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Patient-Provider Communication: Experiences of Low-Wage-Earning Breast Cancer Survivors in Managing Cancer and Work

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Abstract

In 2017, there will be more than 250,000 new diagnoses of invasive breast cancer; most cases will occur in working-age women. The goal of this qualitative study was to explore low-wage-earning breast cancer survivors' experiences communicating with their oncology team about cancer and employment issues. Twenty-four low-wage-earning breast cancer survivors in the USA were interviewed in 2012 using a structured interview protocol. Sociodemographic data, cancer history, and patient-provider communication experiences regarding the management of cancer and work were collected. Interviews were analyzed using grounded theory strategy of constant comparative analysis. Low-wage-earning breast cancer survivors' experiences communicating with their oncology team about employment and cancer focused on three dimensions of patient-provider communication: extent, quality, and content. Over 70% of respondents reported no communication or only routine communication with their providers regarding work; three quarters of women reported poor or standard communication quality, and content of work-related communication covered scheduling issues, work absences, continuing to work during treatment, and financial concerns. Communication between oncology care teams and low-wage-earning cancer patients is critical to the successful management of treatment and work responsibilities given the vulnerable employment situation of these women. There is a need for education of oncology team members about how cancer and its treatment can impact employment for all workers, but especially for low-wage workers, thereby allowing the care team to address these issues proactively and help patients successfully manage both cancer treatment and work responsibilities.

Keywords Low-wage-earning breast cancer survivors · Communication · Working-age women · Employment · Qualitative research

Background

In the USA, 12% of women will develop breast cancer in their lifetime; there will be more than 250,000 new, invasive diagnoses in 2018 [1]. Breast cancer survivors are the largest group of cancer survivors, totaling more than 3.5 million in 2016 [2]. Most breast cancer cases occur in working-age women; approximately 60% are diagnosed in women ages 20 to 69 [3]. Indeed, research suggests over 80% of women return to work within 12–18 months following breast cancer [4], yet returning to work includes challenges such as financial stress, changes to work hour/roles, learning to cope with physical/cognitive limitations, and risk of future unemployment [5].

These challenges may be magnified among low-wage-earning workers diagnosed with breast cancer because low-wage jobs—those that pay less than two thirds of the median male wage [6]—are less likely to offer benefits that aid employed survivors such as the following: paid leave, workplace accommodations, and flexible work hours [7]. Women who hold low-wage jobs are also less likely to take the recommended time off from work following a cancer diagnosis and are more likely to work during treatment [8], given that missing a few days of work could have dire financial consequences, creating a struggle between cancer survival and economic survival

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[8]. This phenomena is particularly concerning given the current prevalence of low-wage employment; these jobs now employ more than 25% of all working Americans [9] and 76% of those who work in the top ten largest low-wage jobs are women [10].

Patient-provider communication (PPC) is critical in cancer care, as education and information provided by oncology providers on how cancer may impact patients' ability to work and/or maintain employment has been linked to positive treatment outcomes [11]. Relatedly, breast cancer survivors have reported that employment is an important source of emotional and financial support [12] and being able to work provides a sense of normalcy and an improved ability to cope with negative side effects [13]. Yet, work-related guidance from providers is often limited and inconsistent [14, 15]. Survivors have reported that their doctors provided no information pertaining to how cancer might influence their work life [14] and oncology providers report feeling limited in their ability to address work topics with patients [16], citing minimal guidance, limited access to work-related resources clients may need, and concerns regarding their knowledge of how cancer may impact work [16].

Research on cancer and work has primarily addressed the return to work and related outcomes, while the role of patient education and the associated responsiveness of the care team to address co-management of work and treatment has received comparatively minimal attention [11]. Furthermore, only recently have studies begun to address PPC specifically from the perspective of the patient and even fewer have examined the perspectives of employed cancer patients, especially low-wage-earning individuals, although patient perceptions of provider communication frequency and/or quality have been found to vary in relation to patient socioeconomic status [17]. To fill this research gap, the purpose of this qualitative study was to examine low-wage-earning breast cancer survivors' experiences with communicating with their oncology team about employment and work issues.

