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Breast Cancer Patient Preparedness for Transition to Survivorship:

Individualized Survivorship Care Plans

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## Breast Cancer Patient Preparedness for Transition to Survivorship:

### Individualized Survivorship Care Plans

#### **Clinical Leadership Theme**

One competency of the Clinical Nurse Leader (CNL), part of Master's Essential Eight, is monitoring the "outcomes of comprehensive plans of care" that concern both disease prevention and health promotion (American Association of Colleges of Nursing, 2013). As a microsystem-based leader, this author plans to lead a multidisciplinary team in the development and implementation of delivery of an individualized breast cancer survivorship care plan, including resources for wellness, community support services and follow-up surveillance following treatment completion and transition into survivorship. This project also involves a number of other competencies, including collaborating with other healthcare professionals to design and implement an improvement opportunity (Essential Two, Competency Seven) and facilitating "transitions across care settings" to support and improve the outcomes of patients (Essential Seven, Competency Seven). The healthcare professionals involved will include oncologists/physicians, the oncology nurse navigator (ONN), social workers and the oncology department manager (project leader/MSN-CNL candidate).

#### **Statement of the Problem**

A cancer "survivor" is a patient who has completed primary treatment (surgery, radiation and/or chemotherapy) and who has the potential for enjoying a long life comparable to similar individuals who have not experienced cancer. Specific improvements in breast cancer care have significantly increased the number of such survivors and their average life span. Survivors, including those who have experienced breast cancer, can live long lives with life expectancies equaling their non-cancer counterparts, but also can suffer recurrence. Breast cancer patients

diagnosed today have an 89% survival rate for five years compared to 49% previously. Rates continue at 83% survivorship in 10 years and 78% in 15 years (Klein & Hawkins, 2015). As the science of oncology care improves, breast cancer survivorship continues to make progress toward the general life expectancies for comparable non-cancer patients. (Klein & Hawkins, 2015).

Many breast cancer patients, however, suffer from chronic conditions following treatment completion and often are not well prepared to manage their wellness. Patients experience decreased quality of life including changes in body image, relationships, isolation and depression that result in poor adherence to their wellness needs (Cheng, Wong, & Koh, 2016). Breast cancer recurrence rates, as well as long-term survival, have been shown to be affected by the wellness habits and follow-up care that survivors adopt. Patient follow-up has focused on surveillance of cancer recurrence, including cancer history and screening for new primary care breast cancer through routine visits to their medical oncologist (American Society of Clinical Oncology, 2015). In the past, patients have not routinely received individualized care plans for survivorship, leading to potential lack the knowledge of available resources, including support for wellness and prevention measures. The time from treatment completion and transition to early survivorship has been described as an uncertain time for patients about what to expect (Burriss, Armeson, & Sterba, 2015).

The literature now recommends that every cancer survivor, including breast cancer survivors, receive an individualized care plan to help guide their new lives as survivors, with the goal of maximizing their health and minimizing the chances of recurrence after primary treatment has been completed (Rocque et al., 2014). While such plans are becoming a standard of care, the exact content and the method of communicating them to survivors is still very much

a matter for discussion. For this microsystem, the ONN is the key healthcare professional to interact with the “outgoing” breast cancer survivors and will coordinate development of individualized survivorship plans; for this improvement project, the team will define the necessary components of each breast cancer survivorship plan and implement a new method of delivering all such plans to the patients—by direct, one-on-one meeting with the ONN to improve the patient’s understanding and retention of survivor wellness and follow-up material. Related to this goal, the team will measure breast cancer survivors’ satisfaction with the care provided to them, including transition to survivorship care.

### **Project Overview**

The journey of a breast cancer patient throughout the continuum from diagnosis through survivorship or end-of-life may be long and complicated, lasting months to years, even decades. The primary emphasis is to first treat the cancer through an individualized patient specific regimen. A multidisciplinary team works in collaboration providing this care. Following treatment completion at this facility, transition of breast cancer patients into survivorship has historically not been individualized or focused on wellness. The overall goal of this improvement project will focus on the breast cancer patient’s personal preparedness to manage wellness following treatment completion and transition into survivorship. Specifically, the project-based team expects to improve the patients understanding and knowledge for symptom management and survivorship strategies, including awareness of available resources, after treatment completion and transition into survivorship.

The oncology team will provide a point of contact through the use of the ONN, who is a registered nurse with specialized knowledge in cancer care to assist throughout the continuum of survivorship; the team’s ONN has now passed the ONN certification examination. The team

will collaborate with the ONN and team manager to construct the framework for individualized breast cancer survivorship plans, and the ONN will provide the plans to the patients/survivors through in-person meetings near or immediately after completion of primary treatment, which usually coincides with completion of a course of chemotherapy. The individualized survivorship care plans will include resources for wellness regarding nutrition, exercise, emotional needs, symptom management and community resources including support groups.

Previous versions of survivorship care plans have not been carefully individualized for each patient, and have been provided to the patient without opportunity to ask questions face-to-face with a nurse or physician. With this project, the new framework for individualized plans and delivering the plans to patients in a meeting with the ONN should increase breast cancer patient knowledge for continuing self-care and follow-up and, hopefully, satisfaction with the healthcare services they are receiving from the oncology team. The team expects the project to have positive results and soon it will expand to all cancer patients who are treated by the team, once the necessary resources (hiring of a second ONN) become available.

