

# Promoting emancipated decision-making for surgical treatment of early stage breast cancer among Jordanian women

Rana F. Obeidat

Faculty of Nursing, Zarqa University, Zarqa, Jordan

Corresponding author: Rana F. Obeidat

E-mail: robeidat@buffalo.edu

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## ABSTRACT

To use the critical social theory as a framework to analyze the oppression of Jordanian women with early stage breast cancer in the decision-making process for surgical treatment and suggest strategies to emancipate these women to make free choices. This is a discussion paper utilizing the critical social theory as a framework for analysis. The sexist and paternalistic ideology that characterizes Jordanian society in general and the medical establishment in particular as well as the biomedical ideology are some of the responsible ideologies for the fact that many Jordanian women with early stage breast cancer are denied the right to choose a surgical treatment according to their own preferences and values. The financial and political power of Jordanian medical organizations (e.g., Jordan Medical Council), the weakness of nursing administration in the healthcare system, and the hierarchical organization of Jordanian society, where men are first and women

are second, support these oppressing ideologies. Knowledge is a strong tool of power. Jordanian nurses could empower women with early stage breast cancer by enhancing their knowledge regarding their health and the options available for surgical treatment. To successfully emancipate patients, education alone may not be enough; there is also a need for health care providers' support and unconditional acceptance of choice. To achieve the aim of emancipating women with breast cancer from the oppression inherent in the persistence of mastectomy, Jordanian nurses need to recognize that they should first gain greater power and authority in the healthcare system.

**Key words:** Breast cancer, early stage, surgical treatment, decision-making, Jordanian, emancipation

## Introduction

The paternalistic approach, the informed approach, and the shared approach are the three analytical approaches to treatment-related decision-making that have been reported in developed countries in recent history.<sup>[1]</sup> Informed by the traditional ethic of Hippocratic beneficence (i.e., that physicians should be authoritarian decision-makers

who take full responsibility for their patients' well-being and should perform any and all acts which they believe are in their patients' best interests), physicians formerly followed the paternalistic approach in interacting with their patients.<sup>[2]</sup> For physicians following the paternalistic decision-making approach, exchanging health-related information with patients and asking patients to play a role in medical decision-making place an unnecessary burden on patients that may interfere with the healing process.

The evolution of medical and communications technology and the increase in democratic thinking around the globe have changed public opinion about the role of patients in their own care and treatment.<sup>[3,4]</sup> Over the last few decades, patient participation in treatment-related decision-making has been promoted as ethically and clinically desirable in most Western

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countries.<sup>[5]</sup> Research has demonstrated the beneficial effects of informing patients about treatment options and inviting them to participate in choosing a treatment; such beneficial effects include better patient compliance, increased patient satisfaction, improved knowledge about disease and treatment, and a better quality of life.<sup>[6]</sup> Thus, the paternalistic model of medical decision-making has been challenged and clients and health care providers alike have stressed the need to better inform patients of their treatment options in order to facilitate shared decision-making.<sup>[3]</sup>

Patients today, particularly those who are younger and well educated, prefer that their health care providers share medical information with them about their diagnoses, care and treatment.<sup>[7-9]</sup> With regard to patients' decision-making preferences, while most patients prefer to have a role in treatment decision-making, some patients prefer to remain passive.<sup>[10-12]</sup>

When a patient is diagnosed with cancer, multiple decision-making situations arise that may be preference-sensitive. In early stage breast cancer (0-II) for example, breast-conserving surgery followed by irradiation is equivalent to a mastectomy in terms of distant disease-free survival and overall survival and quality of life (excepting body image).<sup>[13,14]</sup> Thus, surgical treatment for early stage breast cancer has been cited as an excellent opportunity for the sharing of decision-making between the patient and provider.<sup>[3,15]</sup>

Current decision-making science has focused on decisional aids, decisional conflict resolution, personal values, and emotional control.<sup>[16]</sup> External influences (e.g., social support) and cultural norms (e.g., paternalism) may exert a negative effect on value systems.<sup>[17]</sup> The oppressive treatment of female patients remains common in healthcare systems today. Not all women diagnosed with early stage breast cancer are given the opportunity to participate in the decision-making process regarding surgical treatment; the majority of Jordanian women are not.<sup>[18,19]</sup> Thus, to promote shared decision-making, there is a need to first discuss oppressive treatment and possible strategies for empowering oppressed patients, especially women.

