

## REVIEW ARTICLE

# A Review of Breast Cancer Survivorship Issues from Survivors' Perspectives

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Despite the fact that more breast cancer survivors are currently enjoying longer lifespans, there remains limited knowledge about the factors and issues that are of greatest significance for these survivors, particularly from their perspectives. This review was based on the concept that the topics addressed should focus on the perspectives of current survivors and should be extended to future modalities, which physicians will be able to use to gain a better understanding of the hidden needs of these patients. We intended to choose and review dimensions other than the pathology and the disease process that could have been overlooked during treatment. The eight topics upon which we fo-

cused included: delay of treatment and survival outcome; sexual well-being; concerns about childbearing; tailored follow-up; presence of a family history of breast cancer; diet and physical activity for survivors and their families; qualitative approach toward understanding of breast cancer survivorship, and; mobile health care for breast cancer survivors. Through this review, we aimed to examine the present clinical basis of the central issues noted from the survivors' perspectives and suggest a direction for future survivorship-related research.

**Key Words:** Breast neoplasms, Quality of life, Survivors

## INTRODUCTION

Although definitions of the term vary, a frequently cited definition of cancer survivor is the following: An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition of cancer survivor [1,2]. Despite the dramatic improvements in

cancer diagnostics and treatments, many cancer survivors continue to feel that they have no source to turn to when they need appropriate solutions or supports for a broad range of survivorship issues encountered throughout the period following the diagnosis. A better understanding of the unique needs of the growing population of cancer survivors can be promoted by patient-centered approaches and a new focus on downstream data collection for the identification of possible complications and late effects [3].

To understand dimensions other than the pathology and the disease process that physicians could have overlooked during treatment, we presented the following questions to breast cancer survivors: What was most difficult for you since the diagnosis of breast cancer? What did you feel was the most deficient in the current treatment and care process of breast cancer? As a survivor, what type of service would you like health care providers to offer? In terms of the value of a qualitative approach, which is discussed in detail in the section "Qualitative approach toward understanding of breast cancer survivorship," we believed this would be a pragmatic first step to choose focused topics from among a wide range of survi-

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vorship issues. The summarized transcript of the interview with survivors is shown in Appendix 1 and 2.

Six focused reviews about the survivorship issues upon which we concentrated, based on current survivors' perspectives of the patient experience from diagnosis through treatment to the stage of routine follow-ups, are presented in the following sections. In addition, the utility of qualitative approaches and the emerging potential of smart phones are addressed as complementary modalities for collection of the downstream data, which survivors should be encouraged to report.

Through this review, we aimed to examine the present clinical basis of the central issues noted from the survivors' perspectives and suggest a direction for future survivorship-related research.

## DELAY OF TREATMENT AND SURVIVAL OUTCOME

In cancer care, initiation of definitive treatment is often delayed owing to a variety of patient, provider, and health system factors. The patient-related delay time is the time between the onset of the first symptoms and the first medical visit, the system-related delay time is the time between the first medical visit and the start of therapy, and the total delay time is considered the sum of the abovementioned delay times. Treatment delays following the diagnosis of breast cancer, specifically, cause significant psychosocial distress to patients, and in addition, breast cancer patients often associate time delay with adverse oncologic outcomes and survival. A recent retrospective study based on Korea Central Cancer Registry and National Health Insurance (NHI) data reported that 13.6% of 147,682 patients who underwent definitive surgery for any of six cancers in Korea waited > 31 days from diagnosis to surgery [4]. In another report, also based on the NHI data, the median time from breast cancer diagnosis to surgery was 14 days, and the proportion of breast cancer patients who had undergone surgery within 4 weeks of the diagnosis of cancer was 74.1% [5]. In the United States, a study based on the National Cancer Data Base demonstrated that the time to treatment for breast cancer increased from 17 days (median) in the period from 1995–1997 to 23 days (median) in 2003–2005 [6].

The impact of treatment delay on survival is still uncertain, and the acceptable time interval from diagnosis of breast cancer to initiation of treatment remains controversial. In Korea, two retrospective studies demonstrated a negative impact of delay of surgical treatment on patients' survival outcomes. Yun et al. [4] and Shin et al. [5] reported that treatment delays of > 1 month or 12 weeks, respectively, were associated with worse survival outcomes for breast cancer patients (adjusted

hazard ratio [aHR], 1.59; 95% confidence interval [CI], 1.37–1.84 and aHR, 1.91; 95% CI, 1.06–3.49, respectively). Likewise, in the United States, a recent retrospective study on young breast cancer patients aged 15 to 39 years reported similar outcomes: the 5-year survival rate in women who were treated via surgery and had a treatment delay time > 6 weeks was 80% compared with a rate of 90% among those with a treatment delay time of < 2 weeks ( $p = 0.005$ ) [7]. Interestingly, Vujovic et al. [8] suggested that an interval of > 12 weeks to breast surgery might be associated with decreased survival for mammographic presentation, but it appeared to have no effect on the survival of patients presenting with a palpable breast lump. This suggests that for patients with palpable lumps, if metastasis is to occur, it will have already taken place by the time a breast lump is detected. On the other hand, several other studies have suggested that there is no significant impact of surgical treatment time delay on patients' survival outcomes [9–11].

