

## Sigma's 29th International Nursing Research Congress

### Grounded Theory Study of How Women With Early Stage Breast Cancer Choose Contralateral Prophylactic Mastectomy

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#### **Background:**

The decision to undergo the surgical removal of any healthy body part, and particularly one as universally accepted as a symbol of femininity and motherhood as the female breast, seems, on the surface, unfathomable. Nevertheless, national, statewide, and single-institution studies confirm that women in the United States with a first diagnosis of sporadic unilateral early-stage breast cancer have increasingly chosen to undergo contralateral prophylactic mastectomy, the surgical removal of their unaffected and healthy breast, concurrent with the therapeutic surgical removal of the diseased breast (King et al., 2011; Kummerow, Du, Penson, Shyr, & Hooks, 2015; Kurian et al., 2009; Tuttle, Haberman, Grund, Morris, & Virnig, 2007; Tuttle et al., 2009; Yao, Stewart, Winchester, & Winchester, 2010).

Evidence-based, consensus-driven guidelines and/or position statements by experts in the field fail to demonstrate clear and unwavering support for this irreversible surgical decision among women of average risk for breast cancer (Boughey et al., 2016; Giuliano et al., 2007; Gradishar et al., 2017). Experts note that for the majority of women with Stage I or II breast cancer, the absolute 20-year survival benefit of contralateral prophylactic mastectomy has been calculated as less than 1% among all age, ER status, and cancer stage groups (Portschy, Kuntz, & Tuttle, 2014).

Following nearly a century of paternalistic medical decision making, the rise in patient engagement emerges from two parallel movements over the past 20 years; one toward the explicit use of clinical trial data to guide clinical practice (evidence-based medicine). The other toward patient empowerment and engagement through explicit informed consent, shared decision-making, and patient-centered care (Kierns & Goold, 2009). The Institute of Medicine (IOM), in their conceptual framework for delivering high-quality cancer care, prioritized *engaged patients* making health care decisions in concert with their clinician, over evidence-based cancer care (IOM, 2013). This IOM priority points to a need for a better understanding of a woman's direct engagement in the decision-making process for contralateral prophylactic mastectomy.

Although promotion of patient engagement within the United States weights a patient's values, goals, and preferences in at least equal measure to that of the experts and current best evidence (Institute of Medicine [IOM], 2013), knowledge of how women consider the pros and cons of the decision for contralateral prophylactic mastectomy remains limited. The extant literature on contralateral prophylactic mastectomy decision-making provides little evidence of this question being posed directly to women in a systematic way. Rather, the majority of studies attempting to understand this process have mostly done so through the retrospective secondary analysis of large existing datasets. Such studies have served primarily to advance our understanding about which women choose contralateral prophylactic mastectomy, in terms such as demographics, clinico-pathologic details, and pre-surgical imaging, but not how women engage in the decision-making process for contralateral prophylactic mastectomy (Baker, Mayer, & Esposito, 2013).

The purpose of the research study is to explore the process of how women with the first diagnosis of sporadic unilateral early stage breast cancer choose contralateral prophylactic mastectomy. A prospective qualitative approach offers a clear opportunity to increase nursing knowledge of the process by which truth is arrived, from the perspective of the participant, without the loss of contextual details. Grounded theory methodology as developed by Glaser and Strauss (1967) and described in detail by Glaser (1978, 1998, 2001) and Holton (2010) is ideally suited to discovering how people manage their

lives in the face of existing or potential health challenges (Schreiber & Stern, 2001) offering the opportunity for discovery of a theory that can explain what is “really going on”. The goal of this grounded theory study is to expand nursing knowledge of women's decision-making within the existing social context as a base for health policy development, expansion of nurse's roles, and empowerment of women.

