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An Exploration of Psychosexual Functioning and Factors Affecting the Prophylactic Decision-Making Process in Women of Childbearing Age with a BRCA 1/BRCA2 Mutation

Alexis Hayes
University of Texas Science Center at Houston-Cizik School of Nursing

AN EXPLORATION OF PSYCHOSEXUAL FUNCTIONING AND FACTORS AFFECTING THE DECISION-MAKING PROCESS IN WOMEN OF CHILDEBARING AGE WITH A BRCA1/BRCA2 MUTATION

A DISSERTATION

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIRMENT FOR THE DEGREE OF DOCTOR OF PHILOSOPHY IN NURSING

THE UNIVERSITY OF TEXAS HEALTH SCIENCE CENTER AT HOUSTON CIZIK SCHOOL OF NURSING

BY

ALEXIS ELIZABETH HAYES MSN-ED, APRN, FNP-BC

DECEMBER, 2019

Approval Form D-3

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10/18/19
Date

To the Dean for the School of Nursing:

I am submitting a dissertation written by Alexis Hayes and entitled "*An exploration of psychosexual function and factors affecting the decision-making process in women of childbearing age with a BRCA1/BRACA2 mutation.*" I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing.

Diane Wardell
Diane Wardell, Committee Chair

We have read this dissertation
and recommend its acceptance:

Accepted

Dean for the School of Nursing

Acknowledgments

I would like to express my sincere gratitude to each and every woman that contributed to this research study. Thank you for sharing your personal experiences with me. A special thank you to my mother and father for your continued support and patience throughout my doctoral studies. Thank you to my family and friends for your continued prayers and encouragement. Last but most of all, thank you to my Heavenly Father for keeping me thus far.

Alexis Elizabeth Hayes

An Exploration of Psychosexual Functioning and Factors affecting the Decision-Making Process in Women of Childbearing Age with a BRCA1/BRCA2 Mutation

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Abstract

Background: A breast cancer type 1 and type 2 susceptibility protein (BRCA1/BRCA2) gene mutation carries an 85%- 90% lifetime risk of developing breast cancer and a 27%-65% chance of developing ovarian cancer. There is minimal evidence regarding how psychosexual functioning, the psychological well-being in regards to body image and sexuality, affects the decision to have prophylactic treatment in women of childbearing age (18 - 49) with a BRCA gene mutation. Diagnosis of a BRCA gene mutation presents a dilemma where life-changing medical decisions must be made to prevent breast and ovarian cancer. Throughout decision-making and following surgical prophylactic interventions, such as a bilateral prophylactic mastectomy (BPM) and bilateral salpingo-oophorectomy (BPSO), there are continued effects on social and sexual functioning related to body image, the partners perception, sexual attractiveness and femininity which further affects the woman's psychological well-being.

Aim: The aim of the study was to explore the role of psychosexual functioning in the decision to have prophylactic treatment amongst women of childbearing age who have a diagnosis of a BRCA1/BRCA2 gene mutation.

Methods: A focused medically applied ethnographic design was employed to assist the researcher in exploring, interpreting and describing the experience of women of childbearing age with a BRCA mutation. A purposive sample of 18 women between the ages of 21-49 participated in semi-structured interviews exploring their experience after BRCA diagnosis.

Results: Interpretive descriptive analysis revealed four major themes: *Body image, Sexuality, Femininity and Childbearing/Childrearing*. Women that had undergone BPM (n=8) were concerned about the effects of the surgery, scarring, breast disfigurement and lack of sensation. Although some of the women had not received surgical prophylaxis they all voiced concerns regarding body image and sexuality that caused some hesitancy in their decision-making to have prophylactic surgery.

Conclusion: This study postulates that psychosexual concerns come from both internal and external influences that significantly impact the decision to undergo prophylactic measures. Body image, sexuality and sexual orientation should be addressed at first contact and considered while developing a plan of care. Although women may have

support from family or significant others during the decision-making process psychosexual concerns may not be addressed.

Keywords: Body Image, BRCA mutation, Decision Making, Prophylactic Mastectomy, Psychosexual Functioning, Sexuality

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Summary of Study

There continues to be a gap in knowledge regarding the influence of psychosexual functioning on the decision to have prophylactic treatment in women of childbearing age diagnosed with a BRCA mutation. Women are faced with making a choice decision after diagnosis of a deleterious mutation increasing the risk for breast, ovarian and other cancers. This study sought to explore psychosexual functioning concerns in women of childbearing age with a BRCA1/BRCA 2 mutation.

A focused medically applied ethnographic approach was utilized to explore the individual concerns of women pre-and post-prophylactic mastectomy and/salpingo-oophorectomy. Interpretive description was employed to explore the informant's individual experiences versus the entire group as a culture (Thorne, Kirkham, & MacDonald-Emes, 1997). However, to further establish trustworthiness of the study, conceptualizations were based on the interpretation of multiple participants responses rather than single occurrences.

Analysis of the data began after each interview by evaluating reflexive notes and identifying common descriptors. After each interview, the relationships amongst recurrent themes were identified. Data transcriptions were reviewed repeatedly to formulate the meaning of common descriptors and recurrent themes throughout the analytic process before classification of common themes and qualitative content (Spradley, 1979; Thorne, Kirkham, & MacDonald-Emes, 1997). Reflective journaling assisted with the interpretation of reflective notes and analytic notations throughout the exploration of psychosexual functioning.

The recruitment of participants took place after IRB approval from the University of Texas Health Science Center at Houston's (UTHSC) Committee for the Protection of Human Subjects (CPHS) on March 14, 2019 to June 28 2019. The study participants were English speaking women, 21-49 years of age, with a BRCA1/BRCA 2 mutation. The investigator shared a recruitment flyer (Appendix B) on social media and with group administrators to notify potential participants of study inclusion criteria. Women were initially recruited from online BRCA support groups, state BRCA support groups and a national support organization after permission from the groups 'administrators. All study participants contacted the investigator for participation through Facebook messaging or email.

Once initial contact was made, the participant received a screening questionnaire through Qualtrics, to examine inclusion/exclusion criteria, and supplementary information regarding the study (see Appendix C). Women who were diagnosed with breast or ovarian cancer and those greater than 49 years of age were excluded from study participation. Women who met the aforementioned criteria were sent an informed consent, a link to schedule the interview and their rights as a study participant (see Appendices F and G).

Individual semi-structured in-depth interviews were employed to further explore the participants concerns. Zoom video audio recording was utilized to allow face to face recording, capture nonverbal cues, expressions and real-time recording, however participants had the option to perform audio recording only. Interviews, conducted by the solo investigator, lasted from 11- 46 minutes. The interview consisted of questions regarding the participants experience after being diagnosed with a BRCA mutation,

prophylactic measures considered and feelings about their body image and sexuality (see Appendix D). Participants were sent a link to a demographic questionnaire after the interview and a twenty-dollar Amazon gift card for study participation (see Appendix E). Audio/video recordings were stored in a secure iCloud system and sent to a professional transcription service. All interviews were transcribed verbatim and followed by interpretive description of psychosexual functioning.

A total of eighteen women (Caucasian: n = 14, Hispanic: n = 2, Asian: n = 1 and unknown: n=1), between the ages of 23 and 46 were interviewed over a two-month period. Interpretive description revealed four major themes which included Body Image, Sexuality, Femininity and Childbearing/Childrearing. Within the four major themes were subthemes that arose through repeated review of transcriptions, reflection and submersion into each informant's experience. Body Image included concerns regarding scarring, the presence of the BRCA mutation, isolation versus feeling different, menopausal symptoms, reconstruction, decision-making, internal and external influences, the waiting room and communication with provider. Sexuality included concerns regarding intimacy with partner, and concerns of the sexual minority woman (SMW). The theme Femininity included the participants views of what it means to be a woman. Lastly, the theme Childbearing/Childrearing included subthemes being there, fear of transmission, parenting, future childbearing and breastfeeding.

Following the exploration of concerns regarding psychosexual functioning, the apprehensions related to body image were most prominent. Women had concerns regarding how they viewed themselves and how others (i.e. spouse, sister, children, and strangers) viewed them after being diagnosed with a BRCA mutation and undergoing

prophylactic surgery. Women were concerned about scarring both before and after prophylactic surgery. Scarring on the breast area seemed to be more significant than scars post salpingo-oophorectomy or on any other part of the body. After being diagnosed with the BRCA mutation, the women voiced feeling isolated amongst persons their age and feeling different. Most participants were supported by family and friends throughout their BRCA diagnosis and decision-making process. However, there were concerns about the lack of access to support groups specifically for women of childbearing age.

Women who had undergone prophylactic mastectomy and those women undergoing surveillance for ovarian cancer were concerned about the side effects (i.e. hormones, changes in mood, skin, weight gain) of salpingo-oophorectomy. The women were vocal about the effects of implants and reconstruction on their body image. The change in the "feel", appearance and movement of the breast were common concerns. Throughout the decision-making process various factors such as opinions from family, friends, and even strangers influenced the women in making their prophylactic choices. Even so, some of the women were ambivalent about prophylactic surgery and possible future diagnosis of breast and/or ovarian cancer. The communication with provider regarding plan of care, provider knowledge of the BRCA mutation and provider acknowledgment of the diagnosis concerns were significant.

Sexuality concerns such lack of sensation, decreased libido, pain and even scarring affected intimacy with their partner. Sixteen of the women in the study were heterosexual and there were two women that were bisexual and/or homosexual. Concerns were different amongst the minority in views of what femininity means and self-identity to a partner of the same sex. The breast was an integral part of being a

woman and feeling feminine. The loss of the breast throughout the decision-making process and changes in the appearance of the breast post-surgery affected femininity.

For some, the decision to undergo prophylactic surgery was due to the responsibilities of being a parent, the need to survive and past experiences with mother or grandmother with cancer. There were also concerns regarding breastfeeding and changes in the mother-child relationship after having a prophylactic mastectomy. Finally, the time to prophylactic salpingo-oophorectomy and fertility issues were also a concern in women considering childbearing.

An Exploration of Psychosexual Functioning and Factors Affecting the Prophylactic Decision-Making Process in Women of Childbearing Age with a BRCA 1/BRCA2 Mutation

by
Alexis Elizabeth Hayes

Internal Faculty:
Chair: Diane Wind Wardell PhD, RN, WHNP-BC
Joan Engebretson PhD, RN, AHN-BC, FAAN
Geraldine Wood PhD, RN, FAAN

The University of Texas-Houston Health Science Center Cizik School of Nursing
Doctor of Science in Nursing Program

External Faculty:
Marlyn Allicock MPH, PhD
Department of Health Promotion and Behavioral Sciences
The University of Texas- Health Science Center at Houston School of Public Campus

Abstract

Although body image and sexuality, components of psychosexual functioning, are addressed in women with a diagnosis of breast cancer and ovarian cancer, there is minimal evidence regarding these factors in women of childbearing age (21-49) who have a genetic risk for breast and/or ovarian cancer diagnosed with a BRCA1/BRCA2 mutation. Furthermore, there is minimal evidence regarding how these factors affect the decision to have prophylactic treatment for breast and ovarian cancer. The *long-term goal* of the proposed study is to increase the understanding of factors that affect the decision-making process in women of childbearing age that are diagnosed with a BRCA1/BRCA2 gene mutation. The overall *study objective* is to understand the influence of psychosexual functioning and discover factors affecting the decision to have prophylactic treatment. *Research question:* What are the concerns women of childbearing age, diagnosed with BRCA1/BRCA2 gene mutation, have related to psychosexual functioning? The *specific aim* of this study is to explore the role of psychosexual functioning in the decision and adjustment to have a prophylactic treatment, amongst women of childbearing age who have a diagnosis of a BRCA1/BRCA2 gene mutation. A focused medically applied ethnographic methodology will be utilized to accomplish the aim of this study. There is a *critical need* to explore psychosexual functioning during the diagnosis of the BRCA mutation and throughout the decision to have prophylactic treatment. The *expected outcomes* of the proposed study are to establish the importance of psychosexual functioning in cancer risk management and during prophylactic decision-making. The application is expected to assist with individualized cancer risk management options provided by health care providers. The knowledge gained from this

research will have a ***positive impact*** on cancer risk management by adding a psychosexual component to the limited decision-making tools that are available to BRCA mutation carriers. The research proposed in this application is ***innovative*** because it will provide support to the psychosocial and psychosexual wellbeing of women of childbearing age with a BRCA mutation by understanding the perceptions regarding their experiences, attitudes, body image and sexuality. The contribution is envisioned to be ***significant*** because the findings are expected to transform decision support for BRCA gene mutation carriers and young women with breast and/or ovarian cancer due to a genetic mutation. Ultimately, understanding the decision-making process and assisting women with choosing a preventative option has the potential to decrease the morbidity and mortality of breast and ovarian cancer.

Specific Aims

The diagnosis of a deleterious BRCA gene mutation is devastating for women and is often viewed as a cancer diagnosis. A BRCA1/BRCA2 gene mutation increases the risk of hereditary breast and ovarian cancer to an 85%- 90% lifetime risk of developing breast cancer and a 27%-65% chance of developing ovarian cancer (Donnelly et al., 2013). A diagnosis of a BRCA gene mutation presents a dilemma where life-changing medical decisions must be made to prevent breast and ovarian cancer. The decision to choose amongst prophylactic measures such as intense surveillance, chemoprophylaxis, radiation, bilateral mastectomy, and bilateral salpingo-oophorectomy is a complex process. Furthermore, psychosexual functioning, which includes psychological well-being in regards to body image and sexuality, is often affected by the diagnosis of a BRCA1/BRCA2 gene mutation. Yet, there is minimal evidence regarding how these factors affect the decision to have prophylactic treatment.

Women of childbearing age (21-49) are at a unique stage in life where childbearing, educational goals, career development and the establishment of intimate relationships are most important. Approximately 50% of BRCA1/BRCA2 gene mutation carriers choose intense surveillance however only 70% of all BRCA carriers follow the recommendations for intense screening (Pademsee et al., 2017). Evidence suggests that the psychological state of the individual affects preventive treatment decisions (Pademsee et al., 2017). Therefore, women of childbearing age need to feel understood and have knowledgeable supporters available during the decision-making process. Genetic counseling pre-and post-diagnosis of a BRCA gene mutation is helpful, however assuring that continued psychosexual counseling is available to assist women of childbearing age

with an informed and independent decision is empirical. Therefore, there is a ***critical need*** to explore psychosexual functioning during the diagnosis of the BRCA mutation and throughout the decision to have prophylactic treatment.