It is also uncertain whether treatment delay of postoperative adjuvant therapy, such as radiotherapy and chemotherapy, affects the survival outcomes of breast cancer patients. There are several retrospective studies on radiotherapy that assessed the time interval between breast-conserving surgery and the start of adjuvant radiotherapy, as well as its impact on survival and local recurrence. In Korea, early radiotherapy, within 6 weeks after breast-conserving surgery, was reported to be associated with increased local control [12]. However, other retrospective studies have reported contradictory findings on local recurrence and survival [13,14]. In chemotherapy, immediate reconstruction, re-excision, and use of the 21-gene assay have been identified as factors associated with chemotherapy delay, but, as with reports on adjuvant radiotherapy or surgery, the impact of a delay in chemotherapy has not been confirmed [15,16].

Since the current data available on treatment time delay are limited and retrospective, there is no definitive conclusion on the acceptable wait time and its impact on survival outcome. Treatment delay is not an issue that can be discussed prospectively; therefore, it is difficult to arrive at a consensus on this matter. Studies which supported a negative survival impact of surgical treatment delay suggested 12 weeks, 6 weeks, or 4 weeks as an acceptable wait time. It is difficult to generalize these retrospective findings to diverse clinical settings; however, considering that > 70% of Korean breast cancer patients undergo initial treatment within 1 month, with a median wait time of 14 days, treatment delay may not be a major negative prognostic factor in the current clinical settings. Furthermore, it is crucial that clinicians interpret these findings carefully for breast cancer patients in order to further reduce psychosocial distress among patients.

## SEXUAL WELL-BEING

Sexuality is a basic and important domain of quality of life (QoL) for humans. Sexual dysfunction has a significant impact on the physical, psychological, and social QoL of breast cancer survivors. The sexuality of breast cancer survivors is affected by physiological as well as psychological effects of oncologic treatment [17], and consequently, sexual dysfunction consists of a wide spectrum of issues including physiological, psychological, physical, and interrelational problems [18].

Sexual dysfunction may result from oncologic treatment for breast cancer such as surgery, radiation, chemotherapy, and antiestrogen therapy. In addition, the distress of breast cancer survivors or their partners can damage a person's healthy sexuality [19]. Loss of sexual self-image, loss of nipple sensitivity, and scarring can occur after breast cancer surgery. Although some problems gradually diminish over time, some breast cancer survivors still report problems several years after surgery. Radiation therapy can result in skin fibrosis, loss of sexual sensitivity of the skin, fatigue, and general malaise, thereby negatively impacting sexual desire and response. Chemotherapy is a major determinant of sexual dysfunction and affects all phases of the sexual response cycle [20]. Cytotoxic chemotherapy, besides inducing amenorrhea and ovarian failure, also causes alopecia, alterations in nail color, and weight changes, thereby affecting the survivors' sexual self-concept and consequently their sexual interactions. Various antiestrogen treatments have similar effects on sexual functions, such as vaginal dryness, subsequent dyspareunia, and decreased sexual desire. Many survivors experience a persistent depressed mood and sadness following the diagnosis of breast cancer, even after successful treatment, due to the fear of treatment, body image concerns, fear of recurrence, and fear related to changes in the relationships with their spouse and family [21]. Although sexual dysfunction can result directly from breast cancer and its treatment, issues that are unrelated to breast cancer, such as medical conditions, psychosocial status, and premonitory sexual dysfunction, which may exacerbate or attenuate sexual dysfunction, may also be important factors.

Because young breast cancer survivors are generally more sexually active, the risk of sexual dysfunction is of great importance to them [22]. In addition, young breast cancer survivors seem to have a worse QoL and are more vulnerable to the negative effects of the disease than the older survivors [23]. There are many therapeutic options for sexual dysfunction, including hormonal agents, dilator therapy, lubricants, medications for depression or anxiety, sex therapy, education on sexual intercourse, and counseling for the survivor or partner [18,24]. However, a comprehensive review of management of

sexual dysfunction in breast cancer survivors shows that confirmatory evidence of the benefit of the available treatment options is lacking.

Recent advances in breast cancer screening and treatment have led to increased survival rates. Consequently, the number of breast cancer survivors who experience long-term sexual adverse effects and seek help for these issues may be expected to increase. Moreover, the sexuality of breast cancer survivors is complex with an inherent wide spectrum of problems. For the sexual well-being of breast cancer survivors, all members of the oncology team must employ approaches tailored to each individual breast cancer survivor. Hence, multidisciplinary team members should focus on research regarding the sexual well-being of breast cancer survivors.

## CONCERNS ABOUT CHILDBEARING

Young breast cancer survivors frequently have concerns about childbearing issues including fertility and pregnancy. However, they do not obtain adequate information regarding these issues from their clinicians, and it remains controversial whether pregnancy is safe for breast cancer survivors [25,26]. Pregnancy has been considered harmful to breast cancer survivors, because they could be exposed to high levels of ovarian hormones during pregnancy [27]. However, several studies have shown that pregnancy does not increase breast cancer recurrence and even leads to a favorable prognosis [28,29]. A meta-analysis of 14 studies also demonstrated that pregnancy could decrease breast cancer-related death [28].

