PATHWAYS TO BREAST CANCER DIAGNOSIS AND TREATMENT: EXPLORING THE SOCIAL RELATIONS OF DIAGNOSTIC DELAY

TRAJETÓRIAS PARA O DIAGNÓSTICO E O TRATAMENTO DO CANCÊR DE MAMA: EXPLORANDO AS RELAÇÕES SOCIAIS NA DEMORA DO DIAGNÓSTICO

TRAYECTORIAS DE DIAGNÓSTICO Y TRATAMIENTO DEL CÁNCER DE MAMA: EXPLORANDO LAS RELACIONES SOCIALES DE LA DEMORA EN EL DIAGNÓSTICO

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KEYWORDS: Qualitative research. Breast neoplasms. Women's health.

ABSTRACT: In epidemiological studies, inequitable access to breast cancer care aligns with such variables as income, age, education, ethnicity and residential location. These variables correspond to structural patterns of advantage and disadvantage, which in turn may constrain or facilitate timely access to care. The purpose of this study was to understand the complexities of women's pathways to diagnosis. Thirty-five women from diverse backgrounds and who had clinically detectable breast symptoms at time of diagnosis participated in semi-structured interviews. All were receiving or completing treatment when they participated. Data were analyzed using the strategies of induction, comparison and abduction. All of the participants described a variety of activities involved in seeking care for breast cancer. The findings illustrate how the social relations of health care, rather than simply patient or provider delay, may contribute barriers to timely diagnosis. We illustrate how women's widely differing social and material contexts offer opportunities and barriers to access.

PALAVRAS-CHAVE: Pesquisa qualitativa. Neoplasias mamárias. Saúde da mulher.

RESUMO: Em estudos epidemiológicos, acessos desiguais para o cuidado ao câncer de mama alinham-se a outras variáveis como salário, idade, educação, etnia e local de moradia. Estas variáveis correspondem aos padrões estruturais de vantagens e desvantagens, as quais por sua vez podem restringir ou facilitar o tempo de acesso ao cuidado. A proposta deste estudo foi entender a complexidade da trajetória das mulheres para o diagnóstico. Trinta e cinco mulheres de diversos meios e que tinham sintomas clinicamente identificados no momento do diagnóstico, participaram de entrevistas semi-estruturadas. Os dados foram analisados utilizando-se estratégias de indução, comparação e abdução. Todas as participantes descreveram uma variedade de atividades envolvidas na busca do cuidado para o câncer de mama. Os achados ilustram como as relações sociais do cuidado a saúde, ao invés de simplificar para a paciente ou retardar o processo, podem se constituir em barreiras ao diagnóstico em tempo adequado. Nós ilustramos como os diferentes contextos sociais e materiais oferecem oportunidades e barreiras para o acesso às mulheres.

PALABRAS CLAVE: Investigación cualitativa. Neoplasias de mama. Salud de la mujer.

RESUMEN: De acuerdo a los estudios epidemiológicos, la falta de equidad en el acceso a los servicios de cuidado y tratamiento del cáncer de mama se acompaña de variables tales como renta, edad, nivel de estudios, etnia y lugar de residencia. Estas variables corresponden a patrones estructurales favorecidos o desfavorecidos, que pueden por tanto facilitar o limitar el tiempo de acceso a dichos servicios. El objetivo de este estudio fue el de comprender la complejidad de las trayectorias de las mujeres hacia el diagnóstico. Treinta y cinco mujeres con experiencias diversas y con síntomas de cáncer de mama clínicamente detectables en el momento del diagnóstico, participaron en entrevistas parcialmente estructuradas. Todas ellas recibían y/o habían completado su tratamiento en el momento de su participación. Los datos fueron analizados mediante el empleo de estrategias de inducción, comparación y abducción. Las participantes describieron una amplia variedad de actividades involucradas en la búsqueda de atención de salud para el cáncer de mama. Los hallazgos ilustran cómo las relaciones sociales del cuidado en salud pueden constituir barreras al diagnóstico en un tiempo adecuado, más allá de lo que lo puedan ser el retraso por parte de la paciente o del profesional. Se ilustra además cómo los diversos contextos sociales y materiales de las mujeres generan oportunidades y barreras de acceso a dichos cuidados.