Nurses are ethically and professionally tasked with empowering patients and advocating for them. Hence, nurses should have an active role in the shared medical decision-making process. Unfortunately, a review of the shared decision-making literature in general and of the surgical treatment of early stage breast cancer in particular indicated that in general, nurses are not represented in the decision-making process. Jordanian nurses who provide care to women with breast cancer usually have no role

in either information disclosure or treatment decision-making. Hence, the purpose of this paper is to use critical social theory as a framework to analyze the oppression of Jordanian women with early stage breast cancer in the surgical treatment decision-making process, the lack of a role for nurses in the decision-making process, and the strategies that nurses could use to emancipate themselves and enlighten Jordanian women with breast cancer to make informed treatment choices.

## Critical Social Theory

Critical social theory emerged in Germany during the 1920s as the Frankfurt School; the philosophies of Marx and Hegel served as its foundation. Jürgen Habermas, a German philosopher, further developed critical social theory to include ideas pertaining to communicative rationality, deliberation, emancipation, and the public sphere. Critical social theory condemns oppression to promote positive change.<sup>[20]</sup> Oppression is maintained by social institutions in order to control people, their resources, and their finances.<sup>[21]</sup> The purpose of critical social theory is to expose oppression that may constrain individuals or social freedom in order to emancipate oppressed individuals and replace oppressive social structures, based on a humanistic philosophy premised on the fundamental value of freedom, which begins with the right to choose freely. Another premise of critical social theory is that human behavior is inseparable from social influences that have historically disadvantaged underprivileged groups. Many individuals' life options are influenced by social attitudes; thus, social attitudes and norms may affect women's right to choose in health care. Some authors have claimed that the entire social structure can only be changed by political action<sup>[22]</sup> and that collective autonomy is one of the primary values of critical social theory.

In the subsequent sections, we use critical social theory to analyze the historical, social, economic, and political perspectives that have shaped the current situation of Jordanian women with early stage breast cancer and deprived them of their right to self-determination. We explore the ideologies, assumptions, and social structures that support this situation and provide suggestions about strategies that could be used by nurses to promote emancipated decision-making among women with early stage breast cancer in Jordan.

## Analysis

### *Historical perspective*

Historically, social norms of paternalism have influenced health care decisions. Thus, health care providers, especially

physicians, have traditionally made decisions on their patients' behalf. Women have been considered powerless, voiceless, and marginal, though in some cultures more than others; female patients have been worse off. The oppression of female patients with breast cancer started with the introduction of the highly disfiguring radical mastectomy by William S. Halsted in the early 20<sup>th</sup> century; formerly, it was the only treatment option to cure breast cancer.<sup>[23]</sup> At the time it was introduced, voices were raised against the procedure, but it persisted because physicians did not listen to their critics or their patients. Halsted and his followers had a profound effect on the management of breast cancer.<sup>[23]</sup> Efforts to reduce the incidence of breast cancer and the negative impact of breast cancer treatment, especially radical mastectomy, on women's lives were initiated by the American Cancer Society (ACS) in the 1930s. The ACS emphasized that less extensive cancers result in better outcomes; hence, they started educating women about early detection and screening, breast self-examinations, and mammography. In the 1950s, these efforts were increased to combat the rising mortality of breast cancer. In the late 1970s, radical mastectomy was on the way to disappearing and women's decision-making power grew; this was the most obvious example of the wider challenge to the traditional authoritarian physician-patient relationship in the United States.<sup>[23]</sup>

In 1991, the National Cancer Institute advocated breast-conserving surgery as the preferred surgical treatment for early stage breast cancer.<sup>[13]</sup> Hence, women with early stage breast cancer in Western countries now have the right to choose the type of surgical treatment they prefer. Twenty American states have rules that mandate that surgeons inform women of available treatment options. By contrast, recent research among Jordanian women diagnosed with early stage breast cancer has shown that many women, especially those treated at public hospitals, are presented with mastectomy as their only surgical choice.<sup>[18,19,24]</sup> Physicians have historically dominated the Jordanian healthcare system; the majority still follow the paternalistic decision-making approach. The current situation has a historical background defined by the lack of awareness and social consequences of this dominance; the historical view of women, especially in the Arab world, as subordinate to men in decision-making, even in regard to decisions that concern their own lives and bodies; and the passive role Jordanian nurses play in the treatment decision-making process.

### **Economic perspective**

Financial interests have always played a major role in breast cancer detection, screening, and treatment.