The ***long-term goal*** is to increase the understanding of factors that affect the decision-making process in women of childbearing age that are diagnosed with a BRCA1/BRCA2 gene mutation. Having a thorough understanding of the decision-making process and assisting women with choosing a preventative option has the potential to decrease the morbidity and mortality of breast and ovarian cancer. The overall ***objective*** of the proposed study is to understand the influence of psychosexual functioning on the decision to have prophylactic treatment. ***Research question***: What are the concerns women of childbearing age, diagnosed with BRCA1/BRCA2 gene mutation, have related to psychosexual functioning? A focused medically applied ethnographic approach will be utilized to accomplish the aim of this study. To attain the overall objectives, the following ***specific aim*** will be pursued:

1. To explore the role of psychosexual functioning in the decision to have prophylactic treatment, amongst women of childbearing age who have a diagnosis of a BRCA1/BRCA2 gene mutation. To accomplish this aim, semi-structured interviews will be performed via audio and/or video recording.

At the completion of the proposed research, the expected ***outcomes*** are to establish the importance of psychosexual functioning in cancer risk management and prophylactic decision-making. Additionally, this application is expected to assist with individualized cancer risk management options provided by health care providers. The knowledge gained from this research will have a ***positive impact*** on cancer risk

management by adding a psychosexual component that is not adequately included in decision-making tools for BRCA mutation carriers.

Significance

Overall Scientific Premise. There is a gap in knowledge regarding the influence of psychosexual functioning on the decision to have prophylactic treatment in women of childbearing age diagnosed with a BRCA gene mutation only (without breast cancer diagnosis). Decision-making regarding a BRCA mutation is a particularly complex given the number of choices. Women are faced with a choice situation after being diagnosed with a deleterious BRCA gene mutation. Fomby-White's Theory of Choice (2008) which involves "the process of judging the merits of multiple options and choosing the best one for action" (Fomby-White, 2008, para.1) guides our understanding of decision-making during a choice situation. The decision-making process may have a greater impact on women of childbearing age who remain underrepresented in the literature (Fobair, Stewart, Chang, D'Onofrio, Banks & Bloom, 2006).

Application of this research will focus on the needs of women of childbearing age throughout their individual choice situations. Hayes' s (2016) conceptual framework, *Decision-Making Process when a Woman of Childbearing Age is faced with a Choice Situation Post Diagnosis of a BRCA Mutation*, guides the multidisciplinary healthcare team through the decision- making process as the woman navigates through the prophylactic choice decision (Appendix A). The concepts within the conceptual framework provide a route to explore the choice situation and the effects of those options on body image, sexuality, psychosexual isolation and prophylactic treatment choice. The focus of this study will be on psychosexual functioning, which includes psychological

well-being in regards to body image and sexuality, post diagnosis of a BRCA1/BRCA2 mutation.

Currently, there is a gap in knowledge regarding psychosexual functioning in women of childbearing age with a BRCA gene mutation and how it impacts decision making. It is imperative that nurses and healthcare providers fully understand the decision-making process that women of childbearing age with a BRCA mutation face, henceforth support is available as choices are being considered. This study will have a positive impact on cancer risk management by deepening the understanding of the psychosexual component to the decision-making process.

Scientific Premise for Aim#1. Throughout the decision to have prophylactic treatment, genetic counseling is offered to assist the individual, family and provider with risk management options. Genetic counselors assist with the facilitation of the decision to have a specific prophylactic intervention based on the individual's genetic risk (Evans et al., 2016). Women who are encouraged to have prophylactic treatment often do not comply with even the least invasive options such as surveillance (Evans et al., 2016). In addition, women of childbearing of age, specifically those less than 25 years of age, may not have the cognitive skills to make irreversible and life changing decisions regarding prophylactic measures (Hoskin et al., 2014).

It has been documented that women may have “other needs” that are not being addressed in genetic counseling (Evans et al., 2016; Padamsee, Willis, Yee, & Paskett, 2017). Following prophylactic interventions, such as prophylactic mastectomy and salpingo-oophorectomy there are continued effects on social and sexual functioning related to body image, the partners perception, sexual attractiveness and femininity which

further affects the woman's psychological well-being (Mroczek et al., 2012). Body image and sexuality concerns are present before BRCA diagnosis, post diagnosis and throughout the decision-making process (Mroczek et al., 2012). Sexuality, body image and intimacy are often overlooked by healthcare providers and genetic counselors throughout the treatment process. It has been proposed that women of childbearing age have severe impairments in psychosexual functioning, survival and psychosocial effects than women greater than 50 years of age throughout cancer treatment (Mroczek et al., 2012). Assisting women with feeling "normal" during the process may assist with body image and sexuality by allowing a comfortable environment to discuss psychosexual issues (Ganz et al., 1998). Decker et al. (2015) suggested that to minimize psychosexual morbidity in cancer survivors, body image, sexuality and intimacy must be addressed early in the diagnoses process before treatment is initiated.

Significance of the Expected Research Contribution

Upon successful completion of the proposed study, it is expected that the research contribution will determine key factors in psychosexual functioning and its role in the decision to have prophylactic treatment. *The contribution is expected to be significant because the findings are expected to influence decision support for BRCA gene mutation carriers and young women with breast cancer due to a genetic mutation*. The management of asymptomatic BRCA mutation carriers includes breast self-examination, clinical breast examination, mammogram/MRI, breast and/or transvaginal ultrasound, smoking cessation, weight reduction, chemoprophylaxis and surgical prophylaxis (Teller & Kramer; 2010). Concerns regarding psychosexual functioning are continuous and do not resolve once treatment has been initiated. Therefore, it is empirical that counseling

and support be offered pre, post and during the BRCA gene mutation diagnosis and the prophylactic treatment process to reduce the risk of breast and ovarian cancer (Kew, Nevin & Cruickshank, 2002).

This research will provide support for the psychosocial and psychosexual wellbeing of women of childbearing age with a BRCA mutation by understanding their perceptions regarding their experiences, attitudes, body image, and sexuality. The proposed research study is expected to improve quality of life by decreasing anxiety and cancer worry by enhancing awareness to the psychosexual concerns affecting decision making in these women (Salhab, Bismohun & Mokbel, 2010; Rijnsburger et al., 2004). *The proposed research is innovative, because it represents a substantive departure from the status quo by addressing psychological well-being in regards to body image and sexuality in women of childbearing age with BRCA gene mutation throughout the decision to have prophylactic treatment.* To provide support needed to make fully informed decisions regarding prophylactic treatment, it is imperative that an exploration of what is missing from support given to BRCA gene mutation carriers and multiple factors affecting the decision-making process is achieved. Only then will healthcare providers be able to care for the total woman of childbearing age, thereby opening new horizons for decision-making and support throughout the diagnosis of the BRCA gene mutation and prophylactic treatment.

Approach

Aim #1: To explore the role of psychosexual functioning in the decision to have prophylactic treatment, amongst women of childbearing age, who have a diagnosis of a BRCA1/BRCA2 gene mutation.

Introduction. There is minimal evidence regarding how psychosexual functioning, psychological well-being in regards to body image and sexuality, affects the decision to have prophylactic treatment in women of childbearing age with a BRCA gene mutation. The *objective* for this aim is to understand the influence of psychosexual functioning on the decision-making process to have prophylactic treatment. The *approach* to attaining the objective will consist of a focused medically applied ethnography. The *rationale* for this aim is that successful completion will contribute to cancer risk management by adding insights into the decision-making process. Such insights would be essential to the development of tools that are used to assist BRCA gene mutation carriers throughout the diagnosis and treatment process. Upon completion of Aim #1, it is the researchers' *expectation* to understand the role of psychosexual functioning in cancer risk management and assist with individualized cancer risk options provided by healthcare providers.

Research Design. The study will be a focused medically applied ethnography. An ethnographic approach, using Leininger's Ethnonursing research model, will guide the research study (Leininger, 2005). The ethnographic methodology will assist in the exploration of psychosexual functioning and the decision-making process of BRCA mutation carriers.

Sample and Setting. The population will consist of women between the ages of 21-49, with a positive BRCA gene mutation and/or BRCA gene mutation of undetermined significance. A purposive sampling strategy will be employed to select study participants from a specific cultural domain. The purpose for the homogenous

sample is to explore women who are BRCA positive and seeking support pre-and post-prophylactic treatment.

Inclusion criteria: women 21-49 years of age, diagnosed with a BRCA1 or BRCA2 gene mutation, women 21-49 years of age with a BRCA mutation of undetermined significance, English speaking, access to the internet, Facebook and/or Zoom video recording per phone or computer. Exclusion criteria: Women over 50 years of age and women who have been diagnosed with breast or ovarian cancer. Purposive sampling will take place for eight to ten weeks once permission is obtained from CPHS. The sample size will consist of a minimum of 15 participants to a maximum of 50 and/or until redundancy of the data is met.

Procedure for Data Collection. The study participants will consist of women on Facebook that are members of a BRCA support group and/or prophylactic support group and women from an educational institution. Additionally, flyers (Appendix B) stating "Are you someone that has a BRCA mutation that increases their risk of breast or ovarian cancer?" will be placed in the clinical and/or educational setting(s) in Houston, Texas and on the solo investigators Facebook News Feed. If a specific support group is utilized, a formal invitation will be submitted to the group administrator before posting any content regarding the research topic and announcement of the study. Otherwise participants will be notified of study through Social Media post/flyer on Facebook, Instagram and flyer advertising within local clinic and educational settings. Permission and/or letter of support will be obtained before placement of flyer in clinic and educational settings. Information to contact the solo investigator will be noted on the flyer/social media post and the participant must notify the investigator to be considered for the study. Once

initial contact has been made, an individual email will be sent formally inviting the participant to participate in the research study. The formal invitation and web link will be developed through Qualtrics. The formal letter, which will include a link to an eligibility/screening questionnaire (Appendix C), will evaluate the inclusion and exclusion criteria. The participants responses to the eligibility questionnaire will determine study eligibility and will be autoscored through Qualtrics and reviewed by researcher for accuracy. Persons who respond to any of the exclusion criteria will be excluded from the sample and those who meet the inclusion criteria will be sent a web-link with an informed consent.

Once consent is obtained, the interview will be scheduled with the participant. The interviews are expected to take place in the home of the participant via Zoom (video conference & recording) or at a central location that is quiet and/or comfortable for the participant and the investigator. Zoom will allow face to face communication with participants, allow for the interview to be recorded in real time and allow the interview to be saved to a secure cloud system for retrieval. The purpose of video recording is to capture facial expressions and nonverbal cues throughout the interview. The participant will have the option to opt out of the video recording and complete audio recording of the interview if desired. Individual semi-structured in-depth interviews will be performed to explore the participants experience. The interview will be structured according to Spradley's (1979) guide, with pilot testing of grand tour and probe interview questions (see Appendix D Interview Guide). The interview will be conducted by the solo researcher and will last approximately 30 – 60 minutes per participant. The participants demographics (Appendix E) will be obtained after the interview through a web-link

developed through Qualtrics software. The demographic questionnaire will include items such as age, race, annual household income, family history, treatment offered and treatments chosen and considered.

Method of Measurement. Aim #1**:** To explore the role of psychosexual functioning in the decision to have prophylactic treatment, amongst women of childbearing age who have a diagnosis of a BRCA1/BRCA2 gene mutation. Research Question: What are the concerns women of childbearing age with a BRCA gene mutation have related to psychosexual functioning? The focused medically applied ethnographic design of the study will allow the researcher to explore, interpret and describe the experience of women of childbearing age with a BRCA mutation from their own perspective (Thorne, Kirkham, & MacDonald-Emes, 1997). Thorne (2016) elucidates that interpretive description is needed to explore and make sense of complex issues thus allowing it to be utilized in methodological frameworks such as medically applied ethnography. Interpretive description requires the researcher to submerge in the individual experience of the participant versus only observing a group of participants within a culture (Thorne, Kirkham, & MacDonald-Emes, 1997). Spradley (1979) suggested that this technique will allow the informant to be comfortable and not feel interrogated by sensitive questions regarding body image and sexuality.

Moreover, exploration will include strategies such as repeated explanations and restating of the informant's response to establish rapport with the informant and influence of detailed responses (Spradley, 1979). Data analysis will begin after each interview by evaluating field notes and identification of descriptors and components. Thematic analysis will begin post interview from evaluating the relationships amongst recurrent

themes (Spradley, 1979). Interpretive description will be performed by reviewing data transcriptions repeatedly and thoroughly to formulate the meaning of concepts initially and throughout the analytic process before coding, classification and conceptualization of common themes and qualitative content analysis (Spradley, 1979; Thorne, Kirkham, & MacDonald-Emes, 1997). The solo researcher will seek guidance from a noted qualitative data expert, Dr. Engebretson, to assist in the observation, interpretations and analysis of the data.

Furthermore, to establish rigor a reflective journal will be utilized to record reflective notes, analytic notes, the research process and counteract any bias. Field notes will be documented after each interview to assist with thick descriptions and linkages to develop the phenomena understudy. Field notes will be transcribed from the interview for transferability of data. After each interview, the recording will be evaluated for completion and audio quality. Data retrieved from participants will be reviewed on the same day as the interview to evaluate audibility and completeness. After each interview, the investigator will reflect on the interview process and outcomes, documenting reflections after each field note. Interpretation of main categories and common themes will be determined and agreed upon by the researcher and the qualitative data expert for study rigor. Conceptualizations will be developed by all participant responses rather than individual occurrences to assist with trustworthiness of the phenomena. Triangulation of the data will be accomplished by reviewing the semi-structured interviews, reflexive notes and comparison of the literature to assist with the dependability of study findings. Reflective notes, field notes and major themes will be organized using the Atlas.ti

Qualitative Data Analysis software. An experienced transcriber will evaluate the quality of transcriptions documented.

Expected Outcomes. The researcher expects the application of this study to contribute insight to, "Previvorship", survivors of predisposed cancer before cancer diagnosis versus survivorship (FORCE, 2017). In addition to increasing the quality of individualized cancer risk management options, the researcher expects to gain insight into the internal and external factors that influence the decision-making process. In turn, this can assist healthcare providers in offering clinical support and environmental resources. The expectation is that the application will give genetic counselors, physicians, nurses and specialist in the field of cancer treatment and prevention awareness to the importance of psychological well-being regarding body image and sexuality. The proposed research is expected to increase awareness of prophylactic cancer risk management in anticipation to decrease morbidity and mortality of breast and ovarian cancer in women with hereditary risk.

Potential Problems & Alternative Strategies. Due to the sensitivity of persons with BRCA gene mutation, who face the risk of breast and ovarian cancer, women may be reluctant to share experiences and views in regards to psychosexual functioning. This may be partially due to the stage of diagnosis and stage of decision making the participant is experiencing at the time. If this happens, sampling and interviews will increase. It is possible that although the participants have access to the internet, computer or phone, they may not have access to conferencing. In this instance, face to face interviews would be conducted. During the time of sampling and interview participation the participant may have decided to undergo prophylactic surgery. Interviews may

continue if the participant is comfortable but this may affect sample size. If this happens, follow up interviews would be conducted post-surgery after discharge from hospital at a time convenient for the participant. Participants can also opt out of video recording if they are uncomfortable with performing a face to face interview via video conferencing.

