BREAST CANCER SURVIVORS' PREFERENCES AND BARRIERS RELATED TO DIET AND PHYSICAL ACTIVITY INTERVENTIONS DURING THE COVID-19 ERA

BY

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THESIS

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ABSTRACT

Purpose: Establish the perceived preferences and barriers related to breast cancer survivors' diet and physical activity (PA) programming to inform future optimal diet and exercise combined intervention development in such a post-COVID-19 era.

Methods: This was a cross-sectional study of 224 breast cancer survivors (BCSs) aged 18 years or older and diagnosed with ductal carcinoma in situ (DCIS) or Stage I-IV breast cancer (BC). The BCSs were recruited during routine oncology appointments at a Midwestern cancer center. A survey was conducted to query survivors' level of interest in, preferences for, and perceived barriers to participating in an exercise and dietary intervention program. The acceptability of a technology-based intervention was assessed. Data was also analyzed with pre- and post-COVID-19 comparisons.

Results: More than half of BCSs were interested in participating in a research study about exercise and diet intervention. The most-reported preferred timing(s) for participating in diet and exercise programming were immediately after diagnosis or immediately following treatment. Most participants preferred to meet in person with a Registered Dietitian Nutritionist or an exercise specialist. Participants preferred to receive nutrition and exercise education or counseling in one-on-one sessions and to receive nutrition and exercise information were from written materials such as educational handouts (Nutrition: 77%, Exercise: 69%), in-person (Nutrition: 67%, Exercise: 75%), or via internet/technology-based methods (Nutrition: 62%, Exercise: 59%). The most-reported participation barriers were the lack of extra time and energy that came from family responsibility, work, or lack of time, and physical issues such as fatigue, illness, and surgery. Most of the participants had a tablet, a smartphone that could download

applications, and high-speed internet. More than half of the participants reported being comfortable using their tablets and their smartphones. The most-reported social media or visual communication platforms that they used were Facebook, YouTube, and Pinterest. Thirty Night% of the participants indicated being comfortable participating in a technology-based nutrition and exercise program. The reported preferred delivery modes for program participation were website, mobile applications (apps) for smartphones or tablets, and e-mails.

During the post-COVID-19 period, BCSs' reported increased likeliness to participate in a BC research study testing the benefits of this diet and exercise intervention. Decreases were seen in the percentages of participants who preferred to meet with nutrition or an exercise specialist in person, in addition to receiving nutrition ($p<0.05$) or exercise information in person or to receive nutrition or exercise education/counseling in one-on-one sessions during the post-COVID period. There were also higher preferences for using visual communication tools (e.g., Skype or FaceTime) the most to receive nutrition and exercise information ($p<0.05$) and for meeting with the health specialists via distance-based methods using technology or and. Program participation barriers because of physical issues (e.g., fatigue, illness, surgery) were reported in slightly higher percentages during the post-COVID-19 period. There was lower comfort with using their smartphones (76% pre, 57% post) among BCSs. Increased percentages were seen in those who used high-speed internet (85% pre, 90% post), social media platforms to look for healthy living information (increased by 18%). The top three social media platforms with increased usage percentages were YouTube ($p<0.05$), Instagram and Facebook. Besides, higher percentages were also seen in those who were comfortable with participating in a technology-based nutrition and exercise program (35% pre, 46% post), and those who chose "no preference" (3% pre, 14% post)

or “visual communication tools” (11% pre, 20% post) as their preferred technology delivery modes to participate in such a combined program.

Conclusion: Participants had enthusiasm about nutrition and exercise intervention, different participation preferences for different service types, and barriers of physical issues (e.g., fatigue, illness) and poor energy and time (e.g., family responsibility, work) to their participation in a diet and exercise intervention. Data from the post-COVID-19 showed not only BCSs’ increased participation interests but also their increased programming participation challenges (e.g., physical and COVID-19 related issues). Strategies should be developed to help participants of combined diet and exercise interventions overcome these barriers to participation. There is a great potential in delivering health care services via technology among BCSs, which addresses BCSs’ participation barriers related to geographic location or the COVID-19 lockdown and reduces their physical discomfort from traveling because of disease or treatment-related symptoms. However, support will be needed to address BCSs’ discomfort or unfamiliarity in using technology if they are to participate in any technology-based programs. Future studies should take the specific service preferences, perceived barriers learned from this survey into consideration and investigate in a real-world context during the COVID-19 pandemic to tailor an optimal diet and exercise combined intervention.

Keywords: diet, exercise, preferences, barriers, breast cancer, technology, COVID-19

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Dedication

To Kenneth Ing

Words are not enough to describe your influence on my choosing this path. We'll meet again.

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CHAPTER 1: INTRODUCTION

Among females worldwide, BC is the most common cancer [1]. In 2021, about 281,550 new cases of invasive BC will be diagnosed in American women. The average lifetime risk of a woman in the United States developing BC in her life is about 13%, which means that there is a 1 in 8 chance she will develop BC [2]. Generally, individuals with BC, especially in advanced stages, experience a compromised quality of life, which can be attributed to sociodemographic [3], physical and psychological factors [4], including the life-threatening nature of the disease, treatment burden [5], impaired body and social functioning, body image distress [6] and the fear of disease recurrence and mortality [7]. With notable recent improvements in BC survival rates due to earlier detection and advances in treatment modalities, there were 7.8 million living BCSs between 2015 and 2020 worldwide [2]. Given the growing number of BCSs, investigating optimal supportive care interventions to supplement traditional cancer treatment with the goal to preserve and improve BCSs' health related quality of life (HRQoL), physical functioning, and overall survival rate are considered important to this population [8].

PA at a moderate intensity benefits not only healthy individuals due to its effects in disease prevention [9,10] but also BCSs for its effects in quality-of-life preservation and improvement [11-13]. Current findings also suggest that PA interventions targeting BCSs have positive outcomes [14-16]. It is expected that these PA interventions will also require concurrent nutritional support because overweight and obesity increase the risks of development and death in BC [17,18]. and many BCSs experience significant weight gain often after a BC diagnosis [19]. Despite some mixed results, there is encouraging evidence supporting the efficacy of dietary interventions on numerous health outcomes in BCSs [20-22]. Thus, it is vital that these

healthy lifestyle behaviors are maintained over time to achieve significant long-term health benefits [16]. More research on the benefits of combined diet and PA interventions is needed. There are still concerns, including BCSs' failure to meet the recommended amounts of nutritional intakes and PA [23-25], their special care needs, and the lack of manipulation strategies, to design an intervention.[26] Therefore, more research on developing optimal PA and diet interventions considering BCSs' unique interests, comfort, preferences, and barriers are necessary to increase their participation and adherence to lifestyle interventions.

Technologies have emerged as powerful tools for health professionals to share health-related information and connect patients with professional guidance and services while reducing in-person interactions [27]. Studies show that the interaction between health professionals and cancer survivors using information communication technology appears to be increasing for cancer care and lifestyle intervention [28-29]. Studies show an increased reliance on internet-based health care communication (e.g., web-based, e-mail and text messaging) to obtain health-related information or to participate in home-based delivery of lifestyle interventions among general cancer survivors [30-32]. Interventions delivered via technologies represent convenient approaches that can potentially reduce treatment burden as well as disruption to cancer survivors' lives and integrate distance-based personalized care and reassurance [33]. However, it is vital to consider individual and environmental factors when tailoring interventions to ensure engagement promotes benefits rather than extra burdens for the population. The breakout of the COVID-19 pandemic has placed immense pressure on health care systems worldwide, which resulted in a significant impact on the care of cancer patients [34]. The quarantine and social distancing practices aimed at reducing the transmission of COVID-19 have led to a broader and faster spread, exposure, and usage of healthcare delivery through technology than ever before

[35]. Despite certain shortcomings, healthcare delivered through technologies has become a necessity to improve cancer care and help cancer survivors during COVID-19 and potentially in the future. Several public health agencies have issued guidelines for the use of digital information and communication technologies during COVID-19 [36]. Nevertheless, the long-term impacts of COVID-19 on cancer outcomes at the population level will be unclear for a while because of the time necessary for data collection, analysis, and publication. One of the long-term impacts could be cancer survivors' long-term changes in their attitudes, acceptability, and comfort with integrating and using technologies for healthy lifestyle intervention. To our knowledge, limited research has investigated BC's perceived perceptions on technology-based delivery of nutrition and exercise combined interventions, especially comparing pre- and post-COVID-19 pandemic periods.

The goal of this study was to conduct a survey of BCSs to collect data that can help us identify and describe the strategies for developing an optimal exercise and diet intervention for this population to ultimately increase participation and adherence [37,38]. The primary aim of this study was to establish BCSs' level of interest in, preferences for, and barriers to participating in a diet and exercise intervention, with a focus on BCSs' comfort with technology use in the intervention. The secondary aim was to further perform separate data analyses between the pre- and the post-COVID-19 pandemic and compare the changes to inform future intervention delivery strategies during the post-COVID 19 era.

CHAPTER 2: LITERATURE REVIEW

2.1. Breast Cancer: Incidence, Mortality, Survival, Risk Factors

Breast cancer is the most common cancer worldwide [1]. The average BC development risk of a woman in the United States is about 13%. Breast cancer incidence rates in the United States have increased by 0.5% per year in recent years. Despite the increasing incidence, BC's mortality rates have declined by at least 1% annually since 1998. (ACS, 2021) According to the World Health Organization (WHO), there were 684,996 deaths from BC in 2020 worldwide. (WHO, 2021) Among the overall cancer deaths in American women, BC is the second leading cause, after lung cancer--about 1 in 39 women [2,39]. An estimated one-fourth of women will have a recurrence after their diagnosis, treatment, and cancer-free survival for local or regional invasive BC [40,41].

Although there is a proportion of inherited cases of BC, all women are at risk for BC. Less than 10% of BC cases involve an inherited mutation in a known BC gene (e.g., BRCA1 and BRCA2). Most BC cases are not associated with these inherited mutations. (ACS, 2017-2018) Risk factors include but are not limited to older age, radiation exposure, never having a child, not breastfeeding, high levels of sex hormones, breast implants, drinking alcohol, being overweight or obese, and not being physically active. (ACS, 2020, CDC, 2019)

2.2. Associations of Lifestyle with the Risk of Breast Cancer Development

Certain risk factors are related to lifestyle or personal behaviors, such as diet and exercise [42]. According to Arthur et al., for women at genetic risk of invasive BC development, living an overall healthy lifestyle may attenuate the risk impact [43]. A case-control study conducted by Ghosn et al. showed that the overall risk that an individual with the highest healthy lifestyle

score (HLS) to develop BC was 0.38 times less (OR: 0.62; 95% CI: 0.40, 0.93, $P_{trend} = 0.01$) comparing to those with the lowest score [44]. Similar results could be found in a prospective study done by Chen et al., which supported that a healthier lifestyle (assessed by the HLS) was associated with a lower incidence of postmenopausal BC [45]. In general, healthy lifestyle changes, particularly smoking cessation and weight reduction, were found in many studies to be a protective factor for BC development [46].

2.3. Associations of Lifestyle with Breast Cancer Prognosis and Survival

Breast cancer survivors may experience a wide range of health problems, including compromised physical function because of the disease, side effects of cancer treatment such as pain and lymphedema, high risk of comorbid chronic diseases (e.g., cardiovascular disease and osteoporosis), and a variety of other physical, psychological, and social stressors [47]. The findings of previous studies suggest the combined lifestyle of an individual is not only a factor that is related to the risk of developing BC but also a factor influencing BCSs' prognosis and quality of life [48]. Lofterød et al. suggested that BCSs who reported an unfavorable lifestyle, defined as having 3-5 unfavorable factors categorized by WHO such as sedentary life, smoking, alcohol drinking [49], had almost two times higher overall mortality risk than those who reported a favorable lifestyle (HR 1.96, 95% CI 1.01-3.80). Instead, a healthy lifestyle prevents BC development, postpones its onset, improves BCSs' favorable prognosis and HRQoL, benefits emotional well-being, lowers mortality, and extends their overall life expectancies [50]. These positive outcomes of a healthy lifestyle were seen in BCSs in various treatment stages. Pre-treatment BCSs with lower HRQoL negatively affected treatment compliance [51], and BCSs reported a reduction in adverse treatment-related effects (e.g., musculoskeletal pain, fatigue, stress, insomnia) after healthy lifestyle modification [52].

There is a “teachable moment” among BCSs soon after diagnosis (a period in one’s life where they are highly motivated to make lifestyle changes and open to education and intervention to support such changes) [25]. However, health professionals still have challenges expanding their focus from acute care to managing the long-term healthy lifestyle uptake after BCSs complete active treatment [53, 54]. Besides, although the observed association of a healthy lifestyle with BCSs’ improved prognosis and the possibility that a cancer diagnosis may promote healthy behavior modifications, a study showed that a significant number of BCSs were nonadherent to healthy lifestyle changes. Their original unhealthy behaviors tended to persist after the BC diagnosis [55]. A 15-year follow-up study investigating BCSs’ long-term adherence to health recommendations yielded similar findings, although initial, short-term positive health behavior changes were observed after BC diagnosis [56]. Moreover, a cohort study conducted by Anderson et al. showed no self-reported change in BCSs’ exercise and diet habits, such as increased exercise and healthy food consumption, after their cancer diagnosis [57].

2.4. Associations of Diet and Physical Activity with Breast Cancer

Current literature shows that diet and exercise, as essential components of personal health behavior, have been identified as contributing to BC prevention, development, and recovery [58]. Research shows that more than half of BCSs experience significant weight gain often after BC diagnosis [59]. Some of the mechanisms associated with weight gain after diagnosis include reduced PA and metabolic changes related to cancer treatment, such as chemotherapy [60-62]. Overweight or obesity may increase BC recurrence, comorbidities, second cancers, and mortality [18, 63]. Body fatness, which is related to body energy intake (diet) and expenditure (PA), may promote breast carcinogenesis and the growth of cancer cells by affecting the concentration of circulating hormones such as insulin, leptin, and growth factors [64]. PA, likely through

decreasing body fatness and some metabolic changes (e.g., oestrogen level, inflammation, insulin resistance) linked to cancer development, is beneficial to cancer risk and recovery [65]. It was reported that women who routinely engage in moderate-intensity exercise (e.g., 3 hours per week of brisk walking) have significantly lower mortality and risk of recurrence compared with women who do not exercise at all [66,67]. Diet and PA, which have been reported effective in producing weight loss and weight management, combined intervention may improve BCSs' HRQoL [58], prognosis [19], in addition to reducing recurrence risks [68], disease burdens [69], and mortality [70]. In some short-term diet and exercise intervention programs, significant changes were seen in overweight/obese BSC's dietary nutrients and fatty acid biomarkers levels, suggesting that positive diet changes may be related to BC prognosis and recurrence [71]. The nutrition and PA guidelines developed by The American Cancer Society (ACS) for cancer survivors recommend regular consumption of fruits, vegetables, and whole grains; routine engagement in physical activities, and maintaining a healthy weight [72]. Despite the current recommendations, most BCSs fail to meet these dietary and exercise standards. Although initial positive healthy behavior modifications were observed post-BC diagnosis, maintenance of the modifications over the long-term was poor [56,73]. Besides, the agreement between self-assessed dietary quality and actual diet quality was low [74]. A study showed that BCSs failed to reach recommended PA levels, and their total PA levels were even lower 24 months post-surgery than pre-operatively [75]. Additionally, barriers to exercise such as treatment-related side effects, lack of time, and fatigue exist among BCSs [76]. Despite the gap found between the recommended guidelines and BCSs' real-world practice, a parallel arm randomized controlled pilot study showed BCSs' ability to adhere to a strict diet and exercise program aimed at reducing their body weight and improving their health-related biomarkers and HRQoL [77]. It was suggested that

future intervention practices should integrate personalized behavioral modification (diet and exercise) and provide BCSs with supports to overcome barriers.

In sum, the literature supports the benefits of diet and PA in BC prevention and recovery, emphasizes a need for personalized and systematic implementation strategies to carry out optimal diet and PA intervention programs without causing adverse side outcomes to BCSs [78], and highlights the importance to provide long-term monitoring, counseling, or coaching of diet and PA for BCSs [75].

2.5. Breast Cancer Survivors' Perceptions of Diet and PA Interventions

To help BCSs actively engage in long-term healthy lifestyle modification and maintenance, especially through diet and exercise, it is important to understand BCSs' perceptions (e.g., interests, barriers, preferences) of diet and PA interventions. BCSs have reported a variety of barriers to health behaviors in many different studies [79]. Milosevic et al. found that young BCSs (<40 years) face conflicting beliefs and priorities in different levels between their perceived barriers and the factors motivating them to perform healthy lifestyle behaviors (e.g., prolonging life with a healthy lifestyle vs. enjoying living) [80]. In a randomized controlled trial conducted by Cho et al. in 2017, the most commonly reported barriers to both PA and a healthy diet were physical symptoms (e.g., pain, fatigue), lack of time and not being motivated enough [81], which were consistent with multiple other studies [82-85]. Similar results were found in a cross-sectional study showing that fatigue was the most reported barrier to improving both diet and exercise after BC diagnosis and treatment. Additional reported barriers to improving diet quality included psychological stress, symptoms of the disease, and treatment that impact the desire to eat (e.g., taste alterations, loss of appetite, and craving less desirable foods). Frequently reported barriers to PA included bodily pain and discomfort [86].