Methods

Sample

Between June 2012 and August 2012, breast cancer survivors in Kentucky were recruited for this exploratory study. The data were collected as part of a study with a broader aim of better understanding the cancer-work interface and the decisions and strategies used to co-manage cancer and work responsibilities, as employed by breast cancer survivors working in low-wage jobs [18]. PPC about employment was inclusive within this aim. Eligibility criteria included the following: (1) receiving a new diagnosis of primary, incident breast cancer within the past 3 years, (2) working 30 h/week or more at one or more jobs at time of diagnosis, (3) earning less than $15/h at time of diagnosis, and (4) between ages 18 and 65. Using the social inclusion measure of low-wage work [6], income eligibility criteria was calculated to include those who earned less than two thirds of the median male wage in Kentucky in 2012.[1]

Data Collection

Participants were recruited via community-based, purposive sampling using passive (e.g., newspaper articles, word of mouth, flyers) and active approaches (i.e., letter to breast cancer survivors receiving services from a regional nonprofit cancer organization serving low-income clients). Participants called a designated phone number to inquire about study participation; those who met criteria were interviewed via phone and informed consent was obtained verbally. A total of 24 women participated in the study.

A semi-structured interview protocol—informed by relevant literature and practice expertise of the research team—was used to ensure interviewer consistency [20]. All interviews were digitally recorded, except two cases where notes were taken by the interviewer, including one case where the audio recorder malfunctioned and one participant who did not grant permission for recording. Data was collected on women's sociodemographic characteristics, cancer history, and experiences managing employment and other work-life demands post-cancer diagnosis. Broadly, participants were asked if providers discussed their work situation with them, how providers helped them manage treatment and job responsibilities, and whether or not they received any information to help them concurrently manage job responsibilities and cancer care. Additional probing questions were used to clarify points made by a participant or to solicit more detailed information about their interactions (or lack thereof) with providers. PPC issues also arose spontaneously in other areas of the interview, which we captured in our analysis. Interviews were conducted until reaching saturation, such that no new information was being collected and consistency of findings had emerged [21]. Women received $30 for their participation. Study procedures were approved by the University of Kentucky Institutional Review Board (Protocol No. 12-0005-P6H).

Data Analysis

Participant interviews were manually analyzed utilizing the grounded theory strategy of constant comparative analysis, wherein similarities and differences across interviews were examined and defined through repeated discussions and transcript reviews among the three-member research team [21]. Of

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[1] According to the social-inclusion definition of low-wage [6], low-wage jobs are those that pay less than two thirds of the median wage for men. The median wage for men in KY was approximately $14.50 per hour in 2012 [19]. We rounded this number up to $15.00 per hour for the ease of recruitment and our definition of low-wage is also comparable to 135% of the US poverty line for a family of four in 2012, when this study was conducted.

the 24 women interviewed, two interviews were excluded from analysis, as the interviewer did not explicitly ask participants about PPC regarding cancer and work; the final sample included 22 women. Selective coding allowed for identification and refinement of core categories, both as independent themes and as interrelated concepts [21]. Analyses continued until no additional information was able to be derived from the data and further coding was no longer possible [21]. Study design, methodological rigor, and clinical accuracy were ensured via (1) strategic selection of interdisciplinary researchers with experience in social work, cancer control, and working with cancer survivors in Kentucky and (2) use of an informal advisory panel consisting of oncology providers, cancer advocates, a clinical psychologist, and academic researchers.

Results are organized around three primary dimensions of PPC that emerged from the interviews: extent, quality, and content. *Extent* of PPC about work refers to whether or not conversations about managing cancer and work occurred *and* the scope of these conversations if they did happen. *Quality* of PPC pertaining to cancer and work is defined as the degree to which this communication was patient-centered, or responsive to patient needs, values, and/or preferences, as they pertained to work [22]. *Content* of PPC refers to the work-related topics discussed between patients and providers. These three dimensions were examined separately.

Results

As presented in Table 1, 21 women reported their race as White (96%). The average age was 49.8 years (SD = 8.6) and almost 60% had completed at least some college education. Most women discovered their breast cancer via self-exam (64%); average age at time of diagnosis was 47.9 years (SD = 8.9). Occupations varied, with the largest employment categories being retail (27%) and healthcare/social assistance (23%). The average hourly wage at the time of diagnosis was \$11.54 (SD = \$2.03). Each participant's specific occupation and hourly wage is also listed in Table 2 to provide additional context about the sample of women who participated in the study.

