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Measuring Levels of Preparation for Decision-Making and Patient Satisfaction in a

Breast Cancer Support Group

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A Clinical Research Project submitted to the Graduate Faculty of
JAMES MADISON UNIVERSITY

In

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Dedication

This study is dedicated to all the women who have graciously allowed me to support them through their breast cancer journey.

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I want to thank Dr. Erica Lewis, my project chair and also my preceptor Dr. Kristina Blyer, for providing me the continuing and ever available confidence, guidance, and support throughout this DNP journey. I would like to thank Dr. Tonja Locklear for her expertise and assistance in statistical analysis. A special thank you to Deidre Pennington, my devoted classmate, who consistently provided friendship, emotional support, and laughter throughout the truly unique pursuit of our DNP degrees. Another special thank you to Dr. Jeannie Garber for her steadfast guidance at two different institutions in my quest for my doctoral degree.

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Abstract

The Carilion Clinic Breast Diagnostic Center diagnoses approximately 250 women with breast cancer annually, all of whom are invited to attend the Carilion Clinic Breast Cancer Support Group (CCBCSG). The primary aim of this project was to evaluate if participants with more frequent attendance of CCBCSG had increased levels of preparation for decision-making (PDM) and higher satisfaction with breast cancer treatment decisions. A REDCap survey was emailed to 137 patients who participated in at least one CCBCSG within the past five years, with a 39.4% response rate. The survey assessed levels of patient PDM, patient satisfaction about treatment decisions, and asked the open-ended question, “What else would you like to share about your CCBCSG experience and treatment decision making?” Attendance for the CCBCSG was the independent variable with four levels: one meeting (27.8%), 2-5 meetings (24.1%), 6-10 meetings (20.4%) and 10+ meetings (27.8%). The non-parametric ANOVA test, Kruskal-Wallis, was used to test for differences in the PDM and patient satisfaction among the groups of participants, based on the number of support groups they attended. Descriptive analysis and testing of statistical assumptions were performed with all quantitative variables. Although the study demonstrated that though the PDMS scores were not statistically significantly different ($p=0.0934$) for the four attendance groups, trends demonstrated that those who attended the most meetings (>10) were more prepared for decision-making than any other group. Similarly, those who attended 10+ meetings were also statistically more likely to be satisfied with their experience ($p=0.0290$).

Keywords: breast cancer, decision-making, preparation for decision making,
breast cancer support groups, patient satisfaction

Breast Cancer Support Groups and Preparation for Decision-Making

Introduction

Rayter (2017) explains that cancer of the breast is an archaic health issue first illustrated in documents produced by the Egyptians 3000 years before Christ (BC). The author describes four evolutionary periods that explore the management of breast cancer, The Empiric period (3000-2500 BC) that documents the first surgical excision of the breast; the pessimistic period (131-203 AD), which combines surgery with holistic treatments such as application of milk and vinegar to the tumor to induce shrinkage and the usage of salicylic acid to eat the tumor away; the optimistic period (1757-1956 AD) that illuminates the efficacy of surgery and brings about the evolution of the radical mastectomy; and lastly the realistic period (1960 and ongoing) in which the understanding of the biology of breast cancer and technological advancements in imaging, medical oncology, surgical oncology and cancer prevention currently direct breast cancer treatment recommendations (Rayter, 2017). Rayter (2017) described the multitudes of treatment recommendations necessary for modern treatment decision-making (DM) in breast cancer.

Conversation in the United States among women about a diagnosis of cancer remained unacceptable until the onset of the twentieth century (Osuch et al., 2012). The advent of the founding of the American Society for the Control of Cancer (ASCC), which subsequently evolved into the American Cancer Society (ACS), provided the platform to begin the conversation about cancer and allowed individuals to reveal their diagnoses publicly. (Osuch et al., 2012). Rising awareness about cancer diagnoses resulted in the

development of support groups and catalyzed the formation of political activist groups (Osuch et al., 2012).

In 1970, Babette Rosamond finally gave voice to the diagnosis of breast cancer when she published a book about her experience *What Women Should Know About the Breast Cancer Controversy* (Osuch et al., 2012). In her publication, Rosamond challenged women to become involved in the treatment DM process surrounding their breast cancer diagnosis and not rely only on the advice of the physician; she emphasized a woman's right to decide what would be done to her body (Osuch et al., 2012).

Subsequently in 1974, Betty Ford propelled the civic conversation surrounding breast cancer by publicly speaking about her breast cancer diagnosis in a televised newscast, forever changing the way media would portray and cover the topic of breast cancer and advocate for support for those afflicted by the diagnosis (Dubriwny, 2009).

According to Desantis et al. (2016), breast cancer is the second most diagnosed cancer in women in the United States (US) other than skin cancer and that statistically, one in eight women will face the diagnosis. The American Cancer Society (ACS) (2017) reports that in 2017, there were 252,710 new cases of invasive breast cancer diagnosed, resulting in 40,610 deaths. The death rate declined to 1.3% from 1.9% from 2011-2017 (Augenstein, 2019). The Centers for Disease Control and Prevention (CDC) acknowledges that the risk for breast cancer is multifactorial, with the two most common risk factors being female gender and getting older (Centers for Disease Control and Prevention [CDC], 2019). Because of these risk factors, the average lifetime breast cancer risk for women is low; about 12% (CDC, 2019). There are greater than ten

different pathological diagnoses of breast cancer resulting in multiple treatment algorithms; the most common diagnoses include invasive lobular carcinoma (ILC) and invasive ductal carcinoma (IDC) (Nounou et al., 2015). It is important to note that the early detection of breast cancer is directly related to patient prognosis (ACS, 2017).