In addition to BCSs' perceived barriers, it is important to identify BSC'S interests and preferences in nutrition and PA intervention. However, only limited research has been done to investigate BCSs' interests in and preferences for diet intervention programming. A study at The University of San Francisco (UCSF) Breast Care Center assessing BCSs' preferences for receiving care resources showed that more than half of the participants were interested in psychological services, 27% in nutrition counseling, and 20% in exercise counseling. They were more interested in individual counseling rather than group counseling, and they reported being less interested if it was necessary for them to pay for these services [87]. A study investigating exercise counseling and program preferences found that face-to-face counseling was the preferred modality reported in BCSs [88]. BCSs' preferences reported for a face-to-face care program rather than a distant-based program could also be found in a cross-sectional study [89]. A single-arm intervention study in France showed that more than 80% of the BCSs participants were interested in exercise counseling or a PA program targeting the BC population, and at the end of the study, BCSs preferred to participate in the PA program in a community health center more than at home [90]. A cross-sectional study in Turkey indicated that most BCSs preferred to participate in an exercise program that is supervised, structured, hybrid with moderate intensity (e.g., walking or jogging) and be notified about the opportunity at the time of cancer diagnosis [91]. Similar results about BCSs' preferences for PA programming were reported from studies in Australia and the Netherlands. In the first, preferences for a self-paced, moderate-intensity PA and an outdoor environment were reported [92]. In the second, more than half of the BCSs showed a preference for a prolonged (>8 weeks) program supervised by professionals with expertise in PA and oncology and insecurity about self-managing their physical functioning [93]. A qualitative study investigating the interests and preferences for mHealth PA interventions

among BCSs receiving chemotherapy emphasized the education in PA during chemotherapy and treatment side effects that comprise PA; the feasibility of a structured, tech-supported home-based program with some in-person interactions; the need for intervention personalization and adaptation; and the importance of social support from family, friends or other BCSs [94].

In sum, limited studies have been conducted to understand BCSs' interests, preferences, and perceived barriers to diet and exercise intervention. Among the studies, most focused on PA rather than on diet or diet and exercise combined. Results from the most recent studies indicate that there were various and significant barriers to improving health behaviors among BCSs [81], which usually fail to align with their reported needs, preferences, and interests in such programs shown in the studies [95]. Larger scale research is needed to understand and develop strategies to address barriers and provide evidence-based diet and exercise information and intervention programs tailored to BCSs' specific needs, interests, and preferences [86, 89].

2.6. The Impact of the COVID-19 Pandemic on the Healthcare for Breast Cancer Survivors

The literature above showed us the great potential of diet and PA interventions in BC survivorship care and emphasized the future needs in investigating how to make them more acceptable, accessible, and feasible for BCSs. Nonetheless, the breakout of the COVID-19 pandemic has impacted the quality of life, general well-being of BCSs [96], routine clinical practices, and supportive care services [97]. There is still limited information on how the COVID-19 pandemic has changed health behaviors among cancer survivors thus far. To better design and provide optimal healthy lifestyle interventions to BCSs, it is important for us not to neglect the impacts of the pandemic and to explore more to see if there have been changes, which might be long-term, related to BCSs' life, needs, and their attitude or perception to healthy lifestyle interventions. The available relevant studies found that BCSs have been experiencing

some life challenges caused by the COVID-19 pandemic. The results of a qualitative descriptive study in Turkey indicated that the pandemic caused new physical and psychological symptoms such as lymphedema, pain, burnout, and anxiety among BCSs [96]. Gurgel et al. found decreases in PA level and increases in sedentary time and weight among previously physically active BCSs after the breakout of the pandemic [98]. Similar reductions in BCSs' PA level were found in other studies. The decreases were believed to be associated with their disconnection of supervised PA resources due to the COVID-19 lockdown and sociodemographic characteristics. Himbert et al. found that patients who exercised less were more likely to be unemployed/retired, undergoing active treatment, and had increased pandemic-related alcohol consumption and psychosocial stressors such as loneliness and financial stress. In contrast, patients who exercised more were younger, female, full-time employed, did not consume alcohol, and had good health status and more social interactions [99]. Another study also reported that the negative effects of BCSs' psychosocial issues resulting from the restrictions imposed on the traditional delivery of cancer care could lead to changes in diet quality and PA [100]. Studies showed that interventions through adapted delivery modes (e.g., home-based or supportive technology-based) during the pandemic might lead to better outcomes. During the COVID-19 pandemic, home-based lifestyle intervention programs were shown to be promising in promoting BCSs' cardiometabolic and cardiorespiratory fitness, muscle strength, quality, and quantity of sleep [??], and PA [101-103]. Previous studies discussed above showed a preference among BCSs to participate in face-to-face intervention programming, but the negative impacts seen on BCSs' general well-being and survivorship care services so far and the increased and necessary use of communication technologies during the pandemic may have led to a shift in preferences away from in-person to distance-based delivered via technology. Thus, future research is needed to explore BCSs'

programming barriers and preferences change and their comfort with technology-delivered interventions during the post-COVID-19 era.

CHAPTER 3: METHODS

3.1. Design, Setting and Participants

This was a cross-sectional survey study of 224 BCSs aged 18 years or older diagnosed with ductal carcinoma in situ (DCIS) or Stage I-IV BC from May 2019 – May 2021. Research participants were recruited 1) over the telephone by study researcher at the University of Illinois at Urbana-Champaign (UIUC), 2) in-person during their routine oncology appointments with physicians at Carle Cancer Center's Mills Breast Cancer Institute (MBCI) in Urbana, Illinois, 3) or through an online patient portal by research coordinators. The survey included questions of the history of participation in diet and exercise programming; interest in, preferences for, and barriers to participating in such programming; demographic, clinical and lifestyle factors; social cognitive theory constructs; and health and well-being. The survey took approximately 45-60 minutes for participants to complete and consented participants were given the option of completing the survey either on paper or online. The Institutional Review Board approved all study activities at Carle Foundation Hospital and UIUC. Prospective patients were identified through the institution's cancer registry and prescreened for eligibility via a medical record review. Inclusion Criteria: 1) must be diagnosed with ductal carcinoma in situ (DCIS) or Stage I – IV BC. 2) Must be 18+ years of age. 3) previously treated at the Carle Foundation Hospital. Exclusion criteria included: 1) under the age of 19; 2) non-English speaking, and 3) refusal to participate. To achieve a representative population sample for this pilot study, no exclusion criteria will be made based on cancer stage, treatment modalities, or current stage of disease course.

3.2. Measures

3.2.1. Participant Characteristics

To collect data on participant characteristics, the survey included questions on 1) demographic information (including but not limited to age, sex, ethnicity, race, education, marital status, employment, household income level, travel time from home to the study institution); 2) social cognitive theory constructs (self-efficacy, perceived dietary intervention barriers, social support); 3) current lifestyle factors (smoking, alcohol use, PA, dietary intake); and 4) health and clinical information (BMI, specific cancer type, treatment type, cancer stage at diagnosis, time since diagnosis, comorbidities, quality of life, symptom severity, mental and emotional status)

3.2.2. Intervention Interest

Participants were queried on their likeliness to participate in a BC research study testing the benefits of this nutrition and exercise intervention (not at all, a little bit, somewhat, quite a bit, very much).

3.2.3. Intervention Preferences

Survey questions asked participants for their preferences for 1) the timing to participate in diet and exercise programming (i.e., immediately after diagnosis, during treatment, immediately following treatment, more than a few months after completing treatment) to participate in diet and exercise programming, 2) the location to meet with a registered Dietitian Nutritionist and an exercise specialist (queried about exercise and diet in two separate multiple choice items; options were in person at professional institutions, distance-based using technology, other, no preference), 3) the modality to receive information about exercise and diet

(queried about exercise and nutrition in two separate multiple choice items; options for both were in person, telephone, written materials, DVD with recorded materials, internet/technology-based such as website, text-messaging, YouTube, visual communication such as Skype™ or FaceTime®, other, no preference), 4) in one-on-one or group sessions to receive education/counseling about exercise and diet (queried about exercise and nutrition in two separate multiple choice items; options for both were one-on-one sessions, group sessions with others, other, no preference), 5) separately or simultaneously to receive nutrition and exercise guidance (multiple choice; options were together, separately, no preference, other)

3.2.4. Intervention Barriers

Survey questions asked participants about the barriers interfering with their ability to participate in a combined nutrition and exercise program (multiple choice; options were fatigue, family responsibility, illness, work, transportation, negative perspectives about diet and exercise, surgery, personal or emotional issues, other).

3.2.5. Usage of and Comfort with Technology

Four yes/no items asked participants if they had a tablet (e.g., iPad, Kindle Fire, Samsung Galaxy), a mobile phone with active service, a smartphone that can download and use applications (apps), and high-speed internet where they lived. Three items asked participants how comfortable they would be with 1) using a tablet, 2) using a smartphone, and 3) participating in a nutrition and exercise program delivered via technology (5-point Likert scale for each item; not at all, a little bit, somewhat, quite a bit, very much). Three items asked participants' preferences for 1) using social media/visual communication (multiple choice; options were Facebook, Twitter, Pinterest, Instagram, YouTube , Google Plus, Snapchat, Other),

2) the topics that they used the internet to learn about through social media sites (multiple choice; options were recipes, healthy eating information, exercise tips, food safety information, food budgeting information, do not use any social media sites to look up or read about healthy living, other) 2) the topics that they used the internet to learn about through social media sites (multiple choice; options were Facebook, Twitter, Pinterest, Instagram, YouTube , Google Plus, Snapchat, other), and 3) technology delivery modes to participate in an exercise and nutrition program (multiple choice; options were websites with self-paced pages to click through (which may include video clips), social media posts (e.g., on Facebook), mobile applications (apps), text messages, e-mails, visual communication tools (e.g., Skype or FaceTime), online group support (e.g., group chats or message boards), no preference, not interested, other).

3.3. Data Collection and Management

Survey data were entered and managed using REDCap™ electronic data capture tools hosted at Carle. Participants can choose to complete the survey on-site using the REDCap™ mobile app on an iPad, online through a survey link, or in a paper and pencil format. Data from paper and pencil surveys were entered into the REDCap™ system for analysis. Additional clinical data were abstracted from the Carle electronic medical record systems to supplement data collected as part of the self-administered survey.

3.4. Analytical Procedures

Descriptive analyses were performed for all the survey questions by measures and calculations of frequency (count) and the proportion (percentage) of each question option selected. Likeliness and comfort-related questions were presented in a 5-point Likert scale and collapsed into two groups to increase statistical power when analyzing BCSs' likeliness or

comfort level— “likely” if they responded “extremely likely” or “quite likely” and “not Interested” if responded “not at all likely,” “a little bit likely,” or “somewhat likely”; “comfortable” if they responded “quite a bit” or “ very much”, and “not comfortable” if they responded “not at all”, “a little bit” or “somewhat”.

Data were collected from 130 participants before the COVID-19 pandemic and 94 participants after the pandemic began in March 2020. As such, subset analysis to compare pre-COVD-19 responses to post-COVID-19 responses was performed. The COVID-19 Pandemic hit randomly during our study. The samples in our study were believed to be randomly assigned to the two periods for comparative analysis. Unless there is a theory explaining the disruption of the randomization, we know by an expectation that the demographics are statistically identical in the population. Percentages were mainly used to present the overall results and compare the population’s interests, preferences, and barriers to participating in diet and PA counseling and programming. Percentage differences in quantitative survey responses were analyzed using Two-Proportions Z-Test. All data were analyzed using RStudio (Version 1.2.5042 © 2009-2020 RStudio, Inc). Statistical significance was set as an alpha level < 0.05.

CHAPTER 4: RESULTS

4.1. Participant Characteristics

The results of sociodemographic and clinical characteristics are displayed in Table 1. The mean age of the total study participants was 60.8 years old ±12.5 years. Most participants were white (95%). BMI ranged from 17.0 kg/m2 to 49.9 kg/m2, and average BMI was 28.2 kg/m2. Approximately 82% of the participants had at least a college degree. Most of the participants were employed (43%) or retired (40%). Three-fourths of the participants have an income level between $27,000 to $150,000. Most participants did not smoke (95%). Thirty-two% of the participants had smoked at least 100 cigarettes in their entire life. More than half of the participants were drinkers. The largest proportion of the study population, 41%, were diagnosed with invasive lobular or invasive ductal BC, while 32% were diagnosed with DCIS. Most of the participants had received surgery (87%), and at least half of them had received chemotherapy (50%), radiation therapy (59%), and hormone therapy (57%). The most common comorbidities were hypertension, osteoporosis, and diabetes. Most participants' tumors were estrogen receptor-positive (ER+) and progesterone receptor-positive (PR+) and human epidermal growth factor receptor 2 negative (HER2/neu -). More than half of the participants were postmenopausal when diagnosed, and the average time since their BC diagnosis was 5.8 years ± 3.8 years. The median driving time from home to the medical center was 29.4 minutes (range from 0 to 180 minutes).

Table 1. Sociodemographic and Clinical Characteristics

	Total (N=224)		Pre-COVID (N=130)		Post-COVID (N=94)	
Characteristics	N	%	N	%	N	%
Age (y)						
Mean	60.8		61.0		60.6	

Table 1 (cont.)						
Standard Deviation (SD)	12.5		13.1		11.8	
Max	91.0		91.0		84.0	
Min	30.0		30.0		37.0	
BMI (kg/m^2)						
Mean ± SD	28.2		28.5		28.2	
Standard Deviation (SD)	6.6		6.6		6.4	
Max	49.9		49.9		48.5	
Min	17.0		17.0		17.1	
Time Since Diagnosis (years)						
Mean ± SD	5.8		6.6		4.7	
Standard Deviation (SD)	3.8		3.6		3.7	
Max	21.6		21.6		21.6	
Min	0.08		0.2		0.1	
Driving Time from Home to Treatment Center (minutes)						
Mean	29.4		31.5		26.4	
Max	180		180		150	
Min	0		0		3	
Race [m]						
Black or African American	7	3%	2	2%	5	5%
White	213	95%	127	98%	86	91%
Asian Indian	0	0%	0	0%	0	0%
Asian	1	0%	0	0%	1	1%
American Indian or Alaska Native	2	1%	0	0%	2	2%
Chinese	2	1%	0	0%	2	2%
Filipino	3	1%	1	1%	2	2%
Japanese	0	0%	0	0%	0	0%
Korean	0	0%	0	0%	0	0%
Vietnamese	0	0%	0	0%	0	0%
Other Asian	0	0%	0	0%	0	0%
Native Hawaiian	0	0%	0	0%	0	0%
Guamanian or Chamorro	0	0%	0	0%	0	0%
Samoan	0	0%	0	0%	0	0%
Other Pacific Islander	0	0%	0	0%	0	0%
Other	1	0%	1	1%	0	0%
Education						
Less than 8 years	1	0%	1	1%	0	0%
8 through 11 years	2	1%	1	1%	1	1%

Table 1 (cont.)						
12 years or completed High school	24	11%	17	13%	7	7%
Post high school training other than college	12	5%	5	4%	7	7%
Some college	40	18%	22	17%	18	19%
College graduate	68	30%	35	27%	33	35%
Postgraduate	76	34%	48	37%	28	30%
Occupational Status						
Employed	97	43%	52	40%	45	48%
Unemployed	3	1%	3	2%	0	0%
Homemaker	16	7%	11	8%	5	5%
Student	3	1%	3	2%	0	0%
Retired	89	40%	53	41%	36	38%
Disabled	10	4%	5	4%	5	5%
Other	5	2%	2	2%	3	3%
Annual Household Income						
$0 to $9,999	2	1%	2	2%	0	0%
$10,000 to $14,999	5	2%	3	2%	2	2%
$15,000 to $19,999	5	2%	3	2%	2	2%
$20,000 to $34,999	28	13%	14	11%	14	15%
$35,000 to $49,999	26	12%	14	11%	12	13%
$50,000 to $74,999	26	12%	17	13%	9	10%
$75,000 to $99,999	35	16%	20	15%	15	16%
$100,000 to $199,999	49	22%	27	21%	22	23%
$200,000 or more	20	9%	13	10%	7	7%
Have you ever smoked at least 100 cigarettes in your entire life?						
No	151	67%	85	65%	66	70%
Yes	71	32%	43	33%	28	30%
Do you smoke cigarettes?						
Every day	6	3%	2	2%	4	4%
Some days	4	2%	0	0%	4	4%
Not at all	212	95%	126	97%	86	91%
Drinking Status						0%
Currently	123	55%	71	55%	52	55%
I drank alcohol in the past, but quit it with the last 1 month	4	2%	3	2%	1	1%
I drank alcohol in the past, but quit it with the last 6 months	12	5%	8	6%	4	4%
I drank alcohol in the past, but quit it within the last year	4	2%	2	2%	2	2%

Table 1 (cont.)						
I drank alcohol in the past, but quit it over a year ago	35	16%	19	15%	16	17%
Never	38	17%	24	18%	14	15%
Diagnosis Detail						
DCIS (Ductal Carcinoma in Situ)	71	32%	42	32%	29	31%
Invasive-Lobular	13	6%	8	6%	5	5%
Invasive-Ductal	59	26%	36	28%	23	24%
Invasive-Don't know	21	9%	9	7%	12	13%
Don't know	54	24%	33	25%	21	22%
Treatment History [m]						
Surgery	194	87%	114	88%	80	85%
Chemotherapy	112	50%	63	48%	49	52%
Radiation therapy	133	59%	79	61%	54	57%
Hormone therapy (e.g., Tamoxifen/ Fulvestrant)	128	57%	73	56%	55	59%
Other types of treatment such as Herceptin (IV)	30	13%	18	14%	12	13%
Immunotherapy (e.g., pembrolizumab /Keytruda)	12	5%	7	5%	5	5%
Don’t know	0	0%	0	0%	0	0%
None	0	0%	0	0%	0	0%
Other	11	5%	3	2%	8	9%
History of Health Comorbidities [m]						
Heart Disease	16	7%	10	8%	6	6%
Stroke and Blood Clots	14	6%	10	8%	4	4%
Diabetes	21	9%	11	8%	10	11%
Hypertension	77	34%	47	36%	30	32%
Hip Fracture	5	2%	3	2%	2	2%
Osteoporosis	36	16%	22	17%	14	15%
Primary cancer other than breast cancer	12	5%	8	6%	4	4%
Other	29	13%	16	12%	13	14%
None of these	99	44%	55	42%	44	47%
Hormone-receptor Status [m]						
ER +	106	47%	61	47%	45	48%
ER -	25	11%	11	8%	14	15%
PR+	52	23%	28	22%	24	26%
PR -	20	9%	9	7%	11	12%
HER2/neu +	32	14%	16	12%	16	17%
HER2/neu -	59	26%	25	19%	34	36%
I don’t know	72	32%	50	38%	22	23%
Was not discussed	8	4%	4	3%	4	4%
Menopausal Status When Diagnosed						

Table 1 (cont.)						
Premenopausal	87	39%	50	38%	37	39%
Postmenopausal	128	57%	74	57%	54	57%

[m] = more than one options could be selected.