Low-wage-earning breast cancer survivors' experiences communicating with their oncology team about employment and cancer issues focused on three different dimensions of PPC that we refer to as extent, quality, and content. Subsequently, participant responses were grouped within each of three areas (Table 2). For the purposes of this paper, the dimensions are examined individually; however, there was overlap between them in some cases.

The first dimension of PPC, *extent*, is represented across three categories—none, routine, and extensive. Two women reported that their providers did not ask about their work needs or discuss the concurrent management of treatment and work. For example, when asked if she had any conversations with her doctor about how to manage her treatment appointments along with her work schedule, one woman replied, "No. I kindly managed my appointments myself" [participant 21].

Table 1 Study participant characteristics ($N = 22$)

Variable	*n* (%)
Race	
White	21 (95.5)
Non-White	1 (4.5)
Educational level	
Less than high school	1 (4.5)
High school/GED	8 (36.4)
Some college	2 (9.1)
2-year college degree	3 (13.6)
4-year college degree	4 (18.2)
Master's degree	4 (18.2)
Marital status	
Married	10 (45.5)
Not married	12 (54.5)
Parental status	
At least one child < 18 years of age	7 (31.8)
No children < 18 years of age	15 (68.2)
Industry	
Food/hospitality	2 (9.1)
Healthcare/social assistance	5 (22.7)
Manufacturing	4 (18.2)
Retail	6 (27.3)
Other (e.g., financial)	5 (22.7)
Source of health insurance	
Employer/spouse employer	16 (72.7)
Medicaid	4 (18.1)
Self-insured	1 (4.5)
None	1 (4.5)
Access to paid leave from employer	
Yes	15 (68.2)
No	7 (31.8)
Stage of cancer at diagnosis	
I	7 (31.8)
II	8 (36.4)
III	0 (0.0)
IV	3 (13.6)
Unsure	4 (18.2)
Cancer discovery method	
Mammogram	5 (22.7)
Breast self-exam	14 (63.6)
Exam and symptom(s)	3 (13.7)
Treatment status at time of interview	
Pre-treatment	1 (4.5)
Currently receiving treatment	7 (31.8)
Completed treatment	14 (63.7)
	Mean (SD)
Age (years)	49.8 (8.6)
Age at diagnosis (years)	47.9 (8.9)

Fifteen women reported that the extent of communication they had with their providers regarding cancer and work was routine. *Routine* was defined as the provision of basic information or advice upon request (e.g., how many days to take off for recovery from surgery, physician note for work absences or side effect management, and/or scheduling of medical appointments to fit with work schedule). *Routine* communication about work was generally initiated by the women and

Table 2 Dimensions of patient-provider communication in managing cancer and work among low-wage-earning breast cancer survivors ($N = 22$)

Participant[b]	Occupation	Hourly wage at diagnosis	Patient-provider communication									
			Extent			Quality			Content[a]			
			None ($n = 2$)	Routine ($n = 15$)	Extensive ($n = 5$)	Poor ($n = 1$)	Standard ($n = 14$)	Exemplary ($n = 5$)	Scheduling ($n = 5$)	Time off ($n = 12$)	Continuing ($n = 13$)	Financial ($n = 4$)
1	Uniform store owner	$8.33		X			X				X	
2	Cosmetic consultant	$12.50		X			X				X	
3	Bookkeeper	$11.00		X			X		X	X		
4[c]	Bookkeeper	$14.50		X			X					
5[d]	Computer technician	$13.00	X									
6	Computer repairwoman	$14.91		X			X		X	X	X	
7	Medical receptionist	$12.00		X			X			X		
8	Factory worker/receptionist	$8.50		X			X		X	X	X	
9	Bank teller	$12.00		X			X		X		X	X
10	School cook	$11.82		X			X				X	
11	Stock clerk	$9.37			X			X		X	X	
12	Sales coordinator	$13.00		X			X			X		
13	Residential youth counselor	$10.65			X			X	X	X	X	X
14	Retail office clerk	$10.70			X			X			X	X
15	Certified nursing assistant	$11.35		X			X				X	
16	Warehouse worker	$10.18		X		X				X	X	
17	Certified nursing assistant	$11.00		X			X			X	X	
19	Gas station assistant manager	$9.98			X			X		X		
20	Nursing home activities director	$14.00		X			X			X		
21[d]	Hotel housekeeper	$7.25	X									
22	Factory worker	$14.65			X			X			X	X
24	Cabinet maker	$10.00		X			X			X		
	Mean hourly wage (SD)	$11.54 ($2.03)										