Financial interests were one of the main reasons that the radical mastectomy procedure persisted in the early 20<sup>th</sup> century. The fact that many breast cancer patients paid for their surgeries was welcomed by hospital trustees and administrators; thus, they rewarded their surgical staff with privileges and authority.<sup>[23]</sup> One criticism of the shared decision-making approach in the surgical treatment of early stage breast cancer was that increasing patient involvement in decision-making would lead to greater demand for unnecessary, costly, or harmful procedures, which could impact the rightful allocation of health care resources.<sup>[5]</sup> Furthermore, surgeons might prefer mastectomies over breast-conserving surgery because the former generates greater profits. In Jordan, mastectomies are categorized as major surgeries, whereas breast-conserving surgeries are categorized as minor; thus, surgeons are paid much more for mastectomies. In addition, patients who have received mastectomies require longer hospital stays and more outpatient follow-up than do patients who have received breast-conserving surgery; this means that surgeons who have performed mastectomies can gain greater remuneration in follow-up fees.

### **Social perspective**

Social factors also played a role in facilitating the dominance of radical mastectomy as the treatment of choice for breast cancer in the early 20<sup>th</sup> century.<sup>[23]</sup> One of the main reasons the Halsted operation became respected was the fact that Halsted was a graduate of the medical school at Johns Hopkins, viewed as the best American medical school.<sup>[23]</sup> In addition to the growing public confidence in surgery in the early 20<sup>th</sup> century, the reputations of institutions where radical mastectomies were performed (i.e., modern, technologically sophisticated hospitals as Johns Hopkins hospital) were influential in the operation's popularity.<sup>[23]</sup> After 1970, many women with breast cancer campaigned against the medical profession and the persistence of radical mastectomies in women's magazines and in newspapers and on television; they demanded the right to make decisions about their bodies. These women and sympathetic physicians connected and began to fight against radical mastectomies. As a result of these campaigns and connections, interactions between male surgeons and female patients were permanently transformed in Western culture.<sup>[23]</sup>

In Western countries, women are afforded social rights equal to those of men and have freedom of choice. In other parts of the world, such as Jordan, the situation is different. Women in most Middle Eastern countries, because of wrong interpretations of the Islamic teachings, are considered legal minors who depend on male custodians in decisions

concerning marriage, employment, education, and even access to health care. Mastectomies are still the preferred choice for most surgeons, who withhold options from women with early stage breast cancer.<sup>[19]</sup> The persistence of unnecessary mastectomies among Jordanian women with early stage breast cancer, especially in public health care, can be explained partly by patriarchal sexism and partly by a paternalistic medical profession that portrays patients in general and women in particular as devoid of the competency to decide for themselves. The blind belief of the majority of Jordanian society that only physicians have medical knowledge and are the most capable to make decisions on behalf of patients also has played a role in this situation.

### **Political perspective**

In 1979, states in the US passed informed consent laws mandating that physicians provide women with breast cancer with information about all possible treatment options.<sup>[23]</sup> In 1986, the National Alliance of Breast Cancer Organizations, an umbrella group for organizations across the United States involved in breast cancer awareness and education, was established by a group of breast cancer activists who joined to form an organized, united front to ensure that breast cancer received the publicity it deserved.<sup>[23]</sup> Organized groups and the promulgation of state laws transformed the surgeon-patient relationship in breast cancer treatment in Western countries. To the best of the author's knowledge, there is no rule in Jordan that mandates that surgeons inform patients of available treatment options and gives patients the right to choose the option that best fits their needs and values. On the contrary, the code of ethics of the Jordan Medical Council still states that physicians can withhold information (e.g., diagnosis and prognosis information) from patients if they think it is in the patient's interest (e.g., to protect the patient from emotional shock or loss of hope). There are many reasons for this. The first is the dominant power of the medical establishment in our healthcare system; the Jordan Medical Council is one of the strongest political organizations in the country. Hence, it is difficult to pass any bill without the approval of the council. The second is the unfortunate weakness of nursing as a profession; nurses should be patients' advocates, especially in regard to women health issues. Last, with the exception of the Jordan Breast Cancer Program, which focuses on breast cancer screening and early detection but not treatment, there are no organized groups that represent breast cancer patients and speak on their behalf.

### **Ideologies, assumptions, and social structures**

On account of various ideologies in Jordanian society, many Jordanian women with early stage breast cancer are

denied the right to choose a surgical treatment according to their own preferences and values. The first ideology, the biomedical ideology, is the basis for physicians' control over the healthcare system and has a narrow focus on biological processes and the consequences of the disease; it does not take into account the psychosocial consequences of disfigurement following a mastectomy. In this ideology, the psychosocial consequences of surgery are not important and curing breast cancer is the only important outcome of treatment; furthermore, the breasts are not considered parts of the body that are vital to women's identity.