### **Rationale**

In this oncology microsystem, historically once treatment was completed the breast cancer patient would be scheduled to see their medical oncologist every six months for the first year and then yearly for up to five thereafter. The physician visit focused on surveillance of a new or returning cancer, and included a physical examination and cancer history review. There was no specific follow-up for wellness opportunities-- only a flyer for a cancer support group not specific to breast cancer patients. Some data has been collected from a subset of breast cancer patients to determine their self-perceived satisfaction with care offered by a multi-disciplinary team, as discussed below.

There were 144 newly diagnosed breast cancer cases during the 2016 calendar year, 140 patients were ultimately discussed. Thirty nine complex cases were referred to a multidisciplinary team including medical oncologist, radiologist, breast surgeon and plastic surgeon. In an effort to better understand the patients perceived value and understanding of their plan and care, the project team distributed a survey to these 39 patients. A seven point Likert scale was used scoring as: extremely satisfied, moderately satisfied, slightly satisfied, neither satisfied nor dissatisfied, slightly dissatisfied, moderately dissatisfied, extremely dissatisfied. The following questions were asked.

1. Were you satisfied with your experience with the breast cancer multidisciplinary clinic?
2. How satisfied were you with coordination of care among the providers who visited you during your visit to the breast cancer clinic?
3. How helpful was your visit to the breast cancer multidisciplinary clinic in helping you understand your cancer, the treatment plan and goal?

Ultimately twenty-one patients received the survey and 10 returned it for 47% completion rate. The results found 90% were extremely satisfied with all three questions. The remaining 10% rated question one and two as moderately dissatisfied and question 3 the remaining 10% were moderately satisfied.

In the identified department, approximately 33% of all the cancers treated are breast cancer; no other cancer has that high a percentage. Last year there were approximately 120 newly diagnosed patients. Treatment following diagnosis lasts up to one year. The facility is in the process of gaining accreditation with the Commission on Cancer through the American College of Surgeons, which requires very high quality of care standards to be implemented for oncology patients. As part of the emphasis on individualized care and support services, the

oncology department started in January 2017 a support group specifically for breast cancer patients and survivors that meets twice monthly. The department also has formed a cancer patient advisory group to better understand and support the needs of patients.

None of these measures, however, fulfills the need to educate the breast cancer survivor with an overview and care plan that is specifically designed with the needs of each individual patient in mind. The life-altering experience that is cancer, even when primary treatment is “successful,” will always be with a survivor in one way or another. With that in mind, breast cancer patients can benefit from the knowledge that a survivor care plan imparts, especially if the care plan can be put into a proper context by the healthcare professional who will be most familiar with it—our team’s ONN. For those breast cancer patients who have received survivorship plans per the existing protocol, there is inadequate evidence that they are getting the most out of such plans, and so this improvement is warranted. Avoiding recurrence of breast cancer in survivors is a major goal for this team and facility, so the need for an improved approach toward survivorship guidance is now apparent.

Financially, the cost of preparing individualized plans for each breast cancer patients and delivering them in person via a meeting with the ONN amounts to about \$16,000 per year (two hours per patient at \$80.00 per hour, multiplied by an approximate patient census per year of 100). If this improved care plan and method of delivering it to the patients can help prevent or lessen the impact of one recurrence per year, the cost of providing individualized plans in this manner will be more than worth it. One surgical procedure along with a course of chemotherapy, and all associated costs, can run well in excess of \$25,000. Furthermore, tens of thousands of dollars can be saved in the aggregate if breast cancer survivors know what to expect as far as future side effect symptoms and how to deal with them, as well as taking self-



management of health to heart, which can have non-cancer related benefits (cardiovascular, to name one). So, the financial benefits of personally delivered survivorship care plans for breast cancer patients are apparent.

### **Methodology**

The improvement being sought in this project is enhanced breast cancer survivor knowledge of the plan for their care following conclusion of primary treatment, i.e., the transition into survivorship. Instead of delivery of a generic plan or instructions for cancer patients, each breast cancer patient is to receive an individualized plan. The individualized plan is to be delivered in person by the oncology team's ONN as part of a transition meeting at about the time that chemotherapy treatment concludes, rather than the existing standard practice of simply mailing or giving the plan to the patient without opportunity to discuss its context and importance and to handle any immediate questions about the plan. Kotter's theory of change will help guide implementation of this change in practice, as discussed below.

The site for the project is an adult ambulatory care oncology clinic in northern California, which is part of a regional and national healthcare provider which can be described as a health maintenance organization (HMO). Most breast cancer treatments, i.e. chemotherapy infusions, take place in the ambulatory setting. The breast cancer patient treatment plan involves many members of the multidisciplinary team, including the medical oncologist, breast surgeon, plastic surgeon, oncology pharmacist, breast care coordinator, radiation oncologist, pathologist, chemotherapy nurses, ONN and the oncology medical social worker.

The addition of an oncology nurse who completed her certification as an oncology nurse navigator (ONN) occurred during the last year. The ONN works with the oncologists and serves

as the liaison for patients to assist in their coordination of care from diagnosis into survivorship.

The focus of patients receiving written survivorship care plans was added over the past year

The microsystem focus for this project is to utilize the ONN to deliver in person an individualized survivorship care plan with a written playbook for wellness management including diet and exercise, symptom management and support resources. Breast cancer patients who are stage I, II, III who complete their treatment and transition to survivorship will be offered an appointment with the ONN at the time of their treatment completion to receive and review the individualized care plan and playbook information.