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INTRODUCTION

Breast cancer is the most common malignancy worldwide among women. Annually, it constitutes 22% of all new cancer diagnoses in women and 7% of the 7.6 million cancer-related deaths internationally.[1] In Canada, breast cancer is the most common cancer in women, but due to advances in therapy and participation in screening programs, mortality rates are now decreasing. Delayed diagnosis of breast cancer is a matter of great concern because it may unnecessarily result in affective distress,[2-3] more advanced disease at diagnosis, the need for more aggressive treatment, and poorer prognosis.[4-5]

Constraints to the timely diagnosis of cancer are usually conceptualized as related to patients, health practitioners, or the health care system.[6-11] It is widely argued in the literature that patient related delay is the most significant of the three categories; indeed the majority of research in this field is focused on factors that contribute to patient delays in seeking treatment.[12] However, attributing delay to patients, practitioners or the health care system obscures the possibility that all three may act or interact in ways that constrain timely diagnosis and treatment. Further, this conceptual scheme fails to situate delay within the complex social and material circumstances that frame the lives and activities of women and their health care providers. This paper presents research findings that indicate the need for a new conceptual approach to diagnostic delay.

Background to the study

The negative relationship between socioeconomic status and diagnostic delay in breast cancer is a recurrent finding in the literature.[5,9,13-14] Recent work has sought more information about this relationship. Low income and/or education have been linked to poor access to screening and subsequent late stage diagnosis,[15-16] delayed follow up for abnormal findings during breast screening,[17] and higher mortality.[18] Women with non-dominant ethnoracial background are more likely to experience delayed and late stage diagnosis, however these relationships become less significant or insignificant when controlled for income.[19-22] Among multicultural populations, language is a predictor of time to diagnosis and completion of diagnostic tests, although this is not entirely explained by lack of interpreters.[23]

To understand the origins of patient related lack of screening attendance or delays in seeking care for breast symptoms, some authors have investigated distinctive cognitive decision making and coping responses in particular cultural groups, with emphasis on patterns such as avoidance, denial and fatalism, as well as fear of cancer, death or disfigurement.[12,24-27] However, others have studied "place effects", or patterns related to location of residence. Health services may be less accessible in remote and rural areas, and within urban areas they may be differently provided in some neighborhoods and hospitals than others. Some authors have found that timely diagnosis, access to screening and adequacy of treatment were negatively associated with living in deprived areas.[28-30] In the United States, outreach interventions have been successfully tested in low income urban areas to expedite women's progress through the steps of diagnostic testing and subsequent treatment.[17,31-32]

In summary, it is increasingly apparent that there are complex interactions among women's life circumstances and the structures of health care that may promote or constrain timely diagnosis. For example, Arnsberger and colleagues[23] found that women from non dominant ethnoracial backgrounds benefit from availability of breast health services outside of working hours, suggesting that some women may be forced to choose between their health needs and maintaining employment. However, the true independent influence of income and social position is difficult to determine. It is not clear whether low income influences delay, or if associated lower education levels, misinformation, differences in resources, and financial barriers to access to care are more responsible. Income may exert multiple influences at many points in a woman's health or illness experiences, because it simultaneously influences her social position and material circumstances.[33-35] Clearly, there is a need to explore this problem from a more nuanced perspective that questions the nature of access to health care.

A further necessary step is to analyze the possible ways that social position can exert an impact to delay or expedite the diagnostic process. We sought to contribute to this analysis by describing the experiences and actions of women with different income levels during diagnosis of breast cancer. In the social sciences, some authors have found that income is more strongly related to population morbidity and mortality than are symbolic indicators of class (such as education and occupation), particularly in women.[36] Gender itself is a fundamental component of social position.[37] Hence, women with different incomes and sources of income may be situated within a wide and intricate range of material and social circumstances. These varying circumstances will in turn condition access to health care by constraining or facilitating each woman's self care efforts. Further, women's circumstances will contour their sustained engagement with health care providers as they progress through the stages of diagnosis and treatment.

