

Review

Breast cancer disparities and decision-making among U.S. women

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Abstract

Objective: The impact of breast cancer is immense for all women, but the literature reveals an even greater impact on women of color and among socially and economically disadvantaged populations. Persistent differences in incidence and outcome are undoubtedly due to multiple factors, but one element in poor outcome may be treatment choice. Those treatments shown to be related to best outcomes are less likely to be chosen by certain groups of women. The effects of economic and cultural factors on breast cancer treatment choice have not been thoroughly explored; these factors must be understood if health care professionals are to intervene effectively to address disparities and improve breast cancer outcomes for all women.

Methods: A review of the breast cancer literature was conducted in order to: (1) describe breast cancer disparities in the United States; (2) delineate factors that might contribute to those disparities; (3) assess possible mitigating factors for predominant causes; (4) begin to decide how health care interventions might allay the factors that contribute to disparities in breast cancer incidence and mortality.

Results: Breast cancer incidence and outcome disparities in the United States are due to multiple interacting factors. These include information about treatment, different types of treatment, the emotional context of decision-making, and patient preference for level of involvement. Treatment decision-making is complex.

Conclusion: Health literacy and level of decision-making involvement, both embedded in social and economic reality, are key components in breast cancer treatment decision-making and may contribute to breast cancer disparities in the United States. Current models of shared decision-making may not be generalizable to all breast cancer patients.

Practice implications: Optimal breast cancer outcomes for all women depend on culturally and ethnically appropriate professional support.

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Keywords: Minority women; Breast cancer; Treatment; Disparities; Treatment decision-making; Economically disadvantaged; Women of color

Contents

1. Introduction	159
2. Methods	159
3. Findings	159
3.1. Race and breast cancer incidence and mortality disparities	159
3.2. Disparate breast cancer treatment patterns	160
3.2.1. Mastectomy versus breast-conserving therapy (BCT)	160
3.2.2. Adjuvant therapies: chemotherapy and radiation.	161
3.3. Breast cancer treatment decision-making	161
3.3.1. The role of information in breast cancer decision-making	161

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3.3.2.	Emotional context	162
3.3.3.	Patient preference for level of involvement	162
3.3.4.	The overwhelming complexity of health care decision-making.	162
4.	Discussion and conclusion	162
4.1.	Discussion.	162
4.2.	Conclusion	163
4.3.	Practice implications.	163
	References	163

1. Introduction

With widely available screening for early detection and definitive therapy with tested agents, breast cancer need not be a universally lethal diagnosis. Yet breast cancer levies a high cost for women, particularly those in the ethnically and economically diverse populations least likely to be health literate. Not only can screening measures be underused and ineffective in these communities, but socioeconomic, racial, and ethnic disparities persist in the use of the best evidence-based treatments (with the best outcomes) for diagnosed breast cancer [1–5].

Treatment decisions are complex for those fortunate women and families who have access to care, have health care coverage, and who possess adequate knowledge and skill in navigating the health care delivery system. For women who struggle with any of these factors, the task is even more troublesome. It is appreciated that treatment decisions are complex and linked to patient outcomes, but the interactive decision-making process between the patient, family, and health care team has not been studied in depth among those populations likely to have the poorest outcomes. Moreover, the role of treatment decision-making in contributing to breast cancer disparities is poorly understood. This paper serves to explore disparities in treatment and decision-making in U.S. women, specifically women of color, women who are disadvantaged, and minority women.

2. Methods

In the context of a larger project, searches were conducted on major health care databases (including MEDLINE, PubMed, OVID, and CINAHL), to identify articles concerning breast cancer (including incidence, treatment, and outcomes) in all populations of women. English language articles concerning breast cancer published in refereed medical, nursing, health education, epidemiology, and public health journals were included in the initial review. Reference lists were then used to pull past articles upon which current literature was based. Most articles were published within the last five years, but older research was included if it was not replicated or replaced with more current studies. Both qualitative and quantitative studies were assessed for scientific integrity in the context of

appropriate disciplines. For example, incidence figures concerning breast cancer in various cultural, ethnic, and economic populations were taken from population health and epidemiological sources. Treatment trials tended to appear in the medical literature. Studies concerning treatment decision-making were considered valid if the study was considered methodologically sound in any disciplinary literature. Searching continued until saturation was reached.

