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Opening Doors to Using Nonprofit Community-Based Services to Better Cope With Breast Cancer: A Descriptive Interpretive Study of Women's Experience

Ouvrir de nouvelles voies vers l'utilisation des organismes communautaires à but non lucratif pour mieux faire face au cancer : une étude descriptive interprétative de l'expérience des femmes touchées par un cancer du sein

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Résumé de l'article

Introduction : Les organismes communautaires à but non lucratif (OC) offrent des services complémentaires aux soins spécialisés pour répondre aux besoins des personnes touchées par le cancer. Cependant, leurs services sont sous-utilisés par les femmes vivant avec et après un cancer du sein.

Objectif : Cette étude vise à explorer l'expérience de l'utilisation des services des OC chez ces femmes.

Méthodes : Cette étude qualitative adopte un devis descriptif interprétatif. Dix femmes ayant utilisé les services d'OC ont été rencontrées en entrevues individuelles. Une analyse de contenu thématique a été réalisée selon un codage itératif en 3 cycles pour identifier les facteurs qui influencent les femmes à utiliser les services des OC.

Résultats : Les entrevues révèlent une variabilité dans la reconnaissance des besoins de soutien chez les femmes, leur expérience pour identifier des OC répondant à leurs besoins, et le processus pour accéder aux services et les utiliser. Le concept d'éligibilité émerge comme un processus déterminant de l'utilisation des OC, influencé par la qualité des interactions fortement contextualisées entre les femmes, les équipes de cancérologie et les OC.

Discussion et conclusion : L'intégration des services des OC nécessite des interactions plus productives. Nos résultats montrent comment ces femmes cherchent à répondre à leurs besoins hors des soins spécialisés. La perception d'être éligible aux OC et la légitimation de l'utilisation de leurs services de la part des équipes de cancérologie sont déterminantes. Les interactions productives et l'éligibilité créent un cercle vertueux entre des dispensateurs informés et actifs qui, à leur tour, soutiennent l'autogestion et l'utilisation des services.

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Keywords

breast cancer; nonprofit community-based organization; chronic care model; candidacy; qualitative study

Abstract

Introduction: Nonprofit community-based organizations (COs) are expected to complement specialized cancer care and help meet the needs of people living with and beyond cancer. However, nonprofit community organization (CO) services are underused by women living with and beyond breast cancer (WLWB-BC). **Objective**: The objective of this study is to explore women's experience of using CO services. **Methods**: The study is designed as a qualitative study using Interpretive Description. Ten WLWB-BC with experience using CO services were recruited for individual interviews. Thematic content analysis of interview data relied on an iterative 3-cycle coding process to identify factors that affect women's activation to use CO support services. **Results**: Interviews reveal variations in women's recognition of their need for support, in their experience of identifying COs to meet these needs, and in the process of accessing and using CO services. The concept of candidacy emerges as a determinant process in the use of CO services, influenced by the highly contextualized quality of interactions between women, cancer team professionals and COs. **Discussion and Conclusion**: Integrating CO services requires more productive interactions. Our findings shed light on how WLWB-BC seek response to their needs outside specialized cancer care. An important aspect is how they see themselves as candidates for CO services and how care providers legitimate perceived needs and eligibility. Candidacy and productive interactions create a virtuous circle supporting activated and informed providers, which in turn support WLWB-BC activation in self-management and CO service utilization.

Mots-clés

cancer du sein; organisme communautaire à but non lucratif; modèle de soins chroniques; éligibilité/ candidacy; étude qualitative

Résumé

Introduction : Les organismes communautaires à but non lucratif (OC) offrent des services complémentaires aux soins spécialisés pour répondre aux besoins des personnes touchées par le cancer. Cependant, leurs services sont sous-utilisés par les femmes vivant avec et après un cancer du sein. **Objectif** : Cette étude vise à explorer l'expérience de l'utilisation des services des OC chez ces femmes. **Méthodes** : Cette étude qualitative adopte un devis descriptif interprétatif. Dix femmes ayant utilisé les services d'OC ont été rencontrées en entrevues individuelles. Une analyse de contenu thématique a été réalisée selon un codage itératif en 3 cycles pour identifier les facteurs qui influencent les femmes à utiliser les services des OC. **Résultats** : Les entrevues révèlent une variabilité dans la reconnaissance des besoins de soutien chez les femmes, leur expérience pour identifier des OC répondant à leurs besoins, et le processus pour accéder aux services et les utiliser. Le concept d'éligibilité émerge comme un processus déterminant de l'utilisation des OC, influencé par la qualité des interactions fortement contextualisées entre les femmes, les équipes de cancérologie et les OC. **Discussion et conclusion** : L'intégration des services des OC nécessite des interactions plus productives. Nos résultats montrent comment ces femmes cherchent à répondre à leurs besoins hors des soins spécialisés. La perception d'être éligible aux OC et la légitimation de l'utilisation de leurs services de la part des équipes de cancérologie sont déterminantes. Les interactions productives et l'éligibilité créent un cercle vertueux entre des dispensateurs informés et actifs qui, à leur tour, soutiennent l'autogestion et l'utilisation des services.