Study purpose

Our multidisciplinary team designed a critical ethnography to obtain women's retrospective descriptions of their pathways to cancer care, beginning with detection of a breast abnormality and culminating in treatment. This study was guided by the following questions: 1) what activities do women engage in during the process of being diagnosed with breast cancer? 2) what resources and constraints do women identify in their descriptions of this process? 3) how do accounts of the process differ among women from various income groups?

The intention was to elicit rich descriptions of how women's life circumstances influence access to diagnosis and treatment of breast cancer.

METHODOLOGY

This qualitative study was based in the methodological tenets of critical ethnography, which direct attention to particular facets of social life. Ethnographers are interested in people's activities within specific situations and the social meanings that are embedded in these activities.[38-39] The conditions in which people are situated are important, because of their influence on what can be done and why. These conditions may be social (such as a person's position relative to others they interact with) or material (the tangible available resources or the barriers that may be encountered). Ethnographic studies in the health sciences deal with how people draw on and reproduce local schemas of meaning and behavior while acting on their personal health needs.[38-40] Their decisions and subsequent actions may actually contravene the logics held by health care providers.[41] Furthermore, self care activities are deeply embedded in local gendered divisions of labor that may sustain the livelihood and health of others.

A detailed description of activities is important because it offers a point of entry into analysis of the interplay between individual agency and social structures of inequality. Critical ethnographies of health and illness focus on the logics or "situated rationalities".[41:182] embedded within people's accounts of health – and illness-related activities. Our review of the literature suggests that women with breast cancer are indeed differently situated in the social world. Consequently, they experience different opportunities, barriers and resources as they seek and obtain care for breast symptoms. They will employ different tactics and activities depending on their circumstances, and the true mechanisms of structural inequality may be glimpsed within these differences.

Recruitment and sampling criteria

Ethical review and approval was obtained from the University of Toronto Research Ethics Board in addition to the ethics boards at all participating hospital sites. We recruited women from the surgical clinics at 3 hospitals, a radiation oncology clinic and through community distribution of flyers. We sought diversity in the sample, so the participating hospital sites were selected in part because each served areas with widely different demographic compositions. The radiation oncology clinic, as part of a regional referral system, offered care to all sectors of the population. Women were included in the study if they 1) had completed surgical resection, 2) had a clinically detectable breast lump at time of diagnosis (discovered either by themselves or their primary care physician), 3) had been informed of their diagnosis, 4) were willing to participate in an in-depth qualitative interview, and 5) were able to describe their experiences in English. Recruitment for individual interviews continued over a 20 month period, which enabled concurrent analysis of the data. During the later stages of the study, we recruited additional women to participate in focus group discussions to obtain responses to presentations of the key findings from the preliminary analysis of the data.

Data collection procedures

We developed an interview approach in consultation with a peer support coordinator from a national support service for women with breast cancer. This member of our team offered insights from her experience as a breast cancer survivor and as a support worker who had frequent contact with women at all stages of care. The interviews elicited women's accounts, in a semi structured manner that began with an invitation to talk about any aspects of their experiences that they wanted to start with. As each story unfolded, the interviewer asked open ended questions to draw out further details, but remained careful to follow the sequence of events as presented by the participant. Toward the end of the interview, specific questions were asked about any aspects that had not been spontaneously mentioned at earlier points. The following topics were discussed during the interviews: 1) changes women noticed in their breasts around the time of diagnosis, 2) experiences with diagnostic appointments and tests, 3) how treatment plans were developed and experiences with treatments, 4) things that helped and supported the women, and 5) problems and barriers that the women encountered as they sought care.

Participants shared their experiences in the familiar settings of their homes or other locations of their preference. The interviews were audiotaped with participants' consent and professionally transcribed. All identifying names or places were removed from the transcripts. The women were asked to provide a pseudonym that would be linked with their file. Fieldnotes were recorded as brief jot notes during the interviews, and then were developed in greater detail within 24 hours to ensure clarity of recall.[42] These notes provided a description of each participant, her responses and the immediate surroundings of the interview. The descriptions enabled us to highlight major contrasts in the material and social resources available to each woman, but they were not intended to represent field observation.