Regarding the appropriate timing of pregnancy, previous available studies reported that early pregnancy, within 2 years of diagnosis, did not affect breast cancer recurrence, although most breast oncologists have recommended that breast cancer survivors should wait for at least 2 years from diagnosis [30,31]. In addition, systemic treatments are also taken into consideration for the optimal timing of pregnancy. Young breast cancer survivors should delay their pregnancy for at least 6 months after chemotherapy, and for at least 2 months after antiestrogen treatment [32]. Chemotherapy-induced amenorrhea has been known to be a predictor of infertility, and this is affected by the chemotherapeutic regimen, number of chemotherapy cycles, cumulative dose (particularly the dose of cyclophosphamide), and the patient's age at treatment [33,34]. However, the impact of antiestrogen treatment and radiotherapy on infertility is still controversial [35,36].

Embryo and oocyte cryopreservation are established fertility preservation methods [37]. Because ovarian stimulation could result in a significant increase in estradiol levels and a significant delay of chemotherapy, breast oncologists should

refer all potential patients to the appropriate reproductive endocrinologist to ensure that the patients receive sufficient information and to avoid treatment delays [38]. Other fertility preservation methods such as ovarian tissue cryopreservation and transplantation could be considered, but the effectiveness of these methods remains controversial [39-41].

As the numbers of young breast cancer survivors and their survival times have increased, it has become increasingly necessary to keep these issues of fertility and childbearing in mind in the treatment of breast cancer patients. In addition, individualized decision-making, with the assistance of a multidisciplinary team, should be recommended regarding the optimal timing of pregnancy and the available fertility preservation methods.

### TAILORED FOLLOW-UP

Follow-up after primary treatment for breast cancer is an important component of the care of survivors. Routine follow-up aims at monitoring the adverse effects of primary treatment and providing psychosocial care. Another prominent goal is the early recognition and treatment of potentially curable disease recurrence. Early detection of second primary breast cancer or locoregional recurrence is beneficial for survival [42]. However, routine testing for distant metastasis provides no benefit for survival or health-related QoL [43]. Randomized controlled trials have found that reduced follow-up strategies did not negatively affect patient outcomes or early detection of recurrence, and more intensive follow-up was associated with higher costs without differences in early detection of relapses [44,45].

Since the American Society of Clinical Oncology published an evidence-based clinical practice guideline on breast cancer follow-up in 1997, multiple international guidelines have been published for the surveillance of breast cancer survivors [46]. These guidelines recommend a minimal clinical follow-up including routine history and physical examination and regularly scheduled mammography (MMG). However, these guidelines are not stratified on the basis of cancer stage or tumor biology, and there is no agreement on the optimal frequency or duration of follow-up modes. The Korean Breast Cancer Society (KBCS) guidelines recommend that history taking and physical examinations should be performed every 3 months for the first 2 years, every 6 months for years 3-5, and annually thereafter. MMG should be performed every 12 months. Assessment with complete blood counts, chemistry panels, and tumor markers is recommended every 6 months for 5 years. Further, annual chest radiography should be performed for 5 years. Gynecologic examinations are recom-

mended for women receiving tamoxifen; regular bone mineral density examinations are recommended for women receiving aromatase inhibitors. Bone scintigraphy, liver ultrasonography, computed tomography, positron emission tomography, and magnetic resonance imaging are not recommended for routine follow-up in an otherwise asymptomatic patient with no specific findings on clinical examination.

Despite the lack of evidence supporting routine follow-up testing other than MMG for breast cancer survivors and the presence of recommendations against its use, follow-up testing is performed by many physicians under the assumption that detecting and treating recurrences early results in better outcomes [47]. Moreover, although routine follow-up visits are very stressful for patients attending them, many survivors may favor surveillance that is more intensive, and may overestimate the value of laboratory and imaging studies. Follow-up tests themselves may cause psychosocial and physical harm in healthy survivors owing to false-positive findings, unnecessary investigations, and overtreatment. Little is known about current actual practice patterns of physicians—do they adhere to or deviate from guideline recommendations? Therefore, we devised a plan to evaluate the current follow-up patterns of experienced physicians who provide care for breast cancer patients and monitor them after treatment. We created a survey instrument to accomplish this and chose KBCS members as survey participants, and we are aiming to announce the results by the end of 2014. Additionally, further research is needed to determine the comparative effectiveness of different modes of breast cancer surveillance and the ideal frequency and duration of follow-up.

### PRESENCE OF A FAMILY HISTORY OF BREAST CANCER

Breast cancer survivors face problems regarding family members, including the fear of being cheated on by the husband, feeling sorry for what may be their decreased ability to spend time with or care for their children, and feeling guilty owing to their children's potential inheritance of their disease. Considering that the incidence of breast cancer peaks in the late 40s among the Korean population [48], many sexually active breast cancer survivors face sexual problems with their spouse, and this can be of great significance. In addition, relatively young breast cancer survivors may feel responsible as mothers for providing support such as education, caring, and companionship to their young children. However, above all, breast cancer survivors who are parents experience unbearable distress due to the concept that their children might develop the same disease someday.