[a] Total content counts add up to 34 as multiple topics may have been discussed in one conversation between patient and provider (an average of 1.8 topics)

[b] Participants 18 and 23 were excluded from the analysis because they were not asked about patient-provider communication regarding cancer and work by the interviewer

[c] Participant 4 did not provide detailed information on what topics were discussed regarding cancer and work, therefore Content was not able to be analyzed

[d] Participants 5 and 21 indicated they did not have a conversation about cancer and work, therefore quality and content were not assessed

providers were more reactive in nature versus proactive. A woman employed as a bank teller who continued to work during treatment remarked:

> My doctor, radiation doctor, she told me if I get tired to let her know and she will make another note to them [employer] so they will know but I never [did ask her for another note], when I had my radiation treatment, I was still going to my radiation in the morning and go to work…[the time of medical appointments] was not difficult, I guess, because they worked with me, because at the very beginning [of treatment] I told them that we'd like to have it early in the morning before I start working and they worked around the [work] schedule. [participant 9]

Five women had *extensive* communication with their providers regarding cancer and work. The phrase *extensive* originated from descriptions of women reporting that their provider initiated conversation about work at multiple points throughout treatment, talked with them at length regarding their work responsibilities, and/or addressed multiple work-related needs (e.g., notes for work accommodations/time off, completion of forms, scheduling appointments around work schedule, reviewing side effects, and their impact on work). For example, a woman who continued her work as a counselor during treatment reported extensive communication:

> …when I get chemo…we would always do it on a certain day of the week so that it would be a day that I could have, well we timed it just right so that I would have the most energy possible for my job. If it was certain chemo treatments, they didn't hit you until three days after you got your chemo and then there are certain ones that hit you the next day so we tried to time it out just right for when I got my chemo that I could be working on the best day possible…my oncologist was pretty awesome about that…or if I needed a doctor's note, [the doctor] would give me one. [participant 13]

The second dimension of PPC, *quality* of the conversations about cancer and work, was classified into three categories: poor, standard, and exemplary. *Poor* quality PPC included not only those women who reported that their provider failed to address work needs completely, but also women whose doctor(s) told them not to work without jointly discussing the impact this would have on their life and/or doctors who did not support women who did not follow their advice. One woman in particular reported poor quality communication with her provider regarding cancer and work. Specifically, she worked in a warehouse and had to continue working during treatment against her doctor's recommendation due to family and financial responsibilities [participant 16]. She reported that her doctor did not provide any supportive information when she decided to go back to work against his advice:

> My oncologist…pretty much straight up [said] he did not want me to work; he did not want me to do anything. But you know, of course, I didn't just sit back and take it…I was like…I have a son that's in school and he needs me and you know that [referring to the doctor], it was all at the same time that he was getting his driver's license…I just pretty much kind of went solo and done what I felt like I could handle…I think a lot of times, I guess, the doctors are kind of, I don't know, they're so wrapped up in cancer because that's what they do...I understood my world better than he did… [participant 16]

Standard quality PPC regarding cancer and work included discussion about typical topics (e.g., time off for recovery, side effects, Family and Medical Leave Act (FMLA), and/or disability) and/or paperwork or written communication was provided (e.g., notes to employers stating physical work limitations, doctor's notes for time off, paperwork to ensure patient received FMLA approval or disability coverage). Among the women who discussed quality of the conversation, 14 reported *standard* quality communication with their providers. For example, a woman employed as a certified nursing assistant stated that there was little conversation about her work responsibilities, "they said, you know, you do what you feel like you can do…and, you know, if you don't feel like you can do it, then don't do it" [participant 15].

