
Other (union, client/customer)	2 (1%)	50%	50%
None identified	78 (54%)	N/A	N/A

*N* = 145 meaningful units.

N/A, not applicable.

Many breast cancer survivors specifically referenced the role of their supervisor in their responses ( $n = 16$ ); of those, 81% reported receiving support from their supervisor.

*“There was a couple of weeks where I was depressed and stressed because I was waiting for some test results, and she [supervisor] was totally understanding and flexible with my work.”* – Participant 12

In addition, many survivors referenced the role of coworkers in their responses ( $n = 15$ ); of those, 100% reported receiving support from coworkers.

*“My coworkers provided the most support and help when I was tired. They let me slack and rest and would support me through the treatment. They helped a lot.”* – Participant 106

However, the role of HR was not as positively perceived. A few participants mentioned the HR department in their responses ( $n = 5$ ), but of those, only 30% reported receiving support from HR.

*“HR could have played a bigger role in coordinating and assisting with my short-term disability options as an employee.”* – Participant 54

Other organizational members cited in responses were the employer ( $n = 8$ ), and others related to the work organization (union, clients/customers) ( $n = 2$ ).

## DISCUSSION

Our study highlighted the types of support desired by working breast cancer survivors from their employing organizations in relation to the types of support actually received from their organizations. We were encouraged by the significant response rate to the single open-ended survey question posed to survivors, as well as the richness of ideas presented in terms of defining important elements of organizational support that may have been missed by quantitative approaches. One concerning finding was that a substantial portion of survivors (12%) reported that they did not receive any support, which suggests an opportunity to raise awareness generally within organizations about the needs of workers living with chronic health conditions such as cancer, the importance of providing them various types of support, and the most beneficial types of support to provide workers.

The most frequently-reported desired and received types of support were related to instrumental support (practical, tangible assistance) provided to breast cancer survivors by members of the organization, particularly those related to job modifications (reduced hours or workload) and flexible work arrangements, in which workers are given the leeway to carry out their work responsibilities outside the temporal/spatial boundaries of standard work arrangements (ie, flextime, flexplace).<sup>34</sup> This is consistent with the results of Kennedy et al<sup>14</sup> suggesting that this type of support is not only crucial during early survivorship but is also important over time throughout the survivorship journey. More recent research has shown that instrumental support

(practical help related to adapting job tasks, work environments, and working hours) is considered by employees with cancer as one of the most desired actions for employers to take during the return-to-work process and beyond,<sup>13</sup> as health-related challenges do not always end once a survivor returns to work. Cancer survivors reported work adjustments such as utilization of flexible work arrangements as a means of managing work and health demands, which is consistent with studies showing that flexibility promotes harmonization between work and personal life.<sup>35</sup>

## Addressing Barriers to Support

The difficulty of navigating the complexity of the health care and disability systems was a common problem raised by study participants. One solution to this difficulty could be a return-to-work coordinator, which are often provided through health care and insurance systems to assist workers with more acute injuries or health events; however, intermittent or chronic problems rarely receive this level of individualized support. Still, the availability of a return-to-work coordinator is recognized as an essential and evidence-based element of organizational support for ill or injured workers.<sup>36,37</sup> As we found in our study, workers with other chronic health conditions report similar frustrations with complex benefit structures and the lack of communication between HR, healthcare providers, and supervisors to reach satisfactory accommodation or sick leave arrangements.<sup>38</sup> Future programs might investigate whether the addition of a system navigator or return-to-work coordinator for working cancer survivors might improve occupational outcomes.

Emotional support was particularly important, consistent with recent findings that emotional support (ie, showing interest, being involved and understanding) is perceived by employed cancer survivors as one of the most desired employer actions during the return-to-work process.<sup>13</sup> Although emotional support is important in and of itself, it may also be the key to formal support, as some participants in this study reported that even when formal organizational support exists in the form of policies, programs, and practices that are helpful to survivors, there is not always informal (emotional) support for survivors when they want to use those benefits or entitlements.