To implement this improvement, the author will be utilizing Kotter's eight step theory for change (King & Gerard, 2016).

1. Establishing urgency
2. Creating a guiding coalition
3. Developing a vision and strategy
4. Communicating the change vision
5. Empowering broad based action
6. Generating short term wins
7. Consolidating gains and producing more change
8. Anchoring new approaches in the culture

Kotter's theory of change is appropriate for this project because it lends itself to expansion of improvements once initial changes of limited scope have been made. In this project, the improvement to survivorship care plans and their delivery will be limited to breast cancer patients and then, when steps seven and eight are reached in Kotter's theory, expanded to all cancer patients as appropriate.

Data collection will be by way of survey administered to breast cancer patients immediately before their survivorship meeting with the ONN, to establish a baseline, and then approximately six weeks after the meeting, once the patient has had a chance to settle into a survivor routine. The survey will focus on knowledge gained through the presentation of the survivorship plan and the value added by meeting with the ONN. Open questions are part of the survey for patients to give more detailed feedback if desired. The draft survey is attached as Appendix C. The six week data will be checked against the baseline data for improvement in survivor knowledge as well as satisfaction with ONN and survivor support. Based on individualization of plans and ONN interaction when plans are delivered, the oncology team anticipates improved knowledge and satisfaction at six weeks' post-treatment.

#### **Data Source Literature Review**

The clinical issue for this CNL project is the preparation of the breast cancer patient to manage their wellness following treatment completion and transition into survivorship with the intervention of an oncology nurse navigator delivering an individualized care plan to the patient by way of an in-person meeting with the ONN at or near the time of the last treatment. The PICO statement literature review included: (P) patients are adult females with breast cancer who have completed treatment and are transitioning into survivorship; (I) intervention consists of the oncology nurse navigator (ONN) preparing and reviewing an individualized survivorship care plan in person; (C) comparison interventions are ONN guidance without a plan, ONN guidance with a non-individualized plan or ONN providing individualized plan to the patient without an in-person meeting; and, the desired outcome (O) would be measurable improvement in the patient's knowledge of the survivorship transition, challenges, resources and self-management strategies.

The literature review revealed that breast cancer patient's treatment often leads to chronic conditions during survivorship that are not often managed or understood by the survivor as they transition following treatment. Burris, Armeson and Regan-Sterba (2015) surveyed breast cancer patients in a randomized clinical trial regarding their unmet survivorship needs. Using a 42 item Cancer Survivors' Unmet Needs survey instrument, measuring symptom severity and symptom "interference," the researchers obtained the baseline data at two to three weeks before completion of treatment (and before the tested intervention) and then 10 weeks after completion of treatment. The researchers found the top five unmet needs pertained to (1) information; (2) interaction with other survivors; (3) explaining cancer to others; (4) stress management; and (5) complications from treatment.

Changes in relationships and the role of the breast cancer patient was studied by (Cheng, Wong & Koh, 2016). The results of the symptoms, quality of life and unmet needs of breast cancer survivors at less than two years' post-treatment and then between two and five years' post-treatment. As to unmet needs, the authors concluded that most fell into categories of health care information needs and patient support needs, which respectively may be related to decreased contact with health care professionals and the lack of a holistic approach to post-treatment care for survivors. The higher the unmet needs of the participants were, the lower their quality of life. Since many breast cancer patients are surviving longer a large portion of patients are older. Faul et, al (2014), used a telephone interview based research and tracked the experience of breast cancer survivors over the age of 65 with survivorship plans. Patients were treated at 78 different group sites, with only 35 percent having received survivorship plans based on the information provided by the patients. Interestingly, for every year over 65, there was a five percent lower chance that a participant had received a survivorship plan. The researchers also found that those

who did receive survivorship plans had improved understanding of breast cancer follow-up care, but their functioning was about the same as the non-recipients one year post-treatment. Every breast cancer patient who is stage I, II or III will have the opportunity to receive a survivorship care plan regardless of age.

Breast cancer patients were identified as experiencing higher levels of fatigue than other types of cancers such as colorectal and prostate as high as 40 % more fatigue in a study by (Jones, et al 2016). Three distinct survivorship time frames were measured 6 to 18 months; two to three years; and five to six years, post-treatment. The rates of fatigue were approximately the same across the three survivorship time cohorts, indicating that fatigue did not lessen over time. Keesing, Rosenwax & McNamara (2016) discovered three common themes with breast cancer survivors and their male partners from a period ranging six months to five years following completion of treatment. The researchers used thematic analysis to develop three themes discovered across all survivors: (1) disruption of the relationship because of the survivor's need to prioritize her health and needs; (2) reformulation of relationships by partners, using certain "strategies"; and, (3) the need for support from outside the relationship to negotiate and maintain their connection.

Transition from active treatment to survivorship for the patient involves moving from a provider phase of managing disease into a self-care model. What motivates the patient to manage disease was described in a study by Kvale, Meneses, Demark-Wahnefried, Bakitas, & Ritchie (2015). A qualitative study using the descriptive method with five different focus groups comprised from twenty breast cancer survivors. Utilizing the Health Belief Model and Social Cognitive Theory, the group leaders used interview techniques to obtain information about the participants' self-management techniques and strategies during survivorship. Themes were

developed that included (1) the breast cancer experience as catalyst for self-management; (2) fear of recurrence as a catalyst; and, (3) the meaning of breast cancer as impact on readiness for self-management.

