





# Toronto's Portuguese-speaking community potential for creating a social support-networks for breast cancer\*

*Potencial da comunidade lusófona de Toronto para a criação de uma rede de apoio social para o câncer de mama*

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## ABSTRACT

An ethnographic study explored ideas about the possibility of creating social support networks for breast cancer within the Portuguese-speaking community in Toronto (Canada). Nineteen men and women from Angolan, Brazilian and Portuguese communities informed about a social support network with a focus on enabling versus challenging conditions for its construction. The fundamental components in creating social support networks were: the demystification of breast cancer and its prevention, emphasis on health education, mobilizing volunteers and direct social support to women living with breast cancer. The potential enabling factors were the participation of older women as social leaders, and the utilization of schools and religious institutions. Perceived barriers were: breast cancer believed to be women's disease, lack of knowledge about its cure/ rehabilitation, as well as a limited sensitivity to cancer. Social support networks should consider the communities' diverse cultural and tangible needs, as well as more informal social support services.

**Descriptors:** Social Support; Social Capital Breast Neoplasms; Emigrants and Immigrants; Qualitative Research.

## RESUMO

Estudo etnográfico que explorou ideias sobre a possibilidade de criação de redes sociais de apoio para o câncer de mama na comunidade lusófona em Toronto, (Canadá). Dezenove homens e mulheres das comunidades angolana, brasileira e portuguesa discutiram sobre a criação de uma rede de apoio social com foco em condições facilitadoras e dificultadoras para seu estabelecimento. Os componentes fundamentais para essa criação foram: a desmistificação do câncer de mama e sua prevenção, ênfase na educação em saúde, mobilização de voluntários e apoio social direto às mulheres que vivem com câncer de mama. Os fatores facilitadores potenciais foram a participação de mulheres mais idosas como líderes sociais e a mobilização de escolas e instituições religiosas. As barreiras percebidas foram: a crença de que câncer de mama é uma doença feminina, falta de conhecimento sobre sua cura/reabilitação, como também uma sensibilidade limitada ao câncer. As redes de apoio social devem considerar as diversas necessidades culturais e tangíveis das comunidades, assim como serviços de apoio social mais informais.

**Descritores:** Apoio Social; Capital Social; Emigrantes e Imigrantes; Neoplasias Mamárias; Pesquisa Qualitativa.

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## INTRODUCTION

Breast cancer is one of the leading causes of death among women in Canada, and the most commonly diagnosed type of cancer in Ontario<sup>(1)</sup>. Evidence across various ethnic groups in North America has shown that women with wider and stronger social support networks have a better chance of survival from breast cancer (BC), as well as improved quality of life compared to those with minimal social support<sup>(2-5)</sup>. Social networks influence health outcomes of women who experience BC by providing informational, emotional, tangible, and appraisal support<sup>(2)</sup>. Social networks also serve as a community's social capital as they avail opportunities for members to accrue resources even if members do not have direct access to actors and institutions<sup>(6)</sup>. The use of a community's social capital enables and strengthens social identity, perceived self-efficacy and empowerment<sup>(7)</sup>, and bridges resources and social network membership<sup>(8)</sup>. Social connections unite segregated communities enabling further actions towards social capital's maintenance/enrichment<sup>(9)</sup>.

Social Support Networks' (SSNs) creation to support minorities dealing with issues of capacity-building, and healthcare equity for diseases holding a strong cultural stigma is a major challenge to all social actors. This is applicable for breast cancer (BC) in Toronto (Canada), where 52% are female inhabitants and 49.1% are not native English-speakers<sup>(10,11)</sup>. In the census 2011 (not in the 2016 one), it was retrievable specific information that Portuguese is one of 160 linguistic minorities found in Toronto and comprises 1.4% of Toronto's population making Portuguese the 8<sup>th</sup> most spoken non-English language<sup>(10)</sup>.