Emotional support in the form of understanding and empathy was an unmet need for some survivors in this study. Empathy has two important components including perspective taking (ie, cognitively understanding another person's point of view and seeing the world from their perspective) and empathic concern (ie, emotionally attending and responding to another person's situation and/or emotions).<sup>39</sup> According to Burch and colleagues,<sup>40</sup> empathy can be perceived at various socioecological levels (eg, intrapersonal, interpersonal, group, organizational, etc). Within workplaces, empathic practices are associated with more positive organizational cultures and interpersonal interactions; within individuals, they are linked with prosocial behaviors (eg, providing help) and better job performance, particularly among organizational leaders.<sup>41–43</sup> Empathy is a skill that can be learned through training, coaching, and other professional and leadership development initiatives and should be examined further as a means of providing needed organizational support for working survivors.<sup>44</sup>

Another form of emotional support pertains to people at work learning about and respecting a survivor's wishes regarding discussing their cancer, which is a subjective matter and a personal decision. Some survivors prefer to maintain privacy by not disclosing or discussing their cancer diagnosis with anyone at work, while others want to be open about their situation and to have others at work acknowledge what they are going through. Recent research suggests that there may be a discrepancy between how employers assume survivors want to be treated and how survivors themselves actually want to be treated.<sup>13</sup> Specifically, in a study on what employers and employees perceive to be the most important employer actions to support the return to work of employees with cancer, employers perceived that one of the most important supportive actions was to treat the employee

with cancer as if they were not ill; however, this action was not endorsed as most important by survivors themselves.<sup>13</sup> Our findings suggest that for some employees, such "business as usual" treatment may in fact be detrimental. Paying attention to the preferences of individual survivors about how they want to be treated, rather than making broad and uninformed assumptions, may be an important way to help survivors feel supported by their organizations. Greidanus et al<sup>45</sup> encourage researchers to develop interventions that avoid a one-size-fits-all approach and use effective workplace-survivor communication to tailor organizational support to survivors' individual preferences and needs. This is a topic that warrants further research.

## Time off for Health

While we found that instrumental support was valued mainly because it allowed survivors to remain connected to their work role (ie, by reducing their workload or making it easier to manage demands), time-off support was valued because it allowed survivors to disconnect from their work role to permit time for medical care and recovery, without the worry about losing their jobs. Health-related activities can require considerable time, particularly for people who are in poor health, have a disability, or are older.<sup>46,47</sup> Cancer patients need time for primary treatment, medical follow-up, and rehabilitation, but they also require time for ongoing health-related self-care.<sup>48</sup> This includes self-management activities such as monitoring health, managing symptoms, navigating health services, engaging in health behaviors, maintaining psychological well-being, using social support, and nurturing a fulfilling lifestyle.<sup>49,50</sup> People with chronic health conditions report insufficient time to attend to health-related activities.<sup>51–54</sup> They often attribute this situation to the work role placing simultaneous and incompatible demands on the same finite time and energy resources needed to engage in health-related activities; this distressing situation may be exacerbated when family role demands are high, which is especially relevant to women.<sup>55,56</sup>

The mounting evidence for this type of interrole conflict—work-health conflict—corroborates the call by other researchers to expand the scope of research on the work-life interface, which has overlooked other life roles and focused almost exclusively on the work and family domains.<sup>57</sup> Our findings support the existence of a health role, a relatively underdeveloped concept from medical sociology referring to how society expects people to behave to protect and promote their health.<sup>58–60</sup> That is, people (even healthy ones) are generally expected to avoid behaviors that bring about poor health and behave in ways that are conducive to good health, engaging in self-care activities that enhance health, prevent disease, limit illness, and restore health.<sup>61,62</sup> For critically ill people, the health role may feel like a full-time job<sup>51</sup> and may even require prioritization above other life roles, including one's paid job, which is why work leave is essential. Conventional role theory requires an upgrade, and a deeper examination of the health role—as well as its relation to the work role—is warranted to more fully understand the lived experiences of the working survivor population. This may enable organizations to better support the health role, which seems to be a key factor to survivor health and work retention.