The role of the nurse navigator in an ambulatory program that had a navigator in place for one year found patient satisfaction increased regarding education, emotional support and returning telephone calls based on written anonymous surveys given to patients according to Malone & Bruno (2016). Outreach to patients and support for lifestyle interventions were studied in a randomized control trial by Park, Cho, Salner, & Dornelas (2016). Two different written interventions were mailed to breast cancer survivors bi-weekly for four months. The participants in two intervention groups and one control group of 58 participants each, were assessed at baseline after four months (post-treatment) and at seven months (follow-up) for fruit and vegetable intake; fat intake and moderate to vigorous physical activity. While fat intake did not vary significantly, the researchers obtained data that showed the interventions were associated with healthier behaviors in fruit/vegetable intake and physical activity.

The impact of measuring patient's increased knowledge and awareness of their care during survivorship based on the receipt and review by a navigator of a written care plan and if it made a difference was studied by Rocque et al. (2014). In a pilot, randomized control study, the researchers developed a survey to measure the knowledge of cancer survivors as to diagnosis, treatments, late effects and follow-up as impacted by their having received survivorship care plans. Only two previous studies, both Canadian, has attempted to measure the impact of survivorship care plans, and those studies were criticized for assessing phenomena (distress, functioning and well-being) that are not directly targeted by such plans. In this first study, as to the knowledge of survivors, the data was not statistically strong enough to show that

survivorship care plans had a significant impact on patient knowledge, but the authors emphasize that the data is consistent with a larger cohort showing such an impact. A larger, multi-center trial is ongoing.

Shockney (2015) presents a very informative history of cancer patient navigation services with an emphasis on breast cancer patient navigation. She includes a discussion of the navigation process and different approaches to navigation. The development and use of survivorship care plans is covered, including the importance of such plans in the transition from specialized oncology care to patient self-management and primary care post-treatment.

An assessment tool was developed for surveillance by Todd, Feuerstein, Gehrke, Hydeman, & Beaupin (2015). The evidence suggests the assessment tool covers the symptoms and other issues experienced by breast cancer patients after primary treatment. The importance and formative stage of development of survivorship care plans as background for the need to have an assessment tool which can be used by breast cancer survivors as part of their self-management strategy (or by their primary care physician). The assessment tool, called the Cancer Survivor Profile, achieved positive results in its design as a workable tool that survivors can use to evaluate which symptoms they are experiencing and how those symptoms may be affecting them.

A study from the Breast Health Center in British Columbia surveyed breast cancer patients who received nurse navigator services from shortly after diagnosis. Surveys were administered with quantitative and qualitative components, and addressed the information provided by the navigators, emotional support and coordination of care, among other issues. Patient responses indicated high satisfaction overall with navigator services, with room for improvement noted for receiving better information about psychosocial support from counseling

and community services. This clinic also saw a need in the data for the navigator to call the patient on a periodic basis because the patient had a built-in hesitancy to initiate telephone communication with their nurse (Trevillion, Singh-Carlson, Wong, & Sherriff, 2015).

### **Timeline**

The project timeline will be patterned after the change theory to be employed, as follows:

1. Establishing urgency. The issue of improving the survivorship plan and utilizing ONN resource to establish the plan is set forth through evidence based research. (August 1, 2016).
2. Creating a guiding coalition. Team members across the oncology team are consulted regarding the individualization of survivorship plans and new ONN role and responsibilities. (September 15, 2016).
3. Developing a vision and strategy. Coalition of team members come together to provide guidance on the project and how they will design the new individualized survivorship plans for breast cancer patients. (September 15, 2016).
4. Communicating the change vision. New ONN role is implemented with revision of survivorship plans communicated to ONN and frameworks for plans designed. (December 15, 2016).
5. Empowering broad based action. The project leaders incorporate other team members, including oncologists and chemotherapy nurses, to support the ONN and department manager in implementing the project. (December 15, 2016).
6. Generating short term wins. Project leaders begin implementing new survivorship plans and patient meetings with ONN to go over survivorship plans. (January 15, 2017).



7. Consolidating gains and producing more change. Project leadership implements surveys of breast cancer patients at time of completion of treatment, and follow-up approximately six weeks later. (March 15, 2017).
8. Anchoring new approaches in the culture. The change data are reviewed and analyzed, and broadening the scope of the improvement is considered to patients beyond the breast cancer cohort. (May 1, 2017).

See Appendix D (Timeline) for detailed information and descriptions, including responsible persons.

### **Expected Results**

Because of this project, the author expects increased knowledge of survivorship strategies and resources on the part of breast cancer patients treated at this facility. It is also hoped that the delivery of survivorship plans by the ONN as part of an in-person meeting with each patient will increase uptake of the survivorship plan by all patients, and that the plan content and ONN meeting will create greater satisfaction with the support offered to survivors at this ambulatory oncology department.

If each patient gives positive feedback for improvement on the six weeks' post treatment survey, as compared to the initial survey before meeting with the ONN, the team will have achieved a positive improvement as a result of this project. For example, a patient who moves from "somewhat satisfied" to "satisfied" (a one point, positive increase on the survey scale) on a majority of questions on the survey will represent a successful improvement. The key improvement will be in actual knowledge of survivorship self-care; for specifics as to such knowledge, the author will look at qualitative responses to open-ended questions on the survey.