Breast cancer is most likely diagnosed in early stages in the province of Ontario (46.6%) which indicates a high probability of survival<sup>(1)</sup>. The diagnosis gradually increases with age with expected new cases for those aged 60–79 years old (5,561 cases) and for 40–59 years old (4,155 cases). The majority of BC in 2013 were diagnosed at stage I (42.9%) or stage II (38.3%) with an incidence of 11,762 projected cases for 2018. BC had a 5-year relative survival of 88.9% for the 2009–2013 time period<sup>(1)</sup>. Generally, the earlier breast cancer is diagnosed and treated, the higher the chances for long-term survival<sup>(12)</sup>. Survival outcomes does vary by race and ethnicity, but data is limited. Incidence and death rates for breast cancer are higher among non-Hispanic white and non-Hispanic black women<sup>(12)</sup>. None were found for Portuguese-speaking communities. Yet, clinical observations from one hospital site in Toronto tells us they see more advanced-stage diagnosis within this population. Response to this population's service demands without a cancer population ethnic registry introduces an extra challenge to health policy-makers and healthcare providers working with numerous cultural cancer meanings, traditional cancer knowledge, and linguistic diversity.

This study considered the diversity of several characteristics found in the social reality of Portuguese-speaking women that would sustain BC SSNs' creation. The meaning of volunteerism to work with cancer among Portuguese and Brazilian women varies according to its attributed importance and it was reported in a seminal work analyzing both countries' perspectives<sup>(13)</sup>.

A multilingual clientele is at high risk for health inequities. For instance, in the USA, immigrants who do not speak fluently English have received less preventative care, less healthcare access and coverage, leading to less favorable health outcomes<sup>(14)</sup>. In Toronto, health services to a multilingual population had Portuguese as the top language accounting for 22% of participants. Clients were (61%) served in community health centers, and were older females highly satisfied (85%)<sup>(15)</sup>.

In Brazil, BC survivors reported self-blame brought by perceptions of having caused the disease, and the need to rebuild a new identity as a woman and BC survivor<sup>(16)</sup>. Women reported living with constant negative feelings, uncertainty and insecurity<sup>(17)</sup>. Close relatives' social support was a fundamental asset in dealing with stressful conditions due to more emotional roots, such as respecting the loved one, providing peace of mind, and encouragement when women and relatives equally face uncertainty, and conversing in sad moments<sup>(18)</sup>. Positive religious/spiritual coping strategies were significantly associated with better coping with stressful situations related to the various BC treatments<sup>(19)</sup>.

In Portugal, prevalent issues regarding the extent and quality of cancer screening to prevent late stage BC diagnosis<sup>(20)</sup> corroborated the relevance of community work to increase BC screening compliance. Moreover, popular views of BC as a destructive entity with unimaginable consequences co-exist with intention of preventive behaviors rebuilds causal understanding<sup>(21)</sup>. Integration to a social network accounted for uncertainty on how to approach BC's psychosocial impact due to one's self-perception of being loved, valued, and belonging to a group and their integration, mutual obligations, type of social network and number of social roles they play<sup>(22)</sup>. This evidence remains eloquent in the last 15 years in Portuguese studies in this area due to the scarce literature on an in-depth investigation on the dynamics of social networks in BC experiences. However, it is known that psychological damages can be prevented by promoting more comforting beliefs to sustain self-efficacy to enhance QOL<sup>(23)</sup>, since they relate to body image for BC survivors<sup>(24)</sup>.

This type of network is a trans-ethno-cultural issue, including the notion of social solidarity and mobilization of social forces to improve health outcomes. The knowledge gaps addressed by this study concern the mobilization of

the Portuguese-speaking community's social capital, its members, and stakeholders in order to act on BC prevention and rehabilitation matters concerning women and men interconnected by bonds of solidarity.

Bourdieu's types of capital<sup>(25)</sup> guided this study as a conceptual framework. Capital is defined as an instrument that enables social energy in the definition of social changes, opportunities, possibilities, and relationships. It can be economic, social, or cultural. Cultural capital includes the personification of culture in one's mind and one's way of behaving in the world, affecting one's assimilation and integration. The dissemination of cultural capital tends to perpetuate its existence, and its expression is associated with the concept of *habitus*, which represents mental biases ingrained by the family, for instance, and manifested in different ways in each individual. *Habitus* is a system of lasting preferences that impacts how individuals perceive, judge, and behave in the world. *Habitus* defines coherence in several activities in multiple spheres of life, which explains events and standards of behavior. Another form is social capital, which relates to the notion of networking to access real/potential resources, and nurture lasting connections while navigating obligations. Relationships and mutual recognition, material and symbolic exchanges, and the links in social and geographic spaces are part of social capital.