Breast cancer disparities research was the second focus of the search. Disparities in cancer are a major research focus of the National Cancer Institute [6], so current literature was plentiful. Those articles served as the basis for this inquiry, supplemented by the latest studies in health care decision-making and cancer decision-making found in previous searches.

3. Findings

The findings from this search resulted in several themes. These are described in detail below and include breast cancer disparities in the United States across ethnic and socioeconomic groups; treatment disparities; decision-making about treatment, level of involvement in the decision-making process; and the complexity of decision-making.

3.1. Race and breast cancer incidence and mortality disparities

Jemal et al. [7], citing the National Center for Health Statistics, state that nearly 216,000 women were expected to be diagnosed with breast cancer in the United States in 2004. As seen in Table 1, differences in breast cancer incidence and mortality exist in the United States. The national incidence rate for breast cancer is about 135 per 100,000 but relative risk and incidence rates vary by race and ethnicity.

Breast cancer incidence rates for women of color are lower than for Caucasian women, but mortality rates are disproportionately higher. Disparities in survival are partially a function of diagnosis at a more advanced stage [8–10], possibly related to limited information available about breast cancer risk factors, limited opportunities for screening, or cultural beliefs about risks and mortality [11,12]. Other factors, including disparate effects of

Table 1
Breast cancer incidence and mortality in women

	Incidence per 100,000	Mortality per 100,000
National 2004 projection (National Center Health Statistics)		
Overall	135	27.7
Hispanic	90	17.9
African American	122	35.9
Non-Hispanic White	141	27.2
Texas 1997–2001 (Texas Cancer R0egistry)		
Overall	119.3	25.9
Hispanic	81.8	19.6
African American	113.1	38.3
Non-Hispanic White	130.5	26
Bexar County 2000 (Texas Cancer Registry)		
Overall	123.1	25.9
Hispanic	91.9	19.8
African American	115.3	38.2
Non-Hispanic White	150.5	26

therapy, may also play a role in mortality rates as minority women display worse stage-specific survival [7,9,13]. Disparities may also emerge from interactions between genetic predisposition and various risk factors such as the effect of culturally related behaviors such as dietary and exercise patterns in certain individuals [14]. There are also links between race/ethnicity and indicators of disadvantage, such as low income, low educational level, and lack of health insurance that are themselves independently associated with advanced stage diagnosis and diminished survival [15–18]. To magnify the deleterious effect of social and economic risk factors, current treatments for palpable breast masses and diagnosed stages I and II cancers are reportedly used less frequently by disadvantaged and minority patients [1].

3.2. Disparate breast cancer treatment patterns

Certain women are less likely to choose treatment measures validated as most effective through clinical trials [1]. Health care professionals search for the underlying causes of this threat to public health, but as with most intricate social phenomena, multiple forces have an impact on treatment disparities, including treatment decision-making.

The type of treatment a woman receives for early stage breast cancer has complex determinants, including clinical variables such as patient age and the tumor size, location, and grade at diagnosis [19]. In addition, a patient's health insurance status may have an impact on her seeking or receiving care [20]. Physician practice patterns are known to vary by individual and by geographic area [21–25] as well as by hospital teaching status [22]. Several studies have shown that women choose various treatments related to geographic proximity to radiation treatment and other health care facilities [26–29].

Interpersonal variables may also have an impact on treatment decisions, such as the quality of the doctor–patient interaction [28–30], the availability of treatment-related knowledge (culturally and education-style appropriate), and the presence or absence of preconceived notions concerning treatment options [31–35]. The literature suggests that ethnically diverse and disadvantaged women are less likely to receive culturally appropriate information from their physicians [2], to be involved in the therapeutic decision [3,4], and to receive definitive treatment for early stage breast cancer [5].

It might be anticipated that treatment patterns will vary, given the number of interacting contributing factors, but one would not expect treatment patterns to vary so strongly along cultural, racial, ethnic, and economic boundaries. In fact, with the wide availability of sophisticated, trials-based information concerning best practice in breast cancer, it is surprising that more consistency is not seen in breast cancer treatment.

3.2.1. Mastectomy versus breast-conserving therapy (BCT)

Strong randomized trial evidence on equivalent survival following mastectomy versus breast conserving therapy has been available since the 1980s [36–38]. The 1990 NIH consensus statement on treatment of early stage breast carcinoma recommended BCT [39] and confirmed the wisdom of the recommendation through emergent evidence [40–42]. However, a high proportion of women categorized as low income and/or less educated continue to receive mastectomy rather than BCT [5,28,31,43–48].