If the results are as expected, one would conclude that individualized survivorship plans for breast cancer patients have a greater impact than generic plans or sets of “discharge” orders from oncology physicians. The observer could also conclude that the one-on-one, face-to-face involvement with the ONN is measurably helpful in the breast cancer patient gaining knowledge of what she can expect and where she can go for support as a new survivor.

### **Nursing Relevance**

This project hopefully in a small way can corroborate the findings of Rocque et al. (2014) concerning survivorship plans and the contribution that individualized versions of such plans can make to survivor knowledge of self-care issues and solutions. With positive results from feedback surveys of the affected breast cancer patients, this project may take a small step toward a new standard of care regarding how survivorship care plans are created and then presented to cancer patients/survivors. By giving patients a valuable opportunity to ask questions and discuss the survivorship plan and survivorship issues face to face with the ONN will help make the self-care reality for the patient something that is understandable and full of possibilities for positive long-term health behaviors and, most of all, hope.

### **Summary Report**

This project aims to improve breast cancer survivors’ knowledge and satisfaction/comfort levels with their transition from primary treatment to survivorship. The specific protocol and intervention to achieve this result consist of a personalized or “individualized” survivorship care plan, prepared by and delivered personally in a one-on-one meeting to the patient by an ONN. The meeting should take place whenever possible on or close to the patient’s final day of primary treatment (usually the patient’s last chemotherapy infusion) while also being sensitive to patient energy levels and scheduling restrictions.

The healthcare setting selected for this improvement effort is an oncology department in one of the Northern California facilities of a national HMO where the author is the department manager supervising a team that includes one ONN, one medical social worker and 15 chemotherapy/infusion registered nurses, among other employees. The yearly new breast cancer patient census is approximately 130, who are about one-third of all the cancer patients treated at this location. The organization has a pending application for Commission on Cancer accreditation for this facility with a projected completion date in late 2017.

The improvement was implemented as a collaboration between the author/MSN candidate, the oncology department's ONN and the surgery department's breast cancer care coordinator. The author directed preparation of SCP format and content requirements by the ONN, who developed a template for the SCP's. The breast cancer coordinator provided input especially for the treatment summary portion of the SCP template. Under the author's supervision, the ONN began providing SCP's to breast cancer patients during 2016, with one-on-one, in-person meetings on the last day of primary treatment beginning from December 2016.

Identifying breast cancer patients immediately after their initial positive pathology tests, the ONN meets with them early in their course of treatment and as part of patient education apprises them of the potential for survivorship issues that will be discussed in the SCP to be prepared and delivered at an end-of-treatment meeting. Once the breast cancer patient has a final treatment schedule, typically a final round of chemotherapy, the ONN schedules her in-person survivorship meeting with the patient. In the meantime, the ONN prepares the individualized SCP for the patient, incorporating information from the patient's EHR and previous interactions with the ONN and oncologist including results of stress and symptom testing. When possible, the ONN schedules the in-person survivor meeting for the same day as the patient's final

chemotherapy infusion to increase patient convenience and to encourage immediate consideration by the patient of survivorship information and utilization of resources. Patient improvement data has been collected via Likert-scale surveys for about 50 percent of patients who met in person with the ONN from December 2016 to April 2017. Others in the patient cohort either did not receive their SCP via an in-person meeting with the ONN or did not agree to administration of the survey.

The baseline data for the target patient population—breast cancer patients being treated at the facility—consists solely of general data because survivorship care plans have been provided to breast cancer patients at this location for approximately one year, with no similar patient feedback surveys having been administered. In terms of general data relevant to the impact of the project, the ten-year survival rate for the breast cancer patients treated at this facility mirrors national averages at well over 80 percent; with approximately one-third of all cancer patients having cancer of the breast, the relevance of SCP's that could have a positive effect on the health of survivors is high, not to mention the potential for reducing cancer recurrence rates.

For implementation of individualized SCP's at this location, comparative feedback survey results were obtained from five patients—at the time of delivery of the SCP (initial) and approximately six weeks later (follow-up). An additional seven patients have completed initial surveys but less than four weeks have elapsed from their SCP meeting with the ONN and so follow-up surveys could not yet be administered. Eight of the twelve total patients providing survey feedback provided qualitative data responses in addition to their five-point Likert scale responses. See Appendix E for survey results in tabular format.

Of the twelve patients who completed the initial survey, two were 40 years of age or younger, three were 41-59 and seven were over the age of 60. The five who also completed the

follow-up survey consisted of one 40 or younger, one 41 to 59 and three over 60. With a Likert scale ranging from “1” (strongly disagree) to “5” (strongly agree), the predominant response for all 10 questions was a “5” (strongly agree), with an average of more than 4.9. For the initial survey, the lowest average was 4.6 for question five (“Learning about diet and exercise for my survivorship I felt to be valuable”), indicating a relatively lower overall level of agreement with that statement; one response to that question was the only “N/A” response option utilized by any patient on any of the surveys, with the patient in question noting that she had explored nutrition issues on her own. Question five also was the only instance of a survey respondent indicating she was neutral (a “3”) in terms of agreeing with the statement.

The follow-up survey, taken four to six weeks later with results obtained from five of the twelve patients who took the initial survey, resulted in an unanimous response of “5” for all survey questions except for the same diet and nutrition statement discussed above (question five), where two of the five responded with a “4” (mildly agree). Particularly notable in comparing the follow-up results with the initial survey was that two of the five patients had chosen “4” (mildly agree) for question seven (“I will use the survivorship plan to help self-manage my wellness”) on their initial survey responses; in their follow-up survey, these two patients changed their answers for question seven to a “5” (strongly agree). The same two respondents also changed their answers to the diet and nutrition question five from a “4” to a “5.” (See Exhibit E, highlighted data.)