INTRODUCTION

Breast cancer is the second most common cancer in Canada and the first among women (Canadian Cancer Statistics Advisory Committee in collaboration with the Canadian Cancer Society et al., 2021). Statistics in Canada report that breast cancer survival rates have increased up to a relative rating of 80% (Canadian Cancer Statistics Advisory Committee in collaboration with the Canadian Cancer Society et al., 2023), but vary greatly according to stage at diagnosis and type of breast cancer. While the estimated five-year survival for women with breast cancer is almost 100% for those diagnosed at stage I, the proportion decreases to 23% for stage IV (Ellison & Saint-Jacques, 2023). Some authors also observe that late recurrence can manifest up to 10 years after the initial diagnosis (Kamata et al., 2022). Given this context, breast cancer in women can be conceptualized as a chronic disease with long-term effects.

A large and varied spectrum of sequelae is associated with both the disease and its treatment, potentially affecting all aspects of a woman's life over a long period of time (Feuerstein & Nekhlyudov, 2018; Mokhtari-Hessari & Montazeri, 2020). A broad range of needs have been identified in studies of patients and survivors diagnosed with different cancers (Hodgkinson et al., 2007; Jacobs & Shulman, 2017; Knobf, 2015). The most acute and common problems faced by women living with and beyond breast cancer (WLWB-BC), which could be addressed in part by community-based organizations, can be grouped into five broad domains: symptom burden, day-to-day functions, health behaviors, healthcare-seeking skills, and economic strain (Tremblay et al., 2019). Up to 90% of WLWB-BC confront life-altering effects and may feel abandoned to their own devices after acute treatment (Feuerstein & Nekhlyudov; Lovelace et al., 2019). Many women may require ongoing support outside the cancer center to proactively recognize, report and manage physical, emotional, psychological and economic problems (Ross et al., 2022). Ross and colleagues stress the need to reduce the risk of cancer patients getting lost in transition and left with unmet needs. A comprehensive response would involve enabling self-management and recognition of warning signs, information about community-based resources to access for different needs, and the perception that using these services is legitimate (Lunders et al., 2023). While these efforts are underway to improve health system responsiveness for WLWB-BC, questions remain regarding their utilization of services in the community.

Nonprofit community-based organizations (COs) are complementary to health system resources such as specialized cancer care (Campbell et al., 2011) and primary care (Yeoh et al., 2018). Unfortunately, their integration suffers from the siloed functioning of health systems that is resistant to intersectoral integration (Flieger et al., 2021). This persistent fragmentation of care (Hui et al., 2021), also described as "invisible walls" between different professionals and organizations (Liberati et al., 2016), amplified by social distancing during the COVID-19 pandemic (Li et al., 2023), emphasizes that efforts are needed to optimize the contributions of all available resources, including COs (Austin et al., 2021).

The Chronic Care Model (CCM) (Feuerstein & Nekhlyudov, 2018; Wagner, 1998) appears as a valuable approach to addressing unmet needs of the growing number of WLWB-BC. The CCM positions community-based organizations as complementary resources to supporting people in their efforts to contend with long-lasting multifaceted effects of chronic conditions, including cancer, and to develop self-management capacities. It explicitly integrates healthcare and community sectors and calls for collaboration among and between providers to assure follow-up care beyond acute treatment, along with self-management (Haggstrom et al., 2012; Howell et al., 2023; Jacobs & Shulman, 2017; Taplin et al., 2015). The CCM posits that improved health outcomes depend on productive interactions and relationships between prepared, proactive providers and informed, activated patients, and recognizes the influence of health system design in bringing these pieces together. The tenets of the CCM are in line with elements of the Quebec Cancer Program (Ministère de la Santé et des Services sociaux [MSSS], 2013, 2017).

