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A Qualitative Study Identifying Challenges Resulting from Complex Evidence on Lifestyle Factors and Cancer: Perspectives from Black and Latina Cancer Survivors and Health Care Providers

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Abstract

Purpose: Most breast cancer survivors have challenges with adopting healthy lifestyle behaviors. This may be due to contextual challenges that result from the complex nature of the evidence. To address this gap, we explored the experiences of breast cancer survivors of color and oncology healthcare providers.

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Author contributions

Margaret S. Pichardo, Melinda L. Irwin and Yamile Molina contributed to the study conception and design. Material preparation and data collection were performed by Margaret S. Pichardo. Data analysis was performed by Margaret S. Pichardo, Abigail Ginader and Thai Hien Nguyen. The first draft of the manuscript was written by Margaret S. Pichardo, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript. Funding support and resources acquisition for this study were provided by Melinda L. Irwin and Tara Sanft.

Competing Interest

The authors have no relevant financial or non-financial interests to disclose.

Ethics approval

The study was conducted according to the guidelines of the Declaration of Helsinki and approved by the Yale Human Investigation Committee (HIC # 2000025065).

Consent to participate

Verbal Informed consent was obtained from all individual participants included in the study.

Methods: Content analysis with inductive and deductive approaches was used for semi-structured interviews with 26 female breast cancer survivors and 10 oncology healthcare providers from Greater New Haven, Connecticut.

Results: Survivors identified substantial confusion on the evidence regarding lifestyle behaviors and breast cancer, stemming from inadequate healthcare provider counseling and an overreliance on informal sources of information. Providers identified lack of evidence-based knowledge as a barrier to counseling on these topics. There was a mixed perspective regarding the consistency of evidence, stemming from a combination of gaps in the available evidence and accessing evidence-based knowledge from a wide range of professional resources. Some providers perceived the guidelines as consistent; others felt guidelines were constantly changing, impacting how and on what they counseled. Therefore, many healthcare providers in oncology care relied on generic messaging on lifestyle behaviors after a cancer diagnosis.

Conclusion: Inconsistent information sources, the rapidly changing evidence, and gaps in the current evidence contribute to generic messaging about lifestyle behaviors and may inhibit a survivor's ability to engage in behavior change. Consistent and uniform healthy lifestyle guidelines for cancer outcomes may address both provider and patient level barriers to knowledge.

Keywords

Race/ethnicity; Nutrition guidelines; Physical Activity guidelines; Cancer Information overload; Cancer Prevention; Breast Cancer Survivorship

Introduction

Leading national organizations like the American Cancer Society [1, 39], the National Comprehensive Cancer Network [9], and others [35] encourage cancer survivors to follow a plant-based diet, limit alcohol consumption, stop smoking, and adhere to physical activity guidelines to promote well-being and overall energy balance [19]. However, breast cancer survivors often do not meet all the lifestyle behavior recommendations [44], and racial/ethnic disparities exist in adherence [6, 31, 44, 46].

A major premise in existing intervention research is that simple education to survivors [15, 51] and providers [22, 23] should be sufficient. However, these programs do not appear sufficient to encourage long-term behavior change maintenance [14, 16, 22, 51] especially for breast cancer survivors of color. [11, 13, 51] Observational research provides a more realistic, complex picture. Randomized trials [36, 37] have failed to show that dietary modification reduces the risk of either developing breast cancer or breast cancer recurrence. The World Cancer Research Fund [49] found the only consistent association between dietary factors and breast cancer risk or outcome in observational literature was the association between alcohol intake and postmenopausal breast cancer risk [50]. The evolving nature and complexity of available evidence on lifestyle factors and cancer results in major challenges for the dissemination of actionable, evidence-based information and ultimate adoption of lifestyle behaviors recommended for survivors.

Here, we focus on theoretical, largely unstudied, challenges that may contribute to varying perceptions and awareness about available lifestyle guidelines. First, we characterize how variable awareness of the complex evidence on lifestyle factors and cancer manifests among survivors of color. Second, we identify the contextual challenges that patients and providers face, which contribute to variable awareness and perceptions of the evidence. We focused on the setting of breast cancer, where lifestyle counseling is more readily available [27], and interviewed breast cancer survivors of color and oncology healthcare providers.