4.2. Intervention Interest

(Table 2) More than half (55%) indicated they would have been likely to participate in a research study testing the benefits of this exercise and diet intervention if they had had the opportunity.

4.3. Intervention Preferences

Intervention Preferences are shown in Table 2. Most participants were interested in participating in exercise and diet programming immediately after diagnosis (34%) or immediately following treatment (31%). The most significant proportion of participants indicated that they preferred to meet in person with a Registered Dietitian Nutritionist (45%) or an exercise specialist (56%). The top three choices for participants to receive nutrition and exercise information were from written materials such as booklets or educational handouts (77%, 69%), in-person (67%, 75%), or via internet/technology-based methods (62%, 59%). Most of the participants preferred to receive nutrition and exercise education/counseling in one-on-one sessions (42%, 42%), similar but slightly lower percentage of participants preferred to receive them in group sessions with other BCSs (32%, 41%), and 22% of them indicated no preference in nutrition, 15% in exercise education/counseling. They would have been more interested in receiving nutrition and exercise guidance simultaneously (56%).

Table 2. Intervention Interest and Preferences (N=224)

Question	N	%
Interest (Nutrition & Exercise)		
If you had the opportunity to take part in a breast cancer research study that tested the benefits of nutrition and exercise, how likely would you have been to participate?		
Not at all likely	12	5%
A little bit likely	23	10%
Somewhat likely	63	28%
Quite likely	67	30%
Extremely likely	57	25%
Preferences (Nutrition)		
How would you most likely prefer to meet with a Registered Dietitian Nutritionist?		
In person at hospital/clinic	100	45%
Distance-based (from home) using technology	62	28%
No preference	55	25%
Other	2	1%
How would you most prefer to receive nutrition information? (Pick your top 3 choices)		
In person	149	67%
Over the telephone	33	15%
Written materials (booklets or educational handouts)	172	77%
DVD with recorded material	48	21%
Internet/technology-based (e.g., Website, text-messaging, YouTube)	139	62%
Visual communication tools (e.g., Skype or FaceTime)	49	22%
Other	6	3%
No preference	18	8%
How would you most prefer to receive nutrition education/counseling?		
One-on-one sessions	95	42%
Group sessions with other breast cancer survivors	70	31%
Group sessions with others	2	1%
No preference	50	22%
Preferences (Exercise)		
How would you prefer to meet with an exercise specialist?		
In person at hospital/clinic	125	56%
Distance-based (from home) using technology	40	18%

Table 2 (cont.)

No preference	52	23%
Other	5	2%
How would you most prefer to receive exercise information? (Pick your top 3 choices)		
In person	167	75%
Over the telephone	16	7%
Written materials (booklets or educational handouts)	154	69%
DVD with recorded material	80	36%
Internet/technology-based (e.g., website, text-messaging, YouTube)	133	59%
Visual communication tools (e.g., Skype or FaceTime)	47	21%
Other	5	2%
No preference	11	5%
How would you prefer to receive exercise education/counseling?		
One-on-one sessions	95	42%
Group sessions with other breast cancer survivors	81	36%
Spouse/ significant other	8	4%
Other family members	2	1%
Other	1	0%
No preference	33	15%

Preferences (Nutrition & Exercise)

During which phase do you think would be the best time for breast cancer survivors to participate in diet and exercise programming?		
Immediately after diagnosis	75	34%
During treatment	56	25%
Immediately following treatment	70	31%
More than a few months after completing treatment	20	9%
Would you prefer to receive nutrition and exercise guidance together or separately in a healthy lifestyle program?		
Together	125	56%
Separately	43	19%
No preference	51	23%
Other	1	0%

4.4. Intervention Barriers

The most-reported barriers (Figure 1) were lack of extra time and energy that came from family responsibility (46%), work (38%), or lack of time (3%), and physical issues such as fatigue (49%), illness (14%) and surgery (5%).

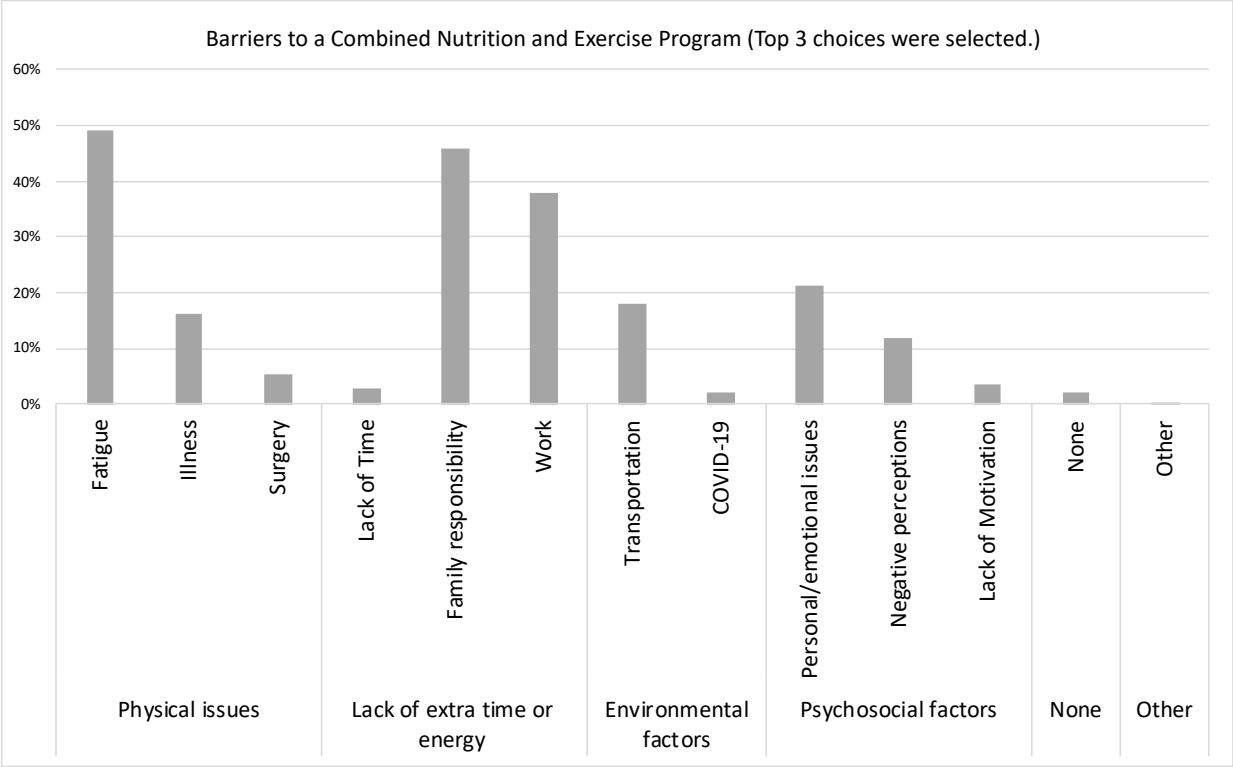

Figure 1. Intervention Barriers

4.5. Usage of and Comfort with Technology

The outcomes with percentages of responses of participants' usage of and comfort with technology are shown in Table 3. A majority of the participants had a tablet (68%), a mobile phone with active service (84%) or a smartphone that could download applications (84%), and

high-speed internet where they lived. Slightly more than half of the participants reported that they would be comfortable (35% “very much”, 20% “quite a bit”) using their tablets and their smartphones (25% reported “very much” and 42% reported “quite a bit”). When asked if they used social media sites to look up or read about healthy living, the most reported topics they looked up or read about were recipes (37%), healthy eating information (24%), and exercise tips (19%). The most-reported social media or visual communication platforms that they used were Facebook (29%), YouTube (20%), and Pinterest (19%). Less than half of the participants (39%) indicated being comfortable participating in a technology-based nutrition and exercise program. However, if they were to participate in the program delivered via technology, the modes they preferred to use were a website with self-paced pages to click through or might include video clips (58%), mobile applications (apps) for smartphones or tablets (49%), and e-mails (27%).

Table 3. Usage of and Comfort with Technology

Questions	N	%
Do you have a tablet (e.g., iPad, iPad Mini, Kindle Fire, or Samsung Galaxy)?		
Yes	152	68%
No	68	30%
Do you have a mobile phone with active service?		
Yes	209	93%
No	6	3%
Do you have a Smart Phone that can download and use applications (“apps”)?		
Yes	189	84%
No	17	8%
Do you have high-speed internet where you live?		
Yes	196	88%
No	23	10%
Do you use any social media sites currently to look up or read about healthy living, if yes, what healthy living topics have you used the internet to learn more about in the past month? (Mark all that apply)		

Table 3 (cont.)

Recipes	138	37%
Healthy eating information	92	24%
Exercise tips	70	19%
Food safety information	33	9%
Food budgeting information	9	2%
No. I don't	28	7%
Other	7	2%
Which social media/visual communication platform do you use? (Mark all that apply.)		
Facebook	123	29%
Twitter	25	6%
Pinterest	80	19%
Instagram	55	13%
YouTube	87	20%
Google Plus	32	7%
Snapchat	18	4%
Other	9	2%
How comfortable are you with using your tablet?		
Not at all	1	0%
A little bit	8	4%
Somewhat	24	11%
Quite a bit	44	20%
Very much	79	35%
How comfortable are you with using your Smart Phone?		
Not at all	6	3%
A little bit	7	3%
Somewhat	31	14%
Quite a bit	57	25%
Very much	93	42%
How comfortable would you be with participating in a technology-based nutrition and exercise program?		
Not at all	34	15%
A little bit	27	12%
Somewhat	67	30%
Quite a bit	47	21%
Very much	41	18%
If you were to participate in a nutrition and exercise program delivered via technology, which mode would you prefer? (Pick your top 3 choices)		
No preference	17	8%

Table 3 (cont.)

Not interested	25	11%
Website with self-paced pages to click through (may include video clips)	131	58%
Social media posts (such as on Facebook)	41	18%
Mobile application (app) for Smart Phone or tablet	109	49%
Text messages	50	22%
E-mails	60	27%
Visual communication tools (e.g., Skype or FaceTime)	33	15%
Group support, such as online group chats or message boards	44	20%
Other	5	2%

4.6. Pre- and Post-COVID-19 Comparisons

Survey questions' response percentages were compared between pre-COVID-19 (pre-) and post-COVID-19 (post) pandemic periods.

4.6.1. Pre- and Post-COVID-19 Comparison: Intervention Interest

Increased percentages were seen (Table 4) in the likeliness (quite likely; extremely likely) of BCSs' participation in a breast cancer research study testing the benefits of this diet and exercise intervention (53% pre, 59% post).

4.6.2. Pre- and Post-COVID-19 Comparison: Intervention Preferences

Table 4 compares BCSs' intervention preferences between per- and post-COVID-19 pandemic. An increased proportion of BCSs reported "during treatment" being the best time to participate in diet and exercise programming (22% pre, 29% post). The percentages of participants who preferred to meet with a Registered Dietitian Nutritionist (48% pre, 39% post) or an exercise specialist (59% pre, 52% post) in person, and to receive nutrition (74% pre, 59% post-, $p<0.05$) or exercise (80% pre, 68% post) information in person decreased during the post-COVID period. Instead, higher percentages of participants preferred to meet with the diet or

exercise professionals at a distance (from home) using technology or had no preference. Besides, significant increases were seen in both the proportions of participants who chose visual communication tools (e.g., Skype or FaceTime) as their most preferred methods to receive nutrition (22% pre, 32%) and exercise (14% pre, 31% post) information ($p<0.05$). Written materials were reported slightly more preferred as ways to receive nutrition information (74% pre, 81% post), while less preferred methods to receive exercise information (71% pre, 66% post) during the post-COVID period. Regarding participants' preferences for receiving education/counseling, participants' preferences for receiving it specifically in one-on-one sessions were reported less than before for both nutrition (46% pre, 37% post) and exercise (58% pre, 37% post) topics. Meanwhile, higher percentages of participants reported no preference for receiving nutrition (19% pre, 27% post) or exercise (12% pre, 18% post) education/counseling during the pandemic than before. The proportion of the participants who preferred to receive nutrition and exercise guidance separately was larger than that of the participants from the pre-COVID pandemic period (17% pre, 22% post).

Table 4. Pre- and Post-COVID-19 Comparison Intervention Interest and Preferences	Pre (N=130)		Post (N=94)	
Question	N	%	N	%
Interest (Nutrition & Exercise)				
If you had the opportunity to take part in a breast cancer research study that tested the benefits of nutrition and exercise, how likely would you have been to participate?				
Not at all likely	5	4%	7	7%
A little bit likely	14	11%	9	10%
Somewhat likely	40	31%	23	24%
Quite likely	38	29%	29	31%
Extremely likely	31	24%	26	28%

Table 4 (cont.)

Preferences (Nutrition)

How would you most likely prefer to meet with a Registered Dietitian Nutritionist?				
In person at hospital/clinic	62	48%	37	39%
Distance-based (from home) using technology	35	27%	26	28%
No preference	27	21%	28	30%
Other	2	2%	2	2%
How would you most prefer to receive nutrition information? (Pick your top 3 choices)				
In person *	96	74%	55	59%
Over the telephone	22	17%	11	12%
Written materials (booklets or educational handouts)	96	74%	76	81%
DVD with recorded material	29	22%	19	20%
Internet/technology-based (e.g., Text-messaging, YouTube)	81	62%	60	64%
Visual communication tools (e.g., Skype or FaceTime) *	19	15%	30	32%
Other	0	0%	2	2%
No preference	12	9%	6	6%
How would you most prefer to receive nutrition education/counseling?				
One-on-one sessions	60	46%	35	37%
Group sessions with other breast cancer survivors	40	31%	30	32%
Group sessions with others	0	0%	2	2%
No preference	25	19%	25	27%

Preferences (Exercise)

How would you prefer to meet with an exercise specialist?				
In person at hospital/clinic	77	59%	49	52%
Distance-based (from home) using technology	20	15%	20	21%
No preference	29	22%	24	26%
Other	2	2%	1	1%
How would you most prefer to receive exercise information? (Pick your top 3 choices)				
In person	104	80%	64	68%
Over the telephone	9	7%	7	7%
Written materials (booklets or educational handouts)	92	71%	62	66%
DVD with recorded material	54	42%	26	28%
Internet/technology-based (e.g., website, text-messaging)	77	59%	56	60%
Visual communication tools (e.g., Skype or FaceTime) *	18	14%	29	31%
Other	0	0%	4	4%
No preference	6	5%	5	5%

Table 4 (cont.)

How would you prefer to receive exercise education/counseling?				
One-on-one sessions	58	45%	37	39%
Group sessions with other breast cancer survivors	48	37%	33	35%
Spouse/ significant other	4	3%	4	4%
Other family members	1	1%	1	1%
Other	0	0%	1	1%
No preference	16	12%	17	18%
Preferences (Nutrition & Exercise)				
During which phase do you think would be the best time for breast cancer survivors to participate in diet and exercise programming?				
Immediately after diagnosis	45	35%	30	32%
During treatment	29	22%	27	29%
Immediately following treatment	41	32%	29	31%
More than a few months after completing treatment	13	10%	7	7%
Would you prefer to receive nutrition and exercise guidance together or separately in a healthy lifestyle program?				
Together	74	57%	51	54%
Separately	22	17%	21	22%
No preference	30	23%	21	22%
Other	0	0%	1	1%

* $p<0.05$

4.6.3. Pre- and Post-COVID-19 Comparison: Intervention Barriers

Figure 2 compares BCSs' the intervention barriers of per- and post-COVID-19 pandemic. Physical issues (e.g., fatigue, illness, surgery) were reported slightly higher in percentages as barriers interfering the most with their ability to participate in a combined nutrition and exercise program (69% pre, 72% post). The total percentages of barriers related to the lack of time or energy from family responsibility (45% pre, 47% post), work (38% pre, 38% post), and lack of time (3% pre, 2% post) were similar (86% in total, 87% in total). The COVID-19 pandemic was reported explicitly as an issue by 5 participants interfering with their overall participation in such

a program. Psychosocial issues were reported in higher percentages in the post-COVID period (34% pre, 41% post). In general, the average number of barrier types was reported more per person (2.1, 2.2) after the pandemic outbreak.