The status of COs in Quebec as autonomous organizations (Jetté, 2017) whose services complement those of the healthcare system appears consistent with the position of community support in the CCM. Quebec's national cancer program emphasizes their contribution to meeting the needs of people with cancer in an integrated network-based structure (MSSS, 2013). However, while the need for improved linkages between nonprofit community organization (CO) services and specialized cancer care is recognized (Feuerstein & Nekhlyudov, 2018), there is little empirical research available on the experience of using CO services. In an umbrella review of systematic reviews on survivorship care interventions for breast cancer survivors (Kemp et al., 2022), authors conclude that only 4.3% of 323 studies examine contextual domains such as healthcare delivery structures, care coordination, and communication or decision-making. Moreover, this review did not find any studies on interventions designed to support CO service utilization. Studies addressing CO services are mainly descriptive about their benefits and do not explore people's experience of finding out about, accessing and using these services (Campbell et al., 2011; Yli-Uotila et al., 2016, 2018). As well, the few studies available have been undertaken in health systems very different from Quebec's. For example, some Finnish studies have examined how people living with all types of cancer perceive the integration of community services and health services (Campbell et al.; Yli-Uotila et al.). However, the transferability of the findings is limited by the specificities of the Finnish health system and the highly context-dependent accessibility of CO services and their use by WLWB-BC.

OBJECTIVE

The main objective of this study was to explore the experience of using the services of nonprofit community-based organizations, from the perspective of WLWB-BC. Specific objectives were to identify the barriers to utilization of CO services revealed by these experiences and to suggest how care and service providers might proactively support WLWB-BC in better integrating CO services into their trajectory.

METHODS

STUDY DESIGN

This exploratory study is designed as a qualitative study using interpretive description (Thorne, 2016). Interpretive description was chosen for its ability to help researchers capture the subjective experience of individuals (WLWB-BC), drawing on lessons from broader patterns within the phenomenon. In this study, this method is a means of understanding the nature, significance and variability of interactions between care and services providers, and service users. It has practical implications for driving change in natural settings, fulfilling what some describe as a pragmatic obligation (Teodoro et al., 2018; Thorne).

SETTING AND PARTICIPANTS

The study was conducted in an ambulatory cancer center in a regional hospital that houses a comprehensive cancer center in Quebec, Canada. The center received 56,931 visits in 2019-2020, including 324 women newly diagnosed with breast cancer. CO services in the region include local nonprofit organizations and chapters of provincial and national philanthropic organizations with a charitable mission (Government of Canada, 2021). Some organizations have a general supportive mission, while others have a mission that contributes specifically to improving the health and well-being of WLWB-BC, whether by promoting healthy lifestyles or by offering psychosocial support (Canadian Cancer Society, 2022; Quebec Breast Cancer Foundation, 2023; Quebec Cancer Foundation, 2023). WLWB-BC who have first-hand experience with CO utilization were recruited using convenience sampling (Thorne, 2016). A nurse member of the ambulatory cancer clinic team volunteered to recruit participants upon arrival for a follow-up in the ambulatory clinic. Inclusion criteria for this convenience sample were 1) adult women diagnosed with breast cancer, 2) who had used at least one CO during the last year, 3) being able to describe their experience in French, and 4) agreed to participate in the study. Participants received a $50 financial

compensation for their participation in the interview.

Data Collection

Individual semi-structured interviews lasting between 32 and 57 minutes (mean = 47 minutes) were conducted from May to July 2019 at locations chosen by the participants (research center, home, ambulatory care center). One of the authors (BG), trained in qualitative health sciences research and with no clinical relationship to the participants, conducted the interviews. All participants provided written informed consent. In line with elements of the CCM (Wagner, 1998), the interview guide (Table 1, end of document) included questions on proactive behaviors of WLWB-BC, cancer care teams and COs, as well as on perceived linkages between the cancer team and CO service providers. For example, participants were asked: "At what point in your trajectory would you have liked to have had access? Can you tell us about an especially positive experience you had in using CO services? How do you think links could be improved between specialized cancer teams and the providers of CO services? How do you think we could improve the WLWB-BC's knowledge of the tools and resources available in the community for people undergoing or having undergone treatment for cancer?" Rich data emerged from the reflexive nature of interviews that were audio-recorded, transcribed verbatim and imported into the QDA Miner (5.0.19) software to organize and code the data (Provalis Research, 2020). A pseudonym was used to protect the participants' identification.