Data analysis

We worked from a philosophical foundation known as critical realism, which proposes that some dimensions of social reality are difficult to grasp and study because they are not always readily apparent, even to those who are directly involved.[43] There may be multiple contravening influences on individual experience; therefore it is difficult to fully predict what will happen and why. These principles dictate that data analysis should be staged or layered, with attention to several different cognitive strategies.[44-45] Two of these strategies, induction and comparison, are familiar hallmarks of qualitative research.[38,46] Inductive description involves developing a detailed understanding of events or phenomena based on concrete observations and careful attention to the meanings underlying lay constructs or terminologies. Constant comparison entails thorough assessment of cases in relation to one another to better understand influences that contribute to differences and similarities. We accomplished these tasks by developing "maps" or visual pathways of each woman's progress to diagnosis, beginning with discovery of a breast abnormality. Maps were compared and areas of difference were identified.

In addition to the above, we used the strategies of analytical resolution and abduction to continue this work. Analytical resolution requires identification of major areas of focus for the analysis so that efforts can fruitfully be applied to the most critical issues. The transcripts were read and reviewed until they could be segmented into components during the process of coding, another technique that is commonly used in qualitative data analysis.[47] Based on recurrent issues noted in review of coded sections, the most central concepts were identified, grouped, and analyzed further. The fourth cognitive strategy, abduction, involves further interpretative analysis of experiential differences using selected theoretical frameworks. For example, we drew on Smith's.[48] Institutional Ethnography, a critical social methodological approach that encourages attention to the everyday, mundane work that often goes unnoticed. We also referred to Bourdieu's,[49] work on social capital because it assists in refining analysis of social disparities in health by highlighting the forms of capital which may or may not be available to people from different socioeconomic backgrounds. These cognitive strategies were not always pursued in separate stages; in fact, they were often simultaneous and recurring. They permeated the analytic tasks of reading and discussing the transcripts of early interviews soon after they were completed, developing and solidifying a coding scheme, meeting frequently as an investigative team to reflect on accumulated observations as coding of data progressed, developing conceptual maps of events or activities in each woman's pathway to breast cancer diagnosis, and reviewing differences or similarities among the maps.

FINDINGS

Sample

Thirty-five women from diverse backgrounds participated in the in depth interviews (see Box 1). Eight (23%) were receiving social assistance or had incomes below the Low Income Cut-Off levels (LICO). Individuals or families with incomes in the LICO category spend more than 70 per cent of their income on shelter and food, and therefore have little or no income left to spend on transportation, health, personal care, education, household operation, recreation or insurance (Statistics Canada, 1999). In contrast, 17 women (49%) had high incomes. About two thirds of the sample was under 60 years of age. This reflects that, although the risk of breast cancer increases with age, it is the most common cancer in adult women of every age group.[1] Among the total sample, 14 were immigrants to Canada, 12 were members of visible minorities, 2 identified themselves as lesbians and 2 were women with disabilities. Because participating women had different lives, backgrounds, and resources, there were wide variations in experience. There were often very different perspectives on which aspects of breast cancer care need to be changed. Throughout the analysis we paid particular attention to women's different accounts of the major steps towards diagnosis.

Box 1 - Description of sample. Toronto, Ontario, Canada, 2005-2006.

Age	Range 41 – 83 years old (two thirds were under age 60)
Living arrangements	With spouse or partner: 19 With other adult(s): 9 Alone: 7
Family Structure	No children household: 18 Couple with children < 25 yrs: 11 Female lone parent with children < 25 yrs: 1 Male lone parent with children < 25 yrs: 0 Couple or single parent with children >= 25 yrs: 3
Education	High School: 10 Some post-secondary: 6 women Post secondary degree(s) or diploma: 19
Employment status during treatment for breast cancer	Employed full time or part time: 11 Not employed – 4 Retired – 7 women Taking sick leave – 13 women
Total Household Income	Low (< $30,000 CDN): 10 Middle ($30,000 – $59,999): 7 High ($60,000): 17 Unknown: 1
Immigrants to Canada	14
Members of visible minorities	12
Lesbian women	2
Women with disabilities	2

One major similarity ran through all of the experiences described by our participants: engaging with practitioners and the health care system involved a period of intense new activities and tasks. Some of these were related to diagnosis and treatment, while others involved changes in the usual activities of daily living. One woman described this busy time as a "whirlwind". We called this increase in activity "health work" and discovered that it overlapped with most everyday patterns of activity. These areas of overlap could be seen in women's descriptions of 1) obtaining health care, 2) maintaining employment and income, 3) attending to home and loved ones, and 4) accessing needed resources. Each of these issues is discussed in more detail below.