Risk and Benefits to Subject. Consideration will be given to the confidentiality, security and proper disposal of the recordings. The recordings will be saved to an iCloud (which includes security coding) that only the solo researcher and the qualitative data expert will have access to. Transcriptions of each interview will be saved to the flash drive that will be stored in a locked cabinet in a secured office. Any information removed from the flash drive that will be stored on a password protected computer according to university requirements. No identifying information will appear on any of the data collected. All field notes, reflexive journal and demographic information will be on a password protected computer and locked in a file cabinet.

The participants will be given specific provisions regarding the recording within the consent. The consent form will include an allotted time frame of five years to dispose of the video recordings as well as permission to archive the recording for future research. This will ensure time for secondary analysis. Recordings and transcripts will be properly disposed of using a professional data disposal service. The participants will also be able to verify their recording and reflect on their own experiences. There is no specific health, social, legal or psychological risks to the participants. Each participant will receive a thank you letter and a 20-dollar gift card for their participation. There may be no direct benefits to each participant at the time of the study but the knowledge obtained from

study findings is likely to benefit women throughout their individual choice experience in the future.

Future Directions

At the conclusion of the proposed research, the researcher would like to continue the study through an Exploratory Sequential Design to develop a scale of measurement that addresses psychosexual functioning and common themes exclusive to women of childbearing age with a BRCA gene mutation. Interpretative descriptive data retrieved from the current study will be utilized in a larger population of women, meeting the aforementioned criteria, to inform the collection of quantitative data. In addition to common themes from the transcriptions, scales of measurement that address psychosexual functioning will be tested for further scale development.

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Appendix A

The Decision

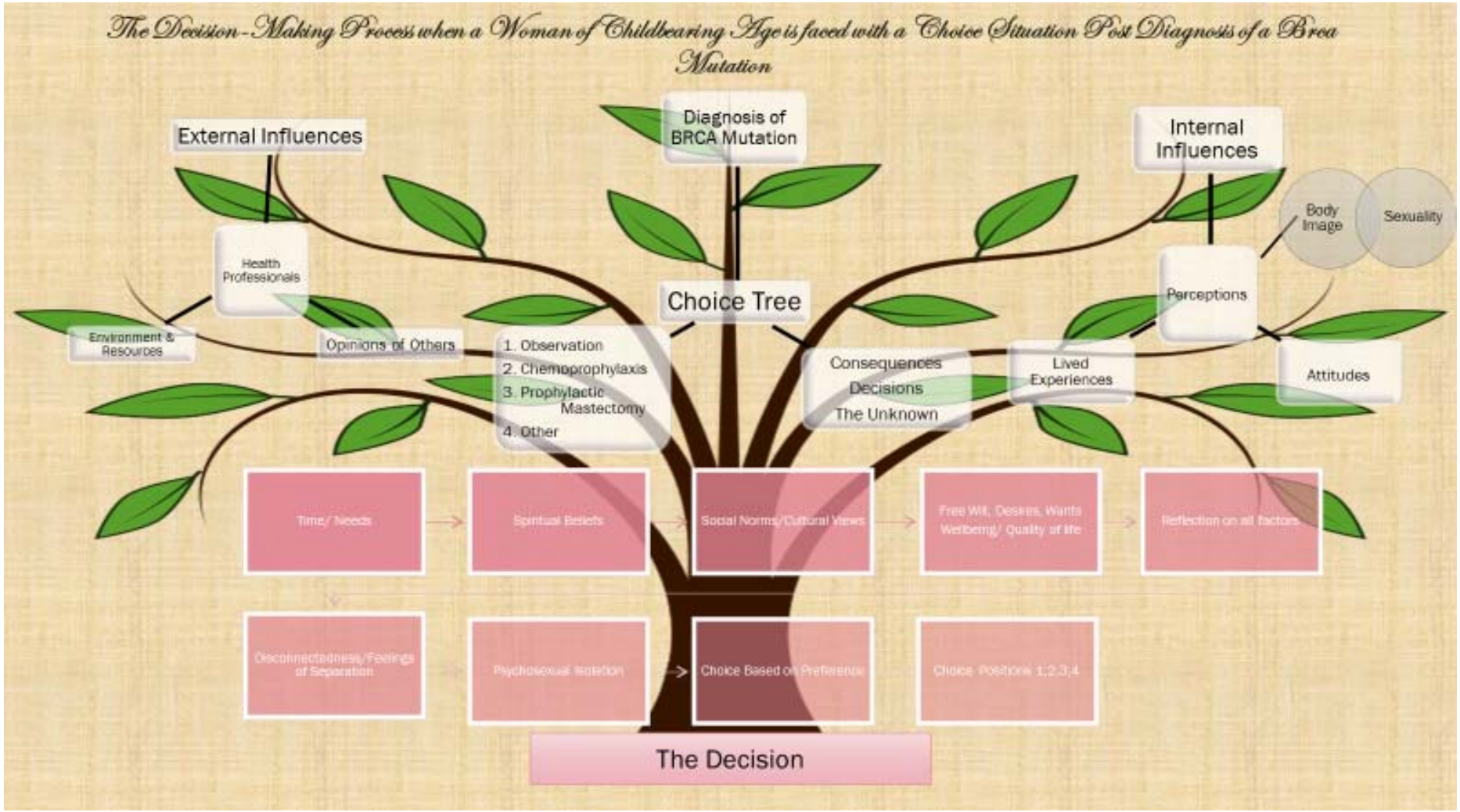

Figure 1.0. Decision-Making Process when a Woman of Childbearing Age is faced with a Choice Situation Post Diagnosis of a BRCA Mutation. Adapted from Decision Making in Women of Childbearing Age with A BRCA1/2 Mutation: A Conceptual Framework by A. Hayes, 2016, Unpublished manuscript. Graduate School of Nursing, University of Houston Health Science Center, Houston, Texas.

Appendix B

Research Study for Young Women with A RRCA Mutation Flyer

Research Study for Young Women with A BRCA Mutation

Are you someone that has a BRCA mutation that increases your risk for breast or ovarian cancer?

The UT Health Cizik School of Nursing is recruiting women to participate in a research study to increase the understanding of factors that affect the decision-making process in women of childbearing age that are diagnosed with a BRCA1/BRCA2 gene mutation.

To participate you would need to be

1. A female, 21-49 years of age, diagnosed with a BRCA1 or BRCA2 gene mutation OR
2. A female, 21-49 years of age with a BRCA mutation of undetermined significance,
3. English speaking, be able to understand and read English
4. Have access to the internet, Facebook and/or Zoom video recording per phone or computer.
5. Complete a 30 – 60-minute interview that would consist of questions about your experience being diagnosed with a BRCA mutation. Information about your BRCA history, your body perception (body image and sexuality) will be collected. All data will be collected confidentially.

For more information or to participate, you can contact:

Alexis Hayes PhD (c), MSN-Ed, APRN, FNP-BC
UT Health Science Center Cizik School of Nursing
Email: alexis.e.hayes@uth.tmc.edu
Phone: 225-978-1053

IRB Approval # HSC-SN-19-0078
Approval date: 3/12/2019

Appendix C

Screening Questionnaire Template

Please read and answer all of the following questions:

1. Are you a woman between 21-49 years of age? Yes or No
2. Have you been diagnosed with breast or ovarian cancer? Yes or No
3. Have you ever been diagnosed with a BRCA1 or BRCA2 gene mutation? Yes or No
4. Have you been diagnosed with a BRCA mutation of undetermined significance? Yes, No or Not Sure.
5. Can you speak and read English? Yes or No
6. Do you have access to the internet? Yes or No

Appendix D

Interview Guide

Grand Tour Questions

- What have you heard about the BRCA mutation? (Probes: from family friends, media, doctors and etc.)
- Tell me about how you felt after being tested for the BRCA Mutation?
- How do you feel the diagnosis of a BRCA mutation has affected you?
- Tell me about your journey/experience throughout your decision-making process?

Mini Tour Questions

- Have you undergone any prophylactic treatment? If so, how has it affected you?
- What prophylactic options have you considered? (i.e. Surveillance and/or frequent screening, mastectomy/removal of breast, chemotherapy, salpingo-oophorectomy/ removal of ovaries)
- If married, dating, or single, how has the diagnosis and/or treatment options affected your relationships?
-

Probes

- How do you feel about the effects of prophylactic options? (i.e. Body image, sexuality, intimacy, femininity, confidence, childbearing)
- Have there been any external influences that have assisted you throughout the decision-making process? (PCP, Family, Resources)
- Tell me about your internal influences? (Self: what influenced you to make the decision to have or not have screening and/or treatment)
- Do you feel isolated/different from other young women or women your age after being diagnosed with a BRCA mutation?
- Do you feel isolated/different from other young women or women your age after undergoing prophylactic treatment? If so how?
- At what age where you diagnosed with a BRCA mutation and/or How long have you known about your BRCA mutation?
- How long did it take to start prophylactic treatment (i.e. Mastectomy, chemotherapy or salpingo-oophorectomy)?

Appendix E

Demographics

Study ID: _____ (Interviewee ID number)
Interview Date: _____
Interviewer: _____

Please read carefully and answer all of the following questions:

- **What is your age? _____**

- **What is your race?**
  - ☐ Black and/or African American
  - ☐ Caucasian
  - ☐ Indian
  - ☐ Asian
  - ☐ Hispanic
  - ☐ Islander
  - ☐ Other Please specify _____

- **What is your highest level of education?**

☐ High school/GED
☐ Some College
☐ Associates degree
☐ Bachelor's Degree
☐ Master's Degree
☐ Doctoral Degree or Higher

- **What is your annual household income?**

☐ 10,000-29,999
☐ 30,000-49,999
☐ 50,000-69,999
☐ 70,000-79,999
☐ 80,000-89,999
☐ 100,000 or higher

- **What is your relationship status?**

☐ Single
☐ Married
☐ Divorced
☐ Widowed
☐

- **How many children do you have?**

□ _____

- **Do you have family history of breast cancer?**

□ Yes

□ No

□ Don't know

- **Has anyone in your family been diagnosed with a BRCA Mutation?**

□ Yes

□ No

□ Don't know

- **What prophylactic measures have you considered? Select all that apply**

□ Surveillance
□ Prophylactic Mastectomy
□ Prophylactic Salpingo-oophorectomy
□ Preventative Chemotherapy
□ Radiation
□ All of the above
□ None

October 18, 2019

Dr. Cynthia A Graham, PhD
Editor: The Journal of Sex Research

Dear Dr. Graham,

Attached please find our manuscript entitled "An Exploration of Psychosexual Functioning and Factors Affecting the Prophylactic Decision-Making Process in Women of Childbearing Age with a BRCA 1/BRCA2 Mutation," for your review for possible publication in *The Journal of Sex Research.* The manuscript includes 10602 words, two figures and one table.

The manuscript is based on a dissertation project delivered on October 18, 2019 at the University of Texas Health Science Center Cizik School of Nursing in Houston, Texas. The manuscript is a focused medically applied ethnographic study (n=18) to explore, interpret and describe concerns of women of childbearing age (WCBA) after the diagnosis of a breast cancer type 1 and type 2 susceptibility protein (BRCA1/BRCA2) gene. The research question answered in this study was "What are the concerns women of childbearing age, diagnosed with BRCA1/BRCA2 gene mutation, have related to psychosexual functioning?". The study suggest that body image, sexuality and sexual orientation should be addressed at initial contact with a healthcare provider and throughout the decision to undergo prophylactic measures.

Neither the enclosed manuscript nor any part of its content has been submitted to, accepted for or published by any other journal. The undersigned have no financial interest in any element of the study, which was approved by the institutional review board of the University of Texas Health Science Center as Houston's (UTHSC) Committee for the Protection of Human Subjects (CPHS). Alexis Elizabeth Hayes will serve as the corresponding author for this manuscript. The five authors have read and approved the current version.

Sincerely

Alexis Elizabeth Hayes PhD, MSN-Ed, APRN, FNP-BC
23814 Hartford Springs Trail
Katy, Texas 77493
225-978-1053
alexis.e.hayes@uth.tmc.edu

Diane Wind Wardell PhD, RN, WHNP-BC
Joan Engebretson PhD, RN, AHN-BC, FAAN
Geraldine Wood PhD, RN, FAAN
Marlyn Allicock MPH, PhD

Abstract

Background A breast cancer type 1 and type 2 susceptibility protein (BRCA1/BRCA2) gene mutation carries an 85%- 90% lifetime risk of developing breast cancer and a 27%-65% chance of developing ovarian cancer. There is minimal evidence regarding how psychosexual functioning, the psychological well-being in regards to body image and sexuality, affects the decision to have prophylactic treatment in women of childbearing age (18 - 49) with a BRCA gene mutation. Diagnosis of a BRCA gene mutation presents a dilemma where life-changing medical decisions must be made to prevent breast and ovarian cancer. Throughout decision-making and following surgical prophylactic interventions, such as a bilateral prophylactic mastectomy (BPM) and a bilateral prophylactic salpingo-oophorectomy (BPSO), there are continued effects on social and sexual functioning related to body image, the partners perception, sexual attractiveness and femininity which further affects the woman's psychological well-being.

Aim The aim of the study was to explore the role of psychosexual functioning in the decision to have prophylactic treatment amongst women of childbearing age who have a diagnosis of a BRCA1/BRCA2 gene mutation.

Methods A focused medically applied ethnographic design was employed to assist the researcher in exploring, interpreting and describing the experience of women of childbearing age with a BRCA mutation. A purposive sample of 18 women between the ages of 21-49 participated in semi-structured interviews exploring their experience after BRCA diagnosis.

Results Interpretive descriptive analysis revealed four major themes: *Body image, Sexuality, Femininity and Childbearing/Childrearing*. Women that had undergone BPM (n=8) were concerned about the effects of the surgery, scarring, breast disfigurement and lack of sensation. Although some of the women had not received surgical prophylaxis they all voiced concerns regarding body image and sexuality that caused some hesitancy in their decision-making to have prophylactic surgery.

Conclusion This study postulates that psychosexual concerns come from both internal and external influences that significantly impact the decision to undergo prophylactic measures. Body image, sexuality and sexual orientation should be addressed at first contact and considered while developing a plan of care. Although women may have support from family or significant others during the decision-making process psychosexual concerns may not be addressed.

