# The Feminist Approach in the Decision-making Process for Treatment of Women With Breast Cancer

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#### **Abstract**

Introduction: The principal aim of this review was to investigate a feminist approach to the decision-making process for women with breast cancer. Empirical research into patient preferences for being informed about and participating in healthcare decisions has some limitations because it is mostly quantitative and designed within the dominant medical culture. Indigenous medical knowledge and alternative medical treatments are not widely accepted because of the lack of confirmed efficacy of such treatments in evidence-based literature. While discussing their treatment options with oncologists, women with breast cancer frequently express many concerns regarding treatment side effects, and sometimes decline conventional treatment when the risks are too high. Methods: A search of all relevant literary sources, including Pub-Med, ERIC, Medline, and the Ontario Institute for Studies in Education at the University of Toronto was conducted. The key words for selection of the articles were "feminism," "decision-making," "patients preferences for treatment," and "breast cancer." Results: Fifty-one literary sources were selected. The review was divided into the following themes: (1) limitations of the patient decision-making process in conventional medicine; (2) participation of native North American patients in healthcare decisions; (3) towards a feminist approach to breast cancer; and (4) towards a feminist theory of breast cancer. Conclusion: This article discusses the importance of a feminist approach to the decision-making process for treatment of patients with breast cancer. As the literature suggests, the needs of minority patients are not completely fulfilled in Western medical culture. Introducing feminist theory into evidence-based medicine will help patients to be better informed about treatment choices and will assist them to select treatment according to their own beliefs and values.

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### Introduction

The ethical theories employed in healthcare today generally assume a modern Western philosophical framework, which is applied to many issues such as abortion, euthanasia, consent for treatment and organ transplantation. The application of this approach to non-Western cultures needs critical examination.

Modern biomedical culture operates with its own norms and standards, but ethical sensitivity requires Western biomedicine to recognise itself as a distinct culture and to interact with other cultures in a sensitive and respectful, rather than imperialistic, way. One example in everyday medical practice of the need for biomedical science (and the physicians who are its representatives) to approach patients and their beliefs sensitively and respectfully is the process of decision-making for treatment. Such a relationship is even more essential in the case of a lifethreatening illness such as breast cancer.

There is considerable evidence that personal decision-making for treatment is widely desired and practised to the point of being a multicultural principle.<sup>2</sup> In the estimation of most patients, the version of autonomy called *extreme individualism* or *extreme rationalism* is neither desired nor legitimate. Contemporary ethicists increasingly

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acknowledge that autonomy cut off from familial, community and cultural settings is distorted and destructive.<sup>3,4</sup> Some mechanisms being made available specifically to facilitate rational decision-making are not being used with the expected frequency, despite publicity and availability.

Empirical research into patient preferences about being informed and participating in healthcare decisions has very real limitations because it is mostly quantitative and designed within the dominant medical culture.<sup>5-8</sup> What is needed is research in the area of breast cancer patients' decisional preferences that has a more ethnographic and individual focus. Also, very few studies have investigated breast cancer patients' participation in treatment from the feminist perspective.

Feminism involves the elimination of factors that contribute to continued systemic subordination of women. While feminists disagree about the nature of and solutions to this problem, all of them agree that existing sexist oppression is wrong and must be abolished. The supremacy of medical hegemony over women patients with breast cancer is but one example of such oppression.

Historically, feminists argue that most ecological harm can be traced to modern patriarchal cultural and scientific domination, beginning with the Enlightenment, which viewed both women and nature as passive, worthless and dispensable, and therefore to be controlled, exploited and disposed of, <sup>10</sup> as exemplified by witch burnings and the beginning of ecosystem destruction in that era. <sup>11,12</sup> In modern Western society, women have, for the most part, lost knowledge of their own bodies, as "experts" dictate the health and other procedures to be followed. Indigenous medical knowledge and alternative medical treatments are not widely accepted in conventional medicine because of the lack of confirmed efficacy of such treatments in evidence-based literature.

