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Research Article

Survivorship Care Focus Group Discussions for Breast Cancer Survivors and Primary Care Clinicians

Hillary S. Klonoff-Cohen^{1*} and Mounika Polavarapu²¹Saul J. Morse & Anne B. Morgan Professor in Applied Health Sciences, Department of Community Health, University of Illinois Urbana-Champaign, Champaign, Illinois, USA²Assistant Professor, School of Population Health, The University of Toledo, Ohio, USA

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ABSTRACT

Purpose: This is the first pilot study to examine survivors' experiences and primary care physicians and nurse practitioners' knowledge and behaviour practices with respect to late effects (e.g., fatigue, chemobrain, lymphedema, cardiac problems, reproductive, infertility and sexual health issues, bone problems, and pain).

Methods: Two separate focus groups consisting of 5 breast cancer survivors and 5 primary care physicians and nurse practitioners recruited from a local hospital in Central Illinois answered predetermined questions about cancer survivorship care. We intentionally limited the sample in order to conduct a detailed discussion (90 minutes) to gain every participant's perspective.

Results: Breast cancer survivors expressed a void in discussion and lack of knowledge among their primary care physicians regarding late effects as well as psychological consequences, referrals to support groups, and availability of resources (e.g., finances), thereby negatively affecting survivors' quality of life. A primary care clinician (PCC) focus group revealed a service gap for mental health services for all patients, knowledge deficit about late effects, and lack of awareness of patient resources. Both cancer survivors and PCCs were extremely supportive about a shared care survivorship model between oncology and primary care. All focus group participants were unequivocally receptive about enhancing survivorship care throughout a cancer survivor's lifetime.

Conclusion: Complementing cancer survivorship care with primary care clinicians in the areas of late effects, in addition to psychological consequences, screening, and lifestyle habits will enhance a cancer survivor's health-related quality of life.

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Introduction

According to the National Cancer Institute (NCI), breast cancer survivors comprise the largest group of cancer survivors, at nearly 3.8 million in the US today with a 5-year survival rate of 91% [1]. Survivors struggle daily with late effects, constant fear of cancer recurrences, anxiety and depression, unemployment, and financial problems [2]. Nationally, only 13% of cancer care facilities have a formal survivorship programme [3]. It is expected that patient oncology visits will increase by 48% in 2020; yet the projected supply of oncologists will rise by only 14%, leaving a shortfall of 9.4-15.1 million oncology visits [4].

The exponential increase in the cancer survivor population and shortfall of oncologists has produced a national crisis in survivorship care delivery [5]. Involving Primary Care Physicians (PCPs) in a shared care model is a promising way to address this health care delivery gap [6-9]. The major aim of this pilot study was to examine both breast cancer survivors' experiences and primary care physicians and nurse practitioners (NPs)' knowledge and behaviour practices with respect to late effects. Additionally, psychological consequences, screening practices, lifestyle habits, and health-related quality of life were assessed.

*Correspondence to: Hillary Klonoff-Cohen, Ph.D., University of Illinois Urbana Champaign, 1206 S Fourth Street, Champaign, IL 61820, USA; Tel: 2172446242; E-mail: klonoffc@illinois.edu

Methods

Inclusion criteria for breast cancer survivors consisted of: i) Women ≥ 18 years and of all racial/ethnic backgrounds, ii) those who have completed treatment and are transitioning to follow-up survivorship care, and iii) English-speaking individuals. Exclusion criteria consisted of breast cancer survivors who were diagnosed with neurological and cognitive dysfunctions. Breast cancer survivors may have had other comorbid conditions and were not required to remain cancer-free in order to participate.

Inclusion criteria for primary care clinicians (PCCs) consisted of: i) physicians board-certified in family or internal medicine, or nurse practitioners with a Master's of Science in nursing degree, and ii) those routinely providing care for breast cancer survivors. This project was approved by the University of Illinois Office of the Protection of Research Subjects. All subjects provided written informed consent and were reimbursed for participation in the study. The Head of Primary Care at a large hospital in Champaign, Illinois, invited eligible clinicians to participate in a focus group discussion. Breast cancer survivors were recruited for a separate focus group from the Support Group at a large hospital in Champaign, Illinois. Each focus group was approximately 90 minutes long. The facilitator used a predetermined set of questions based on the 2015 American Cancer Society-American Society Clinical Oncology guidelines to obtain perceptions, opinions, beliefs, and attitudes about late effects and breast cancer survivorship care [10].