Genetic predisposition is, of course, one of the most important risk factors for breast cancer and accounts for 5% to 10% of all breast cancers [49]. To date, five high-penetrance genes (*BRCA1*, *BRCA2*, *TP53*, *PTEN*, and *LKB1*), four intermediate-penetrance genes (*ATM*, *BRIPI*, *CHEK2*, and *PALB2*), and various low-penetrance loci (rs3803662, rs889312, rs3817198, and rs13281615) have been discovered [50]. Among those, approximately 50% to 70% of the hereditary breast cancers are caused by *BRCA1/2* gene mutations [51]. *BRCA1/2* mutations are present in 12.7% of the high-risk patients as compared with 2.8% of unselected patients. Not all carriers of *BRCA1/2* mutations develop breast cancer, but the penetrance for breast cancer has been reported to be as high as approximately 70% in *BRCA1* mutation carriers and 60% in *BRCA2* mutation carriers in their lifetime [52].

The majority of breast cancer survivors suffer from misconceptions regarding the genetic implications of having a breast cancer patient in their family. More than 10% of the probability of harboring the *BRCA1/2* gene mutation can be reasonably suspected, and genetic counseling should be provided for high-risk breast cancer survivors with the following: young age (< 40 years) at diagnosis, bilateral breast cancer, multiple organ cancer, or male breast cancer [53]. According to the results from the Korean Hereditary Breast Cancer Study, although the overall prevalence of the *BRCA* mutation among familial breast cancer survivors was 21.7% (*BRCA1*, 9.3% and *BRCA2*, 12.4%), the prevalence of the *BRCA* mutations among subgroups that had two breast cancer survivors in a family, with both survivors aged > 50 years at diagnosis, was only 4.1% [54]. Currently, genetic counseling is routinely recommended to all newly diagnosed women who have a family history of at least one relative with breast cancer at any age of diagnosis, but such counseling needs to be tailored considering the proband age at diagnosis.

The misunderstanding that children of mothers with breast cancer will inevitably develop the disease should be resolved to reduce unnecessary guilt among mothers and diminish the exaggerated possibility of inheritance.

## DIET AND PHYSICAL ACTIVITY FOR SURVIVORS AND THEIR FAMILY

Breast cancer patients and their families tend to be particularly careful about their diets and their use of supplements; however, little is known about the association between dietary factors and breast cancer prognosis among breast cancer patients. Although breast cancer prevention and etiology studies have long provided information on dietary modification strategies for cancer prevention, research on diet for breast cancer

survivors is relatively limited, partly because changes in diet and the use of supplements have been considered relative to therapeutics, stage/grade, hormone receptor status, and other prognostic factors.

Two large intervention trials [55,56] and a few prospective studies [57-63] analyzed the effect of diet on breast cancer prognosis, and the evidence from studies on diet and food choices for breast cancer patients is increasing, but is not yet conclusive. A healthy dietary pattern, including high consumption of fruits and vegetables, whole grain, poultry, and fish, has been examined in a few epidemiologic studies [57,58, 64,65] and was found to be associated with a lower risk of breast cancer recurrence or death. Recent prospective studies have reported that consumption of fruits and vegetables and dietary components that are abundant in fruits and vegetables, such as carotenoid and dietary fiber, improves breast cancer prognosis [59,66]. However, intensive counseling intervention promoting high consumption of vegetables, fruits, and fiber and low consumption of fat did not reduce the risk of breast cancer recurrence or mortality during a 7.3-year follow-up period among women with early breast cancer in the Women's Healthy Eating and Living Study [56]. Cancer patients were more likely to use dietary supplements than the general population in the United States [67], and a similar pattern was observed in Korea. However, results from prospective cohort studies are not conclusive [68,69] and warrant additional prospective studies to examine the effect of such supplements on breast cancer prognosis.

The Women's Intervention Nutrition Study found that a low-fat diet reduced the risk of recurrence among postmenopausal breast cancer survivors, especially women with estrogen receptor-negative tumors [55]. High intake of saturated fat or trans fats was found to increase the risk of death from any cause in the Collaborative Women's Longevity Study [60]. A recent review of five cohort studies examining soy products and breast cancer survival reported that soy product intake was associated with better survival and lower risk of recurrence [70]. The vitamin D status may be also important with regard to breast cancer risk and survival. It has been hypothesized that a low vitamin D status worsens breast cancer prognosis; however, the current studies provide contradictory evidence [71,72].

On the basis of the current findings from existing prospective or intervention studies, physical activity is the most well-established lifestyle factor associated with breast cancer survival among breast cancer patients. A recent large collaborative work of four cohort studies including 13,302 breast cancer patients, the After Breast Cancer Pooling Project, suggested that breast cancer survivors who met the physical activity

guidelines from the U.S. Department of Health and Human Services of 10 metabolic equivalent-hours/week for 18 to 48 months postdiagnosis had a lower risk of death [73].