That patients do not always come first is made clear by feminist Wendy Harcourt<sup>13</sup>:

In the name of science, vast sums of money are spent which have a narrow focus while women as complex social beings are reduced to a particular condition. The development of these practices is often determined by the technical feasibility, scientific ingenuity, and funding available and based on the needs or acceptability of these techniques for women.

In addition, Hynes<sup>14</sup> states that women may be exposed to serious side effects from conventional medicine:

Despite evidence of demonstrated risks of uterine cancer from hormone replacement therapy and strongly suspected risks from the pills and menopausal estrogens at all stages of women's reproductive cycles, doctors continue to treat women with synthetic hormones

While discussing their treatment options with oncologists, women with breast cancer frequently express concern about treatment side effects, sometimes declining conventional treatment when the risk of side effects is too high. It is not uncommon for patients who are unsatisfied with conventional medical options to turn to traditional or alternative approaches for their cancer treatment.

# **Limitations of the Patient Decision-making Process in Conventional Medicine**

Many studies that investigate patients' decisional preferences for cancer treatment do not take gender differences into consideration. Despite the fact that demographics and gender are frequently included in clinical studies, the final results characterise a "standard patient". This gendered bias does not allow for a full understanding of the differences between male and female patients in terms of their role in the decision-making process. In addition, when female patients are identified and characterised in the decision-making literature, the diversity among women is not fully recognised. Such determinants as age, race and sexual orientation are often not taken into consideration. Also, cultural differences among women patients and their reactions and coping mechanisms when facing life-threatening illness are not fully understood by medical practitioners, and the relationship between the socioeconomic status of women cancer patients and their preferences for treatment are not sufficiently researched.

At the same time, the influences of indigenous peoples' knowledge, faith and alternative treatments on women with breast cancer and their treatment preferences are not clear to medical professionals. As well, relationships between female patients and physicians are overlooked in research publications. Many barriers to these relationships – such as lack of understanding of medical language and the choices that physicians arbitrarily offer to patients who do not speak or understand the language – subject women to choices that might not necessarily be in their best interest.

In order to overcome these limitations, healthcare professionals have developed and use a variety of tools to facilitate the patient's treatment decision-making process. <sup>16</sup> However, decision or medical knowledge transfer aids such as decision boards, videos, traditional medical consultation, audiotapes and Internet sources are not satisfactory for many female patients. These tools may be culturally unacceptable to many, as they are designed to serve a "standard patient".

One reason why patient autonomy and participation in

treatment decision-making have lately been encouraged in conventional medicine is the substantial evidence in the literature that physicians cannot accurately predict their patients' decision-making preferences. Bruera's study<sup>17</sup> at the Department of Palliative and Rehabilitation Medicine, University of Texas M. D. Anderson Cancer Center investigated not only treatment decisional preferences in breast cancer patients, but also physicians' perceptions of patients' treatment preferences. In the study, 89% of 57 women with breast cancer preferred either an active or a shared role in decision-making. Full agreement between patients and physicians about decision-making preferences occurred in only 42% of cases.

This study suggests a need for enhanced communication between patients and physicians in the treatment decisionmaking process. Receiving the right type and amount of information is particularly important for people with cancer. A cancer diagnosis is still regarded with considerable fear and feelings of shock, grief, uncertainty and loss of control. 18-21 Fear and apprehension often make individuals reluctant to ask for specific information, believing they will be told all they need to know. The subject of cancer is emotionally loaded, and health professionals often feel limited in their ability to communicate effectively.<sup>22,23</sup> Doctors are concerned that they will upset the patient or dispel hopes for a cure, 24 and death is still a taboo subject that some doctors do not know how to discuss.<sup>25</sup> Providing adequate information to women with breast cancer is of particular importance, since a choice of treatment may exist.