Our findings about paid and unpaid time off from work being an unmet need among survivors are consistent with a recent study's findings that sufficient time off for sick leave is considered by employees with cancer as among the most desired actions experienced from employers during the return-to-work period.<sup>13</sup> Among private employers in the US, only 75% of workers have paid sick leave benefits, and the median limit is 15 paid sick days per year.<sup>63</sup> In our study, job-protected unpaid leave was perceived as important, but the value of paid leave employment benefits, such as sick days and vacation time, must be underscored as they relieve stress and prevent financial hardship by reducing the need to take unpaid time off during cancer

treatment and recovery.<sup>64</sup> Paid leave has associations with worker well-being, financial security, and longevity.<sup>65</sup>

Our study results pertaining to work leave are not always found in similar studies of organizational support (mostly international), likely due to our sample being based in the United States where there is no publicly mandated employment standard permitting workers paid time off for medical reasons. Rather, sick leave varies by employer, and 40% of U.S. workers do not have paid sick leave,<sup>64</sup> and part-time workers rarely have sick leave. State and national policies in the United States are important as these are the levels at which (in addition to health insurance) many employment regulations are enacted, including national policies that apply differently based on employer size (eg, Americans With Disabilities Act, Family Medical Leave Act) and state policies additionally enacted by individual states (eg, some US states provide paid family and medical leave).<sup>66</sup> A study of paid sick leave policies in 22 rich counties globally (highly ranked in economic and human development) found that the United States is the only country that does not guarantee any form of paid sick leave.<sup>67</sup>

Surprisingly, informational support was absent. It is unlikely that informational support was not provided to the breast cancer survivors, so this finding may be due to the wording of the open-ended survey item which asked breast cancer survivors to report on various types of support, and from various sources. It could also be that informational support was not the most valuable type of organizational support and was thus overshadowed in self-reports by more valued types of support. However, it should be noted that another recent study<sup>13</sup> also did not find that informational support was considered by employees with cancer as among the most desired types of employer support during return to work. It is possible that survivors prefer informational support from their cancer clinicians rather than their work organizations, as was found in a previous study.<sup>68</sup>

### Support From Organizational Sources

There was a clear indication from cancer survivors of the need for improved organizational support from managers and HR contacts. Supervisors and HR professionals may have difficulty understanding and acting on complex diseases. They may benefit from training designed to make communication and accommodation efforts more effective and to find the right balance between providing empathy and support while also respecting individual privacy concerns. In other studies of workers with chronic health conditions, supervisors have indicated a need for better training related to communication and job accommodation and have expressed concerns about how to respect worker privacy, understand company policies, and adhere to disability regulations.<sup>69</sup> Supervisors have also recognized that the accommodation process for chronic conditions can involve iterative processes and regular adjustments.<sup>70</sup> Training programs for supervisors could help to clarify elements of job leeway, productivity goals and requirements, and the need for coordination with other workers or workplace systems while heeding established policies and regulations. This may, in turn, help cancer survivors to feel more confident about making appropriate requests for accommodation.

Our findings also suggest a deficit in institutional policies and employee communications. While documentation is available regarding national (eg, FMLA) and union policies regarding long-term medical leave, a future area of research would be to evaluate the ease of obtaining documentation and receiving adequate guidance from HR, employees' direct supervisors, or union staff. In a review of studies testing return-to-work interventions, Tiedtke and colleagues<sup>71</sup> suggest that multidisciplinary approaches to policy development are critical to ensure critical concerns are addressed (eg, treating physicians, employers, insurance providers) and as a basis to improve and coordinate communications with working cancer patients. While there remains a paucity of evidence about successful programs, a randomized trial assessing the effectiveness of a multidisciplinary return-to-work program for employees is underway in the Netherlands.<sup>72</sup>

### Theoretical Significance

Our findings, though preliminary, support prior literature suggesting that two forms of support from House's<sup>9</sup> taxonomy are particularly important for survivors to receive from employing organizations to help with employment-related concerns: instrumental and emotional support.<sup>3,9,10</sup> Our findings tentatively suggest that survivors may not value informational support to the same degree as instrumental and emotional support at work. This is consistent with another recent study,<sup>13</sup> which also found that informational support was not considered by survivors among the most desired types of employer support during return to work. Being that it is likely that employees with cancer do receive informational support, possibly from clinical sources,<sup>68</sup> future research ought to direct specific survey questions regarding informational support to further position its value in relation to other forms of support at work. Moreover, we extend the literature on this topic by identifying another facet of support—time-off support—that may be influential in the experiences of cancer survivors in addressing their health- and work-related concerns. Work-health conflict is an emerging theme that should be explored further within role theory, especially in the context of paid/unpaid time off, sick leave, and flexible work arrangements, which were identified as commonly valued, but often unmet needs.