The origins of this disparity in treatment could be related to any of the factors mentioned above, or to other factors associated with patient choice. Researchers and physicians have assumed that “informed” women would choose a less disfiguring procedure over mastectomy, but the underpinnings of the decision are apparently more complex than simple body image concerns or the need for information. Even well-informed women's apprehension about the risk of recurrent disease in the operated breast and the need to receive radiation therapy or other relatively disruptive ongoing treatments may outweigh other concerns [43,45,49].

There is conjecture that as more economically and ethnically diverse groups of patients are given greater input into their health care decisions, they choose treatments that may not yield the greatest health benefit or that may not conform to the physician's idea of the ideal treatment for that woman [45,50]. There is the possibility that a woman's choice of mastectomy reflects an inadequate appreciation for the evidence against that decision, but there is an alternative explanation. The decision may reflect a concomitant avoidance of inconvenient adjuvant therapies that reflects her taking into consideration the total impact of her decision on herself and her family. It is intriguing to posit that health care barriers and the inconvenience of the system for many

women, including those without transportation or childcare, might weigh more heavily into a woman's decision than physicians realized. As was previously mentioned, there is evidence that some women choose treatment regimen based on their geographic proximity to radiation treatment and other health care facilities [26–29]. Many women must consider emotional and experiential issues as well as practical issues in making a decision for mastectomy, including pressures not to miss work, or be absent from family responsibilities during radiation therapy or how financial issues may spring from not having health insurance coverage.

3.2.2. Adjuvant therapies: chemotherapy and radiation

African American, Mexican American, Puerto Rican, uninsured, and low income women in the United States receive what is widely considered to be substandard therapy (such as lumpectomy without subsequent radiation) at high rates [20,46–49]. The public health implications of such statistics are alarming: women who fail to receive post-lumpectomy radiation therapy have a 39% risk of cancer recurrence in the operated breast versus 14% with radiation [40]. Inadequate treatment has also been associated with reduced survival in observational studies [51–53]. What is not understood is how those treatment decisions are made: are women not adequately informed, do they not understand their options, or do they forgo treatments that entail multiple visits and/or long convalescence?

While all women may encounter these issues, for those who are disadvantaged, the issues may pose a highly individualized role in personal decision-making. Thus, supporting breast cancer treatment decision-making is more complex than just providing treatment information. Clear, comprehensive information regarding not only treatment options, but also length of time required for treatment, physiological impact, and unanticipated financial and lifestyle costs must be included.

3.3. Breast cancer treatment decision-making

It is widely assumed that treatment decisions in the 21st century will emerge from a collaborative process between the patient and the provider, but there is no published evidence concerning the actual contribution of shared decision-making to the eventual decision outcome or to the health status outcome in any group of patients. If disparities in survival are to be addressed, the entire process and context of breast cancer treatment decision-making must be understood from the patient's perspective.

3.3.1. The role of information in breast cancer decision-making

Traditionally, health care knowledge has been considered necessary and sufficient in supporting patient treatment decision-making. Yet the utility of knowledge is influenced by the decision-making context and a myriad of intrapersonal dynamics. In health care settings, patients are faced with

foreign or technical terms, complex ideas, multiple options, and the need to differentially weigh the relative value of unfamiliar choices. In order to cope, patients may reduce their decision burden using potentially maladaptive strategies such as allowing the most readily understood factor to prevail or denying the existence of certain bothersome factors.

The cognitive burden of decisions can be reduced through materials that provide details on procedures, risks, and benefits in a logically structured format. Such tools have been applied in a variety of clinical settings and they have been demonstrated to not only improve knowledge but to reduce decisional conflict [54–61]. For example, a “decision board” is a poster-sized display upon which information regarding treatment options, potential complications, and treatment outcomes is printed. A sliding panel allows portions of the display to be revealed sequentially as the patient and presenter move through the content together. One advantage of the decision board over other informational aids such as multimedia interventions [55,56] is that it presents information in distinct, rather isolated and sequential pieces, limiting the amount of information to be processed at any one moment. The activity also is highly interactive, consistent with evidence that women facing breast cancer decisions desire interpersonal communication in health care decisions [2,62]. Cognitive retention issues are addressed as patient retain materials. Such tools are designed to support analytic learning and in those patients that are comfortable with analysis, improved satisfaction has been demonstrated [53,63].