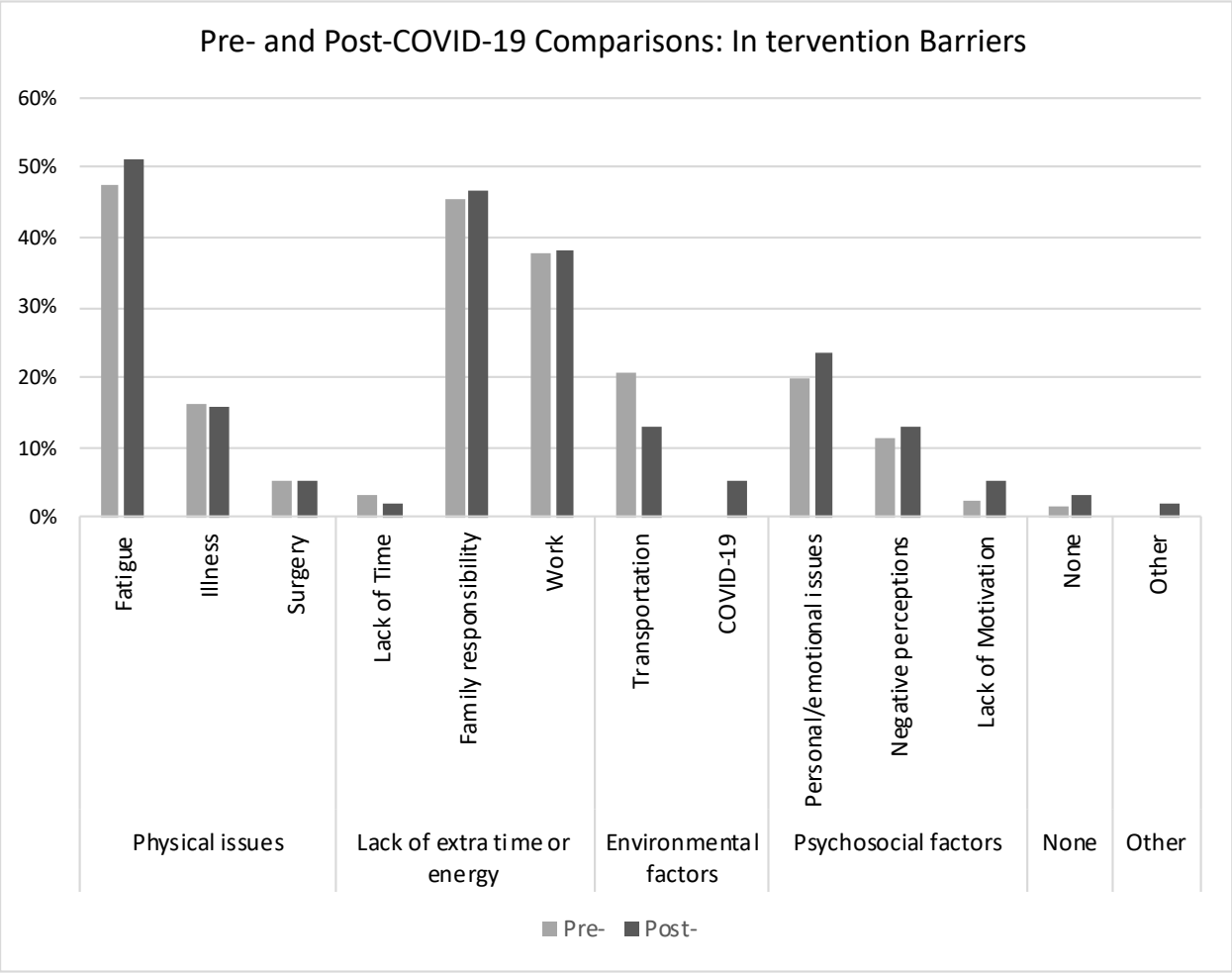

Figure 2. Pre- and Post-COVID-19 Comparisons: Barriers

4.6.4. Pre- and Post-COVID-19 Comparison: Usage of and Comfort with Technology

Table 5 displays BCSs' usage of and comfort with technology during pre- and post-COVID-19 pandemic. The proportions of participants' use of tablets, mobile phones, or

smartphones remained similar. However, a slight increase was reported in the percentage of participants' use of high-speed internet than before (85% pre, 90% post). Participants' reported comfort with using their tablets remained similar (55% pre, 54% post), and lower if asked about their comfort with using their smartphones (76% pre, 57% post). However, the percentages indicating their comfort with participating in a technology-based nutrition and exercise program were higher (35% pre, 46% post). The percentages of their usages of social media sites to look for healthy living were higher than before (increased by 18 percentage points), and the top three social media platforms with increased usages reported were YouTube ($p<0.05$), Instagram and Facebook. The increased percentages of topics that they used the social media sites to learn about were recipes (58% pre, 66% post), healthy eating information (37% pre, 47% post), Exercise tips (28% pre, 36% post) and Food budgeting information (3% pre, 5% post). The percentages of participants who chose "no preference" increased from 3% to 14%, and "visual communication tools (e.g., Skype or FaceTime)" increased from 11% to 20% as their preferred technology delivery modes to participate in such a combined program, while the percentages of other technology delivery modes preferred remained similar (e-mails, text messages, group support) or decreased (websites, social media posts, mobile apps) to different degrees.

Table 5. Pre- and Post- COVID-19 Comparisons: Usage of and Comfort with Technology	Pre (N=130)		Post (N=94)	
Questions	N	%	N	%
Do you have a tablet (e.g., iPad, iPad Mini, Kindle Fire, or Samsung Galaxy)?				
Yes	88	68%	64	68%
No	40	31%	28	30%
Do you have a mobile phone with active service?				
Yes	123	95%	86	91%
No	2	2%	4	4%

Table 5 (cont.)

Do you have a Smart Phone that can download and use applications ("apps")?				
Yes	110	85%	79	84%
No	11	8%	6	6%
Do you have high-speed internet where you live?				
Yes	111	85%	85	90%
No	16	12%	7	7%
Do you use any social media sites currently to look up or read about healthy living, if yes, what healthy living topics have you used the internet to learn more about in the past month? (Mark all that apply)				
Recipes	76	58%	62	66%
Healthy eating information	48	37%	44	47%
Exercise tips	36	28%	34	36%
Food safety information	20	15%	13	14%
Food budgeting information	4	3%	5	5%
No. I don't	20	15%	8	9%
Other	5	4%	2	2%
Which social media/visual communication platform do you use? (Mark all that apply.)				
Facebook	66	51%	57	61%
Twitter	10	8%	15	16%
Pinterest	45	35%	35	37%
Instagram	24	18%	31	33%
YouTube*	42	32%	45	48%
Google Plus	19	15%	13	14%
Snapchat	11	8%	7	7%
Other	4	3%	5	5%
How comfortable are you with using your tablet?				
Not at all	0	0%	1	1%
A little bit	7	5%	1	1%
Somewhat	16	12%	8	9%
Quite a bit	27	21%	17	18%
Very much	45	35%	34	36%
How comfortable are you with using your Smart Phone?				
Not at all	5	4%	1	1%
A little bit	4	3%	3	3%
Somewhat	17	15%	14	13%

Table 5 (cont.)

Quite a bit	34	29%	23	21%
Very much	55	47%	38	36%
How comfortable would you be with participating in a technology-based nutrition and exercise program?				
Not at all	21	16%	13	14%
A little bit	15	12%	12	13%
Somewhat	42	32%	25	27%
Quite a bit	22	17%	25	27%
Very much	23	18%	18	19%
If you were to participate in a nutrition and exercise program delivered via technology, which mode would you prefer? (Pick your top 3 choices)				
No preference	4	3%	13	14%
Not interested	13	10%	12	13%
Website with self-paced pages to click through (may include video clips)	79	61%	52	55%
Social media posts (such as on Facebook)	27	21%	14	15%
Mobile application (app) for Smart Phone or tablet	66	51%	43	46%
Text messages	30	23%	20	21%
E-mails	35	27%	25	27%
Visual communication tools (e.g., Skype or FaceTime)	14	11%	19	20%
Group support, such as online group chats or message boards	25	19%	19	20%
Other	2	2%	3	3%

* $p<0.05$

CHAPTER 5: DISCUSSION

This study investigated BCSs' interest in, preferences for and perceived barriers to diet and PA intervention participation through a survey (paper-based or online) and their comfort with technology, aiming at improving BCSs' cancer survivorship care by informing the design of future optimal intervention and the intervention delivery strategies in such a post-COVID-19 era.

Primary findings indicate BCSs' enthusiasm in both research and non-research-related nutrition and exercise healthcare resources. Compared to other phases among BCSs' healthcare continuum, early programming opportunities (e.g., immediately after cancer diagnosis, immediately following treatment) interested them the most. Besides, they preferred to meet with nutrition or exercise professionals in person at professional institutions, receive education/counseling in one-on-one sessions, receive information through written material, in-person, and internet/technology-based methods, and receive nutrition and exercise guidance simultaneously. Previous data showed BCSs' interests in resources of psychological services (>50%), 27% in nutrition counseling, and 20% in exercise counseling, and their PA preferences in individual counseling rather than group counseling [104], and in a face-to-face care program rather than distance-based [89, 90]. The results suggested that BCSs had different preferences related to different service types. The more preferred ways (i.e., in-person, in one-on-one sessions) that BCSs reported to meet with nutrition and exercise professionals or to receive education/counseling indicated that nutrition and exercise appointments that provide BCSs with more personal interactions with health professionals might be more appealing to them. The information delivered in-person, via written materials or technology, and nutrition guidance provided together with exercise guidance would be promising approaches for a nutrition and

exercise intervention according to BCSs' preferences. Overall, designing tailored diet and exercise interventions with hybrid care services according to the participant's specific participation preferences for the particular type of the service may be one key to increasing program participation and adherence.

Despite BCSs' interests and preferences, there were barriers to nutrition and exercise combined intervention participation. Results of previous studies showed that physical issues (such as pain and fatigue), lack of time and motivation were the top three barriers to a program that had only exercise intervention [81]. The results of previous research were similar but slightly different from the most reported barriers in our study. The reported barriers of BCSs in our study were more concentrated in their physical issues and their poor energy and time because of family responsibility and work, with fatigue, family responsibility, and work being the most reported barriers, psychosocial barriers (e.g., personal, or emotional issues) followed, and lack of motivation being reported in a very small proportion. It was an interesting finding that in comparisons to previous research that had been done, a much lower proportion of our participants reported lack of motivation as a barrier to participation in diet and exercise combined intervention, and more than half of them preferred to receive nutrition and exercise guidance simultaneously. Previous research showed that poor lifestyle habits tend to co-occur [55,56] and that multi-behavior interventions have potential in a greater impact than do single-behavior interventions among the general population [105]. In sum, while a future investigation is needed to address these specific barriers of BCSs to increase their adoption of healthy lifestyle behaviors and thus better outcomes, we may also want to further look into the motivation and more basic principles of BCSs' participation in nutrition and exercise intervention program singularly or simultaneously in the future.

Although barriers to a healthy lifestyle program participation existed among BCSs, findings of our study also showed potential in technology use in a healthy lifestyle intervention delivery, which could be a promising delivery mode to reach and meet the needs of BCSs who might otherwise be unable to participate due to their geographic location or their disease or treatment-related symptoms. The majority of the participants had suitable device(s) (e.g., iPad, smartphone), the internet, and the comfort with using them to receive technology-delivered information or guidance. Two-fifths of the participants reported comfort in a technology-based nutrition and exercise program participation. The modes they preferred to use for such a program were websites, mobile applications, and e-mails. When asked if used social media sites to look for healthy living information, topics about recipes (37%), healthy eating information (24%), and exercise tips (19%) were reported. The most-reported social media or visual communication platforms that they used were Facebook, YouTube, and Pinterest. A systematic review has shown a certain level of acceptability of home-based behavior change intervention programs [106]. Overall, these findings were informing because technology as a broad-reach intervention delivery modality could address distance-related barriers and help the growing number of BCSs access more survivorship care of the quality that meets their specific cancer care needs. [107,108]

By separating the data according to when the lockdown happened due to the COVID-19 pandemic and performing analyses of the data from pre- and post- COVID separately, we were able to compare the COVID-related changes in BCSs' interests in, preferences for, barriers to diet and exercise intervention and their comfort with technology use.

During the post-COVID-19 period, participants seemed to be more likely to participate in a research study testing the benefit of diet and exercise intervention but less comfortable

engaging in a diet and exercise intervention in person or with others. This was supported by the decreased proportion of participants who reported preferences for in-person diet and exercise resources (e.g., information, counseling), and the decreased proportion who reported preferences for one-on-one education/counseling sessions during the post-COVID period.

In contrast, participants' preferences for distance-based methods or using visual communication tools (e.g., Skype or FaceTime) to meet with the health specialists or to receive nutrition and exercise information had noticeable increases. Overall, the results showed decreased comfort in in-person healthcare contacts and increased preferences for home-based diet and exercise intervention programs using technologies and the relevant information delivered through visual communication tools. Recent studies have provided preliminary evidence that internet/web-based, computer-tailored interventions were promising as a welcome addition to increase BCSs' PA [109, 110]. The evidence, together with the findings above, indicated a great potential of technology-delivered cancer supportive services and care during post-COVID-19.

Most recent data showed that BCSs have been facing new environmental, physical, and mental challenges since the breakout of the pandemic. The average number of barrier types that BCSs reported increased from 2.1 to 2.2. This finding aligns with the most recent data which showed that BCSs have been facing more environmental, physical, and mental challenges since the breakout of the pandemic [97,100,111]. Program participation barriers because of Physical issues (e.g., fatigue, illness, surgery) were reported in slightly higher percentages, while the total percentages of barriers related to the lack of extra time or energy because of work, family responsibility, and lack of time remain nearly unchanged, but with an only slight increase in family responsibility (45%, 47%). Besides, participants reported preferred to receive nutrition

and exercise guidance separately slightly more than simultaneously during the post-COVID-19 period. These results might be associated with the shifts of the working environment from worksites to home because of the COVID-19 lockdown and its quarantine policies, which had advantages such as work-life balance and greater work control [112] and more time and energy without daily commuting, as well as disadvantages such as increased housework, childcare and compromised psychosocial health [113]. In sum, BCSs' increased participation interests and the increased challenges they might have been facing suggested they may have more unmet needs during this special period. Thus, post-COVID interventions should be carried out with health care resources or strategies that help address BCSs' physical barriers, which were reported in higher percentages.

During post- COVID-19 period, BCSs' usage of technology and comfort with and technology-based program participation seemed to be higher overall, which was supported by their increased high-speed internet and social media platforms use, increased comfort with a technology-based nutrition and exercise program, and increased preference for "visual communication tools" as the delivery mode for the program. Notably, compared to other social media platforms (e.g., Snapchat, Twitter), the percentage of participants who reported YouTube as a visual/social media platform they used was significantly higher before ($p<0.05$), indicating that educational information in video formats may be a good way to help BCSs engage in behavior change in diet and exercise. However, despite the higher usage of technology and their increased interests in technology-based intervention captured, there seemed to be a higher discomfort in technology use, especially in BCSs' smartphone use (76%, 57%). According to Haleem et al., the COVID-19 lockdown has limited the movement of people in communities or around the world and caused significant impacts such as disruptions in health care and

economics and challenges in social and supply chain sectors [114]. Currently, increased engagement of technology (e.g., smartphone, computer) is required for work, educational and social purposes [115], and for connecting and following up with the updated information about the pandemic [116]. Thus, the higher demand for technology usage and the decreased reported comfort with using smartphones indicated that there might be some unsolved problems in BCSs' smartphone usage during the pandemic. Nonetheless, the increased usage of high-speed internet and social media platforms and the increased comfort with a technology-based nutrition and exercise program reinforced an increasing potential of technology integration (e.g., visual communication platforms such as YouTube) in BCSs' healthcare services delivery. However, specific technology use for health services should consider BCSs' specific preferences; and guidance to address participants' unfamiliarity with some technology will also be needed.

Some strengths were identified in this study. This study allowed eligible participants to complete the survey not only online but also on paper, which reduced the bias towards only BCS who have access to the internet. Previous studies focused on investigating BCSs' preferences for and barriers in mostly their participation in PA programs rather than nutrition related programs. Importantly, this study is the first study known to have investigated BCSs' interests in, preference for, and barriers to a diet and exercise program combined with pre- and post-COVID comparisons. The investigation was important because of the increased number, challenges, and potential unmet needs of BCSs during this special time. Moreover, this study examined BCSs' usage of and comfort with technology for diet and exercise supports with pre- and post-COVID-19 comparisons, informing future integration of technologies in the traditional cancer supportive care delivery. In general, this study adds to the field of breast cancer research and clinical care by informing the development of diet and exercise intervention programs tailored to BCSs and

providing strategies to facilitate BCSs' adherence to these programs that have the potential to improve health outcomes in this ever-growing breast cancer survivor population.

The results of this study should be considered with some limitations. First, the majority of the study participants were white (95%), employed (43%) or retired (40%), had an average of 5.8 years since their cancer diagnosis and lived somewhere within 30 mins driving time around the treatment center, indicating that the study participants represented a more specific scale of BCSs that were white and had the access to cancer treatment. The data were cross-sectional and only provided a snapshot of BCSs' perceptions of diet and exercise programming. There could be questions in the survey that failed to provide an option that applied to the situation of some participants, and specific strategies to overcome participation barriers were not inquired. It is possible that conducting a mixed-method study with specific COVID-19 related questions, rather than our current design, would have led us to a better understanding of participants' perceived preferences and how to address the challenges and barriers interfering with their participation in diet and exercise programming. However, the random breakout of COVID-19 challenged our original research process, and the budget and time constraints we faced prevented us from developing a more in-depth study with a mixed-method design.

CHAPTER 6: CONCLUSION

This study investigated BCSs' preferences and barriers related to diet and exercise interventions during the COVID-19 era. Participants had enthusiasm about nutrition and exercise intervention, different participation preferences for different service types, and barriers of physical issues (e.g., fatigue, illness) and poor energy and time (e.g., family responsibility, work) to their participation in a diet and exercise intervention. The pre- and post-COVID-19 comparisons showed not only BCSs' increased participation interests but also their increased programming participation challenges (e.g., physical and COVID-19 related issues). Strategies should be developed to help BCSs overcome their barriers to future diet and exercise intervention participation and their long-term adoption of healthy lifestyle behaviors. Technology integration has a great potential in delivering health care services, addressing BCSs' participation barriers related to geographic location or the COVID-19 lockdown, and reducing the physical discomfort from traveling among BCSs with disease or treatment-related symptoms. Importantly, guidance or support will be needed to address BCSs' difficulty, discomfort, or unfamiliarity in using technology if they are to participate in any technology-based programs. Future interventions should take what we have learned from this survey to develop intervention designs and strategies that can cater to preferences and overcome perceived barriers in order to optimize participant recruitment and retention.