Breast cancer survivors were queried about: i) knowledge of their cancer diagnosis and treatments; ii) awareness of late effects (e.g., fatigue,

chemobrain, lymphodema, cardiac problems, reproductive, infertility and sexual health issues, bone problems, and pain); iii) understanding of their health and psychological outcomes in relation to cancer survivorship (e.g., anxiety, depression, stress, relationships, body image); iv) screening protocol discussions with healthcare providers; v) consulting PCPs for comorbidities; vi) contacting PCPs for mental health related issues; vii) observance of health behaviour guidelines and healthy lifestyles (e.g., physical activity, diet, supplements, weight management, alcohol consumption, yoga, acupuncture, and smoking); viii) receiving survivorship care plans, and ix) satisfaction with survivorship care.

During the PCC focus group discussions, they were asked about: x) Knowledge of their patient's cancer diagnosis and treatments; xi) Awareness of late effects; xii) Understanding of health and psychological outcomes related to cancer survivorship; xiii) Understanding of comorbidities and psychological outcomes NOT related to cancer; xiv) Knowledge of screening guidelines; and xv) Observance of health behaviour guidelines and healthy lifestyles.

Statistical Methods

Consensual qualitative research (CQR) was conducted in 3 general steps: i) Responses to open-ended interview questions were divided into topic areas; ii) core ideas were constructed within each topic area for each case; and iii) categories were developed to describe consistencies in the core ideas within topic areas across cases. Data was independently transcribed and coded by two research assistants and discrepancies were resolved using audio recordings.

Table 1: Description of Breast Cancer Survivors in Focus Group Discussion.

Participant Number	Age	Type, stage, year, and age at cancer diagnosis	Type of Treatment	Receipt of Survivorship Care Plan and Discussion of cancer care with Primary Care Physicians
1	63 years	Stage II B lobular breast cancer (ER/PR positive), 2012; 57 years	Lumpectomy Chemotherapy Radiation	Did not receive any survivorship care plan. Discussed cancer survivorship care with PCP.
2	51 years	Stage I A invasive ductal carcinoma (triple positive), 2014; 47 years	Mastectomy Reconstruction Chemotherapy	Received survivorship care plan but did not discuss any such plan with the PCP.
3	52 years	Stage I Ductal carcinoma in situ, 2006; 40 years	Lumpectomy without clean margins Double bilateral mastectomy	Received verbal information from oncologist but no formal standardized care plan. Tried to have survivorship discussions with PCP by being proactive.
4	46 years	Stage II B invasive triple negative ductal carcinoma, 2011; 39 years	Lumpectomy Radiation Chemotherapy	Did not receive any survivorship care plan. Discussed cancer survivorship care with PCP.
5	43 years	Stage II B hormone positive and HER2 positive breast cancer, 2013; 38 years	Left mastectomy Chemotherapy Radiation treatment Currently receiving hormone replacement therapy.	Received survivorship care plans from surgeon and NP. PCP did not regularly discuss any survivorship care plan instead, only discussed care related to any active symptoms or issues the patient had.

Results

I Focus Group Discussion – Breast Cancer Survivors

A total of 5 breast cancer survivors who were diagnosed with different types of breast cancer attended the guided focus group discussion (Table 1). The participants unanimously agreed that survivorship care plans

were nearly non-existent. None of the primary care physicians asked survivors about any late effects including, fatigue, chemobrain, cardiovascular disease, reproductive, and sexual or bone problems. Furthermore, clinicians did not broach body image. Breast cancer survivors stated that depression and anxiety were not recognized as a consequence of cancer/cancer treatment and that they felt stigmatized about having mental health problems. Participants also stated that neither

PCPs nor oncologists provided support group referrals. Two of the participants asked their social worker for counseling (patients 1 & 2), and two found their support groups online (patients 4 & 5), while the remaining participant did not volunteer any information about support groups (patient 3). As far as prevention, primary care physicians did not address healthy lifestyle behaviours.

Participants requested that specific information should be emphasized by their PCCs including: i) an explanation of late effects particularly neuropathy, lymphedema, and chemobrain and ii) the use of supplements and complementary medicine. Additionally, breast cancer patients had split care, whereby treatment and radiation took place in different states; however, the information was not shared between health care providers. An important and lasting impact on patients' health-related quality of life was medical insurance. Two participants stated they wished they were aware of the financial impact of cancer.