Five women reported *exemplary* quality PPC, which was displayed by providers who went above and beyond in supporting their patients' work-related needs. This included doctors who provided multiple letters for work-related matters, encouraged patients to share any concerns or needs about managing cancer and work, counseled patients to listen to the needs of her body in making work decisions, engaged in shared decision-making about working during/after treatment, and/or elicited and listened to their preferences or emotions regarding the management of cancer and work. One woman, who worked in a factory throughout treatment stated:

> …they wanted to know pretty much exactly what it was I did, so he [oncologist] would know, if he felt I could be able to do it and they also listened to me if I thought, I could do it, and things like that. They would take…into consideration my feelings and stuff, then listened very intently when I told him [oncologist] exactly what it is I did and they wanted to know exactly what kind of jobs I did and things like that…[participant 22]

The third dimension of PPC pertains to the *content* that was discussed between patients and their providers. Nineteen women reported discussing specific topics related to work with their provider(s) and the majority (53%) discussed more than one topic. Five women reported specific discussions about *scheduling their treatment to accommodate work*, including ensuring medical appointments were scheduled to occur before or after work and/or scheduling treatments to ensure that the patient was experiencing as fewer side effects during work hours. For example, one woman stated, "they [oncology provider] were very flexible…to work my appointments where it would best [fit] in my day [along with my work schedule] [participant 6].

Twelve women reported discussing *time off from work for treatment and/or recovery.* Some of these conversations included the provision of specific recommendations specifying how much time the patient would need to take off for treatment and/or recovery and/or providing paperwork that detailed for the employer the amount of time off that was recommended. Certain women received both specific recommendations and documentation for their employer, as evidenced by the following response:

> I had my last chemo on March 31st [and] I gave them [employer] a note [from oncologist]; the note said that you know she [participant] needs a month for her immune system to kick in [before returning to work]… when it came time for documentation for work, they [oncologist] would rewrite and rewrite you know, even if it was rephrasing the same letter 3 times over…my doctors were great. [participant 19]

This topic area also included conversations about taking time off from work without the doctor providing specific recommendations of how much time to take off.

Thirteen women reported that they discussed *continuing to work during treatment* with their providers; topics included when the patient should return to work after taking intermittent time off, how best to manage side effects while continuing to work during treatment, and/or providing notes or brochures that detailed side effects, physical work limitations, or necessary work accommodations that a patient could give to her employer. Participant 11 noted that when she continued working after her biopsies, her doctor wrote a note letting her employer know "for the next three days that I shouldn't be lifting over 25 pounds."

Four women discussed *financial issues* related to cancer and work with their providers, such as resources to aid patients who needed to take time off (e.g., FMLA, disability) and/or paperwork to ensure patient received FMLA approval or disability coverage. Participant 14 stated that "They [oncology provider] filled out my papers…I had FMLA papers…and you know basically that protects my job."

Discussion

To our knowledge, this is one of the first studies focused entirely on exploring the experiences of low-wage-earning breast cancer patients in discussing the co-management of treatment and work demands with their oncology providers. The experiences of the women in this study varied greatly. More than 70% of the women either did not discuss work with their provider, or experienced communication about work that simply provided routine (basic) information, often only after the women initiated this conversation. Additionally, providers' acknowledgement of patients' employment circumstances ranged from little to none to full engagement and inquiry. However, it was encouraging that almost all providers communicated in some way about work with almost all of the women in this sample, even if it was limited or routine in nature. These findings are consistent with prior research which has found that although providers may address work-related issues [11, 16], this information is often basic in nature and does not always address work concerns in a patient-centered manner [14, 16].

For the majority of women, the quality of PPC surrounding work was standard. Often, general statements were made after surgery or treatment that briefly mentioned resting and recuperation; however, the length of time needed for recovery or questions addressed to the patient about constraints placed on her by her employer and financial situation were absent from the conversation. These findings are consistent with previous research showing that most providers do provide basic work-related advice [16]. In several instances, women reported that their doctor specifically mentioned physical limitations involving lifting heavy objects, reflecting the physical demands of the occupations held by many of these women.

The most common work-related issue women reported discussing with their oncology team was the issue of continuing to work during treatment. Most often, the provider team recognized this need to continue working during treatment and attempted to be flexible and accommodating by scheduling appointments around a patient's work schedule. While this perceived accommodation of work schedules was prominent among women, not all workers in low-wage jobs have access to fixed and routine work hours. In fact, an increasing number of hourly workers report schedules which are irregular, unpredictable, and/or unstable [7, 23]. This change in standard scheduling practices makes communication between patients and their oncology team even more critical, as schedule unpredictability could make it more difficult for low-wage workers to schedule medical appointments, heightening the risk of missing these appointments altogether.