Keywords: Body Image, BRCA mutation, Decision Making, Prophylactic Mastectomy, Psychosexual Functioning, Sexuality

Introduction

The diagnosis of a deleterious BRCA gene mutation is devastating for women and they often view the mutation as a cancer diagnosis (Press, 2005). This perspective is not an unfounded response as having a BRCA1/BRCA2 gene mutation carries an 85%- 90% lifetime risk of developing breast cancer and a 27%-65% chance of developing ovarian cancer (Donnelly et al., 2013). Therefore, a diagnosis of a BRCA gene mutation presents a dilemma where life-changing medical decisions must be made to prevent breast and ovarian cancer. The decision to choose a prophylactic measure such as intense surveillance, chemoprophylaxis, radiation, bilateral mastectomy, and bilateral salpingo-oophorectomy is a complex process (McQuirter, Castiglia, Loiselle, & Wong, 2010). Furthermore, psychosexual functioning, which includes psychological well-being in regards to body image and sexuality, is likely affected by the diagnosis of a BRCA1/BRCA2 gene mutation (Hamilton & Hurley, 2010; Hoskins, Werner-Lin, & Greene, 2014; Matloff, Barnett & Bober; 2009). A review of the literature revealed that there is minimal evidence regarding how these factors affect the decision to have prophylactic treatment.

Women of childbearing age (18-49) are at a unique stage in life where childbearing, educational goals, career development and the establishment of intimate relationships are most important (Hamilton & Hurley, 2010). Approximately 50% of BRCA1/BRCA2 gene mutation carriers choose intense surveillance however only 70% of all BRCA carriers follow the recommendations for intense screening (Pademsee, Willis, Yee, & Paskett, 2017). Evidence suggests that the psychological state of the individual affects preventive treatment decisions (Pademsee et al., 2017). Therefore, women of childbearing age need to feel understood and have knowledgeable support available during the decision-making process. Genetic counseling pre-

and post-diagnosis of a BRCA gene mutation is helpful, however assuring that continued psychosexual counseling is available to assist women of childbearing age with an informed, and independent decision is empirical. Therefore, there is a critical need to explore how psychosexual functioning is impacted by a diagnosis of the BRCA mutation, how it may influence the decision to have prophylactic treatment and its impact post prophylactic intervention.

The long-term goal of this study is to increase the understanding of factors that affect the decision-making process in women of childbearing age that are diagnosed with a BRCA1/BRCA2 gene mutation. Having a thorough understanding of the factors affecting body image and sexuality can assist women with making a fully informed decision when choosing prevention options. Individualized and supportive care specific to the concerns of the women of childbearing age has the potential to decrease the morbidity and mortality of breast and ovarian cancer.

The overall objective of the study is to understand the influence of psychosexual functioning on the decision-making process from diagnosis of the BRCA mutation and through pre/post prophylactic treatment. The aim of the study was to explore the role of psychosexual functioning in the decision to have prophylactic treatment amongst women of childbearing age who have a diagnosis of a BRCA1/BRCA2 gene mutation. A focused medically applied ethnographic approach was utilized to accomplish this study's aim. The expected outcome of the study was to explore the significance of psychosexual functioning in cancer risk management and prophylactic decision-making. The knowledge gained from this study will provide data for further study and identify factors that may have a positive impact on individualized cancer risk

management by adding a psychosexual component that is not adequately included in decision-making tools for BRCA mutation carriers.

Research question: What are the concerns women of childbearing age, diagnosed with BRCA1/BRCA2 gene mutation, have related to psychosexual functioning?

Background and Significance

Presently, there is a gap in knowledge regarding the influence of psychosexual functioning in women of childbearing age with a BRCA gene mutation and how it impacts decision making (Hayes, 2016). It is imperative that nurses and healthcare providers fully understand the influences that affect the prophylactic decision-making process that women of childbearing age with a BRCA mutation face, henceforth support is available as choices are being considered. Prophylactic options to reduce the risk of breast cancer consist of intense surveillance (i.e. clinical breast exam, breast ultrasound, mammography and magnetic resonance imaging (MRI) screening), chemoprevention, and the surgical removal of healthy breast tissue known as a bilateral prophylactic mastectomy (BPM) (Zeichner, Stanislaw, & Meisel, 2016). Risk reduction options to prevent ovarian cancer include intense surveillance (i.e. transvaginal ultrasound and CA-125 measurement) and removal of the ovaries and fallopian tubes known as a bilateral prophylactic salpingo-oophorectomy (BPSO) (Pademsee et al, 2017; Zeichner, Stanislaw, & Meisel, 2016).

BPM is recommended to reduce the risk of breast cancer by 90%, however it may result in changes to body image and sexuality. BPSO is recommended at 35-40 years of age (after completion of childbearing) which will result in surgical menopause (Zeichner, Stanislaw, & Meisel, 2016). Surgical menopause leads to infertility and may cause changes in sexual functioning (i.e. difficultly with arousal, orgasm and painful intercourse) which in turn may

affect body image (Bober et al., 2015). Women who are encouraged to have prophylactic treatment often do not comply with even the least invasive options such as surveillance (Evans et al., 2016). It has been reported that noncompliance may be due to barriers in physician knowledge and education regarding prophylactic options and the individuals understanding of all prophylactic options available (Pademsee et al., 2017).

Additionally, women of childbearing of age, specifically those less than 25 years of age (Hoskin, Werner-Lin & Greene, 2014), may not have the cognitive skills to make irreversible and life-changing decisions regarding prophylactic measures (Hamilton & Hurley, 2010). It has been documented that women may have "other needs" that are not being addressed in genetic counseling (Evans et al., 2016; Pademsee et al., 2017) to assist with psychosocial stressors specific to women of childbearing age. Following surgical prophylactic interventions, such as a BPM and BPSO, there are continued effects on social and sexual functioning related to body image, the partners perception, sexual attractiveness and femininity which further affects the woman's psychological well-being (Mroczek et al., 2012).

Body image and sexuality concerns are present before BRCA diagnosis, post diagnosis and throughout the decision-making process (Mroczek et al., 2012). During the evaluation of decision support needs in BRCA positive women, changes in body image, sexuality, understanding provider recommendation and environmental resources were prominent themes identified by Underhill and Croster's (2013) study of the decision support needs of women with a BRCA1/BRCA 2 mutation. Sexuality, body image and intimacy are often overlooked by healthcare providers and genetic counselors throughout the treatment process (Dikmans et al. 2019; Rolnick et al., 2007; Underhill & Croster;2013). Decker et al., (2015) suggested that to minimize psychosexual morbidity in cancer survivors, body image, sexuality and intimacy must

be addressed early in the diagnosis process before treatment is initiated. Ganz et al., (1998) suggested that assisting women with feeling "normal" during the process may assist with body image and sexuality by allowing a comfortable environment to discuss psychosexual issues.

It has been proposed that women of childbearing age have more severe impairments in psychosexual functioning, survival and psychosocial effects than women greater than 50 years of age throughout cancer treatment (Mroczek et al., 2012). The purpose of this study is to understand the influence of psychosexual functioning, in women of childbearing age with a BRCA mutation, throughout their prophylactic decision-making process. *Research question: What are the concerns women of childbearing age, diagnosed with BRCA1/BRCA2 gene mutation, have related to psychosexual functioning?*

Theoretical Framework and Conceptual Framework

The foundation for this research derives from Fomby-White's Theory of Choice (2008) which involves "the process of judging the merits of multiple options and choosing the best one for action" (Fomby-White, 2008, para.1). Women are faced with a choice situation after being diagnosed with a deleterious BRCA gene mutation. Therefore, this research study focused on the needs of women of childbearing age throughout their individual choice situations. Hayes's (2016) conceptual framework, *Decision-Making Process when a Woman of Childbearing Age is faced with a Choice Situation Post Diagnosis of a BRCA Mutation*, guides the multidisciplinary healthcare team as the woman navigates through the prophylactic choice decision (Appendix A). The concepts within the conceptual framework provide a route to explore the choice situation and the effects of those options on body image, sexuality, psychosexual isolation and prophylactic treatment choice. As this study focused on psychosexual functioning, which

includes psychological well-being in regards to body image and sexuality, post diagnosis of a BRCA1/BRCA2 mutation the framework helped to elucidate areas of concern.

Methods

Design

A focused medically applied ethnographic design was employed to explore, interpret and describe the experience of women of childbearing age with a BRCA mutation. Thorne (2016) elucidates that interpretive description designs are needed to explore and make sense of complex issues thus allowing it to be utilized in methodological frameworks such as medically applied ethnography (Thorne, Kirkham, & MacDonald-Emes, 1997). Interpretive description requires the researcher to submerge in the individual experience of the participant versus only observing a group of participants within a culture (Thorne, Kirkham, & MacDonald-Emes, 1997). Spradley (1979) suggested that this technique allows the informant to be comfortable and not feel interrogated by sensitive questions and in this case, those regarding body image and sexuality.

Further exploration included strategies such as repeated explanations and restating of the informant's response to establish rapport and promote detailed responses (Spradley, 1979). Data analysis was initiated after each interview by evaluating field notes for the identification of descriptors and components. Interpretive description was performed by reviewing data transcriptions repeatedly and thoroughly to formulate the meaning of concepts initially and throughout the analytic process before coding, classification and conceptualization of common themes and qualitative content analysis (Spradley, 1979; Thorne, Kirkham, & MacDonald-Emes, 1997). Thematic analysis began post-interview evaluating the relationships amongst recurrent themes (Spradley, 1979). The researcher sought guidance from a noted qualitative data expert to assist in the observation, interpretation and analysis of the data.

Additionally, a reflective journal was employed to record reflections, analytic notes, and the research process. The journal was used to assist in counteracting bias and to assist with thick descriptions and linkages. Also, the interview data retrieved from each participants' recording was evaluated for completion and audio quality. Interviews were transcribed to further assist with the transferability of the data. An experienced transcriber evaluated the audio quality of transcriptions documented.

After each interview, the investigator reflected on the interview process and outcomes, documenting reflections after each field note. Interpretation of main categories and common themes were determined and agreed upon by the researcher and qualitative data researchers, (JE, DW), for study rigor. Conceptualizations were developed by several participant responses rather than individual occurrences to assist with the trustworthiness of the phenomena. Data triangulation was accomplished by reviewing the semi-structured interviews, reflexive notes and comparison of the literature to assist with the dependability of study findings. Reflective notes, field notes and major themes were organized using the Atlas.ti Qualitative Data Analysis software.

The credibility of this study was obtained by triangulation of transcripts, field notes and review of literature (Polit & Beck, 2017). Confirmability of the study was established by reviewing the audible transcriptions of all interviews during analysis. Confirmability and creditability were validated by assuring findings were interpreted correctly by discussing results with faculty. Additionally, transferability of the data was obtained by utilizing thick descriptions of participant responses.

Recruitment

IRB approval was obtained from the University of Texas Health Science Center at Houston's (UTHSC) Committee for the Protection of Human Subjects (CPHS) recruitment took place between, March 14, 2019 to June 28, 2019, until data saturation occurred. Study participants consisted of women who were part of an online BRCA support and/or Prophylactic support groups, local BRCA support networks and Facing Our Risk Empowered (FORCE), a national organization, after permission from the organization's administrator. A flyer (Appendix B) stating "Are you someone that has a BRCA mutation that increases your risk of breast or ovarian cancer?" was given by the investigator to the groups administrators to notify the participants of the study and information for initial contact. To be included in the study, the participant had to be 21- 49 years of age, diagnosed with a BRCA1 or BRCA2 gene mutation, women 21- 49 years of age with a BRCA mutation of undetermined significance, English speaking, have access to the internet and Facebook and/or Zoom video recording per phone or computer. The exclusion criteria included women over 50 years of age, and women who have been diagnosed with breast or ovarian cancer.

Procedure

Once the participants contacted the investigator, they were sent a link to the Screening Questionnaire developed through *Qualtrics*. In addition to the questionnaire, participants were sent information regarding the study including CPHS/ethical approval. Participants who met the aforementioned criteria were sent a letter of eligibility, informed consent, a copy of participant rights and a link to schedule the interview. Zoom video and audio recording was utilized for all face to face recording and/or audio recording which allowed real time recording and a secure iCloud system for interview retrieval. The purpose of video recording was to capture facial

expressions and nonverbal cues throughout the interview. The participant was given the option to opt out of the video recording and complete audio recording of the interview if desired. However, none of the participants elected to opt out of the video recording. At the completion of the interview, the participants were sent a web link to a Demographic Questionnaire, developed using *Qualtrics*, and twenty-dollar Amazon gift card for participation in the study. The demographic questionnaire included items such as age, race, annual household income, family history, treatment offered, treatments chosen and treatment considered.

Materials

Individual semi-structured in-depth interviews were performed to explore the participants' experience. The interview was constructed according to Spradley's (1979) guide, with pilot testing of grand tour and probe interview questions. The interviews were conducted by the principal investigator (AH) and lasted 11-46 minutes per participant with an average of 27 minutes. Questions regarding the women's experience after being diagnosed with the BRCA mutation, prophylactic options considered and if either entity affected their body image femininity or sexuality such as "*Tell me the story of your experience receiving the diagnosis of the BRCA mutation from the beginning until now.", "Have you undergone any prophylactic treatment? If so, how has it affected you?"* and "How *do you feel about the effects of prophylactic options*? (i.e. Body image, sexuality, intimacy, femininity, confidence and childbearing probes)".

Participants

Thirty-five, English speaking respondents completed the initial screening questionnaire. Those excluded had a history of breast cancer (n=3), did not meet the age criteria (n=1), verbally decided not to move forward with the study after scheduling of interview (n=3), completed

questionnaire but did not schedule an interview (n=7) or did not present for interview at schedule time (n=3). Efforts were made to re-engage these respondents with minimal response. A total of eighteen women (Caucasian: n = 14, Hispanic: n = 2, Asian: n = 1, Unknown: n = 1), between the ages of 23 and 46 were interviewed over a two-month period. One participant failed to complete demographic questionnaire after follow up attempts. The demographic questionnaire (see Appendix F) included relationship status (Married: n=10, Single n=6, Divorced; n =1, education (Some College: n = 1, Bachelor's Degree: n = 5, Master's Degree n = 7, Doctoral degree or higher: n = 4), family history of breast cancer (n =13), family history of BRCA mutation (n = 14) and number children (None: n = 10, 1 child: n = 3, 2 or more children (n =3).

All women (n=18) were diagnosed with a BRCA mutation within the past ten years with an average of 4 years. The treatment options that were considered by participants included surveillance (n = 15), Prophylactic Mastectomy (PM) (n=14), and Prophylactic Salpingo-oophorectomy (PSO) (n = 12). None of the participants disclosed considering preventive chemotherapy. Two participants, ages 23 and 43 with no children, considered surveillance only. Participants had chosen PM (n= 8), PSO (n=3) and undergoing surveillance and considering future surgical options (n=8). All interviews were transcribed verbatim and interpretive description was employed to explore the concerns women of childbearing age with a BRCA mutation had regarding their body image and sexuality.

Although N = 8 of the women had not received surgical prophylaxis they all voiced concerns regarding body image and sexuality that caused some hesitancy in their decision-making to have prophylactic surgery. Women that had undergone BPM (n=8) were concerned about the effects of the surgery, scarring, breast disfigurement and lack of sensation. For women that were considering BPM were concerned about scarring, the fit of clothing and feeling like a

woman after breast removal. Women that were considering PSO (n=12) were concerned about menopausal symptoms and future effects of a possible hysterectomy and/or PSO. Women who had undergone hysterectomy and/or PSO (n=2) were concerned about the effects of BPM such as scarring and feeling sexually attractive.