Women diagnosed with breast cancer face challenging decisions about their treatment choices and can face anxiety and high emotion at the time of breast cancer diagnosis (Kokufu, 2012). Unclear evidence and practical tensions among the treatment options can lead to DM conflict and subsequent negative emotions about their diagnosis (Lim & Shon, 2016). The investment in making treatment decisions and those who help shape the treatment decisions hold different significance for each woman, and many women seek guidance from multiple sources, including family and friends (Wallner et al., 2017). Many women, however, attend breast cancer support groups during that time to gather information and receive support, especially those who lack spousal, familial, or other means of support (Helgeson & Cohen, 2000).

The Carilion Clinic Breast Diagnostic Center (CCBDC), located in Roanoke, Virginia, is an outpatient diagnostic mammography facility, to which women of all ages come for diagnostic workups and biopsies for breast problems; breast biopsies result in the diagnosis of 250 breast cancers annually. The CCBDC also provides the setting and structure for The Carilion Clinic Breast Cancer Support Group (CCBCSG), established in 2002, which is a bi-monthly, free, facilitated, “rolling” support group; all women diagnosed with breast cancer at the CCBDC are invited to attend. The CCBCSG process involves a peer-to-peer discussion about each woman’s unique breast cancer experience,

diagnosis, and question exchange concerning emotional and social support and treatment DM. Women may attend the support group as many or few times as they choose.

The women who attend the CCBCSG, because of their local diagnosis, also share the care of the same breast cancer specialists. The congruence of breast cancer care allows for easy dialogue and comparison of treatment modalities, including medications, surgeries, and ancillary oncology therapies. The women who attend the CCBCSG have also created a “private” Facebook (FB) page; the CCBCSG invites all women who attend the group to join the FB page. The purpose of the FB page is to extend the “reach” of the face-to-face support group.

Background

Breast Cancer Support Groups

According to Gottlieb and Wachala (2007), cancer support groups provide the structure for a planned intervention for those diagnosed with cancer. Most purport that support groups involve recurring face-to-face meetings of a small number of survivors who share the common diagnosis of cancer (Gottlieb & Wachala, 2007). Van Uden-Kran et al. (2008) stress that people seek out support groups when faced with a serious illness or traumatic or stressful situations. Breast cancer support groups are highly ranked compared to other disease-related support groups for sharing information and navigating a breast cancer diagnosis (Till, 2003). A breast cancer support group provides the structure for women to seek out tangible emotional, social, and informational support and to meet others who may be struggling with similar health concerns and treatment choices (Namkoong et al., 2010; Setoyama, Yamazaki, & Nakayama, 2011). Nationally, breast

cancer support groups vary in structure such as open versus closed participation, weekly versus monthly meetings, and educational sessions versus peer support (Cella et al., 1993; Gottlieb & Wachala, 2007). The groups also happen during various phases of illness, including the diagnostic phase, the treatment phase, the recovery phase or the phase of palliative care, as well as vary in length of group sessions (Zabalegui, Sanchez, Sanchez, & Juando, 2005).

Zabalegui et al. (2005) claim that a support group for those with cancer serves four basic goals: to permit expression of feelings about living with cancer, to nurture mutual support of participants in the group, to inform group participants about the illness and treatment options available, and to improve group members coping skills to resolve emotional conflict. The structure of support groups provides a beneficial intervention for patients with cancer resulting in improvements in quality of life, coping and social relations as well as providing a venue to find understanding, and receive personal interaction to receive ideas and advice about treatments (Zabalegui et al., 2005; Winefield, Coventry, Lewis, & Harvey, 2003).

Decision-Making and Breast Cancer Support Groups

Miriam Webster defines decision-making (DM) as “the act or process of deciding something, especially with a group of people” (2019). Reyna, Nelson, Han, & Pignone (2015) purport that most unaware people believe that a cancer treatment decision is straight-forward -- either opt for the treatment that prolongs life or maximizes the life expectancy from the disease. The authors stress that treatment decisions are much more difficult and are often complicated by the ambiguity surrounding the effectiveness of

treatment and the balance of risk versus harm (Reyna et al., 2015). Patient treatment DM involves reviewing all treatment options, researching the pros and cons of each option, narrowing treatment choices to pursue, and making the final treatment choice, all of which must be done to reach a final decision outcome (Reyna et al., 2015).

Weber, Solomon, & Meyer (2013) conclude that a diagnosis of breast cancer necessitates that women make multiple decisions about their breast cancer treatments. An enhanced perception of urgency associated with a new diagnosis of breast cancer can affect the treatment DM process by women diagnosed with breast cancer (Kokufu, 2012; Brown et al., 2012). Women diagnosed with breast cancer expect emotional and substantial support in the process of treatment DM (Lim & Shon, 2016).

