Study explores how women make decisions about breast cancer surgery

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For women just diagnosed with breast cancer, one of the important decisions confronting them is whether to have a lumpectomy or mastectomy. A diagnosis of breast cancer will affect one in every eight women in the United States, according to the American Cancer Society, causing them to have to decide quickly about treatment.

Most studies investigating how women make this choice have surveyed women months and sometimes even years after their decision was made. Recently, however, the publication of a new University at Buffalo study, one of the few to focus on the time period between women's breast cancer diagnosis and surgery, provides insight into what women are thinking when faced with this decision.

In the study published in the September issue of *Oncology Nursing Forum,* women who were diagnosed with early-stage breast cancer were interviewed during the period just after surgical consultation and before surgery. Performing the interviews at this time allowed for an in-the-moment snapshot of how women arrived at their decisions. These interviews were then transcribed, coded and analyzed to identify themes in the participants' thought processes.

"This is one of the very few studies to be conducted in the pretreatment period when women were actually engaged in the decision-making process, whether they had declared a decision or were still contemplating -- these thoughts were fresh and appointments with physicians still ongoing," according to primary investigator Robin Lally, PhD, RN,

assistant professor of nursing in the UB School of Nursing and adjunct assistant professor at Roswell Park Cancer Institute.

One of the study's most interesting findings was that when women were presented with options and felt they had control over their choices they considered this to be a positive prognostic indicator -- or an encouraging sign of their future survival. "Women reported gaining confidence in their decision-making role through the confidence and support they felt from their surgeon and staff," Lally said. "The women in the study valued receiving options, even if they had one already in mind, and though they may not have seen themselves as a person who is typically good at making decisions, they drew confidence from the support provided to them by their health care team while making the decision."

Most often, women's surgical treatment decision making has been studied using a structured response format that limits the nature of the answers by providing predetermined choices (multiple choice or yes/no answers). This structured approach eliminates the context in which decisions are made and limits women's ability to reveal their thoughts behind how and why they make certain choices.

In contrast, the qualitative research approach used by Lally in this study assembles participants who can provide rich insight and expert knowledge on a particular phenomenon so that it can be better understood in a real-world context.

"This research provides insight into what women newly diagnosed with breast cancer may do, think about and expect even before they see the surgeon at the clinic for the first time," Lally said.

Specifically, Lally's research showed that women felt that information about breast cancer was important, but that they needed to manage the amount and timing of the information they took in, in order to prevent

themselves from becoming overwhelmed. More was not necessarily better. Some women preferred to use only the verbal information provided by their care team on which to base their decision and put the breast cancer literature away until just days before their surgery.

Age was not a defining factor in how much information women wanted or whether they used what was provided. Women of all ages used information that answered their questions and tended to avoid information that upset them emotionally.

Lally found that many women already had a plan in mind when they entered the surgeon's office which they then weighed against the surgeon's input. Their surgical treatment decisions were motivated by the desire to: eliminate future inconvenience and worry about cancer balanced by avoiding mastectomy unless medically required; maintain physical function and appearance; and recover rapidly. Most women felt that mastectomy should be reserved only for the worst breast cancers. Older women saw advanced age as an advantage -- age protected them from worry of recurrence and/or the significant concern over loss of their breast although they still chose lumpectomy.

Women of all ages expressed surprise that their surgeons did not make a definitive recommendation, but that the choice of mastectomy or lumpectomy was ultimately their own. Even women who wanted to make their own decision still desired a recommendation from the surgeon. When making a choice, however, they drew confidence from the surgeons' support of their decision.
Lally hopes that surgeons and nurses will be inspired by her findings to assess their breast cancer patients' expectations and understanding regarding their options and the decision-making process at the beginning of each consultation and be aware of the important role providers play in supporting women's ability to make this decision.

Breast cancer survivors can also benefit from this research. Lally hopes that, "survivors reading this study may find 'a little of themselves' in the women's narratives and feel comforted in the realization that others also had moments of feeling overwhelmed, uncertain or surprised by the surgical decision-making process -- you are not alone."

Lally currently has a grant under review in collaboration with Roswell Park Cancer Institute's Breast Center to study the thought processes of African-American women in response to their breast cancer diagnosis. She intends to use all of her research to develop assessment and intervention tools for health care professionals in order to identify women who may be at risk for ongoing distress beyond this early time period.

Source: University at Buffalo

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