In the Asian population, including Korea, China, and Japan, an increase of > 100% in breast cancer mortality has been observed from the 1970s to the present [74], clearly suggesting a relationship between lifestyle factors and breast cancer progression. Additionally, a progressive improvement in overall breast cancer survival during the past decades has led to increased interest in the effect of diet and exercise on breast cancer prognosis. Although the current evidence is insufficient to provide health professionals and patients with specific and detailed guidelines, a healthy diet high in fruits, vegetables, and soy products and low in fat seems to be important for breast cancer patients. However, it is still unclear whether any specific dietary component can influence breast cancer prognosis. In addition, current evidence largely arises from Western studies, where postmenopausal breast cancer is more common than premenopausal breast cancer and the proportion of overweight or obesity in breast cancer patients is greater than that among Korean breast cancer patients. Therefore, the lifestyle factors that improve breast cancer prognosis should be explored in the Korean population specifically. Regarding physical activity, considering the evidence accumulated over the past decades, breast cancer patients can be counseled to increase or maintain a moderate level of physical activity.

### QUALITATIVE APPROACH TOWARD UNDERSTANDING OF BREAST CANCER SURVIVORSHIP

With the growing number of breast cancer survivors, ensuring the overall health of these individuals by providing the optimal health care services is proving to be a challenge for health care professionals. Breast cancer survivors have numerous medical and psychosocial concerns or needs that must be addressed in the posttreatment period [75]. Therefore, it is necessary to understand their experience from their point of view, and a qualitative method serves this purpose. Not surprisingly, qualitative research methods are gaining popularity in medicine and health care fields, and an increasing number of qualitative studies are being published in medical journals [76].

Qualitative methods aim to understand phenomena in a naturalistic environment and from the participant's perspective rather than an outside perspective [77]. Aimed at understanding how the survivorship shapes the experience of breast cancer, qualitative methods emphasize the meanings and views of all the participants [78]. Quantitative and qualitative methods are complementary but each has its own theoretical

and methodological assumptions. The quantitative method is variable-oriented, whereas the qualitative method is case-oriented [79]. Their differences are well summarized by Camic, Rhodes, and Yardley in the following description: "Quantitative research as the process of producing a map of a place and qualitative research as the process of producing a video of that place." Although a map is unable to convey an understanding of what it is like to be at a place, a video conveys vivid and subjective experiences of being in that position [80].

Qualitative methods provide significant contributions to the understanding of breast cancer survivorship. These methods help us understand the needs of the under-represented or under-researched individuals and stimulate theory development, allowing unknown or novel phenomena to be later tested using quantitative methods. Qualitative methods also help to explain mechanisms underlying relationships among variables found in quantitative results [81]. Generally, qualitative methods are particularly suitable for research questions regarding experiences, thoughts, perceptions, expectations, motives, and attitudes [82]. For instance, breast cancer survivors' perceptions and attitudes about their healthcare utilization, screening, and information needs were previously explored via a qualitative approach [83]. Further, the experience of transitioning from a patient to a survivor was previously explored in a longitudinal qualitative 2-year follow-up study of survivors [84]. Delicate sequelae issues such as fertility [85] and sexual concerns [86], and breast cancer patients' perceptions of and attitudes toward the adverse effects of chemotherapy such as alopecia [87] have also been explored via qualitative means.

Qualitative research methods have been found to be a useful means for the development of QoL instruments [82] and complement the shortcomings of objective QoL instruments [88]. Owing to the subjective nature of the QoL, the impact of breast cancer and its treatment cannot be fully understood using predetermined scales, and important issues that patients experience are overlooked [89]. In fact, QoL issues and needs in a minority population have been popular topics of qualitative methods in the literature on breast cancer survivorship [90-92]. A prominent concern among cancer survivors is the fear of recurrence, and the approach that breast cancer survivors use to deal with this issue was reported on the basis of in-depth interviews [93]. Communication issues, such as the patients' view of how doctors should communicate with them, have also been addressed via qualitative approaches in breast cancer [94,95]. Qualitative research methods have additionally been applied to the understanding of health behaviors among survivors, because an understanding of why survivors behave as they do is crucial for any positive change [96]. For

instance, in a large-scale qualitative study, identifying psychological, physical, and contextual and environmental barriers, Hefferon et al. [97] aimed to explore the perceived barriers to exercise implementation 5 years after breast cancer diagnosis. Similarly, Miedema and Easley [98] used qualitative methods to examine barriers to rehabilitative care for young breast cancer survivors.

To understand how a survivorship care plan created by oncologists could improve the quality of survivorship care, focus group interviews were conducted to assess the perspectives of survivors and health care professionals [75]. A qualitative method can be also useful for exploring the experiences of participants in clinical trials. For example, Nelson et al. [99] examined the experiences of participants in the National Cancer Research Institute ZICE clinical trial, a randomized trial assessing two types of bisphosphonate treatment in breast cancer patients with bone metastases.