Analysis

Thematic analysis involved an agile iterative process (Braun & Clarke, 2022) in line with qualitative interpretive description method (Thorne, 2016). In the first coding cycle, the research team sorted and organized the data using a coding frame to identify segments that revealed aspects of WLWB-BC's experience based on response to our interview questions. A second coding cycle related to these analytic inputs looked for patterns in these data fragments and identified themes related to the efforts women undertook to connect with CO services, barriers to using CO services, and the experience of CO services utilization. A third interpretive coding cycle moved beyond these themes, using the latent approach to focus on underlying meanings (Braun & Clarke) that help understand why and how proactivity takes shape in WLWB-BC and between cancer care and CO service providers. Regular discussions among co-authors were held throughout each coding cycle to refine codes, themes, and interpretations, and ensure coherence with the CCM and quality criteria for the chosen method (Thorne). Illustrative quotes are presented to support the interpretation of themes and increase the transparency of the analysis. To ensure that important aspects of qualitative research are adequately reported, we follow the Consolidated criteria for reporting qualitative research (COREQ) checklist for qualitative studies (Tong et al., 2007).

Ethical Considerations

The study received ethical approval [CE-HCLM-17-036] from the Research Ethics Committee of the *Centre de santé et services sociaux de la Montérégie-Centre*.

Results

Ten out of 11 women consecutively visiting the cancer clinic and meeting inclusion criteria accepted to participate in the study. The mean age of the participants was 56 years (35-78y), and their education level varied from high school to college and university. At the time of the interview, half of the participants were on sick leave, two were working part-time, two were retired, and one was receiving social welfare support (Table 2). Two participants had been diagnosed with breast cancer 4 and 5 years before the interview, respectively, while the others were diagnosed 4 to 18 months prior to the interview.

Our initial coding cycle showed that WLWB-BC have a generally positive perception of their experience with using CO services once they have obtained them. However, patterns that emerged from our second cycle revealed that the process of identifying and accessing services that meet their needs was effortful and inadequately supported.

Table 2

Sociodemographic Characteristics of Participants (n = 10)

Pseudonym	Age (Years)	Employment Status	Education Level	Moment in Trajectory	Metastatic Cancer	Living Situation
Alexandra	58	Part-time	College	Post-treatment	No	Alone
Annabelle	53	Part-time	College	Active treatment	No	With partner
Anne	66	Retired	High school	Active treatment	Yes	Alone
Bianca	78	Retired	University	Post-treatment	No	Alone
Camille	47	On leave	University	Active treatment	Yes	With partner + child
Hélène	56	On leave	High school	Active treatment	Yes	With partner
Isabelle	58	On leave	University	Post-treatment	No	Alone
Jessica	53	On leave	High school	Post-treatment	No	Alone
Karine	35	Social aid	High school	Active treatment	No	Alone
Vanessa	58	On leave	College	Active treatment	No	With grown child

Our final analytical outputs revealed three themes that help understand interactions between WLWB-BC, cancer teams and CO services providers that influence the experience of obtaining support from COs: recognition of needs by both WLWB-BC and cancer teams; navigation between cancer care and CO services; and conditions for accessing CO services. The following sections focus on these outputs that drive utilization of CO services.

Recognition of Needs by Both WLWB-BC and Cancer Teams

A first theme to emerge from participant accounts is the difficulty of recognizing that they have needs requiring support beyond their own existing self-management capacities, and that COs are a potential source of support in rebuilding health. These are described as a first step to recognizing a need as legitimate and considering the possibility of recourse to CO services. The capacity to absorb information is influenced by where women are in their cancer journey. Several participants mention the timing of information by the cancer team around the availability of CO services as an impediment to following up on seeking services. Alexandra shares her experience: "It's unfortunate that we don't find out at the right time [about CO services]. When you first find out you have cancer or when you're undergoing chemotherapy, your brain just isn't capable of taking in all that information." (Alexandra, 58 years old, lives alone, part-time freelance worker) Jessica reports a similar experience:

> They give it to you at the beginning [information about available CO services], but at that point, you're not really taking anything in. She [the nurse] talked to me about a whole bunch of things. But it went in one ear and out the other. (Jessica, 53 years old, lives alone, on leave from work)

Some participants like Karine appear to realize after the fact, and even during the study interview, that they have faced unmet needs and might have benefitted from additional CO services: "I should have called the volunteer organizations in my neighbourhood to come help me at home, [...] I could have received some help." (Karine, 35 years old, lives alone, on social welfare)

Participants consider that when information is delivered alongside the cancer diagnosis, they are still struggling to face the situation and are not yet receptive. Their testimonies reveal that cancer professionals could be more attentive to WLWB-BC receptivity to information to serve as more prepared and proactive practice teams.