The significance of the study of contralateral prophylactic mastectomy decision-making is directly linked to its prevalence, outcomes, and the availability of alternative approaches to risk reduction. With increasing numbers of women in the United States diagnosed with early stage breast cancer choosing contralateral prophylactic mastectomy seemingly against evidence-based, consensus-driven guidelines and/or position statements by experts in the field (Boughey et al., 2016; Giuliano et al., 2007; Gradishar et al., 2017), the process of making such an irreversible and life-changing decision needs to be more fully understood by nurses and other health care providers. Such an understanding serves to expand nursing knowledge, add depth to the literature, inform best care practices, and attain optimal health outcomes for this ever growing population.

### **Purpose:**

The purpose of the research study is to explore the process of how women with the first diagnosis of sporadic unilateral early stage breast cancer choose contralateral prophylactic mastectomy.

### **Methods:**

The present study will use grounded theory methodology as developed by Glaser and Strauss (1967) and described in detail by Glaser (1978, 1998, 2001) and Holton (2010).

#### Context/Setting

The context of the research is prospective. Initial interviews with participants familiar with the phenomenon of interest will be conducted *after* the surgical decision for contralateral prophylactic mastectomy has been made by participant and *prior* the surgery itself. The setting for the research will be dependent on the preferences of the participants, distance, and available space,

#### Participants

The research will begin with nonprobability purposive sampling among participants initially selected because they can shed light on the phenomenon under investigation, namely women at average risk for breast cancer (American Cancer Society [ACS], 2015) with a first diagnosis of unilateral breast cancer who have made the decision for contralateral prophylactic mastectomy. Sample size cannot be predicted at the beginning of a grounded theory study since the researcher does not know beforehand what concern will emerge as problematic and how it will be resolved (Artinian, Giske, & Cone, 2009; Glaser, 1978). Subsequent sampling will be related to the findings that emerge from the course of the study and may include textual material, and interviews with significant others and/or healthcare providers.

#### Recruitment

The initial nonprobability purposive sample will be recruited with the use of a flyer distributed to breast surgical practices within the multisite healthcare system where the researcher is employed; breast surgical practices in the community; and through the local chapter of the Oncology Nursing Society of which the nurse researcher is a member.

#### Procedure

Data will initially be collected through tape-recorded interviews and will begin guided by the following question: tell me about your breast surgery decision. The research will follow the non-linear steps outlined by Glaser (1978). These steps include collection of data, open coding, theoretical sampling, generating memos, emergence of core social psychological problems and processes, theoretical sampling, and continued coding and memoing as analyst focuses on the core. These steps will occur simultaneously, rather than linearly, and will end with the writing of a substantive or formal theory.

#### Analytic Approach

The analytic approach in a grounded theory study, simultaneously with all other steps, employs the process of constant comparison of data and involves three levels of conceptual perspective analysis (Glaser, 1998). First, data will be analyzed line-by-line and coded. Codes will then be organized into conceptual categories and their properties. Finally, there will be an overall integration of data into a theory (Glaser 1998)

#### Results:

Not available

#### Conclusions:

Not available

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#### Title:

Grounded Theory Study of How Women With Early Stage Breast Cancer Choose Contralateral Prophylactic Mastectomy

#### Keywords:

Contralateral prophylactic mastectomy, Grounded theory and Shared decision-making

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#### **Abstract Summary:**

Increasingly, U.S. women with the first diagnosis unilateral breast cancer are choosing contralateral prophylactic mastectomy against expert advice. This grounded theory study aims to expand nursing

knowledge of women's decision-making within the existing social context as a base for health policy development, expansion of nurse's roles, and empowerment of women.

### **Content Outline:**

Introduction: The decision to undergo the surgical removal of any healthy body part, and particularly one as universally accepted as a symbol of femininity and motherhood as the female breast, remains poorly understood.