Despite the potential of qualitative methods to record breast cancer survivors' experiences while allowing for individuality and subjectivity, these methods have issues with reliability and validity which must be improved [96]. Quantitative and qualitative approaches should be seen as complementary methods, and not as opposites. In fact, these two methods can be successfully combined into a mixed approach toward a systematic and objective, yet broader, deeper, and also subjective understanding of the issues of breast cancer survivorship. Qualitative methods can be preliminary to quantitative research, supplement it, and explore complex phenomena or issues that quantitative methods cannot resolve [78,82].

### MOBILE HEALTH CARE FOR BREAST CANCER SURVIVORS

Electronic health (eHealth) can be defined as the practice of medicine and public health using information and communication technology (ICT) devices such as computers, mobile phones, and satellite communications [100]. The term mobile health (mHealth) refers to a subsegment of eHealth and is now used when the practice involves wireless communications, especially mobile or smart phones, the penetration of which amounts to over 70% (as of 2013) in the United Arab Emirates, South Korea, Saudi Arabia, and Singapore.

In recent years, the Cochrane Collaboration has provided substantial evidence from systematic reviews to advocate the effectiveness of mobile phone-based clinical applications among patients with chronic health problems including psychiatric disorders and human immunodeficiency virus (HIV) infection. Computer-based diabetes self-management interventions to manage type 2 diabetes mellitus had a small bene-

ficial effect on blood glucose control, but the effect was larger in the mobile phone subgroup [101]. Under some conditions, short message service and multimedia message service have been reported to have a positive impact on the health status of patients with diabetes mellitus, hypertension, and asthma and on their ability to self-manage their conditions [102]. For short-term prescriptions for diverse medical problems, several simple interventions increased adherence to medication and improved outcomes; however, for long-term treatments, no simple intervention and only a few complex interventions led to improvements in health outcomes [103]. The use of telephone voice interventions may play a role in improving medication adherence, reducing risky sexual behavior, and reducing depressive and psychiatric symptoms in patients with HIV infection [104]. A meta-analysis that studied health behavior outcomes of healthy populations showed that strategies with mobile communications that aimed at smoking cessation increase the long-term quit rates compared with control programs (relative risk, 1.71; 95% CI, 1.47–1.99; over 9,000 participants) [105] and promote enrollment of smokers into cessation programs (participants enrolled: 0% in the control group; 1.3% in the postcard group; and 20.6% in the telephone call group) [106].

Currently, studies addressing the use of mobile technologies to promote a new era of healthcare, especially in the management of cancer survivors, are few. The noteworthy feature of mHealth is the feasibility of the use of mobile phones to assist in the collection of data on disease-related vital signs [107], treatment-related adverse effects [108], and a possibly comprehensive psychological status [109]. According to a recent randomized trial of interactive social networking sites, Facebook-based intervention may help cancer survivors receive health information and support that promotes physical activity and other health behaviors [110]. Since physical activity is the most well-established positive lifestyle factor among breast cancer survivors, and its beneficial effects are more pronounced with moderate or vigorous intensity compared to mild intensity [111], this mobile phone-based intervention may improve disease outcomes as well as related QoL among breast cancer survivors. Although there are important concerns about the use of mobile phones for health-related purposes, such as the risk of "driving while texting" or "brain tumors" [112], studies assessing the value of incorporating mobile phone-based health applications into breast cancer survivors' care are being conducted.

### CONCLUSION: WHAT THE FUTURE HOLDS

Since cancer has the potential to affect every aspect of the

survivor's life, including the physical, psychological, social, economic, and existential or spiritual aspects [113], a comprehensive and multidisciplinary approach should be considered for breast cancer survivorship research. Our cancer survivorship research focuses on the etiology and prevention of breast cancer, management of treatment-related adverse effects, lifestyle modification, and QoL issues to optimize the physiologic, psychosocial, and functional outcomes for breast cancer survivors. To achieve the ultimate goals of reducing the cancer burden and providing guidance for survivors, understanding the integration and interaction of multidisciplinary research domains is of prime importance. To date, however, most survivorship research has been performed in a fragmented fashion, and an evidence-based comprehensive framework for survivorship research has yet to be established.

Owing to the ongoing evolution of novel breast cancer therapies, it is essential for clinicians to understand both the acute and long-term effects of new treatment agents on breast cancer survivors' health and functioning. In addition, cancer survivorship research needs to evolve in parallel with global evaluation of trends including demographics, economics, and patterns of cancer-related and non-cancer-related morbidity and mortality. Moreover, the ICT sphere offers potential as a complementary element to the traditional healthcare system and it is rapidly changing in Korea and other developing countries; therefore, we particularly need to focus upon its improvement. Healthcare is not a product; it is a service that is coproduced between the providers and the users, and it has value only when survivors use it. Therefore, the service design could play a crucial role in innovating the healthcare delivery system to balance different perspectives [114].