For example, whether breast cancer is treated with a mastectomy or with more conservative surgery followed by radiotherapy makes no demonstrable difference in terms of long-term survival. Providing women with a choice of treatment has been found to improve long-term adjustment to the disease. To facilitate decision-making, adequate information must be provided. More importantly, women breast cancer patients should be involved in the design of studies. More qualitative and ethnographic studies should involve a diverse group of women cancer patients working with healthcare professionals to develop adequate study methodologies, where all aspects of decisional preferences should be examined and addressed from women's point of view

# Participation of Native North American Patients in Healthcare Decisions

To better understand women's participation in treatment, these processes should be looked at for minority groups such as native North American patients. Coward and Ratanakul<sup>1</sup> partly discuss decisional participation in treatment by native North American patients in their book *A Cross-Cultural Dialogue on Health Care Ethics*. The

authors present interesting but limited information about the attitudes and expectations of North American Natives as participants in medical systems, particularly in healthcare decisions. They use more qualitative sources of information, such as cases reported and discussed by anthropologists and others, as well as accounts by Native commentators of traditional beliefs and attitudes. When one goes to a healer to seek a cure, Native medicine does not isolate one "medicinal" aspect from the others and from the responsibilities of life. Health is a proper balance of mental, physical, spiritual and emotional elements. In that context, it should not be surprising that traditional patient-healer relationships and processes are highly participatory for both

Coward and Ratanakul also describe relationships of Native patients with Western physicians. Often Native patients who participate actively in the treatment decisionmaking process with a Native healer can be passive and submissive in their relationship with Western physicians. This passivity may be related to the following:

- 1. the insensitivity of physicians and other healthcare providers to the Native patient's concerns and values;
- 2. limited knowledge of the physician's language and the need in some cases to communicate through interpreters;
- 3. socioeconomic disadvantages;
- 4. an attitude of resignation and alienation stemming from historical contact with a colonial, domineering medical system;
- 5. previous unpleasant personal contacts with modern healthcare and paternalistic healthcare providers;
- 6. institutional obstacles to establishing trusting personal relationships in hospitals and other health centres.

Some of these factors also encourage passivity and discourage trusting relationships between non-Native patients, particularly women, and their physicians.

## **Towards a Feminist Approach to Breast Cancer**

It is well-known that women experience distinctive health problems, yet medical research is limited – even more so in the social sciences and humanities – with respect to women's health, particularly their perspectives and priorities. <sup>28</sup> Women are the main healthcare providers. They comprise the majority of workers in the healthcare system and are almost wholly responsible for care within the family and community. They make the greatest use of health services.

"It is a central tenet of feminism that women's invisible private wounds often reflect social and political injustices. It is a commitment central to feminism to share burdens. And it is an axiom of feminism that the personal is political." Nancy Datan, a feminist psychologist who died of breast cancer, wrote these words in calling for development of

feminist theory and practice around the issues associated with breast cancer. To understand the process of decision-making for patients with breast cancer from a feminist point of view, someone has to look at the harm done to women with breast cancer, both by orthodox medicine and by alternative philosophies of "self-help".

Breast cancer is a major health issue for women. Among Canadian women, 180,000 breast cancer cases are diagnosed annually.<sup>30</sup> Despite significant improvements in screening and treatment, breast cancer is one of the leading causes of death for women aged 45 to 64 years. The incidence of breast cancer doubles for women who postpone childbearing until after age 30 or who do not have children; lesbians thus experience an increased incidence of breast cancer.<sup>31</sup>

Breast cancer is not only physically debilitating but also causes tremendous emotional distress. Patients diagnosed with breast cancer frequently feel totally vulnerable, about to die, or completely terrorised by the illness. In addition, many women have suicidal thoughts during their recovery from a mastectomy.<sup>32</sup> A few feel they are getting adequate support from their family and friends, but in one study more than half the women said that support was inadequate, and nearly three-quarters said that other people seemed to fear and avoid them.<sup>33</sup> Spence<sup>34</sup> states that the experience of breast cancer is clearly influenced by a cultural emphasis on breasts as objects of male sexual interest. Women are expected to look beautiful and to be the object of the male gaze, at the same time preserving autonomy over their bodies.