Materials and Methods

This study was approved by the Yale Human Investigation Committee (# 2000025065). All participants, including those in the pilot study, reviewed and provided informed consent prior to the start of the interview. To ensure anonymity of responses, signatures on informed consents were waived.

Pilot study

A pilot study was conducted with four breast cancer survivors. Women were recruited from personal networks, local support groups, and participants in prior studies. Interviews were conducted via phone or email in English and Spanish. Eligibility criteria included having a breast cancer diagnosis and identifying as a racial/ethnic minority. At the end of each interview, participants were debriefed on the purpose of the study, provided a copy of the interview guide and asked to provide feedback on the interview questions and probes. After the four interviews were analyzed, modifications were made to the final interview guide, the recruitment strategy, and the eligibility criteria.

Recruitment

Recruitment occurred from March 2019 through March 2020 in the Greater New Haven, Connecticut area among women who self-identified as Black/African or Hispanic/Latino with a history of breast cancer. Survivors within the Yale New Haven Health System’s catchment area were identified through various mechanisms including, electronic medical records, flyers, word of mouth, provider referral, during breast cancer clinic visits, and through community support groups. Women were then either approached in-person during a clinic visit and/or received a letter via mail describing the study. Any survivor who was interested in participating contacted the study coordinator. Participants were screened to ensure they met eligibility criteria (being 18 years or older, not having a psychiatric illness, and not currently enrolled in a lifestyle intervention), and if so, were scheduled for an in-person or phone interview based on participant choice. We approached a total of 41 breast cancer survivors of color. Our final survivor sample consisted of 26 breast cancer survivors (16 Black and 10 Hispanic/Latino women). Reasons for refusal were not collected.

Healthcare providers from hospital and community settings affiliated with the Yale New Haven Health System were approached and eligible to participate if they worked in an oncology setting and were likely to provide lifestyle counseling or offer referrals in the setting of cancer survivorship (e.g., surgery, medicine, nursing, dietetics, physical therapy and rehabilitation, and nursing). An email with a brief study description was sent to each provider. A reminder email was sent approximately 3 weeks later. A total of 27 healthcare providers were approached to participate and 10 healthcare providers were enrolled. Reasons for refusal were not collected.

Data collection

Audio-recorded, semi-structured interviews were conducted by one interviewer (MSP) in English or Spanish and lasted 60 to 120 minutes. The breast cancer survivor interviews inquired about cultural perceptions of cancer, experience with diet quality and physical activity since a cancer diagnosis, and sources of information (e.g., “What are your beliefs regarding unhealthy foods and breast cancer?”). Provider interviews inquired about perceptions of barriers/facilitators to lifestyle counseling, experiences with communicating with patients of color about healthy lifestyles, and sources of information (e.g., “Where do you get information about the current evidence regarding diet/exercise and cancer?”).

All audio recordings were professionally transcribed verbatim in their original language. Interviews in Spanish were analyzed in Spanish to retain validity due to potential loss of meaning in cultural bound words or phrases during translation and interpretation. [47] De-identified transcriptions were uploaded to Dedoose for analysis.

Data analysis

A team of three coders (MSP, THN, AG) conducted a content analysis with deductive and inductive approaches. [4, 18] We first used deductive codes informed by likely responses to questions asked, given previous literature in the field of lifestyle behaviors [21] and socioecological research with Hispanic/Latina breast cancer survivors. [28] New inductive codes were identified from raw interview data. The coding team read every transcript independently and met weekly to discuss codes, assess interpretation and foster inter-coder-reliability. Disagreements were settled through transcript reviews and discussions of perspectives until a consensus was achieved. Peer debriefings were held throughout the coding process, wherein the emerging themes and analyses, interpretations and framings were reviewed by another team member (YM). [8, 29] Because our study was not designed to enumerate associations, we did not quantify information regarding our qualitative data (e.g., frequency distributions). [42, 45]

Results

Descriptive information for all survivors and healthcare providers are provided in Tables 1 and 2, respectively. Among our survivor sample, a majority were over the age of 50 (85%), Black (58%), foreign-born (54%), and had at least a high school education (88%). Forty-two percent of survivors were diagnosed within the previous 2 years and 42% had Stage I cancer. Among our healthcare provider sample, the majority had over 20 years of experience in oncology care, over 10 or more years of education/training and there was an equal proportion of males and females.