To meet these demands for knowledge in a timely manner, efforts to identify specific research to clarify relevant issues and foster collaboration in diverse fields are important. The Korean Breast Cancer Survivorship Research Group was organized to meet the demands of breast cancer survivors. Various members including breast surgeons, surgical oncologists, and specialists in service design, food and nutrition, and psychology are actively participating to establish a scientific paradigm in survivorship research, which looks beyond treatment and represents a shift from a medical deficit-dysfunction model, toward a multi- and interdisciplinary focus.

Future research on breast cancer survivorship needs to provide management guidance for clinicians, personalize and enhance follow-up care, facilitate early detection and prevention of treatment-related adverse effects, provide timely intervention for long-term effects, enhance QoL and psychosocial functioning, and promote a healthy lifestyle among breast cancer survivors. Fundamental basic research is required to

understand the mechanisms and etiology of breast cancer, treatment-related sequelae, and late effects. Currently, there are limited clinical data on breast cancer survivorship, and intervention studies to address the management of long-term effects, QoL issues, and lifestyle modification must be conducted. The next generation of survivorship research will need to use validated and reliable measures for surveillance and monitoring of both physiologic and psychosocial variables.

To incorporate this perspective, a framework could be established for survivorship research. Evidence-based knowledge should be achieved through fundamental research, intervention research, and surveillance and monitoring to promote clinical guidance (such as a survivorship care plan) for breast cancer survivors. With the appropriate provision of clinical guidance through health care systems and social policies, the burdens of breast cancer survivors can be reduced in the future.

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## CONFLICT OF INTEREST

The authors declare that they have no competing interests.

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**Appendix 1.** Comments from breast cancer survivors supporting the themes identified in the interview

Theme	Supporting comments
1. Greater anxiety for tumor progression or recurrence before and after the treatment than during the treatment	<p>“The most difficult time for me was the period after diagnosis and before treatments started, which was approximately a month.”</p> <p>“After surgery, while I was receiving chemotherapy and radiation therapy, I actually felt at ease even though it was taxing for my body.”</p> <p>“You would think that after 5 years of treatment with tamoxifen, survivors would feel more at ease; instead, this is the start of anxiety for many survivors.”</p> <p>“For survivors like me who cannot even take tamoxifen, it’s difficult simply because there is no medication that I can take.”</p> <p>“Thoughts about recurrence really worsen after all treatments are over. After 2 years of using Zoladex, I wished I could increase my treatment time.”</p>
2. Concerns on having intercourse or a baby	<p>“During treatment, sexual desire really decreases, and even if I tried to have intercourse with my husband, it hurt too much and simply did not work. I sometimes felt that my husband would cheat on me, and I think this could be a cause of depression.”</p> <p>“Last month, my periods resumed, which had stopped because of chemotherapy. Before that, seeing my husband wanting intercourse made me want to avoid it and everything bothered me.”</p> <p>“However, now that my period is back, I feel myself wanting intercourse with my husband even before he does. I feel like things are back to the way they were. Back then, there was no one to explain these problems to me.”</p> <p>“For single women like me, there are no outlets to obtain information about future pregnancy and childbearing problems, even though this is a big area of concern.”</p>
3. Lack of tailored information on follow-up interval and image modalities	<p>“I visit the doctors for follow-ups every 6 months, but I worry that this duration is not appropriate, and I should undergo checkups more often. People say the tests themselves are harmful to the body, so that is another worry.”</p> <p>“Six-month gaps for follow-ups are too long. Everything is all right up to the third month, but from the fourth and fifth months, I start to worry and have throbbing pains in my breast. I am unhappy that they do not perform tests more often, even though I was diagnosed with stage 3 breast cancer.”</p>
4. A sense of duty or guilt toward the family members about the cancer experience	<p>“During the treatment process, I only thought about myself and could not take care of my family, so I felt very sorry.”</p> <p>“I even felt guilty for having to inform my daughter about the family history, which was hard for me.”</p> <p>“I also felt it was my duty to control the food my family ate; the things we should eat and should not eat suddenly became really important.”</p>
5. Needs of more timely and practical information from health care providers	<p>“Unspecific comfort and encouragement, for example, questions such as how do you feel right now, what do you think you will feel once treatment starts, what is your attitude towards treatment, seemed like vague and senseless and were not helpful.”</p> <p>“I wanted more substantial and applicable support and advice, for example, when you go through chemotherapy, all your hair will fall out, but you can use a wig. However, in reality, it was not like that.”</p> <p>“I simply could not relate to healthy regular people, but talking with the survivor volunteers actually helped because of the commonality of the disease. However, there were medical and technical limitations to the counseling.”</p> <p>“Education for the family is really lacking, and this is unfortunate. For married women, education for husbands, and for single women, education for mothers is necessary.”</p>
6. Needs of new mobile health services that could be helpful for survivors	<p>“Education programs about survivorship are well organized while patients are hospitalized for surgery, but there is relatively little information imparted for the periods before and after hospitalization, even though the things we want to know differ greatly with each phase in the treatment spectrum.”</p> <p>“In actuality, those who get depressed get really depressed, and those who live well with the disease live really well. Therefore, I do not think that personalized medical care is possible.”</p> <p>“It may be difficult but phase-specific text messages or information about a variety of education seminars through mobile phones would be helpful.”</p>