Looking forward to creating and consolidating SSN for BC based on social and cultural assets, this research sought to identify the meanings from male and female non-diagnosed community members from the Angolan, Brazilian and Portuguese communities in Toronto about the potential within Portuguese-speaking communities.

## METHOD

### Design

A qualitative approach guided by ethnographic principles<sup>(26)</sup> that explored the social and cultural values of Portuguese-speaking communities, their potential for action through strategies and SSNs to promote their health in general and related to BC, as well as understanding their cultural health-related ideologies. Participants were engaged in a reflexive, cyclical, and collaborative process to understand cultural ideologies, social psychologies, social networks, and mechanisms that support health in ways that are either health-enhancing or health-damaging<sup>(27)</sup>.

### Participants

For this study, Portuguese, Brazilian and Angolan groups were chosen since they composed the largest number of

Portuguese-speakers in Toronto. Participants were not BC patients nor survivors and were made up members of these groups who were immigrants and/or refugees living.

### Recruitment

Advertisements through radio, television, consulate sites, letters, posters, referral of individuals by participants, and visits to community organizations.

### Sampling

Snow-balling sampling was used to select participants. The inclusion criteria included: (i) immigrant and/or refugee adult male or female; and (ii) capable of verbalizing ideas and values related to social solidarity in their communities of ethno-cultural affiliation for the support of BC for their communities. For sample socio-demographic characteristics see Table 1.

### Data collection

The data were collected in Portuguese (October-December 2010) using focus group discussions with the participation of a bilingual researcher. This method explored the consensual view of SSNs construction for BC. Four groups were formed and separated by country of origin and the groups met at the residences of two participants and at the social headquarters of a community organization. The researcher moderated the discussions and recorded them using a digital audio recorder. Each session lasted 90 minutes discussing existing key resources/services, informal/formal networks, as well as needed actions to create the network. Plus, negative factors and primary and, the cultural community leaders who would assist.

As the cultural insider, she supervised the work of bilingual (Portuguese-English) research assistants (RAs) who worked with e-audio file transcription, verbatim coding, findings analysis, as well as verbatim Portuguese-to-English translation.

### Data analysis

Data analysis was provided by two Brazilian RAs, trained by the bilingual researcher, transcribed the digital audio files, and coded transcribed discussions using qualitative software. Along with the RAs, she completed the thematic analysis<sup>(28)</sup> of the coding report using the following procedures: determination of an initial list of codes; identification of themes after intensive and repeated readings of the coding report; creation of a thematic index with reflections about the content of the discussions and attempts to re-group the themes; codification of transcribed discussions using six predefined themes; refinement of the theme titles; and answering the research questions using the final theme titles.

**Table 1.** Participant characteristics.

	Angolan	Brazilian	Portuguese
Female (F)	n=2	n=12	n=3
Male (M)	-----	n=2	-----
Age	32–40 years old	F=19–64 years old H=25–47 years old	28–34 years old
Canadian-born	-----	-----	n=1
Years since immigration	7–10 years	F=17 months–18 years M=5–8 years	18–30 years
Schooling	Completed high school	F=Did not complete high school/ Completed university degree M=Completed high school/Completed university degree	Completed high school / Completed university degree
Occupation/ Profession	Shopkeeper, Administrative assistant	F=6 psychologists, 1 community educator, 4 unemployed, and 1 student M=construction workers	Administrative assistant

## Verification of final interpretation

Portuguese-speaking RAs and invited three individuals belonging to the communities being studied verified the final interpretation of the findings in individual discussions with the bilingual researcher (January–February 2013).

Ryerson Research Ethics Board (REB-2009-221) and York University Ethics Board-Canada (Certificate Number 2009-157) approved this study.