Patients who are directly involved in the process of treatment DM make more significant and effective progress on all decision-related outcomes (Brown et al., 2012). There is evidence about online support groups and the effects of DM and insight into how support groups may assist in the process of preparation for decision-making (PDM). Silence (2013) examines the way that cohorts exchange information in an online breast cancer support group for use in DM. Study results detail that most women ask for advice by disclosing information about their diagnosis or asking for opinions; women structure questions to target similar people, and most advice-solicited is for social or emotional support (Silence, 2013). Similarly, Wallner et al. (2016) and Bruce, Tucolka, Steffens, & Neuman (2015), examine the use of online breast cancer support for DM. The authors explore how much women with breast cancer utilize online resources for treatment DM, and if it helped their decisions (Wallner et al., 2016). Study results found that frequent

users of online information had more positive experiences with treatment decisions than infrequent users (Wallner et al., 2016). Bruce et al. (2015) evaluate the quality of online information to support treatment DM for breast cancer. The study concludes that many websites exist for women diagnosed with breast cancer to seek information about DM; however, most do an inadequate job of providing reliable and prerequisite details necessary for adequate treatment DM. Although there is less evidence about treatment DM for women experiencing breast cancer who elect to attend in-person support groups, strong evidence in this area for online support groups that DM is a worthwhile outcome to measure. Moreover, the known complexity of the decision at hand further supports this measure.

Patient Satisfaction and Breast Cancer Support Groups

Jefford and Tattersail (2002) relay that patient acquisition of health information about a cancer diagnosis and treatment options are beneficial, and results in an increase in patient satisfaction and clinical outcomes. Women diagnosed with breast cancer often attend support groups to glean treatment information, but the question remains whether the attendance of a support group is a satisfying experience? Review of the literature reveals two studies that measure patient satisfaction from the attendance of a breast cancer support group, suggesting that patient satisfaction is an important outcome measure for such groups.

Glachen and Magen (1995) conducted a pilot study that evaluated the process, outcomes, and satisfaction in three different types of community-based breast cancer support groups that meet over an eight-week period. The authors noted that a group

facilitator was present at the meetings and that members of the group provided the agenda for each meeting (Glachen & Magen, 1995). Meeting attendees, after conclusion of the group process, received a post group satisfaction questionnaire that inquired about group process and consumer satisfaction about the group. The questionnaire contained three consumer satisfaction questions, and two open-ended questions inquiring what each patient liked or disliked about the group (Glachen & Magen, 1995). Survey outcomes revealed that on a Likert scale of 1-5, one being dissatisfied and five being very much satisfied, their experience rated 4.61, inferring that clients are very satisfied with the support group experience (Glachen & Magen, 1995).

Morse, Gralla, Petersen, & Rosen (2014), explored patients and care-givers partialities in the support group process and content to be discussed at a support group to evaluate the members' satisfaction with the group experience. The cross-sectional design of the study included demographic and clinical variables, including perception of social support, and compared information between patients and the caregivers who attended the group (Morse et al., 2014). Variables included demographic and background data, topic importance ratings, and social support; group satisfaction was compared between patient and caregiver using chi-square (Morse et al., 2014). Nine hundred thirty-four participants reported group satisfaction data, resulting in group satisfaction ratings of 43% and 33% from patients and caregivers, respectively; fewer than half of those participating in the group reported satisfaction with the experience (Morse et al., 2014).

Preparation for Decision-Making Scale Used in a Breast Cancer Support Group

Hawley, Newman, Griggs, Kosir, & Katz (2016) explored the use of a decision aid/intervention for improving DM in patients with breast cancer. The authors relayed that provision of an interactive decision tool or platform assisted patients with difficult treatment decisions (2016). Bennett et al. (2010) communicated that the use of patient decision aids is helpful in treatment DM because they provide options, clarify values, and add to recommendations made by the health care provider. This study evaluated the validity of the preparation for DM scale, which was used to evaluate levels of preparation for DM gained from the use of decision aids/interventions; only 68 studies reference the preparation for DM validation study (Bennett et al., 2010).

Stacey et al. (2012) explored cancer treatment-decision making and examined the extent that cancer patients perceived they were involved in the DM process, and what specific factors influenced their decisions. Stacey et al. (2012) used the PDMS as one of their instruments in this descriptive study. Results reveal that patients were more involved in the DM process when offered decision choices, but the study did not involve or use a breast cancer support group as the decision aid/intervention to improve preparation for DM (Stacey et al., 2012). Literature review reveals no evident studies that evaluate or measure levels of preparation of DM resulting from attendance of a breast cancer support group.

Theoretical Framework

In 1965, a group of community leaders from healthcare and business-related organizations convened to discuss factors that affected public health, such as social and economic research, the structure of community health organizations, and health care

quality (Ayanian & Markel, 2016). Among this group of leaders was Avedis Donabedian, who at the time was a medical school professor contracted to evaluate research specific to the assessment of healthcare quality (Ayanian & Markel, 2016). Donabedian's research led to the publication of "Evaluating the Quality of Medical Care" in 1966, which outlined the make-up for his theoretical framework of health care quality (Donabedian, 2005).

Donabedian's theoretical framework is composed of the three components of structure, process, and outcomes, which assess health care quality (Donabedian, 2005). Donabedian defined "structure" as the health care setting, provider qualifications, staffing, and health care equipment; "process" as the elements and appropriateness of care delivery and evaluation of medical error; and "outcomes" as progression of illness, survival, and complications in care or illness (Donabedian, 2005).

Donabedian's framework provides the optimum platform for this scholarly project. The CCBCSG provides the support group (structure) with interactive discussion (process) in place. The assessment of increased levels of preparation for DM through participation in the CCBCSG and levels of patient satisfaction will provide the outcomes for the study (see Figure 1).