Navigation Between Cancer Care and CO Services

A second theme involves women's initiatives to identify appropriate CO services. Even after having recognized a need and considered the potential of CO services to help restore their health and well-being, women do not always know who to contact, or how to find out about available services. Participants report having to make multiple attempts before succeeding in accessing

CO services to meet needs related to their cancer experience, whether fatigue, distress, financial difficulties, or home help. Almost all participants state that they rely mainly on advice from people around them or, like Anne, look up resources on the Internet by themselves: "I figured out how to access [CO services] by myself!" (Anne, 66 years old, lives alone, retired)

In some cases, women request and obtain assistance from the nurse or other members of the cancer team to find information on what CO services are available:

> I asked my pivot nurse if there was any financial help available from somewhere, because, at one point, money was becoming very tight, and I actually had to move because I couldn't see the light at the end of the tunnel. (Karine, 35 years old, lives alone, on social welfare)

These quotes reveal that women may have to invest considerable effort into becoming informed and activated to find the CO services they need to support self-management. Participants point to a lack of complete information on the range of services available locally. They also suggest that nurses on the cancer team could play a role in supporting women's efforts to navigate, including on the Internet, and find appropriate support.

Participants consider that cancer teams and the general population have little awareness of CO services. In addition, it is difficult to know if a service will respond to a specific need encountered at a particular moment in the cancer trajectory. Though one participant reports getting help from a person at the CO to find the right service at the right time, others, like Hélène describe a lack of visibility of CO services and challenges in connecting with these organizations: "You leave your number, but no one from the CO calls you back [...]. The pivot nurse helped me. She called and that sped up response from the CO. They called me back." (Hélène, 56 years old, lives with her partner, on leave from work)

Some women, like Jessica, report that once they were participating in one CO activity, it became easier to find out about additional CO services to meet their needs: "I would say it's important not to stop at just one service; [...] you find out [about other CO services] from community services you use..." (Jessica, 53 years old, lives alone, on leave from work)

Conditions for Accessing CO Services

A third theme to emerge is around accessing CO services. Participants in the study report that, even after a CO has been identified, additional barriers to access appear. These include the need to fill in many complex forms to request services, the burden imposed by their symptoms, and the limited availability of the CO staff to provide information when needed: "When you're undergoing treatment, it's not easy to fill out all that [forms to obtain help from a CO]. You'd be amazed how many documents they requested [...] when you have no energy, it's not easy." (Jessica, 53 years old, lives alone, on leave from work)

Some women receive help from a member of the cancer team to complete the access request; however, interactions between CO service providers and WLWB-BC are of variable quality. Hélène recounts a difficult experience:

> It wasn't easy. [The CO service provider] was never reachable, she was out [...] she was busy; maybe she would call me back. She would take my name, my number, and call back 5 or 6 days later to say: 'I have no availability' while you're panicking because your hair is falling out. (Hélène, 56 years old, lives with her partner, on leave from work)

Overcoming the barriers to recognizing needs, identifying CO supports and accessing CO services appears even more important given the benefits WLWB-BC report deriving from CO services once they have obtained them. Participants describe their experience of using CO services as positive in helping them rebuild their health: "I participated in the yoga program offered by [the foundation] because I have metastatic breast cancer. [...] It helped me a lot, it gave me the strength to combat fatigue." (Camille, 47 years old, lives with her family, on leave from work)

Participants benefit from accompaniment, peer support and a place where they can discuss the various emotions they are feeling, reflect on their priorities, live in the moment and stay positive and strong to face cancer. Other services, such as help with medical expenses, alleviate the financial anxieties experienced by some WLWB-BC:

"Financial assistance was what helped me most; I was very anxious at the beginning [...] at the financial level it's just crazy, so I could calm down when the social worker helped me find help." (Vanessa, 58 years old, lives with a grown child, on leave from work)

The improvements described by study participants in their ability to manage the impacts of breast cancer and its treatments support the CCM's propositions that productive interaction between COs and WLWB-BC improves outcomes.

In summary, barriers to utilization of CO services that support women's efforts to cope with the sequelae of breast cancer suggest that interactions are not optimally productive between all parties. Barriers arise first in the recognition among WLWB-BC that they have needs and that COs might help, second in the identification of appropriate CO services, and third in completing the steps to participate in those services.

Discussion

This study deepens our understanding of WLWB-BC's experience of using CO services. Results reveal that the factors likely to influence this experience relate to the recognition by WLWB-BC and cancer teams of needs and of the potential for COs to meet them; to the identification of available COs; and to the ease of access to their services. Our study provides unprecedented data for developing interventions to overcome the underutilization of community organizations and thus meet some of WLWB-BC's needs (Kemp et al., 2022). The CCM encourages us to recognize that the self-management efforts undertaken by WLWB-BC depend, at least in part, on the self-management support offered by providers in the context of a chronic disease such as cancer. "Effective self-management support and linkage to relevant community services help to create 'Informed, Activated Patients'" (Wagner, 2019, p. 661). In 2021, The Global Partners on Self-Management in Cancer issued a call to action for self-management in cancer care (Howell et al., 2021). The present study highlights that COs play a crucial complementary role to cancer teams in supporting patients in self-management. Importantly, it also shows that, beyond assuring that such services exist, it is crucial to understand what leads and enables women to recognize needs as legitimate and seek support. Interviews suggest that women's perception that it is appropriate and acceptable for them to seek help from a CO is constructed through their interactions with cancer teams and COs.

