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A Model of Knowledge Acquisition in Early Stage Breast Cancer Patients

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Abstract

To meaningfully participate in the decision-making regarding a newly diagnosed breast cancer, a patient must acquire new knowledge. We describe a model of knowledge acquisition that can provide a framework for exploring the process and types of knowledge that breast cancer patients gain following their diagnosis. The four types of knowledge presented in this model—authoritative, technical, embodied, and traditional—are described and potential sources discussed. An understanding of knowledge acquisition in early stage breast cancer patients can provide healthcare practitioners with an important framework for optimizing decision-making in this population.

Keywords

breast cancer; decision-making; knowledge acquisition

Long-term studies have demonstrated that breast conservation surgery (BCS) with radiation therapy has equivalent survival rates when compared with mastectomy, resulting in the acceptance of BCS as appropriate treatment for early stage breast cancer (1,2). Women currently have three options for the surgical treatment of early stage breast cancer: BCS, mastectomy alone, or mastectomy with breast reconstruction. Recently, the use of institutional rates of BCS as a measure of quality of care has been proposed (3,4). Implicit in this recommendation is that, following the data supporting the medical appropriateness of either option, women should want BCS if offered. However, approximately one-third of patients continue to undergo mastectomy, which has prompted some researchers to speculate that this may be the result of a lack of patient knowledge or participation in decision-making (5). Challenging this theory are recent studies that suggest that mastectomy is associated with more patient involvement in the decision-making process (6–8).

In order for a patient to adequately participate in the decision-making process, she must acquire new knowledge. The majority of women when faced with a diagnosis of breast cancer know very little about the disease beyond what has been publicized through national awareness campaigns and popular media. To understand how early stage breast cancer patients opt for their course of surgical treatment, we must have a model for understanding the types of knowledge these patients acquire prior to surgical decision-making. An awareness of the knowledge needs of early stage breast cancer patients and how they acquire this knowledge provides an important foundation for understanding patient decision-making and informed choice and ensuring optimal patient care.

Using a knowledge acquisition framework proposed by Mendlinger and Cwikel (9), the complexities of knowledge acquisition in early stage breast cancer patients can be explored. Knowledge acquisition has been defined as the knowledge that one acquires through both informal and formal processes (10,11), and serves as the basis of attitude formation and decision-making about health topics. The Mendlinger and Cwikel model suggests that knowledge acquisition relies on four types of knowledge: authoritative, technical, embodied, and traditional. We applied this framework to discuss knowledge acquisition in early stage breast cancer patients, particularly related to decision-making about surgical treatment. Please refer to Figure 1 for a schema of this framework and to Table 1 for sources of the types of knowledge that early stage breast cancer patients may acquire.

Authoritative knowledge is that which is provided by figures of authority. In the context of early stage breast cancer patients, such knowledge might include an understanding of the extent of their disease, the likelihood of cure, the prognosis, and the types of treatments available. The most common sources of authoritative knowledge in healthcare are members of the healthcare team; in the case of early stage breast cancer, this includes breast surgeons, plastic surgeons, medical oncologists, and radiation oncologists. Other sources include breast cancer decision-aids, and print media such as books or information pamphlets. The importance of authoritative knowledge has been demonstrated by studies that show that healthcare practitioners are the most widely used and the preferred source of knowledge for most cancer patients (12). Decision-aids have also been reviewed, and some have been found to decrease decisional conflict and increase patient satisfaction (13). Other research has highlighted inequities that can result if select authoritative knowledge is not offered. For example, one major factor influencing the surgical decision-making process is whether or not surgeons discuss reconstruction as an option. Studies have suggested that only 33–40% of general surgeons had a discussion with their patient about breast reconstruction (14,15). This has significant impact on decision-making because documentation of this discussion was associated with women being 4–6 times more likely to receive a mastectomy compared with those who did not (14,15).

Technical knowledge refers to an understanding of what options are feasible in terms of both the clinical situation and the limitations of the healthcare system. Technical knowledge about how a mastectomy or breast conserving surgery is performed is probably acquired from the same sources discussed above, i.e., healthcare providers and other healthcare specialists. It is critical that a patient understands the contraindications to breast conservation, as well as the need for radiation therapy and what that entails. Another example of technical knowledge involves the usability and appearance of breast prostheses. Consultation with a prosthesis specialist in advance of surgical decision-making can provide patients with important technical knowledge that may influence clinical management. Other important types of technical knowledge include what services and specialists are available given healthcare coverage and proximity to healthcare centers. Health insurance providers are often important sources of this type of knowledge.

Knowledge acquired outside the traditional medical system by women diagnosed with breast cancer can be more difficult to define and yet may significantly influence the final surgical decision; embodied knowledge and traditional knowledge are included in this category.