Problem/Purpose/Aims

Women who attend the CCBCSG state anecdotally, that the face-to-face support group process is fulfilling and provides a platform that assists in making satisfying

treatment decisions and building lasting friendships and support. The women also report regret when they must miss a meeting.

Despite anecdotal local evidence, and evidence in the literature to support positive outcomes for breast cancer support groups, it is problematic that there is no assessment of the outcomes for patient's PDM and higher patient satisfaction for the local CCBCSG. Thus, the purpose of this project was to complete an evidence-based assessment of these outcomes for the local CCBCSG.

The primary aim of this project was to evaluate if participants with more frequent attendance of CCBCSG have increased levels of PDM and higher satisfaction with breast cancer treatment decisions. The secondary aim was to identify other potential outcomes of group attendance.

Methods

Survey Implementation

This evidence-based study was a cross-sectional survey that included the PDMS instrument and single item demographic question created by the research team. The study was mixed method in design. Approximately 137 participants who have attended the CCBCSG from 2014-2019 were recruited via an emailed survey that they were asked to complete and return. A reminder email was sent to the participants who had not responded to the survey, 2 weeks after the first survey had been sent as suggested by Dillman, Tortora, & Bowker, 1998). Survey design followed the recommendations of Dillman et al. (1998) to keep coverage error, sampling error, measurement error, and non-response error low. Survey design began with a motivational welcome screen that

provided simple instruction on actions needed to continue to the next page to begin the survey (Dillman et al., 1998). Each question in the survey was constructed in a similar format. Survey questions were easy to comprehend and limited in length (Dillman et al., 1998). The format of the survey allowed the respondent the ease of scrolling from question to question to complete it (Dillman et al., 1998). Carilion Clinic's REDCap (Research Electronic Data Capture) (Harris et al., 2019) software was used as the central location for data collection. Key facilitators for this study included support from the REDCap (Harris et al., 2019) team in survey design, data collection, and data analysis. REDCap (Harris et al., 2019) provided a secure, web-based application designed to support data management and collection for research/QA/QI studies. Carilion's REDCap (Harris et al., 2019) servers are securely housed on-site in a limited access data center, and all data are stored on Carilion's firewall-protected network. The Health Analytics Research Team (HART) supported the proper development of the project and survey in REDCap (Harris et al., 2019), observing appropriate change control and enforcing appropriate security controls. Data collection projects were built with a study-specific data dictionary, enforcing intuitive, accurate, consistent, and complete data entry. REDCap (Harris et al., 2019) also provided a survey tool for building and managing online surveys. The time frame to review returned surveys was one month from the first recruitment email. The HART team analyzed all collected data using SAS Enterprise Guide version 7.11 (SAS Institute, 2015).

Demographics

The REDCap (Harris et al., 2019) survey contained demographic questions, as well as the survey instrument. For the demographic section, patients were asked to identify their race, age, preferred language, access to the internet and type of breast cancer diagnosis.

Preparation for Decision-Making Scale

The REDCap (Harris et al., 2019) survey also contained the instrument for the study, which was the well-validated (Bennet et al., 2010) PDMS instrument from the Ottawa Hospital Research Institute (The Ottawa Hospital Research Institute [OHRI], 2019). The PDMS instrument can be found in Appendix A. The internal consistency in the validation article ranged from $\alpha=0.92$ to $\alpha=0.96$, which is very strong (Bennett et al., 2010). Additionally, the authors relayed that this scale/instrument, specific to practice implications, is well designed to evaluate the complex healthcare decisions patients must make.

Satisfaction with Treatment Decisions

The REDCap (Harris et al., 2019) survey contained one Likert-type, five-level patient satisfaction question. The patients were asked to choose a level of satisfaction (very satisfied – 1 to very unsatisfied – 5) with treatment decisions. The question and response choices can be found in Appendix B.

Qualitative Assessment

The REDCap (Harris et al., 2019) survey included the open-ended question, “What else would you like to share about your CCBCSG experience and treatment decision-making?”. This question was used to investigate the secondary aim of this study, to identify other potential outcomes of group attendance.

Ethical Considerations

Institutional Review Board (IRB) approval was obtained from the Carilion Clinic Healthcare System and James Madison University to perform this study. Patients performed a waiver of written verification of consent by completing the survey. There were no ethical concerns for patients participating in this study. There was no direct benefit to individuals who participated in this study, outside of knowing that their feedback may contribute to science at large. There was a potential benefit to the local healthcare system since findings may guide the system in its evaluation of the CCBCSG and potentially build understanding of outcome measures for other similar support group programs. These findings may also be helpful to oncology nurses as they work with administration to develop these programs. These findings may also be used to begin testing outcomes for other local support groups. Moreover, publications of this work may inform the science on this topic such that future scientists know whether to research PDM and satisfaction as outcomes for breast cancer support groups and hence benefit nursing and medical science. One potential conflict of interest is that the study primary investigator works within this system and has work responsibilities for the support group. This risk was mitigated by including other expert researchers and clinical experts in all aspects of the study design, implementation, and analysis.

Analysis

Descriptive analysis was completed for all quantitative variables. Counts, percentages, standard deviations, and means were calculated as appropriate for each variable. Attendance frequency was calculated by the patients' responses to the survey question pertaining to the number of times they participated in the group sessions.