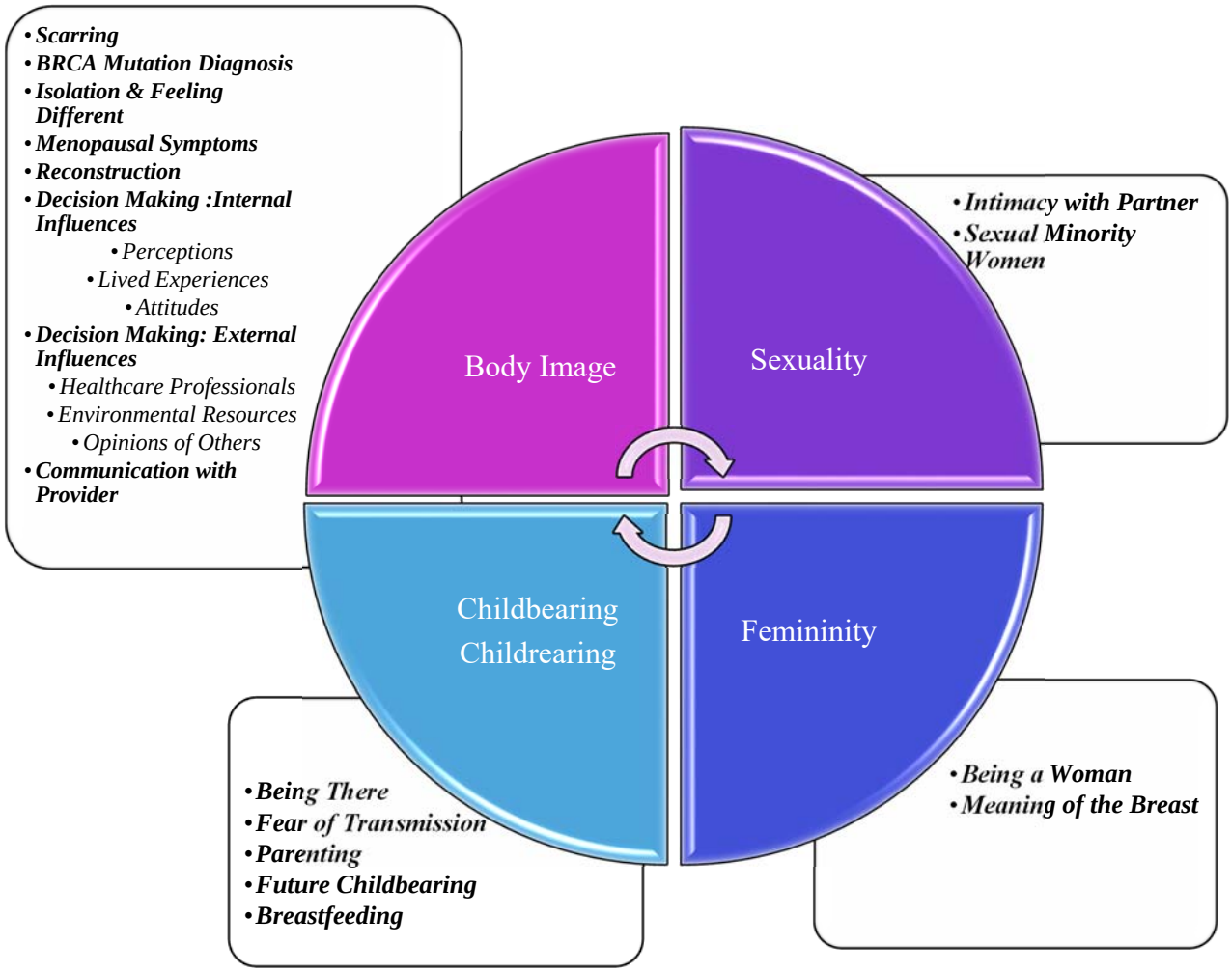

Figure 1. Schematic of the concerns women of childbearing age with a BRCA mutation, have related to psychosexual functioning. At study, major themes revealed included concerns related to *Body Image, Sexuality, Femininity* and *Childbearing/Childrearing*. Subthemes (depicted in italics) include specific concerns that were found within each major theme. The recursive arrow within the diagram depicts that body image, which is how a woman views herself, her functionality and how others view her, impacts sexuality, femininity and childbearing/childrearing concerns. The internal and external influences within body image not only impact decision making but all components displayed.

Findings

Interpretive descriptive analysis revealed four major themes: *Body image*, *Sexuality*, *Femininity* and *Childbearing/Childrearing*. Within the major themes are specific subthemes. The first major theme, Body Image, included concerns regarding scarring, the BRCA mutation, isolation versus feeling different, menopausal symptoms, reconstruction, decision-making: internal and external influences, the waiting room, and communication with provider. The second major theme, Sexuality, included specific concerns regarding intimacy with partner and concerns of the sexual minority woman (SMW). The third major theme Femininity included accounts of women perceptions of being a woman. The fourth major theme Childbearing /Childrearing included subthemes being there, fear of transmission, parenting, future childbearing and breastfeeding (see Figure 1.0). Body image, including the internal and external influences not only affect the decision-making process to have prophylactic treatment but impacts how women of childbearing age with a BRCA mutation view their sexuality, femininity and childbearing/childrearing.

In the exemplars to follow, participants will be identified by a participant number (P#) to retain confidentiality. Information regarding the participants age range (~ to the nearest half-decade), marital status (M=married, S=Single), year diagnosed, prophylactic option (i.e. PBM), and parental status (number of children) are included with each exemplar. An example is P#1, ~40, married, dx in 2016, BPM, child=1.

Body Image

Body image is defined as not only how a woman views herself but her functionality and how others view her (Pelusi, 2006). The women discussed several views of themselves and concerns about how not only their partner viewed them but family and persons unknown.

Scarring

Scarring was a prominent concern affecting women (n=12) pre-and/or post prophylactic surgery. There was more concern about scarring on the breast area than scarring on any other part of the body. There was also a difference in scarring that is visible (n=7) such as a scar from PM compared to laparoscopic incisions from the PSO or a healed scar (n= 3) from a previous C-section. Scarring of the breast was referred to as being "ugly", "disappointing", "not perfect", "wanting to hide them" and "in my face". In discussion of how the scars affect body image, there was some ambivalence (n=2) as noted by being content with not have having breast cancer but disappointed in the outcome of BPM and fear of future surgical scarring (n=2) noted amongst the participants who had undergone surgical prophylaxis with one stating:

> *I'm kind of like well wait, so it's awesome about not having breast cancer, like I won't have it. Um, but it's a sense of like I don't feel comfortable taking my top off when I'm with my husband, you know what I mean*? (P1, ~40, married, diagnosed in 2016, BPM)

One participant disclosed the scars did not bother her but considered covering them in the future with the following:

> *I got my very first tattoo, right before I had the surgery, the mastectomy. Like, about a month before. ...so, I got a unicorn…the reason I got a unicorn. Well, there are several reasons I got a unicorn. …I have a PhD in linguistics and that's what I've been teaching and specifically, I teach about meaning… one of the things we really like to talk about is things that don't exist. And unicorns are my perfect example of talking about things that don't exist… And somehow the tattoo was really helpful in kind of like, having control over something, if that makes sense… So, I got that. And I feel really good about that and I really like it. And pretty soon after the surgery I kind of thought, maybe I want*

another tattoo. Having a tattoo is not going to make me not look different than I did before. I don't want to look at, at the scars. You know? I want to look at something that's prettier. (P15, ~35, single, diagnosed in 2018, BPM)

The participants openly discussed struggles with their body image before surgery and reflecting on how scarring may affect them post prophylactic surgery. One participant stated:

> *invisible ones don't like—I think that's probably why the ovaries and things like that don't bother me because it's not… if I remember correctly, it's a pretty small scar. Like, it's not in your face but a mastectomy it's definitely the visible things that bother me more. I'm very self-conscious about visible things. and things like that, I mean, could you really wear a swimsuit again?* (P14, ~25, single, diagnosed in 2016, surveillance)

Another said:

> *I remember looking down at the scar. Because I already had a Cesarean scar from my son's birth, and that was okay. But this scar, it was huge. It's from hip to hip, and I was just like holy crap, did they like cut me? Like how far did they cut me? and it's still a huge scar, and I remember looking down and going, what the hell? Like what did they do to my boobs? Like where's my nipple? Like what happened to my stuff?* (P1, ~39, married, diagnosed in 2016, BPM)

Diagnosis of a BRCA Mutation Leads to Feelings of Isolation & Feeling Different

Women were asked about their experience after being diagnosed with a BRCA mutation during the study. Mostly all (n=14) of the women felt supported by their family and significant others after diagnosis of the BRCA mutation. There was a sense of empowerment noted after being diagnosed with the BRCA mutation in that there was an increased awareness regarding the importance of health and an increased awareness of their body during the decision-making

process and post prophylactic surgery. Along with the diagnosis of the BRCA mutation participants expressed feeling different (n=9) and isolated (n=7) by the diagnosis and decision-making process. One woman stated:

> *The first couple of years, I would be on the bus. I'd look around and you're just like, these people… You don't know if they have it or not. But it's likely that they're not dealing with that. And you think about how you used to go through life not thinking about having cancer. And every little twinge you feel, you worry, it might be something growing. And so, it's, especially finding out in your early thirties, it's a sense of your own mortality that people at that age generally aren't faced with felt like I was now part of a club no one wants to be a part of. And that many people aren't. And people would ... talk about things. And then I would realize, oh, I'm not going to have that in my life. I will have to have breast surgery. And I will have to have these problems. You definitely feel like you're, kind of, walking the path alone.* (P8, ~40, single, diagnosed in 2011, surveillance)

Another said:

> *I felt like I was now part of a club that no one wants to be a part of.*
>
> (P4, ~35, married, diagnosed in 2014, BPM & HYS).

Age was a factor in feeling isolated after being diagnosed with the BRCA mutation. The women voiced feeling different due to making decisions early in life that other women their age did not have to consider such as egg freezing due to surgical menopause, breastfeeding and childbearing. A participant voiced feeling she was not part of the group anymore post PM and HYS amongst peers.

One stated:

> *Especially right after, there were still a lot of moms that I knew from my daughter's age that were having babies and I definitely felt like I wasn't in that group anymore because having more children was not something I could do. Even though I didn't want to have more, I felt like that, [laughs]—like I kind of left that area of the women that were getting pregnant and having babies, like, far behind.*
>
> (P5, ~40, married, diagnosed in 2014, BPM & HYS, child= ≥ 2)

Being knowledgeable of the BRCA mutation was also a factor that caused the women to feel different. Reports of being aware of a" sense of mortality" that other women their age do not have to think about was mentioned verbatim by two women. Not having access to support groups exclusive to women who had the BRCA mutation, without the diagnosis of cancer, caused women to feel different. One participant voiced feeling alone in her "personal life" but not in her "social media life" (P10, ~30, married, diagnosed in 2015, surveillance). She disclosed that interacting with women her age with the same diagnosis online assisted her with not feeling isolated. One participant voiced that she did not feel different in regards to fertility and breastfeeding because she accepted the option of not having children before surgery (P4, ~35, married, 0 children, diagnosed in 2014, BPM & HYS).

Women reported that guidelines available for BRCA mutation carriers and decision making were specific to women that were older caused them to feel isolated. The youngest participant, age 23, denied feeling isolated but could see herself being isolated in the future once she has surgical prophylaxis (P14, ~26, single, diagnosed in 2014, surveillance).

Another said:

> *I definitely do, especially because a lot of the information I have about having the mutation, or what to do, or a lot of guidelines see to be for older women.*
>
> (P11, ~39, married, diagnosed in 2014, surveillance, child=1)

Menopausal Symptoms

Eight women voiced concerns regarding menopausal symptoms while considering PSO. Seven of the women were concerned about the effects of hormone loss specifically such as bone density loss, weight gain, hot flashes, negative emotions/mood, and decreased sex drive. One of the women was concerned about how menopausal symptoms would affect her depression and anxiety and stated:

> *As far as the prophylactic surgery like for the ovaries and such I am just concerned about the change in hormones..… And I'm worried about that adjustment period, like how is that going to affect my depression? How is that going to affect my anxiety? How is it going to affect my sex life? If I'm a 30-year old woman that's going through menopause, how is that going to seem? Uh, that's going to be kind of crazy. And then I worry about like bone density issues and things like that, like keeping myself healthy. I'm already struggling with like body image because I've gained a lot of weight recently from my depression.* (P11, ~30, married, diagnosed in 2014, surveillance, child = 1)

Two of the women were ambivalent about surgical menopausal symptoms with one stating:

> *I'm not sure how I feel about going into surgical menopause. So, it gets to the point where, you know, you've kind of asked, would I prefer to have an increased risk of*

> *cancer, or an increased risk of heart disease, osteoporosis and all of these other wonderful things.* (P15, ~36, single, diagnosed in 2018, BPM)

Implants and Autologous or Flap Reconstruction.

Eight of the eighteen women, who had breast reconstruction, openly discussed the effects of this surgery breast and their own individual experiences with implants. The movement of the implant, "feel" of the implant, implant versus autologous reconstruction and the experience of expanders placed before reconstruction were mentioned. One of the women waiting to have prophylactic mastectomy wanted to "look like a woman" while one of the participants felt while going through the process of reconstruction she was "not quite woman". The "flipping" of the implants and her experience with her husband's response to the implants was captured by this response:

> *I sleep basically on top of two cantaloupes right now. I haven't been able to sleep properly in a long time. I took my U-shaped pregnancy pillow out of the bed and then my implants have been flipping. My surgeon finally taught me how to flip them back. He's like, "This is just something that's going to happen." And I was like, "Well, this stink." You know, one day I asked my fiancé to do it. And he's like, "Listen- When it's wound care and I have to take care of you, that's one thing. But this kind of grosses me out." And that made me feel like—Yeah. I was like, Uuuh..."* (P4, ~35, married, diagnosed in 2014, BPM & HYS)

One of the participants described the pain, appearance of the muscle overlying the breast after autologous flap reconstruction as "disgusting", disappointment regarding breast size being larger than agreed upon and not being fully informed of other reconstructive options as evidenced by this exemplar.