## RESULTS

Results presented in this section regard cultural features within the Portuguese-speaking ethnic communities that had remained unchanged for the past 10 years. Accounts of 19 men and women having no prior BC diagnosis, discussed their communities' social and cultural capitals in relation to the feasibility of BC SSNs' creation. These networks would be instrumental to respond to prevention needs, as well as address BC survivors' social/financial/emotional needs. All participants emphasized their limited contact with BC-related information both in Canada and their home country. Such information was delivered by popular media, conversations with family members or in in-service education and other occupational health initiatives. Few Brazilian participants (two women and one man) reported having some BC knowledge or having previous experience with BC among friends and relatives. Only three of the 17 women described having consistent preventative practices geared towards BC screening.

## Key elements to create Social Support Networks

For Angolan women, the creation of a true community environment would be fundamental, since their

interpersonal relationships eroded due to the collective immigration experience and political refuge. To demystify the commonly held fatalistic view of BC, the Angolan women emphasized the need for community-tailored educational activities geared towards BC causes, to teach the community about the adoption of preventive behaviors and practices. They recommended that activities should start through projects promoting BC awareness that target mothers, especially in elementary schools, to ensure information reaches households having children as major information holders. They suggested to offer help with domestic chores and childcare; provide an escort service to the hospital and supply alternative methods of transport to doctor's appointments.

The Brazilian participants suggested community BC awareness/promotion initiatives as the initial activity. They proposed a BC-awareness week reminding volunteers of the importance of honoring their commitment to their proposed work, which is a valuable suggestion since volunteerism is not a well-established practice in Brazilian culture. Health education was suggested through specific means, such as: creating educational pamphlets, promoting lectures given by BC survivors in churches and community social events (including barbecues); and promoting workshops on preventative actions. The existence and activities of an SSN should be advertised in community newspapers/magazines to emphasize the availability of volunteers to meet some of the supportive needs for BC screening. They recommended that these types of services/support be publicized in churches and other social sites. The common suggestion of churches is due to ministerial social leadership, its embraced humanitarian and religious philosophy, and the agglutination power expressed by

promoting social connectedness. These strategies accounted for widespread information about the SSNs' existence, infra-structure, assets, and operation.

Other suggestions included: social support group creation; home visits to women living with BC; emotional/psychological/instrumental support (e.g., cooking, cleaning, shopping); education about social and financial benefits; couple psychotherapy; survivor groups creation, led by survivors themselves; creation of a specific group for women who are still undergoing treatment; support groups for spouses and children; and interpersonal support through direct contact or by telephone. The Portuguese women suggested that publicity of SSNs availability should also target men from all three communities in clubs, cafes, and bars to reach out to those who may be experiencing BC in their families. Another strategy is teaching the Portuguese community how to engage, participate, and offer help in the BC SSN.

All participating women emphasized the need for the SSN to offer services to help with domestic chores. The creation of self-help groups exclusively to Portuguese women to ensure the opportunity to overcome the idea of being a minority, as well as being shy about speaking openly of personal experiences, and respect for the cultural trait related to being proud, which can hinder expressing themselves to others.

### Enabling assets/key resources to create Social Support Networks

Angolan women suggested mobilizing older women to lead the SSN services. Working with schools will be a key strategy due to perception that schools have credibility as informal sources of health information. The Brazilian participants highlighted strong social solidarity, a good sense of humor, pleasure in sharing social events, and being an affective and emotional culture, as well as the highly valued family and friends.

The Portuguese women explained that religious and recreational institutions allow for the identification of a social cohesion bringing new meaning to family. Social cohesion confirmed a collective consciousness in the state of social isolation experienced by women who have BC or survived it. For them, this social capital is expressed as community values with meanings attributed to family and friends, a key value of the Portuguese culture resulting in family union and responsibility to care, shared by family members of several generations.