What do we Learn About the Experience of Using COs?

The CCM framework was developed to improve person-centered care, self-management, health system design, and CO services (Yeoh et al., 2018). The results of the present study align with prior research to support the added value of CO services for improved outcomes, and the perspectives of WLWB-BC reflect the transition process to constructing life after cancer that is not the same as before (Hébert et al., 2016). Our findings suggest that the cancer network could be more responsive to the needs of WLWB-BC. Up-to-date information on services and a formal referencing mechanism would facilitate productive interactions that improve access to COs. A recent evaluation found that most CO programs for cancer patients end up with the active phase of treatment and are too scarce to respond to the needs of current and future cancer survivors (Canadian Partnership Against Cancer, 2019).

What this Means for Interactions Between Cancer Teams, WLWB-BC and COs?

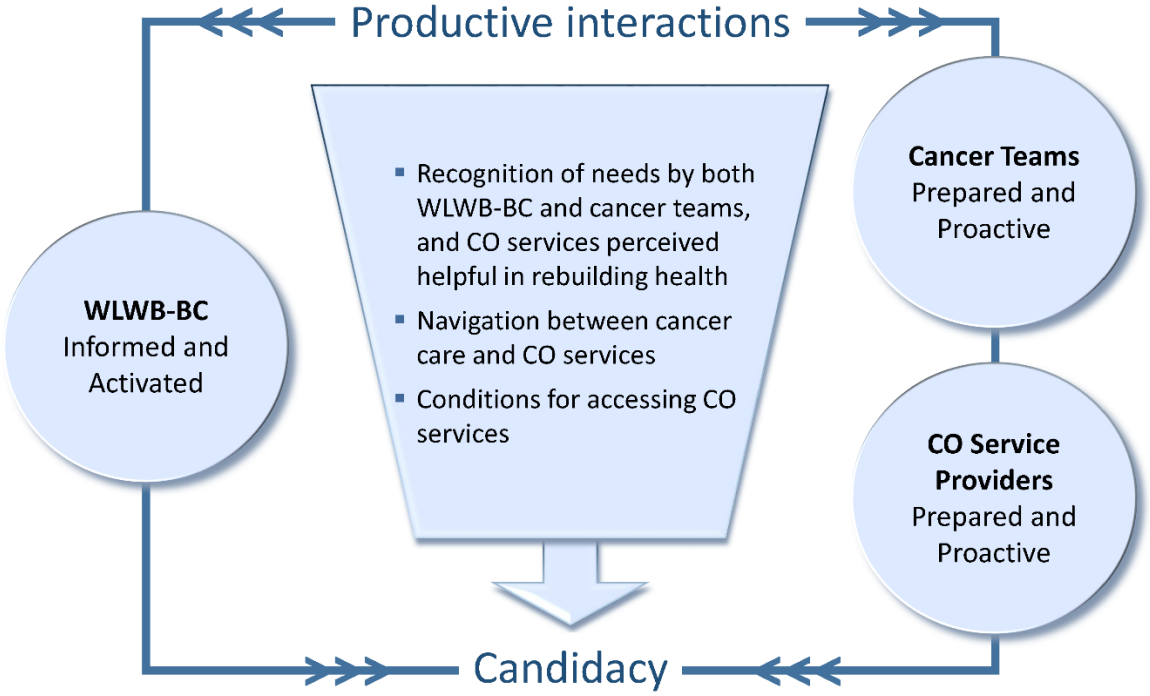
An important finding is that a first step in overcoming utilization barriers involves interventions to support women's perception that their needs and seeking help for these needs are legitimate. This study provides insight into how perceived eligibility for CO services is constructed and helps to understand why some WLWB-BC use CO services and others do not. Perceived eligibility for CO services is influenced by interactions between organizational forms and professional practices. The findings that emerge through the interviews, such as the timing of information along the cancer trajectory, the lack of visibility of available CO resources, the reticence of WLWB-BC to see themselves as CO service users and the burden of identifying and navigating fragmented

services, point to actions that cancer teams and COs might take to improve communication and permeability of services leading to the likelihood of WLWB-BC seeking and obtaining support from COs. These results connect with the concept of "candidacy".