Below, we report emergent themes that reflect the contextual challenges that patients faced in knowledge about lifestyle factors and cancer, which affected adoption and maintenance of behavior changes. Quotes are shown in Table 3. Themes manifested similarly among Black and Latina breast cancer survivors; given the lack of appreciable differences, we present their perspectives together. We distinguish the perspectives of survivors and oncology healthcare providers separately, given they described different contextual challenges.

Barriers to knowledge about lifestyle risk factors and cancer among survivors

Theme #1. Knowledge and perceptions about causes of cancer.—Most breast cancer survivors indicated limited awareness about the available evidence. There was confusion on the causes of cancer in general and breast cancer specifically, with most discussions centering around diet and dietary components. In part, survivors believed this was due to a lack of available evidence, although sources information commonly mentioned included informal ones like family, friends, the news/media, or the internet. Many survivors also identified a lack of trust in the evidence of which they were aware, which was partly attributed to the constant flow of new information from informal sources and at times was contradictory and generated confusing, ultimately leading to cancer information overload.

Theme #2. Knowledge and perceptions about diet and cancer.—While there was uncertainty on causes of cancer in general, most conversations centered on diet as an important cause of cancer, although survivor's knowledge of how to improve their diet after diagnosis differed from each other. There was variation in terms of *how* diet influenced cancer (e.g., types of food, food preparation processes). Some survivors emphasized the processing of the food (i.e., canned, frozen, processed meats). Others, conversely, emphasized that there were specific foods that should be avoided (e.g., avoiding sugary drinks, salt, refine grains, processed or fried foods and meats, sweets/candy), but often were not sure about which foods specifically should be avoided according to the evidence. Survivors identified strategies they thought were useful, including being more mindful of the meals they consumed by developing varied meal plans, using moderation strategies (e.g., portion sizes, food preparation) and; avoidance self-control strategies

Theme #3. Knowledge and perceptions about other lifestyle factors and cancer.—While most survivors recognized that exercise and lack of alcohol consumption are good for overall health (e.g., bones, mental health), few made the connection between exercise and cancer. Only three survivors identified exercise and weight gain prevention as important factors to prevent breast cancer recurrence. Notably, the lack of knowledge appeared to stem from inconsistency in the information received about what causes cancer, a reliance on non-professional sources for information (e.g. Google, friends, family), and inadequate or lack of counseling by health care providers on the explicit connection between diet, exercise and cancer. Nonetheless, many participants discussed being more engaged in physical activity for overall well-being and building it into their work schedules (e.g., parking further away, attending local gyms, using buddy system) to facilitate increased activity throughout the day.

Other factors like alcohol consumption, smoking, body mass index (BMI) were rarely mentioned as important for cancer prevention or important for health after cancer diagnosis. When explicitly probe about these lifestyle factors, many survivors explicitly noted that they were unaware of evidence about the relationship of these factors and cancer. Many did not link smoking directly to breast cancer. Most survivors engaged in alcohol avoidance or limiting alcohol consumption after their diagnosis, but none associated or mentioned alcohol consumption and its association with cancer.

Contextual determinants that affect perceptions about lifestyle risk factors for cancer survivors

Survivors' awareness of the complex evidence regarding what causes cancer and what are healthy lifestyle behaviors after cancer was influenced by their sources of information. Providers also described various structural and institutional determinants influenced their ability to support survivors of color, such as their limited awareness about actionable information stemming from the rapidly changing guidelines that made access and complexity of available evidence more challenging to understand and disseminate.