Some qualitative data was also obtained from the survey respondents who volunteered to give it. Notable patient statements included: the SCP “taught me things I did not know about side-effects of Taxotere” (Patient five, follow-up); “I felt a sense of abandonment when finished with treatment—the fact that the nurse navigator followed up with me was amazing and

supportive” (Patient seven); “I keep the plan on my bedside table and use it almost daily as a reference” (Patient nine); “I could use more information about nutrition” (Patient ten); and, the outreach by the ONN “following my treatment was so unexpected—I did not feel I was alone” (Patient eleven). Regarding question three (“The nurse navigator reviewed my survivorship plan and I felt this to be valuable”), one patient selected “4” (mildly agree) and noted that she was “really upset” at the time and “unable to comprehend” (Patient twelve).

Overall, the survey data show that the SCP’s are viewed as helpful by the breast cancer patients who received them and that the ONN in-person meeting added significant value to the process of receiving and understanding the SCP and survivorship in general. The changed responses from “mildly agree” to “strongly agree” by two patients in their follow-up surveys regarding question seven (using the SCP to help manage their wellness) is particularly encouraging to the author.

The survey results were more positive than expected. Because this is a new program and has had little opportunity for refinement, the author expected more “mildly agree” and lower responses (neutral or disagree). The strong level of agreement on the Likert scale responses could be attributable to the small number of completed surveys, the timing of the initial survey (immediately after SCP meeting with ONN) and the excellent nursing skills of the single ONN who prepared and delivered the SCP’s. Also, the limited numeric scale (one to five) may not have provided a sufficient range of responses; one of the first revisions to the survey should be to expand the Likert scale to seven points (e.g., “strongly agree, agree, mildly agree, neutral, mildly disagree, disagree, strongly disagree”).

The improvement of individualized SCP’s with a focus on the specific patient, their treatment and individual considerations, and delivery of the SCP by an in-patient meeting with

an ONN, has proven so far to be a positive one. Patient feedback has been uniformly positive, while showing that there is noticeable room for additional improvement such as how the SCP (and ONN meeting) deal with nutrition and diet. One patient response also indicates that the ONN may need to be sensitive to the patient's receptiveness at the time of the meeting and may need to simplify or even re-schedule the SCP meeting if the patient is not in the right state of mind to receive the information.

If the oncology team were to modify the SCP process and patient survey in other ways, a focus on knowledge might produce additional value to the patient. After going through the SCP, the ONN might orally quiz the patient on important topics concerning survivorship to ensure that as much information as possible has been absorbed. Additionally, the feedback survey might be expanded or modified to test patient knowledge about survivorship information and resources with a few questions on important issues relevant to that particular patient.

To sustain and further develop this cancer survivorship improvement, the organization will need to dedicate additional financial resources to SCP preparation, refinement and delivery to the patient. After breast cancer patients began receiving SCP's in 2016, the SCP program was expanded to skin cancer (melanoma) patients—but with delivery by the patients' dermatologists rather than the ONN. In March 2017, colorectal cancer patient survivors began receiving SCP's. In order to expand beyond these current SCP-provided patient populations, however, a second ONN will probably need to be added to the team.

Survey feedback will continue to be obtained when possible in order to further refine the preparation of the SCP's and the interaction between the patients and the ONN. The oncology team will continue to monitor evidence of best practices in published literature as well as in the guidelines provided by ASCO and other cancer/oncological organizations. Through exchanges

with the organization's regional oncology peer group, as well as informal exchange of information between oncology departments of other facilities in the region, improvement of SCP and ONN services will continue.

The improvement of providing individualized survivorship care plans to breast cancer patients who are transitioning to survivor status, as part of an in-person meeting with the oncology nurse navigator who prepared the patient's plan, is justified by evidence-based practice. At this specific facility's department, the preliminary feedback for this improvement has been positive to a large degree and breast cancer patients appear to be benefitting from the improvement. Over the next year, assuming results of the SCP intervention continue to be positive, survivorship care plans should be provided to all cancer patients treated at this facility and the benefits of the improvement measured and shared with other oncology departments in the region.