> *What bothers me the most is seeing the muscle on top, and seeing flexion and not having the same kind of soft tissue as I did before… It's clear that it's muscle with something underneath it. It's big... it doesn't react the same way to movement...like drying myself off after I shower…Flexes the pectoral muscles, and I look at it, and I'm like, "Uh, that's disgusting." [laughs] You know, so I don't like to look in the mirror because of that…. during the process of expansion. It was painful. I had some struggles physically whenever we would expand, they'd try to expand too much; and then, I'd have a big reaction. So, we had to slow it down. And then I stopped it and said, "I'm where I want to be," which was smaller than they thought I should be. Like, "Nope, this is where I want to be." We went into reconstruction, and I was adamant, I told everyone, the surgeons, the PA, "This is as big as I want to be. I do not want to be any bigger than that." I came out of reconstruction bigger than that, and I was mad. I was so mad.* (P9, ~40, married, diagnosed in 2017, BPM, child=1)

Only one participant had a positive response in regards to implants as evidenced by this exemplar.

> *I was pretty flat-chested before, and now I actually have boobs…. I haven't been in a situation yet where, like, naked in front of somebody else. So, I don't know if that would be different in terms of sexuality, but so far —my friends are pretty jealous.* (P12, ~34, single, diagnosed in 2018, nipple-sparing BPM)

External influences on Decision Making

External influences are factors that affect the woman's choice decision from outside sources such as health care professionals, environmental resources and the words/opinions of others (Hayes, 2016). For example, in lieu of being knowledgeable of the risk of breast cancer

there is still hesitancy in decision making even after hearing about the experience of others being diagnosed with breast cancer. For example, one participant was very confident in her decision to have prophylactic mastectomy despite outside influences:

> *I didn't move ahead until I felt super, super secure with my decision, with my team, with my plan of attack. And then there were outside influences that were like, "Why are you going to… cut open a perfectly healthy body? It's not like you're a car. You can't just take pieces in and out. I felt so secure with my plan that I wasn't really influenced by their feedback.* (P4, ~35, married, diagnosed in 2014, BPM & HYS)

Four of the women discussed external influences that assisted with the decision to undergo prophylactic surgery as having a parent, friend or sibling with the diagnosis of breast cancer, undergoing treatment and/or mastectomy. One participant said that her experience with speaking to other women with breast cancer in the waiting room assisted her in making the decision to have prophylactic mastectomy.

> *I remember one woman, she had no hair or anything like that, and she was waiting, going in to go see a plastic surgeon, and I told her mine [story]and she told me hers, and I was still in this process of like I'm not sure yet, I'm just here to talk to them. She was all like, "You know, if I knew I had, if I had a chance to get rid of my boobs when I was your age," because she thought I was 20. We didn't do ages yet. She was like, "I would do it." " I would automatically get it done. Because you don't want this." And I remember looking at her, and I'm like, "Okay, yeah, I don't want that." (Laughs) kind of a thing.* (P1, ~39, married, diagnosed in 2016, PM, child= ≥2)

Internal Influences: Perceptions, Lived Experiences and Attitudes

Internal influences are factors that affect the individual from within (Hayes, 2016) whether she perceives the diagnosis of BRCA mutation as a disease, illness or cancer diagnosis (Pelusi, 2006). Internal influences such as the idea of having ovarian cancer that could go undiagnosed in later stage versus breast cancer (P7, ~40, divorced, diagnosed in 2019, HYS, child=1). Ambivalence regarding which prophylactic option or procedure was noted in women who had chosen surveillance and those post prophylactic surgery.

Concerns about whether people would be able to tell if they had surgery, looking different, or being viewed as "less of a woman" for having breast prosthesis versus breast implants were salient. Although concerned with body image and effects of surgery the women voiced the decision to have prophylaxis was better than a diagnosis of cancer as depicted in the following statement:

> *I think the mastectomy brought with it more concerns about body image or whether…people could tell that I had the surgery…. I've made this choice prophylactically. I never had the cancer diagnosis. I don't know if I would have and I'm pretty comfortable with making the decision that I'd rather do it prophylactically than—have cancer. But, there's also a little part of me that wonders if I've moved heaven and earth for potentially nothing... If I never would have gotten cancer.*
>
> (P3, ~45, married, diagnosed in 2017, BPM, child=≥ 2)

Another stated:

> *I feel weird about it. I'm not necessarily pleased or bummed, not also un-pleased. I'm kind of like well wait, so it's awesome about not having breast cancer, like I won't have it but it's a sense of like I don't feel comfortable taking my top off when I'm with my*

husband, you know what I mean? (P1, ~40, married, diagnosed in 2016, BPM, child = ≥2)

Communication with Provider and Setting

Nine women discussed their interaction with the provider either at diagnosis, during surveillance follow-up and post-reconstruction. They were concerned about the knowledge of the provider regarding the BRCA mutations and necessary recommendations, how the BRCA diagnosis was received, failure in communication amongst the healthcare team and not being given all options for reconstruction. Two participants said they received results of the BRCA mutation over the phone. Some women were referred from their gynecologist to a surgical oncologist without information to see a genetic a counselor. Concerns regarding the medical providers acknowledgement of the BRCA gene during annual visits was evident with the following statement by a young woman:

> *My doctor makes me feel like she doesn't even know that I have this gene. During my annual physicals it never gets brought up. She'll do the typical… you know feeling around your boobs for like, lumps or things like that. She'll do that. But for me, I figure, that's probably normal for girls like, 18 and older. I don't know. I think that's my biggest like, insecurity and discomfort about it is having a doctor where it never gets brought up. It never… Could I talk to her about it? Maybe. But I don't know that I'd want to…that's definitely my biggest frustration with this*. (P14, ~25, single, diagnosed in 2016, surveillance)

Several women also discussed their visit to the oncologist and experiences while being in the waiting room. They felt that maybe they should be in a different waiting room or even have a different appointment schedule than persons who had an actual diagnosis of cancer. The

difference in their age versus the other patients' age and that materials given and available were not individualized to younger women with a BRCA mutation without the diagnosis breast cancer.

> *My surgeon commented, and I agreed, that it is a little hard for a person who's doing this prophylactically because— there's a whole world of pink ribbon stuff out there. And so, walks and fundraisers, and a lot of people think that I should probably be really involved in that because of my family history. I'm not really, in part, because it just brings up so many emotions for me. And, as my surgeon pointed out, really most of the materials out there are for women who have a cancer diagnosis. And so, like, if I go and look at that, there's a lot of emotion attached to it. It's also for women who are going through a different path than I am. So, I would have preferred—This is a little detailed, but…. my surgeon's office gave me some little comfort care pillows and little pouches to hold the drainage bottles in. All of that was wonderful, and, you know, I never turn down, I guess, bags. Like, I also started crying when it was all pink and pink ribbonry— because, then, I suddenly felt like a cancer patient.* (P3, 46, married, diagnosed in 2017, PM, child = ≥ 2)

Sexuality

Sexuality is defined as the individual's sexual function, how they feel within a sexual relationship including their sexual interest and sexual expression to others (Pelusi, 2006). Sexuality concerns for the participants consisted of intimacy with partner after surgery, sensation loss, scarring, decreased libido and sexual minority needs.

Intimacy with Partner

Women discussed concerns that affected intimacy with their partner after prophylactic surgery including the presence of scarring, pain, lack of sensation, altered sensation and decreased libido. Two subjects discussed accommodations for their partner in order to enhance intimacy by utilizing nipple prosthesis and being less aware of sexual advancements post prophylactic mastectomy. Scarring, pain, sensation loss and change in breast size before prophylactic mastectomy (i.e. breast lift) affected intimacy (n=4) for both partners and the idea of additional scarring from an autologous flap procedure also caused more intimacy issues.

> *There are accommodations that I feel like I have to make to keep him from being distracted by the fact that I am not the same as I was. So, things like making sure I'm covered there, or that I have the prosthetic nipples on. (*P9, ~40, married, diagnosed in 2017, PM, child=1)

Concerns with lack of sensation of the breast and not having a breast were difficult to verbalize in the following exemplar.

> *I think it's been difficult for me to verbalize, especially, at first, sort of, my fears, in terms of like, body image and sexuality. And just not either having breasts or having breasts that I can't feel. I think that has been harder for me much more than talking about having cancer. Or having to go through chemo or radiation.* (P10, ~30, married, diagnosed in 2015, surveillance)

Contrary to the concerns most of the women had regarding their body image and intimacy within their heterosexual relationship, there were also concerns from women in who were in same sex relationships (sexual minority women (SMW). There were two SMW who were interviewed, one of which was diagnosed with a BRCA mutation within the past two years

and still processing the diagnosis (P14, age ~25, single, diagnosed in 2019, surveillance) and another who has been undergoing surveillance for the past two years (P18, ~30, single, diagnosed in 2016, surveillance). SMW women may have other needs and insights than heterosexual women as evidenced by this participants exemplar.

> *A further resource is that I think would be really helpful to have something for those of us who are diagnosed who are LGBTQ—it's just a different level of dealing with when it comes to dating— …because I have different concerns. I think dating, it's always assumed it's a man that you're dating and that you're having conversations—about bringing kids in or like this traditional version of marriage, I think— …for a gay woman, as myself, the question of femininity is a little different. It's hard because like the person I'm dating is someone that has the same body as I do, right. Like—she knows what my body is like and because it's the same as her own and— that makes it much more understanding and which is really nice. Like she understands what menopause could be like but—…it also is more difficult because I think there's this sort of feeling of inferiority in certain ways. Does that make sense? I don't know why. Like, but that her body is working and my body is not*. (P18, ~30, single, diagnosed in 2016, surveillance).

Femininity

Femininity is defined as the quality and nature of the female sex (Merriam-Webster, n.d). Femininity concerns were manifested while discussing common concerns associated with the loss of the breast and being a woman. There were also concerns about the fit of clothing with changes in the size and contour of the breast. The women disclosed "*breasts are different"* than any other part of the body, removing the breast was verbalized as "*its taking away all the things that make me a woman", "it's important for me to keep my breast" that's how women are*

portrayed. Like women have breast" and *"they were apart of how I saw myself as a woman."* The breast was considered part of the self-identity of a woman as evidenced in this exemplar.

> *A couple of weeks ago I was talking with this older gentleman and he had some health issues. And I said, I'm sorry. he expressed that he'd been dealing with prostate cancer for about 10 years. And how he was just struggling with that. I shared my experience with having this mutation. And I was like, I understand what it's like to get those tests and worry about it all the time. And he said to me, well, why don't you just cut your breasts off? [laughs] I was just like…Because they're a part of who I am. And I'm in my thirties. I almost wanted to say to him, would you cut your testicles off.* (P8, ~40, single, diagnosed in 2011, surveillance)

After being diagnosed with a BRCA mutation the women voiced becoming more aware of being a woman and their femininity regardless of their sexual orientation. The perception of the breast after mastectomy was viewed as being "*not quite woman*" while going through reconstruction and considering hysterectomy was noted.

> *It's stitches, it's scarring, it's blue, it's all that stuff." She's like, "It'll pass. Once all this is over, it's going to look fine. They're going to look like breasts." But right now, I'm at the point where they don't look like breasts right now, so I'm still not quite woman, I don't feel like different, but I feel like not quite womanly, you know what I mean? It's just like not quite woman, you know? (Laughs) Because …. I'm not quite. When we go to the beach or the pool or something like that, I feel uncomfortable. I don't feel the same as them, you know? Because I still have the huge scarring from hip to hip, um, and I still— I don't feel like I can wear like certain suits or I feel like I can't wear certain things*

because of like—So, I'm not quite, you know." (P1, ~40, married, diagnosed in 2016, PM, child=≥ 2)

One participant openly discussed her struggle and frustration with wearing nipple prosthesis, the constant projections of the nipple in clothing and being content with not having nipples. However, another participant who had chosen a nipple sparing mastectomy voiced that nipples were important in making her feel "normal."

Childbearing/Childrearing

Being There

Many of the women expressed they decided to undergo surgical prophylaxis for their children. There was a need to survive to continue being a parent and seeing their future grandchildren. Most of the women who voiced this concern had a grandmother, mother, sister or friend that had breast cancer or ovarian cancer.

Fear of transmission

Fear of passing the genetic mutation on to their children in the future was also noted. The participants' experience of taking care of their own parents, who were diagnosed with breast and/or ovarian cancer, was a concern as they continue to move closer to age 40 and did not want a similar burden for their children.

Parenting

One participant discussed her experience post PM and PSO with four young children and the emotional impact it had on her being a parent.

It was very difficult physically, but also emotionally not to be able to pick up my kids. And I needed help with cooking and cleaning and, childcare and carpooling. then emotionally, it's hard to go from being a mom taking care of people to being taken

care of and not being able to do a lot on your own. (P5, ~40, married, diagnosed in 2014, PM & PSO, child = ≥ 2)

Future Childbearing

One participant was pregnant during the interview and considered PM and PSO but surgical prophylaxis was not a concern at the time because she was "*not finished using those parts*." There were two women, ages 39 and 40, who had concerns regarding the ability to have children by a certain time, fertility issues while undergoing IVF and considerations whether to have a surrogate or adoption. One stated:

I'm dealing with the process of realizing that I'm not going to meet somebody in time to have a family. And so that part has been hard. because I have a date when, or a year when I need to get my ovaries out. And that will be the end of my opportunity to have kids. And so…, there's a part of me that's, kind of like, well, I spent all of this anxiety and kept my ovaries for all this time and now I'm not even going to use them. (P8, ~40, single, diagnosed in 2011, surveillance)

Breastfeeding

Most of the participants who had not had children (n=9) stated concerns regarding breastfeeding. Breastfeeding was very important to the women without children and caused some reservation in considering prophylactic mastectomy. A sense of "grief" was recurrent amongst women who would not be able to breastfeed. Indeed, the need to breastfeed was a common reason for continued surveillance instead of surgical prophylaxis. One participant discussed the emotional impact the inability to breastfeed had on the relationship between her and her son.

I *was breastfeeding my son at the time. That was really important to him. I had to wean and, you know, and tell him, "Sorry." I didn't realize for him how important my breasts*

were to him. And when I had surgery, he was 18 months old and it created massive relationship challenges with he and I, and we still haven't repaired those. Because I no longer have breasts, he doesn't trust me the same way he trusts my husband. So, he goes to my husband for comfort. He immediately, he used to have his hand down my shirt for comfort when he had anxiety…he goes to my husband now because my husband has nipples and I don't. (P9, ~40, married, diagnosed in 2015, PM)

Discussion

The findings of this study closely relate to the conceptual model and theoretical framework applied to this study's methodology (Appendix A). After diagnosis of having a BRCA mutation, the participants were faced with decision making regarding prophylactic care. In considering the options available there were internal and external influences, including the consequence of the different prophylactic options and concerns for what is unknown after such procedures have been sought. Body image and sexuality, as separate but overlapping entities, were a part of the participants perceptions and attitudes which in turn are the internal influences in decision making.

Body image is imperative to sexual functioning and the perceptions of others highly impact body image (Sheppard & Ely, 2008). External influences such as communication with providers, other opinions, the setting for care and the experience of family members also affected body image and the decision to undergo prophylactic treatment.