Theme #1. Inadequate quality patient-provider communication.—Survivors noted that they experienced a lack of counseling by health care providers. For some, this manifested as a lack of counseling or referral to lifestyle experts (e.g., dietitians/nutritionists, physical therapists). For others, the discussions lacked counseling on the explicit connection between diet, exercise, and cancer. Survivors noted a strong desire to receive lifestyle information from their oncologists and other lifestyle experts that could enable accountability. The desire for external sources of accountability likely stemmed from both experts' knowledge *and* their separation from survivors' complex social environments. Interestingly, providers rarely discussed factors influencing survivors' control as a barrier to behavior change. In the two instances that providers addressed it, it involved lifestyle experts—individuals who may be keenly aware of these factors because of their line of work. In part, lack of understanding of factors related to control and how to counsel patients by providers, may have led survivors to depend on others for support and accountability. This was congruent with survivors' experiences of receiving generic advise from their cancer specialists, their desire for additional follow up appointments with lifestyle experts, or reliance on their social networks for support.

Theme #2. Use of informal sources of information on lifestyle behavior change after cancer.—Most survivors identified a lack of formal sources of information likely influencing survivors to rely on alternate, non-medical sources for information (e.g., Google, friends, family). Some survivors had supportive family members, friends, and co-workers who would counsel them on behaviors to change and engage in behavior change with them, although these individuals did not necessarily have knowledge about best practices or strategies for behavioral control, leaving survivors to be the 'experts' for themselves and others. While other survivors lacked support and accountability in their social circles. Consequently, to achieve behavior change goals, these survivors would choose to avoid social events or family gatherings; would redirect others' attention from what they were eating in social circles; and cooked or ate separately.

Theme #3. Providers' perceptions of healthy lifestyle guidelines influenced by a reliance on diverse sources of information.—Overall, providers emphasized that lifestyle counseling was complex and in fact, granular details regarding the evidence on diet, exercise, and alcohol consumption were rarely came up during the interview. Like survivors, providers appeared to vary in what sources of information they used (e.g., cancer task forces, professional organizations, or cancer networks), except that a majority relied on peer-reviewed literature. A wide heterogeneity in providers' information seeking behaviors was evident, even when seeking information from cancer-specific sources. Non-lifestyle experts often cited peer review journals as common sources of information for general guidelines on diet and exercise. Lifestyle experts and non-lifestyle experts with greater interest in lifestyle guidelines, indicated greater preference for cancer specific and behavior specific guidelines, such as those coming from diet, exercise, or cancer associations. Such variability in preference for generic versus survivors-specific guidelines, created two camps for providers: a group that believed the recommendations were pretty consistent over time and often relayed generic messaging to their patients (e.g., fruit/vegetable intake, 150 minutes of physical activity per week) and another, mostly composed of lifestyle experts, who perceived that other providers generally lacked granular insight to what the exact recommendations where—the duration, frequency and types of physical activity and the exact foods that should avoided, reduced or added to one's diet. The former group was more often involved in generic education of healthy lifestyle behaviors, while the latter group focused on cancer specific education and providing strategies to achieve and maintain behavior changes.

Theme #4. Providers' perceptions on the evidence, due to perceived consistency of evidence regarding healthy lifestyle guidelines, may contribute to generic messaging.—Providers often appeared to provide general messages to survivors, although the motivations for generic information differed. On the one hand, some providers did not appear to be aware of the guidelines for cancer survivors and relied on general information (e.g., meat vs. red and processed meat intake, increasing exercise vs. engaging in at least 150 minutes of physical activity and two strength training sessions per week). On the other hand, others were aware of specific components of the healthy lifestyle guidelines but emphasized that they rapidly changed resulting in a lack of granular insight to what the exact recommendations were. Consequently, providers often used generic messages.

Discussion

Existing intervention literature identifies patients' lack of knowledge as a barrier to lifestyle behavior change in the setting of breast cancer. Current evidence stems predominantly from a large body of observational research, which provides structural challenges in its dissemination and implementation across breast cancer survivorship. In the present study, survivor's lack of uniform knowledge about risk factors linked to cancer in general and breast cancer specifically were identified as a major determinant of long-term maintenance of healthy behaviors for Black and Latina survivors. Knowledge level and perceptions of the current evidence was directly influenced by contextual determinants experienced by both survivors and providers. Contextual determinants included inadequate quality patient-provider communication, a reliance on the non-medical community and media sources among survivors. Variable provider awareness stemmed from a reliance on different sources of information and perceived consistency/inconsistency of the evidence.