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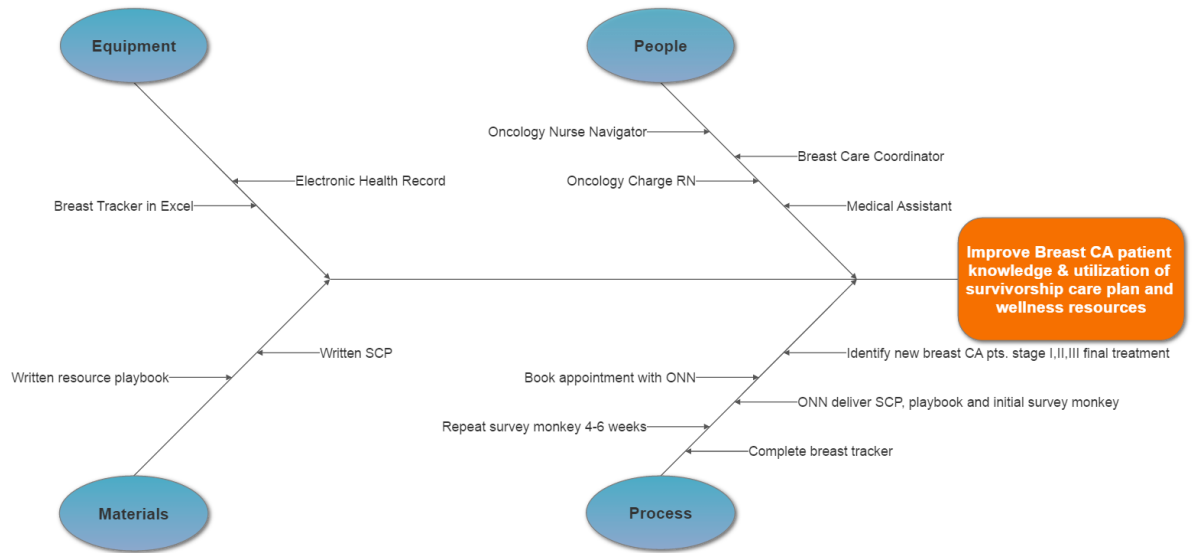
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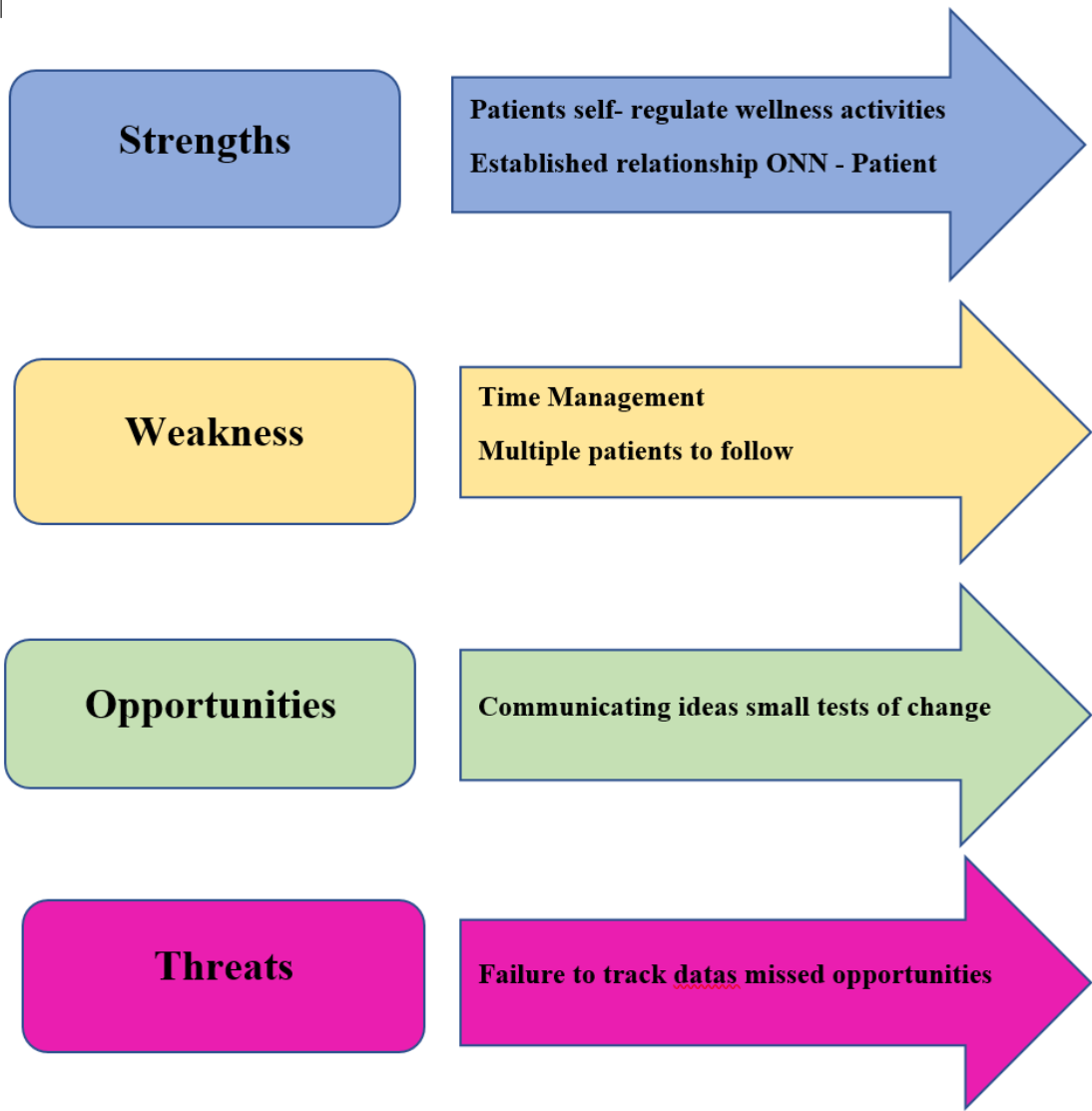
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### Appendix A



Appendix B

SWOT Analysis



## Appendix C

**[Facility Name – Location] Nurse Navigator Survey Tool**

Please choose one of the following:  This is my initial survey  This is my follow-up survey