PDMS

The PDMS instrument consisted of ten Likert-type questions with the higher score indicating a higher level of PDM. The PDMS score was calculated by totaling all 10 items in the instrument and dividing the sum by ten following methods recommended by Bennet and colleagues (2010).

Patient Satisfaction

The patient satisfaction rating was determined from the Likert-type response to one specific satisfaction question, "Overall, how satisfied are you with your experience of attending the CCBCSG to help you make breast cancer treatment decisions?" Mean patient satisfaction scores were calculated by averaging the patient satisfaction scores for each patient included in each attendance group. A lower patient satisfaction score indicates a patient with a higher level of satisfaction (i.e., 1-very satisfied, 5-very unsatisfied).

Testing of Differences

The, Kruskal-Wallis test, was used to test for differences among the groups of participants, based on the number of support groups they attended, to determine whether there were differences in PDM and patient satisfaction (Aim 1).

Narrative Analysis

An open-ended question, “What else would you like to share about your CCBCSG experience and treatment decision making?” was used to collect qualitative data on participants to identify any additional potential outcomes of support group attendance (AIM 2). Qualitative content analysis followed Graneheim and Lundman’s 2004 procedures to describe responses to the open-ended question (Aim 2) (Graneheim & Lundman, 2004). For this, all participant comments were broken down into the simplest meaningful unit, coded, grouped into categories, and used to identify themes (Graneheim & Lundman, 2004). Quantitative data were entered into SAS Enterprise Guide version 7.11 (SAS Institute, 2015) for analysis. Qualitative research data relied on Sandelowski’s (2001) assertion that numbers are valuable in presenting qualitative work to establish its worth, document what is identified about the research topic, describe the study sample, and generate meaningful data.

Results

Out of the 137 surveys sent to participants of the CCBCSG, 55 surveys were answered. One survey was not completed; therefore, 54 patients completed the survey and were used in the analysis for a 39.4% response rate. Attendance for the CCBCSG,

the independent variable, was categorized into four groups: one meeting (27.8%), 2-5 meetings (24.1%), 6-10 meetings (20.4%) and 10+ meetings (27.8%).

Demographic Information

Most patients who completed the survey were English speaking (90.7%) and Caucasian (98.1%). 55.6 % of the patients who completed the survey fell into the age range of 30-49 years. Additional demographics can be found in Table 1. Two breast cancer types, Ductal Carcinoma in Situ (DCIS) and Invasive Ductal Carcinoma (IDC), accounted for 74.1 % of all patients' self-reported breast cancers. Additional breast cancer information is provided in Table 2.

PDMS Score

The PDMS scores were not statistically significantly different ($p=0.093$) based on the attendance groups. Out of the potential ranges of meeting attendance of 10+, 6-10, 2-5, and 1, those patients who attended 10+ meetings had the highest PDMS score ($M=4.35$, $SD=0.78$) and those who attended only one meeting had the lowest PDMS score ($M=3.33$, $SD=1.34$) (see Figure 2). For the patients who attended 2-5 meetings and 6-10 meetings, their PDMS average scores were 4.08 ($SD=0.77$) and 3.53 ($SD=1.63$), respectively.

Patient Satisfaction Score

Patients who attended 10+ meetings were the most satisfied (mean=1, $SD=0$) with all 15 patients selecting "very satisfied" as their response to the patient satisfaction question. Those who attended only one meeting were the least satisfied (mean=1.87, $SD=1.30$). For the patients who attended 2-5 meetings and 6-10 meetings, their average

satisfaction scores were 1.15 (SD=0.38) and 1.45 (SD=0.69), respectively (See figure 3). The overall patient satisfaction score was statistically significantly different ($p=0.0290$) among the four different attendance group levels. A posthoc analysis (Dwass, Steel, Critchlow-Fligner Method) was used to determine which levels were statistically different from one another. The analysis indicated that people who attended 10+ meetings were statistically more satisfied ($p=0.038$) with their overall experience than those who attended only one meeting.

Qualitative Assessment

The open-ended question (“What else would you like to share about your CCBCSG experience and treatment decision-making?”) used for the qualitative analysis was completed by 38 (70.4%) of the 54 participants. 34 of the 38 participants (89.5%) claimed to gain some form of support from attending the support group sessions (see figure 4). Keywords used in patient responses were “supportive”, “sisterhood”, “empowering”, “reassuring”, “valuable”, “companionship”, etc. Four out of the 38 patient responses (10.5%) to the qualitative question did not claim to receive any support from attending group sessions, because of finding their diagnosis harder to discuss with strangers and experiencing increased stress after listening to others’ testimonials.

Discussion

This study intended to investigate if patients who had a more frequent attendance of CCBCSG had higher levels of PDM and satisfaction with treatment decisions. Hawley et al. (2016) explored the use of a decision aid for improving patient treatment DM, but to the best of our knowledge, this study is the first to use the PDMS instrument as a decision

aid to measure levels of preparation for PDM in a breast cancer support group. The results of this study indicate that while attendance frequency may be important to patient outcomes other factors are also likely important and that more information is needed not only about the frequency of attendance but also about support group characteristics such as meeting mode (in-person vs. online) and group dynamics.