### Possible barriers to Social Support Network creation

Angolan women reinforced the influence of recent political factors in Angola, causing loss of social cohesion

in the community in Toronto resulting in lack of solidarity, mutual respect, and emotional connections, as well as a lack of education regarding interpersonal relationships. A sense of low collective self-esteem persists within the Angolan community and co-exists with a discriminatory perception by members of the Portuguese community. Contact within the Brazilian community occurs more spontaneously. Angolan women reported the greatest cultural barriers being the taboo and mystical view surrounding cancer in general, and the notion that BC is a disease only experienced by women. Therefore, men do not participate nor give their opinion about the issue, which fosters disbelief/disinformation about the procedures to detect BC.

Brazilian participants identified cultural barriers (e.g., taboo about BC, lack of knowledge about BC possibilities), along with conflicting information about BC, and a limited collective consciousness about its prevention and early diagnosis. Identified social barriers included failure to appreciate the activities of the SSN since they do not feel sensitized or affected by BC. Another social barrier was the lack of motivation to accept volunteer work in churches. The varied work schedule of Brazilians demands a greater flexibility in the SSN operation to accommodate the availability of volunteers, as well as use of the services by the target population. Brazilian women criticized the fact that religious leaders are mostly male and they might not be sensitive to the issue of BC. They discussed how this perceived view would need to be further assessed with male leaders in influential positions so that potential barriers to speaking about BC screening could be broken down. Some means of social interaction among Brazilian individuals should be targeted by awareness activities: the fear of asking for help and the possible refusal to participate in the network due to alleged work overload.

The Portuguese women explained the notion of pride/autonomy as a trait of the women's cultural capital to explain how it is a barrier towards asking for help from strangers/non-family members. The context of experiencing BC alone is added to the taboo about it, related to the lack of knowledge and understanding of BC and its management. The male attitude of not getting involved in female health issues results in the refusal of spouses to support the women in their BC-screening activities, in their treatment decision-making or to participate in support groups where, often, personal and family experiences are expressed.

### Possible participation of community leaders in Social Support Networks creation

All participants suggested diplomats should participate and collaborate in the SSNs due to their administrative

knowledge, and social and cultural leadership. Regarding religious leadership involvement, the Angolan and Brazilian women mentioned priests/pastors, while the Portuguese women suggested the wives of pastors. For Angolan women, school principals could be leaders as well. Most of the participants mentioned communication entrepreneurs, as well as communication and journalism professionals. The interviewees stressed the need to disseminate information about all aspects related to BC.

For Brazilian participants, the goal of mobilizing representatives of these communities who are professionally engaged in Toronto society is to promote facilitating agents to counteract the language and social isolation of families with less schooling and who are not part of the labor force. The little amount of BC-related information available in Portuguese, the absence of BC preventive practices among women, the culture of silence about BC, and the educational inequalities in the communities substantially limit the users' critical view of BC-related information.

The interactions with their established social networking components, such as well-known community organizations, highly active popular media, recognized social leaders, sponsors and stakeholders, physical locations of common assembly of men, women, children and youth, a solid family tradition of respect for relatives and strong bonds of friendships, and acknowledgment of the importance of women's family roles are contributing elements for the SSN. It is also noteworthy to say that the new politically engaged discourse about the social work, commitment and leadership of religious organizations weighs in as a very influential element to support this community capacity-building project.

Challenging conditions include rebuilding trust among individuals within and inter-communities, and awakening the collective awareness to the value inherent to volunteerism. A particular challenge concerns the culturally-rooted gendered perception of health issues added to the systemic lack of BC knowledge, as it remains perceived as an exclusive matter of women's health.

## DISCUSSION

The possible creation of BC SSNs relies on the intersection of multiple axes-of-influence with the entrenched gender norms/roles/relationships. The proposed provision of indirect social support to women experiencing BC is suggestive of the gendered social organization of care work. Breast cancer can be either a solitary or a family experience, and secrecy can limit discussions due to stigma and taboo, lack of understanding, family pride, financial concerns, and an inappropriate topic of conversation<sup>(29)</sup>. Non-disclosure of emotions lack of communication with social networks has

been determined to have a negative outcome on quality of life BC survivors<sup>(4)</sup>.