Survivors identified a lack of uniform understanding regarding what specific behaviors are associated with cancer outcomes. For diet specifically, the lack of knowledge stemmed from an overwhelming reliance on lay media sources and non-medical community (e.g., friends, family, support groups), which in part may have generated cancer information overload, manifesting itself through the confusion and uncertainty about the evidence. [20, 33, 48] In turn, cancer information overload has been associated with negative experiences with information seeking [2], less trust in the scientific credibility of the information [20], and reduced adherence and adoption of diet, physical activity and smoking recommendations. [12] Such challenges speak to the ongoing debate of how to disseminate a body of scientific research for affected patient populations and society at large. [3, 10] In recent decades, unlike for diet, the evidence behind alcohol and smoking has been less controversial. Therefore, lack of knowledge on the evidence on these behaviors may be less from cancer information overload and more due to contextual determinants that impacted both survivors and providers.

Survivors identified a lack of adequate quality patient-provider communication as a challenge impacting awareness of available evidence. The lack of provider counseling is inconsistent with cancer survivor’s desire for these conversations with their oncologists. [17] There are sparse data to understand oncology healthcare providers’ experiences with lifestyle counseling [25], with most being referral-based counseling. [5, 24] Consistent with our findings, limited literature documents a widespread missed opportunity by oncology care providers to engage survivors in lifestyle and cancer conversations. [7, 17, 34] Inadequate communication among providers, in part, stems from provider-level barriers, such as time constraints (i.e., time to counsel during a oncology visit and/or time to seek education on lifestyle topics), lack of resources, lack of knowledge about the cancer prevention guidelines [25], lack of reimbursement, and a lack of access to lifestyle experts via multidisciplinary teams, leading to an overreliance on referral-based lifestyle counseling. Although our providers identified similar concepts, barriers related to time and lifestyle counseling responsibility have been widely reported in the literature [3, 32]; therefore, the present study did not focus on these concepts.

Newly identified barriers to provider knowledge in this study included a wide variety of sources of information and two sets of perceptions, that evidence-based guidelines either changed constantly when it came to specifics regarding the link between diet/exercise and cancer or that the guidelines were constant, without much change in the last decade. The mixed perception on the consistency of the evidence on lifestyle and cancer is valid and stems from an explosion of literature on this topic in the last three decades, albeit it reflects a lack of effective translation of evidence among communities of survivors and healthcare providers. Consistent with some providers’ beliefs, the general guidelines on eating more fruit and vegetables as well as limiting intake of red meat have been consistent. [30, 38, 50] Adding to the perceived inconsistencies is the fact that numerous organizations have developed similar, but not identical, guidelines [26, 39], which are constantly changing and expanding independently of one another. [40] The continuous updating of the recommendations reflects the increasing evidence and strength of the evidence to support those recommendations. Current guidelines for nutrition and physical activity for cancer prevention [40] as well as those for cancer survivors [41] largely provide high-level recommendations based on mostly observational evidence and limited randomized clinical studies, that is not specific to the prevention or treatment of breast cancer, but encompasses many obesity related cancers. These extant gaps create knowledge barriers for both providers and patients; and contribute to generic guidance as information is transferred from academic institutions, to providers, and to patients, ultimately impacting the adoption of healthful lifestyle behaviors after a cancer diagnosis.

The present study highlights the imperative to consolidate healthy lifestyle guideline information for cancer prevention and mortality. There is a need for a national authority that brings together all stakeholders and professional organizations to agree on a consistent and uniform message that medical and surgical oncologists and allied health professionals can relay to their patients. These guidelines should include effective strategies that account for how communities and individuals use and process knowledge, the context in which people live and factors that would influence behavior change, given that the uptake of knowledge alone doesn't necessarily translate to behavior change. [10]

Our study had notable strengths and some limitations. While we focused on the perspective of Black and Latina survivors of breast cancer, the identified themes were not culturally specific and may be universal for other cancers and women from other backgrounds. Our findings may have been affected by our limited success with recruiting a more diverse sample, including less educated, lower income survivors and survivors with stage III or IV breast cancer. Our sample of healthcare providers was small and did not include primary care providers, limiting our ability to make within group comparisons among healthcare providers (e.g., nurses versus physical therapists) and to confidently state that provider-identified themes solely reflect systematic gaps.