Body image and sexuality were also influenced by what would be considered normal in women of childbearing age (i.e. breast feeding, mastectomy post-cancer diagnosis, BPSO after childbearing). The women in the study considered societal norms, their own wants and

wellbeing which includes psychosexual functioning. Isolation and feeling different was a common theme while considering prophylactic options.

The women who had chosen BPM, were continuing to make decisions regarding breast reconstruction, time to childbearing and BPSO as applicable. Women, specifically those with a family history of ovarian cancer, were concerned about finding a partner in time to conceive and conceiving before BPSO. The women who were under surveillance and considering BPM and/or BPSO were in the process of deciding when the prophylactic measure should take place. The process of considering the prophylactic options, considering the consequence of going through with prophylactic options, considering the consequences of not going through with the prophylactic options (i.e. breast cancer, ovarian cancer, colon cancer, skin cancer) and fear of the unknown (i.e. unknown possibility of not getting cancer at all).

Moreover, this further suggests that the decision-making process is a continuous process before, during and after prophylactic options have been chosen. Although body image and sexuality are considered mainly internal influences, this study postulates that body image is impacted by external influences as well. It must be implicit that psychosexual functioning is not solely based on the individual views of self but is also influenced by the environment, the resources available, the views and opinions of others which includes communication with the healthcare provider and multidisciplinary healthcare team.

Dissatisfaction with the appearance of the breast and scarring after BPM has been reported in the literature (Glassy et al. ,2018). However, the issues of dissatisfaction were not discussed as concerns preoperatively or postoperatively. There is evidence from the literature and support from this study, that women do not feel comfortable asking questions concerning body image and sexuality due to fear of being ridiculed for being more concerned with change in

appearance (Matloff, Barnett & Barber, 2009) rather than the severity of cancer risk. Several studies have determined that women are not given realistic expectations regarding potential outcomes of surgery which is also supported in this study (Dikmans, van de Grift, Bouman, Pusic & Mullender, 2019; Glassey et al. 2018; Matloff et al., 2009; Rolnick et al, 2007; Underhill & Croster, 2013). Lack of sensation, scarring, changes in sexuality and body image are not being adequately explained by surgeons, and healthcare providers (Dikmans et al. 2019; Rolnick et al., 2007) were also validated.

This study also supported previous findings that the differences between reconstructive procedures such as nipple-sparing mastectomy versus non-nipple sparing mastectomy, reconstruction with implants versus autologous reconstruction, implant failure and the scarring that may occur with each procedure are not clearly communicated to the previvor (Dikmans et al. 2019; Rolnick et al., 2007). Providing information regarding the side effects of BPSO such as difficulty with orgasm, decreased libido and menopausal symptoms are lacking preoperatively that are imperative to sexual health and intimacy (Matloff et al., 2009; Rolnick et al., 2007). Bober et al. (2014) suggest that psychosexual intervention post prophylactic intervention improves psychosexual functioning, self-efficacy (over external and internal influences) and knowledge regarding sexual health while decreasing somatic symptoms and anxiety through cognitive therapy and sexual health education.

In this study, a unique view of femininity and prospectus of body image of a SMW was discovered who previously have been underrepresented in the literature. It has been reported that SMW who have had bilateral mastectomy have insignificant changes in body image or femininity and are pleased with the removal of breast tissue compared to heterosexual women (Rubin & Tanenbaum, 2011) but this was not supported in this study as SMW participants had concerns

about breastfeeding, the association of their breast with their own self-identity as female, feeling attractive and the appearance of breast after BPM.

Boehmer and Case (2004) discovered that physicians also fail to acknowledge disclosure of sexual orientation in developing a plan of care and SMW may not actively disclose their sexual orientation. SMW women with cancer not only lack information about sexuality during the operative process but have worse outcomes in diagnosis of breast cancer i.e. lack of breast self-exam, nulli parity, perceived objectivity of the breast, and fear of discrimination or bias affecting healthcare access (Boehmer et al. 2013; Bowen, Powers & Greenlee, 2006; Rubin & Tanenbaum, 2011).

Body image and sexuality are affected once women see the scar or the effects of chemotherapy on an aunt, sister, mother or grandmother with breast cancer (Matloff et al., 2009). The diagnosis of a genetic mutation can have a negative impact on body image and sexuality (Kenen, Shapiro, Hantsoo, Friedman & Coyne, 2007) and is often viewed a definitive cancer diagnosis (Pelusi, 2006). This study supported the premise that a waiting room that is separate from the typical cancer care clinic may improve the receipt of genetic counseling, decrease anxiety, increase well-being, enhance communication between the provider and avoid the perception of being a "cancer patient" (Phelps et al., 2008). Women who do not have cancer but are undergoing genetic counseling for prophylactic options to prevent future cancer occurrence, should receive care in an environment that is comfortable, and welcoming to their specific needs.

Furthermore, not only are family, friends, and environmental resources primary external influences, but the providers' recommendation was most significant in the decision-making process. Previous research has shown that provider mistrust, inaccurate provider recommendations, inaccurate provider information and lack of provider knowledge regarding the

BRCA mutation further prohibits the ability to develop an individualized plan of care (Glassey et al., 2018; Matloff, 2009). In addition to an individualized plan of care, the appropriate referrals and recommendations specific to WCBA needs are imperative to not only psychosexual functioning but the decision-making process (Bober et al., 2014; Underhill & Croster, 2013).

Women in this study who were in a relationship voiced being supported throughout their diagnosis and decision to have prophylactic surgery by their significant other. Even so, the women voiced feeling isolated and/or different from peers' due to diagnosis of the mutation, childbearing status and decision to have prophylactic surgical intervention. The participants felt that support groups such as FORCE provided an opportunity for them to gain support from women who are experiencing the same diagnosis, age, time to surgery and prophylactic procedure similar to the study by (McQuirter et al. 2010).

Any part of a woman's body is considered a part of a woman's' self-identify (Fernandes, Papaikonomou & Nieuwoudt, 2006; Kocan & Gursoy, 2016). The breast, in particular, symbolizes being a woman, beauty, femininity, sexuality, attractiveness and mothering through breastfeeding (Kenen et al., 2007; Kocan & Gursoy, 2016). From this study, it can be surmised that understanding that any change in the appearance of the breast not only affects body image but also affects one's identity unbiased to sexual orientation. For WCBA simple gestures, such as giving their child a hug or picking up/embracing the child for comfort is critical to the mother-child relationship (Kenen et al., 2007). In addition to the ability to breastfeed, changes that can occur after BPM and breast reconstruction such as hardening of the implant, movement of the implant and pain can affect emotional expression within mother-child relationships (Kenen et al., 2007).

In reviewing the main themes childbearing and breastfeeding were closely interrelated to body image and sexuality similar to previous studies by Kenen et al., (2007) and Kocan and Gursoy (2016) as the WCBA perception of self and lived experiences. This further elucidates body image and sexuality concerns should be addressed in multiple aspects. The consideration of sexual orientation, marital status, childbearing status and psychosexual functioning should be addressed before diagnosis of the BRCA mutation.

Conclusions

WCBA diagnosed with a BRCA mutation have to consider prophylactic options that affect body image and sexuality as preventative strategies. WCBA, with a BRCA diagnosis, have concerns regarding psychosexual functioning throughout the decision-making process and beyond. Body image, sexuality and sexual orientation should be addressed at first contact and considered while developing a plan of care. Although women may have support from family or significant others during the decision-making process psychosexual concerns may not be addressed due to humiliation and isolation.

This study postulates that psychosexual concerns come from both internal and external influences that significantly impact the decision to undergo prophylactic measures. Body image and sexuality concerns may be present before diagnosis and further affect the individual's perception of self after BRCA diagnosis. External influences which include but are not limited to lack in provider communication (i.e., regarding the BRCA mutation, body image, sexuality), inadequate preparation for realistic surgical outcomes, provider knowledge regarding the BRCA mutation and appropriate referral after BRCA diagnosis are factors that can be improved to assist WCBA throughout the decision-making process and enhance psychosexual functioning.

Implications

Healthcare providers can assist by assuring body image, and sexuality concerns are addressed. There is a dearth of literature that suggests referral to a sexologist to assist with body image and sexuality at surgical consultation and limited to no discussion on assistance from nurse navigators. In addition to genetic counseling, targeted psychological and sex therapy maybe indicated before and after prophylactic measures to assist with adjustment issues. Communication amongst the multidisciplinary healthcare team is paramount (primary care provider, genetic counseling, gynecologist, oncologist, surgeon and nurse navigators/decision support) to assure recommendations and plan of care are congruent.

Furthermore, with the up rise of genetic testing being ordered and results being given by primary care providers instead of oncologists there appears to be a need to improve delivery of this information to assure informed decision-making. Minimally, it is imperative that providers are comfortable with discussing body image, sexuality, and understanding differences in sexual expression in young women. It is also important to be sensitive to the needs of young women but also sexual minority women in discussing sexuality concerns and expression of self-identity. In addition to intimacy within partner relationships, changes in the breast also affect the mother-child relationship which should be considered when addressing body image and femininity.

Limitations

The medically applied ethnographic approach utilized within this study yielded a few limitations which included the possibility of recall bias and inability to generalize findings to all women considering surgical prophylaxis including those with a BRCA mutation of undetermined significance. Further discussion on the specific type of breast reconstruction may have given insight to satisfaction with the breast before surgery, outcome expectations following

reconstruction and its influence on body image and sexuality. Women who participated in this study were either considering prophylactic surgery or had a prophylactic procedure within the past 5 years so their views might have evolved over time. The majority of women participating were Caucasian, followed by Hispanic and Asian but there were no African American participants. Incidentally, the African American women (n=2), ages 21 and 49, that attempted to participate in the study had been diagnosed with cancer. Sexual orientation of women was an incidental finding and should have been placed within the demographic questionnaire. The experiences of the women included within the study may not apply to all WCBA with a BRCA mutation. Therefore, the study contributes to bringing attention to concerns affecting this unique population that are not usually addressed.

Recommendations

To enhance the practice paradigm for providers who are assisting women with BRCA mutations, further research is warranted. This study suggest that it is crucial that healthcare providers asses the concerns related to psychosexual functioning to individualize plan of care, and improve healthcare delivery. Further studies should assess psychosexual interventions in WCBA deciding to undergo prophylactic treatment so that such intervention may be added to guideline-concordant care. Qualitative inquiry exploring the views of providers in assessing and discussing body image and sexuality is also recommended to further understand the lack of provider knowledge and communication. A mixed-methods longitudinal study utilizing measurement tools such as the Female Sexual Functioning Index and the BREAST-Q, before BRCA diagnosis, post-diagnosis and after prophylactic intervention may provide useful information on how best to serve these women (i.e. psychological and sex therapy) (Bober et al.,2015; Dikmans et al., 2019).

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Appendix F

Demographics of Study Sample

Table 1

Demographics of Study Sample

Factors	Number	%
Sample (n)	n=18	100%
Age		
21-25	n=2	11%
26-30	n=5	28%
31-35	n=2	11%
36-40	n=6	33%
41-45	n=2	11%
46-49	n=1	6%
Race		
African American	n=0	0%
Asian	n=1	1%
Hispanic	n=2	11%
Caucasian	n=15	83%
Relationship Status		
Married	n=10	56%
Divorced	n=1	1%
Single	n=6	33%
Childbearing Status		
No children	n=10	56%
One Child	n=3	17%
Two or more children	n=3	17%
Education		
Some College	n=1	1%
Bachelor's Degree	n=5	28%
Master's Degree	n=7	39%
Doctoral Degree or higher	n=4	22%
Family History of BRCA Mutation	n=14	78%
Family History of Breast Cancer	n=13	72%
Prophylactic option		
Surveillance	n=8	44%
Bilateral Prophylactic Mastectomy (BPM)	n=8	44%
Bilateral Salpingo-oophorectomy (BPSO)	n=3	17%
BPM and BPSO	n=2	11%

Appendix G

Study Protocol

Protocol Title:	An Exploration of Psychosexual Functioning and Factors affecting the Decision-Making Process in Women of Childbearing Age with a BRCA1/BRCA2 Mutation
Principal Investigator:	Alexis E. Hayes, PhD (c), MSN-Ed, APRN, FNP-BC
Population:	Approximately 15- 20 participants, women of childbearing age, ages 21-49, diagnosed with a BRCA1 / BRCA2 mutation, accessible through Facebook and/or locally within the Houston area.
Number of Sites:	Facebook/Social Media Platform, Face to Face Video Conference, Supported Clinical and Educational Institutions in the Houston Area
Study Duration:	Approximately 12 Months
Subject Duration:	Approximately 30 – 60 minutes per individual interview

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General Information

There is a gap in knowledge regarding the influence of psychosexual functioning on the decision to have prophylactic treatment in women of childbearing age diagnosed with a BRCA gene mutation only (without breast cancer diagnosis). At the completion of the proposed research, the expected outcomes are to establish the importance of psychosexual functioning in cancer risk management and prophylactic decision-making. Additionally, the study is expected to assist with individualized cancer risk management options provided by health care providers. The knowledge gained from this research will have a positive impact on cancer risk management by adding a psychosexual component to the limited decision-making tools that are available to BRCA mutation carriers.

Background Information

- *Body image and sexuality* are addressed in women with a diagnosis of breast cancer and ovarian cancer, there is a minimal evidence regarding these factors in women of childbearing age (21-49) who have a genetic risk for breast and/or ovarian cancer. Psychosexual functioning, which includes psychological well-being in regards to body image and sexuality, is affected by the diagnosis of a BRCA1/BRCA2 gene mutation. Furthermore, there is minimal evidence regarding how these factors affect the decision to have prophylactic treatment for breast and ovarian cancer.
- *BRCA1/BRCA2 Mutation:* The diagnosis of a deleterious BRCA gene mutation is devastating for women and is often viewed as a cancer diagnosis. A BRCA1/BRCA2 gene mutation increases the risk of hereditary breast and ovarian cancer. Female BRCA gene mutation carriers have an 85%- 90% lifetime risk of developing breast cancer and a 27%-65% chance of developing ovarian cancer (Donnelly et al., 2013). A diagnosis of a BRCA gene mutation is a dilemma where life-changing medical decisions must be made to prevent breast and ovarian cancer.
- *Decision-Making*: The decision to choose a prophylactic measure such as intense surveillance, chemoprophylaxis, radiation, bilateral mastectomy, and bilateral salpingo-oophorectomy is a complex process. Furthermore, there are dispersed discussions on psychosexual functioning, which includes psychological well-being in regards to body image and sexuality, that is affected by the diagnosis of a BRCA1/BRCA2 gene mutation. There is minimal evidence regarding how these factors affect the decision to have prophylactic treatment.