Weber et al. (2013) supported that a breast cancer diagnosis requires that women must make multiple decisions about their treatment. Brown et al. (2012) also claimed that patients who are directly involved in their process of treatment DM make more meaningful and effective progress on all decision-related outcomes. The study demonstrated that even though the PDMS scores were not statistically significantly different ($p=0.093$) for the four attendance groups, the analysis supported that patients who attended the CCBCSG most often (10+) had a higher level of PDM than any other group. Additionally, one-half of the patient qualitative survey responses specifically mentioned decision-making as a benefit of group attendance such as, “It’s extremely helpful to bounce ideas off other women who are facing the same decisions,” “There is support for any and all decisions to be made even when women make different choices. Someone else has always been there first. No judgment, ever. Unconditional,” and “The group helps me make choices about my treatment and the results I want to experience.”

Together these findings indicate that some participants find support groups help them to prepare for DM specifically and that either those who attend most often are likely to feel prepared to make decisions or conversely those who feel prepared to make decisions subsequently elect to attend more frequently. This indicates that PDM is an

important outcome measure for breast cancer support groups and that more research is needed to better understand the relationship between attendance, attendance frequency, and PDM.

Conversely, some participants do not find support groups to be helpful. One outlier comment was that the group was “the worst experience of my breast cancer journey”. However, others too found this group to be less supportive.

Based on the quantitative results the question remains whether persons who were most satisfied attended the group more often; a logical conclusion. However, the qualitative comments enrich the understanding of this support. Approximately one-half of the survey responses also mentioned patient satisfaction as a direct benefit of group attendance such as “This group helped with the feeling of being overwhelmed,” and “The CCBCSG offered me a lifeline during my cancer treatment, and I hung on tight! I continue to feel empowered by the information and support the group provides.”

The qualitative analysis of the study corroborates Zabalegui et al.’s (2005) claim that a cancer support group serves four basic goals: permits expression of feelings, nurtures mutual support, informs participants about treatment options, and improves coping skills. Lim and Shon (2016) also reported that women with a new breast cancer diagnosis expect emotional and substantial support with treatment DM. Examples from the CCBCSG survey respondents’ statements supporting these findings and included “The group changed my entire perspective on my cancer, my treatment, and the importance of having a safe place to talk with other survivors,” and “I am inspired by all

the women in the group and do not feel alone in my diagnosis and decisions I have facing me.”

Interestingly, participants continued to participate in the support group process because they wanted to help support those women who were newly diagnosed with breast cancer and help them begin making treatment decisions and provide emotional support. Two direct participant responses supporting this finding stated “The support group has been such a help to me and I appreciate the feeling that it provides the opportunity to be helpful to other members,” and “Most of my decisions were already made before I joined the group – I’m several years out, so I benefit from attending in other ways that are supportive to me and others.”

Zabalegui et al. also (2005) noted that women attend support groups during various phases of illness. This study, however, did not collect data that would correspond to each specific phase of illness the support group attendees were experiencing as they attended group meetings. Further research could explore what treatment phases were the most common for group attendance.

Limitations

The study sample was limited in size and diversity and, therefore, not likely to be representative of the full population of patients who have attended the CCBCSG over time. The findings also may not be generalizable to all patients who have attended the CCBCSG. The data for the study collected may have been influenced by recall bias as to how many meetings may have been attended. Some patients may have already made a treatment decision before attending the CCBCSG, therefore reducing the impact group

attendance would have on their PDM. Older patients or those with less technical savvy may have had a harder time understanding and completing an online survey. There were no significant barriers to the study due to administrative and HART team support.

Constructive consequences of the project included that respondent groups, as a consequence of self-selection of survey answers, were evenly distributed and that all 15 group members who attended 10+ meetings noted that they were very satisfied with the group. The negative open-ended comment that touted the group as “the worst experience of my breast cancer journey” was an unintended negative consequence of the study.

Implications

The current study increases the knowledge of nurses and other breast cancer care providers about how attendance of a breast cancer support group can assist patients in making important and satisfying treatment decisions. The study highlights the role that oncology nurses can hold as advocates for their breast cancer patient population. It also allows the realization of the value that breast cancer support groups afford their patients to share comparable experiences and exchange information with others in similar circumstances. Oncology nurses are in a strategic position to implement and develop cancer support groups within their institutions and garner administrative support in order to sustain them. The evaluation of treatment DM in a breast cancer support group in this study may be used as an exemplar for other institutions when evaluating the best survivorship care for their cancer patient populations.

Conclusion

Many patients diagnosed with breast cancer need to obtain satisfying information about treatment DM and receive support throughout their cancer journey. This study demonstrates that women who have more frequent attendance of a breast cancer support group can gain satisfying support in making treatment decisions through support group attendance. Further research could include investigating if support group attendance is more beneficial to patients in different phases of their illness, as well as investigating the benefits women who continue coming to a support group get out of supporting others with a new diagnosis.

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Appendix

Appendix A – Patient Preparation for Decision Making Scale

Appendix B – Single Item Satisfaction Question

Appendix C – Table 1 – Patient Demographics

Appendix D – Table 2 – Breast Cancer Type

Appendix E – Figure 1 – Donabedian Model

**Appendix F – Figure 2 – Preparation for Decision Making Average Scores Per
Attendance Groups**

Appendix G – Figure 3 – Overall Patient Satisfaction Ratings

Appendix H – Figure 4 – Aim 2 Results – Qualitative Assessment

Appendix A – Patient Preparation for Decision Making Scale

Preparation for Decision Making Scale

Definition - The Preparation for Decision Making scale assess a patient’s perception of how useful a decision aid or other decision support intervention is in preparing the respondent to communicate with their practitioner at a consultation visit and making a health decision (treatment/diagnostic/screening, etc.)