However, the high-quality composition of our study sample is exemplified by including the perspective of understudied populations like Spanish-speaking survivors who were interviewed in Spanish. In addition, because survivors and healthcare providers were recruited from the same geographic area, thereby providing multiple angles of a shared lived experience for oncology healthcare. Future studies examining structural determinants to lifestyle knowledge in cancer would benefit from targeting a large and diverse sample of healthcare providers that would enable comparisons across specialties and subspecialties. Our post-hoc analysis suggested thematic saturation had been reached, given no new codes were found within the final interviews (last 9 survivors, last 3 providers) [43]. Future qualitative studies in this area should consider incorporating more rigorous approaches to saturation to capture themes that may be generalizable and confidently highly structural gaps in the transfer of cancer information and knowledge.

Conclusions

In conclusion, the rapidly changing evidence, and gaps in the current evidence contribute to generic messaging about lifestyle behaviors and may inhibit a survivor's ability to engage in behavior change. Combined, these factors work to inhibit survivor's ability to engage in healthy lifestyle changes throughout the survivorship period. This study highlights the imperative for national authorities to come together and develop a consistent set of healthy lifestyle guidelines for cancer prevention for the general population as well as guidelines to optimize health for cancer survivors to address both provider and patient level barriers to knowledge.

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Appendix A. Sample Questions from Semi-structure Interview Guide for Survivors and Health Care Providers

Survivors

1. What support with nutrition and exercise did you receive from your community? Friends? Family?
2. How could your community have supported you with nutrition and exercise?
3. Thinking back to when you were receiving cancer treatment, what has changed about your eating habits since you were diagnosed?
    a. Specific foods? Drinking? Exercise? Smoking?
    b. Why did you change your habits?
    c. What changes were easy or difficult to implement?
    d. What made them easy or difficult?
    e. Did you feel supported to make these changes? By who?
4. Thinking back to when you were receiving cancer treatment What information did you receive about nutrition and exercise during treatment?
    a. What resources did you have to support you to eat healthier and exercise while you were receiving treatment?
    b. How did your doctors support you to eat healthier and be active?
5. Thinking back to the time after you had completed your cancer treatment, did you receive a survivorship care plan after completing treatment?
    a. What did you like or dislike about your care plan?
    b. Did your care plan include counseling on nutrition and exercise?
    c. What resources did you have to support you to eat healthier and exercise?

    d. How did your doctors support you to eat healthier and be active?

6. Thinking about the present, how do you make decisions about what foods to eat and what to avoid?
    a. What are things that you believe to cause cancer?
    b. What are your beliefs regarding unhealthy foods and breast cancer?
    c. What makes food healthy or unhealthy?
7. Thinking about the present, how do you make decisions about whether to engage in exercise or not?
8. How could your care team have supported you with nutrition and exercise after you completed your treatment?

Health Care Providers

1. What do you think is your role in providing lifestyle counseling to survivors?
2. Tell me about a time when you offered counseling on diet and exercise to a patient of color?
    a. What difficulties, if any, did you experience?
3. In your daily work, what makes it difficult to counsel patients on lifestyle?
    a. What resources are available to support your ability to counsel patients on lifestyle behaviors?
    b. What would make it easier for you to regularly counsel patients on lifestyle?
4. How do you confirm that patients have received information about lifestyle behaviors?
5. What resources do you have to offer breast cancer survivors regarding lifestyle behaviors?
6. Where do you get information about the current evidence regarding diet/exercise and cancer?
7. What barriers do you think women of color face to adopt healthy lifestyles?

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Table 1.

Demographic and clinical characteristics of survivors of breast cancer, n = 26

Demographics	
Age at interview (years)	
<40–50	4 (15%)
51+	22 (85%)
Race/ethnicity	
Hispanic/Latino	10 (38%)
Black/African American	15 (58%)
Mixed race/ethnicity	1 (4%)
Place of Birth	
Continental USA	14 (54%)
South America	3 (12%)
Caribbean islands	8 (31%)
West Africa	1 (4%)
Interview Language	
Spanish	8 (31%)
English	18 (69%)
Highest level of education	
Less than a high school degree	2 (8%)
High school/GED	8 (50%)
Some College or beyond	16 (62%)
Missing	1 (4%)
Marital status	
Married	9 (35%)
Not married	17 (65%)
Clinical characteristics	
Years since diagnosis	
0–2	11 (42%)
3–5	3 (12%)
6–11	10 (38%)
11+	2 (8%)
Cancer stage	
0	6 (23%)
I	11 (42%)
II	8 (31%)
III	0
IV	0
Unknown	1 (4%)
Surgery type	
Lumpectomy	6 (23%)
Mastectomy	17 (65%)