The second ideology is the sexist and paternalistic ideology that characterizes Jordanian society in general and the medical establishment in particular. Women are considered emotional creatures that may not have the cognitive competence to make rational decisions as men do. Thus, surgeons may not give options to women with breast cancer because they may assume that women are incompetent at making decisions by themselves even if options are given to them. Male surgeons are still performing radical surgeries on women's breasts because they may assume that women's breasts have no cosmetic value for her. The ideology of profit-making and physicians' authority that was responsible for the persistence of the radical mastectomy in Western countries until the 1970s remains evident in Jordanian society today. Physicians strive to maintain their power and control over the healthcare system by preventing knowledge and the right to make decisions from being transferred to other health care providers (e.g., nurses) or to their patients.

Finally, although women in Jordan have more freedom, are more educated, and are able to play greater roles in politics and business compared with women in other Arab countries, certain persistent social structures support past ideologies and are responsible for their continuity. For example, in the Jordanian health care system, physicians are in charge of all financial and administrative responsibilities. Furthermore, the financial and political power of the Jordanian Medical Council itself, the weakness of nursing administration in the healthcare system, and the hierarchical organization of Jordanian society, where men are first and women are second, support these ideologies. Finally, Jordan has few female breast surgeons who can relate to women's feelings about their breasts and their importance in regard to conceptions of femininity and beauty.

### **Strategies for action**

Based on the preceding analysis, strategies for action can be proposed. By raising awareness about women's oppression and by enabling women to be informed

decision-makers, Jordanian women with early stage breast cancer can be empowered to make emancipated decisions for surgical treatment. Empowerment is a process of liberation that promotes autonomy and self-determination through the sharing or transmission of power, including the power to have and use knowledge. Thus, empowerment could ultimately challenge the paternalistic approach that has traditionally dominated health care.<sup>[25]</sup> Empowering patients by providing them with quality, unbiased information and inviting them to participate in treatment decision-making can encourage them to take personal responsibility for their health, enable them to make informed decisions which accord with their own values and preferences, and increase their feelings of personal autonomy, which will ultimately increase their self-esteem and improve their quality of life.<sup>[6,25,26]</sup> The literature on decision-making contains strong evidentiary support for the notion that knowledge (e.g., information about the disease and available treatment options) is important in patients' involvement in decision-making. Although information provision has been identified as a precondition for and a facilitator of patients' involvement in treatment decision-making,<sup>[27,28]</sup> a lack of medical knowledge and inadequate information provision were identified as barriers to patients' involvement.<sup>[27,29]</sup> van Tol-Geerdink *et al.*<sup>[30]</sup> investigated the effect of a decision aid on prostate cancer patients' preferences for involvement in the choice of radiation dosage and found that 35% (52/150) of patients wanted their physician to make treatment decisions before the introduction of the aid, whereas 75% (39/52) of this same group of patients changed their preference to involvement after the introduction of the decision aid and made their own treatment decisions. Furthermore, Moumjid *et al.*<sup>[31]</sup> investigated French patients with early stage breast cancer unaccustomed to shared decision-making; the patients were presented treatment options and a decision aid related to these options was introduced. Once given the opportunity and the means to be involved in treatment decision-making, the majority of the patients opted to make their own choices either alone or in collaboration with the surgeon.

Nurses could play an important role in empowering Jordanian women diagnosed with early stage breast cancer. Jordanian nurses could empower women with early stage breast cancer by enhancing their knowledge regarding their health and the options available for surgical treatment. Bedside nurses, community health nurses, nurse educators, and nurse researchers could all participate in the process of empowering Jordanian women diagnosed with early stage breast cancer. However, to emancipate women with breast cancer from the oppression inherent in the persistence of

mastectomy, Jordanian nurses must first tackle major issues associated with empowerment in health care.

The first of these issues is nurses' own power and authority. There is a power imbalance between nurses and physicians, where physicians are positioned at the top of the hierarchy and nurses as their subordinates; this is a persistent problem worldwide, particularly in Jordan.<sup>[32-35]</sup> In many Western countries, in contrast to Jordan, nurse practitioners can run clinics or even their own practices. The nurse-physician power imbalance could be explained on the basis of several interrelated factors. Traditionally, nursing has been considered a caring profession in which patient care is nurses' main objective. Some authors have regarded this as the source of the profession's power,<sup>[36]</sup> whereas others have regarded it as an obstacle preventing nurses from gaining power or getting used to being in power.<sup>[25]</sup> What complicates this situation and makes the power imbalance between nurses and physicians more prominent in Jordan is the fact that, because of the sexism and paternalism alluded to in previous sections, medicine is still considered a masculine and nursing a feminine profession.<sup>[35]</sup> Physicians are in charge of the majority of Jordanian hospitals and medical institutions and thus have authority and responsibility for financial decisions, resource allocation, and overall management of the healthcare system. Nurses, however, must carry out the orders of physicians without the right or the power to go against any of these orders.