The intent of decision support tools is to provide concrete evidence for a treatment decision. But simply reducing cognitive burden is not enough. Gurmankin et al. [64] and decision support ethicist Ubel [65] warn that the use of decision support tools may lead patients to decisions that are inconsistent with their own stated preferences. Sanders and Skevington explain that providing information differs from providing “interpretation,” or “adequate knowledge” [66]. In their theory, they state that in unfamiliar situations, people will construct preferences that vary according to social and contextual variables. Patients' perceptions, then, perhaps result as much from providers' manner of interaction as from the actual information that is imparted. This can produce a difference between what the health care team perceives as having been presented and what the breast cancer patient and family have perceived, demonstrating a deficit in what Sanders would put forth as “adequate knowledge.”

The literature supports this theoretical model. In Keating et al.'s studies [67,68], 29% of women eligible for breast conserving treatment did not recall their surgeon discussing the procedure. Patients and surgeons actually disagreed in one-third of cases as to whether BCT had even been discussed; disagreement doubled in a less-educated patient group. A similar proportion of women in another study (33%) did not perceive that they had a choice of procedure at all [50]. If information is not *heard* by patients, choices cannot be properly structured and weighed. Whether the lack of perception can be attributed to emotional context,

cognitive inabilities, or faulty communication, the outcome is the same: women and the health care team are not working together to make the best breast cancer treatment decisions for individual women. Information, then, while indeed central to patient decision-making, is necessary but not sufficient. Other facets of decision-making – attitudes, culture, experience, and emotion – may affect the perception of information or render facts inconsequential.

3.3.2. Emotional context

Health care decision-making is laden with emotional as well as cognitive determinants. Lam et al. [69] caution that providing information is not enough to ensure health literacy and sound decision-making. Patients can be emotionally overwhelmed by decision-making; the Chinese women Lam interviewed stated that they had insufficient knowledge to make a critical treatment decision. They described this feeling as “gambling” with their health. Mcvea et al. [28] described similar responses within their Nebraska cohort. Women involved in the *Nuestras Historias* [70] project (2004) in San Antonio echoed many such comments.

Patient, family, and physician variables are part of the emotional context in decision-making. Culver et al. [71,72] state that reactions to the diagnosis and coping skills vary between ethnic groups. Spencer et al. [73] stated that Hispanic women seem to be more affected in several life domains and may make decisions differently because of it. The emotional context of health care decision-making is embedded in culture and role theory, so no breast cancer treatment decision can be supported without an appreciation of the social and familial emotional context. Additionally, the emotional context may influence the patient’s interest and ability to be involved in the treatment decision process.

3.3.3. Patient preference for level of involvement

It has been shown that individual patients differ in their preference for level of decision-making involvement, from taking complete authority for a decision, to shared decision-making with their clinician, to deferring to the clinician’s decision [22,62,74–76]. This added variable further complicates how treatment decisions are made. Not only is the emotional context at play but also appropriate information should be presented in a culturally appropriate manner. Thus, the health care team must be able to assess quickly and accurately how much authority a woman wants to exercise in decision-making. Then he or she must respond to that assessment by structuring a dynamic situation to provide appropriate levels of support and validation for that individual. In today’s health care delivery system, those tasks are likely to be difficult due to time constraints for providers.

3.3.4. The overwhelming complexity of health care decision-making

Deber et al. [77] suggest that treatment decision-making may be even more convoluted than simply information,

context, and emotion: decisions are made in a dynamic process of structuring choices (problem solving) and weighing those choices through two (often simultaneously operating) decision-making modes, analytic and experiential. The analytic mode applies conscious reasoning, weighing facts to gradually construct decisions. This mode is most easily addressed in practice with tools to present factual information. In contrast, the experiential mode applies to emotional responses, associations, and intuition to judging information, including cultural, ethnic, and economic elements. Although many health care interventions have addressed the analytic mode, the less “rational” mode is difficult to anticipate and support in any individual. Unanticipated effects emerge when analytic knowledge is anticipated as the major underpinning of breast cancer decision-making.