REFERENCES

1. Agarwal G, Pradeep P, Aggarwal V, Yip C, Cheung P. Spectrum of Breast Cancer in Asian Women. World Journal of Surgery. 2007;31(5):1031-1040.

2. How Common Is Breast Cancer? | Breast Cancer Statistics [Internet]. Cancer.org. 2021 [cited 26 November 2021]. Available from: https://www.cancer.org/cancer/breast-cancer/about/how-common-is-breast-cancer.html

3. Sharma N, Purkayastha A. Factors affecting quality of life in breast cancer patients: A descriptive and cross-sectional study with review of literature [Internet]. 2017. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5496284/

4. Freire M, Sawada N, França I, Costa S, Oliveira C. Health-related quality of life among patients with advanced cancer: an integrative review. Revista da Escola de Enfermagem da USP. 2014;48(2):357-367.

5. Lee M, Bhati R, von Rottenthaler E, Reagan A, Karver S, Reich R et al. Therapy choices and quality of life in young breast cancer survivors: a short-term follow-up. The American Journal of Surgery. 2015;206(5):625-631.

6. Hormes J, Lytle L, Gross C, Ahmed R, Troxel A, Schmitz K. The Body Image and Relationships Scale: Development and Validation of a Measure of Body Image in Female Breast Cancer Survivors [Internet]. 2008. Available from: https://pubmed.ncbi.nlm.nih.gov/18323550/

7. Otto A, Szczesny E, Soriano E, Laurenceau J, Siegel S. Effects of a randomized gratitude intervention on death-related fear of recurrence in breast cancer survivors. Health Psychology. 2016;35(12):1320-1328.

8. Megari K. Quality of life in chronic disease patients. Health Psychology Research. 2013;1(3):27.

9. van Sluijs E, van Poppel M, Twisk J, Chin A Paw M, Calfas K, van Mechelen W. Effect of a Tailored Physical Activity Intervention Delivered in General Practice Settings: Results of a Randomized Controlled Trial. American Journal of Public Health. 2011;95(10):1825-1831.

10. Benton M, Schlairet J, Graham B. Impact of functional training on cardiac autonomic modulation, cardiopulmonary parameters and quality of life in healthy women. Clin Physiol Funct Imaging [Internet]. 2016;36(4):318-325. Available from: https://pubmed.ncbi.nlm.nih.gov/26033271/

11. Duijts S, Faber M, Oldenburg H, van Beurden M, Aaronson N. Effectiveness of behavioral techniques and physical exercise on psychosocial functioning and health-related quality of life in breast cancer patients and survivors-a meta-analysis. Psycho-Oncology. 2011;20(2):115-126.

12. Ligibel J. Physical activity for cancer survivors: meta-analysis of randomised controlled trials. Breast Diseases: A Year Book Quarterly. 2012;23(4):328-330.

13. Lahart I, Metsios G, Nevill A, Carmichael A. Physical activity for women with breast cancer after adjuvant therapy. Cochrane Database of Systematic Reviews. 2018;.

14. Campbell A, Mutrie N, White F, McGuire F, Kearney N. A pilot study of a supervised group exercise programme as a rehabilitation treatment for women with breast cancer receiving adjuvant treatment. European Journal of Oncology Nursing. 2005;9(1):56-63.

15. Mutrie N, Campbell A, Whyte F, McConnachie A, Emslie C, Lee L et al. Benefits of supervised group exercise programme for women being treated for early stage breast cancer: pragmatic randomised controlled trial. BMJ. 2007;334(7592):517.

16. Travier N, Velthuis M, Steins Bisschop C, van den Buijs B, Monninkhof E, Backx F et al. Effects of an 18-week exercise programme started early during breast cancer treatment: a randomised controlled trial. BMC Medicine. 2015;13(1).

17. Jiralerspong S, Goodwin P. Obesity and Breast Cancer Prognosis: Evidence, Challenges, and Opportunities. Journal of Clinical Oncology. 2016;34(35):4203-4216.

18. Nichols H, Trentham-Dietz A, Egan K, Titus-Ernstoff L, Holmes M, Bersch A et al. Body Mass Index Before and After Breast Cancer Diagnosis: Associations with All-Cause, Breast Cancer, and Cardiovascular Disease Mortality. Cancer Epidemiology Biomarkers & Prevention. 2009;18(5):1403-1409.

19. Cancer Survivors Overestimate Quality of Their Diets [Internet]. Breastcancer.org. 2021 [cited 26 November 2021]. Available from: https://www.breastcancer.org/research-news/survivors-overestimate-quality-of-diets

20. Chlebowski R, Blackburn G. Dietary Fat Reduction and Breast Cancer Outcome: Interim Efficacy Results From the Women's Intervention Nutrition Study. JNCI Journal of the National Cancer Institute [Internet]. 2006;98(24):1767-76. Available from: https://pubmed.ncbi.nlm.nih.gov/17179478/

21. Pierce J, Natarajan L, Caan B, Parker B. Influence of a Diet Very High in Vegetables, Fruit, and Fiber and Low in Fat on Prognosis Following Treatment for Breast Cancer: The Women's Healthy Eating and Living (WHEL) Randomized Trial. JAMA [Internet]. 2007;298(3):289-298. Available from: http://10.1001/jama.298.3.289.

22. Morey M, Snyder D, Sloane R, Cohen H, Peterson B, Hartman T et al. Effects of Home-Based Diet and Exercise on Functional Outcomes Among Older, Overweight Long-term Cancer Survivors. JAMA. 2009;301(18):1883.

23. Harrison S, Hayes S, Newman B. Level of physical activity and characteristics associated with change following breast cancer diagnosis and treatment. Psycho-Oncology. 2009;18(4):387-394.

24. Demark-Wahnefried W, Peterson B, McBride C, Lipkus I, Clipp E. Current health behaviors and readiness to pursue life-style changes among men and women diagnosed with early stage prostate and breast carcinomas. Rehabilitation Oncology [Internet]. 2000;88(3):674-684. Available from: https://pubmed.ncbi.nlm.nih.gov/10649263/

25. Demark-Wahnefried W, Aziz N, Rowland J, Pinto B. Riding the Crest of the Teachable Moment: Promoting Long-Term Health After the Diagnosis of Cancer. Journal of Clinical Oncology. 2005;23(24):5814-5830.

26. Abdin S, Lavallée J, Faulkner J, Husted M. A systematic review of the effectiveness of physical activity interventions in adults with breast cancer by physical activity type and mode of participation. Psycho-Oncology. 2019;28(7):1381-1393.

27. How technology is impacting healthcare delivery in a COVID-19 world | Events | DLA Piper Global Law Firm [Internet]. DLA Piper. 2021 [cited 26 November 2021]. Available from: https://www.dlapiper.com/en/us/insights/events/2021/01/how-technology-is-impacting-healthcare-delivery-in-a-covid-19-world/13-january-2021/

28. Beckjord E, Finney Rutten L, Squiers L, Arora N, Volckmann L, Moser R et al. Use of the Internet to Communicate with Health Care Providers in the United States: Estimates from the 2003 and 2005 Health Information National Trends Surveys (HINTS). Journal of Medical Internet Research. 2007;9(3):e20.

29. Valle C, Tate D, Mayer D, Allicock M, Cai J. A randomized trial of a Facebook-based physical activity intervention for young adult cancer survivors. Journal of Cancer Survivorship. 2013;7(3):355-368.

30. Shirke M, Shaikh S, Harky A. Tele-oncology in the COVID-19 Era: The Way Forward?. Trends in Cancer. 2020;6(7):547-549.

31. Chou W, Liu B, Post S, Hesse B. Health-related Internet use among cancer survivors: data from the Health Information National Trends Survey, 2003–2008. Journal of Cancer Survivorship. 2011;5(3):263-270.

32. Valle C, Tate D, Mayer D, Allicock M, Cai J. A randomized trial of a Facebook-based physical activity intervention for young adult cancer survivors. Journal of Cancer Survivorship. 2013;7(3):355-368.

33. Liu B, Yabroff K, Zheng Z, Tamler R, Han X. Internet-Based Health Care Communication Among Cancer Survivors, 2011–2018 National Health Interview Survey. Preventing Chronic Disease. 2021;18.

34. Cox A, Lucas G, Marcu A, Piano M, Grosvenor W, Mold F et al. Cancer Survivors' Experience With Telehealth: A Systematic Review and Thematic Synthesis. Journal of Medical Internet Research. 2017;19(1):e11.

35. Paterson C, Bacon R, Dwyer R, Morrison K, Toohey K, O'Dea A et al. The Role of Telehealth During the COVID-19 Pandemic Across the Interdisciplinary Cancer Team: Implications for Practice. Seminars in Oncology Nursing. 2020;36(6):151090.

36. Healthcare Workers [Internet]. Centers for Disease Control and Prevention. 2020 [cited 26 November 2021]. Available from: https://www.cdc.gov/coronavirus/2019-ncov/hcp/telehealth.html

37. Stull V, Snyder D, Demark-Wahnefried W. Lifestyle Interventions in Cancer Survivors: Designing Programs That Meet the Needs of This Vulnerable and Growing Population. The Journal of Nutrition. 2007;137(1):243S-248S.

38. Green H, Steinnagel G, Morris C, Laakso E. Health behaviour models and patient preferences regarding nutrition and physical activity after breast or prostate cancer diagnosis. European Journal of Cancer Care. 2014;23(5):640-652.

39. Breast Cancer Advocacy & Support | National Breast Cancer Coalition [Internet]. National Breast Cancer Coalition. 2021 [cited 26 November 2021]. Available from: https://www.stopbreastcancer.org/

40. Colleoni M, Sun Z, Price K, Karlsson P, Forbes J, Thürlimann B et al. Annual Hazard Rates of Recurrence for Breast Cancer During 24 Years of Follow-Up: Results From the International Breast Cancer Study Group Trials I to V. Journal of Clinical Oncology. 2016;34(9):927-935.

41. Park C, Mitsumori M, Nixon A, Recht A, Connolly J, Gelman R et al. Outcome at 8 Years After Breast-Conserving Surgery and Radiation Therapy for Invasive Breast Cancer: Influence of Margin Status and Systemic Therapy on Local Recurrence. Journal of Clinical Oncology. 2000;18(8):1668-1675.

42. Lifestyle-related Breast Cancer Risk Factors [Internet]. Cancer.org. 2021 [cited 26 November 2021]. Available from: https://www.cancer.org/cancer/breast-cancer/risk-and-prevention/lifestyle-related-breast-cancer-risk-factors.html

43. Arthur R, Wang T, Xue X, Kamensky V, Rohan T. Genetic Factors, Adherence to Healthy Lifestyle Behavior, and Risk of Invasive Breast Cancer Among Women in the UK Biobank. JNCI: Journal of the National Cancer Institute. 2020;112(9):893-901.

44. Ghosn B, Benisi-Kohansal S, Ebrahimpour-Koujan S, Azadbakht L, Esmaillzadeh A. Association between healthy lifestyle score and breast cancer. Nutrition Journal. 2020;19(1).

45. Chen S, Braaten T, Borch K, Ferrari P, Sandanger T, Nøst T. Combined Lifestyle Behaviors and the Incidence of Common Cancer Types in the Norwegian Women and Cancer Study (NOWAC). Clinical Epidemiology. 2021;Volume 13:721-734.

46. Botteri E, Berstad P, Sandin S, Weiderpass E. Lifestyle changes and risk of cancer: experience from the Swedish women's lifestyle and health cohort study. Acta Oncologica. 2021;:1-8.

47. Jeong S, Park S. Care for Breast Cancer Survivors. [Internet]. 2021 [cited 26 November 2021];. Available from: https://link.springer.com/chapter/10.1007%2F978-981-32-9620-6_27

48. Hamer J, Warner E. Lifestyle modifications for patients with breast cancer to improve prognosis and optimize overall health. Canadian Medical Association Journal. 2017;189(7):E268-E274.

49. Cancer Prevention Recommendations - WCRF International [Internet]. WCRF International. 2021 [cited 26 November 2021]. Available from: https://www.wcrf.org/diet-and-cancer/cancer-prevention-recommendations/

50. Lofterød T, Frydenberg H, Flote V, Eggen A, McTiernan A, Mortensen E et al. Exploring the effects of lifestyle on breast cancer risk, age at diagnosis, and survival: the EBBA-Life study. Breast Cancer Research and Treatment. 2020;182(1):215-227.

51. Montagnese C, Porciello G, Vitale S, Palumbo E, Crispo A, Grimaldi M et al. Quality of Life in Women Diagnosed with Breast Cancer after a 12-Month Treatment of Lifestyle Modifications. Nutrients. 2020;13(1):136.

52. Addison S, Shirima D, Aboagye-Mensah E, Dunovan S, Pascal E, Lustberg M et al. Effects of tandem cognitive behavioral therapy and healthy lifestyle interventions on health-related outcomes in cancer survivors: a systematic review. Journal of Cancer Survivorship. 2021;.

53. Di Meglio A, Soldato D, Presti D, Vaz-Luis I. Lifestyle and quality of life in patients with early-stage breast cancer receiving adjuvant endocrine therapy. Current Opinion in Oncology. 2021;33(6):553-573.

54. Malam S, Lawrence B, Bradley C, McBride K, Clement A, Conrad T et al. Integrating Survivorship Care Into a Radiation Medicine Program. Cureus. 2020;.

55. Di Meglio A, Gbenou A, Martin E, Pistilli B, Ligibel J, Crane T et al. Unhealthy behaviors after breast cancer: Capitalizing on a teachable moment to promote lifestyle improvements. Cancer. 2021;127(15):2774-2787.

56. Tollosa D, Holliday E, Hure A, Tavener M, James E. A 15-year follow-up study on long-term adherence to health behaviour recommendations in women diagnosed with breast cancer. Breast Cancer Research and Treatment. 2020;182(3):727-738.

57. Anderson C, Sandler D, Weinberg C, Houck K, Chunduri M, Hodgson M et al. Age- and treatment-related associations with health behavior change among breast cancer survivors. The Breast. 2017;33:1-7.

58. Roldán-Jiménez C, Pajares B, Ruiz-Medina S, Trinidad-Fernández M, González-Sánchez M, Ribelles N et al. Design and implementation of a standard care programme of therapeutic exercise and education for breast cancer survivors. Supportive Care in Cancer. 2021;.

59. Vance V, Mourtzakis M, McCargar L, Hanning R. Weight gain in breast cancer survivors: prevalence, pattern and health consequences. Obesity Reviews. 2010;12(4):282-294.

60. Demark-Wahnefried W, Peterson B, Winer E, Marks L, Aziz N, Marcom P et al. Changes in Weight, Body Composition, and Factors Influencing Energy Balance Among Premenopausal Breast Cancer Patients Receiving Adjuvant Chemotherapy. Journal of Clinical Oncology. 2001;19(9):2381-2389.

61. Irwin M, McTiernan A, Baumgartner R, Baumgartner K, Bernstein L, Gilliland F et al. Changes in Body Fat and Weight After a Breast Cancer Diagnosis: Influence

of Demographic, Prognostic, and Lifestyle Factors. Journal of Clinical Oncology. 2005;23(4):774-782.

62. Makari-Judson G. Weight gain following breast cancer diagnosis: Implication and proposed mechanisms. World Journal of Clinical Oncology. 2014;5(3):272.

63. Jiralerspong S, Goodwin P. Obesity and Breast Cancer Prognosis: Evidence, Challenges, and Opportunities. Journal of Clinical Oncology. 2016;34(35):4203-4216.

64. World Cancer Research Fund/American Institute for Cancer Research. Continuous Update Project Expert Report 2018. Diet, nutrition, physical activity and breast cancer. [Internet]. 2021 [cited 26 November 2021];. Available from: http://dietandcancerreport.org

65. McTiernan A. Mechanisms linking physical activity with cancer. Nature Reviews Cancer. 2008;8(3):205-211.

66. Holmes M. Physical Activity and Survival After Breast Cancer Diagnosis. JAMA. 2005;293(20):2479.

67. Irwin M, Smith A, McTiernan A, Ballard-Barbash R, Cronin K, Gilliland F et al. Influence of Pre- and Postdiagnosis Physical Activity on Mortality in Breast Cancer Survivors: The Health, Eating, Activity, and Lifestyle Study. Journal of Clinical Oncology. 2008;26(24):3958-3964.

68. Demark-Wahnefried W, Rock C. Nutrition-related issues for the breast cancer survivor. Seminars in Oncology. 2003;30(6):789-798.

69. Alfano C, Day J, Katz M, Herndon J, Bittoni M, Oliveri J et al. Exercise and dietary change after diagnosis and cancer-related symptoms in long-term survivors of breast cancer: CALGB 79804. Psycho-Oncology. 2009;18(2):128-133.

70. Irwin M, Alvarez-Reeves M, Cadmus L, Mierzejewski E, Mayne S, Yu H et al. Exercise Improves Body Fat, Lean Mass, and Bone Mass in Breast Cancer Survivors. Obesity. 2009;17(8):1534-1541.

71. Buckland G, Travier N, Arribas L, del Barco S, Pernas S, Zamora E et al. Changes in dietary intake, plasma carotenoids and erythrocyte membrane fatty acids in breast cancer survivors after a lifestyle intervention: results from a single-arm trial. Journal of Human Nutrition and Dietetics. 2019;32(4):468-479.

72. Kushi L, Byers T, Doyle C, Bandera E, McCullough M, Gansler T et al. American Cancer Society Guidelines on Nutrition and Physical Activity for Cancer

Prevention: Reducing the Risk of Cancer With Healthy Food Choices and Physical Activity. CA: A Cancer Journal for Clinicians. 2006;56(5):254-281.

73. Kelly D, Yang G, Starkweather A, Siangphoe U, Alexander-Delpech P, Lyon D. Relationships Among Fatigue, Anxiety, Depression, and Pain and Health-Promoting Lifestyle Behaviors in Women With Early-Stage Breast Cancer. Cancer Nursing. 2018;43(2):134-146.