Health work

Women being treated for breast cancer are very busy with activities related to their care. Participants described their many steps to obtain a diagnosis and go through treatment. They took on a daunting number of tasks, with varying degrees of assistance from others. These tasks included (but were not limited to): communicating with health providers, seeking information, traveling to and from clinics, making difficult decisions, finding ways to meet uninsured costs of care, and maintaining self care for other health problems. Most women felt poorly prepared to deal with these tasks at a time when they were feeling ill and under stress.

Other everyday tasks remained. These were essential to the health and wellbeing of the women and their loved ones, and not all women were able to pass these on to others. Some still had to take care of details like care of children and other family members, house work, obtaining and preparing food, managing finances, and coordinating schedules. Some women struggled to prioritize their own health needs within these multiple sites of responsibility and even postponed seeking care for a breast abnormality.

Obtaining health care

Having a regular provider of primary health care usually made it easier for women to obtain a prompt diagnosis and access to appropriate forms of treatment. When they regularly see the same doctor, women have time to learn the best ways to get an appointment, communicate with their doctor, and recognize problems that need immediate attention. However, some women did not have a regular source of primary health care and had to look for a family doctor when they needed help with a breast abnormality. Others struggled to get timely or convenient appointments when their everyday responsibilities conflicted with their doctors' scheduling arrangements. Taken together, all of these points showed that women do health work when they arrange to see their family doctor.

Furthermore, many women trusted their family doctors to detect a breast abnormality, to decide if further testing was needed, and to make the right referrals. In contrast, others explained that they themselves took some role in making sure that they got the best possible care. This was not always easy, because in the Canadian publicly funded system, access to most levels of care depends on having a referral from a family doctor. In some cases, extra time was spent finding and working out alternatives, then negotiating with a family physician to make the desired referral.

Attending appointments for diagnostic testing, specialist consultations, surgeries and treatments was another time consuming dimension of health work. Self care and coordination of schedules were required in response. Women visited numerous sites as their care plans unfolded. Doctors' offices, outpatient clinics, diagnostic labs, and hospitals were among these places and they were not always conveniently located in close proximity. At every new location, women worked to establish and maintain open communication and good relationships with a different set of health providers.

Maintaining employment and income

Many women who participated in our study were employed. Employment often meant access to benefits such as sick leave and extra medical insurance. But having a job also brought obligations that sometimes made it difficult to take time away for medical appointments, tests, and treatments. Health work and employment did not always fit together well. Not all of the women had flexible work schedules that permitted time off on short notice during the phase of diagnostic testing. Some women wished they could take extended time off during and after the treatment phase to rest and heal, but could not do so because of work responsibilities. Others preferred to work throughout their treatment because it gave them other things to think about. Flexibility to choose was valued. Supportive co-workers and employers were also appreciated.

Not everyone had jobs that offered sick benefits or insurance. Those who were self employed or worked on a contract or commission basis suffered loss of income during treatment. On the other hand, some women appreciated the flexibility that this type of work offered. Also vulnerable were women who were not employed and instead had limited fixed incomes such as pensions or social assistance. These women did not have benefits, and they did not have the means to pay for additional expenses. In these situations, extensive work was sometimes necessary to find other sources of support and/or financial assistance.

Attending to home and loved ones

Homes and the people who live in them need different amounts of maintenance and care. Women are often primarily responsible for this. As with employment, these pressures could limit opportunities to make and go to appointments for medical attention, tests, and treatments. Some participants had family or others who stepped in to provide a range of assistance with health work, including transportation to medical appointments, emotional support, housecleaning, shopping, and cooking. On the other hand, many women worried about burdening others and some even tried to limit the amount of help they accepted, although they deeply appreciated such acts of kindness.