One interesting implication that requires further study concerning the experiences of workers who have breast cancer (and those treated for cancer generally) is the shift in work environments due to COVID-19. Many more persons have worked from home, and indications are that this may be a relatively permanent change after COVID-related work patterns diminish. The result may be that some work arrangements found to be important in this study—such as flexibility in work setting and timing, may be more acceptable when managing situations related to cancer treatment or sequelae. At the same time, social support and having coworkers share a survivor's workload could diminish as a result of fewer opportunities for in-person interaction. Only further comparative study can answer such important questions.

### Study Limitations

The survey item wording made the qualitative analysis challenging as we had one question with multiple possible responses; some respondents answered part of the question while others answered multiple parts. Our survey question did result in valuable insights, and the decision to create and examine meaningful units allowed us to capture responses to all facets of the question, but trying to answer three research questions with a single open-ended survey question posed a challenge. A better option would have been to break down the open-ended question into a minimum of two parts, so that one survey item addressed type of support, while a second survey item assessed the source of support. Caution should be used when interpreting study results, given that only 65% of the original sample was included in our content analysis (because they responded to the open-ended survey question central to this study), while a sizeable percentage of respondents did not answer the question. It is also possible that our findings could have been different if the survey question had been posed in a more parsimonious manner.

This study used convenience-based sampling rather than a population-based sampling approach and caution should be used when extrapolating the frequency of response items to working breast cancer survivors more broadly. Furthermore, the sample population was a highly educated, mostly married, English-speaking group from a wealthy Northeast state in the US, which does not represent workers who face the greatest health, work, and financial hardships, including those with lower household incomes, who are unmarried, of racial/ethnic minority status, and residing in rural areas.<sup>66</sup> Workers with lower-status jobs, insecure employment, or part-time positions may also lack access to comprehensive, affordable health insurance coverage,

flexible work arrangements, job accommodations, and job-protected work leave (ie, paid or unpaid sick leave, vacation time, and short-term disability pay). This raises further caution regarding the generalizability of our findings to a different type of working population.

### Practical Significance

Given the qualitative nature of this study, as well as the small and limited sample, further research is needed to confirm our initial findings. However, our findings about valued, but infrequently received forms of work-related support (ie, paid and unpaid time off, sick leave, navigation/coordination) would suggest that in the United States, employers may lack the resources, tools, and communication skills to appropriately address the employment-related concerns of a segment of working breast cancer survivors. Given the lack of publicly mandated policies regarding paid time off for medical reasons, educating employers about the specific needs of working cancer survivors and support for their health role through other avenues, such as interventions and training, seems crucial. This is in line with international research suggesting that some survivors report increased support when they live in countries with stronger initiatives for educating employers about their responsibilities and how to make accommodations for cancer survivors.<sup>70</sup>

In addition, beyond merely educating employers, establishing means for providers and employers to coordinate a structured return-to-work process in advance of the return may be helpful in supporting survivors. This is congruent with a qualitative study regarding supportive practices for breast cancer survivors, in which the importance of preparing ahead of time with the employer for the return to work was underscored.<sup>73</sup> In the long term, such findings suggest that beyond the organizational level, survivors could receive more support if changes were made at the policy level as well. Ultimately, there would be great value in determining what factors produce a profile for successful work retention among survivors, although fully assessing barriers to continued work participation may require different methods than those used in our study, such as studying participants who were not able to return to work, or those who changed their job after cancer diagnosis and treatment.

### CONCLUSIONS

Breast cancer survivors perceive organizational support as important to day-to-day coping and workplace retention. Our study highlighted survivors' specific unmet needs for organizational support related to navigation/coordination, understanding/empathy, and availability of job-protected time off. More research examining social support in this group is needed to confirm these initial findings. In particular, further study could identify ways that organizations can help workers manage their health role and diminish work-health conflict, as conventional role theory and social support delineations do not capture these key workplace factors to successful work sustainment. Findings from our study can inform the design of targeted interventions to better support survivors and possibly workers living with other chronic health conditions, including a broader set of organizational and policy tools that are considered central by the survivor population. There remains a substantial gap of knowledge, however, about stakeholder-based processes to develop best practice return-to-work programs.

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