As reported by study participants, rarely did providers consult the women about managing symptoms at work, or acknowledge the negative impact work-life stressors may have on recovery. This is consistent with research that has noted minimal explicit conversations between women diagnosed with breast cancer and their doctors regarding how cancer and its treatment might impact work ability [15]. There was also minimal attention paid to the impact that not working would have on the lives of these women; in several instances, medical recommendations were provided without discussing this impact and consequently some women opted to work against the advice of their doctor. The consequences of treatment on co-managing employment is a fundamental concern for all working breast cancer survivors, but especially for low-wage-earning women who fear that missing work will result in termination, lost wages, and financial insecurity [8, 18]. As such, the content, extent, and quality of communication between a breast cancer survivor and her oncology care team members must consider employment circumstances and context [8].

Although this study provides important information, there are limitations that should be considered when interpreting results. Data regarding PPC were self-reported and may not provide a completely accurate summary of the communication that occurred between women and their providers. Participants were not asked who initiated the discussion regarding work, or if there were any specific challenges in discussing employment issues or financial strain with their provider. These are important components of PPC that were not able to be evaluated in this study. Additionally, varying lengths of time since completion of treatment across respondents may have introduced recall bias. Generalizability is limited due to the small, homogenous sample, convenience sampling strategy, qualitative methodology, and the fact that the data used in this study was collected in 2012. The delivery of cancer care has evolved since this time, and patient-centered care, which often attends to psychosocial issues (including employment), is becoming more common and PPC dynamics may be different today. Nonetheless, this is among the first studies to examine this issue among breast cancer patients employed in low-wage jobs.

As shown in our findings, extensive communication overlapped with communication that was also deemed to be of exemplary quality, potentially suggesting that the more one talks to their provider about work-related issues, the more likely the communication is perceived as high-quality and patient-centered. Future research could provide further detail regarding how the constructs of extent and quality may or may not differ from one another. Future research could also focus on including perspectives from oncology providers as well as observational recordings of specific patient-provider dyads. There is a need for comparative research regarding how PPC experiences may differ between low-wage-earning cancer patients and patients with middle and high-wage incomes. Additionally, existing PPC interventions known to improve general communication between patients and providers could be adapted to address work-related issues among low-wage-earning breast cancer survivors.

Most patients prefer a patient-centered communication style [22], which occurs when providers respond to the emotions and thoughts that patients express regarding their illness and make joint decisions with patients about treatment [24]. A foundational element of patient-centered communication is that the aforementioned emotions and thoughts are addressed within each patient's unique psychosocial context, which includes work. A true understanding of patient needs, values, and concerns cannot be ascertained without discussing the role work plays in one's life and the impact that cancer and its treatment may have on one's employment circumstances.

The findings of our study indicate that PPC may play an important role in helping low-wage-earning women with breast cancer co-manage treatment and work responsibilities. Specifically, informing oncology team members about employment circumstances allows women to disclose the strains in managing treatment within the context of work and for oncology team members to have a broader understanding of patients' circumstances that may influence decision-making. Moreover, PPC about cancer and work allows providers to advocate for patients who may be employed in precarious work environments through the provision of documentation that may assist with securing workplace accommodations, flexible work schedules, and/or reassigned duties. Indeed, this has implications for oncology team members who work with patients employed in low-wage jobs while simultaneously undergoing treatment. Previous research has highlighted the lack of consistency in how providers approach communicating about issues surrounding cancer and work with patients [16] and provider education could allow for a more systematic approach to be used. Education about how cancer and its treatment can impact employment for low-wage workers would also remove an obstacle reported by providers—lack of information/resources pertaining to work-related support for patients [16].

Therefore, clinical implications also could include using a screening tool to identify potential issues that might arise in managing cancer and work, allowing providers to proactively address patients' work-related challenges. Breast cancer patient education is also important, such that informing women about work-related challenges that may accompany a cancer diagnosis could empower them to proactively discuss work issues with providers. This element of patient education is important, as research shows that women often do not know if work problems fall within the scope of what should be discussed with their cancer care providers [25]. In sum, enhancing PPC about cancer and work may improve cancer care, work outcomes, and relationships between patients and their oncology care teams.

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