An interesting artifact of new patterns in breast cancer decision-making seems to be a decrease in how many women choose therapies for which random controlled trials evidence exists: lumpectomy with adjuvant therapy. Study participants indicated the desire to avoid the subsequent radiation therapy necessary with BCT, independent of concerns about body image [63]. Using tools to increase analytic knowledge, such as in Whelan’s study [77,78], was perceived as helpful to patients. A large majority (81%) indicated that the tool helped them make a decision. But a comparison of surgical choices before and after the introduction of the decision board noted a decline in the use of BCT. A subsequent randomized trial by the same investigators [63] found that patients randomized to the decision aid stated that they were better informed and more satisfied with the clinical decision-making, even though they might not have chosen the alternative associated with clear scientific evidence.

Redelmeier et al.’s classic article [79] warned that patients making intuitive decisions were also endangering their health. These statements lend support to arguments that providing information will not necessarily lead patients to the most predictable decisions, particularly in the absence of a culturally appropriate context. When breast cancer treatment decision-making is parsed into its components, it becomes less surprising that ethnic and economically disadvantaged women not only choose in a manner that cannot be predicted by physicians, but that outcomes are relatively poor for these populations.

4. Discussion and conclusion

4.1. Discussion

Emerging patterns of complex interactions between health status, health care access and delivery, and decision-making create a maze of possibilities in which women tend to preserve their own identities and preferences, independent of the health care authority hierarchy. The health care system

is not easy to use for anyone, and the fewer resources a woman and her family have, the less manageable the system will be for extended periods of intervention. One would wonder if mistrust in the medical care system would almost preclude identification with the preferred choice of the physician, especially if the physician does not seem to empathize with the woman's life stresses and barriers to care.

The themes that emerge from the research on decision-making upon breast cancer diagnosis must be explored in the context of culture. Those studies already done with women of ethnically diverse populations deserve clarification and amplification [6–65,80–83]. To mitigate extant racial, ethnic, and economic disparities and improve cancer outcomes for all women, health care providers must understand what factors can be addressed to decrease mortality from breast cancer in order to meet goals such as the Healthy Border 2010 initiative: to decrease breast cancer mortality by 20% [84].

Treatment decisions are exceptionally complex. The presentation of factual information, even in well-designed, comprehensive decision support tools, is perhaps not going to solve the problem of women choosing breast cancer treatment options that do not cohere with current research. It appears that the decision-support tools do provide women facing breast cancer treatment with information, person-to-person interaction, and participation in the treatment process. However, treatment decisions also include cultural and family considerations that may have nothing to do with evidence or clinical trials. If disparities in survival are to be addressed, the entire process and context of breast cancer treatment decision-making must be understood from the patient's perspective.

4.2. Conclusion

As more economically and ethnically diverse groups of patients are given greater input into their health care decisions, some choose treatments that may not yield the greatest health benefit or that may not conform to the physician's idea of the ideal treatment for that woman [45,50]. There is the possibility that a woman's choice of mastectomy (despite evidence supporting BCT with lumpectomy and adjuvant therapy) reflects an inadequate appreciation for the evidence against that decision. The decision may also reflect a concomitant avoidance of inconvenient adjuvant therapies that reflects her taking into consideration the total impact of her decision on herself and her family. Health care barriers and the inconvenience of the health care delivery system for many women, including those without transportation or childcare, might weigh more heavily into a woman's decision than physicians realized. If those barriers are keeping some women from benefiting from the treatments that have been shown to improve survival, health care professionals must mitigate those barriers to afford all women access to optimal care.

Information cannot convince a woman to choose a treatment option in isolation from her life's reality. Thus, in order to improve the chance of survival from breast cancer in ethnic women, knowledge and facts must be presented in a humanistic matrix of emotions, culture, and the reality of health care delivery for each individual. It may be necessary to modify the treatment delivery system to support women of all cultures and economic strata to enable them to tolerate the treatment regimen.

4.3. Practice implications

The themes that emerge from the research on decision-making upon breast cancer diagnosis must be explored in the context of the specific cultures. Those studies already done with Hispanic women deserve clarification and amplification. A large population of women, soon to be the majority ethnic group in the United States as it is in south Texas, deserves the best form of support in breast cancer decision-making. More studies are needed that yield insight into actual decision-making within the total context of a complex delivery system and how health care professionals might encourage and facilitate best practice interventions for those least likely to choose those interventions. What can be learned in studying decision-making in breast cancer can benefit generations of women, no matter their culture, socioeconomic status, or ethnicity.

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