Candidacy emerges in seminal work on access to, and utilization of, healthcare by vulnerable groups (Dixon-Woods et al., 2006; Mackenzie et al., 2013). Candidacy is useful in understanding how healthcare utilization experience is shaped through interactions between health system features and user characteristics. Results from the present study (Figure 1) converge with four interdependent and non-linear moments in the candidacy process: 1) identification of candidacy: recognition of self-management limits and view of oneself as a legitimate candidate for CO services; 2) navigating services: having timely information to contact and access CO services that can respond to a particular self-management challenge and unmet needs; 3) adjudication by professionals, which involves the recognition or validation of candidacy by cancer team members; and 4) operating conditions and local production of candidacy (Mackenzie et al.). Operating conditions include incorporating complementary CO services into the dynamic between multiple care team members and patients (Liberati et al., 2022; Mackenzie et al.). The concept of candidacy has not yet, to our knowledge, been used to understand utilization of CO services by cancer patients. However, it provides a valuable framework to overcome barriers between specialized cancer teams and COs, and helps challenge a number of common beliefs that impede the use of CO services: that only specialized cancer teams can respond to the needs of patients and survivors, and that CO services are intended only for socially or economically vulnerable people (Jetté, 2008).

Figure 1

Utilization of Nonprofit Community Organization (CO) Services by WLWB-BC



The concept of candidacy adds a missing link to the CCM notion of productive interactions between service users and service providers to improve quality of care (Dixon-Woods et al., 2006). Candidacy and productive interactions create a virtuous circle supporting activated and informed providers, which in turn support WLWB-BC activation in self-management and CO service utilization.

What can be Done to Improve Navigation, Promote Candidacy and Support Self-Management?

This study reveals some of the access barriers that prevent women from obtaining more effective navigation, recognition of candidacy, support of self-management and other benefits; too often, the efforts involved in obtaining assistance constitute a burden in themselves. Cancer team members can play a role in reducing these barriers, notably by formalizing access to certain CO services (Kemp et al., 2022).

Prior research describes the role of "peer/lay navigator" as a best practice to facilitate access to CO resources, as they can respond "to particular needs in different contexts without waiting for standardized models or professional reference" (Canadian Partnership Against Cancer, 2019, p. 22) and facilitate access to information about available community resources (Loo et al., 2022). In Quebec, the contribution of peer navigators, more recently called patient accompaniment by Pomey and colleagues, has been recognized and promoted for many years (Pomey et al., 2023). Pivot nurse and social worker roles are important in supporting peer navigator efforts. Some studies regard these roles as a form of professional navigation within the health system (Emfield Rowett & Christensen, 2020; Johnson, 2015). However, studies of both professional and peer navigation have focused primarily on navigation within the formal health system. Our findings indicate that despite the presence of professionals on cancer teams with responsibilities to help people access CO services, this role is poorly supported by organizational structures and is exercised unevenly.

The lack of centralized up-to-date information about CO services contributes to access difficulties. Challenges include the variability in CO services between regions and the instability of smaller COs. In one region of Quebec, a group of key actors created a directory of CO services organized by type and relevance at given points in the cancer trajectory (Centre intégré de santé et de services sociaux de Chaudière-Appalaches, 2016).

The present study contributes to the understanding of how WLWB-BC experience the use of CO services as complements to the services of cancer teams. Considering CO services within the health system structure allows us to distinguish their contributions to "Improved Outcomes" (Wagner, 2019). Findings provide new knowledge about how eligibility, or candidacy, for CO services is established in WLWB-BC and supported by nurses and other members of the cancer team. Findings also allow us to better understand how the space between specialized care and CO services could be managed to enable women to achieve better outcomes.

Strengths, Limitations and Future Research

A strength of this exploratory study is the use of triangulation strategies that enhance the credibility of results: use of probing techniques during interviews, field notes that integrate insights drawn from interviews and the context in which they take place, keeping of a reflective diary, and discussions among co-authors with applied health research knowledge (BG); nursing expertise and experience in health services and oncology (DT); healthcare sociology, primary care and intervention with vulnerable groups (CL); and public health (SU) (Thorne, 2016). Another strength is the mobilization of the CCM with the pragmatic aim of clarifying the interface between clinical practice, community support and the organization of the health and social services system. This model guided data collection, analysis and interpretation (Thorne et al., 2004). Also, the COREQ checklist for qualitative studies is used to assure reporting of important aspects of the research (Tong et al., 2007).