- Body
  1. National, statewide, and single-institution studies confirm that women in the United States with a first diagnosis of sporadic unilateral early-stage breast cancer have increasingly chosen to undergo contralateral prophylactic mastectomy.
    1. i) In 2007 and 2009, two Surveillance Epidemiology End Results (SEER) studies reported that the rate of CPM had increased 148% and 150% among all patients for noninvasive and invasive cancer, respectively (Tuttle, Haberman, Grund, Morris, & Virnig, 2007; Tuttle et al., 2009).
    2. ii) A report from the National Cancer Data Base (NCDB) showed an increase in CPM from 0.4% in 1998 to 4.7% in 2007 (Yao, Stewart, Winchester, & Winchester, 2010).
  - iii) A 2011 study from Memorial Sloan Kettering reported that 6.7% mastectomy patients underwent CPM in 1997, which increased to 24.2% in 2005 (King et al., 2011).
  2. iv) A California Cancer Registry study in 2014 reported that the rate of bilateral mastectomy increased from 2.0% (95% CI, 1.7%-2.2%) in 1998 to 12.3% (95% CI, 11.8%-12.9%) in 2011, an annual increase of 14.3% (Kurian et al., 2009).
  3. v) A national 2015 study demonstrated rates of bilateral mastectomy for unilateral disease increased from 1.9% in 1998 to 11.2% in 2011 (Kummerow, DU, Penson, Shyr, & Hooks, 2015).
  1. Evidence-based, consensus-driven guidelines and/or position statements by experts in the field fail to demonstrate clear and unwavering support for this irreversible surgical decision among women of average risk for breast cancer.
    1. i) The 2017 National Comprehensive Cancer Network (NCCN) Breast Cancer guidelines discourage prophylactic mastectomy of a breast contralateral to a known unilateral breast cancer among women of average risk (Gradishar et al., 2017).
    2. ii) Consensus statement from the American Society of Breast Surgeons agreed that contralateral prophylactic mastectomy should be discouraged for an average risk women (Boughey et al., 2016).
  - iii) The most recent Society of Surgical Oncology (SSO) position statement recommends contralateral prophylactic mastectomy for patients at high risk, for patients in whom subsequent surveillance would be difficult, and for improved symmetry among women with large and/or ptotic contralateral breast or disproportionately sized contralateral breast (Giuliano et al., 2007).
  1. Healthcare decision-making has evolved from a paternalistic approach to a patient centered approach.
    1. i) From 1895 to the mid-1970s, the authority for breast surgery decisions rested, in almost all cases, exclusively with the surgeon for the benefit of a woman typically understood to be both vulnerable and passive (Angelos et al., 2015).
    2. ii) In 1982, as part of the *President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research*, the adoption of shared decision-making was urged as a means to reform physician-patient communication and to improve the day-to-day implementation of meaningful informed consent to medical treatments (Katz, 2002).

- iii) The Institute of Medicine (IOM), in their conceptual framework for delivering high-quality cancer care, prioritized *engaged patients* making health care decisions in concert with their clinician, over evidence-based cancer care (IOM, 2013).
1. Knowledge of how women consider the pros and cons of the decision for contralateral prophylactic mastectomy remains limited.
    1. i) The majority of studies attempting to understand this process have mostly done so through the retrospective secondary analysis of large existing datasets (Baker, Mayer, & Esposito, 2013).
    2. ii) Such studies have served primarily to advance our understanding about which women choose contralateral prophylactic mastectomy, in terms such as demographics, clinico-pathologic details, and pre-surgical imaging, but not how women engage in the decision-making process for contralateral prophylactic mastectomy (Baker et al., 2013).
  2. Conclusion
    1. i) A prospective study is needed.
    2. ii) Using grounded theory methodology, one may reasonably anticipate the emergence of a theoretical framework, grounded in the data, that "...accounts for a pattern of behavior which is relevant and problematic for those involved" (Glaser, 1978, p. 73).
- iii) This grounded theory will provide relevant predictions, explanations, interpretations, and applications in the substantive area of study and ultimately serve as a basis for developing health policy and expanded nursing roles to meet the needs of women faced with the first diagnosis of early stage breast cancer.

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