74. Xue H, Liu J, Cheskin L, Sheppard V. Discrepancy between perceived diet quality and actual diet quality among US adult cancer survivors. European Journal of Clinical Nutrition. 2020;74(10):1457-1464.

75. De Groef A, Geraerts I, Demeyer H, Van der Gucht E, Dams L, de Kinkelder C et al. Physical activity levels after treatment for breast cancer: Two-year follow-up. The Breast. 2018;40:23-28.

76. Clifford B, Mizrahi D, Sandler C, Barry B, Simar D, Wakefield C et al. Barriers and facilitators of exercise experienced by cancer survivors: a mixed methods systematic review. Supportive Care in Cancer. 2017;26(3):685-700.

77. Arikawa A, Kaufman B, Raatz S, Kurzer M. Effects of a parallel-arm randomized controlled weight loss pilot study on biological and psychosocial parameters of overweight and obese breast cancer survivors. Pilot and Feasibility Studies. 2017;4(1).

78. Basen-Engquist K, Alfano C, Maitin-Shepard M, Thomson C, Schmitz K, Pinto B et al. Agenda for Translating Physical Activity, Nutrition, and Weight Management Interventions for Cancer Survivors into Clinical and Community Practice. Obesity. 2017;25(S2).

79. Ventura E, Ganz P, Bower J, Abascal L, Petersen L, Stanton A et al. Barriers to physical activity and healthy eating in young breast cancer survivors: modifiable risk factors and associations with body mass index. Breast Cancer Research and Treatment. 2013;142(2):423-433.

80. Milosevic E, Brunet J, Campbell K. Exploring tensions within young breast cancer survivors' physical activity, nutrition and weight management beliefs and practices. Disability and Rehabilitation. 2019;42(5):685-691.

81. Cho D, Park C. Barriers to physical activity and healthy diet among breast cancer survivors: A multilevel perspective. European Journal of Cancer Care. 2017;27(1):e12772.

82. Aycinena A, Valdovinos C, Crew K, Tsai W, Mata J, Sandoval R et al. Barriers to Recruitment and Adherence in a Randomized Controlled Diet and Exercise

Weight Loss Intervention Among Minority Breast Cancer Survivors. Journal of Immigrant and Minority Health. 2016;19(1):120-129.

83. Blaney J, Lowe-Strong A, Rankin-Watt J, Campbell A, Gracey J. Cancer survivors' exercise barriers, facilitators and preferences in the context of fatigue, quality of life and physical activity participation: a questionnaire-survey. Psycho-Oncology. 2011;22(1):186-194.

84. Brunet J, Taran S, Burke S, Sabiston C. A qualitative exploration of barriers and motivators to physical activity participation in women treated for breast cancer. Disability and Rehabilitation. 2013;35(24):2038-2045.

85. Oyekanmi G, Paxton R. Barriers to physical activity among African American breast cancer survivors. Psycho-Oncology. 2014;23(11):1314-1317.

86. Keaver L, McGough A, Du M, Chang W, Chomitz V, Allen J et al. Self-Reported Changes and Perceived Barriers to Healthy Eating and Physical Activity among Global Breast Cancer Survivors: Results from an Exploratory Online Novel Survey. Journal of the Academy of Nutrition and Dietetics. 2021;121(2):233-241.e8.

87. Wong E, Kaplan C, Barulich M, Melisko M. Assessing preferences for receiving supportive care resources among patients seen at a Breast Care Center. Breast Cancer Research and Treatment. 2020;183(2):381-389.

88. Rogers L, Markwell S, Verhulst S, McAuley E, Courneya K. Rural breast cancer survivors: exercise preferences and their determinants. Psycho-Oncology. 2009;18(4):412-421.

89. Meer L, Vallance J, Ball G, Johnson S. Examining Lifestyle Information Sources, Needs, and Preferences among Breast Cancer Survivors in Northern British Columbia. Canadian Journal of Dietetic Practice and Research. 2017;78(4):212-216.

90. Delrieu L, Vallance J, Morelle M, Fervers B, Pialoux V, Friedenreich C et al. Physical activity preferences before and after participation in a 6-month physical activity intervention among women with metastatic breast cancer. European Journal of Cancer Care. 2019;29(1).

91. Yildiz Kabak V, Gursen C, Aytar A, Akbayrak T, Duger T. Physical activity level, exercise behavior, barriers, and preferences of patients with breast cancer–related lymphedema. Supportive Care in Cancer. 2020;29(7):3593-3602.

92. Maxwell-Smith C, Hagger M, Kane R, Cohen P, Tan J, Platell C et al. Psychological correlates of physical activity and exercise preferences in

metropolitan and nonmetropolitan cancer survivors. Psycho-Oncology. 2020;30(2):221-230.

93. ten Tusscher M, Groen W, Geleijn E, Sonke G, Konings I, Van der Vorst M et al. Physical problems, functional limitations, and preferences for physical therapist-guided exercise programs among Dutch patients with metastatic breast cancer: a mixed methods study. Supportive Care in Cancer. 2019;27(8):3061-3070.

94. Nielsen A, Welch W, Gavin K, Cottrell A, Solk P, Torre E et al. Preferences for mHealth physical activity interventions during chemotherapy for breast cancer: a qualitative evaluation. Supportive Care in Cancer. 2019;28(4):1919-1928.

95. Johnston E, Pols J, Ekberg S. Needs, preferences, and experiences of adult cancer survivors in accessing dietary information post-treatment: A scoping review. European Journal of Cancer Care. 2020;30(2).

96. Seven M, Bagcivan G, Pasalak S, Oz G, Aydin Y, Selcukbiricik F. Experiences of breast cancer survivors during the COVID-19 pandemic: a qualitative study. Supportive Care in Cancer. 2021;29(11):6481-6493.

97. Brown M, O'Connor D, Murphy C, McClean M, McMeekin A, Prue G. Impact of COVID-19 on an established physical activity and behaviour change support programme for cancer survivors: An exploratory survey of the Macmillan Move More service for Northern Ireland. Supportive Care in Cancer. 2021;29(10):6135-6143.

98. Gurgel A, Mingroni-Netto P, Farah J, de Brito C, Levin A, Brum P. Determinants of Health and Physical Activity Levels Among Breast Cancer Survivors During the COVID-19 Pandemic: A Cross-Sectional Study. Frontiers in Physiology. 2021;12.

99. Brown M, O'Connor D, Murphy C, McClean M, McMeekin A, Prue G. Impact of COVID-19 on an established physical activity and behaviour change support programme for cancer survivors: An exploratory survey of the Macmillan Move More service for Northern Ireland. Supportive Care in Cancer. 2021;29(10):6135-6143.

100. Himbert C, Hathaway C, Daniels B, Salas K, Ashworth A, Gigic B et al. Impact of the COVID-19 pandemic on exercise habits among cancer patients. 2021;.

101. Natalucci V, Marini C, Flori M, Pietropaolo F, Lucertini F, Annibalini G et al. Effects of a Home-Based Lifestyle Intervention Program on Cardiometabolic Health in Breast Cancer Survivors during the COVID-19 Lockdown. Journal of Clinical Medicine. 2021;10(12):2678.

102. Ochi E, Tsuji K, Narisawa T, Shimizu Y, Kuchiba A, Suto A et al. Cardiorespiratory fitness in breast cancer survivors: a randomised controlled trial of home-based smartphone supported high intensity interval training. BMJ Supportive & Palliative Care. 2021;:bmjspcare-2021-003141.

103. Di Blasio A, Morano T, Lancia F, Viscioni G, Di Iorio A, Grossi S et al. Effects of activity tracker-based counselling and live-web exercise on breast cancer survivors' sleep and waking time during Italy's COVID-19 lockdown. Home Health Care Services Quarterly. 2021;:1-19.

104. Wong E, Kaplan C, Barulich M, Melisko M. Assessing preferences for receiving supportive care resources among patients seen at a Breast Care Center. Breast Cancer Research and Treatment. 2020;183(2):381-389.

105. Prochaska J, Spring B, Nigg C. Multiple health behavior change research: An introduction and overview. Preventive Medicine. 2008;46(3):181-188.

106. Bluethmann S, Vernon S, Gabriel K, Murphy C, Bartholomew L. Taking the next step: a systematic review and meta-analysis of physical activity and behavior change interventions in recent post-treatment breast cancer survivors. Breast Cancer Research and Treatment. 2015;149(2):331-342.

107. Moghaddasi H, Rabiei R. A Model for Measuring e-Health Status Across the World. Telemedicine and e-Health. 2013;19(4):322-327.

108. Wantland D, Portillo C, Holzemer W, Slaughter R, McGhee E. The Effectiveness of Web-Based vs. Non-Web-Based Interventions: A Meta-Analysis of Behavioral Change Outcomes. Journal of Medical Internet Research. 2004;6(4):e40.

109. Short C, Rebar A, James E, Duncan M, Courneya K, Plotnikoff R et al. How do different delivery schedules of tailored web-based physical activity advice for breast cancer survivors influence intervention use and efficacy?. Journal of Cancer Survivorship. 2016;11(1):80-91.

110. van de Wiel H, Stuiver M, May A, van Grinsven S, Aaronson N, Retèl V et al. (Cost-)effectiveness of an internet-based physical activity support program (with and without physiotherapy counselling) on physical activity levels of breast and prostate cancer survivors: design of the PABLO trial. BMC Cancer. 2018;18(1).

111. Xiao Y, Becerik-Gerber B, Lucas G, Roll S. Impacts of Working From Home During COVID-19 Pandemic on Physical and Mental Well-Being of Office Workstation Users. Journal of Occupational & Environmental Medicine. 2020;63(3):181-190.

112. Ipsen C, van Veldhoven M, Kirchner K, Hansen J. Six Key Advantages and Disadvantages of Working from Home in Europe during COVID-19. International Journal of Environmental Research and Public Health. 2021;18(4):1826.

113. Graham M, Weale V, Lambert K, Kinsman N, Stuckey R, Oakman J. Working at Home. Journal of Occupational & Environmental Medicine. 2021;63(11):938-943.

114. Haleem A, Javaid M, Vaishya R. Effects of COVID-19 pandemic in daily life. Current Medicine Research and Practice. 2020;10(2):78-79.

115. Garfin D. Technology as a coping tool during the coronavirus disease 2019 (COVID-19) pandemic: Implications and recommendations. Stress and Health. 2020;36(4):555-559.

116. Iyengar K, Upadhyaya G, Vaishya R, Jain V. COVID-19 and applications of smartphone technology in the current pandemic. Diabetes & Metabolic Syndrome: Clinical Research & Reviews. 2020;14(5):733-737.

APPENDIX A: RESEARCH CONSENT FORM

Confidential

Page 1

Study 16082 Survey

Please complete the survey below.

Thank you!

Please read the following consent form and print a copy for your records, if you so desire.

[Attachment: "16082_Paper_Consent_09242019.pdf"]

Research Information and Consent for Participation in a Research Study

Carle 16082: Counseling and programming preferences for a combined nutrition and physical activity intervention for breast cancer survivors
Principal Investigators: Anna Arthur, Ph.D., M.P.H., R.D.N.
Department and Institution: University of Illinois at Urbana-Champaign/Carle Cancer Center
Address: 386 Bevier Hall, 905 S. Goodwin Ave., Urbana, IL 61801

Thank you for your interest in this joint research study between Carle Cancer Center and the University of Illinois at Champaign-Urbana.

Researchers are required to provide a consent form to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

What is the purpose of the research?
You are invited to complete a survey to help us learn about what types of nutrition and exercise programs breast cancer survivors would like to participate. In the future, we hope to offer nutrition and exercise programs that have been designed with your needs in mind. This study is being conducted by Dr. Anna Arthur, in the Department of Food Science and Human Nutrition, from the University of Illinois Urbana-Champaign affiliated with the Carle Foundation Hospital Cancer Center.

What procedures are involved?
This survey will take approximately 45-60 minutes of your time. You will be asked to complete questions about your history of participation in diet and exercise programming; interest in, preferences for and barriers to participating in such programming; demographic, clinical and lifestyle factors; and health and well-being.

Your decision to participate or decline participation in this study is completely voluntary and you have the right to terminate your participation at any time without penalty. You may skip any questions you do not wish to answer. If you want do not wish to complete this survey just close your tab.

What are the potential risks and discomforts?
To the best of our knowledge, the study activities in which we are asking you to participate have no more risk of harm than you would experience in everyday life.

1. The primary risk of this research is a loss of privacy (revealing to others that you are taking part in this study).

2. You may feel some discomfort when disclosing personal information. You may skip any of the questions that you do not want to answer or discontinue filling out the survey at any time.

3. While we will protect your privacy and the information collected about you the very best we can, there is always a small chance of a breach of confidentiality. However, we have safeguards in place to help minimize the chance that this would happen.

Are there benefits to taking part in the research?
Although your participation in this research may not benefit you personally, you are contributing to the development of a combined nutrition and physical activity intervention for breast cancer survivors. The study findings will help inform and expand upon the existing Breast Cancer Survivorship Clinic services. There are no risks to individuals participating in this survey beyond those that exist in daily life. Your decision to participate, decline, or withdraw from participation will have no effect on your current status or future relations with the University of Illinois.

What other options are there?
You have the option to not participate in this study.

What about confidentiality?
We respect your right to keep your information private. We cannot promise complete confidentiality. People who may look at your information include the Investigator, research staff, members of the Institutional Review Board (a committee that oversees human subject protections at Carle Foundation Hospital), and representatives of the Sponsor of the research. Your information may also be seen by government employees, such as representatives of the FDA or the Office for Human Research Protections at the Department of Health and Human Services. Other officials, such as state health officials, may also need to see your information.

To help assure quality in research, quality assurance and compliance employees of Carle Foundation Hospital [and the Investigator] may also have access to your information. Employees who work to assure quality and compliance protect the confidentiality of your information unless disclosure is required by law.

We will keep records that include your information safe and will put them in Name the secure location, such as locked cabinets when they are not being used. If records that include your information are put on computers, we will use reasonable actions to keep those computers secure.

Once your information is no longer traceable to you, we may share your information with other researchers. Your information will be combined with information about other people participating in the study to be analyzed. Your name will not be used when we publish results. Information from the study will be reported in a way that combines the results of many participants. If possible, we will replace identifiable information about you, such as your name or birth date, with number codes that cannot be connected to you. Only research staff will have access to the key that connects the number code to your identifiable information.

What are the costs of participating in this research?
There are no costs to you for participating in this research.

Will I be reimbursed for any of my expenses or paid for my participation in this research?
For completing the survey, you will be eligible to receive a $10 Amazon gift card.

Can I withdraw or be removed from the study?
Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future dealings with the University of Illinois at Urbana-Champaign or Carle. If you decide to participate, you are free to withdraw at any time without affecting that relationship. Data previously recorded will be kept on file but no new data will be entered for later on data analysis.

The researchers also have the right to stop your participation in this study without your consent if they believe it is in your best interest.

In the event you withdraw or are asked to leave the study, you will still be compensated as described above.

Who should I contact if I have questions?
Contact Dr. Anna Arthur (Principal Investigator) at aarthur@illinois.edu (217-300-3014):
• if you have any questions about this study or your part in it,
• if you have questions, concerns or complaints about the research,
• if you have any questions about a research-related injury.

"Please note that unencrypted emails are not a secure or private means of communication. Email messages can be intercepted and read by others with access to your email account. Because of these risks, we recommend you avoid sending any health information or sensitive information via email unless encryption is used. However, the best means of communication is up to you".

What are my rights as a research subject?
If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Carle Institutional Review Board (a group of people who review the research to protect your rights) at 217-383-4366.
If you are an employee of the University of Illinois or Carle, your participation in this research is in no way a part of your employment duties, and your refusal to participate will not in any way affect your employment with or the benefits, privileges, or opportunities associated with your employment at the University of Illinois at Urbana-Champaign or Carle. You will not be offered or receive any special consideration if you participate in this research.

Remember:
Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University or Carle. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

Please print a copy of this consent form for your records, if you so desire.

I have read and understand the above consent form, I certify that I am 18 years old or older and, by clicking "Yes", I indicate my willingness to voluntarily take part in the study.

◯ Yes
◯ No

Dear Participants,

Thank you for your interest in our Counseling and Programming Preferences for a Combined Nutrition and Physical Activity Intervention for Breast Cancer Survivors research project.

Before you begin, we would like to ask you two questions to ensure your eligibility for this study.

Are you a woman 18 years or older?

◯ Yes
◯ No

Have you been diagnosed with ductal carcinoma in situ (DCIS) or Stage I-IV breast cancer?

◯ Yes
◯ No

Were you previously treated at the Carle Foundation Hospital?

◯ Yes
◯ No

Would you be willing to provide us with your First and Last name and Date of Birth or Medical Record Number so that the researchers can link your survey responses to important data in your medical record such as details about your breast cancer type and the treatment you received?
**Note: If you agree, only the project principal investigator and other Institutional Review Board approved study team members will have access to your private health information.

◯ Yes
◯ No

Below is the HIPAA form for Authorization to Use and/or Disclose your medical information. Please read, and provide your printed name, date of birth, today's date and signature below.

[Attachment: "16082_StampedHIPAAauth_2018_0605.pdf"]

Authorization to Use and/or Disclose (Release)
Individually Identifiable Health Information for Research Purposes

1. PROTOCOL INFORMATION
Carle ID #: 16082 - 16CCC1259 Version: 06/05/2018
Study Title: Counseling and Programming Preferences for a Combined Nutrition and Physical Activity Intervention for Breast Cancer Survivors
Principal Investigator (PI): Anna Arthur, PhD, MPH, RD
Principal Investigator's Mailing Address: University of Illinois at Urbana-Champaign, Department of Food Science and Human Nutrition, 382B AESB 1304 W. Pennsylvania Avenue, Urbana, IL 61820
Principal Investigator's Phone Number: 217-244-4890

2. PURPOSE OF USE AND/OR DISCLOSURE OF HEALTH INFORMATION
By signing this form, I am giving permission to Carle and Carle affiliated health care provider organizations to use and/or disclose my health information that individually identifies me for the purposes of the research study ("Study Title") listed above. I authorize my healthcare providers and healthcare institutions to release my medical information to Carle (or the PI) for use in this research study.