Breast cancer survivors stated that, "We would definitely prefer seeing our PCPs compared to physician extenders (e.g., nurse practitioner, and physician's assistant) because of our lack of confidence in their

proficiencies." All participants strongly believed the reason they were ultimately satisfied with their survivorship care was because they were proactive in researching and openly discussing this with their physicians. However, "Not all survivors are assertive, especially after a hard diagnosis." Patients were extremely receptive to a system where there was a shared-care model between health care providers and their oncologists.

II Focus Group Discussion—Primary Care Clinicians (PCCs)

A total of three physicians and two nurse practitioners (NPs) participated in the focus group discussion (Table 2). During routine checkups, all physicians and/or NPs stated that they followed all American Cancer Society/ American Society of Clinical Oncology screening recommendations and provided appropriate referrals (e.g., pain management, genetic counseling). PCCs were confident about treating other comorbid conditions in cancer survivors. However, all clinicians unanimously agreed that they were never educated about late effects during or after their medical training and did not feel confident recognizing or treating these complications.

Table 2: Description of Primary Care Clinicians in Focus Group Discussion.

Participant number	Sex	Specialty	Years of experience	Number of breast cancer survivors seen in practice
1	Female	Physician: Family Medicine	34 years	10 survivors/month
2	Male	Physician: Internal Medicine	32 years	No information*
3	Female	Physician: Family Medicine	14 years	1-2 survivors/month
4	Female	Nurse Practitioner: Family Medicine	14 years	2-4 survivors/year
5	Female	Nurse Practitioner: Family Medicine	2 months	Just beginning her practice.

*arrived late to the focus group discussion

The clinicians strongly believed that improvements with mental health services in Illinois were necessary. Seventy-five percent of all patients in their practices reported mental health problems and therefore, mental health was always brought up with breast cancer survivors. However, PCCs were unaware of the specific psychological consequences that could afflict cancer survivors. As far as psychological services, there was only one social worker available for patients, and they waited on average for 9 months to visit a psychologist or psychiatrist.

The sole lifestyle habit that clinicians focused on during the discussion was body weight. Nurse practitioners, but not physicians, regularly discussed insurance with breast cancer survivors. Finally, PCCs were very receptive about embracing discussions about resources (costs) and believed this would be extremely valuable to their patient practices. In summary, both physician and breast cancer survivor focus group participants were unequivocally receptive about enhancing survivorship care throughout the cancer survivor's lifetime.

Discussion

In the literature, the majority of focus group discussions specific to cancer survivors, assessed unmet needs, concerns, and quality of life [11-15]. Apart from our study, only one other study by Signorelli reflected on PCPs and knowledge of late effects, but within the pediatric cancer population [16]. One hundred twenty survivors and parents of young cancer survivors completed interviews, and only 23% of survivors and 10% parents visited their PCP for cancer-related care [16]. Similar to our

study on breast cancer survivors, PCPs had high unmet information needs (94%) relating to survivors' late effects risks [16].

In our pilot study, breast cancer survivors reported PCCs lack of knowledge regarding late effects, specific psychological consequences related to cancer survivors, referrals to support groups, and availability of resources (e.g., finances). PCCs described a knowledge gap about late effects, lack of awareness of patient resources (e.g., insurance) and service gap for mental health services within the hospital. Both cancer survivors and PCCs were extremely supportive about a shared care survivorship treatment model between oncology and primary care.

Our major limitation was the limited sample size. We intentionally limited the sample in order to conduct a detailed discussion to gain every participant's perspective, while preventing a disorderly or fragmented discussion. With the inevitable growing number of cancer survivors annually, and looming shortage of oncologists, PCPs should be educated to i) care for late effect complications, ii) provide preventive services and surveillance, iii) promote the medical and psychosocial health, as well as iv) enhance the quality of life of cancer survivors.

Author Contributions

Dr. Hillary Klonoff-Cohen conceptualized and designed the study. Both authors contributed to the material preparation, data collection and analysis, and manuscript preparation. Both authors read and approved the final manuscript.

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Conflicts of Interest

None.

Ethical Approval

The methodology and data collection for this study was approved by the University of Illinois Office of the Protection of Research Subjects (Ethics approval number: 00008584).

Consent to Participate

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

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