Preparation for Decision Making Scale

Please show your opinion of the **Carilion Clinic Breast Cancer Support Group (CCBCSG)** by circling the number to show how much you agree with each statement.

		Not at all	A little	Somewhat	Quite a bit	A great deal
	Did the CCBCSG....					
1.	Help you recognize that a decision needs to be made?	1	2	3	4	5
2.	Prepare you to make a better decision?	1	2	3	4	5
3.	Help you think about pros and cons of each option?	1	2	3	4	5
4.	Help you think about which pros and cons are most important?	1	2	3	4	5
5.	Help you know that the decision depends on what matters most to you	1	2	3	4	5
6.	Help you organize your own thoughts about the decision?	1	2	3	4	5
7.	Help you think about how involved you want to be in this decision?	1	2	3	4	5
8.	Help you identify questions you want to ask your doctor?	1	2	3	4	5

9. Prepare you to talk to your doctor about what matters most to you?		1	2	3	4	5
10. Prepare you for a follow-up visit with your doctor?		1	2	3	4	5

Preparation for Decision Making Scale © JD Graham, AM. O’Conner 1995, revised 2005

Directions for Use

This questionnaire is administered after a patient visits their practitioner to discuss treatment options, etc.

Scoring and Interpretation

- a) Items can be summed and scored (sum the 10 items and divide by 10).
- b) Scores can be converted to a 0-100 scale by: subtracting 1 from the summed score in part a) and multiplying by 25.

High scores indicate higher perceived level of preparation for decision making.

Psychometric Properties

Alpha coefficient ranges from .92 to .96 [1,2,4] Item-total correlation analyses were also high (0.75-0.81).[4]

Scale discriminates significantly between different decision support interventions [1,4]; the effect size is 1.8 [1]

Total test reliability is high at 0.944. [4]

Appendix B – Single Item Patient Satisfaction Question

“Overall, how satisfied are you with your experience of attending the Carilion Clinic Breast Cancer Support Group to help you make breast cancer treatment decisions? “

Circle one response.

Very Satisfied Satisfied Neutral Unsatisfied Very Unsatisfied

Appendix C – Table 1 – Patient Demographics

Table 1

<i>Demographics</i>	
Variables	N (%)
Race	
Caucasian	53 (98.1%)
African American	1 (2.0%)
English Speaking	
Yes	49 (90.7%)
No	5 (9.3%)
Age Range	
30-49	11 (20.4%)
50-69	30 (55.6%)
70+	13 (21.4%)
Access to Internet	
Yes	53 (98.1%)
Blank	1 (1.9%)

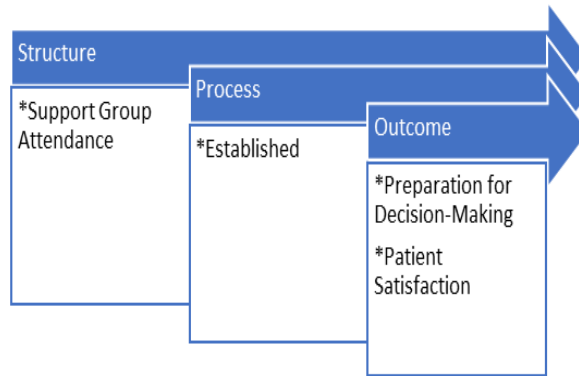
Appendix D – Table 2 – Breast Cancer Type

Table 2

<i>Breast Cancer Type</i>	
Types	N (%)
Ductal Carcinoma in Situ (DCIS)	11 (20.4%)
Lobular Carcinoma in Situ (LCIS)	1 (1.9%)
Invasive Ductal Carcinoma (IDC)	29 (53.7%)
Invasive Lobular Carcinoma (ILC)	8 (14.8%)
Inflammatory	1 (1.9%)
Other (ACC and Triple Negative)	2 (3.7%)
Blank	2 (3.7%)

Appendix E – Figure 1 – Donabedian Model

Figure 1. Donabedian Model



Appendix F– Figure 2 – Preparation for Decision Making Average Scores Per Attendance Groups