3. WHAT HEALTH INFORMATION MAY BE USED AND/OR DISCLOSED?
Carle may use and/or disclose my past, present and future records and information as described in the study's informed consent document approved by the Institutional Review Board which may include:
☐ Lab test results (which may include genetic tests, HIV/AIDS tests and/or tests for other communicable diseases if part of my records)
☐ Procedure reports
☐ Hospitalization records
☐ Operative reports
☐ Outpatient/Office visits, exams, consultations, phone call records and notes
☐ Radiology/x-ray images and/or reports
☐ Registration and billing information
☐ Emergency room reports
☐ Medication information including chemotherapy, and other drugs, vitamins, and herbal remedies
☐ Questionnaires and diaries
☐ Pathology reports
☐ Other (describe):

4. RECIPIENTS OF MY HEALTH INFORMATION
My health information listed above may be used by and/or disclosed to any person or entity that needs access to the information for this research Study, such as, but not limited to:
☐ The Principal Investigator (listed above) and his/her research staff;
☐ Data coordinators and coordinating centers;
☐ Government representatives and other regulatory agencies;
☐ Oversight organizations involved in keeping research safe;
☐ Research collaborators;
☐ Sponsors including persons or entities that are working for or owned by the sponsor;
☐ Institutional Review Boards; and/or
☐ Data Safety and Monitoring Boards
☐ Other (describe):

5. OTHER
Once my health information has been disclosed, the information may no longer be protected under the laws and regulations that apply to Carle. Therefore, I am aware that the recipients may share the information with others without my permission, if permitted by laws governing them.

I do not have to sign this Authorization. If I decide not to sign the Authorization:

☐ It will not affect my treatment, payment or enrollment in any health plan or affect my eligibility for plan benefits, but
☐ I will not be allowed to participate in this research study.

After signing this authorization form, I can change my mind at any time and revoke the authorization by sending written letters to:

☐ The Principal Investigator at the mailing address on the first page; and
☐ Carle Health Information Management, 3310 Fields South Drive, Champaign, IL 61822
If I revoke this authorization, Carle may not continue to use and/or disclose my health information for this Study, except that:

☐ My health information that has already been disclosed before I revoked this Authorization cannot be taken back; and
☐ Carle and the recipients may continue to use and disclose my health information already collected for this research Study for the purposes of maintaining the integrity of the Study, and for regulatory compliance.

If I change my mind and revoke the authorization, I will not be allowed to continue to participate in the Study.

This authorization has no expiration date.

If I have any questions or concerns about my privacy rights, I should contact the Carle Human Subject Protection Office at 217-383-4366.

I am the subject or am legally authorized to act on behalf of the subject. I have read this form, and may receive a copy of this authorization after it is signed.

Carle IRB approved HIPAA
07/18/2018

Electronic Signature

_____

Today's Date:

_____

Patient First Name:

_____

Patient Last Name:

_____

Patient Date of Birth:

_____
((MM/DD/YYYY))

If known, please enter your Patient Medical Record Number.

_____

Contact Information

If you would like to receive a $10 Amazon gift card for completing this survey please provide your contact information below

First name:

_____

Last name:

_____

Email address:

_____

Mailing address:

_____

May we contact you about potentially participating in future studies conducted by the Nutrition and Cancer Survivorship Lab at the University of Illinois?

◯ Yes
◯ No

**Note: Once you start this survey, the survey cannot be stopped or returned to if you close out of the tab.

APPENDIX B: SURVEY INSTRUMENT

Confidential

Nutrition

Since your breast cancer diagnosis, have you received any information, education, counseling, and/or therapy related to nutrition?

◯ Yes
◯ No

From whom did you receive the information? (Please mark all that apply.)

☐ Registered Dietitian Nutritionist
☐ Exercise Specialist (exercise physiologist, rehabilitation practitioner, etc.)
☐ Personal Trainer
☐ Nurse
☐ Physician/Oncologist
☐ Cancer patient or survivor
☐ Cancer Support Group
☐ Family/friends
☐ Other

If other, please specify.

_____

When did you receive information? (Please mark all that apply.)

☐ During treatment
☐ Immediately after completing treatment
☐ Within the first 6 months after treatment
☐ Between 6 months to 1 year after treatment
☐ More than 1 year after treatment
☐ Other

If other, please specify.

_____

	Not at all helpful	A little bit helpful	Somewhat helpful	Quite helpful	Extremely helpful
If you received nutrition information, how helpful was the information provided?	◯	◯	◯	◯	◯

If not helpful, who/what was the source of information? (Please mark all that apply.)

☐ Internet/Online Articles
☐ Social Media (eg. Posts share on Facebook/Twitter/Instagram etc.)
☐ TV Shows
☐ Magazine articles
☐ Friends and Family
☐ Other

If other, please specify.

_____

If you have not received nutrition information from a health professional, why not?

- ◯ Was not offered
- ◯ Was not interested
- ◯ Other

If other, please specify.

_____

Exercise

Since your breast cancer diagnosis, have you received any information on exercise therapy or education?

- ◯ Yes
- ◯ No

From whom did you receive the information? (Please mark all that apply.)

- ☐ Registered Dietitian Nutritionist
- ☐ Exercise Specialist (exercise physiologist, rehabilitation practitioner, etc.)
- ☐ Personal Trainer
- ☐ Nurse
- ☐ Physician/Oncologist
- ☐ Cancer patient or survivor
- ☐ Cancer Support Group
- ☐ Family/friends
- ☐ Other

If other, please specify.

_____

When did you receive information? (Please mark all that apply.)

- ☐ During treatment
- ☐ Immediately after completing treatment
- ☐ Within the first 6 months after treatment
- ☐ Between 6 months to 1 year after treatment
- ☐ More than 1 year after treatment
- ☐ Other

If other, please specify.

_____

	Not at all helpful	A little bit helpful	Somewhat helpful	Quite helpful	Extremely helpful
If you received exercise information, how helpful was the information provided?	◯	◯	◯	◯	◯

If not helpful, who/what was the source of information? (Please mark all that apply.)

- ☐ Internet/Online Articles
- ☐ Social Media (eg. Posts share on Facebook/Twitter/Instagram etc.)
- ☐ TV Shows
- ☐ Magazine articles
- ☐ Friends and Family
- ☐ Other

If other, please specify.

_____

If you have not received exercise information from a health professional, why not?

◯ Was not offered
◯ Was not interested
◯ Other

If other, please specify.

_____

	Immediately after diagnosis	During treatment	Immediately following treatment	More than a few months after completing treatment
We are planning on developing healthy lifestyle programs for Carle Cancer patients and survivors. During which phase do you think would be the best time for breast cancer survivors to participate in diet and exercise programming?	◯	◯	◯	◯

	Not at all likely	A little bit likely	Somewhat likely	Quite likely	Extremely likely
If you had the opportunity to take part in a breast cancer research study that tested the benefits of nutrition and exercise, how likely would you be to participate?	◯	◯	◯	◯	◯

If you were to participate in a healthy lifestyle program that includes nutrition and exercise guidance, would you prefer to receive nutrition and exercise guidance together or separately?

◯ Together
◯ Separately
◯ No preference
◯ Other

If other, please specify.

_____

How would you most likely prefer to meet with a Registered Dietitian Nutritionist?

◯ In person at hospital/clinic
◯ Distance-based (from home) using technology
◯ No preference
◯ Other

If other, please specify.

_____

How would you most prefer to receive nutrition information? (Pick your top 3 choices)

☐ In person
☐ Over the telephone
☐ Written materials (booklets or educational handouts)
☐ DVD with recorded material
☐ Internet/technology-based (e.g. website, text-messaging, YouTube)
☐ Visual communication tools (e.g. Skype or FaceTime)
☐ Other
☐ No preference

If other, please specify.

_____

Out of your top 3, which method of receiving nutrition information is your number 1 preference?

◯ In person
◯ Over the telephone
◯ Written materials (booklets or educational handouts)
◯ DVD with recorded material
◯ Internet/technology-based (e.g. website, text-messaging, YouTube)
◯ Visual communication tools (e.g. Skype or FaceTime)
◯ Other
◯ No preference

If other, please specify.

_____

	One-on-one sessions	Group sessions with other breast cancer survivors	Group sessions with others	No preference
How would you most prefer to receive nutrition education/counseling?	◯	◯	◯	◯

If you would prefer group session with others, please specify.

_____

How would you prefer to meet with an exercise specialist?

◯ In person at hospital/clinic
◯ Distance-based (from home) using technology
◯ No preference
◯ Other

If other, please specify

_____

How would you most prefer to receive exercise information? (Pick your top 3 choices)

- ☐ In person
- ☐ Over the telephone
- ☐ Written materials (booklets or educational handouts)
- ☐ DVD with recorded material
- ☐ Internet/technology-based (e.g. website, text-messaging, YouTube)
- ☐ Visual communication tools (e.g. Skype or FaceTime)
- ☐ Other
- ☐ No preference

If other, please specify.

_____

Out of your top 3, which method of receiving exercise information is your number 1 preference?

- ◯ In person
- ◯ Over the telephone
- ◯ Written materials (booklets or educational handouts)
- ◯ DVD with recorded material
- ◯ Internet/technology-based (e.g. website, text-messaging, YouTube)
- ◯ Visual communication tools (e.g. Skype or FaceTime)
- ◯ Other
- ◯ No preference

If other, please specify.

_____

	One-on-one sessions	Group sessions with other breast cancer survivors	Spouse/ significant other	Other family members	Other	No preference
How would you prefer to receive exercise education/counseling?	◯	◯	◯	◯	◯	◯

If other, please specify.

_____

	With other cancer survivors	Spouse/ significant other	Family members other than spouse	Friends	Other
If you were to participate in group exercise education, with whom would you prefer to exercise?	◯	◯	◯	◯	◯

If other, please specify.

_____

	In person / hospital clinics	Gym/Fitness Center supervised under an exercise specialist	Home using technology	Other
Where would you most prefer to exercise?	○	○	○	○

If other, please specify.

_____

What is the farthest you are willing to travel for nutrition counseling and/or exercise programs?

○ Up to 15 miles
○ Up to 30 miles
○ Up to 45 miles
○ Up to 60 miles
○ More than 60 miles
○ I'd prefer to participate from home

Which barriers do you feel might currently interfere the most with your ability to participate in a combined nutrition and exercise program? (Pick your top 3 choices.)

☐ Fatigue
☐ Family responsibility
☐ Illness
☐ Work
☐ Transportation
☐ Negative perceptions about diet and exercise
☐ Surgery
☐ Personal or emotional issues
☐ Other

If other, please specify.

_____

What could we do to increase participation in a nutrition and exercise program designed for women who are diagnosed with breast cancer that includes nutrition and exercise guidance after breast cancer diagnosis? Please describe.

We are considering developing nutrition and exercise programs that can be delivered via technology so that participation can be done from home. The following questions will help us know where to focus our efforts.

Where do you most often use a computer? (Please mark your top two.)

☐ Home
☐ Family member's or friend's home
☐ Work
☐ Library
☐ School
☐ Store or restaurant
☐ Other

If other, please specify.

_____

Do you have a tablet (such as iPad, iPad Mini, Kindle Fire, or Samsung Galaxy)?

◯ Yes
◯ No

How often do you use your tablet?

◯ Every day
◯ A few times per week
◯ At least one time per week
◯ A few times per month or less

	Not at all	A little bit	Somewhat	Quite a bit	Very much
How comfortable are you with using your tablet?	◯	◯	◯	◯	◯

Do you have a mobile phone with active service?

◯ Yes
◯ No

Do you send and receive text messages from a mobile phone?

◯ Yes
◯ No

Do you have a Smart Phone that can download and use applications ("apps")?

◯ Yes
◯ No

	Not at all	A little bit	Somewhat	Quite a bit	Very much
How comfortable are you with using your Smart Phone?	◯	◯	◯	◯	◯

Do you have high-speed internet where you live?

◯ Yes
◯ No

Do you use the internet currently to look up or read about nutrition or food information?

◯ Yes
◯ No

Do you use any social media sites currently to look up or read about healthy living, if yes, what healthy living topics have you used the internet to learn more about in the past month? (Please mark all that apply.)

☐ Recipes.
☐ Healthy eating information.
☐ Exercise tips.
☐ Food safety information.
☐ Food budgeting information.
☐ No. I don't use any social media sites to look up or read about healthy living.
☐ Other

If other, please specify.

_____

Which social media/visual communication platforms do you use? (Please mark all that apply.)

☐ Facebook
☐ Twitter
☐ Pinterest
☐ Instagram
☐ YouTube
☐ Google Plus
☐ Snapchat
☐ Other

If other, please specify.

_____

Have you made changes to your eating or health habits because of the information you have read online or through social media?

◯ Yes
◯ No

	Not at all	A little bit	Somewhat	Quite a bit	Very much
How comfortable would you be with participating in a technology-based nutrition and exercise program? (For example, Skype, FaceTime, or other communication apps)	◯	◯	◯	◯	◯

If you were to participate in a nutrition and exercise program delivered via technology, which mode would you prefer? (Pick your top 3 choices)

- ☐ No preference
- ☐ Not interested
- ☐ Website with self-paced pages to click through (which may include video clips)
- ☐ Social media posts (such as on Facebook)
- ☐ Mobile application ("app") for Smart Phone or tablet
- ☐ Text messages
- ☐ E-mails
- ☐ Visual communication tools (e.g. Skype or FaceTime)
- ☐ Group support, such as online group chats or message boards
- ☐ Other

If other, please specify.

_____

Out of your top 3, which nutrition and exercise program would you most prefer?

- ◯ No preference
- ◯ Not interested
- ◯ Website with self-paced pages to click through (which may include video clips)
- ◯ Social media posts (such as on Facebook)
- ◯ Mobile application ("app") for Smart Phone or tablet
- ◯ Text messages
- ◯ E-mails
- ◯ Visual communication tools (e.g. Skype or FaceTime)
- ◯ Group support, such as online group chats or message boards
- ◯ Other

If other, please specify.

_____

	Not at all	A little bit	Somewhat	Quite a bit	Very much
As a breast cancer survivor, how important do you feel it is that research be done to improve issues such as daily functioning, quality of life, fatigue/tiredness, and nutrition/exercise in patients diagnosed with this disease?	◯	◯	◯	◯	◯

Besides the issues listed above, what other issues or topics do you feel are important to include in breast cancer research done after breast cancer diagnosis? Please describe.

Is there anything else you would like the researchers to consider as they work to develop nutrition and exercise programming?

These questions are about foods you ate or drank during the past month, that is, the past 30 days. When answering, please include meals and snacks at home, at work or school, in restaurants, and any place else.
Please mark to indicate your answer.

During the past month, how often did you eat hot or cold cereals? Please mark the appropriate answer.

- ◯ Never
- ◯ 1 times last month
- ◯ 2-3 times last month
- ◯ 1 time per week
- ◯ 2 times per week
- ◯ 3-4 times per week
- ◯ 5-6 times per week
- ◯ 1 time per day
- ◯ 2 or more times per day

During the past month, what kind of cereal did you usually eat? - Print cereal, if none leave blank. _____

If there was another kind of cereal that you usually ate during the past month, what kind was it? - Print cereal, if none leave blank. _____

During the past month, how often did you have any milk (either to drink or on cereal)? Include regular milks, chocolate or other flavored milks, lactose-free milk, buttermilk. Please DO NOT include soy milk or small amounts of milk in coffee or tea. Please mark the appropriate answer.

- ◯ Never
- ◯ 1 times last month
- ◯ 2-3 times last month
- ◯ 1 time per week
- ◯ 2 times per week
- ◯ 3-4 times per week
- ◯ 5-6 times per week
- ◯ 1 time per day
- ◯ 2-3 times per day
- ◯ 4-5 times per day
- ◯ 6 or more times per day

What kind of milk did you usually use?

- ◯ Whole or regular milk
- ◯ 2% fat fat or reduced
- ◯ 1%, 1/2%, or low-fat milk
- ◯ Fat-free, skim or nonfat milk
- ◯ soy milk
- ◯ Other kind of milk

If other, please specify _____

During the past month, how often did you drink regular soda or pop that contains sugar? DO NOT include diet soda. Please mark the appropriate answer.

- ◯ Never
- ◯ 1 times last month
- ◯ 2-3 times last month
- ◯ 1 time per week
- ◯ 2 times per week
- ◯ 3-4 times per week
- ◯ 5-6 times per week
- ◯ 1 time per day
- ◯ 2-3 times per day
- ◯ 4-5 times per day
- ◯ 6 or more times per day

During the past month, how often did you drink 100% pure fruit juices such as orange, mango, apple, grape and pineapple juices? DO NOT include fruit-flavored drinks with added sugar or fruit juice you made at home and added sugar to. Please mark the appropriate answer.

- ◯ Never
- ◯ 1 times last month
- ◯ 2-3 times last month
- ◯ 1 time per week
- ◯ 2 times per week
- ◯ 3-4 times per week
- ◯ 5-6 times per week
- ◯ 1 time per day
- ◯ 2-3 times per day
- ◯ 4-5 times per day
- ◯ 6 or more times per day

During the past month, how often did you drink coffee or tea that had sugar or honey added to it? Include coffee and tea you sweetened yourself and presweetened tea and coffee drinks such as Arizona Iced Tea and Frappuccino. DO NOT include artificially sweetened coffee or diet tea. Please mark the appropriate answer.

- ◯ Never
- ◯ 1 times last month
- ◯ 2-3 times last month
- ◯ 1 time per week
- ◯ 2 times per week
- ◯ 3-4 times per week
- ◯ 5-6 times per week
- ◯ 1 time per day
- ◯ 2-3 times per day
- ◯ 4-5 times per day
- ◯ 6 or more times per day

During the past month, how often did you drink sweetened fruit drinks, sports or energy drinks, such as Kool-Aid, lemonade, Hi-C, cranberry drink, Gatorade, Red Bull or Vitamin Water? Include fruit juices you made at home and added sugar to. DO NOT include diet drinks or artificially sweetened drinks. Please mark the appropriate answer.