Many of the women were caregivers for children, grandchildren, partners, or extended family, and these women could not always count on others to take over these responsibilities. As with some forms of paid employment, family caregivers did not get "sick leave" and some found it difficult to get caregiving help. Women with chronic health problems in addition to breast cancer found that they themselves required caregiving help, and those who lived alone were most vulnerable. They sometimes received Home Care support, but this was usually limited to personal care and often did not include housework services.

Accessing needed resources

Access to a surprising number of resources was needed to successfully obtain a diagnosis and undergo treatment for breast cancer. Although many women had easy access to medical attention, this was not always the case. A few did not have a personal physician and had to find one, a small number had interrupted access to their regular family doctor or were new to their doctor's practice, and some had trouble making an appointment with doctors they had been seeing for some time. This delayed cancer care. Time itself was a central and limited resource – appointments for medical attention, tests, and treatments are time consuming and they often conflict with commitments at work and home. Some women dealt with so many demands on their time that they delayed seeking care until they felt the time was "right".

A steady and adequate income, as well as sick leave benefits and extended health insurance, helped some participants to cover illness related costs such as parking, medication, accommodation/travel arrangements, and extra help around the home. However, women with lower incomes spoke to us about income reductions during their illness, problems getting an adequate diet while receiving chemotherapy, and problems ensuring they had a safe and healthful living environment. Low income meant more health work as women searched and applied for various forms of assistance.

Timely and understandable information, as well as support with decision-making were also key resources that women said they needed at various points during care. They wanted to make the right decisions during this period of uncertainty. Some women were comfortable to entrust their health providers with the important details, while others got additional information from the internet, books, support groups, and family or friends who had gone through their own experiences with cancer. To understand, sort, and decide what to do with this information was additional health work that took time and effort.

DISCUSSION

By developing a detailed description of activities related to breast cancer diagnosis and treatment in a diverse sample of women, we illuminated the many possible forms of problem-solving, decision-making and self-care oriented health work that women may encounter. Further, we found that these activities were deeply entangled with the countless other everyday tasks routinely performed by women at other sites of responsibility. For many, it was difficult to divert the time and energy required to navigate the health care system throughout the process of diagnosis and treatment. This difficulty clearly illustrates that accessing and maintaining contact with the health care system during episodes of illness is intensive work that is performed, to a large extent, by its consumers. Here we found that in some cases, much effort was required to find a good source of primary care, secure diagnostic testing and obtain a diagnosis. This analytic focus on the division of labor in health draws attention to the bifurcated logics that govern delivery of health services. Although accessibility is discursively touted as a desirable property of these services, there is less emphasis on the corresponding work of access and self care that consumers undertake as they seek help with potential health problems.

These findings suggest that there are multiple points throughout diagnosis and treatment for breast cancer where women may encounter barriers and require helpful resources. In Bourdieu's terms,[40] multiple forms of capital may be required, including material capital, but also less obvious forms such as cultural capital in the form of health literacy or the capacity to communicate effortlessly with health professionals. Women whose socioeconomic positions did not furnish these resources had to expend more effort to create the conditions necessary for recovery and healing. Archer[50] notes that it is at such critical points where the mechanisms underlying social disparities manifest themselves most noticeably, because until there is a project or goal to pursue, barriers or supportive resources do not exist as such. Thus, each participant in our sample offered examples of different pathways to breast cancer diagnosis depending on the barriers she had to negotiate and the resources she could draw on (if any) to circumvent them.

In conclusion, these findings illustrate how the social organization of health care, rather than simply patient or provider delay, may contribute barriers to timely diagnosis. Health care is primarily activated by consumers and the health work involved is time consuming and intensive. Women's widely differing social and material contexts present opportunities and barriers to access that must be dealt with in the construction of pathways to diagnosis and treatment. Hence, recent studies that test interventions to assist consumers in their efforts to navigate the health care system offer a way forward that is more likely to resolve the mechanisms underlying diagnostic delay than a continuing focus on individual coping styles or demographic variables.

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