I completed my treatment:  1 month ago  3-6 months ago  > 6 months ago

Age:  40 or younger  41- 55  Over 60

**Please circle the number that best describes your personal experiences.**

**5 = strongly agree 4 = mildly agree 3 = neutral 2 = mildly disagree 1 = strongly disagree**

1. I learned new information regarding my cancer experience from my nurse navigator.

**5                    4                    3                    2                    1**

2. I feel my nurse navigator was knowledgeable about my diagnosis and treatment.

**5                    4                    3                    2                    1**

3. The nurse navigator reviewed my survivorship care plan and I felt this to be valuable.

**5                    4                    3                    2                    1**

4. I feel my concerns were taken seriously and addressed by my nurse navigator.

**5                    4                    3                    2                    1**

5. Learning about diet and exercise for my survivorship I felt to be valuable.

**5                    4                    3                    2                    1**

6. The written materials were easy to understand.

**5                    4                    3                    2                    1**

7. I will use the survivorship plan to help self-manage my wellness.

**5                    4                    3                    2                    1**

8. I feel navigation services are necessary for breast cancer patients.

**5                    4                    3                    2                    1**

9. My overall experience with navigation services improved my cancer care experience.

**5                    4                    3                    2                    1**

10. I understand my follow-up plan and how to contact the navigator as needed.

**5                    4                    3                    2                    1**

**Open Survey Questions (optional)**

**Does the survivorship plan make you feel more prepared for your life as a cancer survivor? If yes, please give an example of examples of how it does so. If no, how would you improve the survivorship plan?**

**Do you feel you have gained specific knowledge from the survivorship plan about how to self-manage your wellness and lessen the chance of recurrence? Please give an example, if yes.**

**How did you receive your survivorship plan? Was the method of receiving your plan helpful to your understanding it?**

**Thank you for your time in completing this survey!**

## Appendix D

## Timeline

Step Number	Description of Change Step	Specific Change Step Actions and Considerations in Oncology Microsystem	Step Timeline
1	Microsystem Assessment	Assess the EBP literature re ONN value to oncology microsystems; analyze the data in this oncology practice in terms of patient needs and the continuum of care; identify all physicians, nurses, medical assistants, pharmacists, social workers and other professionals in ambulatory oncology and related departments who will interact with the ONN, supporting and being supported by the ONN. Discuss initial Survivorship Care Plan (SCP) workflow and patient tracking	January 2017
2	Communication Assessment	Discuss ONN role and related changes to cancer patient care and support, including patient flow, education and emotional/psychological/social support services; set up manageable group discussion with the professionals involved and present EBP and local data basis for ONN role; Engage Cancer Patient Advisory Group	Late January Early February 2017
3	Test Initial Work Flow Deliver in person SCP by ONN and Begin Data Entry for Tracking Patients.	Collaborate with Breast Coordinator and ONN to identify 2-3 patients that will receive an in person individualized SCP. Test Tracking database.	February 2017
4	Develop Draft SCP Survey for ONN, Written Materials	Continue to work with charge nurses, key oncology doctors, supportive care doctors, pharmacy representative, social worker and lead medical assistants to identify specific ONN roles and workflow for new and continuing patients, with focus on cancer patient-centered care, as well as continuity and support; develop specific timeline for completing the competencies and role definitions of the ONN; identify those who will write ONN policies, procedures and training	Late February Early March 2017



		<b>materials and timeline for completing those documents.</b>	
<b>5</b>	<b>Begin Draft Outline for Survivorship Play Book</b>	<b>Identify key elements for SC Playbook for nutrition, exercise, symptom management, support groups and community resources. Meet with Cancer patient Advisory Group to seek input. Send Survey and Draft Play Book to Advisory team</b>	<b>Late March Early April 2017</b>
<b>6</b>	<b>Administer SCP and Initial Patients Survey Enter Data into Tracker</b>	<b>Solicit feedback from ONN for effectiveness of written materials. Complete SCP Playbook</b>	<b>April 2017</b>
<b>7</b>	<b>Send secondary survey to patients within 3-4 weeks</b>	<b>Complete version 1 Survivorship Play book and begin delivery by ONN during SCP visit. Mail Playbooks to survivors who have received SCP as of March 2017. Follow-up with phone call within 7 business days.</b>	<b>Late April Early May 2017</b>

**Appendix E**

Patient answers to survey questions (see Appendix C). Specific highlighted data discussed by author:

Patient	Age	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q1*	Q2*	Q3*	Q4*	Q5*	Q6*	Q7*	Q8*	Q9*	Q10*
1	A	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5
2	B	5	5	5	5	5	5	5	5	5	5	5	5	5	5	4	5	5	5	5	5
3	C	5	5	5	5	4	5	4	5	5	5	5	5	5	5	5	5	5	5	5	5
4	C	5	5	5	5	4	5	4	5	5	5	5	5	5	5	5	5	5	5	5	5
5	C	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5
6	C	5	5	5	5	5	5	5	5	5	5										
7	A	5	5	5	5	na	5	5	5	5	5										
8	B	5	5	5	5	5	5	5	5	5	5										
9	B	5	5	5	5	5	5	5	5	5	5										
10	C	5	5	5	5	5	5	5	5	5	5										
11	C	5	5	5	5	5	5	5	5	5	5										
12	C	4	5	4	5	3	5	5	5	5	5										
Average		4.9	5	4.9	5	4.6	5	4.8	5	5	5	5	5	5	5	4.8	5	5	5	5	5

Abbreviations:

A = 40 years or younger

B = 41 to 59 years

C = 60 years or older

\* = Follow-up survey (4 to 6 weeks post baseline survey)