To achieve the goal of empowering patients, nurses in general and Jordanian nurses in particular need to recognize that they should gain greater power and authority in the healthcare system; as the saying goes, "we cannot give what we do not have." To empower women with early stage breast cancer to make emancipated surgical treatment decisions, Jordanian nurses should first emancipate themselves from the oppression inherent in the current structure of the Jordanian healthcare system. Developing positive relationships with a variety of groups (such as with peers, subordinates, and sponsors) can help nurses increase their informal power and ultimately their formal power.<sup>[37]</sup> Jordanian nurses, especially nurse leaders, should prepare themselves to take on leading roles in the healthcare system, engage in political action, form strong lobbies and organized groups, and strive to change their public and political position, which will help to change the overall position of women in Jordanian society.

The second issue regarding empowering patients that nurses should be aware of is that patients have to become familiarized with empowerment. In changing the paternalistic approach to patient-provider interaction,

both health care providers and patients must be included. For example, not all cancer patients want to participate in decision-making. Across studies, the role preferences of women newly diagnosed with breast cancer have ranged substantially: A passive decision-making style was preferred by 8% and 52% of women in Lam *et al.*<sup>[38]</sup> and 52% in Beaver *et al.*,<sup>[39]</sup> respectively; a collaborative decision-making style was preferred by 28% and 59% of women in Beaver *et al.*<sup>[39]</sup> and Lam *et al.*,<sup>[38]</sup> respectively; and an active decision-making style was preferred by 20% and 39% of women in Beaver *et al.*<sup>[39]</sup> and Janz *et al.*,<sup>[40]</sup> respectively. Decision-making preferences among Jordanian women diagnosed with breast cancer have been found to vary; in one study, the majority of Jordanian women (57%) indicated they wanted their physicians to make decisions about treatment, approximately 33% wanted to share the decision with the physician, and only 10% wanted to make their own treatment decisions.<sup>[24]</sup> These results are not surprising for women who were brought up in a tradition of societal and medical paternalism and are unaccustomed to playing a role in their medical care and treatment decision-making. In addition, low levels of health literacy are evident among the Jordanian population.<sup>[41,42]</sup> Thus, a sudden shift toward empowerment could be unwelcomed among the Jordanian public, including women diagnosed with early stage breast cancer. The best approach would be to conduct ongoing, individualized assessments of patients' role preferences to ensure that each patient is given the opportunity to fulfill his or her preferred role while ensuring that the patient has all the information needed to make their own informed decision if they prefer to do so.

To ensure the successful implementation of this approach in clinical practice, establishing a motivation for shared decision-making among health care providers, particularly physicians, is critical.<sup>[43,44]</sup> Hence, Jordanian physicians should be trained in the use of shared decision-making, communication, and patient counseling. To facilitate the acceptance of the shared decision-making approach and ensure its use in clinical practice, it is imperative that Jordanian physicians come to appreciate the positive impacts of this approach on the clinical process and patient outcomes. To encourage acceptance, physicians using the shared decision-making approach, such as physicians at the King Hussein Cancer Center, can share their experience with other physicians and health care providers in Jordan. In addition, the same group of physicians could act as advocates for Jordanian women's right to choose a surgical treatment for early stage breast cancer.

## Summary and Conclusion

The paternalistic approach to decision-making in health care has been eliminated in most Western societies but remains dominant in other parts of the world. The adoption of the paternalistic approach is a form of patient oppression because it deprives patients, especially women with early stage breast cancer, of the right to be self-determining and to make decisions about their own bodies and health. Nurses have professional and ethical obligations toward their patients. One of these obligations is to advocate for their patients' right to autonomy and self-determination. By raising awareness among nurses about the oppression inherent in the persistence of the paternalistic decision-making approach and by providing them with easy-to-understand, unbiased information, patient autonomy and self-determination can be promoted; ultimately, patients can be emancipated from oppression. To successfully emancipate patients, education alone may not be enough; there is also a need for support from health care providers, who must unconditionally accept patients' right to choose. To achieve the aim of emancipating women with breast cancer from the oppression inherent in the persistence of mastectomy, Jordanian nurses need to recognize that they should first gain greater power and authority in the healthcare system.

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