**Appendix 2.** The summarized transcription of the interviews of four survivors

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- Survivor 1 “When I was first diagnosed with breast cancer, I simply could not organize my thoughts about what I should do. Rather than a fear of death, I think I had a greater, indefinable fear of chemotherapy. The most difficult time for me was the period after diagnosis and before treatments started, which was approximately a month. I was extremely restless because of the anxiety from the thought of progression of breast cancer, and I felt that I should be treated as soon as possible. After surgery, while I was receiving chemotherapy and radiation therapy, I actually felt at ease even though it was taxing for my body. During treatment, I was rather relieved because I believed that the breast cancer would not recur; however, after all the treatments were over, I started fearing its recurrence. You would think that after 5 years of treatment with tamoxifen, survivors would feel more at ease; instead, this is the start of anxiety for many survivors.”
- Survivor 2 “For survivors like me who cannot even take tamoxifen, it’s difficult simply because there is no medication that I can take. Additionally, my kids were very young, in first and third grades; therefore, when I was diagnosed with breast cancer, I was first worried for my children.”
- Survivor 3 “Thoughts about recurrence really worsen after all treatments are over. After 2 years of Zoladex treatment, I wished I could increase my treatment time. I visit the doctors for follow-ups every 6 months, but I worry that this duration is not appropriate, and I should undergo checkups more often. People say the tests themselves are harmful to the body, so that is another worry.”
- Survivor 4 “Six-month gaps for follow-ups are too long. Everything is all right up to the third month, but from the fourth and fifth months, I start to worry and have throbbing pains in my breast. I am unhappy that they do not perform tests more often, even though I was diagnosed with stage 3 breast cancer.”
- Survivor 3 “I was actually hurt by the attitude of the medical staff while preparing for surgery after diagnosis. I wanted comfort instead of all the medical explanations that they offered me. However, the physicians continuously talked about the worst-case scenarios, so I actually misunderstood and thought that my cancer was at a more progressed stage. After surgery, the doctors confirmed I had early stage breast cancer. I felt so betrayed by the doctor who had explained everything to me. I even felt a little angry because I had even organized my belongings.”
- Survivor 4 “For me, at diagnosis, I did not have the capacity to think about anything else. Unspecific comfort and encouragement, for example, questions such as how do you feel right now, what do you think you will feel once treatment starts, what is your attitude towards treatment, seemed like vague and senseless and were not helpful. I wanted more substantial and applicable support and advice, for example, when you go through chemotherapy, all your hair will fall out, but you can use a wig. However, in reality, it was not like that.”
- Survivor 3 “Because I had breast cancer, it was hard for me to even decide what to do the next day, which would upset me. I simply could not relate to healthy regular people, but talking with the survivor volunteers actually helped because of the commonality of the disease. However, there were medical and technical limitations to the counseling.”
- Survivor 1 “As I have said before, after initial treatment, anxiety about recurrence increases. Additionally, I suddenly started to feel apologetic towards my family. During the treatment process, I only thought about myself and could not take care of my family, so I felt very sorry. To my daughter, I even felt guilty for giving her family history, which was hard for me. I also felt it was my duty to control the food my family ate; the things we should eat and should not eat suddenly became really important.”
- Survivor 2 “Differences in thoughts between family members also create problems. I kept wishing that my husband would understand me a little more, but I think my husband felt he was sacrificing enough. Actually, many of the problems with my husband were sexual. During treatment, sexual desire really decreases and even if I tried to have intercourse with my husband, it hurt too much and simply did not work. I sometimes felt that my husband would cheat on me, and this could be a cause of depression.”
- Survivor 4 “Last month, my periods resumed, which had stopped because of chemotherapy. Before that, seeing my husband wanting intercourse made me want to avoid it and everything bothered me. I always thought this was because I was sick and tired from treatment. However, now that my period is back, I feel myself wanting intercourse with my husband even before he does. I feel like things are back to the way they were. Back then, there was no one to explain these problems to me.”
- Survivor 3 “For single women, I think the mother plays the largest role in the family. Education for the family is really lacking, and this is unfortunate. For married women, education for husbands, and for single women, education for mothers is necessary. Additionally, for single women like me, there are no outlets to obtain information about future pregnancy and childbearing problems, even though this is a big area of concern. Single women also fear that if they get psychiatric help, there will be records, which makes it hard for them to go for counseling. This is not because we overcome depression, but rather because we fear the associated stigma. In the period after diagnosis and before treatment, there needs to be specialized care not only for age but also for marital status.”
- Survivor 2 “In actuality, those who get depressed get really depressed, and those who live well with the disease live really well. Therefore, I do not think that personalized medical care is possible. It may be difficult but phase-specific text messages or information about a variety of education seminars through mobile phones would be helpful. Further, education programs about survivorship are well organized while patients are hospitalized for surgery, but there is relatively little information imparted for the periods before and after hospitalization, even though the things we want to know differ greatly with each phase of the treatment spectrum.”
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