Convenience sampling and sample size may represent limitations of this study. However, participants' openness to sharing their experiences contributes to the reliability of the data. Moreover, a certain redundancy of the content was observed even in the small sample size (Sandelowski, 1995),

suggesting that the sample could be considered representative of WLWB-BC from a pragmatic perspective. The transferability of results is limited due to different contexts surrounding the provision and use of CO services from one country and setting to the next. Participants were Caucasian French speaking except for one person, which may limit the transferability to women from other cultures. The study was conducted in Quebec (Canada), which has a public healthcare system and a long, though not always easy, history of links between the health system and COs (Jetté, 2017). Participants were mainly in the treatment or recent post-acute treatment phases of their disease. While we know that the use of CO services varies across the trajectory (Yli-Uotila et al., 2016), it would be interesting to explore their use at different points in the trajectory and COs capacity to tailor support accordingly. Future studies could benefit from including the perspectives of other actors (clinicians, managers and policymakers) to obtain a broader perspective of the use of CO services.

Finally, the concept of candidacy appears promising and warrants empirical exploration in future research. First, research could more deeply investigate how people come to view themselves as legitimate candidates for CO services. Second, research is needed on the role of oncology nurses and other team members in legitimizing recourse to CO services (Mackenzie et al., 2013). A third question that merits further research is around operating conditions that promote complementarity between specialized cancer teams and community-based providers who address a wider range of long-term needs and support self-management.

CONCLUSION

Every day, nurses and other members of the cancer team strive to provide quality care that considers the whole person's needs and help people navigate the complex cancer system. However, professional practice remains concentrated within specialized cancer care, allowing only a partial view of the WLWB-BC trajectory. This study highlights ways in which providers might encourage and facilitate the use of nonprofit community-based services that can contribute to improved cancer and survivorship experience. Greater complementarity between cancer services and CO services would support self-management and help prevent the unmet needs of WLWB-BC. Findings point to increased visibility of CO services, more consistent and better-timed navigation support, and greater proactivity, notably from oncology nurses, in helping women acknowledge their needs as promising steps to supporting perceptions of candidacy for support that can, when obtained, improve outcomes.

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Table 1

General Information, Consent Information and Interview Guide

General Information	
Participating site ID code	
Participant ID code	
Date	
Start time	
End time	
Interviewer	
Introduction and Consent Information	
Interviewer's introduction	Thank you for taking the time and making yourself available for this interview about your perspective of COs offering services to women living with and beyond breast cancer (WLWB-BC).
Confidentiality and anonymity	I would like to remind you that any information you reveal to me will remain confidential. If names are mentioned during the discussion, they will be anonymized. Under no circumstances will your name or personal information be revealed when results of the study are presented or published. Only members of the research team will have access to the information for analysis purposes, and they are all committed to respecting the confidentiality of information. You can stop the interview at any time or withdraw your consent, without any consequences. Do you have any questions? Please read and sign the consent form.
Audio recording	This interview will be audio recorded with your permission. The audio recording will be transcribed and anonymized (your name will not appear). Please feel free to ask me to stop the recording at any moment for specific questions if needed. Also, if you wish to remove some content, you can ask me during or immediately after the interview.
Introduction	I will ask you some questions about the different aspects of your experience with COs. What I am interested in is your perspective, experience and perceptions on the subject, so feel free to add anything you think is relevant: there is no good or bad answer or point of view.
Interview Guide	
Themes	Questions and probes
Informed WLWB-BC	• Do you know about resources available in the community? • How did you find about them? • How do you think we could improve the WLWB-BC's knowledge of the tools and resources available in the community for people undergoing or having undergone treatment for cancer?
Productive Interactions	• How were you put in contact with the CO? • At what point in your trajectory would you have liked to have had access?
Prepared, Proactive Practice Team (Cancer care provider)	• How do you think links could be improved between specialized cancer teams and the providers of CO services?

	• How do you think we could improve the cancer care provider's knowledge of the tools and resources available in the community for people undergoing or having undergone treatment for cancer?
Prepared, Proactive Practice Team (CO service provider)	• Can you describe the services you received from the CO?
Improved Outcomes	• Can you tell us about an especially positive experience you had in using CO services? • How did they help you? • In what way did this meet your needs?
Conclusion	• Is there anything you would like to add?
Participant sociodemographic characteristics	• How old are you? (Age: years) • What is your current employment status? • What level of education have you completed? • Are you currently undergoing treatment? • Were you diagnosed with metastatic cancer? • What is your current living situation? (Household)
Acknowledgment	• We are at the end of this interview. Thank you very much for your time and for sharing your lived experience!

Note. CO(s): nonprofit community-based organization(s).