Embodied knowledge is defined as knowledge that is gathered from observing others, such as a friends, relatives, or peers, who navigate a similar experience (16), as well as “one’s own first lived experience”(17). Given that breast cancer is the most common cancer in women and quite prevalent in the United States—one out of eight women will be diagnosed with breast cancer in their lifetimes—most women diagnosed with breast cancer have family or friends who have been diagnosed as well. Using family and peers to learn about breast cancer is a common practice for newly diagnosed women. One study reported that family and friends were identified by 70% of patients as a resource, with 61% of patients rating them as an excellent source of information (12). Many cancer centers believe that this type of knowledge is valuable for patients and therefore have established programs that connect newly diagnosed women with those who have already had similar treatment (18,19). The strength of the personal connection or how similar their personal histories are may influence the likelihood that a woman will make the same decision as her source.

Traditional knowledge is that which is transmitted between generations through rituals, history, and other informal interactions. One example is a woman’s perception of the importance of her breasts to her own beauty or sexuality, which may influence what surgical option to pursue. Studies have demonstrated that body image is frequently more important to women choosing breast reconstruction over those choosing mastectomy alone (8). Age, which in most studies is inversely related to the likelihood of having reconstruction, is another factor associated with surgical decision-making (20,21); studies suggest that age represents the influence of both individual opinions regarding the importance of breasts to one’s body image and sexuality (22). Other factors, such as family and community, have also been found to be associated with the use of reconstruction following mastectomy (23).

The model of authoritative, technical, embodied, and traditional knowledge offers a framework for understanding and discussing knowledge acquisition. As demonstrated by our discussion, many women will use a combination of sources and types of knowledge to inform their decision about breast cancer care. Healthcare providers, in particular breast surgeons, are an important source of information and yet are complemented by a vast array of other sources such as family and friends, peers, health insurance companies, or cultural/social norms. It is important to re-emphasize that patients may gain multiple types of knowledge from a single source. For example, a female breast surgeon who has had breast cancer can provide knowledge about treatment choices (authoritative), as well as the quality of the radiation oncologist practicing in the nearby town (technical), while at the same time sharing stories of her own personal choices and experiences (embodied). A peer can also be a source of multiple types of knowledge—not only could she offer embodied knowledge, but she could also be a source of technical knowledge if she discusses the process of undergoing a mastectomy and the subsequent use of a prosthesis.

The proliferation of popular media in recent years is another example of how one source may provide the different types of knowledge. Although information is being passed through formal channels of communications such as the Internet, we cannot always assume that it is authoritative knowledge based on scientific evidence. The Internet, as an example, is a way to gain knowledge about medical procedures from medical sites or research papers (authoritative), view the outcome of a surgical procedure or examine product availability (technical), read personal stories or blogs (embodied), and understand the codes of behavior or cultural norms such as body image through covert messages (traditional).

It is important to recognize that the amount of knowledge acquired can differ between patients, and that variability in knowledge acquisition may explain some of the inequity that we observe in our current healthcare system. This is especially true for authoritative knowledge, even if the goal of the healthcare provider is to offer an objective opinion. For example, if all physicians assume that women want a shaped breast, and therefore believe that BCS or mastectomy with reconstruction is the best choice, it is likely that the discussion of treatment options will have subtle or overt bias against mastectomy alone. In other instances, the information offered may be influenced by what the practitioner believes is keeping with a patient's preference; for example, there may be an assumption that older women do not desire shaped breasts and therefore the surgeon may only discuss mastectomy alone.

Women with newly diagnosed breast cancer must acquire a large amount of knowledge in a relatively short period of time to meaningfully participate in decision-making about their treatment. Using the Mendlinger and Cwikel model of knowledge acquisition, we have highlighted that an early stage breast cancer patient has the potential to gain many different types of knowledge with which she can inform her surgical choice. A more comprehensive understanding of the process by which patients gain this knowledge will help healthcare practitioners ensure that each patient is able to make decisions consistent with her preferences and values, resulting in improved patient satisfaction and outcomes.

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Figure 1.

Framework for knowledge classification for patients. Knowledge can be conceptualized as medical or nonmedical, and conceptual or experiential. Authoritative and traditional can be “conceptual”, given that these knowledge types represent passive acquisition of information about such things as the disease and its treatment or cultural norms. In contrast, technical and embodied can be “experiential”, given that these knowledge types are actively acquired through experiences, e.g., learning how a breast prosthesis works or observing a family member with breast cancer. Authoritative knowledge and technical knowledge are typically acquired from medical sources, whereas traditional knowledge and embodied knowledge are gained from nonmedical sources.

Table 1

Types and sources of knowledge for early stage breast cancer patients. This Table demonstrates that early stage breast cancer patients can acquire knowledge about surgical options from a variety of sources, and that patients may acquire different types of knowledge from one source

Source	Type of knowledge			
	Authoritative	Technical	Embodied	Traditional
Primary care Physician	X	X	X	
Breast surgeon	X	X	X	
Other Specialists	X	X	X	
Decision aides	X	X		
Health Insurance company		X		
Friends/family			X	X
Peers/survivors		X	X	
Popular media (i.e., print, TV, radio, Internet)	X	X	X	X