The routine use in the medical literature of words like disfigurement and mutilation to describe the postmastectomy patient both reinforces women's sense of their bodily imperfection and reflects men's horror at wounded female bodies. Women's concern about the loss of their breasts is frequently trivialised - "No one will know" or "We can make you a new one." One woman recounts how her surgeon broke the news that she would have to have a mastectomy: "It is not the end of the world," he beamed. "I can make you another one. If you were my wife, I'd want you to have it."35 In many cases, patients' decisions about surgery for breast cancer are influenced by the opinions of their husbands or partners. The literature says that men do often find breast cancer upsetting.<sup>36</sup> About half the women in one study said that their husbands found looking at their scar distressing; ironically, psychologists have developed a "treatment" for such men, including "systemic desensitisation", which entails deep relaxation as steadily more distressing scenarios are presented in sequence.<sup>37</sup>

There is an overwhelming emphasis on sexuality and body image in the literature on mastectomy, and very little discussion on other issues, such as loss of breastfeeding capability or explaining (or concealing) the loss of a breast to a child.<sup>38</sup> Increasingly, heavily marketed "breast reconstruction" procedures may be influencing patients' treatment decisions. For example, in the United States, 20,000 women undergo breast reconstruction every year. The language used in the medical literature to discuss breast reconstruction is frequently about exciting new medical advances to improve women's bodies. The experts write, for example, of "ingenious new techniques" to enable "the exhibition of a modest degree of cleavage".<sup>39</sup> Unfortunately, these views persuade women who may later regret their decisions. One woman describes the pressure put on her, after mastectomy and breast reconstruction, to have a second mastectomy (of her healthy breast) – and her regrets:

My... second mastectomy, performed at the time of breast reconstruction, was prophylactic. My surgeon said he could not offer a good match after reconstruction unless both breasts were reconstructed and I allowed myself to be swayed to his belief. Now, I regret sacrificing my healthy left breast... If I had to do it again, I would not trade a healthy, functioning breast just to try to achieve what a surgeon calls "a better match." It is a lasting regret. I could have breast-fed our son if I had resisted that surgeon's coercion. 40

Similar experiences can be seen in the literature. The dominant values, attitudes, and practices of medical culture overwhelm and do not always take into consideration women's voices and opinions in decision-making for treatment alternatives. Unfortunately, only a few feminists working in cancer medicine have critiqued this man-made orthodoxy and its disregard and distortion of women's experience. It is clear that these lone voices remain largely unheard in the medical world.

Treatment decisions of women cancer patients are very frequently influenced by the plethora of popular books and tapes about alternative medicine. Examples of such books include Rachael Clyne's *Cancer: Your Life, Your Choice* and Colin Rydler Richardson's *Mind Over Cancer.* Another bestseller is a tape by Louise Hay, *Cancer: Discovering Your Healing Power.* These books and tapes emit warmth and hope; they speak of nature, spirituality, and love; their covers depict rainbows (Richardson), hearts (Hay), a circle of people with linked arms (Clyne). All take a holistic view of health and illness: for example, "*Cancer can be broadly viewed as the result of decreasing cooperation with the natural flow of life*" and "*Cancer or similar diseases are illnesses of the weakened spirit which is off balance and has lost the rhythm of life, of love.*"

These books and tapes imply that women are responsible for giving themselves cancer, that they can cure themselves,

can choose whether to get well or not, that it is their own fault if they die. At every step, individual responsibility is the overwhelming message in "self-help" literature. Such messages are dangerous for the distressed and desperate cancer sufferer. They are full of false promises, indulge in victim-blaming of the highest order, and offer the spurious illusion of power over illness. These messages do not admit to causes of cancer over which women have no control, and they take no account of the material reality of most women's lives. They do, however, influence patients' decisional preferences for treatment.

### **Towards a Feminist Theory of Breast Cancer**

Both the orthodox and the alternative approaches can be harmful to women with breast cancer. Sometimes women are confused about their treatment choices. The feminist approach to the decision-making process can be an important step in empowering women with breast cancer. For example, the feminist theory of breast cancer suggested by Wilkinson and Kitzinger<sup>38</sup> in *Women and Health: Feminist Perspectives* explains that women should make their own choices and not accept male definitions of femininity and of women's sexuality as a major factor in choosing treatment. In addition, women cancer patients who choose alternative treatment should be critical and should overcome the victim-blaming fantasies often created by alternative medical sources.