It has been argued that ethnic and language minorities heavily rely on their social networks to access resources as they are often secluded from mainstream institutions and resources<sup>(6)</sup>. Parallel with this notion, our findings suggested lack of awareness, and lack of access to BC-related mainstream resources and social services. BC survivors' less proactive search for social services may be due to weak connections among community organizations and interactions among community members. Weak social connectedness may result from limited use of popular media as a mass targeted strategy to disseminate information about BC prevention, treatment, and rehabilitation, promote community buy-in, and ensure mobilization for BC actions. Knowledge gaps remain about BC educational initiatives, and limited resource access within the Portuguese-speaking communities. The lack of collective visionary leadership regarding the possibility of mobilizing resources towards SSN creation reinforced this situation. The culture of community philanthropic work despite their strong social solidarity values and mutual help in families and friendship circles requires further investigation.

These SSNs would have to be sensitive to the expressions of ethno-cultural affiliations resulting in identity negotiation among different social groups guided by their social and cultural capital<sup>(25)</sup>. Community members usually had to adjust their values when facing new social realities. Immigrants have to reshape their social networks within this reality, and consequently their social/psychological needs. The way each of these communities established such interactions are known as *habitus* practice<sup>(25)</sup>.

For immigrants, *habitus* may acquire a broad implication as related to health practices, imposed by patriarchal family structures in certain ethno-cultural communities. In those communities, women rely on their male relatives for decision-making regarding medical care, and/or subordinate their individual health needs to family needs<sup>(30)</sup>. Due to their acculturation and social isolation, an SSN will spread BC preventative messages to men and women, to stimulate women's early detection practices, and learn about official health/social benefits for breast health.

A potential means to build the social capital of these communities would be to engage them to become active in diverse SSNs. Their actions would be appreciated by the idea of shared presence with intensive exchanges leading to empowerment, which is naturally legitimated by the freedom of giving-receiving. The presence of someone capable of helping them to find resources would be a way to have the social capital mobilized to respond to the socio-linguistic isolation, low schooling and proficiency in a foreign language, and little social insertion<sup>(31)</sup>.

The building of SSNs could also capitalize on existing support even if influence from women's religious beliefs on BC-related health may be controversial. Coming together in an environment would also help these communities in learning and liberating themselves from the view that cancer is a taboo topic and represents an inevitable death. Older women within the targeted Portuguese-speaking communities should be supported to lead the creation of new support networks for their respected and influential role to could help counteract the language and social inequalities to BC resources and education. Educational activities that promotes empowerment to this population towards better breast health should be emphasized<sup>(31)</sup>.

To further encourage the feasibility and sustainability of BC SSNs, collective actions should consider the role of family, friends, as well as, gender and cultural relevance of individual and collective activities. Based on the Portuguese culture's highly appreciated manual artistic work and cultural manifestations, we can cite events involving food, music, dancing, embroidery, and pottery, to alleviate the psychological impact resulting in social isolation and unnecessary suffering.

## CONCLUSION

The creation of breast cancer SSNs' it should take into consideration the diversity of Portuguese-speaking communities due to different social trajectories, as well as varied disposition to help and be helped. Because of the paucity of empirical evidence about the Angolan community, and considering the social isolation and mystical view of BC, we recommend that Angolan social leaders and professionals be asked to design the structure of their SSN according to their specific cultural traits.

Besides offering social support and services, volunteers should have instrumental knowledge to deal with the long-term effects of immigration. Although the primary target is women experiencing the different phases of BC, one cannot forget the importance of providing continuous support to the children and partners/spouses, particularly the latter, due to gender socialization. For meaningful health outcomes, the support should go beyond emotional and informational support from close informal networks, to incorporating formal mainstream institutions.

The main limitation relates to the principle of diversification<sup>(21)</sup> that was not addressed due to the small number of Portuguese participants and insufficient number of Angolan participants, as well as, the recruitment of only two Brazilian men in the final sample. The limited representativity of these expected subjects does limit the findings' transferability to Portuguese men belonging to

Angolan, Brazilian and Portuguese groups, as well as, for Angolan and Portuguese women.

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