◯ Never
◯ 1 times last month
◯ 2-3 times last month
◯ 1 time per week
◯ 2 times per week
◯ 3-4 times per week
◯ 5-6 times per week
◯ 1 time per day
◯ 2-3 times per day
◯ 4-5 times per day
◯ 6 or more times per day

During the past month, how often did you eat fruit ? Include fresh, frozen or canned fruit. DO NOT include juices. Please mark the appropriate answer.

◯ Never
◯ 1 times last month
◯ 2-3 times last month
◯ 1 time per week
◯ 2 times per week
◯ 3-4 times per week
◯ 5-6 times per week
◯ 1 time per day
◯ 2 or more times per day

During the past month, how often did you eat a green leafy or lettuce salad, with or without other vegetables? Please mark the appropriate answer.

◯ Never
◯ 1 times last month
◯ 2-3 times last month
◯ 1 time per week
◯ 2 times per week
◯ 3-4 times per week
◯ 5-6 times per week
◯ 1 time per day
◯ 2 or more times per day

During the past month, how often did you eat any kind of fried potatoes, including french fries, home fries, or hash brown potatoes? Please mark the appropriate answer.

◯ Never
◯ 1 times last month
◯ 2-3 times last month
◯ 1 time per week
◯ 2 times per week
◯ 3-4 times per week
◯ 5-6 times per week
◯ 1 time per day
◯ 2 or more times per day

During the past month, how often did you eat any other kind of potatoes, such as baked, boiled, mashed potatoes, sweet potatoes, or potato salad? Please mark the appropriate answer.

◯ Never
◯ 1 times last month
◯ 2-3 times last month
◯ 1 time per week
◯ 2 times per week
◯ 3-4 times per week
◯ 5-6 times per week
◯ 1 time per day
◯ 2 or more times per day

During the past month, how often did you eat refried beans, baked beans, beans in soup, pork and beans or any other type of cooked dried beans? DO NOT include green beans. Please mark the appropriate answer.

◯ Never
◯ 1 times last month
◯ 2-3 times last month
◯ 1 time per week
◯ 2 times per week
◯ 3-4 times per week
◯ 5-6 times per week
◯ 1 time per day
◯ 2 or more times per day

During the past month, how often did you eat brown rice or other cooked whole grains, such as bulgur, cracked wheat, or millet? DO NOT include white rice. Please mark the appropriate answer.

◯ Never
◯ 1 times last month
◯ 2-3 times last month
◯ 1 time per week
◯ 2 times per week
◯ 3-4 times per week
◯ 5-6 times per week
◯ 1 time per day
◯ 2 or more times per day

During the past month, not including what you just answered about (green salads, potatoes, cooked dried beans), how often did you eat other vegetables ? Please mark the appropriate answer.

◯ Never
◯ 1 times last month
◯ 2-3 times last month
◯ 1 time per week
◯ 2 times per week
◯ 3-4 times per week
◯ 5-6 times per week
◯ 1 time per day
◯ 2 or more times per day

During the past month, how often did you have Mexican-style salsa made with tomato? Please mark the appropriate answer.

◯ Never
◯ 1 times last month
◯ 2-3 times last month
◯ 1 time per week
◯ 2 times per week
◯ 3-4 times per week
◯ 5-6 times per week
◯ 1 time per day
◯ 2 or more times per day

During the past month, how often did you eat pizza? Include frozen pizza, fast food pizza, and homemade pizza. Please mark the appropriate answer.

◯ Never
◯ 1 times last month
◯ 2-3 times last month
◯ 1 time per week
◯ 2 times per week
◯ 3-4 times per week
◯ 5-6 times per week
◯ 1 time per day
◯ 2 or more times per day

During the past month, how often did you have tomato sauces such as with spaghetti or noodles or mixed into foods such as lasagna? DO NOT include tomato sauce on pizza. Please mark the appropriate answer.

◯ Never
◯ 1 times last month
◯ 2-3 times last month
◯ 1 time per week
◯ 2 times per week
◯ 3-4 times per week
◯ 5-6 times per week
◯ 1 time per day
◯ 2 or more times per day

During the past month, how often did you eat any kind of cheese? Include cheese as a snack, cheese on burgers, sandwiches, and cheese in foods such as lasagna, quesadilla, or casseroles. DO NOT include cheese on pizza. Please mark the appropriate answer.

◯ Never
◯ 1 times last month
◯ 2-3 times last month
◯ 1 time per week
◯ 2 times per week
◯ 3-4 times per week
◯ 5-6 times per week
◯ 1 time per day
◯ 2 or more times per day

During the past month, how often did you eat red meat, such as beef, pork, ham, or sausage? Include red meat you had in sandwiches, lasagna, stew, and other mixtures. Red meat may also include veal, lamb, and any lunch meats made with these meats. DO NOT include chicken, turkey or seafood. Please mark the appropriate answer.

◯ Never
◯ 1 times last month
◯ 2-3 times last month
◯ 1 time per week
◯ 2 times per week
◯ 3-4 times per week
◯ 5-6 times per week
◯ 1 time per day
◯ 2 or more times per day

During the past month, how often did you eat any processed meat, such as bacon, lunch meats, or hot dogs? Include processed meats you had in sandwiches, soups, pizza, casseroles, and other mixtures.
Processed meats are those preserved by smoking, curing, or salting, or by the addition of preservatives. Examples are: ham, bacon, pastrami, salami, sausages, bratwursts, frankfurters, hot dogs, and spam. Please mark the appropriate answer.

◯ Never
◯ 1 times last month
◯ 2-3 times last month
◯ 1 time per week
◯ 2 times per week
◯ 3-4 times per week
◯ 5-6 times per week
◯ 1 time per day
◯ 2 or more times per day

During the past month, how often did you eat whole grain bread including toast, rolls, and in sandwiches? Whole grain breads include whole wheat, rye, oatmeal and pumpernickel. DO NOT include white bread. Please mark the appropriate answer.

◯ Never
◯ 1 times last month
◯ 2-3 times last month
◯ 1 time per week
◯ 2 times per week
◯ 3-4 times per week
◯ 5-6 times per week
◯ 1 time per day
◯ 2 or more times per day

During the past month, how often did you eat chocolate or any other types of candy? DO NOT include sugar-free candy. Please mark the appropriate answer.

◯ Never
◯ 1 times last month
◯ 2-3 times last month
◯ 1 time per week
◯ 2 times per week
◯ 3-4 times per week
◯ 5-6 times per week
◯ 1 time per day
◯ 2 or more times per day

During the past month, how often did you eat doughnuts, sweet rolls, Danish, muffins, pan dulce, or pop-tarts? DO NOT include sugar-free items. Please mark the appropriate answer.

- ◯ Never
- ◯ 1 times last month
- ◯ 2-3 times last month
- ◯ 1 time per week
- ◯ 2 times per week
- ◯ 3-4 times per week
- ◯ 5-6 times per week
- ◯ 1 time per day
- ◯ 2 or more times per day

During the past month, how often did you eat cookies, cake, pie or brownies? DO NOT include sugar-free kinds. Please mark the appropriate answer.

- ◯ Never
- ◯ 1 times last month
- ◯ 2-3 times last month
- ◯ 1 time per week
- ◯ 2 times per week
- ◯ 3-4 times per week
- ◯ 5-6 times per week
- ◯ 1 time per day
- ◯ 2 or more times per day

During the past month, how often did you eat ice cream or other frozen desserts? DO NOT include sugar-free kinds. Please mark the appropriate answer.

- ◯ Never
- ◯ 1 times last month
- ◯ 2-3 times last month
- ◯ 1 time per week
- ◯ 2 times per week
- ◯ 3-4 times per week
- ◯ 5-6 times per week
- ◯ 1 time per day
- ◯ 2 or more times per day

During the past month, how often did you eat popcorn? Please mark the appropriate answer.

- ◯ Never
- ◯ 1 times last month
- ◯ 2-3 times last month
- ◯ 1 time per week
- ◯ 2 times per week
- ◯ 3-4 times per week
- ◯ 5-6 times per week
- ◯ 1 time per day
- ◯ 2 or more times per day

Exercise

During a typical 7-Day period (a week), how many times on the average do you do the following kinds of exercise for more than 15 minutes during your free time (write in each box the appropriate number).

STRENUOUS EXERCISE (HEART BEATS RAPIDLY) (e.g., running, jogging, hockey, football, soccer, squash, basketball, cross country skiing, judo, roller skating, vigorous swimming, vigorous long distance bicycling)	_____ (Average Number of Times During a Typical Week)
MODERATE EXERCISE (NOT EXHAUSTING) (e.g., fast walking, baseball, tennis, easy bicycling, volleyball, badminton, easy swimming, alpine skiing, popular and folk dancing)	_____ (Average Number of Times During a Typical Week)
MILD EXERCISE (MINIMAL EFFORT) (e.g., yoga, archery, fishing from river bank, bowling, horseshoes, golf, snow-mobiling, easy walking)	_____ (Average Number of Times During a Typical Week)
During a typical 7-Day period (a week), in your leisure time, how often do you engage in any regular activity long enough to work up a sweat (heart beats rapidly)?	◯ Often ◯ Sometimes ◯ Never/Rarely

Quality of Life

Next, there will be a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

Physical Well-Being					
	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have a lack of energy	○	○	○	○	○
I have nausea	○	○	○	○	○
Because of my physical condition, I have trouble meeting the needs of my family	○	○	○	○	○
I have pain	○	○	○	○	○
I am bothered by side effects of treatment	○	○	○	○	○
I feel ill	○	○	○	○	○
I am forced to spend time in bed	○	○	○	○	○

Social/Family Well-being					
	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel close to my friends	○	○	○	○	○
I get emotional support from my family	○	○	○	○	○
I get support from my friends	○	○	○	○	○
My family has accepted my illness	○	○	○	○	○
I am satisfied with family communication about my illness	○	○	○	○	○
I feel close to my partner (or the person who is my main support)	○	○	○	○	○

I am satisfied with my sex life

○ Not at all
○ A little bit
○ Somewhat
○ Quite a bit
○ Very much
○ Prefer not to answer

Emotional Well-being					
	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel sad	○	○	○	○	○
I am satisfied with how I am coping with my illness	○	○	○	○	○
I am losing hope in the fight against my illness	○	○	○	○	○
I feel nervous	○	○	○	○	○
I worry about dying	○	○	○	○	○
I worry that my condition will get worse	○	○	○	○	○

Functional Well-being					
	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am able to work (include work at home)	○	○	○	○	○
My work (include work at home) is fulfilling	○	○	○	○	○
I am able to enjoy life	○	○	○	○	○
I have accepted my illness	○	○	○	○	○
I am sleeping well	○	○	○	○	○
I am enjoying the things I usually do for fun	○	○	○	○	○
I am content with the quality of my life right now	○	○	○	○	○

Additional Concerns					
	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have been short of breath	○	○	○	○	○
I am self-conscious about the way I dress	○	○	○	○	○
One or both of my arms are swollen or tender	○	○	○	○	○
I feel sexually attractive	○	○	○	○	○
I am bothered by hair loss	○	○	○	○	○
I worry that other members of my family might someday get the same illness I have	○	○	○	○	○
I worry about the effect of stress on my illness	○	○	○	○	○
I am bothered by a change in weight	○	○	○	○	○
I am able to feel like a woman	○	○	○	○	○
I have certain parts of my body where I experience pain	○	○	○	○	○

Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have a lack of energy	○	○	○	○	○
I have pain	○	○	○	○	○
I feel ill	○	○	○	○	○
I have been short of breath	○	○	○	○	○
Because of my physical condition, I have trouble meeting the needs of my family	○	○	○	○	○
I feel fatigued	○	○	○	○	○
I have bone pain	○	○	○	○	○
I am sleeping well	○	○	○	○	○

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I worry that my condition will get worse	○	○	○	○	○
I have nausea	○	○	○	○	○
I have mouth sores	○	○	○	○	○
I am bothered by side effects of treatment	○	○	○	○	○
I am bothered by hair loss	○	○	○	○	○
I am able to work (include work at home)	○	○	○	○	○
I am able to enjoy life	○	○	○	○	○
I am content with the quality of my life right now	○	○	○	○	○

Part 6. Demographics

What is your current age?

_____

What is your height?

(feet component)

◯ 4
◯ 5
◯ 6
◯ 7

(inches component)
(in inches)

◯ 0
◯ 1
◯ 2
◯ 3
◯ 4
◯ 5
◯ 6
◯ 7
◯ 8
◯ 9
◯ 10
◯ 11

What is your weight?

_____
(pounds)

What is your sex?

◯ Male
◯ Female
◯ Other

If other, please specify.

_____

What is your marital status?

◯ Married
◯ Living as married
◯ Divorced
◯ Widowed
◯ Separated
◯ Single, never married

What is your race? One or more categories may be selected. Mark all that apply.

- ☐ Black or African-American
- ☐ White
- ☐ Asian Indian
- ☐ Asian (i.e. original people of the Far East, Southeast Asia, and Indian subcontinent)
- ☐ American Indian or Alaska Native
- ☐ Chinese
- ☐ Filipino
- ☐ Japanese
- ☐ Korean
- ☐ Vietnamese
- ☐ Other Asian
- ☐ Native Hawaiian
- ☐ Guamanian or Chamorro
- ☐ Samoan
- ☐ Other Pacific Islander
- ☐ Other

If other, please specify.

_____

Are you Hispanic, Latino/a, or Spanish origin? Mark all the apply.

- ☐ Mexican American, Chicano/a
- ☐ Puerto Rican
- ☐ Cuban
- ☐ Another Hispanic, Latino/a, or Spanish origin
- ☐ None of these

What is the highest grade or level of schooling you completed?

- ◯ Less than high school 8 years
- ◯ 8 through 11 years
- ◯ 12 years or completed High school
- ◯ Post high school training other than college (vocational or technical)
- ◯ Some college
- ◯ College graduate
- ◯ Postgraduate

What is your current occupational status?

- ◯ Employed
- ◯ Unemployed
- ◯ Homemaker
- ◯ Student
- ◯ Retired
- ◯ Disabled
- ◯ Other

If other, please specify.

_____

Thinking about members of your family living in this household, what is your combined annual income, meaning the total pre-tax income from all sources earned in the past year?

◯ $0 to $9,999
◯ $10,000 to $14,999
◯ $15,000 to $19,999
◯ $20,000 to $34,999
◯ $35,000 to $49,999
◯ $50,000 to $74,999
◯ $75,000 to $99,999
◯ $100,000 to $199,999
◯ $200,000 or more

Do you currently rent or own your home?

◯ Own
◯ Rent
◯ Occupied without paying monetary rent

Which one of these comes closest to your own feelings about your household's income these days?

◯ Living comfortably on present income
◯ Getting by on present income
◯ Finding it difficult on present income
◯ Finding it very difficult on present income

Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare, or Indian Health Service?

◯ Yes
◯ No

What is the primary source of your health care coverage?

◯ A plan purchased through an employer or union (including plans purchased through another person's employer)
◯ A plan that your or another family member buys on
◯ Medicaid or other state program
◯ TRICARE (formerly CHAMPUS), VA, or Military
◯ Alaska Native, Indian Health Service, Tribal Health Services
◯ Other

If other, please specify.

_____

Have you ever smoked at least 100 cigarettes in your entire life

◯ Yes
◯ No

Do you smoke cigarettes?

◯ Every day
◯ Some days
◯ Not at all

Please check the answer that best describes your alcohol drinking.

◯ I currently drink alcohol
◯ I drank alcohol in the past, but quit drinking with the last 1 month
◯ I drank alcohol in the past, but quit drinking with the last 6 months
◯ I drank alcohol in the past, but quit drinking within the last year
◯ I drank alcohol in the past, but quit drinking over a year ago
◯ I have never drank alcohol

What is your current zip code:

_____

About how long does it take for you to drive to the clinic where you receive(d) your cancer treatment? For example, 1 hour 30 minutes.

_____
(hours minutes)

In what month and year were you diagnosed with breast cancer? For example, 12/2017.

_____
(Month/Year)

What are the details of your breast cancer diagnosis?

◯ DCIS (Ductal Carcinoma In Situ)
◯ Invasive-Lobular
◯ Invasive-Ductal
◯ Invasive-Don't know
◯ Don't know

What treatment have you received for your breast cancer? Mark all that you have received.

☐ Surgery
☐ Chemotherapy
☐ Radiation therapy
☐ Hormone therapy (e.g. Tamoxifen/ Fulvestrant/ Aromatase inhibitors)
☐ Other types of treatment such as Herceptin (IV)
☐ Immunotherapy (e.g. pembrolizumab /Keytruda)
☐ Don't know
☐ None
☐ Other

If other, please specify.

_____

What is the hormone status of your breast cancer? Mark all that apply.

- ☐ ER + (estrogen receptor positive)
- ☐ ER - (estrogen receptor negative)
- ☐ PR+ (progesterone receptor positive)
- ☐ PR - (progesterone receptor negative)
- ☐ HER2/neu + (human epidermal growth factor receptor 2) positive
- ☐ HER2/neu - (human epidermal growth factor receptor 2) negative
- ☐ I don't know
- ☐ Was not discussed

At the time of your diagnosis were you pre or postmenopausal?

- ◯ Premenopausal
- ◯ Postmenopausal

Do you have a history of any of the following conditions? Mark all that apply

- ☐ Heart Disease
- ☐ Stroke and Blood Clots
- ☐ Diabetes
- ☐ Hypertension
- ☐ Hip Fracture
- ☐ Osteoporosis
- ☐ Primary cancer other than breast cancer
- ☐ Other
- ☐ None of these

If other, please specify.

_____