(Neoadjuvant[1])	1 (4%)
Missing	2
Treatment type	
Chemotherapy only	1 (4%)
Radiation only	0 (0%)
Hormone therapy only	0 (0%)
Surgery only	4 (15%)
Combination	21 (81%)
In long-term treatment at interview	
Yes	15 (58%)
No	9 (35%)
Not applicable	2 (8%)

[1] Unknown the type of procedure that followed neoadjuvant therapy

Table 2.

Demographic characteristics of healthcare providers, n = 10

Demographics	
Gender	
Female	5 (50%)
Male	5 (50%)
Occupation	
Nursing	1 (10%)
Dietetics	2 (20%)
Physician (surgery/medicine)	4 (40%)
Physician assistant	1 (10%)
Physical therapy/Rehabilitation	2 (20%)
Years of education	
<5	3 (30%)
5–10	3 (30%)
10–15	2 (20%)
15+	2 (20%)
Years of experience in oncology	
<15	1 (10%)
15–20	2 (20%)
20+	7 (70%)

Table 3.

Qualitative themes and quotes from survivors of breast cancer and healthcare providers.

Themes	Participant
Barriers to knowledge about lifestyle risk factors and cancer among survivors	
Theme #1: Perceptions about lifestyle factors and cancer risk among survivors.	"I can't even answer that question ["What do you think causes cancer?"]. I try to listen at other people and, nobody knows, nobody knows." Others indicated cancer information overload. (Survivor #18) "Smoking. The environment. That was something that I learned because I was convinced, I had done something to the causes and all that. And having been a former smoker and the doctor really just assured me and couldn't say it enough that what I had was considered environmentally caused. I think what's in our atmosphere that a lot of the things we don't have control over, but definitely our diet and poor habits […] No specific foods that would necessarily lead directly to breast cancer, but definitely foods that puts your body in a place where you're vulnerable to cancers, if that makes sense. Junk food, fast food. I'm still on the fence about the meat thing. I didn't eat meat for years, but I've come to believe that it's not necessarily eating meat that's going to make someone healthy or sick, but more of the types of meat. How much of it you eat? Yeah, there was a product I thought. Deodorant, but not food at the time. I think that's about it. Junk food, fast food." (Participant #2) "En realidad no lo sé. Mucha gente dice, este, ay, que hay ciertos alimentos que causan cáncer, que, ah, que el cáncer está dondequiera, hasta en el mismo aire, como dicen, un decir. Pero en realidad no lo sé. No, no sé. Yo no sé." [I really do not know. Many people say that certain foods cause cancer, that cancer is everywhere, even in the air, they say, a saying. But I really do not know. I don't now. I don't know.] (Translation for Survivor #22)
Theme #2: Perceptions about diet and cancer.	"I definitely do agree that sugar, I believe, does help with cancer, fatty foods. Those are pretty much the things that I've heard a lot about." Survivor #17 similarly emphasized: As I say, the fats, the chemicals they sometimes put on those things. You bought it from those frozen, in the freezer of the supermarkets, and it has chemicals, they inject hormones, or what do I know. All of that has to do with it [cancer risk] (Survivor #25, Translated from Spanish). "Like nutrition, like where you eat, what you eat. That there are things that one should not eat, and I do not understand any of that. Because as much is one thing, as the other. I don't know, I don't have much to talk about there". (Survivor # 15, translated from Spanish) "I really do not know. Many people say that certain foods cause cancer…But I really do not know". (Survivor #22, translated from Spanish)"
Theme #3: Perceptions about exercise, alcohol consumption, smoking, BMI and cancer.	"I'm not sure if I have any specific connection with exercise and breast cancer other than knowing that all exercise is good for whatever else". (Survivor #1) "I know like for exercise and physical activity like actually for me that that helps with your mental wellbeing. But I don't know, to be honest, I don't know if that will help you know in the long run in preventing or having a role you know whether or not you develop cancer or not". (Survivor #20) "It was really, for us, something surprising, 'cause my mother didn't know it ran in her family. So, I got it first, and then she got lung cancer, but she smoked. I smoked before, you know, for years. I've been a nonsmoker for over 25, but to say whether that caused it or not, that wasn't what caused it, according to the oncologist". (Survivor #9)
Contextual determinants that affect perceptions about lifestyle risk factors among survivors	
Theme #1. Inadequate quality patient-provider communication.	"Did anybody – my doctor- talk to me about the nutrition and the cancer? No." (Survivor #13) "I don't know what foods to avoid, so I just eat everything that I'm supposed to eat. I wish for the best… Doctors don't tell you what not to do. Well, they didn't tell me anyway." (Survivor #3)
Theme #2. Use of non-medical community and media sources	I know about all you know what to eat and what to do, and if I did more research on the particular you know like cancer or the liver that, I just go online and check it out and switch to that food, that's what I do. (Survivor #23) I have a person that works for me that was diagnosed with cancer, and she opted not to take any enzyme, chemicals, chemo, radiation, whatever, and she went on a diet that's high in natural stuff, and, seeds, and she talked to me about it and she sent me to a website, but it didn't grab me, but we had a conversation. I know at least one person that strictly tailored her diet to her cancer. I don't know that diet or lack of diet, proper diet, has any correlation to the breast cancer. I never even looked at it, you know. I think I eat pretty healthy. (Survivor #8)
Theme #3. Providers' perceptions of healthy lifestyle guidelines influenced by a reliance on diverse sources of information.	"We use the National Comprehensive Cancer Network guidelines. Then there's always anything that's ASCO or published in the Journal of Clinical Oncology. Basically, it's just following through on these well-established journals. Aside from the national guidelines, whether it's like in the Journal of Medicine, things like that." (Healthcare Provider #1) "I also get information from the American College] of Sports Medicine. They just updated their recommendations for exercise for cancer survivors, so I get a lot of information from that, as well. I'm constantly on the lookout for new research that's out there and I've also learned to reach out to my colleagues." (Healthcare Provider #4)