Figure 2. Preparation for Decision Making Average Scores Per Attendance Groups

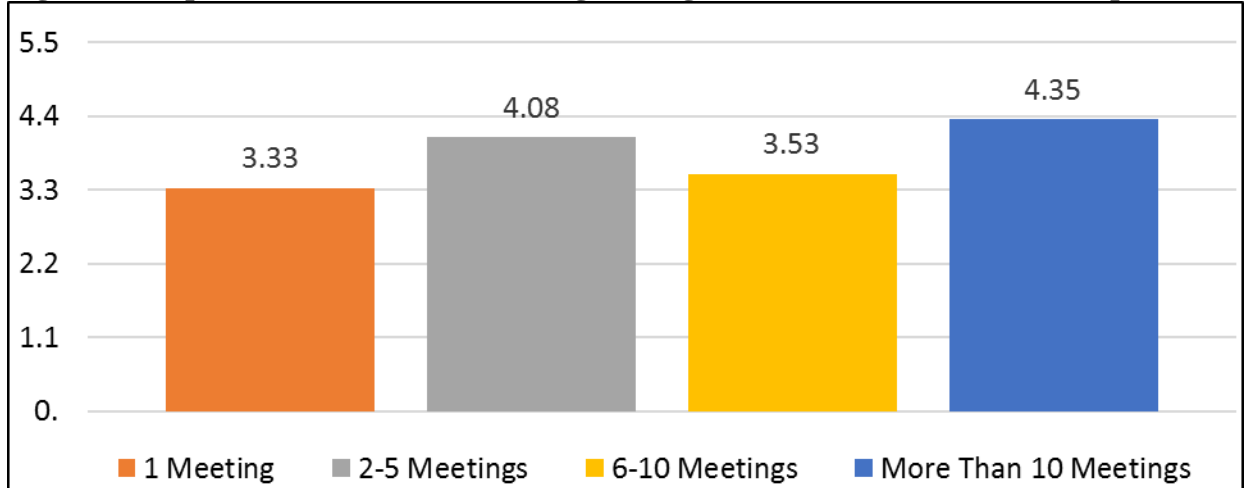
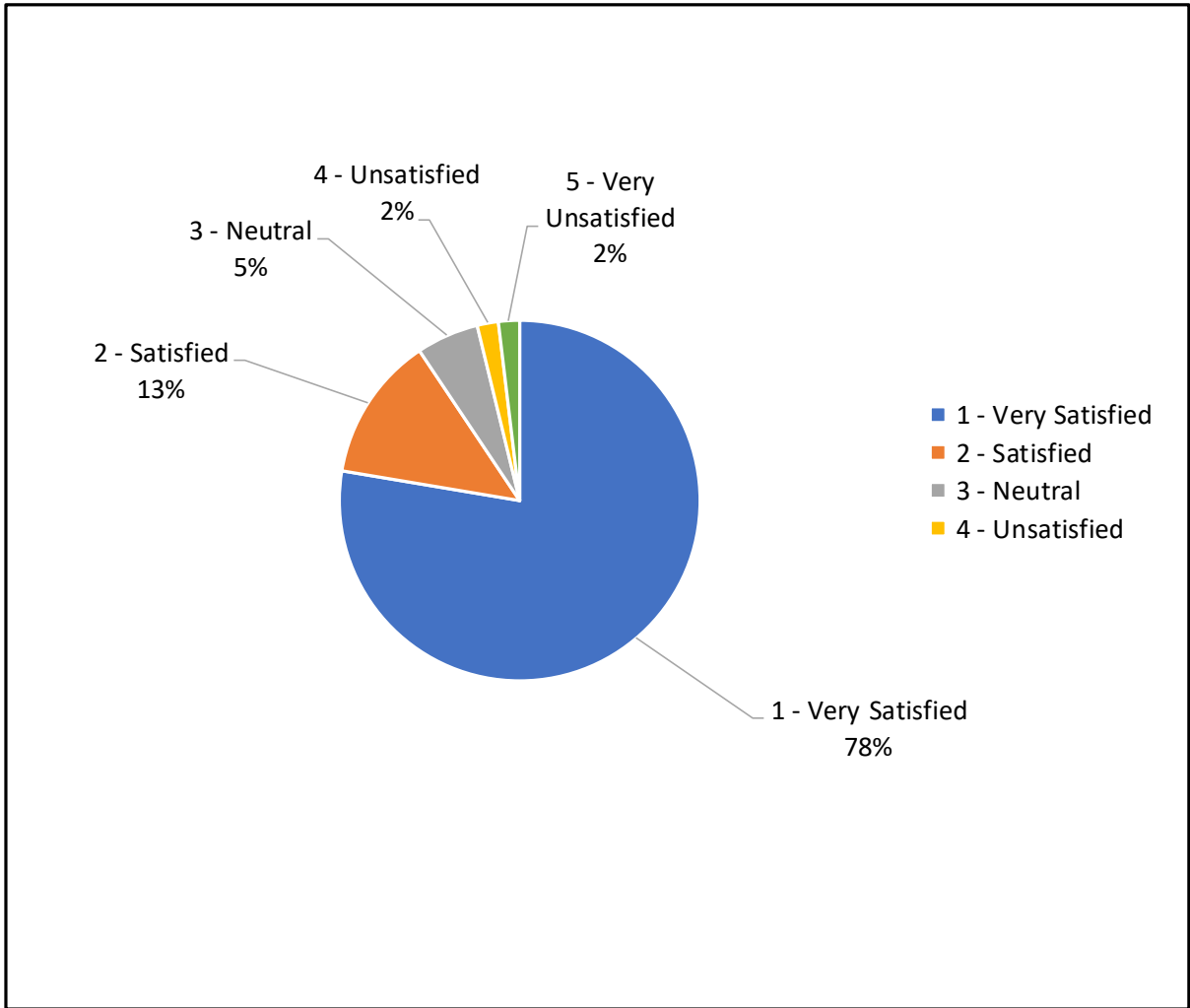


Figure 1. The PDMS Score was not statistically significantly different ($p=0.093$) between the four attendance groups.

Appendix G – Figure 3 – Overall Patient Satisfaction Ratings

Figure 3. Overall Patient Satisfaction Ratings



Appendix H – Figure 4 – Aim 2 Results – Qualitative Assessment

Figure 4. Aim 2 Results - Qualitative Assessment