Wilkinson and Kitzinger suggest that women must lay claim to their experiences of breast cancer through, for example, consciousness-raising, and they must develop a thoroughgoing politics of illness that incorporates industrial society's contribution to ill health and analyses the social and economic forces framing availability and "choice" in "treatments" for cancer. In addition, women should develop feminist practice around breast cancer, through, for example, political lobbying and providing illness support groups.

The words women have spoken about the meaning of breast cancer for their own lives and for feminist politics can be powerful aids in choosing treatment options. Retribution, denial and isolation cannot be overcome until women speak freely of their experiences, whether they are friends or lovers of those with breast cancer or have had breast cancer themselves. Feminist writers such as Audre Lorde, Adrianne Rich, 45-47 and Nancy Datan, 29 in speaking out about the experience of breast cancer, enable others to speak out also, and to expose hetero-patriarchal values inherent in both orthodox medical and alternative treatments for breast cancer.

Women with breast cancer have set up organisations to lobby for better preventive care, increased research funding, and improved insurance coverage. They also provide information and support services for all women whose lives are touched by breast cancer. These organisations include the Women's Cancer Resource Center in Berkeley, California and the Women's Community Cancer Project in Cambridge, Massachusetts (both provide a mix of political action, education, information and support services), and the Mautner Project for Lesbians with Cancer in Washington, DC, which provides direct services to lesbians with cancer and their families and caregivers. Fostering a sense of a feminist community is central to the philosophy of all these projects. This is perhaps seen most clearly in the support groups that exist not to uphold medical establishment opinions and profits, but to provide women with personal and practical resources to face the trauma of breast cancer and to challenge male power.

There is also a need for feminist physicians and researchers who will investigate female patients' needs using feminist qualitative methodologies such as standpoint research or a feminist poststructuralist perspective to increase awareness of issues that cause discrepancies and inequities in women's healthcare. These approaches seek to expose and change the power structures within social and political institutions that prevent women from receiving aggressive evaluation and comprehensive treatment. A feminist poststructuralist perspective also strives to illuminate and amend the subtle pervasive biases of our healthcare system that marginalise women's healthcare needs.

Similarly, extensive literature on women's health promotion from the feminist perspective shows a need for feminist research in oncology - particularly into women's decisional preferences for cancer treatment – and in women's studies that will help them make their own informed choices among many difficult options for treatment. The diversity of women's voices, in terms of race, income level, culture, language, sexual orientation, age and religion, in the decision-making process should be emphasised in these studies. At the same time, effective dialogue with the medical community should be encouraged to make structural changes in the perception of the "standard patient" and to empower women patients in their decisions for cancer treatment. To facilitate this research, a grant programme should be developed to fund participatory action research programmes about women and cancer decision-making for treatment.

A research centre for the promotion of women's voices in cancer treatment should be established, similar to the McMaster Research Center for the Promotion of Women's Health in Hamilton, Ontario. This centre would promote research projects developed according to feminist participatory action research (PAR),<sup>50</sup> which is based on 4 main principles: (1) the research problem is defined by people who share the problem (i.e., women cancer patients) rather than by the academic researcher; (2) the people who

define the problem participate in the research process from beginning to end to ensure that they are creating their own research; (3) the goal of the research is transformation of the dominant medical structures and conventional oncology in women cancer patients' daily lives and experiences; (4) the researchers should help women cancer patients promote this knowledge to other cancer patients in the community.<sup>51</sup> All participants' experiences should be equally valued and promoted.

The development of a research centre for promotion of women's voices in cancer treatment would empower women cancer patients in making difficult decisions during their cancer journey. In addition, it would help women develop leadership skills and help disseminate this knowledge among their various ethnic groups. The development of critical thinking skills and transfer of knowledge skills will help women cancer patients to become equal partners in discussions with medical establishments and help them promote change in the current medical environment.

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