- *Psychosexual Functioning:* A dearth of literature exists investigating psychosexual functioning in BRCA gene mutation carriers of childbearing age. Women of childbearing age, 21-49 years of age, are at a unique stage in life where childbearing, educational goals, career development and the establishment of intimate relationships are most important. Approximately 50% of BRCA1/BRCA2 gene mutation carriers choose intense surveillance however only 70% of all BRCA carriers follow the recommendations for intense screening (Pademsee et al., 2017). Evidence suggest that the psychological state of the individual effects preventive treatment decisions (Pademsee et al., 2017). Once women of childbearing age feel understood and knowledgeable supporters are available, they will be more accepting of support during the decision-making process. Genetic counseling pre-and post-diagnosis of a BRCA gene mutation is favorable, however assuring that continued psychosexual counseling is available to assist women of childbearing age with an informed and independent decision is empirical.

Objectives

- The overall study objective is to understand the influence of psychosexual functioning and discover factors affecting the decision to have prophylactic treatment.
- The specific aim of this study is to explore the role of psychosexual functioning in the decision to have a prophylactic treatment, amongst women of childbearing age who have a diagnosis of a BRCA1/BRCA2 gene mutation.
- A medically applied ethnography methodology will be utilized to accomplish the aim of this study.

Study Design

- The study will be conducted using a medically applied ethnography. The ethnographic approach will assist in the exploration of psychosexual functioning and the decision-making process of BRCA mutation carriers.
- Expected duration of study is approximately 9-12 months with participant observation and interviews for approximately 3 months duration.
- The expected outcomes of the proposed study are to establish the importance of psychosexual functioning in cancer risk management and prophylactic decision-making. The application is expected to assist with individualized cancer risk management options provided by health care providers.
- There is no specific health, social, legal or psychological risks to the participants.

Study Population

- Inclusion criteria: women 21-49 years of age, diagnosed with a BRCA1 or BRCA2 gene mutation, women 21-49 years of age with a BRCA mutation of undetermined significance, English speaking, access to the internet, Facebook and/or Zoom video recording per phone or computer.
- Exclusion criteria: Women over 50 years of age and women who have been diagnosed with breast or ovarian cancer.
- The population will consist of adult women between the ages of 21-49, with a positive BRCA gene mutation and/or BRCA gene mutation of undetermined significance. A purposive sampling strategy will be employed to select study participants from a specific cultural domain. The study participants will primarily consist of women on Facebook that are members of BRCA support or prophylactic mastectomy support group.
- The purpose for the purposive sample is to explore women who are BRCA positive and seeking support pre-and post-prophylactic treatment.
- Anticipated recruitment will take place from February 2019 – March 2019 (8 weeks).
- If a specific support group is utilized a formal invitation will be submitted to the group administrator before posting any content regarding the research topic including discussion post and announcement of the study. Otherwise participants will be notified of study through Social Media post/flyer on

Facebook, Instagram and flyer advertising within local clinics and community organizational settings. Information to contact the solo investigator will be noted on the flyer/social media post and the participant must notify the investigator to be considered for the study.
- Letters of support will be obtained if support groups are utilized to recruit potential study participants.
- Once initial contact has been made an individual email will be sent formally inviting the participant to participate in the research study. The formal invitation and web link will be developed through Qualtrics. The formal letter which will include a link to an eligibility/screening questionnaire which will evaluate inclusion and exclusion criteria. The participants responses to the eligibility questionnaire will determine study eligibility and will be autoscored through Qualtrics and reviewed by researcher for accuracy. Persons who respond to any of the exclusion criteria will be excluded from the sample and those who meet the inclusion will be sent a web-link with an informed consent.
- Once consent is obtained, the interview will be scheduled with the participant.

Study Procedures
- Individual semi-structured in-depth interviews will be performed to explore the participants experience. The interview will be conducted by the solo researcher and will last approximately 30 – 60 minutes per participant (see Interview Guide).
- An additional interview may be performed for clarification of the previous interview or if information obtained in the previous interview is not complete.
- During the interview recording, will request that the participant avoid usage of their name while being interviewed. The interview recordings will be identified by subject number before being sent for transcription.
- Interviews will be transcribed by, Pioneer Transcription Services, a professional transcription service that specializes in interview transcriptions.

Data and Safety Monitoring
- Due to the sensitivity of persons with BRCA gene mutation, who face the risk of breast and ovarian cancer, women may be reluctant to share experiences and views in regards to psychosexual functioning. If this happens, continued sampling and interviews will be conducted to increase data quality.
- It is possible that although the participants have access to the internet, computer or phone, they may not have access to video conferencing. In this instance, interviews would be performed face to face.
- During the time of sampling and interview participation the participant may have decided to undergo prophylactic surgery. Interviews may continue if participant is comfortable but this may affect sample size. If this happens, interviews would be done post-surgery, after the participant has been discharged from hospital setting and content with completing interview.
- A secondary option is to allow for internet interviewees to opt out of video recording if the participant is uncomfortable with performing a face to face interview via video conferencing.
- All data will be reviewed by a qualitative data expert for accuracy.
- The video recordings will be saved to an iCloud (which includes security coding) that only the solo researcher Dr. Wardell and Dr. Engebretson, both qualitative data experts, will have access to. The participants will be given specific provision regarding the video recording within the informal consent.

Statistics
- All eligible participants will be allowed to participate in the study until data saturation is obtained.
- Descriptive statistics (i.e. Mean, range, numbers) will only be used to describe study sample.

Ethics
- IRB approval will be sought from University of Texas Committee to Protect Human Subjects

- Persons who respond to any of the exclusion criteria will be excluded from the sample and those who meet the inclusion will be sent a web-link with an informed consent.

Data handling and record keeping

- The video recordings will be saved to an iCloud (which includes security coding) that only the solo researcher and the qualitative data experts will have access to.
- The participants will be given specific provision regarding the video recording within the informal consent. The consent form will include an allotted time frame of five years to dispose of the video recordings as well as permission to archive the recording for future research. This will ensure time for secondary analysis of which the participants will be asked to give consent to use previous video recordings.
- Video recordings and transcripts will be properly disposed using a professional data disposal service.
- When the initial screening questionnaire is completed in Qualtrics the participant will be asked for their first name only and date of birth. Each participant that completes the questionnaire will be given a Subject ID number which will be used to utilized to link the subject to the data.

Quality control and assurance

- The solo researcher will seek guidance from Dr. Wardell and Dr. Engebretson, both qualitative data experts, to assist in the observation, interpretations and analysis of the data.
- To establish rigor a reflective journal will be utilized to reflect on the research process and counteract any bias. Field notes will be documented after each interview to assist with thick descriptions and linkages to develop the phenomena understudy.
- Field notes will be transcribed from the interview for transferability of data. After each interview, the video recording will be evaluated for completion and audio quality. Data retrieved from participants will be reviewed on the same day as interview to evaluate audibility and completeness.
- After each interview, the investigator will reflect on the interview process and outcomes, documenting reflections after each field note. Interpretation of main categories and common themes will be determined and agreed upon by the researcher and the qualitative data expert for study rigor.
- Conceptualizations will be developed by all participant responses rather than individual occurrences to assist with trustworthiness of the phenomena.
- Triangulation of the data by reviewing the semi-structured interviews, reflexive notes and comparison of the literature to assist with the dependability of study findings.

Publication Plan

- Publication of results will resort within a year of study completion.
- At the conclusion of the proposed research, the researcher would like to continue the study through an Exploratory Sequential Design.
- The researcher would like to develop a scale of measurement that addresses psychosexual functioning and common themes exclusive to women of childbearing age with a BRCA gene mutation.

IRB Approval # HSC-SN-19-0078
Approval date: 3/12/2019

"An Exploration of Psychosexual Functioning and Factors affecting the Decision-Making Process in Women of Childbearing Age with a BRCA1/BRCA 2 Mutation"
(Principal Investigator: Alexis Hayes)

Please read carefully the following information, which explains your rights as a research participant. By agreeing to participate in the study, it is implied that you have read and understand your rights to participate.

1. You have been asked to participate in a study exploring the role of psychosexual functioning (body image and sexuality) in the decision to have a prophylactic treatment, amongst women of childbearing age who have a diagnosis of a BRCA1/BRCA2 gene mutation

2. You are being asked to complete a 30 – 60-minute interview that will consist of questions about your experience being diagnosed with a BRCA mutation. Information about your BRCA history, your body perception (body image and sexuality) will be collected.

3. All data will be collected confidentially.

4. There is always a small risk of unwanted or accidental disclosure. We plan to record the interviews and with your permission. Any notes, recordings, or transcriptions will be kept private by the primary investigator (Alexis Hayes). Any digital files will be encrypted and password protected.

5. There are no anticipated risks to you for your participation in the study.

6. You will be compensated for your participation in this research

7. There are no additional benefits for your participation in this research study other than your experience assisting with exploring the affects of a BRCA1/BRCA 2 mutation in women of childbearing age. However, you may benefit indirectly from the knowledge gained from the research after its completion.

8. Questions about this research may be addressed to Alexis Hayes at alexis.e.hayes@uth.tmc.edu or 225-978-1053.

9. Participation in the study is completely voluntary. You can change your mind at any time and there will be no penalty. You have the right not to answer questions you do not wish to answer.

Please keep a copy of this email for your own records.

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INFORMED CONSENT TO TAKE PART IN RESEARCH

Study Title:	An Exploration of Psychosexual Functioning and Factors affecting the Decision-Making Process in Women of Childbearing Age with a BRCA1/BRCA2 Mutation.
Study Sponsor:	The University of Texas Health Science Center at Houston Cizik School of Nursing
Principal Investigator:	Alexis E. Hayes, PhD (c), MSN-Ed, APRN, FNP-BC
Contacts:	Alexis E. Hayes: 225-978-1053 or alexis.e.hayes@uth.tmc.edu

This is a formal consent inviting you to be in a research study by an investigator at The University of Texas Health Science Center at Houston Cizik School of Nursing. The researcher is interested in exploring the experiences of women (ages 21-49) that are diagnosed with a BRCA 1/BRCA 2 gene mutation which increases the risk of breast and ovarian cancer.

If you agree to be in the study, I will talk to you about your experience for up to an hour and possibly on more than one occasion. You do not have to be in the study if you do not want to: it is your choice. You can change your mind at any time and there will be no penalty. You and myself will decide together how many interviews you will have, and when they will occur. The interviews may happen over the span of three months, if you agree. You do not have to share any information that you are not comfortable sharing. You can stop the participating in the interview at any time.

I will be careful to keep your information confidential. There is always a small risk of unwanted or accidental disclosure. We plan to record the interviews with your permission. Any notes, recordings, or transcriptions will be kept private by the primary investigator (Alexis Hayes). Any digital files will be encrypted and password protected. I request an allotted time frame of five years to dispose of the video recordings, interviews as well as permission to archive the recording for future research. This will allow time for secondary analysis of which the you may be asked to give consent to use previous video recordings. You have the right to accept or decline contact for future research participation.

If you have questions or concerns at any time about the research, you can contact Alexis Hayes at 225-978-1053. If you have any questions about your participation in this research, you can call the Institutional Review Board (IRB) at 713-500-4472. The IRB is a committee that has reviewed and approved this research study.

IRB Approval # HSC-SN-19-0078
Approval date: 3/12/2019

CURRICULUM VITAE

Alexis Elizabeth Hayes, PhD, MSN-Ed, APRN, FNP-BC

EDUCATION:

UT Health Science Center Cizik School of Nursing Houston, Texas	2019	PhD	Nursing
UT Health Science Center Cizik School of Nursing Houston, Texas	2017	Post Masters Education	Nursing
Southern University A& M College School of Nursing Baton Rouge, La	2012	MSN	Nursing
Southern University A& M College School of Nursing Baton Rouge, La	2008	BSN	Nursing

PROFESSIONAL POSITIONS:

The University of Texas Houston Health Science Center at Cizik School of Nursing
Houston, Texas

Clinical Adjunct Faculty: FNP 1 and FNP 2 — 2017-Present

Walgreens Health Care Clinic
The Woodlands, Texas — 2015-Present
Lead Preceptor for North Houston Clinic Division
Family Nurse Practitioner

University of Texas Medical Branch – Women's Correctional Managed Care — 2013-2015
Gatesville, Texas
Family Nurse Practitioner

PROFESSIONAL MEMBERSHIPS:

American Academy of Nurse Practitioners	2012-Present
American Nurses Association	2008-2014
Louisiana Association of Nurse Practitioners	2008-2014
Sigma Theta Tau International Honor Society	2008-Present
Texas Association of Nurse Practitioners	2013-Present
The National Black Nurse Practitioner Association	2019

PUBLICATIONS:

Pending: SAT-2019-0050

The Good, the Bad and Recovery: Adolescents describe the advantages and disadvantages of Alternative Peer Groups. Authors: Dr. Angela Nash, Dr. Nina Z. Smith, Mr. Pablo J. Vasquez, Dr. Nnenna A. Emelogu, Ms. Alexis E. Hayes, Dr. Joan C. Engebretson

Pending:

Hayes, A.E. (2018). Factors Affecting Breast Cancer Treatment Options in African American Women: A Systematic Literature Review. Review. Unpublished manuscript. Cizik School of Nursing, University of Houston Health Science Center, Houston, Texas.

PRESENTATIONS:

Paper

Hayes, A.E. (2018). Factors Affecting Breast Cancer Treatment Options in African American Women: A Systematic Literature Review. Review. Unpublished manuscript. Cizik School of Nursing, University of Houston Health Science Center, Houston, Texas.

Hayes, A.E. (2017). Relationship between Surgical and Nonsurgical Prophylactic Options on Quality of Life in Women of Childbearing Age with a BRCA 1/ BRCA 2 Mutation: A Systematic Literature Review. Unpublished manuscript. Cizik School of Nursing, University of Houston Health Science Center, Houston, Texas.

Hayes, A.E. (2016). Decision Making in Women of Childbearing Age with A BRCA1/2 Mutation: A Conceptual Framework. Unpublished manuscript. Cizik School of Nursing, University of Houston Health Science Center, Houston, Texas.

Hayes, A.E. (2016). Psychosexual Isolation: A Concept Analysis. Unpublished manuscript. Cizik School of Nursing, University of Houston Health Science Center, Houston, Texas.

Hayes, A.E. (2012) *Factors in Decision Making Amongst Women of Childbearing age with a Brca1/Brca2 Mutation who are Faced with Prophylactic Mastectomy,* Southern University School of Nursing Graduate Nursing Programs' Clinical Research Project Presentation Day, Baton Rouge, LA, May, 7, 2012, 10 - 1:30 pm.

Poster Session

Predictors of Female Genital Mutilation/Cutting (FGM/C) Among Young Girls in Egypt.
Authors: Alexis Hayes MSN, APRN, FNP-BC; Ashley Hollins RN, APRN FNP-BC; Padmavathy Ramaswamy MSN, MPH, FNP & Vuong Tran MSN, BSN, RN
Clinical Research Project Presented April 9, 2016

AWARDS AND RECOGNITION:

2015	Patricia L. Starck Scholarship
2015	Crawford and Hattie Jackson Scholarship