Themes	Participant
	“We also have you know, the American Cancer Society, the American Institute for Cancer Research, the Academy of Nutrition and Dietetics … The American Institute for Cancer Research is where we get a lot of our recommendations for diet and for supplements, we might use an actual medicine database to check some supplement information.” (Healthcare Provider #7)
Theme #4. Providers’ perceptions on the evidence, due to perceived consistency of evidence regarding healthy lifestyle guidelines, may contribute to generic messaging.	“We know for breast cancer we say, eat healthy food, but there is not like guidelines, we just say, ‘try to eat as healthy as possible.’ So, I guess it’s all like been standardized. There’s nothing like that changes that much.” (Healthcare provider #9) “There are a number of resources on the Internet where you can, for example, MyPlate.gov, right? Learning about basic nutrition, healthy eating, the importance of getting 150 minutes of exercise, those kinds of things. I think those guidelines are available.” (Healthcare provider #3) “Basically, when it comes to evidence, we just follow closely guidelines. I think they have been very consistent over the last good number of years, and they are very consistent when it comes to cancer prevention and also cardiovascular and other diseases, so they are very much aligned. So, I think there hasn’t been much new over the years. it’s really, to keep working and making sure that, you know, we do our best for people to really adopt these changes. (Healthcare provider #10) “I think another issue is the rapidly changing and nebulous nature of what advice to give, right? So, it’s really simple advice to do more exercise. But then beyond that, the details and how you would structure or how much do you really need. And I don’t think that physicians actually know, I’m not even sure that the data is solid whether you need 30 minutes every day or 90 minutes a week. And diet is even more complicated. I don’t think that physicians actually really know any specific dietary recommendations beyond the general idea that keep a healthy weight, and if you [want to] lose weight, eat less calories than what you need. That’s probably it, that we objectively know some really general [but] not particularly helpful statements, like, “Eat a lot of vegetables.” But what is “a lot”? And fresh fruits.” (Healthcare provider #5)